

**The development of an intervention for carers of stroke survivors  
using an Intervention Mapping approach**

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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## **Abstract**

**Background:** Burden is well documented among carers of stroke survivors, yet current evidence is insufficient for determining the best strategies for reducing negative outcomes. The Medical Research Council (MRC) framework advocates using theories in intervention development, but lacks guidance on how this can be achieved. Interventions targeting carers of stroke survivors often lack theory or provide inadequate descriptions of the active ingredients determining their effects. This research aimed to develop a proposed theory- and evidence-based intervention to reduce burden in carers of stroke survivors.

**Methods:** In conjunction with stakeholder involvement, Intervention Mapping stages one to four guided intervention development: needs assessment; identifying outcomes and objectives; selecting theoretical methods and practical applications; and creating a programme plan. The needs assessment included three components: A systematic review of systematic reviews established the factors that influence burden in carers of stroke survivors and other longer-term conditions; a thematic synthesis of qualitative studies and a qualitative interview study established carers' needs, how and whether they change over time, and the barriers and facilitators to addressing needs. Findings influenced subsequent stages of intervention development.

**Results:** Stakeholders prioritised the need for carers to feel prepared before and during the transition from hospital to home as key to reducing burden. The proposed intervention comprises multiple components based on theoretical methods and practical applications to target relevant determinants. This includes: a training package for information and support providers working with carers; an additional training session for other staff; and elements to support carers to feel prepared.

**Conclusions:** Using Intervention Mapping addressed some of the limitations of previous interventions and fulfilled MRC recommendations by providing a structured framework for systematically incorporating evidence, theories, and stakeholder input throughout intervention development. Further research is required to produce and refine the proposed intervention components before evaluating their effectiveness.

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# **1. Chapter 1: Overview and introduction to the thesis: Why develop an intervention to reduce burden in carers of stroke survivors?**

## **1.1. Introduction to the research topic**

This doctoral study arose from an interest in using behaviour change theories for developing interventions within the context of applied health research. This interest developed from my undergraduate and postgraduate studies, and was further enhanced through my work as a Research Fellow, when I contributed to a programme aimed at developing an intervention to improve longer term outcomes for people living in the community who have had a stroke. Through undertaking this work I also established a keen interest in stroke research, including the impacts of stroke on families.

My role involved interviewing stroke survivors and their carers to understand their unmet needs and factors that have helped or hindered their daily lives. Although experiences primarily focused on stroke survivors, the findings provided some indication of carers' experiences after stroke. However, their narratives focused on their perceptions of the stroke survivors' needs, rather than their own needs. This distinction intrigued me, and I became determined to understand more about carers' needs and what can be done to reduce negative outcomes e.g. burden. This led to the focus of this study which aimed to develop an intervention to reduce burden in carers of stroke survivors, using an Intervention Mapping approach (IM) (Bartholomew et al., 2011).

Before progressing to the next section which highlights why this topic is important, it is necessary to provide some clarity about the terminology I have selected to describe people who have had a stroke, and people who provide their ongoing care. There are differing opinions about the preferred way of describing these individuals. Historically, 'stroke victim' has been commonly used, but its negative connotations led to the introduction of a more positive term 'stroke survivor.' Neither term is favoured by everyone, but the individuals I engaged with during this doctoral study preferred 'stroke survivor', which has been adopted throughout this thesis. 'Carer' and 'caregiver' are used interchangeably in the literature to describe individuals engaging in the caring role. Some carers that I engaged with disliked being labelled in this way, however it was necessary to select a term to collectively describe the population of study in this thesis. Given that 'caregiver' is more commonly used in America, 'carer' was adopted for this purpose to describe individuals who provide unpaid care to their relatives or friends.

## 1.2. Why the research topic is important

Stroke remains a major illness, occurring more than 100,000 times a year in the United Kingdom (UK); four out of 10 stroke survivors in the UK rely upon care from family and friends (Stroke Association, 2015). Similar to other caring roles, this typically involves the provision of emotional support and assistance with daily activities, including physical care (Cameron et al., 2013; Plank et al., 2012; Quinn et al., 2014a).

Within their roles, carers can face negative consequences, problems, and challenges, many of which have been documented within systematic reviews of the stroke caring experience (Greenwood et al., 2009a; McKeivitt et al., 2004). Carers are also at risk of experiencing adverse effects in their psychological, physical, and social functioning (Adelman et al., 2014) and review evidence indicates a high prevalence of burden among carers (Forster, 2005; Kalra et al., 2004; Rigby et al., 2009).

Although the burden of caring has been identified, developing strategies on how best to address those issues has proved more elusive. A Cochrane review of non-pharmacological interventions for carers of stroke survivors found no strong evidence for the effectiveness of the interventions reviewed (Legg et al., 2011). The London Stroke Carer Training Course (LSCTC), a structured in-patient carer training programme, was identified as the intervention with the most potential (Kalra et al., 2004). However, a multicentre cluster randomised pragmatic trial of the LSCTC (n=928) reported this training programme did not reduce carer burden or increase patients' functional independence (Forster et al., 2013). A parallel process evaluation reported the training programme was difficult to deliver at this point in the stroke care pathway, as it competed with other priorities for stroke unit staff, and carers were experiencing stress related to their relative's stroke (Clarke et al., 2014).

Interventions to reduce negative outcomes associated with caring post-stroke are clearly required, hence the aim of this research. Given the varied difficulties faced by carers of stroke survivors, complex interventions are likely to be appropriate for addressing their needs. The following section highlights the importance of theories in the development and evaluation of complex interventions, as advocated by the Medical Research Council (MRC) (Craig et al., 2008; Craig and Petticrew, 2013) and introduces the IM approach (Bartholomew et al., 2011) for developing interventions, with a brief rationale for its use in this study. A more comprehensive account of this approach, including a detailed rationale is provided in chapter four.

### **1.3. Intervention Mapping: A framework for developing a complex intervention**

Complex interventions are comprised of multiple and interacting components and can include additional dimensions of complexity (Moore et al., 2015). The MRC framework (Craig et al., 2008; Craig and Petticrew, 2013) emphasises the importance of theories in intervention development for establishing the causal assumptions that underpin an intervention, and in the evaluation to understand how it works in practice. These considerations are vital for building an evidence base that informs policy and practice (Craig and Petticrew, 2013).

Although using theory in combination with existing evidence is important for developing interventions, many interventions, including most of those in the review by Legg et al. (2011) are developed without reference to theory (Prestwich et al., 2014). A limitation of the MRC framework is that it does not provide detailed guidance on how to develop a complex intervention which incorporates theories. In this study, it was necessary to use a systematic method for developing an intervention, which facilitates appropriate selection of theories for predicting and changing behaviours. Numerous theories, frameworks, and models have contributed to developments in behaviour change research e.g. Theoretical Domains Framework (TDF) (Cane et al., 2012; Michie et al., 2005), Behaviour Change Wheel (BCW) (Michie et al., 2014; Michie et al., 2011). However, I used IM (Bartholomew et al., 2011) to develop a proposed intervention to reduce burden in carers of stroke survivors. IM fulfils criteria recommended in the MRC framework and provides a logical process for effective decision making, including how to integrate theory and evidence throughout intervention development, implementation, and evaluation.

IM includes six stages (further details in chapter four): 1) Logic model of the problem (needs assessment); 2) Programme outcomes and objectives; Logic model of change; 3) Programme design (methods and strategies); 4) Programme production (creating an organised programme plan); 5) Programme Implementation Plan; 6) Evaluation Plan.

Due to the time constraints of this study, the research presented in this thesis reaches the point in stage four where a proposed intervention is developed, including a detailed outline of its components; however, materials are not developed and pre-tested. The following section provides an overview of how the thesis will develop using IM.

### **1.4. The thesis: An overview of chapters**

The thesis is presented in three sections:

Section one 'Background: Problem identification and approach to intervention development' includes chapters two to four. Chapter two provides an overview of relevant literature focused on caring, burden and carer needs, then research questions for the research contributing to this thesis.

Chapter three presents an update of a Cochrane review (Legg et al., 2011) to establish the effectiveness of interventions aimed at reducing negative outcomes in carers after stroke; and whether there are any benefits of a particular type of pre-defined intervention type for reducing negative outcomes in carers. This contributes to understanding developments in intervention research for carers of stroke survivors since the review, before seeking to develop a new intervention.

The rationale for using IM is discussed in chapter four. This chapter starts by outlining key principles of the MRC framework for guiding the development of complex interventions, then an overview of theory in behaviour change and intervention research, before critically reviewing different models and frameworks used to change behaviours. IM stages are presented, and a summary of its strengths and weaknesses, before progressing to the next sections in the thesis, where IM is used to develop an intervention.

Section two: 'Intervention Mapping: (needs assessment)' includes chapters five to seven, which contribute to the first stage of the IM, the needs assessment. Chapter five presents a systematic review of systematic reviews to establish the factors that influence burden in carers of stroke survivors and other longer-term conditions.

Chapter six includes an update of a review by Greenwood et al. (2009a) to establish carers' needs, how they change over time, and the barriers and facilitators to addressing needs. A thematic synthesis approach (Thomas and Harden, 2008) was used to synthesise findings.

Chapter seven is the empirical study contributing to the needs assessment. This is a qualitative semi-structured interview study, including two different groups of carers, one of which were interviewed over time. This focuses on carer needs, the barriers and facilitators to addressing needs and how and whether they change over time. It also includes an exploration of carers' social support networks, using a social network mapping activity (Antonucci, 1986). Thematic analysis using methods by Braun and Clarke (2006) was used to analyse findings. Methods and findings are both presented in this chapter.

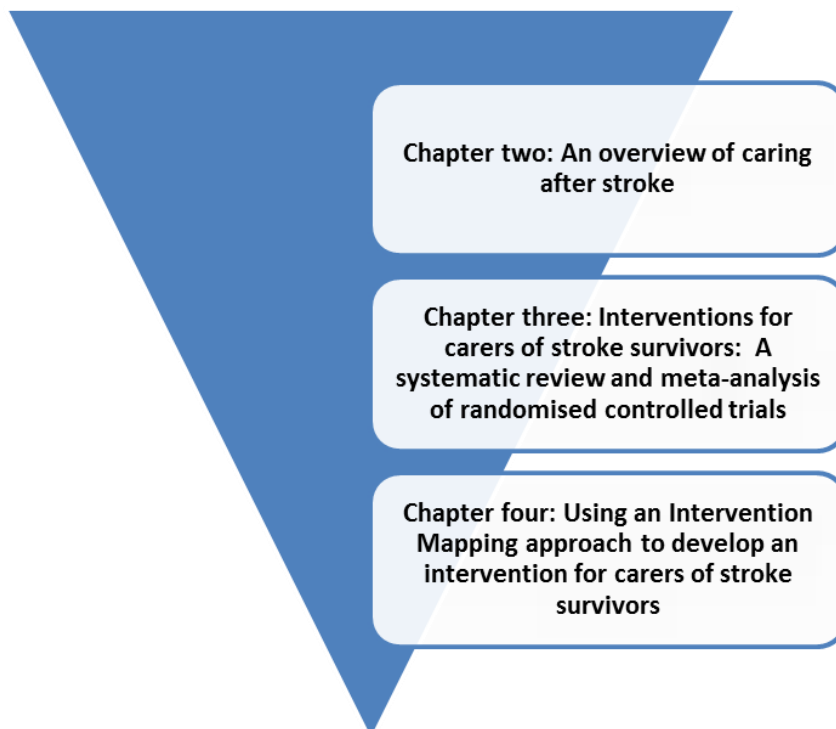
The findings sections in chapters five, six and seven each end with a logic model, together these form the overall logic model of burden, used to inform later stages of IM (chapter eight).

Section three: 'Developing and designing the intervention' includes chapters eight and nine. Chapter eight outlines how IM methods were applied in stages one to four and the corresponding results, including a detailed outline of the components of the developed intervention.

Chapter nine provides an overall discussion including: a summary of key findings, comparisons with published intervention literature, challenges using IM, critical reflections on burden, implications for relevant policies, practice and future research, and strengths and limitations of the research conducted.

## **Section 1: Background: Problem identification and approach to intervention development**

The previous chapter provided an overview and introduction to the thesis, and briefly introduced IM (Bartholomew et al., 2011). This section, including chapters two- four provides a more comprehensive background to the study and a more detailed rationale for using IM (figure one).



**Figure 1: An overview of chapters in section one**



## **2. Chapter two: An overview of caring after stroke**

### **2.1. Introduction**

This chapter is divided into six sections, each of which covers concepts that were guided by the requirements of the 'needs assessment' stage of Intervention Mapping (Bartholomew et al., 2011). The 'needs assessment' is the first stage which focuses on gaining an in-depth understanding of a given problem such as carer burden and the needs experienced by the relevant population of study, in this case, carers of stroke survivors. The first section provides a general introduction to caring across longer-term conditions, before narrowing the focus to stroke carers and relevant policies. The second section discusses the concept of caring in more detail, including different perspectives within the literature (biomedical, sociological, and anthropological). Sections three and four address the complexities associated with burden, first broadly, then in the context of carers of stroke survivors. The fifth and sixth sections focus on needs, both broadly and in the context carers of stroke survivors. The chapter ends with a rationale for this study and research questions relevant to components of work within the thesis.

### **2.2. An introduction to caring and relevant policies**

Over the past thirty years, social care policies in Western Europe have come to assume that dependent individuals are best cared for by their relatives in the community (Means et al., 2008; Pickard et al., 2015). The number of people who are reliant on support to live in the community has increased due to the shift towards an ageing population, improvements in lifespan of those who have lifelong disabilities, and a continuing trend away from institutionalised care (Hudson, 2005). Consequently, there are around seven million carers in the UK and this is expected to increase by 3.4 million by 2030 (Carers UK and Age UK, 2015). An increasing number of carers are also likely to experience more than one episode of providing care throughout their life course (Carers UK and Age UK, 2015).

Due to the rise in the number of family carers, their roles have become subject to greater exploration (Buckner and Yeandle, 2011; Larkin and Milne, 2014; Pickard, 2008). Roles involve preparing meals, shopping, personal care tasks, domestic duties such as cleaning and doing the laundry, and medical tasks such as administering medication. In addition, carers often provide emotional and social support to their loved ones (Milne and Larkin, 2015).

Across many longer-term conditions, caring is often embedded in relationships. Of all carers, over a quarter (26%) care for a spouse or partner, 40% care for parents or parent in laws, and 13% provide care for their sons or daughters (Niblett, 2011). Most carers are

female and aged over 55 years, a quarter are over 65 years of age (Becker and Becker, 2008). Additionally, the time spent caring is variable; 48% of all carers provide care for 20 or more hours a week and 21% provide care for more than 50 hours. Fourteen percent of carers look after two people (Carers UK and Age UK, 2015).

For some individuals, this role can be experienced positively, through improvements in relationships with the cared-for-person, feeling appreciated and feeling an increased self-esteem (Larkin and Milne, 2014; Mackenzie and Greenwood, 2012). However, many longer-term conditions including dementia and stroke place considerable burden on carers (Milne et al., 2012; O'Shea and Goode, 2013).

Taking on this role can lead to health, emotional, and social difficulties (Dearden and Becker, 2004; Hamilton and Adamson, 2013). There are also financial implications of caring, considering many carers struggle to remain in work (Milne and Larkin, 2015). The estimated loss of earnings per year per carer is over £11,000, amounting to an annual loss of £5.3 billion to the UK economy (King and Pickard, 2013). This is inefficient from an economic perspective and leads carers at risk of experiencing poverty and exclusion (Larkin and Milne, 2014).

Although supporting carers remains important across all longer-term conditions, stroke is of particular interest here. Ski et al. (2015) considered the experiences of carers of stroke survivors as categorically different from those providing support to individuals with progressive conditions (e.g. dementia, Parkinson's disease) because of the nature of stroke as an abrupt, unexpected, complex, and life-changing event. This situation is further complicated by the lack of support to prepare and manage the stroke sequelae, which can include emotional, physical, cognitive, and behavioural changes (Gosman-Hedström and Dahlin-Ivanoff, 2012; Saban and Hogan, 2012). Consequently, carers are faced with uncertainties around the stroke survivors' recovery and little time to make modifications to the home to accommodate their physical limitations (Lutz et al., 2011). They can also experience grief attached to the loss of the stroke survivor as they were previously, and further challenges, including disrupted relationships, changes in roles and loss of autonomy and independence (Bulley et al., 2010; Greenwood et al., 2010; Quinn et al., 2014a).

Research demonstrates it is essential that carers of stroke survivors are provided with appropriate skills training and support to meet their requirements (Greenwood et al., 2010; Greenwood et al., 2009b; Mackenzie et al., 2007). The responsibility to assess and meet carer requirements and needs is likely to fall upon relevant professionals in health

and social care environments. Government strategies encourage the involvement of professionals in supporting carers, and emphasise a 'carer centred approach' where carers are recognised as partners in care and for their unique knowledge and expertise when addressing their needs. Strategies include: *Caring for Carers: Recognising, Valuing and Supporting the Caring Role* (Department of Health, 2006) and *Carers at the Heart of the 21<sup>st</sup> Century Families and Communities* (Department of Health, 2008).

Legislation including the 'Carers (Equal Opportunities) Act 2004' (Department of Health, 2004), and the government's National Strategy for Carers (Department of Health, 2008) also contribute to carers being recognised as legitimate recipients of support in their own right. The 'Care Act 2014' (Department of Health, 2014) enshrines the legal duty of a Local Authority to provide an assessment to any carer who requests this or who appears to need support, providing a basis for identifying and meeting support needs by providing help or signposting carers to other organisations e.g. charities.

Additionally, policies focus on protecting carers' health and wellbeing, access to training and employment, and life aside from caring (Lloyd, 2006; Moran et al., 2011). However, the effectiveness of such policies has been questioned, as many carers still experience negative consequences as a result of their caring, due to the inappropriate provision of adequate support to meet their needs (Larkin and Milne, 2015). Further research is required to ensure that policy directives can be translated into practice, considering the experiences of a specific carer population e.g. stroke.

The recently updated National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party (ISWP) 2016) recommends offering carers of stroke survivors educational programmes focusing on the nature, consequences, and prognosis of stroke, managing in the event of another stroke, lifestyle changes and secondary prevention, and knowledge about how to provide care and support, including opportunities to practice; an assessment of their own needs following their return home; appropriate practical and emotional support; and guidance on how to seek further help as problems arise. This would involve having contact details of a named professional (e.g. stroke co-ordinator), who can provide this information and advice where necessary.

In summary, informal carers have become an increasingly significant focus of research interest in health, social care, and policy research. Whilst policies indicate what should ideally be provided to carers, further research to determine how this can be done remains an important priority (Larkin and Milne, 2015).

### 2.3. The concept of caring

The term 'carer' is widely used in research and policy documents to describe people who care for others in a non-professional context and is often preceded by words such as 'informal' or 'family' (Thomas, Morris, and Harman, 2002). However, a common definition of a carer is lacking, raising concerns about the generalisability of these findings (Greenwood et al., 2008). There is some general agreement that such individuals must not be paid to provide care and the terms 'informal carer' and 'family carer' are often used interchangeably to reflect the lack of financial reward for taking on this role (Donelan et al., 2002; Hollander et al., 2009). Other criteria commonly used to define carers are as follows: type of support provided (e.g. instrumental or emotional) and the time spent caring (Donelan et al., 2002).

It is likely that those caring for an ill, frail, or disabled family member or friend fall within the description of an informal carer, but often these individuals would regard themselves as being a good mum, dad, neighbour, or friend and perceive caring as a normal and natural part of their lives (Sadler and McKeivitt, 2013). Alternatively, carers enter the role with reluctance, having had little opportunity to decide whether they want to commence or continue to provide care (Burrige et al., 2007). Similarly, others feel little choice but to provide care to loved ones, due to marital or familial obligations (Burrige et al., 2007; Dunér, 2010).

Caring is bound with complexities and shaped by perceptions of experience. In 1989 Twigg introduced three models of caring to make sense of how carers are perceived by services (carers as resources, carers as co-workers and carers as co-clients) (Twigg, 1989). In 1994, a fourth model, 'the superseded carer' was added (Twigg and Atkin, 1994).

The 'carers as resources' model regards carers as a form of free resource. Carers are expected to provide informal care, and formal care would only be provided if informal care is unavailable. Their own interests and needs are not of primary concern. In contrast, the 'carers as co-workers' model regards carers as being in a joint care enterprise, where their well being and interests are considered, but only on an instrumental basis. In the 'carers as co-clients' model, carers are recognised as in need of help in their own right. This conceptualisation moves beyond just an instrumental focus towards services taking responsibility for providing care to carers, especially the most burdened cases. The 'superseded carer' model places emphasis on enhancing the independence for both carers and the cared for, to reduce burdens placed upon the carer.

According to Twigg and Atkin (1994) the extent to which carers can be incorporated into services is partly dependent on the degree to which the four models have an impact. However, gaining appropriate support from different services is bound with complexities. To some extent this is a two way process that requires a degree of negotiation to establish factors such as carers' needs, whether time and resources are available to meet carers' needs, and whether carers want to accept support. The process of negotiation is also influenced by factors including carers' and professionals' expectations, values, and assumptions.

These different models may not account for the complexities involved in negotiating support from different services for different needs. However the models help to explain how some services consider carers as second to the cared for, and why many carers have an ambiguous role in health and social care systems (Twigg and Atkin, 1994). A focus on carers as 'resources' or 'co-workers' is inconsistent with new policy directives that are more in line with the 'carers as co-clients' and the 'superseded carer' models. This may partly explain why some of the policies outlined in the previous section are not always translated into practice.

A range of additional factors are also likely to influence how care is experienced and the extent to which carers are supported. These include the number of hours spent caring, length of time spent caring, nature of care, relationship to the care recipient, care requirements to meet their needs and access to and acceptability of services. Other factors also contribute to the diversity of carers experiences; examples include but are not limited to gender, race, and sexuality (Larkin et al., 2012; Ridley et al., 2010).

As caring shifts to this public arena, the term can become problematic, raising questions regarding carer duties, rights, and benefits (Sadler and McKeivitt, 2013). Examining the concept of 'carer' through the lens of different perspectives allows for further exploration. This is addressed here, considering biomedical, sociological and anthropological perspectives.

The biomedical approach provides a perspective of caring, often adopted in health services research, where caring is consistently portrayed as burdensome and accompanied by stress and strain (Garand et al., 2005; Ilse et al., 2008). The biomedical perspective assumes that using interventions to address outcomes such as burden will have a positive impact for the caring experience (Sadler and McKeivitt, 2013). However, a systematic review by Legg et al. (2011) found insufficient evidence to indicate which

intervention types (support and information, teaching procedural knowledge, psycho-educational) are most effective for reducing carer burden in carers of stroke survivors.

Such interventions to target negative outcomes in carers do not always consider the diversity of ways in which the caring role is experienced, or how caring relationships are embedded within varied social relations, as is evident in the sociological and anthropological literature focused on caring (Sadler and McKeivitt, 2013). In contrast, sociological and anthropological perspectives attempt to problematise biomedical models of caring by examining the construct of the 'carer.'

The sociological literature has provided numerous critical perspectives on caring to critically de-construct the notion of carer in relation to wider underpinning assumptions e.g. gender and power. Early work by sociologists focused on the critique of the notion of caring from a feminist perspective. During the 1970s and 1980s, feminists exposed the idea of caring as an activity that is gendered and naturally undertaken by women, highlighting the exploitation of women's labour and status in society (Barnes, 2011; Finch, 1993). Feminists argued that women were not being compensated or recognised by the state because they were not supported financially for their unpaid labour. During this era, care focused on providing instrumental support and doing care to another (Ray et al., 2008). This work led to the distinction between 'caring about' and 'caring for.' 'Caring about' includes feelings of concern and 'caring for' relates to the task oriented aspects of caring and is therefore much more about unpaid labour (Ungerson, 1983).

This distinction was challenged in the 1990s and analyses extended to the relational aspects of care. At this point, 'interdependence and reciprocity' characterised dominant perspectives on caring relationships (Walmsley, 1993, pg. 137). These were also often embedded in a shared life course and history (Lyon, 2010). Feminist post-modern interpretations of power that emerged in the 1990s, emphasised 'power in caring relationships is constantly (re)created and (re)negotiated through interaction' and is therefore 'fluid, complex, and constantly shifting' (Dominelli and Gollins, 1997, pg. 412). This perspective of caring challenged the notion of this as fixed and unchanging and simultaneously drew attention to power and relationality in caring relationships.

It was during this era that feminist legal scholar Kimberle Crenshaw coined the term 'intersectionality' (Crenshaw, 1991) to describe a theoretical framework that is emerging as a cornerstone of sociological thought. The fundamental tenet of intersectionality is the notion that factors contributing to the diversity of experience such as gender, race and sexuality are not independent or unidimensional. Instead they are multi-dimensional,

interdependent social identities. According to intersectionality theory, single categories of identity such as race or gender cannot alone explain inequalities or disparate outcomes, without the intersection of the other identity. These factors intersect at a micro level of experience and reflect interwoven systems of privilege or oppression at a broader macro structural level (e.g. sexism and racism). Intersectionality encourages researchers to consider social inequalities in health and provides a theoretical lens for interpreting novel or unexpected findings. Both factors are thought to contribute to informing the development of targeted health interventions (Bowleg, 2012).

The notion of the 'carer' has received less recognition in anthropological literature. However, ethnographic accounts of suffering and illness have explored meanings of caring, locating this in existing relationships, social networks, normative expectations of reciprocity, and obligation, these require negotiation and may also be challenged (Holroyd, 2001; Van der Geest, 2002). Existing anthropological literature focuses on the social and cultural meanings attached to caring and the implications that this role has on the individual, their family, and the wider community (Sadler and McKeivitt, 2013).

Although this study aims to develop an intervention to target burden experienced by carers, and is consistent with some assumptions from biomedical perspective, evidently the nature of care is complex. Different perspectives should be integrated where relevant, with a view to understand caring in the context of people's lives (Taylor and Bury 2007). This is important for ensuring the successful development of an intervention to reduce burden, given the limitations of previous interventions. To understand how this should be done, it is logical to consider some of the complexities associated with carer burden.

#### **2.4. The burden of care**

Caring can be considered as a socially admired role, embedded within the relationship between the carer and recipient of care (Fine and Glendinning, 2005), however, it is often accompanied by the term burden (Molyneaux et al., 2011). The concept of 'carer burden' has become popular in literature because of the tendency of social science research to focus on areas of 'psychological dysfunction', e.g. stress, anxiety, and depression (Bastawrous, 2013).

Burden represents the negative impact of caring for a significant other and is one of the most commonly used variables in the field of caring research, as both an outcome and predictor (Chou, 2000; van der Lee et al., 2014). Findings from measures of burden are used among researchers to inform and measure the development and delivery of interventions to meet carer needs and support them in reducing their burden

(Bastawrous, 2013). However, the use of this term can be problematic, as a consistent definition and conceptualisation in research is lacking (Bastawrous, 2013). The meaning of this term is further complicated by its interchangeable use with words such as “wellbeing,” “stress”, “problems” and “adverse effects” and its multifaceted nature (Adelman et al., 2014).

In 1966 Grad and Sainsbury introduced burden in the context of the family in an examination of community care for the mentally ill. They understood burden as any negative consequences to the patients family (Grad and Sainsbury, 1966). Since then, the term has been commonly recognised in health care literature and numerous definitions have been proposed. George and Gwyther (1986) considered ‘carer burden’ as encompassing ‘the physical, psychological, emotional, social, and financial stresses that individuals experience due to providing care’ (George and Gwyther, 1986, pg. 253). Given that there is no agreed definition of burden within the literature, this definition will be used in this research, as it takes in to account its multifaceted nature, acknowledging the range of factors associated with burden.

Whilst inconsistencies in defining burden can be problematic, distinctions between ‘subjective’ and ‘objective’ burden have added complexities to research focussed on burden. Objective burden refers to the aspects of care, such as number of hours provided that are considered physical or instrumental, whereas subjective burden relates to the emotional aspects of care than accompany this role (Montgomery et al., 1985). The distinction between the two types of burden is not always discussed when multi-dimensional burden measurements are used (Call et al., 1999; Clair et al., 1995). This has implications for understanding burden and how it should be alleviated, as there are different influential factors associated with the two types of carer burden.

Quantitative research approaches to exploring and measuring carer burden largely dominate (Chou et al., 2003; Ganguly et al., 2010). These studies are valuable for establishing statistical significance of correlates of carer burden and can inform evidence-based intervention programmes (Chou et al., 2003; Honea et al., 2008). Quantitative measures are also favoured in clinical settings and by policy makers for providing quick, direct ways of determining individuals at risk of burden (Honea et al., 2008). Despite benefits of using quantitative methods, they have been criticised for minimising context in relation to burden, which is important for gaining a greater understanding of burden in a given population (Bastawrous, 2013).



Qualitative methods provide an alternative approach to understanding the concept of carer burden, including rich, descriptive accounts of individuals' experiences. Ganguly et al. (2010) used focused groups to directly understand experiences of burden in carers of individuals with schizophrenia and bipolar disease. Burden among carers related to different areas, including family functioning, social isolation, financial difficulties, and health. These aspects of burden are not traditionally incorporated into quantitative measures. It is possible that quantitative measures may capture 'burden' in a way that differs from carers' actual experiences of providing care and their descriptions of the phenomenon.

Interestingly, a systematic review of 17 qualitative studies by Greenwood et al. (2009a), based on stroke carers reported that the term 'carer burden' was rarely used in carers' descriptions of their experiences. However, their experiences provided a detailed picture the challenges and satisfactions of caring, as well as negative consequences that could be considered as burdensome. Much can still be learned from qualitative approaches used in addition to quantitative studies. They could enhance the way that the notion of 'carer burden' is investigated, ensuring interventions to reduce burden in carers of stroke survivors are grounded in their experiences.

The next section outlines current understandings of the impacts of carer burden in carers of stroke survivors, and implications for developing an intervention to address this problem.

## **2.5. The impacts of carer burden in carers of stroke survivors**

The burden of caring is a significant health concern (Bastawrous, 2013; Rigby et al., 2009). For carers of stroke survivors, this is also associated with impacts on health and social lives, in addition to physical and psycho-social wellbeing (Cameron et al., 2013; Murray et al., 2003).

Studies have indicated 25-46% of carers experience substantial burden within the first six months of caring after stroke (Hung et al., 2012; Tooth et al., 2005). This time shortly following the stroke has been described as taking up the role (White et al., 2006). In this period carers gain control of their situations, make sense of their new roles, re-arrange their everyday lives, seek information and support, identify the stroke survivors' needs, and develop the skills required to meet them (Brereton and Nolan, 2002; Greenwood et al., 2009b; Lutz et al., 2011).

Severity of burden experienced by carers in this early period is associated with numerous factors including carer and stroke survivor characteristics. Examples include greater stroke survivor disability, disturbances in stroke survivor and carer emotional health, and increased time spent caring (Byun and Evans, 2015; Rigby et al., 2009). Qualitative studies have provided evidence that carers experiences change over time as they develop skills, coping strategies, and new routines to manage care responsibilities (Greenwood et al., 2009b; Quinn et al., 2014a). This could lead to the assumption that burden would lessen with time, however prolonged tiredness and deprivation of personal needs may lead to increased burden for some carers (Adelman et al., 2014; Kamel et al., 2012).

Visser-Meily et al. (2008) assessed carers at one and three years post stroke, using a questionnaire examining five domains of psychological functioning: burden, life satisfaction, depression, harmony in the relationship and social support. Carer burden declined over time; however, 43% of carers still reported strain at the final assessment three years after the initial stroke. Evidently burden is not limited to the early period following stroke. Input to alleviate this in the later care trajectory may be required.

Few studies aside from Visser-Meily et al. (2008) have addressed changes in burden over time. Jaracz et al. (2015) conducted a study which aimed to assess carer burden at six months (time one ) and five years post stroke (time two) to analyse changes in severity of burden with time and the factors (determinants) of carer burden (e.g. socio-demographic, stroke related and psychological characteristics). Eighty-eight patient and carer dyads were assessed and carer burden was measured using the Carer Burden Scale. Forty-four percent of carers reported considerable burden at time one and 30% at time two. These findings are consistent with Hung et al. (2012) and Tooth et al. (2005), confirming a significant proportion of carers are under severe strain in the period shortly following the stroke. Consistent with Visser-Meily et al. (2008), this study found that overall burden decreased with time, as did the proportion of carers with high burden (Jaracz et al., 2015).

However the determinants of burden, identified by Jaracz et al. (2015) extend previous findings by recognising the multifaceted nature of burden and its determining factors. In their study, the levels of burden varied across domains investigated. Higher burden was evident in dimensions including areas such as physical workload, psychological wellbeing and lower in environmental aspects. Interestingly, all significant determinants related to carer factors, which is inconsistent with previous evidence where patient related factors e.g. disability play a role (Byun and Evans, 2015; Rigby et al., 2009).

Determinants of burden at time one included low sense of coherence and increased time spent caring. Anxiety was a determinant at time two, this was considered in the context of aging as carers faced worries about their abilities to provide care in the longer term as they became older. Overall, findings indicated those with poor coping abilities in addition to difficulties finding time to adapt to care in the context of their lives may find adjustment in early period post stroke more difficult.

Jaracz et al. (2015) accounted for the disparity with previous evidence by highlighting that researchers have previously investigated carers shortly following the stroke, when a severe status of disability is more likely to have greater impact on burden compared with assessing this at six months (time one). However, Jaracz et al. (2015) could not determine the actual point when burden declined as this was explored at two fixed time points.

Understanding the care experience over time, carer burden, and its determining factors is crucial for successful intervention development (Jaracz et al., 2015). Findings discussed in this section highlight the difficulties attached to the first few months following the stroke, when carers require attention from health professionals in hospital and community settings, before positive influences that can alleviate burden can take place.

Despite evidence indicating a decline in burden over time and an adaptive response to managing care (Greenwood et al., 2009b; Jaracz et al., 2015; Quinn et al., 2014a; Visser-Meily et al., 2008), a relatively high proportion of carers continue to experience burden years after stroke, highlighting the importance of considering the longer term impacts of caring. Attention to the changes in needs over time is also important for understanding how to intervene appropriately (Cameron et al., 2013; Sadler and McKeivitt, 2013). This extends the focus on alleviating burden that has been presented in this section and is discussed in the following section.

## **2.6. Conceptualising needs**

Although 'need' is a taken for granted term in government policies relevant to carers, varied definitions have been developed in different areas of research, with the view to improve service delivery (Harrison et al., 2013).

One of the early and widely acknowledged attempts to define need was Maslow's Hierarchy of Needs (Maslow, 1943). Five levels of need were specified (psychological, safety, love/belonging, esteem, and self-actualization). According to Maslow, the first four needs (primary deficiency needs) should be fulfilled, leading to the final need for self-actualisation. This sequential hierarchical concept of need received criticism for lacking

attention to complex behavioural responses to more than one of the levels of need at a given time (Fallon and Zgodzinski, 2005). It was also suggested that determining which physical, interpersonal and social aspects of life are causally related to each end state could be difficult (McCall, 1976). The theory is criticised for lacking flexibility and being too general for assessing needs related to health (McCall, 1976; Sheaff, 2002).

Bradshaw introduced a sociological understanding of 'need' in the early 1970's, with the taxonomy of needs (Bradshaw, 1974), comprised of four types: Normative (imposed by professionals such as a vaccination), felt (subjective wants, wishes and desires from the perspectives of individuals), expressed (vocalised needs and actions expressed through demands for services) and comparative needs (determining needs through comparing groups of similar individuals who receive a service to those who do not).

Whilst this conceptualisation of need is argued to be more appropriate for health services (Asadi-Lari et al., 2003), the four types of need are not without criticism. The normative approach suggests needs are imposed by professionals, yet there are external pressures from media and economic intuitions to deliver particular treatments (Komesaroff and Kerridge, 2002). Felt needs are limited by perception, as they focus on individual wishes, wants, and desires. Felt need involves no clinical judgement, making it difficult to determine how this definition would fit with current health care delivery. Expressed needs can be criticised for the likelihood that the rich would gain better care than the poor would, given that this is based on demand (Boulding, 1966). Although it is likely that other factors would also be influential in whether needs are met e.g. economic status, education and class. Lastly, comparative need relies on existence of services; therefore it only applies when these are available.

Despite these weaknesses, Bradshaw's taxonomy of need highlights that the term 'need' has different meanings and can be understood from different perspectives (McGregor et al., 2009). It is also helpful for considering factors that might contribute to reported needs, including cultural influences (Higginson et al., 2007). It also considers complexities that are not addressed from a health services perspective of needs, where these are understood as a capacity to benefit from health care services, and are restricted to 'medically' necessary needs.

As this study is focussed on carers, it is unlikely that they will only have medical needs. Bradshaw's taxonomy of need is appropriate for defining needs in this study, as the four domains appear relevant to developing an intervention for carers. Felt and expressed needs are particularly important for understanding need from the perspective of the

carers themselves, which is important for ensuring that an intervention is tailored to their needs.

Whilst it remains unclear what is meant by the term 'need', different perspectives have offered understandings that can influence how needs continue to be addressed in future. As the debate continues, patients, carers and family members continue to require support for varied needs. The following section attends to how needs have been addressed in carers of stroke survivors.

## **2.7. Needs in carers of stroke survivors**

In the stroke caring literature, the term 'need' is becoming increasingly used. Yet the meaning of the term lacks clarity, as a definition is not always provided. Self-reported needs have previously been explored in community dwelling stroke survivors (McKevitt et al., 2011; Sumathipala et al., 2012). This work has extended to addressing the needs of carers of stroke survivors; examples from the literature include, but are not limited to; information (Wallengren et al., 2010), education (Hafsteinsdóttir et al., 2011), social support (Cameron et al., 2013), improved communication with stroke survivors (Le Dorze and Signori, 2010) and coping with daily life (Saban and Hogan, 2012).

Despite 'needs' lacking consistent definition, support is considered more beneficial if it is tailored to individuals' needs (Cameron and Gignac, 2008; Cutrona, 1990). Yet addressing needs is complicated by the changing nature of the caring scenario (Cameron and Gignac, 2008; Cameron et al., 2013; Gaugler, 2010; Greenwood et al., 2009b). The Timing it Right (TIR) Framework (Cameron and Gignac, 2008) was designed to identify gaps in knowledge and guide the development and evaluation of interventions in accordance with changing needs over time. This was developed based on the expected clinical pathway for stroke and a literature review of 11 studies that discussed support needs and when they occurred in the illness trajectory.

Cameron and Gignac (2008) outlined five phases in the TIR Framework, starting from the point of event/diagnosis, moving towards stabilisation, then preparation and implementation, before the final phase of adaptation. In each phase, a description of the setting and focus of care by professionals and family members is included. A more specific understanding of support needs at each phase is also provided, drawing on four key types of support (informational, emotional, instrumental and appraisal). The framework is based on the premise that providing information and support for phase specific needs will enhance caregiver preparedness, ease transition across the care continuum, and decrease negative outcomes e.g. burden, depression, and other health outcomes.

Following development of the framework, Cameron et al. (2013) conducted semi-structured interviews with 14 health care professionals (HCPs) and 24 carers to identify key providers of support and explore carers' support needs and how they change over time. The TIR Framework was used as a conceptual guide in the analysis of the interviews. Different informational and instrumental needs were apparent for each phase of the framework. However, emotional needs were less variable over time, and stress and strain were experienced consistently. Carers needed to feel supported across all phases and different providers of support were identified e.g. family members HCPs, friends, and peers with an indication of when their support was needed most.

The original framework and these qualitative findings informed the development of the Timing it Right Stroke Family Support Programme (TIRSFSP) which has been tested in a feasibility and pilot randomised controlled trial (RCT) (Cameron et al., 2014a). The TIRSFSP was offered in two formats (self directed by carer or stroke support person directed) and compared to standard care. Preliminary findings indicated this is feasible and may enhance carers' perceived support and mastery, however, this requires testing in a larger scale trial.

Although findings from Cameron et al. (2013) have informed the development of an intervention, they have limitations. Cameron et al. (2013) used a cross-sectional design; different groups of carers were interviewed at different times between one month and one-year post stroke. This relied upon a retrospective understanding of needs, with potential difficulties in recall of needs. There would be benefit from gaining an in-depth understanding of needs over time in a longitudinal study as part of informing the development of an intervention to reduce burden in carers.

Furthermore, Cameron et al. (2013) did not explore the factors that influence whether carers' needs are addressed e.g. barriers and facilitators. These factors are useful for understanding needs in context and the circumstances that dictate whether carers gain appropriate support, including individual factors e.g. willingness to accept support. This is an area that warrants exploration, as limited research has specifically examined the barriers and facilitators to addressing a range of needs in carers of stroke survivors.

Eames et al. (2010) addressed only the barriers to accessing stroke information from the perspectives of both stroke survivors and carers. White et al. (2007) explored both barriers and facilitators to undertaking the caring role, rather than their relation to specific needs. Le Dorze and Signori (2010) explored needs and the barriers and facilitators to addressing needs; however, the focus was limited to carers of individuals

with aphasia. Attention to how barriers and facilitators to addressing needs change as needs change over time would be a valuable contribution to research for developing interventions.

In summary, although evidence highlights the importance of attending to carers needs in the development of interventions (Cameron and Gignac, 2008; Cameron et al., 2014a; Cameron et al., 2013) further work is required to develop a successful intervention for reducing burden in carers of stroke survivors. Focussing on needs establishes key areas for intervention in the context of carers' lives. This establishes 'what' carers want, but we cannot assume that addressing needs directly influences carer burden, without gaining a more in-depth understanding of carer burden, and some of the behavioural and environmental factors that influence this concept. Exploring behavioural and environmental factors and their determinants, in addition to carer needs and the barriers and facilitators to addressing these would provide a valuable contribution to the knowledge required for developing interventions for carers.

As stated previously, the IM approach adopted for the study starts with a comprehensive needs assessment. This provides a framework for incorporating these areas for exploration into developing a proposed theory- and evidence-based intervention for reducing burden in carers of stroke survivors. The following section provides an outline of the research questions addressed within the thesis.

## **2.8. Overview of research questions addressed in the thesis**

### **2.8.1. Section one: 'Background: Problem identification and approach to intervention development'**

#### **Systematic review: An update of the review by Legg et al. (2011) (chapter three)**

Prior to developing a new intervention, a review by Legg et al. (2011) was updated addressing two research questions:

- Are there any effective interventions for addressing negative outcomes in carers of stroke survivors?
- Are there any benefits of a particular type of pre-defined intervention type for reducing negative outcomes in carers?

A narrative account of the findings and a meta-analysis is provided.

Chapter four provides a rationale for using IM to develop an intervention and outlines the context for later work.

### **2.8.2. Section two: 'Intervention Mapping: (needs assessment)'**

As stated previously, each component of work in this section contributes to the first stage of IM, the needs assessment. This stage of the process has two main aims which influenced the research questions for this section of the thesis. The first aim is to gain a detailed description of the behavioural and environmental causes of a problem and their determinants. This led to the second systematic review contributing to this thesis:

#### **Systematic review of systematic reviews (chapter five)**

The systematic review of systematic reviews synthesised evidence regarding the factors that influence burden in carers of stroke survivors and other longer-term conditions. Four research questions were addressed:

- What are the behaviours associated with carer burden in carers of people with longer-term conditions?
- What are the environmental conditions that facilitate or limit behaviours associated with burden?
- What other factors are associated with carer burden (including those related to both the carer and the patient)?
- What are the determinants (predictors) of behaviours and environmental factors associated with carer burden?

A narrative account of findings is presented in chapter five.

The second aim of the needs assessment is to gain an understanding of the 'at risk' group, their needs, and the factors that influence these. This led to the conduct of a third systematic review (chapter six) and an empirical study (chapter seven).

#### **Systematic review of qualitative studies: Thematic synthesis (chapter six):**

A systematic review of qualitative literature was conducted to update an existing review (Greenwood et al., 2009a) to illustrate the experience of carers of stroke survivors between 2005-2015. Three research questions were addressed:

- What are the needs of carers of stroke survivors?
- What is known about how and whether needs change over time?



- What is known about the barriers and facilitators to addressing needs?

A thematic approach to synthesising the data was used (Thomas and Harden, 2008). The methods and results for this review are outlined in chapter six.

**Empirical study: Qualitative interviews (chapter seven):**

This empirical study sought to explore carers experiences over time in two groups of carers using qualitative, semi-structured interviews (Group one: shortly following discharge from hospital, then two further interviews, each separated by 3 months; Group two: nine to 36 months since the stroke). This study also includes an exploration of carers' social support networks, using a social network mapping activity (Antonucci, 1986).

- What are the needs of carers of stroke survivors (at each time point)?
- What are the barriers and facilitators to addressing needs?
- How do needs, and barriers and facilitators to addressing needs change over time?
- What can we understand about carers social support networks?

Thematic analysis (Braun and Clarke, 2006) was used to analyse interview data. The methods and results for this study are outlined in chapter seven.

**2.8.3. Section three: 'Developing and designing the intervention'**

Chapter eight describes the further stages of the IM process, leading to the development of a proposed intervention. Chapter nine provides an overall discussion of the research presented.

### **3. Chapter three: Interventions for carers of stroke survivors: A systematic review and meta-analysis of randomised controlled trials.**

#### **3.1. Introduction**

This chapter presents an update of a Cochrane systematic review of 'non- pharmacological interventions for caregivers of stroke survivors' (Legg et al., 2011). The review was conducted to establish whether existing interventions are effective (i.e. show a statistically significant difference between two groups on an outcome measure) in reducing negative outcomes experienced by carers after stroke. A narrative account of the findings and a meta-analysis is provided; findings are summarised and recommendations for developing future interventions for carers of stroke survivors are considered.

#### **3.2. Rationale for review**

Although there is variability in carers characteristics, their social roles and how they are defined, individuals who adopt this role contribute largely to the care that is provided to stroke survivors (Cecil et al., 2013; Lou et al., 2016). Numerous systematic reviews have summarised the evidence concerning effective interventions for reducing negative outcomes in carers of stroke survivors (Brereton et al., 2007; Eldred and Sykes, 2008; Visser-Meily et al., 2008). Aspects of carer health have also been addressed in two Cochrane reviews (Ellis et al., 2010; Smith et al., 2008a), however carers were not the primary focus.

Legg et al. (2011) conducted a systematic review with a primary focus on carers, to establish the effectiveness of interventions for informal carers of stroke survivors on a range of outcomes. Eight intervention studies from four different countries, over a period of twelve years, provided insufficient evidence to establish which types of interventions were most effective in reducing or preventing carer-specific stress and strain, general stress or distress, depression, anxiety and health related quality of life, compared to receiving no intervention or standard care. A teaching procedural knowledge type intervention, compared to usual care was suggested as the most promising for reducing carer- specific stress and strain, general stress or distress, depression and improving health related quality of life. This was the case when administered to carers prior to the patients' discharge from hospital. However, findings were based on data from one small, single-centre study (Kalra et al., 2004).

Legg et al. (2011) conducted searches in 2010; therefore it was important to update this research addressing the effectiveness of interventions for carers. A systematic review was deemed as an appropriate method, as this collates all empirical evidence according to pre-defined criteria to answer a pre-specified research question, and reduces bias using explicit, systematic methods, leading to more reliable findings (Higgins and Green, 2011).

### **3.3. Aim of review**

Consistent with the review by Legg et al. (2011), the primary aim of this systematic review and meta-analysis was to investigate the effectiveness of interventions targeted towards carers of stroke survivors. A secondary aim was to establish if the benefits of interventions are greater in any pre-defined intervention sub group e.g. teaching procedural knowledge, support and information, or psycho-educational type interventions.

### **3.4. Methods**

The Cochrane review methodology, guided by Legg et al. (2011) included: identifying relevant research, assessing methodological quality of studies, summarising the evidence, interpreting findings, and highlighting implications of the research.

#### **3.4.1. Inclusion and exclusion criteria**

Studies included in the review were RCTs of non-pharmacological interventions targeted towards informal carers with the following features:

- Delivered to an informal carer of a stroke survivor.
- Delivered to an informal carer and a stroke survivor as a dyad (both the informal carer and the stroke survivor are randomised).
- Compared to routine care or no care.
- There is an intention to have an impact on carers' knowledge, beliefs, attitude or behaviour.

Carers were defined as 'a person of any age who provides one or more hours of unpaid help and support per week to a stroke survivor,' however authors definitions were also accepted.

Studies were excluded from the review if stroke survivors were the primary target of the intervention and if the study was not published in English. RCTs of interventions targeted at those with mixed aetiology were excluded if the percentage of stroke survivors in the study was less than 80%.

### **3.4.2. Types of outcome measures**

The outcomes of interest were those outlined by Legg et al. (2011):

#### **Primary outcomes**

1. Informal caregiver stress and strain at the end of the scheduled follow up period.
2. Informal caregiver wellbeing at the end of the scheduled follow up period.

#### **Secondary outcomes**

1. Global measures of stress or distress.
2. Measures of anxiety.
3. Measures of depression.
4. Informal health related quality of life at the end of the scheduled follow up period.
5. Informal caregiver satisfaction.
6. Informal caregiver mortality.

### **3.4.3. Study identification and data extraction**

Databases were searched from 01.01.2009 - 05.02.2015. JH developed a comprehensive search strategy (appendix A) based on expert advice from the Cochrane Stroke Group and guidance from an information specialist. The following databases (n=9) were searched to identify studies for inclusion; AMED, CINAHL, Cochrane Library, HMIC, Medline, PsycInfo, Social Work Abstracts, Web of Science and EMBASE.

JH and another reviewer independently screened all titles and abstracts to assess their eligibility. Studies that did not meet the inclusion criteria were excluded. Full text publications were obtained for potentially relevant studies. Where articles could not be obtained, authors were contacted. The same reviewers independently applied the inclusion criteria to this list. Disagreements were resolved through the involvement of a third reviewer.

Independent data extraction by JH and another reviewer was performed for all eligible studies. A standard data extraction form was used to guide this process, information included: participant data, characteristics of the interventions, outcome measures used, baseline scores for carer demographics, results for continuous and dichotomous outcomes and risk of bias.

### 3.4.4. Assessment of methodological quality

The concept of 'quality' is difficult to define and there is a lack of consensus regarding how this should be measured in systematic reviews (Ryan et al., 2013). The Cochrane Risk of Bias Tool is one of the most comprehensive approaches for assessing biases that could potentially occur in RCTs included in meta-analyses or systematic reviews (Higgins and Green, 2011). The authors recognised limitations in this tool such as the length of time it takes to complete and the lack of extensive research on its reliability. However, greater transparency is provided in comparison with other approaches to assessing bias, and readers can decide whether they agree with supporting judgements that are provided.

Whilst the development of risk of bias assessments is continuing to evolve, based on current evidence, the Cochrane Risk of Bias Tool (Higgins et al., 2011) was selected for this review. Each trial was assessed for risk of bias based on six domains (randomisation sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, selective reporting, and incomplete outcome data). For each, a judgement of high low or unclear bias was made, with support for judgements.

### 3.4.5. Data synthesis

Included studies were grouped into three categories based on those outlined by Legg et al. (2011) and an additional 'other' category (table one). The other category was created for interventions that did not fit discretely into the pre-specified categories. To ensure that this process was unbiased, a group of five researchers independently assigned the interventions to one of these four categories based on an extract with details about the intervention. Results were collated and any disagreements were resolved by consensus.

**Table 1: Types of interventions**

Types of interventions
<b>1. Support and information:</b> Interventions that provide participants with information to connect them with necessary resources, opportunities, or support.
<b>2. Teaching procedural knowledge:</b> Interventions that focus on preparing participants for the work of providing care to a stroke survivor, and are based on manual or practical activities.
<b>3. Psycho- educational:</b> Interventions that reinforce personal strengths, resources and coping skills of participants in order, for example to avoid relapse or contribute to their own health and wellness on a long-term basis.
<b>4. Other:</b> An additional 'other' category was included where the studies did not fit in to any of the discrete categories, or alternatively if they fit it to more than one of the categories.

### 3.4.6. Meta-analysis

Several meta-analyses were conducted and combined with those that were included in the meta-analysis by Legg et al. (2011). Before conducting a meta-analysis, decisions were required regarding the choice of a random effects or fixed effects statistical model.

The fixed effects model is based on the assumption that the single source of variation in outcomes is that occurring within the study, meaning the effect expected from each study is the same (Haidich, 2011). As a result, studies are assumed to be homogenous, with no differences in the population of study or selection criteria, and treatments or interventions are delivered in the same way. These models give more weight to larger studies, where standard error is smaller.

The random effects model is often favoured in comparison with the fixed effects model, as the assumption that the effect of interest is the same across all studies is often flawed (Haidich, 2011). The random effects model is based on the assumption that there is a distribution of true effect sizes, with the goal being to estimate the mean of this distribution (Borenstein et al., 2010). Using the random effects model, more equal weighting is given to studies and these are based on within study and between study variance. Confidence intervals using the random effects model are usually wider than the fixed effect model, unless between study variance is not apparent, in which case both models produce the same finding (Veroniki et al., 2015). Both methods were considered before conducting the meta-analysis and applied appropriately.

Heterogeneity was also considered in the interpretation of findings. To understand variability across studies, it is important to distinguish between different sources of heterogeneity (Haidich, 2011). Clinical diversity encompasses the variability in participants, interventions, and outcomes. Methodological diversity is the variability in study design and risk of bias. It is however argued that statistical heterogeneity is inevitable, as clinical and methodological diversity always occur in a meta-analysis (Higgins et al., 2003).

The chi-square ( $X^2$ ) test is the statistical measure for heterogeneity, used to assess whether differences in findings are as a result of chance. Heterogeneity of intervention effects (variation in effect estimates beyond chance) are indicated by a low P value (or a large chi-squared statistic relative to its degree of freedom). Additional methods have been introduced to establish the impact of the heterogeneity on the meta-analysis. The I-square  $I^2$  statistic is used to outline the percentage of variability in effect estimates that is as a result of heterogeneity, as opposed to chance (Higgins and Thompson, 2002; Higgins

et al., 2003). This ranges from 0% to 100%, where higher values indicate greater heterogeneity. Difficulties in interpreting can arise, as the importance of inconsistency is dependent on numerous factors. Higgins and Green (2011) outlined guidance for interpretation:

- 0% to 40%: might not be important;
- 30% to 60%: may represent moderate heterogeneity\*;
- 50% to 90%: may represent substantial heterogeneity\*;
- 75% to 100%: considerable heterogeneity\*.

\*The importance of the observed value of  $I^2$  depends on (i) magnitude and direction of effects and (ii) strength of evidence for heterogeneity (e.g. P value from the chi-squared test or a confidence interval for  $I^2$ ).

Heterogeneity was assessed through examining forest plots and carrying out the chi-square ( $X^2$ ) test using a P value of less than 0.1 as an indicator of heterogeneity. The effect of heterogeneity was quantified using the  $I^2$  statistic. Guidance for interpretation is outlined above. An  $I^2$  value of 50% or above was considered as substantial heterogeneity (Higgins and Green, 2011).

### **3.4.7. Measures of treatment effect**

#### **3.4.7.1 Continuous outcome**

Continuous outcomes are those where measurements for an outcome are on a numerical scale, usually summarised as means. Legg et al. (2011) analysed the following as continuous outcomes: informal caregiver stress and strain, informal caregiver well-being (the primary outcomes), depression, health related quality of life and satisfaction (secondary outcomes). Means and standard deviations were used under the assumption that they had a normal distribution.

#### **3.4.7.2 Dichotomous outcomes**

Dichotomous data is data from outcomes that can be separated in to two distinct categories, where participants cannot be in both categories. Two types of dichotomous data are relevant for the current review, these are alive or dead and data that have been dichotomised from outcomes that are not dichotomous. Legg et al. (2011) converted measures of anxiety to dichotomous data using published optimal clinical cut-points.

Using optimal cut off points, individuals in one state (e.g. anxiety) can be separated from those in another state. Individuals who lie above the clinical cut point on a scale for anxiety are likely to meet criteria for having anxiety; those who lie below the cut off point are less likely to have anxiety. The measure of effect for dichotomous outcomes was the risk ratio (RR) in the review by Legg et al. (2011). For this review, outcomes were reviewed to determine appropriate methods of analysis.

#### **3.4.8. Statistical software**

RevMan version 5.3 was used for all meta-analyses (Cochrane Collaboration, 2014).



### 3.5. Results

The search identified 9454 references, following de-duplication 8675 remained, of these 22 were considered potentially relevant and the full texts were reviewed (one of the 22 was provided by an author following contact regarding an abstract). Ten studies were excluded (see figure two). Twelve studies were included in February 2015.

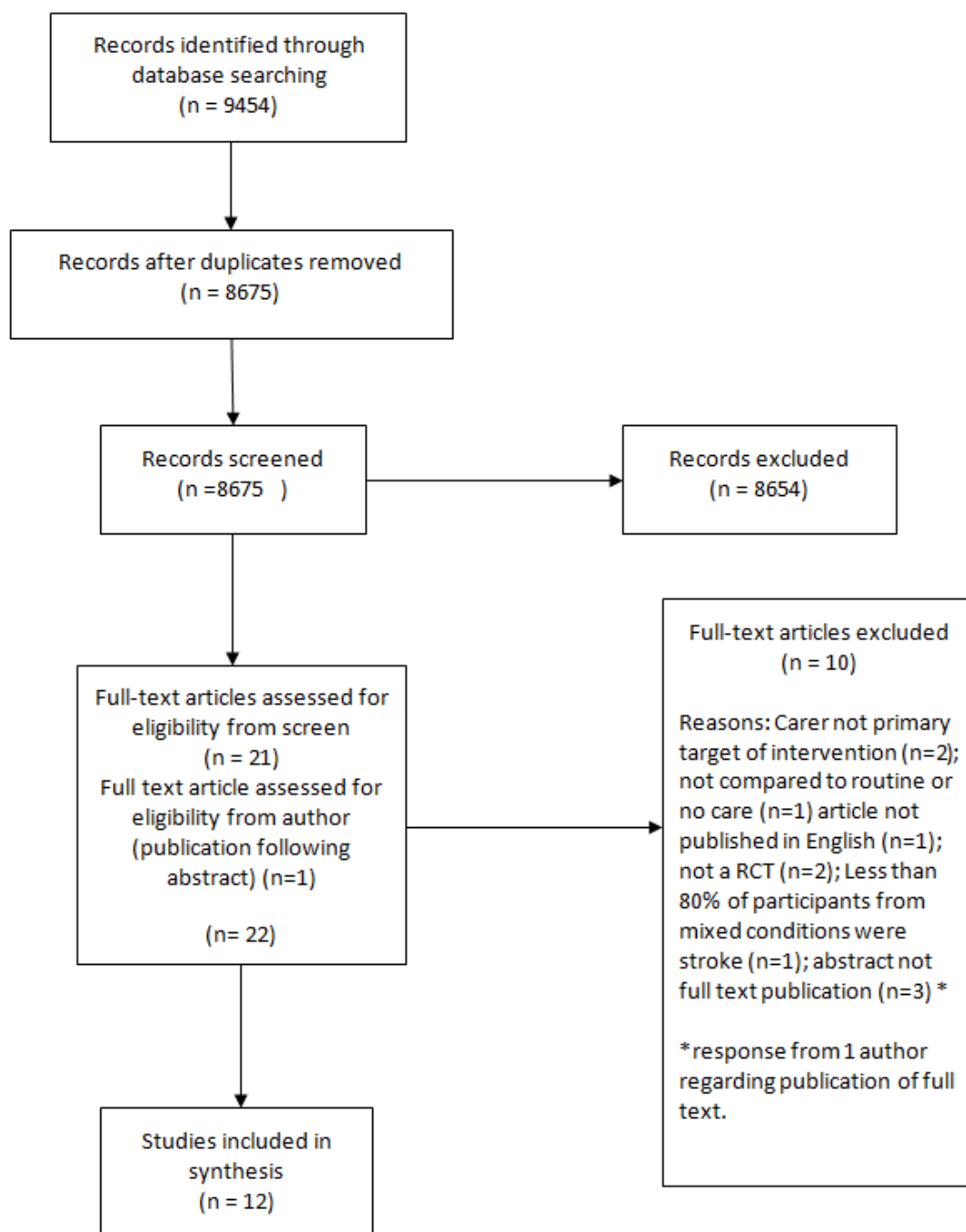


Figure 2: Study selection process diagram (using PRISMA guidelines)

### 3.5.1. Included studies

Twelve new studies in addition to eight identified by Legg et al. (2011), met the inclusion criteria. All studies were published in English and the majority were conducted in America. Other locations included Germany, Canada, Taiwan and the UK. Five studies targeted carer and stroke survivor dyads, remaining studies targeted carers only. The timing of intervention delivery ranged from six weeks to one year, the majority were delivered within the first three months following discharge. Most studies collected demographic data from carers e.g. age and gender (see characteristics of included studies, appendix B).

Table two outlines the studies in accordance with the intervention categories.

**Table 2: Categorisation of interventions**

<b>Support and information:</b> Interventions that provide participants with information to connect them with necessary resources, opportunities, or supports.	<b>Teaching procedural knowledge:</b> Interventions that focus on preparing participants for the work of providing care to a stroke survivor and are based on manual or practical activities.	<b>Psycho-educational:</b> Interventions that reinforce personal strengths, resources and coping skills of participants in order, for example to avoid relapse or contribute to their own health and wellness on a long-term basis.	<b>Other</b> (where interventions could be categorised in more than one of the three defined groups).
(Cameron et al., 2014a; Pierce et al., 2009c)	(Forster et al., 2013; Perrin et al., 2010; Shyu et al., 2010)	(Bishop et al., 2014; Eames et al., 2013; King et al., 2012; Pfeiffer et al., 2014)	(Bakas et al., 2009; Marsden et al., 2010; Smith et al., 2012)

There were seven modes of intervention delivery:

**Table 3: Modes of delivery**

<b>Mode of delivery</b>	<b>Study</b>
1. Written and telephone	(Bakas et al., 2009)
2. Telephone	(Bishop et al., 2014)
3. Face to face group setting	(Marsden et al., 2010)
4. Face to face and telephone	(Cameron et al., 2014a; Forster et al., 2013; King et al., 2012; Pfeiffer et al., 2014; Shyu et al., 2010)
5. Face to face and video calls	(Perrin et al., 2010)
6. Web based	(Pierce et al., 2009c; Smith et al., 2012)
7. Written, face to face and telephone	(Eames et al., 2013)

For details of the study interventions and comparators, see appendix B.

### 3.5.2. Excluded studies

Table four outlines reasons excluding studies:

**Table 4: Excluded studies**

Reasons for exclusion with study references
Less than 80% of participants from mixed conditions were stroke survivors (Elliott et al., 2009)
Not published in English (Frischknecht et al., 2014)
Carers not primary target of intervention (not part of randomisation) (Backhaus et al., 2010; Wang et al., 2015)
Abstract (Bakas et al., 2010; Cameron et al., 2011; Miller et al., 2010)
Not RCT (Forster et al., 2012b; Oupra et al., 2010)
Not compared to usual care or control (Ostwald et al., 2014)

### 3.5.3. Risk of bias in included studies

Findings from the risk of bias assessment are presented for each of the six domains; method of randomisation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, selective reporting and incomplete outcome data.

#### 3.5.3.1 Randomised sequence generation

Ten studies reported methods of randomisation that were considered as low risk of bias (Bakas et al., 2009; Bishop et al., 2014; Cameron et al., 2014a; Eames et al., 2013; Forster et al., 2013; King et al., 2012; Marsden et al., 2010; Perrin et al., 2010; Pfeiffer et al., 2014; Smith et al., 2012). Two studies were unclear, due to insufficient information to make a judgement (Pierce et al., 2009c; Shyu et al., 2010).

#### 3.5.3.2 Allocation concealment

For the majority of studies, allocation concealment was not reported or there was insufficient information to make a judgement (Bakas et al., 2009; Bishop et al., 2014; King et al., 2012; Marsden et al., 2010; Perrin et al., 2010; Pfeiffer et al., 2014; Pierce et al., 2009c; Shyu et al., 2010; Smith et al., 2012). Three studies reported procedures for allocation concealment that were deemed low risk of bias (Cameron et al., 2014a; Eames et al., 2013; Forster et al., 2013).

### **3.5.3.3 Blinding of participants and personnel**

In ten of the twelve cases, unclear risk of bias was assigned for this domain. In some cases this was due to having insufficient information to make a judgement (Bishop et al., 2014; Marsden et al., 2010; Perrin et al., 2010; Pierce et al., 2009c; Smith et al., 2012). In other cases, this was unclear as authors described how personnel were blinded but procedures for blinding participants were not described (Bakas et al., 2009; Cameron et al., 2014a; Eames et al., 2013; King et al., 2012; Pfeiffer et al., 2014; Shyu et al., 2010). Forster et al. (2013) reported procedures for both the participants and personnel and was regarded as low risk of bias. Blinding participants to some of these interventions can be difficult, given that the interventions are compared to controls.

### **3.5.3.4 Blinding of outcome assessment**

In seven of the twelve RCTs, unclear risk of bias was assigned for this domain, due to lack of reporting (Bakas et al., 2009; Bishop et al., 2014; Forster et al., 2013; King et al., 2012; Perrin et al., 2010; Pfeiffer et al., 2014; Pierce et al., 2009c; Shyu et al., 2010). In three of the twelve studies, low risk of bias was assigned as the blinding of outcome assessments was carried out appropriately (Cameron et al., 2014a; Eames et al., 2013; Smith et al., 2012).

One study (Marsden et al., 2010) was assessed as being at high risk of bias, as the research team who undertook secondary outcome measures were not blinded to group allocation, as it was reported there was limited project funds.

### **3.5.3.5 Selective reporting**

All studies were marked as low risk of bias as there were no concerns about selective reporting.

### **3.5.3.6 Incomplete outcome data**

In seven of the twelve studies, unclear risk of bias was assigned for this domain (Bakas et al., 2009; Bishop et al., 2014; Cameron et al., 2014a; Eames et al., 2013; King et al., 2012; Perrin et al., 2010; Shyu et al., 2010). Reasons included a lack of information regarding how data was imputed, and limited reporting of reasons for attrition across groups. Five studies were regarded as being low risk of bias for this domain (Forster et al., 2013; Marsden et al., 2010; Pfeiffer et al., 2014; Pierce et al., 2009c; Smith et al., 2012). In these cases, attrition rates were low and appropriate methods were used to impute missing data.

### 3.6. Effects of interventions

Twelve new studies were included in the current review to update the Legg et al. (2011) review, seven of which were appropriate for inclusion in the meta-analysis. These were pooled with studies previously identified by Legg et al. (2011) (table five). Five studies were excluded from the meta-analysis (Bishop et al., 2014; Cameron et al., 2014a; Perrin et al., 2010; Shyu et al., 2010; Smith et al., 2012) due to having insufficient data to compute. In the study by Bishop et al. (2014), outcomes measured were not relevant to the current review. The outcomes of interest were the same as Legg et al. (2011).

**Table 5: Summary of studies included in the meta-analysis**

<b>Outcome and subgroup</b>	<b>Legg et al. (2011) (previous review)</b>	<b>Current review</b>
<b>Informal caregiver stress or strain</b>		
<i>Teaching procedural knowledge</i>	Kalra et al. (2004)	Forster et al. (2013)
<i>Support and information</i>	(Mant et al., 2000; Yoo et al., 2007)	
<i>Psycho-educational</i>	(Draper et al., 2007; Hartke and King, 2003)	Eames et al. (2013)
<i>Other</i>		Marsden et al. (2010)
<b>Global measures of stress or distress</b>		
<i>Support and information</i>	Mant et al. (2000)	
<i>Psycho-educational</i>	Draper et al. (2007)	
<b>Anxiety (lying above the recommended clinical cut-point for symptoms and signs of anxiety)</b>		
<i>Teaching procedural knowledge</i>	Kalra et al. (2004)	
<b>Anxiety (continuous)</b>		
<i>Psycho-educational</i>		(Eames et al., 2013; King et al., 2012)
<b>Depression</b>		
<i>Teaching procedural knowledge</i>	Kalra et al. (2004)	
<i>Support and information</i>	(Mant et al., 2000; Pierce et al., 2004b)	Pierce et al. (2009c)
<i>Psycho-educational</i>	(Draper et al., 2007; Hartke and King, 2003)	(King et al., 2012; Pfeiffer et al., 2014)
<i>Other</i>		Bakas et al. (2009)
<b>Health related quality of life</b>		
<i>Teaching procedural knowledge</i>	Kalra et al. (2004)	
<i>Support and information</i>	Larson et al. (2005)	

The following outcomes were analysed as continuous variables: informal caregiver stress and strain, global measures of stress or distress, depression, health related quality of life. Means and standard deviations were used under the assumption that the data have a normal distribution. Anxiety was entered as a continuous outcome for the current review; however findings are included from the Kalra et al. (2004) study, identified by Legg et al. (2011), where this was entered as a dichotomous outcome.

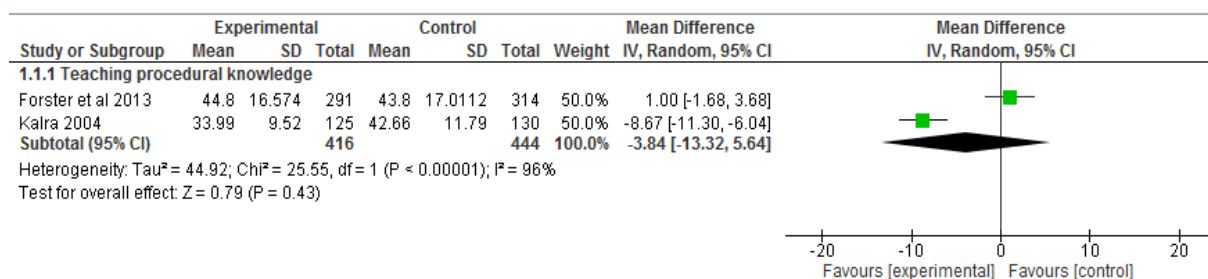
Both random effects and fixed effects were used. For the following outcomes: Global measures of stress or distress and Anxiety (lying above the recommended clinical cut-point for symptoms and signs of anxiety), a fixed effect model was used as each of the studies that were relevant to these outcomes were categorised in to different subgroups, therefore there were no comparisons to be made and the effect of interest remained the same. The random effects model was applied to all other outcomes (Informal caregiver stress and strain; Depression; Health related quality of life and Anxiety (continuous)). This was chosen as there was no restriction by assuming a common prevalence across studies, and conclusions could be drawn about the findings that can be generalised beyond the studies included within the review.

Findings from the meta-analysis are displayed graphically using forest plots. In all cases, the final follow up score data was entered into the meta-analysis.

### 3.6.1. Primary outcomes

#### 3.6.1.1 Informal caregiver stress and strain

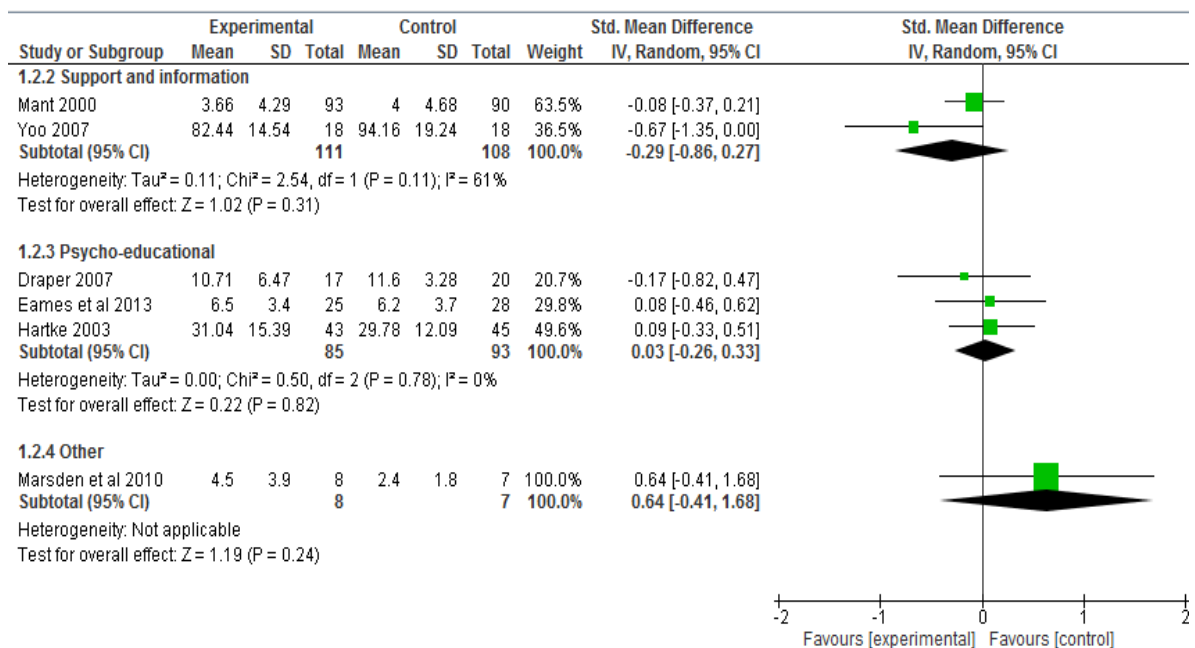
Eight of the nine studies that collected data on measures of informal caregiver stress and strain were computed in the meta-analysis.



**Figure 3: Experimental versus control: Outcome: Informal caregiver stress and strain (MD)**

### 3.6.1.1.1 Teaching procedural knowledge

In addition to one study from the previous review (Kalra et al., 2004), two studies assessed the effect of teaching procedural knowledge type interventions on informal caregiver stress and strain (Forster et al., 2013; Perrin et al., 2010). Findings from Perrin et al. (2010) could not be included in the meta-analysis, as there were insufficient data to compute. The author was contacted for additional information, but this was unavailable. Data from Kalra et al. (2004) and Forster et al. (2013), including 860 participants, were pooled to assess ‘teaching procedural knowledge’ on stress and strain using the Carer Burden Scale (CBS) (Elmstahl et al., 1996). The mean difference (MD) between the intervention and control group at the end of scheduled follow up was – 3.84 (95% confidence interval (CI) -13.32 to 5.64,  $P = 0.43$ ) showing statistical heterogeneity ( $I^2 = 96\%$ ) and no benefit of the teaching procedural knowledge group for reducing informal caregiver stress and strain.



**Figure 4: Experimental versus control: Outcome: Informal caregiver stress and strain (SMD)**

### 3.6.1.1.2 Support and information

No new studies included support and information type interventions for this particular outcome. Two studies were pooled in the meta-analysis from the previous review that included support and information interventions (Mant et al., 2000; Yoo et al., 2007). In total, 219 participants were included across these studies. Yoo et al. (2007) used a measure that was specifically developed for the study and Mant et al. (2000) used the Caregiver Strain Index (CSI) (Robinson, 1983) to measure informal stress and strain. The

pooled result, combined as a standardised mean difference (SMD), was - 0.29 (95% CI - 0.86 to 0.27, P = 0.31), with substantial statistical heterogeneity (P= 0.11, I<sup>2</sup> = 61%).

#### **3.6.1.1.3 Psycho-educational**

In addition to two studies from the previous review (Draper et al., 2007; Hartke and King, 2003) another study (Eames et al., 2013) was included as a psycho-educational type intervention (178 participants). One study (Eames et al., 2013) used the CSI (Robinson, 1983), one (Hartke and King, 2003) used the Burden Interview (Zarit and Zarit, 1983), and one (Draper et al., 2007) used the Relatives Stress Scale (Greene et al., 1982). The pooled result combined as a SMD was 0.03 (95% CI - 0.26 to 0.33, P = 0.82) showed no significant benefit for psycho-educational intervention group, with no statistical heterogeneity (P= 0.78, I<sup>2</sup> = 0%).

#### **3.6.1.1.4 Other**

Marsden et al. (2010) included an intervention regarded as 'other' (15 participants). Informal Caregiver Stress and Strain was measured using the CSI. The MD between the 'other' type of intervention and control group at the end of the scheduled follow up period was 0.64 (95% CI - 0.41 to 1.68, P= 0.24). This indicated no significant beneficial effect for this type of intervention when compared to control.

#### **3.6.1.2 Informal caregiver wellbeing at the end of the scheduled follow up.**

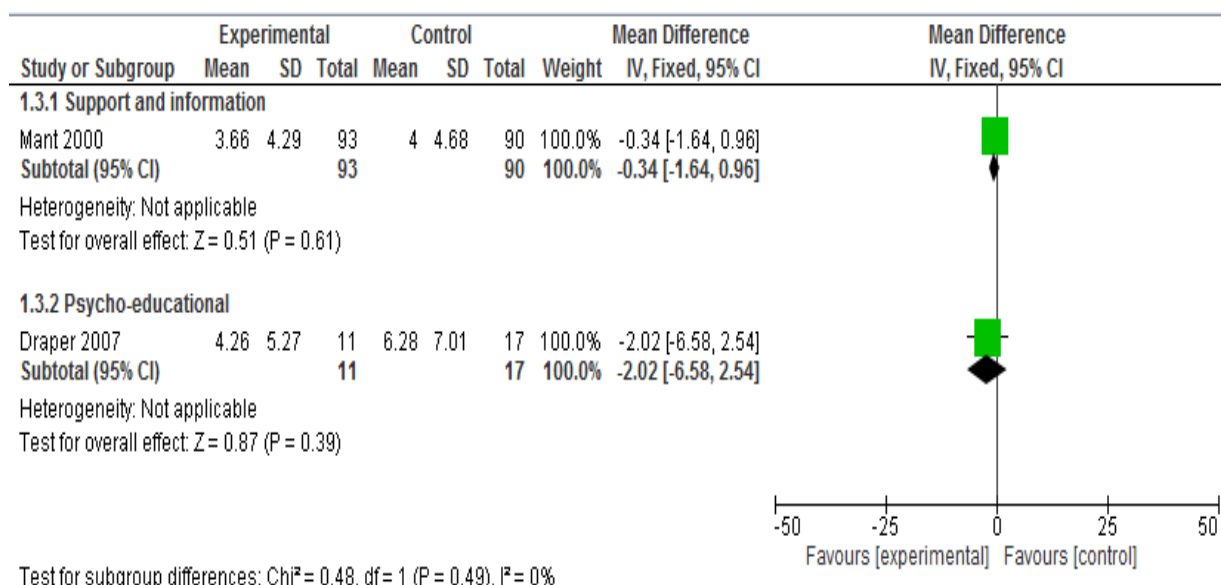
No studies in the previous review by Legg et al. (2011) collected caregiver-specific wellbeing outcomes. From the articles included in the current review, Cameron et al. (2014a) assessed Psychological Wellbeing using the 10 -item Positive Affect Scale. The data provided was insufficient for computing in the meta-analysis. No further information could be obtained from the author.



### 3.6.2. Secondary outcomes

#### 3.6.2.1 Global measures of stress or distress.

Two previously identified studies (Draper et al., 2007; Mant et al., 2000) collected data for this outcome using the General Health Questionnaire 28 (GHQ 28) (Goldberg, 1972). These were not pooled together in the meta-analysis, as they were each categorised as different intervention types.



**Figure 5: Experimental versus control: Outcome: Global measures of stress or distress**

##### 3.6.2.1.1 Support and information

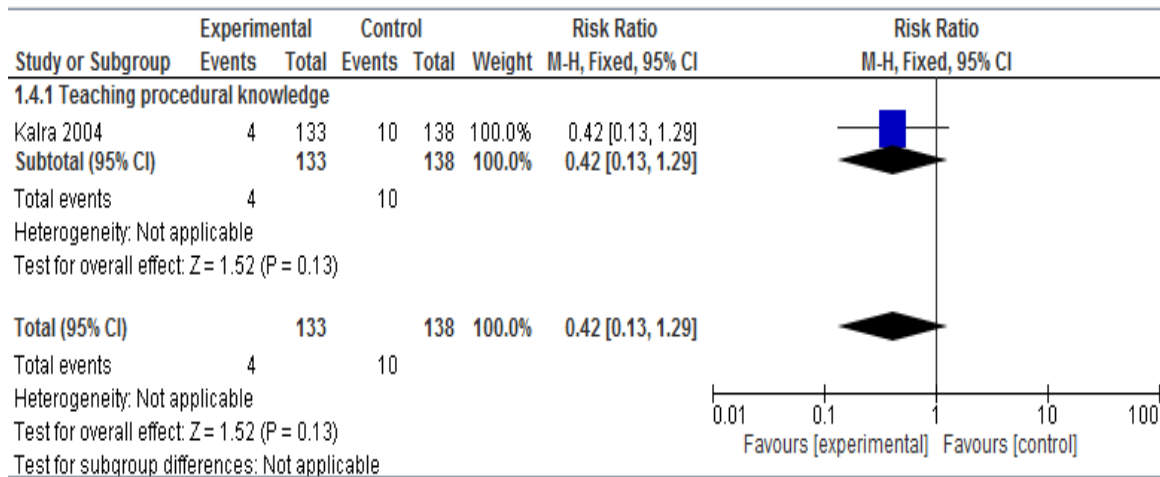
Mant et al. (2000) (including 183 participants) assessed the effects of a support and information intervention on carers levels of stress and distress. The MD between the 'support and information' intervention and control group at the end of the scheduled follow up period was - 0.34 (95% CI - 1.64 to 0.96, P= 0.61). This indicated no significant beneficial effect for support and information type interventions when compared to usual care.

##### 3.6.2.1.2 Psycho-educational

Draper et al. (2007), (including 28 participants) assessed the effects of a psycho-educational type intervention and found no significant difference between this and the wait-list comparator group. MD - 2.02 (95% CI - 6.58 to 2.54, P= 0.39) on level of stress and distress.

### 3.6.2.2 Anxiety

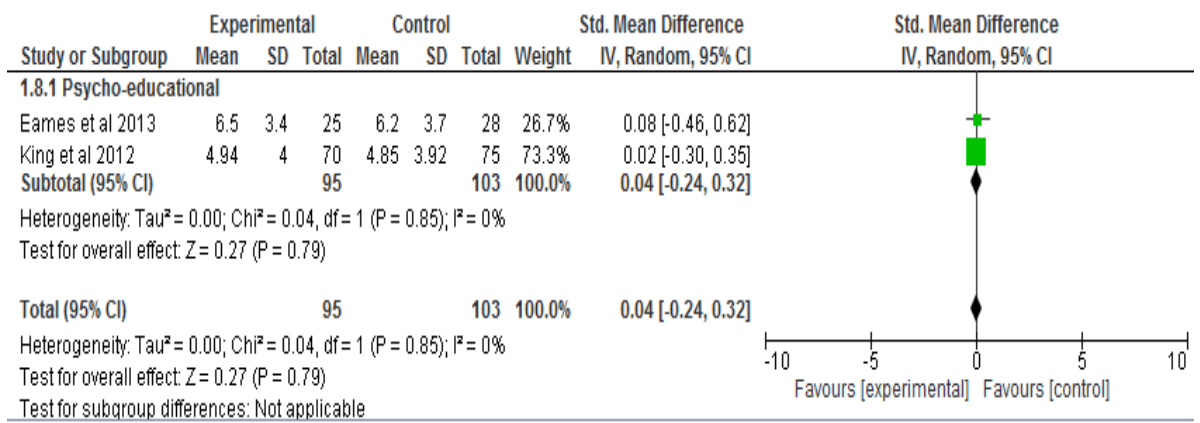
Three studies collected data on measures of anxiety, one was entered into the meta-analysis as a dichotomous outcome and the other two were entered as continuous outcomes.



**Figure 6: Experimental versus control: Outcome: Anxiety (lying above the recommended clinical cut off points for symptoms and signs of anxiety)**

#### 3.6.2.2.1 Teaching procedural knowledge

One study identified by Legg et al. (2011) including 271 participants (Kalra et al., 2004) assessed the effects of a ‘teaching procedural knowledge’ intervention on measures of anxiety using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). There was no significant difference between the intervention and control group: risk ratio (RR) 0.42 (0.13 to 1.29, P= 0.13) on level of anxiety.



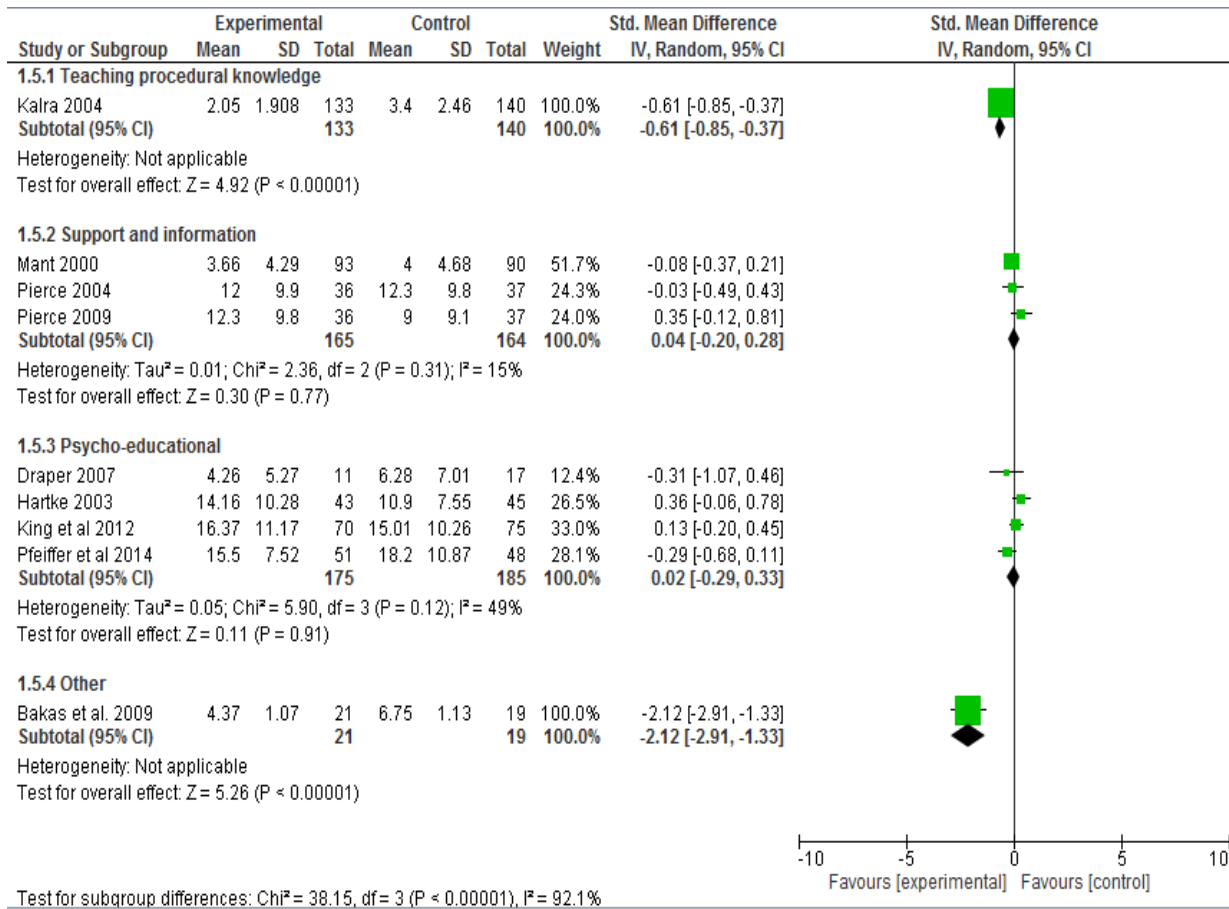
**Figure 7: Experimental versus control: Outcome: Anxiety (continuous)**

### 3.6.2.2.2 Psycho-educational

Two studies (Eames et al., 2013; King et al., 2012) (198 participants) assessed the effects of a ‘psycho-educational intervention’ on measures of anxiety using the HADS (Eames et al., 2013) and Tension Anxiety 5 item sub scale of the Profile of Moods scale short form (King et al., 2012). The pooled result combined as a SMD was 0.04 (95% CI – 0.24 to 0.32, P= 0.79) with no statistical heterogeneity (P= 0.85, I<sup>2</sup> = 0%) and no significant benefit for the psycho-educational intervention group.

### 3.6.2.3 Depression

Nine studies collected data on measures of depression



**Figure 8: Experimental versus control: Outcome: Depression**

#### 3.6.2.3.1 Teaching procedural knowledge

One new study assessed the effect of ‘teaching procedural knowledge’ on measures of depression (Perrin et al., 2010). This could not be entered in to the meta-analysis, as there was insufficient data to compute. The author was contacted for additional information, but this could not be provided. One previously identified study (Kalra et al., 2004) (173 participants) assessed the effect of this type of intervention on measures of depression using the HADS (Zigmond and Snaith, 1983). The MD between the intervention and comparison group at the end of scheduled follow up was -0.61 (5% CI – 0.85 to -0.37, P < 0.0001) in favour of the teaching procedural knowledge type group.

### **3.6.2.3.2 Support and information**

Two studies (Cameron et al., 2014a; Pierce et al., 2009c) were included in addition to the two previously identified studies (Mant et al., 2000; Pierce et al., 2004b). Findings from the study by Cameron et al. (2014a) could not be included in the meta-analysis, as the data was not reported as medians and standard deviations and further data could be obtained from the author.

A total of 329 participants were included in the studies that assessed 'support and information' type interventions on measures of depression (Mant et al., 2000; Pierce et al., 2004b; Pierce et al., 2009c). One study (Mant et al., 2000) used the GHQ 28 (Goldberg, 1972) to measure depression and two studies (Pierce et al., 2004b; Pierce et al., 2009c) used the Centre for Epidemiologic Depression Scale (CES-D) (Radloff, 1977). The pooled result combined as a SMD was 0.04 (95% CI - 0.20 to 0.28,  $P= 0.77$ ) with no significant heterogeneity ( $P= 0.31$ ,  $I^2 = 15\%$ ) and no significant beneficial effect of the support and information intervention group.

### **3.6.2.3.3 Psycho-educational**

Two studies using psycho-educational interventions (King et al., 2012; Pfeiffer et al., 2014) were included in addition to two previously identified studies (Draper et al., 2007; Hartke and King, 2003) (360 participants). One study (Draper et al., 2007) used the GHQ 28 (Goldberg, 1972) and three used the (Hartke and King, 2003; King et al., 2012; Pfeiffer et al., 2014) used the CES-D (Radloff, 1977). The pooled result combined as a SMD was 0.02 (95% CI - 0.29 to 0.33,  $P = 0.91$ ) with moderate heterogeneity ( $P= 0.12$ ,  $I^2 = 49\%$ ) and no significant benefit of this type of intervention for reducing depression.

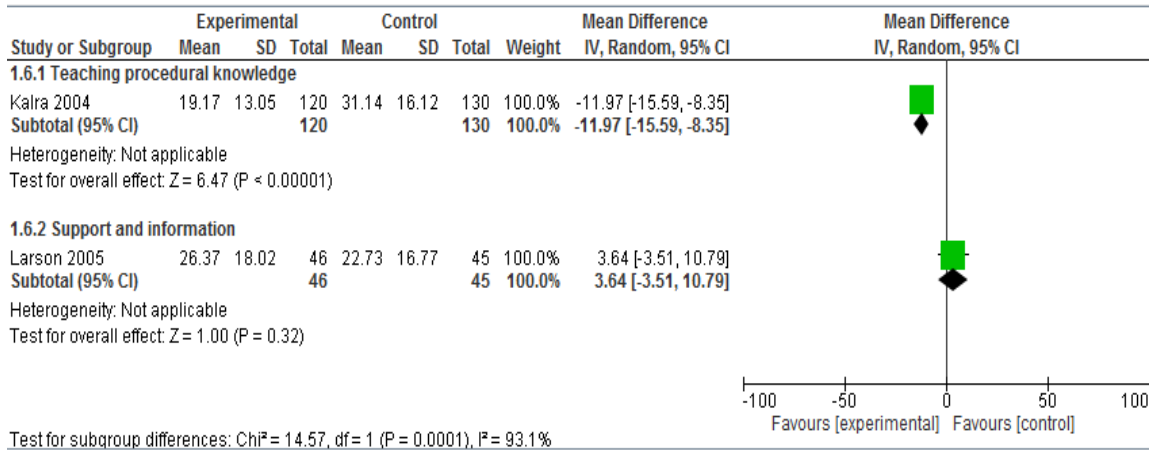
### **3.6.2.3.4 Other**

Two studies (Bakas et al., 2009; Smith et al., 2012) assessed the effects of interventions that were categorised as 'other' on depression. Findings from the study by Smith et al. (2012) could not be included in the meta-analysis; insufficient data was available to compute.

Forty participants were included in a study by Bakas et al. (2009). Depression was assessed using the Patient Health Questionnaire 9 (PHQ 9). The MD between the 'other' type intervention and attention control group at the end of the scheduled follow up period was -2.12 (95% CI - 2.91 to -1.33,  $P= 0.00001$ ). This indicated a significant benefit for this 'other' type intervention for reducing depression.

### 3.6.2.4 Health related quality of life

Five studies assessed health-related quality of life (HRQoL). Two were computed in the meta-analysis.



**Figure 9: Experimental versus control: Outcome: Health Related Quality of Life**

#### 3.6.2.4.1 Teaching procedural knowledge

No additional studies were identified for the teaching procedural knowledge type interventions that assessed HRQoL. Legg et al. (2011) identified a study by Kalra et al. (2004) which assessed health-related quality of life (HRQoL) using the EuroQoL-5D (EQ-5D) (EuroQol Group, 1990) The study found a significant difference in health-related quality of life in favour of the experimental intervention: MD -11.97 (95% CI -15.59 to -8.35, P < 0.0001).

#### 3.6.2.4.2 Support and information

No additional studies were found for support and intervention type interventions that assessed HRQoL. Larson et al. (2005) and Mant et al. (2000) were previously identified. Larson et al. (2005) assessed HRQoL using the EQ-5D (EuroQol Group, 1990) and Mant et al. (2000) assessed HRQoL using the Short Form 36 (SF-36) (Medical Outcomes Trust, 1993). It was not possible to pool data from these two studies as the SF-36 produces eight health domain scores, one psychometrically based physical component summary score and one mental component summary score not one total score. Larson et al. (2005) showed no significant benefit for 'support and information' type interventions on measures of HRQoL, MD 3.64 (95% CI - 3.51 to 10.79, P = 0.32). In the study by Mant et al. (2000) significant improvements were evident in five of 8 SF-36 health domains. These included energy and vitality, mental health, pain, physical function and general health

perception. These favoured the support and information group (data drawn from Mant 2000 paper).

#### **3.6.2.4.3 Other**

Two studies assessed HRQoL. One study (Marsden et al., 2010) assessed HRQoL using the Stroke Impact Scale (SIS) and one study (Shyu et al., 2010) assessed HRQoL using the medical outcomes study SF- 36. It was not possible to pool data from these two studies as the SF-36 produces eight health domain scores, one psychometrically based physical component summary score and one mental component summary score not one total score. The SIS produces nine domain scores rather than one total score.

#### **3.6.2.5 Informal caregiver satisfaction**

Two studies measured satisfaction (Perrin et al., 2010; Pfeiffer et al., 2014), in addition to the three studies identified by Legg et al. (2011) that also measured satisfaction (Grant et al., 2002; Hartke and King, 2003; Mant et al., 2000).

Pfeiffer et al. (2014) assessed the impact of the Problem Solving Intervention on caregivers' satisfaction with leisure time using the Leisure Time Satisfaction questionnaire (Stevens et al., 2004). This is a Likert scale ranging from 0 (not at all) to 2 (a lot) with a total score between 0 – 12 and higher scores indicating greater satisfaction. Twenty-eight participants from the intervention group returned questionnaires to measure their satisfaction. The mean satisfaction score for the intervention group was 91.4 (SD \_ 10.9). 96.4% of participants were "mostly satisfied" or "very satisfied" with frequency and duration of calls. 89.3% of caregivers rated face-to-face contact as "very important." A preference for between one and three additional face-to-face contacts during 12 months was expressed by 21.5% of participants. 39.3% of carers would have liked an earlier onset and longer maintenance period (35.7%) of the intervention.

Perrin et al. (2010) assessed satisfaction with the 'Transition Assistance Programme'; an intervention programme designed for stroke carers. This was assessed using an adapted form from the Veteran Affairs Care Coordination and Home Tele-health Patient Satisfaction Survey. This is a 5-point Likert scale, with 1 being not at all satisfied and 5 being completely satisfied. The study reported that the four items for assessing satisfaction with the program were significantly inversely correlated with caregiver strain ( $r = -0.44, p < 0.01$ ) and depression ( $r = -0.53, p < 0.01$ ). As caregiver satisfaction with the Transition Assistance Programme increased, negative psycho-social factors e.g. strain and depression was reduced. Authors suggested that this finding, coupled with a high rate of

program satisfaction (9.5 out of 10 (SD = 0.95)) suggests that this intervention helped coping among carers.

### **3.6.2.6 Informal caregiver mortality**

No studies collected data on informal caregiver mortality in the Legg et al. (2011) review. In the current review, one study reported that a carer had died (Bishop et al., 2014). Other studies reported deaths overall, yet it is not always clear whether these are the carers or the stroke survivors (Forster et al., 2013; Pierce et al., 2009c).

## **3.7. Discussion**

### **3.7.1. Summary of main results**

This review updated that conducted by Legg et al. (2011), to establish whether any current interventions are effective in reducing negative outcomes in carers after stroke, and if the benefits of these interventions are greater in any pre-defined intervention subgroup. The study by Kalra et al. (2004), identified by Legg et al. (2011) showed some support for interventions that aimed to enhance procedural knowledge on depression and health related quality of life. However Training Caregivers After Stroke (TRACS), a multi-centre trial of the same intervention reported by Kalra et al. (2004) reported no significant effect on caregiver outcomes.

From the new studies included in the review, Bakas et al. (2009) showed a statistically significant benefit for an intervention (included in the 'other' category) for reducing depression when compared with the attention control. There was a 2.64 point difference in the PhQ -9 scores between the two groups. This was statistically significant ( $p = <0.00001$ ) and also clinically significant (i.e. clinically meaningful) to carers of stroke survivors. The Telephone Assessment and Skill Building Kit (TASK) intervention by Bakas et al. (2009) included elements of all three of the categories used for defining interventions e.g. information about stroke, providing physical and instrumental care and stress management strategies. Some aspects of the intervention did not fit in to the defined categories: maintaining realistic expectations, and screening for depressive symptoms.

It is difficult to draw conclusions about which components of this intervention are effective for reducing depression. However, it suggests that other aspects of interventions could be considered, aside from those that are often included e.g. information, support, psycho-education and teaching carers' knowledge. Other than the TRACS study (Forster et al., 2013), the review findings are based on small scale studies, limiting their



generalisability. Current evidence is insufficient for determining which type of intervention is most effective for reducing negative carer outcomes, therefore further research is necessary.

### **3.7.2. Quality of the evidence**

The current review evidence is based on 20 RCTs of interventions for carers of stroke survivors, of which seven were included in the meta-analysis with studies from the previous review (Legg et al., 2011).

It is difficult to draw conclusions about the findings from these studies, as numerous factors play a role in effectiveness of interventions for carers of stroke survivors e.g. timing, nature of the caring situation, type of intervention, length of intervention, and characteristics of carers. Additionally, there are limitations regarding the conduct of the individual RCTs that raise questions about the validity of their findings. For example, the majority of RCTs were small in scale, meaning the statistical power to detect a difference between the intervention and control groups was compromised. Small samples also meant it was often difficult to detect the impact of particular variables e.g. gender, age on the outcomes of interest. Often, samples were not representative of a wider population of carers of stroke survivors, as sampling techniques introduced bias.

Based on an assessment of the quality of evidence using the Risk of Bias tool (Higgins and Green, 2011), few studies indicated a high risk of bias, however many remained 'unclear' on a number of the domains. These studies may be at high risk of bias on particular domains, but in many cases information is insufficient to make judgement.

### **3.7.3. Applicability of the evidence**

The review aimed to establish the effectiveness of interventions for carers of stroke survivors for reducing negative outcomes e.g. burden, depression. As trial participants (carers) are not patients defined by a condition such as stroke, substantial variation is apparent in terms of their characteristics e.g. gender, ethnicity, relationship to stroke survivor etc. This raises questions about the applicability of findings. This variation is not surprising, given that carers are not defined consistently across studies; indeed only two of the new studies provided a specific definition of a carer (Bishop et al., 2014; Marsden et al., 2010).

There was also variability in the 'carer inclusion criteria' for each study; some were more explicit than others. Carers were commonly selected based on criteria such as age, time spent caring, ability of the stroke survivor for whom they are providing care, and language.

Carers were also selected for practical reasons associated with the intervention e.g. access to a landline telephone (King et al., 2012; Perrin et al., 2010). This variation means the individual studies lack generalisability, and comparing interventions for effectiveness becomes difficult, as a number of factors can contribute to their success or failure, including carer and intervention based characteristics. Stroke survivors are often excluded based on communication and cognitive deficits, leading to their carers being excluded. This could lead to a particular sub-group of carers being involved in research of this nature and a neglect of those in circumstances that are more complex.

Although research has identified the positive aspects associated with caring (Mackenzie and Greenwood, 2012); burden and negative consequences that are likely to affect carers are well- documented (Adelman et al., 2014; Greenwood et al., 2008; Saban and Hogan, 2012). The review found insufficient evidence for the effectiveness of interventions aimed at reducing such negative outcomes.

A completeness of understanding for successfully supporting a range of carers may involve moving beyond intervention types (e.g. educational, informational) to consider other factors that contribute to effectiveness, e.g. delivery, nature of caring situation, needs, timing and implementation (Senn et al., 2013).

#### **3.7.4. Potential biases in the review process**

There was minimal bias in the review process. A comprehensive search, based on input from an information specialist was carried out, and authors were contacted where appropriate. However, this review was limited to English language. This could lead to potential bias regarding the studies that have been included and reported.

Strategies were employed in the conduct of the review to reduce bias; two reviewers independently made judgements at both stages of assessing articles for eligibility (screening titles and abstracts and assessing full texts). Data extraction and assessment of methodological quality were also both assessed independently by two reviews. A third reviewer was introduced where any discrepancies were apparent throughout the process.

#### **3.7.5. Agreement and disagreements with other reviews**

Cheng et al. (2014) conducted a systematic review of published and unpublished studies of psychosocial interventions for stroke family carers, based on a search of English and Chinese databases and grey literature sources. The review evaluated the effectiveness of psychosocial interventions for family caregivers of stroke survivors on quality of life,

psychosocial wellbeing and physical wellbeing, in addition to the use of healthcare resources by stroke survivors. Studies included RCTs and results were statistically pooled where possible.

Two independent reviewers, using the Critical Appraisal Checklists from the Joanna Briggs Institute-Meta Analysis of Statistical Assessment and Review Instrument (JBIMAStARI) assessed the methodological quality of the eligible studies. Eighteen studies were included. Findings indicated that psycho-educational interventions aimed at providing carers with problem solving, stress, coping and caring skills have more positive impacts on the carers' psychosocial wellbeing and a reduction in the use of healthcare resources by stroke survivors. Authors concluded that evidence on the effects of these types of psycho-social interventions was limited and more RCTs of psycho-educational programs are required to examine factors such as dose and format.

Another systematic review by White et al. (2015) provided a narrative account of the evidence for the effectiveness of interventions for carers of stroke survivors between 2002 and 2013. This included published studies following a search of electronic databases. Eighteen RCTs were included; a narrative summary was provided and no meta-analyses were conducted. Data extraction included, the setting, sample characteristics, intervention details including mode of delivery, outcome domains, and effects reported in the studies. Two reviewers independently assessed the methodological quality of each study using the Rapid Critical Appraisal Checklist for RCTs (Melnik and Fineout-Overholt, 2011).

Interventions were multi-faceted, including elements of information, education, support, and skill building. A variety of outcomes were measured, including psychological distress, caregiver burden, and quality of life. Half of the interventions were guided by theory. Findings indicated interventions with a skill-building component were more likely to show a significant effect on outcomes such as psychological distress and burden. However, studies were limited, as they had insufficient power to detect significant differences and few studies included ethnic minority groups, making findings difficult to generalise. Authors concluded that interventions could consider the use of technology e.g. internet as a mechanism for intervening with carers.

The main difference between Cheng et al. (2014) and the current review is their specific focus on psycho-social type interventions and the different a priori outcomes of interest (psycho-social wellbeing, physical health and quality of life, and use of healthcare resources by stroke survivors). In their review, studies were not limited to RCTs and additional studies were included. Despite the aim of the review being different, some of

the included studies in the current review are the same as those identified by Cheng et al. (2014), although these were categorised slightly differently across the two reviews.

Bakas et al. (2009) and Marsden et al. (2010) were categorised as 'other' in the current review, whereas Cheng et al. (2014) regarded these as psycho-educational interventions. Perrin et al. (2010) and Shyu et al. (2010) were categorised as 'teaching procedural knowledge' type interventions in the current review, however these were also categorised as psycho-educational by Cheng et al. (2014). Pierce et al. (2009b) was considered a social type intervention in both reviews. This has implications in terms of findings with regards to identifying effectiveness of interventions based on their 'type.' With variability in how different researchers define these, this may prove difficult.

The measure used to assess quality used by Cheng et al. (2014) was different, however there are no clear disagreements regarding methodological quality in the studies that are common to both reviews (Bakas et al., 2009; Marsden et al., 2010; Perrin et al., 2010; Pierce et al., 2009c; Shyu et al., 2010). Despite some differences in the two reviews, the current review agrees that drawing conclusions about the effectiveness of interventions for carers remains difficult, as there are limited studies for each of the types of interventions and often findings are inadequately reported.

The systematic review by White et al. (2015) is similar to the current review, although this provides a narrative overview of the evidence on the effectiveness of interventions for family carers of stroke survivors. Four additional studies (Bishop et al., 2014; Cameron et al., 2014a; Pfeiffer et al., 2014; Shyu et al., 2010) were identified in the current review, since the search conducted by White et al. (2015).

Although the two reviews are similar, White et al. (2015) used the Rapid Critical Appraisal Checklist (Melnik and Fineout-Overholt, 2011); therefore making comparisons in methodological quality is difficult, given that the Risk of Bias Tool (Higgins et al., 2011) was used in the current review. The reliability of such checklists is also questionable (Emerson et al., 1990; Schulz et al., 1995), raising questions about the quality of the studies included in the review by White et al. (2015).

Despite such differences, some conclusions made by White et al. (2015) remain similar to the current review; multifaceted interventions were found to be more likely to increase positive outcomes, this is consistent with the finding that the 'other' type interventions that cannot be categorised in to one intervention type showed some promise for reducing depression. White et al., (2015) also emphasised the importance of considering factors

such as timing of interventions, delivery, context and addressing cultural and individual differences. These are factors to be considered in light of the current review findings.

In conclusion, although there are some differences across these reviews, the current review is in agreement with both Cheng et al. (2014) and White et al. (2015) as there is insufficient evidence to determine which types of interventions are most effective for a range of carer outcomes.

### **3.7.6. Implications for clinical practice and research**

In reviewing the evidence, it is important to consider the reporting of both statistical and clinical significance. Traditionally, tests of statistical significance have been used to evaluate the effects of interventions based on their effect sizes. However, a statistically significant effect size does not always reflect the extent to which findings are clinically significant (Page, 2014). Clinical significance is often used interchangeably with the term 'clinically meaningful differences' and refers to the extent to which a finding is considered important or worthwhile enough to result in changes in the delivery of care (Page, 2014). It is this type of effectiveness that is of importance to the population of study, in this case, carers of stroke survivors.

In evaluation of complex interventions which include RCTs and process evaluations, differences between qualitative and quantitative findings can emerge. Carers may provide positive feedback about interventions, even when they fail to show a statistical or clinical effect. Cameron et al's (2014) feasibility and pilot randomised controlled trial of the Timing it Right Stroke Family support Programme, provides an example of this disparity, as statistically significant group differences could not be established, yet some carers expressed satisfaction with support that they received throughout the intervention. The extent of their satisfaction was influenced by an array of complex factors including the carers' personal characteristics, their pre-existing experiences and knowledge of providing care and navigating support, and the stroke survivors' severity.

Due to the complexities of carers' experiences, it is becoming increasingly important for researchers and health and social care professionals to determine whether interventions are statistically *and* clinically significant. Both are likely to influence whether interventions are commissioned in the current health care system.

Additionally, it is important to understand the mechanisms through which interventions have an impact on behaviour change in carers of stroke survivors. Without this, research implications remain limited as nothing is learned following a negative trial regarding

improvements required for the intervention (Improved Clinical Effectiveness through Behavioural Research Group, 2006).

The Improved Clinical Effectiveness through Behavioural Research Group (2006) argue that RCTs of interventions aiming to change behaviours in a given population e.g. carers could be made more effective with the appropriate application of theories. This is necessary for making clear links between the interventions and their impact on outcomes, and is important for developing and evaluating new interventions for carers of stroke survivors. With this understanding, current interventions could be refined accordingly.

Eleven of the twenty included studies included a conceptual model or theoretical framework (Bakas et al., 2009; Bishop et al., 2014; Cameron et al., 2014a; Eames et al., 2013; Grant et al., 2002; Hartke and King, 2003; King et al., 2012; Pfeiffer et al., 2014; Pierce et al., 2004b; Pierce et al., 2009c; Smith et al., 2012). Examples included: Stress Coping Model, Stress Process Model, Problem Solving Model, Health Belief Model, Friedemann's framework of systemic organisation and the Timing it Right Framework. In the majority of cases, these models guided the design of the intervention, aside from Bakas et al. (2009) who used a conceptual model based on Lazarus' theory to evaluate their intervention.

Although these studies attempted to include a theoretical basis for their interventions, an adequate description of the models or frameworks was lacking. It was difficult to determine the links between these and the resultant intervention components. Using theory alone is also insufficient without considering how this is operationalised and whether this is appropriate for the context. If theories are poorly operationalised, they can potentially divert attention away from factors that influence the outcomes of interest (Improved Clinical Effectiveness through Behavioural Research Group, 2006).

In studies where there was no theoretical understanding provided, there was also little description of the content of the intervention and its development (Kalra et al., 2004; Larson et al., 2005; Marsden et al., 2010; Shyu et al., 2010). Limitations in articles, complexity of some interventions and lack of agreement commonly account for this (Conn and Groves, 2011; Craig et al., 2008); however, details should be reported adequately to determine the elements important for success (Lokker et al., 2015).

RCTs should also work towards including process evaluations to clarify why certain interventions work or fail to work in a given context. Only one study included a detailed process evaluation (Forster et al., 2013). This, in conjunction with measures of statistical

and clinical effectiveness is particularly important for successfully implementing complex interventions (Proctor et al., 2013).

### **3.8. Conclusions**

The review demonstrates that current evidence is insufficient for determining which type of intervention is most effective for reducing negative carer outcomes. Only one intervention showed a significant reduction in depression (Bakas et al., 2009), in addition to the previous identified 'teaching procedural knowledge' type intervention' regarded as promising for reducing depression and increasing quality of life when compared to usual care (Kalra et al., 2004).

Bakas et al. (2009) included a conceptual model to evaluate the intervention. Some support for its use was provided in their discussion commentary, however, the 'active ingredients' and the mechanisms by which the intervention may reduce depression was not explained. Additional research is warranted to develop an intervention with a theoretical basis to gain an understanding of the mechanisms that contribute to their effectiveness or ineffectiveness. IM provides a framework for drawing upon behaviour change theories throughout each stage in the process of developing interventions. The following chapter focuses on this method in more detail, including its strengths and limitations and how it is applied in this study.

### 3.9. Addendum: Updated evidence 2017

An updated search in August 2017 identified four additional RCTs since studies were identified in February 2015 to update the Legg et al. (2011) review:

**Table 6: Included studies following an update**

Authors and date	Study title
Kuo et al. (2016)	A home-based training programme improves family caregivers' oral care practices with stroke survivors: a randomised controlled trial.
Forster et al. (2015)	Cluster Randomized controlled trial. Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care.
İnci and Temel (2016)	The effect of a support programme on the resilience of female family caregivers of stroke patients: Randomised controlled trial.
Lindley et al. (2017)	Family-led rehabilitation after stroke in India (ATTEND): a randomised controlled trial.

These studies have not been included or added to the meta-analysis in this updated systematic review. The review intended to establish the effectiveness of interventions for reducing negative outcomes in carers of stroke survivors to inform how the intervention presented in this thesis could be developed, based on available evidence at the time (February 2015).

Findings from these four studies have not impinged upon and are unlikely to alter conclusions stating current evidence (based on 20 studies) is insufficient for determining which type of intervention is most effective for reducing negative carer outcomes. Kuo et al (2016) trialled an oral intervention which showed significant improvements in carers' self efficacy and knowledge, but provided no contributions about the best strategies for reducing negative outcomes in carers. İnci and Temel (2016) found a significant difference between their support programme and control group, for reducing carer burden, yet this was based on a small sample size (n=34 experimental group, n=34 control group). The interventions included in the two large scale trials did not show a reduction in negative carer outcomes, including carer burden (Forster et al., 2015; Lindley et al., 2017).

These four studies are briefly considered in the discussion chapter (nine) regarding how they impact upon, challenge, and inform my proposed intervention.



## **4. Chapter 4: Using an Intervention Mapping approach to develop an intervention for carers of stroke survivors**

### **4.1. Introduction**

Chapter three outlined the current evidence for the effectiveness of interventions for carers of stroke survivors. Conclusions suggested considering a method which guides the selection of appropriate behaviour change theories for developing future complex interventions in this population. This chapter starts by defining complex interventions, and then considers MRC guidance for developing complex interventions (Craig et al., 2008; Craig and Petticrew, 2013), followed by the role of theory in behaviour change and intervention research. Following this, methods for developing health based behaviour change interventions are introduced, including IM (Bartholomew et al., 2011) and justification for its use in this study.

### **4.2. Complex interventions**

Complex interventions are likely to be required to address carer needs, given the complexities of their experiences and their increased risks of carer burden. Although complex interventions are characterised by their multiple and interacting components and additional dimensions of complexity e.g. implementation difficulties (Moore et al., 2015), they have other characteristics that must be considered. These include the behaviours required by those delivering and receiving the intervention; the number of levels targeted by the intervention (e.g. individual, organisational); amount and variability of outcomes; and the flexibility and extent to which the intervention can be tailored to address relevant outcomes in a target population (Craig et al., 2008). The number of components and range of effects may vary widely in different complex interventions.

### **4.3. Medical Research Council (MRC) guidance for developing complex interventions**

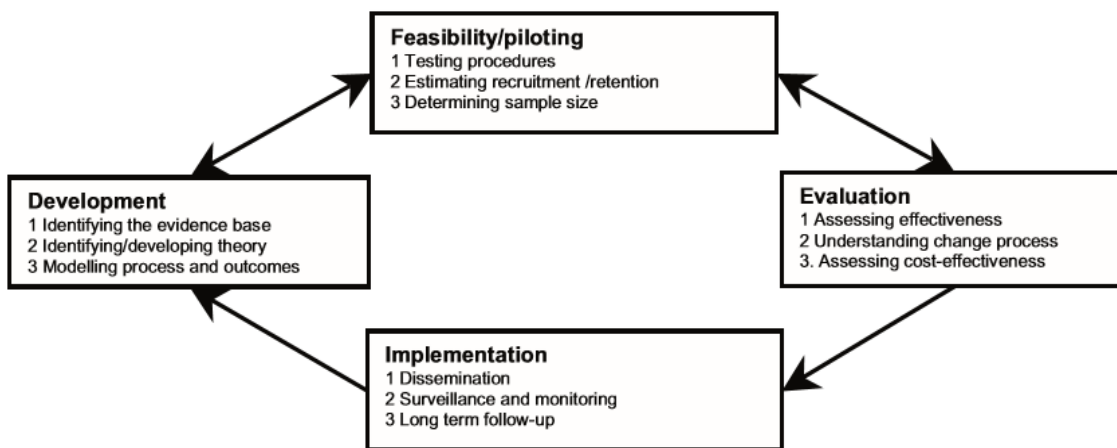
Complex interventions present numerous problems for researchers and evaluators, in addition to practical and methodological difficulties attached to conducting any successful evaluation. The MRC published a framework for designing and evaluating complex interventions in 2000 to assist researchers and research funders to adopt appropriate methods in their research practice. This was a widely cited and influential framework (Campbell et al., 2000).

A revised, updated version was published in 2008 (Craig et al., 2008), providing a more flexible and less linear model of complex intervention design and evaluation. This gives more weight to the development and implementation, in addition to evaluation, and provides examples of successful approaches used to develop and evaluate complex interventions, ranging from clinical trials to natural experiments (Craig et al., 2008).

The updated guidance in 2008 intended to encourage a phased, iterative approach to researching complex interventions, with emphasis on careful development work and questions about implementation (Craig et al., 2008). The authors formed a diagrammatical representation of stages in the development, evaluation, and implementation of complex interventions, outlined in the following section.

#### 4.3.1. Development, evaluation, and implementation of complex interventions

According to MRC guidance, the process from development through to implementation of a complex intervention takes different forms. The main stages in the process including key functions and activities are outlined. Arrows represent main interactions between phases. Although it is useful to think in terms of stages, often these will not follow a linear or even a cyclical sequence (Thomson et al., 2004).



**Figure 10: Key elements of the development and evaluation process**

To achieve best practice, Craig et al. (2008), argued complex interventions should be developed systematically, using the best available evidence and appropriate theories. Interventions should be tested using a carefully phased approach, starting with a series of pilot studies, before moving on to an exploratory then definitive evaluation. Following this

process, results should be widely disseminated and further research should assist with monitoring the implementation process.

The first two key considerations outlined in the development stage are relevant to this study. For 'identifying the evidence base' the authors recommend conducting a systematic review to identify relevant, existing evidence. This can involve updating an existing review and maintaining this as the intervention development and evaluation proceeds. For 'identifying/ developing theory' the authors emphasised the importance of theory for enhancing the likelihood of an effective intervention compared to a purely empirical or pragmatic approach, and understanding the processes of change. This can be achieved by drawing upon existing evidence and theory, supplemented with additional research and involvement from stakeholders. Numerous competing or overlapping theories could be used here; appropriate theories based on the subject should be identified.

Although Craig et al. (2008) expect that experience and evidence will continue to accumulate and should be used to keep guidance up to date in future, the current recommendations are vital for building an evidence base that informs policy and practice and have informed thinking in this study.

It should be possible to reduce carer burden by targeting behaviours of those who are at risk, and behaviours of health professionals and significant others who are responsible for ensuring effective, evidence based practice (Michie et al., 2009b). Behaviour change theories can be incorporated in this type of intervention, as advocated by the MRC guidance (Craig et al. 2008). The following discussion focuses on the role of theory in behaviour change and intervention research. Attention is drawn to the reasons that could account for ineffective interventions and the advantages of using theory in intervention design. It also includes the challenges associated with using theory, which may account for why researchers continue to develop interventions where this is lacking.

#### **4.4. The role of theory in behaviour change and intervention research**

Effective behaviour change interventions exist, targeting individual, community and population levels (Abraham et al., 2009; Albarracín et al., 2005; Michie and West, 2013), yet there are examples of ineffective interventions with limited and varied effects (Coleman, 2010; Summerbell et al., 2005). Numerous reasons could account for this finding, examples being a lack of rationale for the chosen intervention and inappropriate methods used to design the interventions (Davies et al., 2010; Van Bokhoven et al., 2003).

However, it is difficult to determine the reasons for ineffective interventions without a detailed description of the stages of intervention development and its components, and the assumptions about how the intervention should work (causal mechanisms) (Schaalma and Kok, 2009). Therefore, efforts ought to be made towards maximising the effectiveness of interventions, in addition to better reporting (Davis et al., 2015). This further emphasises the importance of the theory, as outlined in MRC guidance (Craig et al., 2008).

There are several reasons for using theory in intervention design. Firstly, the factors associated with a given behaviour and the determinants of change can be identified and appropriately targeted by the intervention (Hardeman et al., 2005; Michie et al., 2008). Behaviour change techniques can also be selected and refined accordingly (Michie and Prestwich, 2010; Rothman, 2004). Secondly, theoretical mechanisms of action (i.e. mediators) can be investigated to establish how the intervention has an effect (Rothman, 2004), so interventions can be refined efficiently (Michie and Abraham, 2004; Rothman, 2004). Thirdly, theory provides a summary of knowledge around how to make behavioural changes across different populations, behaviours and contexts. Finally, using theory as part of an intervention means this can be tested, leading to the development of more useful theories, which subsequently support intervention optimisation (Rothman, 2004).

Although the advantages of theory have been established, researchers often design behaviour change interventions without reference to theory (Davis et al., 2015; Prestwich et al., 2014). Establishing whether interventions based on theory are more effective than those that are not based on theory is a complex task (Davis et al., 2015). Evidence is mixed, as some reviews have found a positive association (Albada et al., 2009; Albarracín et al., 2005; Taylor et al., 2012) yet others have found either a negative association or no association at all (Gardner et al., 2011; Stephenson et al., 2000).

This mixed picture of evidence leads to attempts to understand why this may be the case. Poor application of theory can be a contributing factor. Michie and Prestwich (2010) conducted a review including 29 studies to investigate the application of theory using a 19 item coding scheme. Only 10% of studies including theory based interventions documented links between behaviour change techniques and theoretical constructs, and only 9% reported that behaviour change techniques had been used to target all constructs. Appropriate choice of theory is also a possible influential factor. The theoretical constructs within a theory must be relevant to a given behaviour (Davis et al., 2015). However, theory selection can be challenging, due to the vast number of theories available and little guidance on how to select a theory for a particular purpose (Michie et al., 2008).

Examples of theories within health psychology that have been used to understand and predict behaviour are: Health Belief Model (Janz and Becker, 1984), Theory of Planned Behaviour (Ajzen, 1985) and the Trans-theoretical model also referred to as the ‘Stages of Change’ model (Prochaska and DiClemente, 1992). Developments in behaviour change research have led to the introduction of models and frameworks e.g. the Behaviour Change Wheel (Michie et al., 2014) and IM (Bartholomew et al., 2011) that provide structure for systematically selecting theories for a particular purpose, considering both prediction and change. This is important, given the recognised challenges associated with the application and choice of theory in previous research, and the lack of guidance in the MRC framework about how to develop a complex intervention that incorporates theories.

Although numerous theories, frameworks and models have contributed to developments in behaviour change research, only some of these are discussed in the sections to follow, with a critique of their use in developing interventions. These were reviewed before adopting IM for this doctoral study.

#### **4.5. Models and frameworks for developing behaviour change interventions**

##### **4.5.1. Theoretical domains framework (TDF) (Cane et al., 2012; Michie et al., 2005)**

The TDF (Cane et al., 2012; Michie et al., 2005) attempted to address the plethora of different overlapping theories and the lack of guidance for selecting an appropriate theory. A team of psychologists and implementation researchers developed the TDF, using an expert consensus process and validation to identify theory, (psychological and organisational) relevant to health practitioner clinical behaviour change (French et al., 2012). One hundred and twenty eight explanatory constructs from 33 theories of behaviour were identified and grouped in to 12 domains:

**Table 7: 12 Theoretical Domains (Michie et al., 2005)**

1. Knowledge
2. Skills
3. Social/Professional Role and Identity
4. Beliefs about Capabilities
5. Beliefs about Consequences
6. Motivation and Goals
7. Memory, Attention and Decision Processes
8. Environmental Context and Resources
9. Social influences
10. Emotion
11. Behavioural Regulation
12. Nature of Behaviours

The TDF domains have been used across many contexts to: understand behaviours e.g. blood transfusion and hand hygiene; inform theoretically developed interventions; and to identify problems in guideline implementation (Dyson et al., 2010; Francis et al., 2009; Michie et al., 2007). The framework was later refined to include 14 domains and 84 component constructs following a validation study (Cane et al., 2012).

**Table 8: 14 Theoretical Domains (Cane et al., 2012)**

1) Knowledge
2) Skills
3) Social/Professional Role and Identity
4) Beliefs about capabilities
5) Optimism
6) Beliefs about consequences
7) Reinforcement
8) Intentions
9) Goals
10) Memory, Attention and Decision processes
11) Environmental Context and Resources
12) Social Influences
13) Emotions
14) Behavioural Regulation

A key strength of the TDF is the comprehensive coverage of the possible influences on behaviour, by including 14 domains and clarity about each of the domains, as each is specified by component constructs from 33 theories of behaviour. Findings from the validation study by Cane et al. (2012) have strengthened the evidence for both the structure and content of the domains. This has also increased confidence in the usefulness of the TDF and its application in different contexts for laying the foundations for theoretically informed interventions.

The framework can also be flexibly applied, using qualitative (e.g. focus groups or interviews) or quantitative methods (e.g. questionnaires). In the study by Patey et al. (2012), the TDF informed an interview topic guide for understanding anaesthesiologists and surgeons views on ordering routine tests (e.g. chest x-ray) for healthy patients undergoing low risk surgery. Identifying the factors that could influence test ordering behaviour in accordance with TDF domains was important for understanding why anaesthesiologists and surgeons continue to order pre-operative tests when no clinical indicators exist, despite guidelines stating that these should be ordered based on a judgement of the individual patients' health status (Merchant et al., 2011).

The TDF has provided a valuable contribution to this field of work, as previous attempts to understand clinicians' behaviour in this context have been a-theoretical (Jamtvedt et al., 2006; Walker et al., 2003) or based on limited theory (Eccles et al., 2007; Godin et al., 2008). Despite this, the TDF is limited to identifying what behaviours should change across different contexts, rather than *how* to change such behaviours. Using this framework alone, it is not possible to establish how behaviour change may be achieved. Instead, the TDF can be used in the context of a broader, theoretically based framework for developing complex interventions e.g. IM (Bartholomew et al., 2011) or the BCW (Michie et al., 2014; Michie et al., 2011), which is more appropriate here, given the aim of this study.

The limitations of the TDF when used alone highlight the need to advance understandings regarding the development, implementation and evaluation of behaviour change interventions. As part of this, it is important to find ways to understand the content of the intervention and be able to establish the 'active ingredients' for change. The need to develop a shared and standardised method for classifying the content of interventions led to the development of the Behaviour Change Taxonomy (BCT), developed following the first version of the TDF and was later refined (Abraham et al., 2009; Michie et al., 2013).

#### **4.5.2. Behaviour Change Taxonomy (Abraham et al., 2009; Michie et al., 2013)**

Abraham and Michie (2008) developed the BCT to reliably characterise interventions according to their behaviour change techniques (BCTs), by building on previous intervention content analyses (Albarracín et al., 2005; Hardeman et al., 2000). BCTs have been defined as:

*"An observable, replicable and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour; that is, a technique proposed to be an active ingredient"* (Michie et al., 2013, pg. 4).

The BCT is comprised of 26 techniques, widely used for different purposes including reporting interventions and synthesising evidence (Gardner et al., 2010; Michie et al., 2009a). This was later refined by Michie et al. (2013) to maximise scientific advances by developing agreed labels, definitions and reliable procedures for identifying and applying BCTs across different behaviours, disciplines and countries. Delphi methods and an open-sort grouping task produced the Behaviour Change Taxonomy v1, including 93 BCTs grouped into 16 clusters. Clear definitions and examples to be used in specifying the 'active ingredients' of interventions were provided. This taxonomy was identified as the

first published consensus-based, cross-domain taxonomy, including reliability data for the most frequent BCTs. However, this is likely to be refined again in future (Michie et al., 2013).

The taxonomy can be used in the development and replication of interventions, however this remains a tool for specifying intervention content, therefore the link between BCTs and theories of behaviour change needs to be addressed (Michie et al., 2013). Similar to the TDF, its use alone remains limited. It is more suitable in conjunction with other methods for changing behaviour e.g. BCW (Michie et al., 2014; Michie et al., 2011). The BCW is discussed in the following section, with attention to its strengths and limitations.

#### 4.5.3. Behaviour Change Wheel (Michie et al., 2014; Michie et al., 2011)

The BCW was developed to assist intervention designers in moving from a behavioural analysis of a problem to an intervention, drawing upon behaviour change theories and empirical evidence. The BCW incorporates an understanding of the nature of behaviour to be changed and a way of characterising interventions and components.

The BCW, comprised of three layers (figure 11) was developed from a systematic review, including 19 studies, describing 19 frameworks which were coded in accordance with three criteria for usefulness, determined by the research team prior to conducting the systematic review (1. Comprehensive coverage, 2. Coherence and 3. Links to an overarching model of behaviour). The ‘capability,’ ‘opportunity,’ ‘motivation’ and ‘behaviour’ model (COM-B) model (figure 12) forms the central part of the wheel and identifies the source of behaviour that an intervention could target based on its included components (Michie et al., 2014). Nine intervention functions surround the central model; the outer layer includes seven policy categories that support the delivery of the intervention functions.

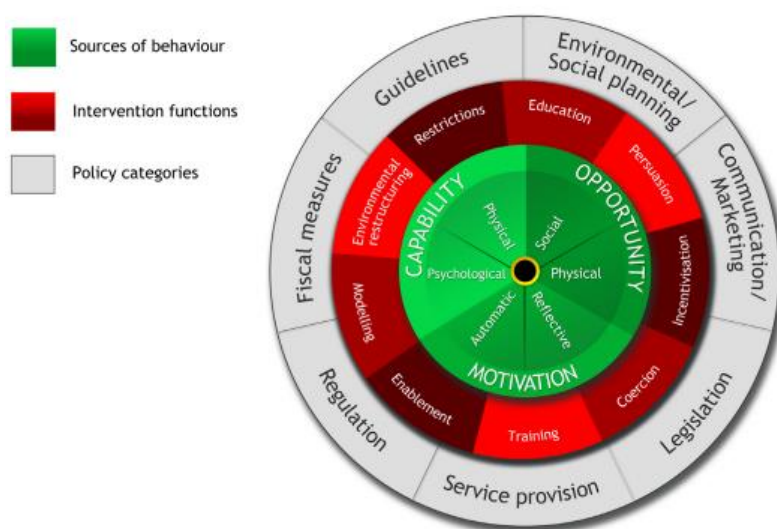
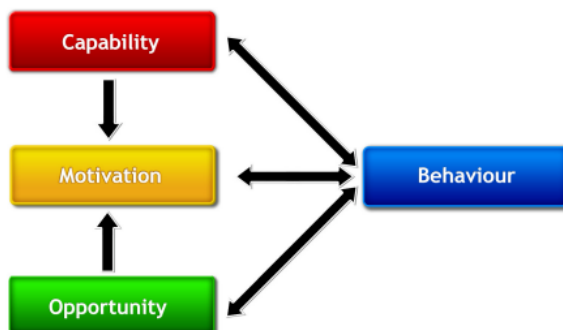


Figure 11: The Behaviour Change Wheel (Michie et al., 2011)



The arrows in the COM-B model represent potential for causal inference. Michie et al. (2014) proposed an individual must have the capabilities, opportunity and motivation, for a given behaviour to occur. Behaviours can also influence these three components and capabilities and opportunity can influence motivation.



**Figure 12: The COM-B model: a framework for understanding behaviour**

Michie et al. (2011) recognised that insufficient attention is often given to analysing behaviours as a starting point in intervention design; instead, this process often starts with an intervention type, before matching relevant behaviours. The BCW approach defines the problem in behavioural terms in the first instance as a foundation for developing an intervention (Michie et al., 2014; Michie et al., 2011). The process involves a number of stages:

**Stage one:** reviewing relevant literature and defining the problem in behavioural terms; defining the target behaviour using evidence including empirical work about the factors that influence the behavioural problem; and prioritising the target behaviour based on four criteria (Michie et al. 2014): likely impact, ease of implementation, likely spill over (collateral impact), ease of measurement.

**Stage two:** specifying and describing target behaviour(s), and describing who will perform the behaviour e.g. health professionals, what they would specifically need to do, and in what context (i.e. when and where) in order to bring about the desired change.

**Stage three:** carrying out a behavioural analysis using the COM-B model to assess whether those who are performing behaviours have the capability opportunity and motivation to carry out the behaviour. The COM-B can be used in conjunction with the TDF domains to theoretically understand the target behaviour and the factors that influence this.

**Stage four:** building the intervention using the work from the previous stages as a basis for selecting the intervention functions that are likely to be effective for changing the identified target behaviour.

**Stage five:** identifying BCTs using the BCT (Michie et al., 2013) (e.g. goal setting, motivational interviewing) that are appropriate for delivering intervention functions e.g. education.

**Stage six:** considering functions and modes of delivery for the intervention with attention to the evidence for effectiveness, their local relevance, practicability, affordability and public, professional and political acceptability of the mode of delivery.

Using the BCW including the COM-B in conjunction with the TDF and BCT provides a systematic method for establishing the function of an intervention, based on a detailed behavioural analysis (Atkins and Michie, 2013). Since 2011, the BCW has received a lot of academic interest and has been used to develop or examine the implementation of interventions across different contexts e.g. antibiotic prescribing (Fleming et al., 2014) and delivery of paediatric services (English, 2013).

A key strength of the BCW is the attention to context in the opportunity component of the COM-B model which considers social and environmental factors that influence behaviours. The motivation component also includes automatic processing, moving away from systematic cognitive processing that is often included in models of behaviour in health psychology (e.g. Theory of Planned Behaviour). This broadens understandings of behavioural motivation.

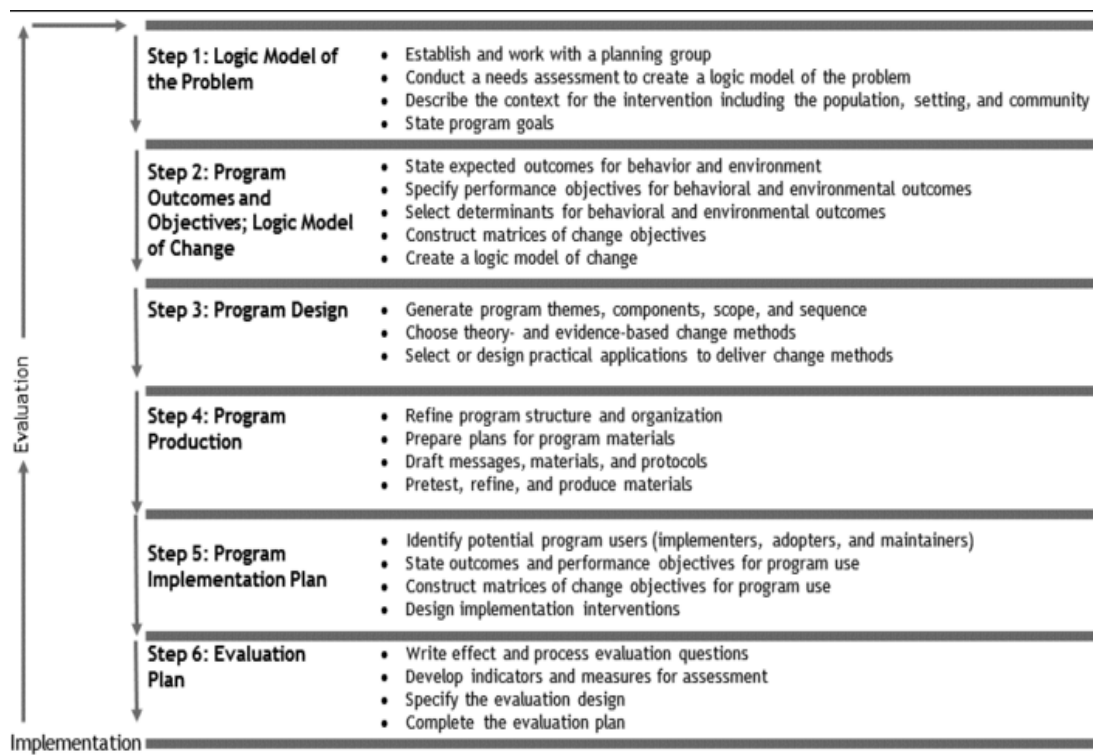
However, Michie et al. (2011) highlighted its limitations. Intervention functions were identified based on a systematic review of existing frameworks; therefore it is possible that important frameworks may have been missed during this process, meaning some intervention functions could also be missing. Research judgements also contributed to conceptualising the intervention functions and policy categories. There are numerous ways in which this could have been done, suggesting the one used to develop these components of the wheel may not have been optimal. As this research is relatively new, it is possible that the BCW could be difficult to use, despite efforts to ensure that this is comprehensive and reliable for characterising interventions.

Webb et al. (2016) used the BCW to develop an intervention aimed at improving the frequency of delivering advice from nurses about physical activity to cancer patients. The BCW was considered useful for designing the intervention using judgement and evidence,

but the process was criticised for being time consuming. The volume of choice for selecting intervention functions and policy categories was also overwhelming because the nature of the intervention meant that all possibilities were available. This led to a tendency to want to include everything, rather than creating a targeted intervention. Michie et al. (2011) recognised IM (Bartholomew et al., 2011) as a useful, alternative framework which has contributed to making intervention design more systematic.

#### 4.5.4. Intervention Mapping (Bartholomew et al., 2011)

IM was originally developed as a systematic planning framework for designing theory- and evidence-based health promotion programmes, including materials that aim to address programme outcomes and objectives to match specific populations and contexts (Bartholomew et al., 1998). IM maps the path of intervention development from the problem towards the solution, working through six stages:



**Figure 13: Stages of Intervention Mapping (Bartholomew et al., 2011)**

Each stage includes a number of tasks, where completion is required to create foundations for the following stage. However, the process is iterative rather than linear, despite this being presented as stages (Kok and Mesters, 2011).

IM is also based on three over-arching perspectives: 1) a socio-ecological approach; 2) multi-theory and evidence based approach; 3) stakeholder participation. Each perspective is outlined briefly, before considering how IM has been used previously to develop interventions.

**A socioecological approach:** The socio-ecological perspective underpins IM (Bartholomew et al., 2011). This has been extensively used in health promotion research and public health practitioners and scholars have called for more interventions that incorporate this perspective (Glass and McAtee, 2006; Kok et al., 2008). This perspective suggests that individual characteristics influence behaviours (e.g. attitudes) as well as the contexts in which they live (e.g. social norms within a community) (Bronfenbrenner, 1977; McLeroy et al., 1988). Human behaviours and interventions to address behaviours are considered as being part of a complex system, influenced by factors at multiple levels (Hawe et al., 2009; Kok et al., 2014).

Bartholomew et al. (2011) acknowledged the difficulties attached to developing an intervention targeting multiple levels; however, they judged the dangers of oversimplification to be greater. IM provides a framework for systematically incorporating this perspective, making complexities manageable without oversimplification.

**Multi-theory and evidence-based approach:** IM also advocates the use of multiple theories and evidence for describing and addressing the factors to achieve change (Bartholomew et al., 2011). The challenge is ensuring that relevant elements of a given problem are linked to useful theories (Bunk and Van Vugt, 2008). This process involves identifying a question or questions about a health or social issue, then accessing a range of relevant theories and evidence at multiple levels (individual, interpersonal, organisational). Bartholomew et al. (2011) described evidence as: *'not only data from research studies as presented in the scientific literature, but also the opinion and experience of community members and planners.'* (Bartholomew et al., 2011, pg. 9). This highlights the importance of the third perspective which follows.

**Stakeholder participation:** Involvement of stakeholders at all stages including development, adaptation, implementation, and evaluation is regarded as essential for success for various reasons. It helps to ensure that the developed intervention reflects the concerns of the target population. It also brings expertise, skills, knowledge and is useful for problems where they may be conflicting interpretations, as well as different goals, values, and life experiences; and it avoids relying on solely expert driven approaches (Bartholomew et al., 2011; Kreuter et al., 2004).

By incorporating these perspectives, IM fulfils criteria specified in the MRC framework (Craig and Petticrew, 2013) and has been applied world-wide to develop complex interventions aimed at promoting health behaviours or preventing diseases. Examples include but are not limited to: an information and consultation based intervention to promote pap test screening in Chinese women in Taiwan (Hou et al., 2004); a lay-health worker delivered educational intervention to promote breast and cervical cancer screening in Hispanic farm workers (Fernández et al., 2005); an outreach and group based interventions to prevent HIV in heterosexual, migrant men (Wolfers et al., 2007); a physical injury prevention programme to reduce physical activity related injury in primary schools (Collard et al., 2009); a multi-component intervention to change flu vaccination behaviours among care workers in nursing homes (Looijmans-van den Akker et al., 2011); a lay-health worker delivered intervention to promote cervical cancer screening among American women (Byrd et al., 2012); and a culturally appropriate intervention to prevent childhood obesity (Taylor et al., 2013).

Most published IM articles include detailed descriptions of how interventions were developed, using stages one to four of the process. Despite considering this as time-consuming, authors, including those referred to above have regarded this as a useful process for ensuring that theory and evidence guided the selection of appropriate methods and strategies to address identified determinants. IM is also valued for being a systematic, comprehensive, and transparent procedure for intervention development (Looijmans-van den Akker et al., 2011); which provides opportunities for engagement with community members (Byrd et al., 2012) and captures the complexities associated target behaviours (Gray-Burrows et al., 2016).

Despite its widespread use in designing and developing health promotion and disease prevention programmes, such as those outlined, there is comparatively less evidence on interventions that have been developed further and tested in RCTs. However, some of the interventions included in studies referred to above have been evaluated in cluster RCTs (Collard et al., 2010; Looijmans-Van Den Akker et al., 2010) or individual RCTs (Byrd et al., 2013; Fernández et al., 2005; Hou et al., 2002).

Results from these studies all indicated a statistically significant difference between the IM intervention and control groups, indicating that using the IM approach to develop interventions can lead to a decrease in physical- activity related injury in low- active children (Collard et al., 2010) and increased uptakes of: flu vaccines among health workers (Looijmans-Van Den Akker et al., 2010), and screening for breast and cervical cancer (Byrd et al., 2013; Fernández et al., 2005; Hou et al., 2002).

Although IM has not been used to address problems in carers of stroke survivors, the evidence for its successful application in planning, developing, implementing and evaluating interventions is promising for the development of future interventions using this approach. Conclusions in chapter three indicated that an approach such as IM, underpinned by behaviour change theories would be appropriate for developing an intervention for carers of stroke survivors, to overcome some limitations of existing interventions. These included: poor descriptions of intervention components and how they were developed; and a lack of detail about the mechanisms by which the interventions were thought to have an effect, even where theories, conceptual models and frameworks were included.

The IM approach was adopted for the research presented in this thesis, as its systematic nature ensures that the development and content of the intervention is clear, and it guides the appropriate selection of theory for establishing the causal mechanisms underpinning the intervention to maximise its effectiveness (Bartholomew and Mullen, 2011). The importance of theory throughout the IM process becomes evident in the following section where the six stages are outlined with examples of how they can be applied to address carer burden.

#### **4.6. IM stages**

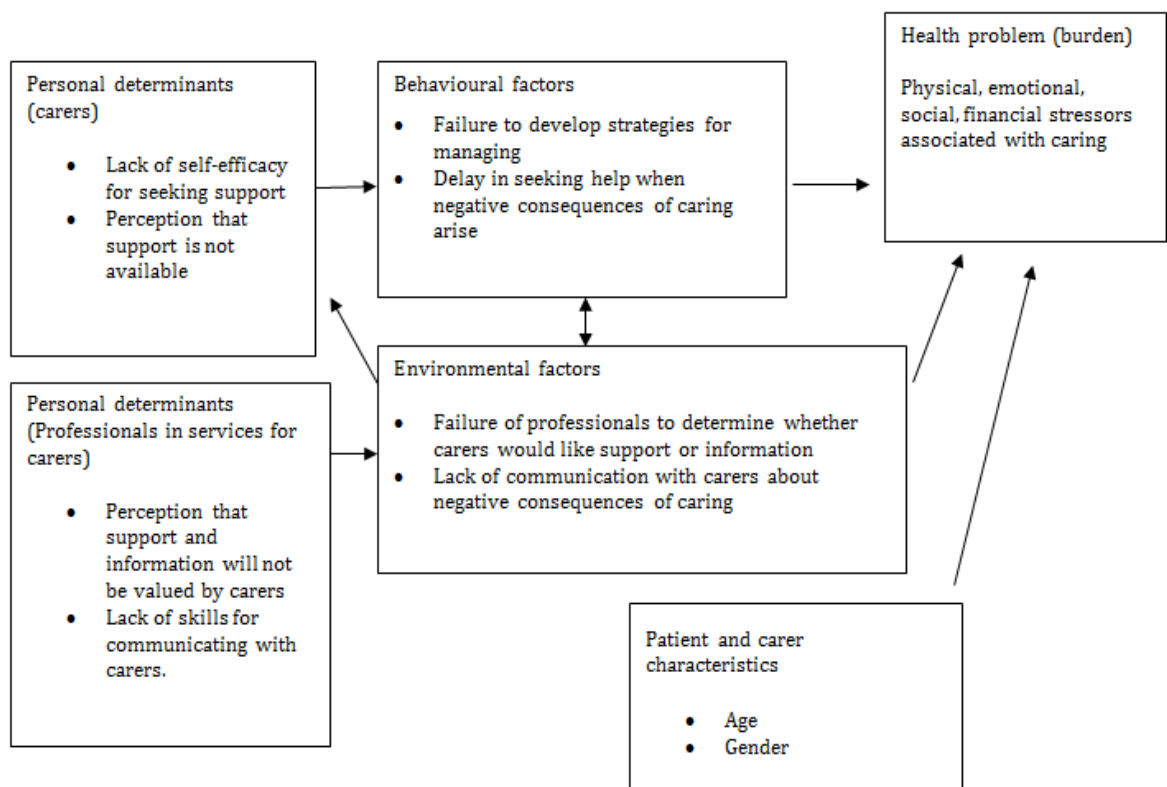
##### **4.6.1. Stage one: Logic Model of the Problem (Needs assessment)**

The 'needs assessment' seeks to gain an understanding of a given health problem from a behavioural perspective by: gaining a detailed description of the behavioural and environmental causes of a problem and their determinants (the factors that influence the behavioural and environmental causes); and an understanding of the 'at risk' group (i.e. carers of stroke survivors), their needs and the factors that influence these (Bartholomew et al., 2011).

In the needs assessment in this study, an in-depth description of the experiences of providing care to the stroke survivor will be gained, in addition to factors contributing to the logic models. Whilst this stage of the process shares some similarities with the BCW in that they both address behaviours attached to a given problem, there are differences in the conduct of the behavioural analysis. Using the BCW, the COM-B model guides the analysis after the target behaviour is selected. In IM, theory is introduced later and different logic models are developed in the first two stages.

A logic model demonstrates causal relationships between concepts as part of understanding a problem e.g. carer burden. These help researchers and programme developers to consider the complexities attached to certain health problems and the range of possible solutions (Bartholomew et al., 2011). They also demonstrate clear pathways of programme effects and provide a clear rationale for programme activities (Kirby, 2004). In addition to their use in IM, they are more widely used in health programme development and evaluation, and are supported by the MRC (Moore et al., 2015) as a fundamental framework for programme evaluation.

To create the logic model of the problem, theory and evidence are used to describe the health problem and its behavioural and environmental causes and determinants. An example of how this can be created for the health problem in this study (carer burden) is outlined in figure 14.



**Figure 14: Hypothetical logic model of the problem**

This logic model is traditionally formed based on relevant qualitative and quantitative work to address the problem and contributions from the stakeholder group. Bartholomew and Mullen (2011) recognised that literature around the behavioural and environmental factors associated with at risk groups often lacks a theory base, but by reviewing existing literature an evidence-based understanding of carer burden can still be gained. Using a

logic model to map out the problem means behavioural factors and environmental factors that influence burden can be broadly considered before appropriate theory is applied in the intervention development.

Starting with a theory before mapping out the problem could lead to ignoring important factors that do not fit in to a single existing theory, or it could hinder us from addressing known problems in a new way (Nilsen, 2015). This is a strength of IM, as a detailed description of the problem is gained before working towards a solution. This process also helps to establish behavioural and environmental outcomes of the intervention. The behaviours that become the focus of change are identified from the logic model of change.

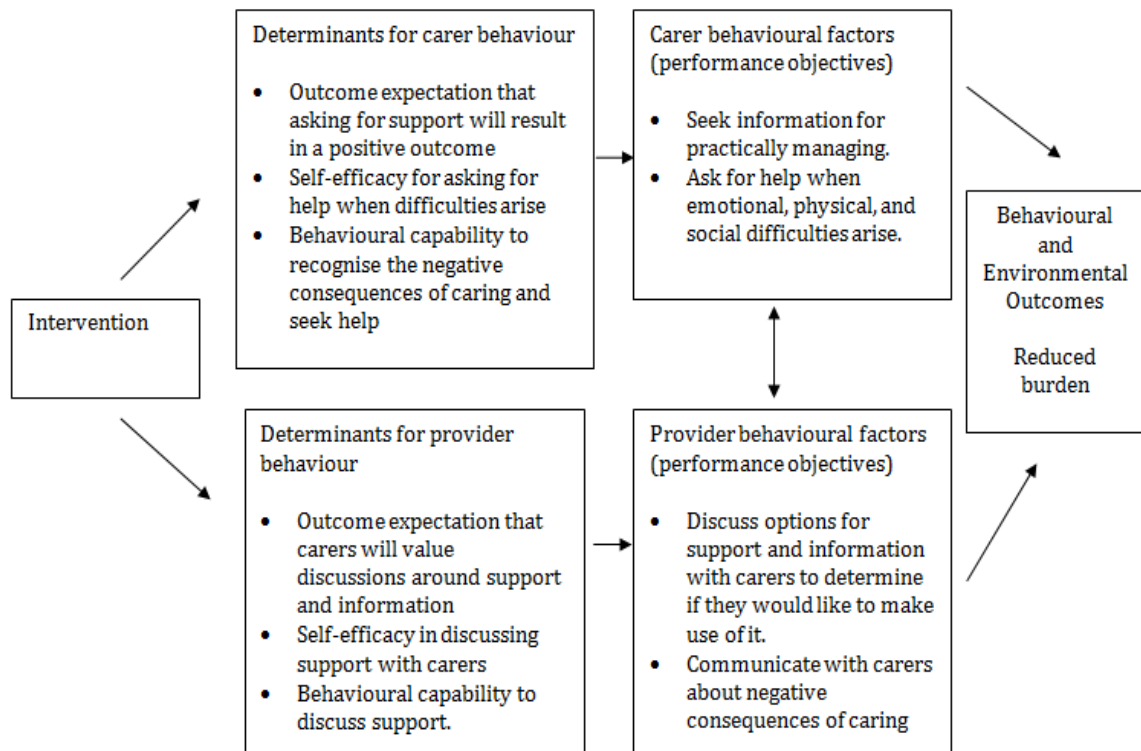
#### **4.6.2. Stage two: Program Outcomes and Objectives; Logic Model of Change**

In stage two, the focus shifts from a logic model of the problem, to a logic model of change, which is the output of this stage. The logic model of change outlines pathways of the programme effects rather than pathways to identify causes of the problem (Bartholomew and Mullen, 2011).

To create the logic model of change, behavioural and environmental outcomes of the intervention are specified based on evidence gathered at stage one. Then specific behaviours that should occur to achieve the outcomes (performance objectives) and factors that influence changes in behaviours are specified (determinants of behaviours). Performance objectives are cross-matched with determinants in matrices of change, and change objectives are established. The change objectives state what the intervention should modify to influence performance objectives to achieve the behavioural and environmental outcomes.

To develop a list of determinants, theoretical constructs from the literature are selected, based on their importance for changing behaviours. A single, unifying theory is not necessary at this stage; however, sometimes the nature of behaviours and their determinants suggest a theory, e.g. social cognitive theory (Bandura, 1989). Three constructs from this theory (self-efficacy, outcome expectancy and behavioural capability) are used as an example in the hypothetical logic model of change (figure 15).





**Figure 15: Hypothetical logic model of change**

Selecting appropriate theory or theories relies upon judgement and requires careful consideration. However, selecting theory based on the behaviours that are required to change to meet the intervention outcome ensures that this is not restricted to a single model. This is a strength of IM, as it draws upon different theories for different purposes. This supports the argument by Nilsen (2015) that combining multiple theoretical approaches will add to a more complete understanding of an area of intervention.

Table nine is an example of a ‘matrices of change objectives.’ Using theory at this stage facilitates decisions around *what* needs to change (e.g. self-efficacy and outcome expectancies).

**Table 9: Matrices of change objectives**

Behavioural performance objectives	Determinants		
	Outcome expectancy	Self-efficacy	Behavioural capability
BPO.1. Ask for help when emotional, physical and social difficulties arise.	Carer expects that asking for help will result in positive outcome.	Carer has confidence in seeking help when difficulties arise.	Carer has behavioural capability to recognise when they should ask for help.
Environmental performance objectives	Determinants		
	Outcome expectancy	Self-efficacy	Behavioural capability
EPO.1. Discuss options for support with carers to determine if they would like to make use of it.	Health professional expects that carers will value discussions about support.	Health professional has confidence in discussing support.	Health professional has ability to discuss support.

IM provides a structured, detailed approach as each behaviour is underpinned by theory and environmental factors are considered. Whilst the TDF has its limitations, it could be used in this process to select the determinants for behaviour change.

#### **4.6.3. Stage three: Programme Design (Methods and strategies).**

Ideas for the programme design are generated with involvement from stakeholders, and then theoretical methods and practical applications are selected.

To facilitate the selection of theoretical methods, Bartholomew et al. (2011) developed a comprehensive list of methods, related theory, parameters for use and practical examples in relation to determinants that are commonly found to result in behaviour change (e.g. skills, self-efficacy etc.). The theoretical methods address *how* behaviour change outlined in the matrix is achieved (e.g. carer has confidence in seeking help when difficulties arise). Appropriate methods from the comprehensive list are selected to match the change objectives according to their determinants, outlined in the behaviour change matrix (e.g. ‘belief selection’ based on the theory of planned behaviour (Ajzen, 1985) could be used to change self-efficacy around seeking advice). Selecting theoretical methods before practical applications ensures these are guided by theory, instead of being selected because they are attractive to the audience (Bartholomew and Mullen, 2011).

Following selection of theory based methods; practical applications for achieving them can be specified e.g. a programme to reinforce the belief that carers have confidence to seek advice. The importance of context is emphasised by ensuring the parameters for

effectiveness are considered in the translation from the methods to the practical applications. Parameters for effectiveness are the specific conditions under which the behaviour change methods are effective (Kok et al., 2012; Schaalma and Kok, 2009).

For example, goal setting is considered an effective method for behaviour change but only under certain conditions e.g. the goal is both challenging, achievable and personally relevant for the individuals being targeted (McAlister et al., 2008). This needs to be considered in the translation from the theoretical method 'goal setting' to the practical applications; this includes ensuring that in the actual programme, the goals are appropriate. If unachievable goals were set, either too low or high this would mean that the parameters for effectiveness are violated and the programme could be less effective or even counterproductive (Kok et al., 2015).

This consideration in IM emphasises the importance of distinguishing between methods for change that are underpinned by theory and the practical applications for delivering the intervention. Considering parameters is regarded as crucial both in terms of designing effective interventions, and ensuring an adequate analysis of the intervention content (Kok et al., 2015).

#### **4.6.4. Stage four: Programme Production (creating an organised programme plan)**

Stage four focuses on establishing the main elements of the intervention and producing programme components and materials to pre-test. Part of this process includes establishing design preferences, and creating relevant documents contributing to an organised programme plan (e.g. design documents, programme, scope, and sequence) (Bartholomew et al., 2011).

It is likely that the programme will be complex, with components that attend to at risk groups e.g. carers of stroke survivors, and environmental agents e.g. health professionals, family members. Different elements of the overall programme may be supported with varied products and materials. The challenge is producing a creative programme which captures thinking from the matrices of change, and the selection of appropriate methods and practical applications. Re-consideration of context is important here.

To facilitate this process, consultation with stakeholders, including intended programme participants is required to establish their design preferences. This influences creative thinking that is required to develop a 'programme, scope and sequence' document and design documents. The programme, scope and sequence document outlines details about

the intervention content, key messages, and the scope and sequence of the included components. The design documents include details about design features and the impact of different intervention components. During the development of these documents it is important to ensure that each intervention component still meets the programme goals, change objectives, and the parameters for methods and practical applications.

Following this clear documentation, programme materials are developed and pre-tested before making plans for implementation and evaluation.

#### **4.6.5. Stage five: Programme Implementation Plan**

IM includes plans for implementation and evaluation in stages five and six. Stage five focusses on programme adoption and implementation, this includes considering the sustainability of the programme. Those involved in delivering the programme are considered at this stage and this an essential step in the programme development (Kok et al., 2014). This is based on the assumption that interventions will never be successful if they are not used in their intended context, or discontinued prematurely (Durlak and DuPre, 2008; Oldenburg and Glanz, 2008).

Firstly, potential programme users (implementers, adopters, maintainers) are identified. Then matrices similar to those developed in stage two are developed with adoption, implementation, and maintenance performance objectives and their theory based personal and external determinants. From this, change objectives are created with a focus on promoting programme adoption, use, and maintenance. Change objectives are operationalised using theory based methods and strategies that inform plans for adoption, implementation and maintenance. A detailed implementation protocol is produced to ensure that the developed programme will be adopted and sustained for as long as is necessary.

#### **4.6.6. Stage six: Evaluation Plan**

In stage six an evaluation plan is created. This evaluation is broadly to determine whether decisions were made correctly at each mapping step. The logic models formed in stage two and the developed intervention guides evaluation questions and measurement. The process of evaluation involves different stages, starting with decisions around what outcome variables to measure based on the logic model of the problem. Then the focus shifts to the logic model of change, where the researcher asks evaluation questions about how the intervention has effects on behaviours and determinants. Measuring these determinants that are considered mediating variables is important alongside the primary

outcomes. Potential moderators that were identified in the logic model of the problem are considered e.g. carer demographics. Including this detailed understanding of the intervention effects contributes to understanding how and why the intervention was effective or ineffective.

#### **4.7. Intervention Mapping: A summary of strengths and weaknesses**

Changing behaviours, regardless of the methods used remains a challenging task (Kok et al., 2014). IM provides a valuable contribution to the development and evaluation of interventions. The nature of the process means that the programme is clearly outlined and documented with detail around what it is expected to accomplish and how the programme will work to achieve the expected outcomes (Kok and Mesters, 2011).

A key strength of this approach is the use of theory at varied stages in the process, given the advantages of its use that were highlighted in section 4.4. Other researchers support the use of theory, as it is thought to reduce the research- practice gap (Cane et al., 2012; Sales et al., 2006). This is the alternative to using a common-sense approach to developing interventions, which involves drawing upon a groups shared knowledge and has been advocated by critics of a theory based approach (Bhattacharyya et al., 2006; Oxman et al., 1995).

Despite their differences, the use of BCTs and theory based methods in intervention development is a strength of IM and the BCW. However, the context in which these techniques are effective is emphasised in IM, where parameters of effectiveness are considered during the translation to practical applications. IM is a promising approach to developing interventions, as lack of attention to the parameters of effectiveness could lead to intervention failure, even when they have been designed with effective theory based methods (Kok et al., 2014).

However, this approach is not without its limitations. A potential drawback of the process is that it will be used as a cook book with little flexibility (Bartholomew et al., 1998). A balance is required between using the framework to guide this process, whilst maintaining an iterative and interactive approach to developing an intervention.

Throughout the process of intervention design, equal importance is placed upon behavioural and environmental factors that influence a particular health problem. Although it could be considered a strength that IM considers environmental and behavioural factors, deciding what should be targeted in an intervention following the

development of multiple change objectives can be overwhelming. This was the case in a study which used IM to develop a work-site physical activity intervention (McEachan et al., 2008) and is likely to be the case in this study, given the varied factors contributing to carer burden and multiple behaviours that could be targeted.

McEachan et al. (2008) overcame this difficulty by involving stakeholders in a process to filter change objectives and strategies to those that could pragmatically be achieved. Involvement from stakeholders at each stage is a strength as they can guide decision making (Kok and Mesters, 2011). However, intervention development would become weakened by an inappropriate stakeholder group, or in a situation where the perspectives of all those involved were not taken in to account. Emphasis remains on ensuring an appropriate group is developed to contribute to creating a programme which balances evidence and pragmatism (Taylor et al., 2013).

Even with a balance of evidence and pragmatism, there is a danger with IM that the logic models could be faulty if a problem is not well understood, or inadequate theory is chosen (Kok and Mesters, 2011). However, wrong decisions can be rectified by returning to the previous stages of the process and engaging in discussions with stakeholders; hence the iterative nature of the process (Kok and Mesters, 2011). Being able to analyse the possible causation of programme failure or the factors that lead to the interventions success using logic models in as an important aspect of the process, and is consistent with MRC guidance (Craig et al., 2008; Craig and Petticrew, 2013).

In addition to some of the potential drawbacks and difficulties using IM, the approach is consistently described as time consuming and exhaustive, and this is acknowledged to some extent by the authors (Bartholomew et al., 2011). However it has proved useful for ensuring that interventions are developed at a higher level, leading Kok and Mesters (2011) to believe the advantages outweigh the disadvantages.

#### **4.8. Using Intervention Mapping in this research**

Throughout the chapter, IM has been considered in light of other approaches and through examining its strengths and limitations, it is deemed an appropriate approach for addressing the complex area of intervention for this study. Time constraints were recognised, therefore this study focuses on IM stages one-four, with the outcome being a proposed intervention to reduce burden in carers of stroke survivors. A detailed description of the components of the intervention will be provided, rather than a fully developed intervention. The following sections re-address the overarching perspectives of

IM outlined in section 4.6 and outline how they apply to the research presented in the following sections of this thesis.

#### **4.8.1. Theoretical underpinnings and perspectives**

Researchers using IM are likely to bring multiple theoretical and experiential perspectives to a given problem and advocate the use of both qualitative and quantitative methods to generate evidence required for intervention design (Bartholomew et al., 2011). Therefore the research presented in this thesis is underpinned by pragmatism. Research methods used within the wider framework of IM were selected based on whether they appropriately addressed the research aims and are not constrained by methods underpinned by a philosophical position (Seale, 1999).

Although methods used to conduct research within an IM framework are not constrained by a philosophical position, the three over-arching perspectives of IM: 1) a multi-theory and evidence based approach; 2) an ecological approach; 3) stakeholder participation have informed thinking in the research presented. The next section outlines how they are applied in the research presented in this thesis.

#### **4.8.2. Applying Intervention Mapping perspectives**

##### **4.8.2.1 A multi-theory and evidence-based approach and stakeholder participation**

According to these perspectives, the use of multiple theories, evidence and stakeholder involvement provide important contributions to the development of a coherent intervention. Section two, including the needs assessment (chapters five-seven) outlines the evidence collated to inform intervention development. Theories used for prediction and change are applied throughout the process, particularly in the identification of theory based determinants which predict behaviour change (stage two) and the application of theoretical methods (stage three). Details about use of theory at different stages are included in chapter eight. Stakeholder involvement is also discussed in chapter eight, with specific details about how they contributed throughout the process. A more detailed outline of how a socio-ecological perspective is applied in the thesis is provided below:

##### **4.8.2.2 Socio-ecological approach**

The socio-ecological model by McLeroy et al. (1988), has been commonly used to guide intervention development at different levels, and can be used in the context of IM. This

model is applied in this research in accordance with relevant stages of the IM process.

McLeroy et al. (1988) proposed the following definitions for each of the related levels:

- **Individual:** Individual characteristics that influence behaviours e.g. knowledge, skills, self-efficacy.
- **Interpersonal** (family, friends, peers, professionals): Interpersonal processes and groups that provide identity and support.
- **Organisational** (community organisations, churches): Rules, regulations, policies, structures that influence individual behaviours.
- **Community** (wider social networks): Community norms and regulations
- **Policy:** Policies and laws that regulate or support healthy practices or actions.

The three components of research contributing to the first stage in the process, the needs assessment (chapters five-seven) include different applications of this model.

In chapter five, the factors that influence burden in carers of stroke survivors and other longer-term conditions are established. These factors are identified at behavioural and environmental levels. The term 'behavioural factors' applies to those that reflect the 'individual' level of the model. Environmental factors relate to the remaining levels (interpersonal, organisational, community and policy). In chapters six and seven, barriers and facilitators to addressing needs are identified. Similarly, these reflect different levels of the model. Behavioural barriers and facilitators relate to the individual level and environmental barriers and facilitators relate to the remaining levels.

This research is influential for informing subsequent stages in the IM, where use of the socio-ecological model is maintained. This model is used to guide the development of objectives and outcomes and matrices of change in stage two of the process. This also informs thinking throughout the development of the intervention (stages three and four) to ensure that this is not developed in isolation contextual factors (chapter eight).

This chapter concludes this section of the thesis. Section two that follows includes chapters contributing to stage one of IM, the needs assessment.



## Section two: Intervention Mapping: Logic model of the problem (needs assessment)

This section includes chapters five- seven. Table ten outlines the four stages of IM that are the focus of this study. Each chapter in this section contributes to the first stage IM: logic model of the problem (needs assessment).

**Table 10: Stages of Intervention Mapping**

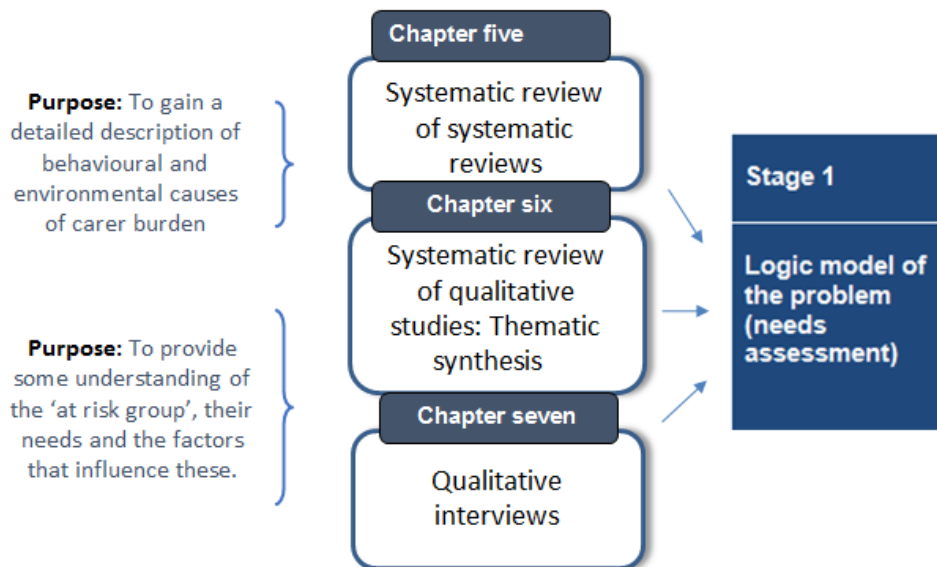
Stage 1	Stage 2	Stage 3	Stage 4
Logic model of the problem (needs assessment)	Programme Outcomes, Performance Objectives, and Determinants; Logic Model of Change	Programme Design (Methods and strategies)	Programme Production (creating an organised programme plan)

The needs assessment has two main aims (Bartholomew et al., 2011):

- To gain a detailed description of the behavioural and environmental causes of a problem and their determinants.
- To gain an understanding of the 'at risk' group, their needs, and the factors that influence these.

The findings from the needs assessment are drawn together to form a logic model of the problem (referred to in this study as the: overall logic model of burden). Once the problem is fully analysed, priorities are established and programme goals are specified before progressing to the subsequent stages.

Figure 16 outlines three components of work contributing to the needs assessment and their purpose.



**Figure 16: An overview of the first stage of Intervention Mapping**

Chapter five (which follows) addresses the first aim outlined above. This is a systematic review of systematic reviews to establish the factors that influence burden in carers of stroke survivors and other longer-term conditions e.g. dementia, Parkinson’s disease. More specifically, this presents the behavioural and environmental conditions associated with carer burden, and their determinants, together with carer and patient characteristics that influence carer burden. All of these factors contributed to a logic model of the problem presented within the chapter.

Chapters six and seven address the second aim outlined above. Chapter six presents an update of a systematic review by Greenwood et al. (2009a) to establish carers’ needs, how they change over time and the barriers and facilitators to addressing needs. Findings were synthesised using a thematic synthesis approach (Thomas and Harden 2008). Establishing needs provides a detailed understand of the ‘at risk’ group, in this case, carers of stroke survivors.

Additionally, this work intended to inform the overall logic model of burden. Barriers and facilitators were categorised as behavioural or environmental, informed by the socio-ecological model (McLeroy, 1988). Behavioural and environmental barriers were included in the developing logic model of the problem (presented at the end of the chapter) as well as determinants of carer and professional behaviours, where relevant.

Chapter seven is the empirical study contributing to the needs assessment. This is a qualitative- semi-structured interview study including two different groups of carers, one of which were interviewed over time. Similarly this focuses on carer needs, the barriers and facilitators to addressing needs and how and whether they change over time. It also includes an exploration of carers' social support networks, using a social network mapping activity (Antonucci, 1986). Findings were synthesised using thematic analysis (Braun and Clarke, 2006).

Similarly, this intended to gain an in-depth understanding of the 'at risk' group and inform the overall logic model of burden. As in chapter six, barriers and facilitators were categorised as behavioural or environmental, and behavioural and environmental barriers were included in the developing logic model of the problem (presented at the end of the chapter) as well as determinants of carer and professional behaviours, where relevant. Due to the focus on changes in carer experiences over time, evidence intended to contribute to establishing an appropriate time-point of the intervention.

Overall, findings from this research informed what should be prioritised as IM progressed. Chapter eight (section three) outlines how IM methods were applied in stages one to four, corresponding results and a summary discussion.

## **5. Chapter five: Identifying the factors that influence burden in carers of stroke survivors and other longer-term conditions: A systematic review of systematic reviews.**

### **5.1. Introduction**

This systematic review of systematic reviews is the first of three components of work contributing to the 'needs assessment' stage of IM. It sought to establish the factors that influence burden in carers of stroke survivors and other longer-term conditions to inform a logic model of the problem. This research was conducted based on guidance for review of reviews by (Smith et al., 2011) and a synthesis of findings guided by evidence required for the logic model of the problem is provided. This outlines the behavioural and environmental conditions associated with carer burden, a range of carer and patient characteristics that influence burden, and the determinants of the behavioural and environmental conditions. The logic model of the problem will be combined with findings from chapters six and seven to form the overall logic model of burden.

### **5.2. Rationale for review**

Chapter four outlined IM stages applicable to this study. The first stage, the 'needs assessment' required research to assess carer burden, considering its related behaviours and environmental conditions, and determinants of these behaviours and environmental conditions.

Although the focus of the intervention development is carers of stroke survivors, this review of reviews sought to establish the factors that influence burden in other conditions in addition to stroke e.g. dementia, Parkinson's disease. Drawing upon the wider literature had the potential to produce an in-depth, theoretical understanding of burden beyond stroke carers. This was considered important, given that carer burden is arguably a clinical and public health concern across different longer-term conditions (Milne and Larkin, 2015; Sadler and McKeivitt, 2013).

Whilst stroke has been considered as categorically different from other longer-term conditions, due to its abrupt and unexpected nature, leading to distinct differences in the trajectory of illness compared to other conditions (Ski et al., 2015), much can be learned about the factors that influence burden, as the impacts of caring and the daily duties remain similar (Lim and Zebrack, 2004).

### **5.3. Aim and research questions**

Aim: To synthesise evidence regarding the factors that influence burden in carers of stroke survivors and other longer-term conditions.

Research questions:

- What are the behaviours associated with carer burden in carers of people with longer-term conditions?
- What are the environmental conditions that facilitate or limit behaviours associated with burden?
- What other factors are associated with carer burden? (including those related to both the carer and the patient)
- What are the determinants (predictors) of behaviours and environmental factors associated with carer burden?

### **5.4. Methods**

Following guidance by Smith et al. (2011), the process involved identifying relevant reviews, quality appraisal for all reviews, comparing conclusions and their strengths, with the aim of providing the best evidence for IM.

#### **5.4.1. Inclusion and exclusion criteria**

To be included, reviews needed to be in English language and published between January 2010 and November 2015. They also had to be systematic reviews, with a focus on carer burden and associated behaviours, environmental conditions and/or theoretical determinants in stroke and other longer-term conditions.

Systematic reviews could either be defined by authors as a 'systematic review' (within the title or the main body of the text); or meet all the following criteria outlined by Pope et al. (2007):

- An available review protocol to guide the review process
- Comprehensive literature searching using a pre-defined search strategy
- Critical appraisal of studies and grading of evidence
- Explicit (transparent) inclusion and exclusion criteria
- Explicit (transparent) data extraction
- Explicit (typically statistical) analysis

There is no single agreed definition of burden; therefore reviews referring to 'carer burden' could be included.

Longer term conditions were defined using the Department of Health definition:

*"A condition that cannot, at present be cured; but can be controlled by medication and other therapies"* (Department of Health, 2012, pg. 3). Examples of longer-term conditions include stroke, dementia, Parkinson's disease, cancer, diabetes, and mental health conditions e.g. schizophrenia.

Reviews were excluded if they were not systematic reviews; if they focussed on acute conditions or palliative care; if they included intervention studies where carer burden was an outcome and there was no attention to behaviours, environmental factors or determinants; or they included carers of individuals less than 18 years of age.

#### **5.4.2. Study identification and data extraction**

JH developed a comprehensive search strategy based on expert advice from two information specialists (Appendix C). This was performed from 01.01.10 until 03.11.15 using the following databases to identify systematic reviews for inclusion (n= 7): Medline, the Campbell Collaboration, the Cochrane Collaboration, Joanna Briggs Database of Systematic Reviews and Implementation Reports, Social Care Institute for Excellence (SCIE), Web of Science and CINAHL.

JH and another reviewer independently screened all titles and abstracts from the original search to assess their eligibility. Studies that did not meet the inclusion criteria were excluded. Full text publications were obtained for potentially relevant studies. Where articles could not be obtained, authors were contacted. JH applied the inclusion criteria to the list of full texts and 20% of these were reviewed by a second reviewer. Disagreements were resolved through the involvement of two additional reviewers.

JH performed independent data extraction for all eligible studies. A second researcher carried out data extraction on 20% of studies.

#### **5.4.3. Assessment of methodological quality**

More than 24 tools are available to assess quality of systematic reviews; however, there remains no clear guidance for which tool to use. A review of 24 tools found many lacked rigour in the development and provided little guidance for their use in practice (Shea et al., 2001). For this review the 'Assessment of Multiple Systematic Reviews' tool (AMSTAR) (Shea et al., 2007) was used. This is comprised of 11 items, has good agreement, reliability,

construct validity and feasibility for assessing the quality of systematic reviews (Shea et al., 2009).

Each systematic review was appraised for methodological quality. In each of the 11 items, the choice of four responses is provided (yes, no, can't answer, not applicable). If the criterion is met, this is scored as one. A score of 0 is allocated if the criterion is not met; it cannot be answered or is not applicable. An overall score of the review quality can be calculated between 0-11 (a sum of scores from the 11 items). Quality is categorised at three levels: 0-3 is low quality, 4-7 is medium quality, and 8-11 is high quality.

#### 5.4.4. Data synthesis

Results of the systematic review of reviews should provide the reader with major conclusions through answering the research questions, whilst providing evidence on which the conclusions are based and an assessment of the quality of evidence (Smith et al., 2011). A narrative approach to synthesising findings was adopted to fulfil these recommendations. Each research question (section 5.3) was developed to inform the 'logic model of the problem':

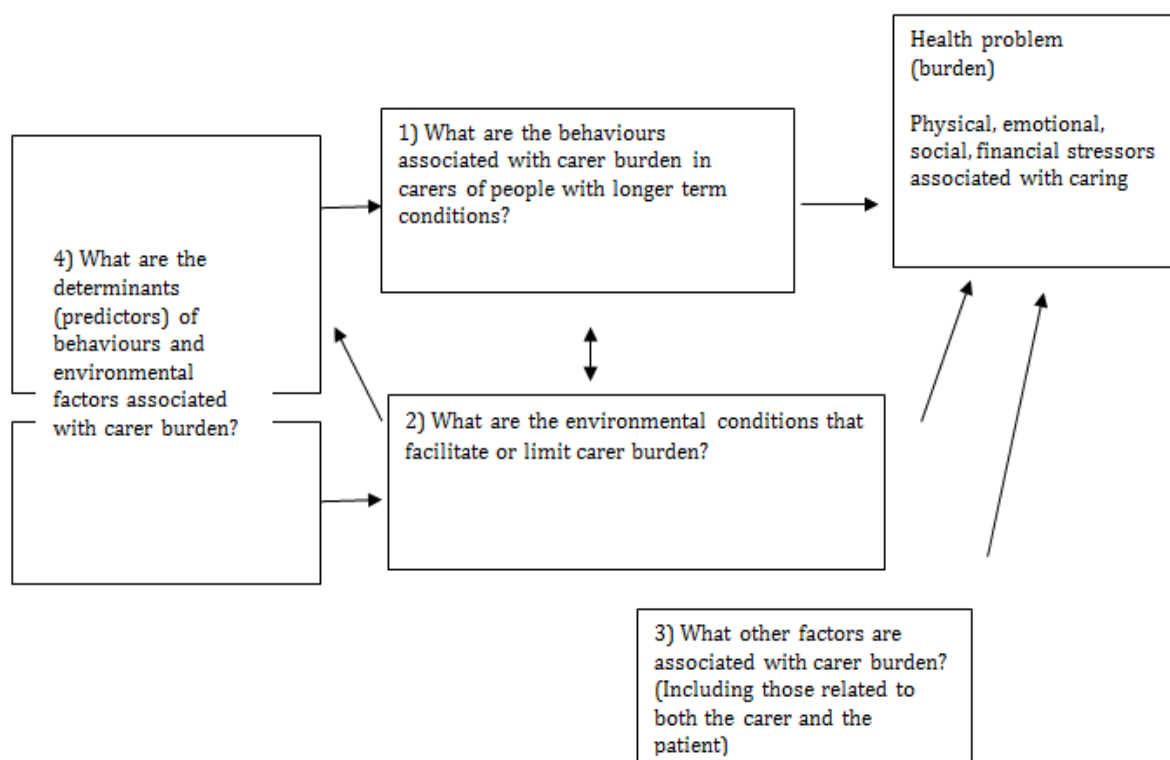


Figure 17: Research questions mapped onto the logic model

## 5.5. Results

The search identified 1725 references, following de-duplication 1481 remained, of these 99 were considered potentially relevant and the full text was reviewed. Eighty-five of these reviews were excluded, fourteen were included.

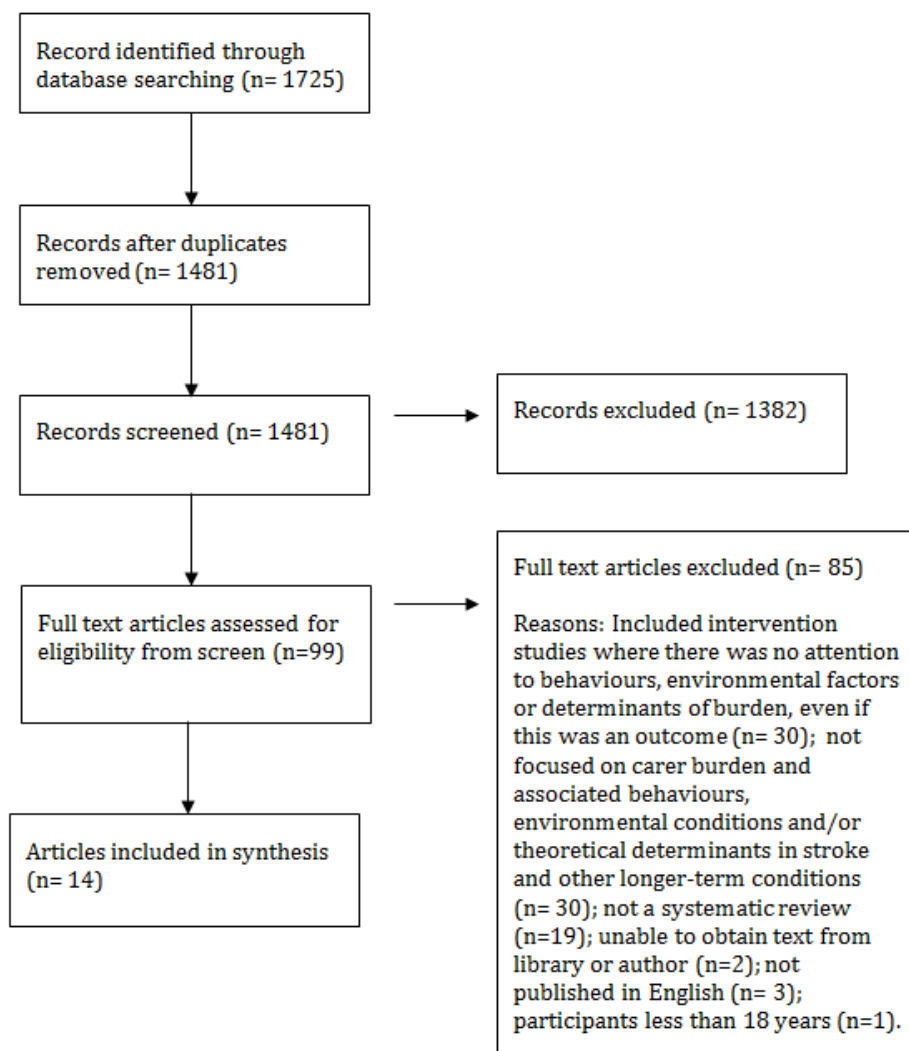


Figure 18: Study selection process (using PRISMA guidelines)



### **5.5.1. Included reviews**

Fourteen systematic reviews, published in English met the inclusion criteria. Included studies for each review ranged between four and 192, providing a total of 612 studies, different study designs, both qualitative and quantitative, were included within and across the reviews (see Appendix D).

Half the included reviews focussed on dementia or specific types of dementia e.g. Frontotemporal lobar degeneration (FTLD). Other longer-term conditions included cancer, stroke, Parkinson's disease, and mild cognitive impairment (MCI). A wide range of relationships between the patient and carer were detailed across the reviews, including spouses, other relatives, daughters, sons, friends, siblings, and neighbours. Few reviews reported details about the time spent caring in individual studies, however some provided details about hours spent caring per day. Data about gender, age and ethnicity were not always reported; therefore comparisons across all reviews in relation to these characteristics cannot be made.

Authors did not always define or conceptualise the terms 'carer,' or 'burden' making findings from the reviews difficult to compare.

### **5.5.2. Excluded reviews**

A record of reasons for excluded reviews is outlined in Appendix E.

### 5.5.3. Methodological quality

The 14 systematic reviews received AMSTAR ratings between 0 and 6 out of 11. Nine reviews were rated as low quality, five medium quality, and none high quality:

**Table 11: Quality assessment scores**

Low AMSTAR score (0-3)		Medium AMSTAR score (4-7)		High AMSTAR score (8-11)
Azzani et al. (2015)	2/11	del-Pino-Casado et al. (2011)	5/11	No reviews with high score
Chiao et al. (2015)	1/11	Greenwell et al. (2015)	4/11	
Gaugler (2010)	2/11	Orgeta and Miranda-Castillo (2014)	6/11	
Hesamzadeh et al. (2015)	2/11	Seeher et al. (2013)	4/11	
Nunnemann et al. (2012)	2/11	Van Vliet et al. (2010)	4/11	
Stenberg et al. (2010)	2/11			
Stenberg et al. (2014b)	0/11			
van der Lee et al. (2014)	1/11			
Wolfs et al. (2012)	2/11			

The table below outlines the responses to the 11 items for all 14 reviews. This shows the differences between the reviews and which criteria were influential in how they were scored using the AMSTAR tool.

**Table 12: Summary table of methodological quality for all included reviews**

<b>AMSTAR tool items to assess methodological quality (items 1-11)</b>											
✓ = yes (score =1), x = no (score = 0), CA= can't answer, (score = 0), NA= not applicable (score =0)											
<b>Included studies</b>	1. Was an 'a priori' design provided?	2. Was there duplicate study selection and data extraction?	3. Was a comprehensive literature search performed?	4. Was the status of the publication (i.e. grey literature) used as an inclusion criterion?	5. Was a list of studies (included and excluded) provided?	6. Were the characteristics of included studies provided?	7. Was the scientific quality of the included studies assessed and documented?	8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	9. Were the methods used to combine the findings of studies appropriate?	10. Was the likelihood of publication bias assessed?	11. Was the conflict of interest included?
1. Azzani et al (2015)	x	CA	✓	x	x	CA	✓	x	NA	x	NA
2. Chiao et al. (2015)	x	CA	x	x	x	✓	CA	x	NA	x	NA
3. Del-Pino-Casado et al. (2011)	x	CA	✓	x	✓	✓	✓	✓	NA	x	NA

4. Gaugler (2010)	x	CA	✓	x	x	✓	x	NA	NA	x	CA
5. Greenwell et al. (2015)	x	✓	✓	x	x	✓	CA	✓	CA	x	NA
6. Hesamzadeh et al. (2015)	x	CA	✓	x	x	✓	CA	CA	NA	x	NA
7. Nunnemann et al. (2012)	x	CA	✓	x	x	✓	CA	x	NA	x	NA
8. Orgeta and Miranda-Castillo (2014)	x	✓	x	x	✓	✓	✓	✓	✓	x	NA
9. Seeher et al. (2013)	x	✓	✓	x	x	✓	x	NA	✓	x	CA
10. Stenberg et al. (2014b)	x	CA	x	x	x	x	CA	x	NA	x	CA
11. Stenberg	x	✓	✓	x	x	x	x	NA	NA	x	CA

et al. (2010)											
12. Van der Lee et al. (2014)	x	CA	x	x	x	✓	x	NA	NA	x	CA
13. Van Vliet et al. (2010)	x	CA	x	CA	x	✓	✓	✓	✓	x	NA
14. Wolfs et al. (2012)	x	CA	x	x	x	✓	✓	x	NA	x	CA

Despite the AMSTAR tool being considered as a reliable and feasible tool for assessing the quality of systematic reviews (Shea et al., 2009), its application in this research has highlighted its potential weaknesses. Allocating a 'yes' response was difficult when multiple criteria had to be met within an item. For example, regarding item two, authors more commonly outlined the procedure for duplicate study selection, rather than data extraction. Lack of detail about the latter led to 10 reviews being allocated 'can't answer', scoring 0. Similarly, in item three authors commonly conducted a comprehensive search, using multiple sources, but supplementary strategies were often lacking. Regarding item five, many reviews included a list of included studies, yet excluded studies were not always provided or referenced. There is no way of differentiating between reviews that meet some of the multiple criteria within an item and those that met none.

Allocating 0 to all the other responses (no, can't answer and not applicable) is also problematic as it is difficult to differentiate between reviews that did not meet criteria at all, those that did not report enough information to make judgement, and those that were not applicable to items on the tool. Item 11 proved problematic as the wording suggests that there must be a conflict of interest to score a 'yes' and be allocated a higher score. Some reviews did not include a section about 'conflict of interest', and were allocated 'no.' Other reviews included this section but had no conflicts of interest, hence being marked as 'not applicable.'

Overall quality scores may need to be treated with caution as reviews often included elements that could indicate they are of a higher quality, which could not be captured in the AMSTAR scoring system.

## **5.6. Narrative findings**

This section includes findings, summarised in a narrative form in accordance with the research questions contributing to the logic model of the problem, following Smith et al. (2011). Table 13 presents a summary of findings, indicating which reviews were relevant to each research question.

**Table 13: Summary of findings from systematic review of reviews**

Included studies (author and date)	Long term condition	Review questions				Theories used to explain burden in carers	
		1) What are the behaviours associated with carer burden in carers of people with longer-term conditions?	2) What are the environmental conditions that facilitate or limit burden?	3) What other factors are associated with carer burden?  Carer	Patient		4) What are the determinants (predictors) of behaviours and environmental factors associated with carer burden?
1. Azzani et al. (2015)	Cancer	✓	✓		✓		
2. Chiao et al. (2015)	Dementia	✓	✓	✓	✓		
3. del- Pino-Casado et al. (2011)	Dementia (9 studies) Non trauma induced cognitive impairment (1 study)					✓	✓
4. Gaugler (2010)	Stroke					✓	✓
5. Greenwell et al. (2015)	Parkinson's Disease		✓		✓	✓	✓
6. Hesamzadeh et	Stroke	✓	✓			✓	✓

al. (2015)							
7. Nunnemann et al. (2012)	Frontotemporal lobar degeneration (FTLD)- a type of dementia				✓	✓	
8. Orgeta and Miranda-Castillo (2014)	Dementia			✓			
9. Seeher et al.(2013)	MCI			✓	✓		✓
10. Stenberg et al. (2014b)	Cancer	✓	✓	✓	✓		
11. Stenberg et al. (2010)	Cancer	✓	✓			✓	
12. Van der Lee et al. (2014)	Dementia		✓	✓	✓	✓	✓
13. Van Vliet et al. (2010)	Early onset dementia (EOD)			✓	✓		
14. Wolfs et al. (2012)	Dementia				✓		
<b>Overall summary</b>							
		5 reviews in the	6 reviews in the	7 reviews in	9 reviews in the	7 reviews in the	6 reviews



		<p>following conditions:  Cancer (n= 3)  Dementia (n=1)  Stroke (n= 1)</p>	<p>following conditions:  Cancer (n=3)  Stroke (n=1)  Dementia (n=2)</p>	<p>the following conditions:  Dementia (n= 3)  Cancer (n= 1)  Early Onset Dementia (n=1)  Parkinson's Disease (n= 1)  MCI (n = 1)</p>	<p>following conditions:  Dementia (n=3)  Cancer (n=2)  Parkinson's Disease (n=1)  FLTD (n=1)  Early onset dementia (EOD) (n=1)  MCI (n=1)</p>	<p>following conditions:  Stroke (n= 2)  Parkinson's Disease (n=1)  Cancer (n=1)  Dementia (n=2)  FTLD (n=1)</p>	<p>including theory to explain burden in carers in the following conditions:  Dementia (n=2)  Stroke (n=2)  Parkinson's Disease (n=1)  MCI (n= 1)</p>
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### **5.6.1. Behaviours associated with carer burden**

Of the 14 reviews, five included behaviours associated with carer burden across three different conditions. Some provided evidence for different behaviours that led to increased burden, and others included adaptive behaviours for reducing burden. Behaviours associated with burden related to engagement in care tasks. Adaptive behaviours related to managing care and managing financial difficulties. Each are outlined in table 14 and supported with written commentary.

**Table 14: Behaviours associated with carer burden**

<b>Author(s) and date</b>	<b>Long term condition</b>	<b>Review question: What are the behavioural associated with carer burden in carers of people with longer-term conditions?</b>
<b>Burdensome behaviour: engagement in care tasks</b>		
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Heavy patient care load and greater burden (Froelich et al., 2009; Kim et al., 2009; Skarupski et al., 2009).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>• Increased engagement with informal caring and caring tasks associated with heightened illness burden (Molassiotis et al., 2011; Van Ryn et al., 2011; Wagner et al., 2011).</li> </ul>
Stenberg et al. (2010)	Cancer	<ul style="list-style-type: none"> <li>• Increased burden from trying to meet the needs of others family members as well as the cancer patient (Schubart et al., 2008).</li> <li>• Personal tasks (e.g. feeding and washing patient) more burdensome than non-personal tasks (e.g. transportation) (Bakas et al., 2001; Carey et al., 1991; Oberst et al., 1989).</li> </ul>
<b>Adaptive behaviours for managing caregiving tasks</b>		
Hesamzadeh et al. (2015)	Stroke	<ul style="list-style-type: none"> <li>• Behavioural coping strategies included: having accommodation for the stroke survivor and avoiding institutionalized care (Bäckström and Sundin, 2009; Strudwick and Morris, 2010; Wu, 2009) using experience and knowledge through trial and error (Wu, 2009), assisting with hygiene (Pierce et al., 2009b), organising new patterns of interdependence (Jongbloed, 1994), developing patterns and routines (Shah, 2011) using schedules and timetables (Greenwood et al., 2009b).</li> <li>• Social coping strategies included behaviours such as: seeking help from other people (Wu, 2009), seeking information, acquiring knowledge about stroke care (Dalvandi, 2011; Greenwood et al., 2009b; Wu, 2009), requesting assistance to manage daily tasks (Pierce et al., 2009b), sharing thoughts and feelings with friends and stroke carer groups (Jongbloed, 1994; Pierce et al., 2004a).</li> </ul>
<b>Adaptive behaviours for managing financial burden</b>		
Azzani et al. (2015)	Cancer	<ul style="list-style-type: none"> <li>• 40% of participants avoided expensive purchases, 4% sold property (Bona et al., 2014).</li> <li>• 16.5%- 21.8% of participants borrowed money, others sold stocks (81%) and 8.1% to 15.5% withdrew money from savings (Shankaran et al., 2012).</li> <li>• Paying for treatments using loans, credit cards and selling property (Heath et al., 2006).</li> </ul>

### **5.6.1.1 Burdensome behaviour: Engagement in care tasks**

Three reviews provided evidence for the association between burden and engagement in tasks among dementia carers (Chiao et al., 2015) and cancer carers (Stenberg et al., 2014b; Stenberg et al., 2010). Three studies included by Chiao et al. (2015) found an association between engaging in a heavy patient care load and greater burden. Stenberg et al. (2014b) supported this finding, as heightened illness burden and difficulties with coping were associated with increased engagement in tasks across some included studies.

Stenberg et al. (2010) included one study where increased burden was associated with trying to meet the needs of others in the family alongside the cancer patient. In other included studies, personal tasks were perceived as more burdensome, compared to non-personal tasks and care was described as a difficult, disruptive, and time-consuming activity.

### **5.6.1.2 Adaptive behaviours for managing caregiving tasks**

One review (Hesamzadeh et al., 2015) provided numerous examples of adaptive behaviours, categorised as behavioural social coping strategies associated with managing caregiving tasks within families of stroke survivors. These provide a valuable contribution to understanding how carers may seek to overcome burden, however they do not contribute to the logic model, as this is problem focused. These have been outlined in table 14 but are not discussed within this section.

### **5.6.1.3 Adaptive behaviours for managing financial burden**

One review by Azzani et al. (2015) included three studies that outlined adaptive behaviours associated with reducing financial burden among carers of cancer patients. Similarly, these do not contribute to the logic model.

### **5.6.2. Environmental conditions that facilitate or limit burden**

Of the 14 reviews, six included environmental conditions that facilitate or carer burden across three different conditions (table 15). Environmental conditions largely related to social support and financial circumstances.

**Table 15: Environmental conditions that facilitate or limit burden**

Author(s) and date	Long term condition	Review question: What are the environmental conditions that facilitate or limit carer burden?
<b>Social support</b>		
Hesamzadeh et al. (2015)	Stroke	Examples of environmental conditions likely to lead to family crisis: <ul style="list-style-type: none"> <li>• Rehabilitation support that lacks continuity at home and in the community (Dalvandi, 2011; Dalvandi et al., 2011).</li> <li>• Services and organisations that fail to engage in adequate planning as part of the stroke survivors' rehabilitation (Subgranon, 1999).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>• Family support is an important factor for understanding burden in family carers of cancer patients (Carey et al., 1991; Chen et al., 2009; Daly et al., 2009; Francis et al., 2010; Gaugler et al., 2008; Yusuf et al., 2011).</li> </ul>
Stenberg et al. (2010)	Cancer	<ul style="list-style-type: none"> <li>• Carers with limited social networks are more likely to feel burdened (Goldstein et al., 2004).</li> </ul>
<b>Financial circumstances</b>		
Azzani et al. (2015)	Cancer	Examples of environmental conditions that facilitated perceptions of financial burden: <ul style="list-style-type: none"> <li>• Distance from hospital and single parent households (Heath et al., 2006).</li> <li>• Households with low income (Heath et al., 2006; Longo et al., 2006; Markman and Luce, 2010; Pezzin et al., 2009; Shankaran et al., 2012; Zaidi et al., 2012).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>• Financial and employment problems were evident among cancer patients (Carey et al., 1991; Chen et al., 2009; Daly et al., 2009; Francis et al., 2010; Gaugler et al., 2008; Yusuf et al., 2011).</li> </ul>
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Low monthly income was associated with increased burden (Andrén and Elmståhl, 2007; Kim et al., 2009).</li> </ul>

### **5.6.2.1 Social support**

Three reviews included findings about the association between support and carer burden (Hesamzadeh et al., 2015; Stenberg et al., 2014b; Stenberg et al., 2010). As is evident in table 15, Stenberg et al. (2014b) identified family support as an important factor for understanding burden in carers of cancer patients, based on findings from numerous studies. Further details were not provided regarding how this influences burden, due to how findings were reported. Stenberg et al. (2010), provided evidence for an association between heightened burden and limited social networks, based on findings from one study.

Difficulties with support extended beyond informal support. From three studies included by Hesamzadeh et al. (2015), examples of environmental conditions linked to family crises (i.e. burden) included: rehabilitation support that lacks continuity at home and in the community and services and organisations that fail to engage in adequate planning as part of the stroke survivors' rehabilitation.

### **5.6.2.2 Financial circumstances**

Three reviews addressed financial circumstances as an example of an environmental condition associated with burden (Azzani et al., 2015; Chiao et al., 2015; Stenberg et al., 2014b). Stenberg et al. (2014b) included numerous studies where related financial and employment problems were evident among carers of cancer patients.

Azzani et al. (2015) identified different environmental conditions across numerous studies that facilitated perceptions of financial burden, including: distance from hospitals, single parent households and households with low incomes. Chiao et al. (2015) also included studies where low income was associated with increased burden. Financial difficulties such as those outlined in these reviews are difficult to address in an intervention focused on behaviour change, however this insight is still important.

### **5.6.3. Other carer factors associated with carer burden**

Seven of the 14 reviews, included 'other' factors related to carers that were associated with burden across five conditions (table 16). These 'other' factors are those that would not be considered as behaviours or environmental conditions. These are still important for understanding who is at risk of burden when forming a logic model of a problem.

Examples of 'other' factors included: carer socio-demographics demographics, interpersonal factors, psychological and physical health, and personality traits. The findings that follow are organised in to these four categories in the table and narrative summary.



**Table 16: Other factors associated with carer burden**

Author(s) and date	Long term condition	Review question: What other factors are associated with carer burden? (Those related to the carer)
<b>Carer socio-demographics</b>		
<b>Gender:</b>		
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>Three of 21 studies found an association between female gender and burden (Kim et al., 2009; Skarupski et al., 2009; Yeager et al., 2010).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>Females at risk of increased burden (narratively reported without specific reference).</li> </ul>
Van Vliet et al. (2010)	Early onset dementia	<ul style="list-style-type: none"> <li>Females experienced higher burden than males (Takano and Arai, 2005).</li> </ul>
Van der Lee et al. (2014)	Dementia	<ul style="list-style-type: none"> <li>Females experienced higher subjective burden compared to males (Barusch and Spaid, 1989).</li> </ul>
Seeher et al. (2013)	MCI	<ul style="list-style-type: none"> <li>Gender did not predict any outcome (Blieszner and Roberto, 2010; Bruce et al., 2008; Garand et al., 2005).</li> </ul>
<b>Age:</b>		
Seeher et al. (2013)	MCI	<ul style="list-style-type: none"> <li>Age unrelated to burden in carers (Bruce et al., 2008).</li> </ul>
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>Mixed evidence. In two studies, younger carers experienced increased burden (Andrén and Elmståhl, 2007; Skarupski et al., 2009), in another study, older carers experienced heightened burden (Rinaldi et al., 2005).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>Younger carers more at risk of burden (narratively reported without specific reference).</li> </ul>
<b>Educational level:</b>		
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>Carers with lower educational levels were at greater risk of burden (narratively reported without specific reference).</li> </ul>

Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Low educational levels associated with increased burden (Kim et al., 2009; Sinforiani, 2010).</li> </ul>
<b>Ethnicity and race:</b>		
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Non-Hispanic Caucasian ethnicity associated with increased burden (Skarupski et al., 2009; Sun et al., 2010).</li> </ul>
Seeher et al. (2013)	MCI	<ul style="list-style-type: none"> <li>• Race did not predict any outcome (Blieszner and Roberto, 2010).</li> </ul>
<b>Employment:</b>		
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>• Being employed associated with burden</li> </ul>
<b>Carer interpersonal factors</b>		
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Cohabitation with patient associated with increased burden (Conde-Sala et al., 2010).</li> <li>• Spousal relationships with person related to higher burden in some studies (Hong and Kim, 2008; Rinaldi et al., 2005) and adult children as carers in others (Andrén and Elmståhl, 2007; Conde-Sala et al., 2010; Yeager et al., 2010).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>• Carers with ambivalent attachments and spousal relationships at increased risk of burden</li> </ul>
Seeher et al. (2013)	MCI	<ul style="list-style-type: none"> <li>• Relationship with patient and co-residing status did not predict any outcome (Blieszner and Roberto, 2010; Lu et al., 2007).</li> <li>• Reduced subjective burden associated with marital quality, specifically marital satisfaction (Garand et al., 2005).</li> </ul>
Van der Lee et al. (2014)	Dementia	<ul style="list-style-type: none"> <li>• Good relationship with the patient reduced burden and unwanted participation in a role increased burden (Campbell et al., 2008).</li> </ul>
<b>Carer psychological and physical health</b>		
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Greater burden was experienced by dementia carers with: poor psychological health (Andrén and Elmståhl, 2007; McConaghy and Caltabiano, 2005), poor perceived well-being (McConaghy and Caltabiano, 2005), high depressive symptoms (Davis and Tremont, 2007; Yeager et al., 2010), poor religious coping skills (Sun et al.,</li> </ul>

		2010), poor symptom management (Gallagher et al., 2011), high anxiety, aggressiveness, and authoritarianism (Zawadzki et al., 2011).
Van der Lee et al. (2014)	Dementia	<ul style="list-style-type: none"> <li>• Burden was associated with depressive symptoms (Gonyea et al., 2005), depression (Kang et al., 2007) and mood disorders (Davis and Tremont, 2007).</li> <li>• In one study, higher subjective wellbeing predicted reduced burden (Aminzadeh et al., 2006).</li> </ul>
Greenwell et al. (2015)	Parkinson's Disease	<ul style="list-style-type: none"> <li>• Mental health status predicted burden (Shin et al., 2012a; Shin et al., 2012b).</li> <li>• Depression predicted burden in numerous studies (Aarsland et al., 1999; Carter et al., 2012; Leroi et al., 2012; Miller et al., 1996; Sarandol et al., 2010; Tanji et al., 2013; Thommessen et al., 2002).</li> <li>• In one study depression was only a predictor in the USA sample, not the Japanese sample (Tanji et al., 2013).</li> <li>• In another study, depression was only predictive of carer burden in those who experienced impulse control disorders (Leroi et al., 2012).</li> </ul>
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>• Diagnosed health problems associated with increased burden (narratively reported without specific reference).</li> </ul>
Orgeta and Miranda-Castillo (2014)	Dementia	<ul style="list-style-type: none"> <li>• Physical activity reduced subjective carer burden, measured using the Screen for Caregiver Burden Scale, but not objective carer burden (Castro et al., 2002; King and Brassington, 1997).</li> </ul>
<b>Carer personality traits</b>		
Van der Lee et al. (2014)	Dementia	<ul style="list-style-type: none"> <li>• Caregiver neuroticism predicted higher burden (Kang et al., 2007; Melo et al., 2011; Reis et al., 1994; Shurgot and Knight, 2005) while confidence, (Campbell et al., 2008) extraversion and agreeableness reduced burden (Melo et al., 2011).</li> <li>• Higher expressed emotions also linked to increased burden (Vitaliano et al., 1991).</li> </ul>
Greenwell et al. (2015)	Parkinson's Disease	<ul style="list-style-type: none"> <li>• Optimism and pessimism predicted baseline depression and burden at year 10 in a longitudinal study (Lyons et al., 2004).</li> </ul>

### **5.6.3.1 Carer socio-demographics**

Five reviews addressed carer socio-demographical factors associated with burden (Chiao et al., 2015; Seeher et al., 2013; Stenberg et al., 2014b; van der Lee et al., 2014; Van Vliet et al., 2010) including gender, age, educational level, ethnicity and race, and employment.

#### ***Gender***

In four out of five reviews, female carers of dementia and cancer patients were most at risk of burden (Chiao et al., 2015; Stenberg et al., 2014b; van der Lee et al., 2014; Van Vliet et al., 2010). In contrast, the review of MCI carers (Seeher et al. 2013) found gender did not predict any outcome.

#### ***Age***

Findings provided mixed evidence for the association between age and burden. In one review (Seeher et al. 2013), age was unrelated to burden in carers of MCI patients. In another review (Chiao et al. 2015), the evidence was mixed across included studies. In some studies, older carers were more at risk, whereas in others burden was associated with younger carers. Similarly, Stenberg et al. (2014b) reported that younger carers of cancer patients are at more at risk of burden.

#### ***Educational level***

Two reviews including carers of individuals with cancer and dementia highlighted an association between a lower educational level and burden (Chiao et al., 2015; Stenberg et al., 2014b).

#### ***Ethnicity and race***

Two reviews addressed the association between ethnicity and race and burden. Chiao et al. (2015) identified an association between non- Hispanic Caucasian ethnicity and increased burden among those caring for patients with dementia in two studies. One study included by Seeher et al. (2013) found race did not predict any outcome, including burden.

#### ***Employment***

Stenberg et al. (2014b) narratively reported the association between being employed and burden.

### **5.6.3.2 Carer interpersonal factors**

Four reviews addressed interpersonal factors associated with burden (Chiao et al., 2015; Seeher et al., 2013; Stenberg et al., 2014b; van der Lee et al., 2014) including living circumstances, relationship types, and degree of satisfaction in relationships and roles.

Mixed findings were evident regarding living circumstances and relationships. Chiao et al. (2015) included a study where cohabitation with the dementia patient was associated with increased burden. Others studies provided mixed evidence for different relationships that were associated with increased burden. Spousal relationships related to higher burden in some studies and adult children as carers in others. Stenberg et al. (2014b) reported that those with ambivalent attachments and spousal relationships were at more risk of burden. Conversely, Seeher et al. (2013) included two studies that indicated that the relationship with the patient and co-residing status did not predict any outcomes, including burden.

Two reviews addressed satisfaction with relationships, and found an association between degree of satisfaction and burden. Seeher et al. (2013) found a significant association between reduced burden and the degree of marital satisfaction among carers of those with MCI in one study. Similarly, Van der Lee et al. (2014) reported the link between relationships perceived as 'good relationships' and reduced burden in one study including dementia carers. In the same study, heightened burden was more common among those who did not want to participate in their caring roles.

### **5.6.3.3 Carer psychological and physical health**

Three reviews focussed on the association between psychological factors and burden among carers with dementia (Chiao et al., 2015; van der Lee et al., 2014) and Parkinson's disease (Greenwell et al. 2015). A range of psychological factors were evident across these reviews; however, depression was explored as a predictor of burden across many studies.

Based on findings from numerous studies, Chiao et al. (2015) indicated that greater burden was experienced by carers of people with dementia with: poor psychological health, poor perceived well-being, high depressive symptoms, poor religious coping skills, poor symptom management, high anxiety, aggressiveness, and authoritarianism. Van der Lee et al. (2014) included a study which supports some of these findings, as an association between burden and depressive symptoms was evident. These review findings also showed burden was also associated with depression and mood disorders in two studies. In another study, higher subjective wellbeing was predictive of reduced burden.

In the review by Greenwell et al. (2015), depression was a predictor of burden across seven studies. This is consistent with findings outlined in other reviews (Chiao et al., 2015; van der Lee et al., 2014). However, in one study this was only the case for carers of individuals with impulse control disorders. In another study, depression was only a predictor of burden in the USA sample not the Japanese sample.

Physical health was also included in two of the 14 reviews. Stenberg et al. (2014b) found diagnosed physical health problems were associated with increased burden among carers of cancer patients. Orgeta and Miranda-Castillo (2014) examined physical activity in relation to burden among carers of dementia patients. Two studies found an association between reduced subjective carer burden and physical activity when measured using the Screen for Caregiver Burden Scale. However, there was no association between physical activity and objective burden.

#### **5.6.3.4 Carer personality traits**

Two reviews addressed the association between burden and personality traits in carers of individuals with dementia (Van der Lee et al. 2014) and carers of those with Parkinson's disease (Greenwell et al. 2015). Van der Lee et al. (2014), concluded that carer neuroticism predicted higher burden, while confidence, extraversion and agreeableness reduced burden. Higher expressed emotions also linked to increased burden. Greenwell et al. (2015) found that optimism and pessimism predicted burden at ten years based on a longitudinal study.

#### **5.6.4. Patient factors associated with carer burden**

Nine of the 14 reviews included factors related to patients that are associated with carer burden across six conditions (table 17). Broadly, these included patient socio-demographics, functional status, behavioural and psychological factors, and illness factors.

**Table 17: Patient factors associated with carer burden**

<b>Author (s) and date</b>	<b>Long term condition</b>	<b>Review question: What other factors are associated with carer burden? (Those related to the patient)</b>
<b>Patient socio-demographics</b>		
<b>Gender:</b>		
Wolfs et al. (2012)	Dementia	<ul style="list-style-type: none"> <li>Some factors were classed as potential predictors when they related to objective burden in one or two studies. Patient gender was included in these factors.</li> </ul>
<b>Age:</b>		
Wolfs et al. (2012)	Dementia	<ul style="list-style-type: none"> <li>Age was included as a potential predictor based on the definition outlined above.</li> </ul>
Azzani et al. (2015)	Cancer	<ul style="list-style-type: none"> <li>Patients who younger were more at risk of financial burden (Rogers et al., 2012).</li> </ul>
<b>Educational level:</b>		
Wolfs et al. (2012)	Dementia	<ul style="list-style-type: none"> <li>Patient educational level was included as a 'potential predictor' based on the definition outlined above.</li> </ul>
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>Levels of education among patients with dementia were predictive of carer burden (Agüera-Ortiz et al., 2010; Kim et al., 2009).</li> </ul>
<b>Functional status</b>		
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>Poor functional status associated with carer burden (Gallagher et al., 2011; Kim et al., 2009; Rinaldi et al., 2005; Sink et al., 2006; Yeager et al., 2010).</li> </ul>
<b>Behavioural and psychological factors</b>		
Stenberg et al. (2014b)	Cancer	<ul style="list-style-type: none"> <li>Caring for a patient who suffers from depression or anxiety can exacerbate burden (narratively reported, no specific reference).</li> </ul>
Van der Lee et al. (2014)	Dementia	<ul style="list-style-type: none"> <li>Patient mood disorders such as depression were significantly associated with burden (Bédard et al., 2005; Bédard et al., 1997).</li> </ul>
Greenwell et al. (2015)	Parkinson's Disease	<ul style="list-style-type: none"> <li>Two studies found a positive relationship between person with Parkinson's depression and carer burden (Aarsland et al., 1999; Miller et al., 1996). One study found a relationship but the direction was not reported (Sarandol et al., 2010), two found no relationship (Carter et al., 2012; Fernandez et al., 2001).</li> </ul>
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>An association between increased burden and high prevalence of behavioural disturbances (Boutoleau-</li> </ul>



		Bretonnière et al., 2008; Conde-Sala et al., 2010; Davis and Tremont, 2007; Lim et al., 2011; Mohamed et al., 2010; Rinaldi et al., 2005; Sink et al., 2006) and a high level of neuropsychiatric symptoms (Conde-Sala et al., 2010; Gallagher et al., 2011; Mohamed et al., 2010; Sink et al., 2006; Tun et al., 2008; Yeager et al., 2010).
Wolfs et al. (2012)	Dementia	<ul style="list-style-type: none"> <li>• Predictors of objective burden included cognitive impairment, behavioural disturbances and impairments related to activities of daily living.</li> </ul>
Seeher et al. (2013)	MCI	<ul style="list-style-type: none"> <li>• Patient depression not predictive of burden (Bruce et al., 2008).</li> <li>• Behavioural symptoms associated with burden (Bruce et al., 2008).</li> </ul>
Van Vliet et al. (2010)	Early onset Dementia	<ul style="list-style-type: none"> <li>• One study found no significant association between carer burden and cognitive function and behavioural disturbances (Freyne et al., 1999).</li> <li>• In another study, behavioural disturbances were positively associated with carer burden in early onset and late onset dementia carers (Arai et al., 2007).</li> </ul>
<b>Illness factors</b>		
Van Vliet et al. (2010)	Early onset Dementia	<ul style="list-style-type: none"> <li>• Illness severity was associated with burden in late onset dementia patients.</li> </ul>
Chiao et al. (2015)	Dementia	<ul style="list-style-type: none"> <li>• Carer burden associated with worsening severity of dementia and (Lim et al., 2011; Mohamed et al., 2010; Sink et al., 2006; Skarupski et al., 2009) and patients with Frontotemporal dementia (Boutoleau-Bretonnière et al., 2008).</li> <li>• A longer duration of illness was associated with greater burden (Kim et al., 2009).</li> </ul>
Seeher et al. (2013)	MCI	<ul style="list-style-type: none"> <li>• Symptom duration was significantly associated with carer burden even when cognitive function and behavioural disturbances were controlled (Bruce et al., 2008).</li> </ul>
Wolfs et al. (2012)	Dementia	<ul style="list-style-type: none"> <li>• Comorbidity of the patient was classed as a 'no predictor' because it did not lead to objective burden.</li> </ul>

#### **5.6.4.1 Patient socio-demographics**

Three reviews addressed patient socio-demographical factors associated with burden (Azzani et al., 2015; Chiao et al., 2015; Wolfs et al., 2012) including gender, age, and educational level.

##### ***Gender***

Wolfs et al. (2012), considered patient gender as a 'potential predictor' of objective burden in dementia carers. However, it is difficult to determine the relevant studies and whether males or female patients were more likely to lead carers to feel burdened.

##### ***Age***

Patient age was also a 'potential predictor' of objective burden in the review by Wolfs et al. (2012). Again, there was a lack of clarity around which studies contributed to this finding, and whether carer burden increased or decreased with patient age. Azzani et al. (2015) included one study where younger cancer patients were more at risk of financial burden. Links between patient financial burden and the resultant impact on financial burden in carers were not explicit.

##### ***Educational level***

Wolfs et al. (2012) included patient educational level as a 'potential predictor' of objective burden. The lack of clarity remained around which studies were relevant to this finding. Levels of education among patients with dementia were also predictive of carer burden in two studies included by Chiao et al. (2015). However, across both reviews, it was unclear whether higher or lower educational levels were more indicative of burden.

#### **5.6.4.2 Functional status**

One review by Chiao et al. (2015) found an association between patients with poor functional status and carer burden across five studies.

#### **5.6.4.3 Behavioural and psychological factors**

Seven reviews examined the association between patient behavioural and psychological factors and carer burden, across different conditions including : Parkinson's disease (Greenwell et al., 2015), MCI (Seeher et al. 2013), cancer (Stenberg et al. 2014b) and

dementia (Chiao et al., 2015; van der Lee et al., 2014; Van Vliet et al., 2010; Wolfs et al., 2012).

Four reviews provided mixed evidence for the association between patient depression and burden in carers. Stenberg et al. (2014b) reported that caring for a cancer patient with either depression or anxiety can exacerbate carer burden. Depression was a common psychological indicator of burden across studies. This was significantly associated with burden in two studies in the review by Van der Lee et al. (2014). Some evidence from Greenwell et al. (2015) supports this finding, as a positive relationship between depression and carer burden patients with Parkinson's disease was evident in two of their included studies. However, in another study there was a relationship, but the direction was not reported and in another two there was no relationship. Evidence from Seeher et al. (2013) supports the latter finding, as patient depression was not predictive of burden in carers of MCI patients.

Three reviews including carers of dementia patients addressed the association between carer burden and behavioural factors and provided mixed findings (Chiao et al., 2015; Van Vliet et al., 2010; Wolfs et al., 2012). Chiao et al. (2015) included seven studies indicating an association between increased burden and high prevalence of behavioural disturbances and six studies indicating a high level of neuropsychiatric symptoms. Wolfs et al. (2012) found cognitive impairments, behavioural disturbances, and impairments related to activities of daily living predicted objective burden. Seeher et al. (2013) supported this finding as an included study found an association between increased burden and behavioural symptoms.

Conversely, Van Vliet et al. (2010) included a study that found no significant association between carer burden and cognitive function and behavioural disturbances. In the same review, another study found a positive association between behavioural disturbances and carer burden in early onset and late onset dementia carers.

#### **5.6.4.4 Illness factors**

Four reviews, addressed burden and illness factors e.g. severity, duration, and comorbidities (Chiao et al., 2015; Seeher et al., 2013; Van Vliet et al., 2010; Wolfs et al., 2012).

Severity of illness was associated with increased carer burden in two reviews including patients with different types of dementia (Chiao et al., 2015; Van Vliet et al., 2010) and longer duration of illness was associated with greater burden in two reviews including

patients with dementia and MCI (Chiao et al., 2015; Seeher et al., 2013). Only Wolfs et al. (2012) addressed co-morbidity of the patient, and categorised this as a 'no predictor' as this was not associated with objective burden.

#### **5.6.5. Determinants (predictors) of behaviours and environmental factors associated with carer burden**

This section addresses the determinants (predictive factors) of these behaviours and environmental conditions associated with carer burden that were outlined in section 5.6.1. These factors contribute to the boxes at the left side of the logic model, outlined earlier in section 5.4.4. In this section, these are outlined as determinants of behaviours associated with carer burden and determinants of environmental conditions.

Determinants were evident in seven reviews, some of these were non-theoretical, and others were theoretical (taken from models or theories of carer burden). Table 18 presents a summary of determinants included in the reviews and outlines where theories or models were used to understand carer burden.

**Table 18: Determinants of behaviours and environmental factors associated with carer burden**

<b>Author(s) and date</b>	<b>Long term condition</b>	<b>Review question:</b> What are the determinants (predictors) of behaviours and environmental factors associated with carer burden?
<b>Determinants of behaviours associated with carer burden</b>		
<b>Time spent caring</b>		
Greenwell et al. (2015)	Parkinson's Disease	<i>Findings based on Goldsworthy and Knowles' stress appraisal model (Goldsworthy and Knowles, 2008).</i> <ul style="list-style-type: none"> <li>Hours spent caring – mixed findings.</li> </ul>
<b>Build-up of strain over time</b>		
Hesamzadeh et al. (2015)	Stroke	<i>(Findings based on the Double ABCX model extended by McCubbin and Patterson (1981) based on Hill's classic family theory (Hill, 1958).</i> <ul style="list-style-type: none"> <li>Family stresses and demands: Pileup (aA) component: striking a balance vs being drained of energy to continue in role.</li> </ul>
Gaugler (2010)	Stroke	<i>(Findings based on Pearlin et al's (1990) stress process model) (Pearlin et al., 1990)</i> <ul style="list-style-type: none"> <li>"Proliferation" (extent to which individuals can adapt to spread of stress)– mixed findings from different study types (cross-sectional, longitudinal and qualitative).</li> </ul>
<b>Carers perceptions of their roles and abilities</b>		
Van der Lee et al. (2014)	Dementia	<i>(Findings based on a range of models that included different types of patient and caregiver determinants)</i> <ul style="list-style-type: none"> <li>Carer role captivity and carer overload (model by Campbell et al. (2008)) – increased burden.</li> <li>Sense of coherence (SOC) (<i>confidence that things will work out as can reasonably be expected</i>) (two models (Andrén and Elmståhl, 2007; Barusch and Spaid, 1989) – decreased burden.</li> <li>Self-efficacy (competence) High self-efficacy - reduced burden.</li> <li>High self-esteem and frequency of having a break - (less) burden.</li> </ul>

Greenwell et al. (2015)	Parkinson's Disease	<i>(Findings based on Goldsworthy and Knowles' stress appraisal model (Goldsworthy and Knowles, 2008) and a new conceptual model).</i> <ul style="list-style-type: none"> <li>• Lower self efficacy for dealing with stressors- greater burden.</li> <li>• Lower sense of coherence- greater caregiver burden.</li> </ul>
Nunnemann et al. (2012)	FTLD (type of dementia)	<i>(Findings not based on a specific model or theory)</i> <ul style="list-style-type: none"> <li>• Sense of competence - no effect on burden.</li> </ul>
<b>Coping types</b>		
<b>Problem focussed coping</b>		
del-Pino-Casado et al. (2011)	Dementia	<i>(Findings based on models of coping by Lazarus and Folkman (1984) or Moos et al. (1990)</i> <ul style="list-style-type: none"> <li>• Problem focussed coping (Lazarus and Folkman 1984) – mixed findings</li> </ul>
Van der Lee et al. (2014)	Dementia	<i>(Findings based on a range of models that included different types of patient and caregiver determinants)</i> <ul style="list-style-type: none"> <li>• Problem focussed coping - lower burden</li> </ul>
<b>Emotion focussed coping</b>		
del-Pino-Casado et al. (2011)	Dementia	<i>(Findings based on models of coping by Lazarus and Folkman (1984) or Moos et al. (1990).</i> <ul style="list-style-type: none"> <li>• Emotion focused coping (oriented towards managing emotions)- from Lazarus and Folkman (1984) – higher burden</li> </ul>
Van der Lee et al. (2014)	Dementia	<i>(Findings based on a range of models that included different types of patient and caregiver determinants)</i> <ul style="list-style-type: none"> <li>• Emotional coping - higher burden</li> </ul>
<b>Avoidant and passive coping</b>		
Hesamzadeh et al. (2015)	Stroke	<i>(Findings based on the Double ABCX model extended by McCubbin and Patterson (1981) based on Hill's classic family theory (Hill, 1958)).</i> <ul style="list-style-type: none"> <li>• Avoidant coping strategies from model provided but not considered in relation to burden (see written</li> </ul>

		commentary).
Van der Lee et al. (2014)	Dementia	<i>(Findings based on a range of models that included different types of patient and caregiver determinants)</i> <ul style="list-style-type: none"> <li>• Avoidant coping and problem focussed coping not significantly associated with burden.</li> </ul>
Nunnemann et al. (2012)	FTLD (type of dementia)	<i>(Findings not based on a specific model or theory)</i> <ul style="list-style-type: none"> <li>• Passive coping strategies- increased burden and decreased health quality of life</li> </ul>
del-Pino-Casado et al. (2011)	Dementia	<i>(Findings based on models of coping by Lazarus and Folkman (1984) or Moos et al. (1990).</i> <ul style="list-style-type: none"> <li>• Avoidance coping (<i>attempts to avoid problems and engage in indirect attempts to reduce distress</i>)- from Moos et al. (1990)</li> <li>• Positive association between subjective carer burden and avoidance coping</li> <li>• Positive association between escape-avoidance coping and carer burden</li> </ul>
<b>Approach coping</b>		
del-Pino-Casado et al. (2011)	Dementia	<i>(Findings based on models of coping by Lazarus and Folkman (1984) or Moos et al. (1990).</i> <ul style="list-style-type: none"> <li>• Approach coping (<i>attempts to reappraise, modify and solve problems</i>)- from Moos et al. (1990):</li> <li>• Positive association between active behavioural coping as part of approach coping and subjective burden; and a negative association between subjective burden and active cognitive coping as part of approach coping.</li> </ul>
<b>Behavioural, social, cognitive and family coping</b>		
Hesamzadeh et al. (2015)	Stroke	<i>(Findings based on the Double ABCX model extended by McCubbin and Patterson (1981) based on Hill's classic family theory (Hill, 1958)).</i> <ul style="list-style-type: none"> <li>• Behavioural, social, cognitive and family coping strategies included within model, yet not considered in relation to burden.</li> </ul>
<b>Determinants of environmental conditions associated with carer burden</b>		
<b>Perceived availability and perceived satisfaction with support</b>		

Stenberg et al. (2010)	Cancer	<p><i>( Findings not based on specific model or theory)</i></p> <ul style="list-style-type: none"> <li>• Burden associated with perceived availability of social support, rather than amount of assistance provided</li> </ul>
Greenwell et al (2015)	Parkinson's Disease	<p><i>(Findings based on Goldsworthy and Knowles' stress appraisal model (Goldsworthy and Knowles, 2008)and a new conceptual model).</i></p> <ul style="list-style-type: none"> <li>• Satisfaction of support- mixed evidence as a predictor of burden.</li> <li>• Poor social support – mixed evidence</li> </ul>
Van der Lee et al. (2014)	Dementia	<p><i>(Findings based on a range of models that included different types of patient and caregiver determinants)</i></p> <ul style="list-style-type: none"> <li>• Less satisfaction with support - higher burden</li> </ul>



## **5.6.5.1 Determinants of behaviours associated with carer burden**

### **5.6.5.1.1 Time spent caring**

Engagement in care tasks was outlined as a burdensome behaviour in section 5.6.1.1. One review included hours spent caring as a factor that may determine whether engagement in care tasks leads to burden (Greenwell et al. 2015). Evidence was mixed, as this was a predictor of burden in one study (Peters et al., 2011) but not another (Sarandol et al., 2010). According to the stress-appraisal model used to interpret results (Goldsworthy and Knowles, 2008), hours spent caring was mediated by perceived social support and frequency of breaks, which could account for the mixed findings.

### **5.6.5.1.2 Build-up of strain over time**

In section 5.6.1.2 adaptive behaviours for reducing burden were outlined, based on Hesamzadeh et al.'s (2015) findings. The final product of the Double ABCX model, included in their review is 'family adaptation (xX factor).' This is the outcome of a family effort to achieve new balance and functioning in response to the negative outcomes attached to caring after stroke. Within this model, numerous factors determined 'family adaptation.' The component 'family stress and demands: pile up (aA)' attended to the impacts of managing care on other domains of life. The extent of such impacts determined whether carers could overcome negative outcomes such as burden. Included studies provided examples of these impacts: loss of independence and autonomy, loss of normal relationships, inability to plan daily living; and loss of certainty for both the stroke survivor and carer (Bäckström and Sundin, 2009; Dalvandi, 2011; Green and King, 2009; Greenwood et al., 2009b) The main theme identified leading to a positive outcome was 'striking a balance' (Eaves, 2006). Carers were unable to adapt and overcome stress and burden when they became drained of energy to continue in the role (Bäckström and Sundin, 2009).

The notion of a 'pile up of demands' is linked to findings in the review by Gaugler (2010). The findings in their review were examined in the context of the Stress Process Model (Pearlin et al., 1990). Gaugler (2010) considered whether the temporal mechanism 'proliferation' determined burden in carers of stroke survivors. Proliferation is included in the Stress Process Model and is the spread of stress, strain, and conflict from actual care to other life domains. Mixed findings were produced for this concept as an influential factor in carer burden across different types of studies (cross-sectional, longitudinal and qualitative).

Cross-sectional studies discount the effect of time on carer outcomes and did not consider the temporal mechanism, proliferation as a determinant of burden. Studies using more advanced longitudinal techniques provided some support for the stress process model and the proliferation of stress as a determinant for carer burden (Bacon et al., 2009; Grant et al., 2006a; Jones et al., 2000; Ostwald et al., 2009; Perrin et al., 2009). Qualitative study findings supported the process of proliferation, as carers managed the stress from primary domains e.g. practical care to secondary stressors e.g. work and family conflicts.

According to the Stress Process Model (Pearlin et al., 1990), the extent to which carers can adapt to this spread of stress from actual care would influence whether carers become burdened.

#### **5.6.5.1.3 Carers' perceptions of their roles and abilities**

The extent of burden experienced from actual care was also influenced by carers' perceptions of their roles and carers perceptions of their abilities and internal resources to manage of adapt to the caring role.

Role perceptions included the extent to which they felt overloaded and the extent to which things would work out as reasonably expected (sense of coherence). Van der Lee et al. (2014) included findings based on a range of models relevant to dementia carers that included different types of carer determinants. Carer role captivity (unwanted participation in role) and carer overload were significantly related to increased carer burden in the model by Campbell et al. (2008). Across two reviews (Van der Lee et al 2014; Greenwell et al 2015), sense of coherence was a determinant of burden. Greenwell et al. (2015) included one study where a lower sense of coherence predicted greater burden (Caap-Ahlgren and Dehlin, 2002). Consistent with this finding, two models included in the review by Van der Lee et al. (2014) indicated a higher sense of coherence was significantly associated with decreased burden (Andrén and Elmståhl, 2007; Barusch and Spaid, 1989).

Examples of common carer determinants related to carers' perceptions of their abilities to provide care included self-efficacy (competence) and self-esteem. Mixed findings were evident across three reviews regarding self-efficacy as a determinant of carer burden. A study included by Greenwell et al. (2015), including carers of persons with Parkinson's disease found lower self efficacy predicted higher burden (Caap-Ahlgren and Dehlin, 2002). Van der Lee et al. (2014) similarly found an association between high self efficacy and reduced burden. Conversely, Nunnemann et al. (2012) included a study with

contrasting findings among carers of those with FTLD (a type of dementia), as sense of competence had no impact on burden (Riedijk et al., 2009).

Self-esteem was included as a determinant in one review (Van der Lee et al. 2014). In one study, high self-esteem and frequency of breaks were associated with being less burdened (Chappell and Reid, 2002).

#### **5.6.5.1.4 Coping types**

Coping types were included in some of the reviews (del-Pino-Casado et al., 2011; Hesamzadeh et al., 2015; Nunnemann et al., 2012; van der Lee et al., 2014). These were influential in whether carers carried out adaptive behaviours as part of caring and ultimately whether they experienced burden. Examples of coping types that were examined in relation to carer burden included: problem focussed coping, emotion focussed coping, approach coping, avoidant (or passive) coping, behavioural, social, cognitive, and family coping.

##### ***Problem focussed coping***

Two reviews included problem focussed coping (del-Pino-Casado et al., 2011; van der Lee et al., 2014). Mixed evidence was found for whether this type of coping determined carer burden. Van der Lee et al (2014) included two studies indicating that this leads to lower burden (Chou et al., 1999; Riedijk et al., 2009). Del-Pino- Casado et al. (2011) included the same study by Chou et al. (1999) therefore, supporting these findings. However, another included study found no association between a strategy included in problem focussed coping (seeking instrumental support) and subjective burden (Montoro-Rodriguez and Gallagher-Thompson, 2009).

##### ***Emotion focussed coping***

The same two reviews also included emotion focussed coping (del-Pino-Casado et al., 2011; van der Lee et al., 2014). Van der Lee et al. (2014) included two studies where this type of coping was associated with higher levels of burden (Chou et al., 1999; Riedijk et al., 2009). This was supported by three studies (Chou et al., 1999; Kramer, 1997; O'Rourke and Wenaus, 1998) included by del- Pino- Casado et al. (2011), one of which was the same.

##### ***Avoidant and passive coping***

Four reviews included avoidant or passive coping types (del-Pino-Casado et al., 2011; Hesamzadeh et al., 2015; Nunnemann et al., 2012; van der Lee et al., 2014). Rather than

determining whether these strategies related to burden, Hesamzadeh et al. (2015) provided some examples of how these related to carers of stroke survivors' experiences across studies. Examples include: avoiding what had transpired in the new phase of lives (Green and King, 2009), avoiding thinking about the future (Greenwood et al., 2009b) and abandoning the idea that everything could go back to the way that life had been before (Bäckström and Sundin, 2009).

The other three reviews provided mixed evidence for the association between avoidant strategies and carer burden. One of the models included in the review by Van der Lee et al. (2014) indicated no significant association between avoidant coping and burden (Di Mattei et al., 2008). However, findings from the other two reviews (del-Pino-Casado et al., 2011; Nunnemann et al., 2012), provided support for avoidant coping styles and increased burden. One study included by Nunnemann et al. (2012) reported that passive coping strategies were associated with increased burden and decreased health quality of life for all carers (Riedijk et al., 2006). Del- Pino- Casado et al. (2011) included studies that analysed coping strategies categorised as avoidance coping. Four studies found a positive association between avoidance coping and subjective carer burden (Cooper et al., 2008; Hinrichsen and Niederehe, 1994; Kim et al., 2007; Matsuda, 1995) and two studies reported a positive association between escape-avoidance coping and carer burden (Artaso et al., 2003; Montoro-Rodriguez and Gallagher-Thompson, 2009).

### ***Approach coping***

Del-Pino-Casado et al. (2011), also addressed approach coping. One study indicated a positive association between active behavioural coping as part of approach coping and subjective burden; and a negative association between active cognitive coping as part of approach coping and subjective burden (Hinrichsen and Niederehe, 1994).

### ***Behavioural, social, cognitive, and family coping***

Behavioural, social, cognitive, and family coping were also included as part of the Double ABCX model in the review by Hesamzadeh et al. (2015). As mentioned previously, Hesamzadeh et al. (2015) provided examples from studies rather than whether these related to burden. Some behavioural and social strategies were outlined in section 5.6.1.2. Examples of cognitive coping strategies include: Refocusing on the meaning of family and mutual relationship, preserving self-worth, ensuring the patient's quality of care, reconstructing ordinary life, and maintaining optimism through making comparisons with others who were worse off (Bäckström and Sundin, 2009; Greenwood et al., 2009b).

Examples of family coping strategies include: Refocusing of time and energy on the elements of the recovery process, redefining new role patterns, getting organised with house chores and sharing care (Jongbloed, 1994; Roecker et al., 2012).

### **5.6.5.2 Determinants of environmental conditions associated with carer burden**

#### **5.6.5.2.1 Perceived availability and perceived satisfaction with support**

Social support was an example of an environmental condition that facilitates or limits burden in section 5.6.2.1. Three reviews (Greenwell et al., 2015; Stenberg et al., 2010; van der Lee et al., 2014) also included determinants related to support that influence whether carers experience burden. These related to perceived availability and perceived satisfaction with support. Therefore, there was a subjective element attached to this, beyond the presence of social support or a social network of support that was described in section 5.6.2.1.

Supporting this notion, Stenberg et al. (2010) concluded that carer burden is based on subjective experiences of support, i.e. the perceived availability of social support, rather than the amount of assistance provided. Two other reviews provided evidence for the association between burden and satisfaction with support in carers of persons with Parkinson's disease (Greenwell et al. 2015) and dementia carers (Van der Lee et al. 2014). Greenwell et al. (2015) included mixed evidence for satisfaction of support as a predictor of burden. Perceiving carer social support as poor predicted burden in two studies (Edwards and Scheetz, 2002; Shin et al., 2012a) but not others (Caap-Ahlgren and Dehlin, 2002; Miller et al., 1996). In another included study, poor social support was a predictor of burden in offspring carers but not spousal carers (Shin et al., 2012a). Studies included in the review by Van der Lee et al. (2014) indicated that being less satisfied with support predicted higher burden (Reis et al., 1994), and positive perceptions of support reduced burden (Coen et al., 1997; Gold et al., 1995).

### **5.6.6. A logic model of the problem**

The findings from this section are presented in a 'logic model of the problem.'

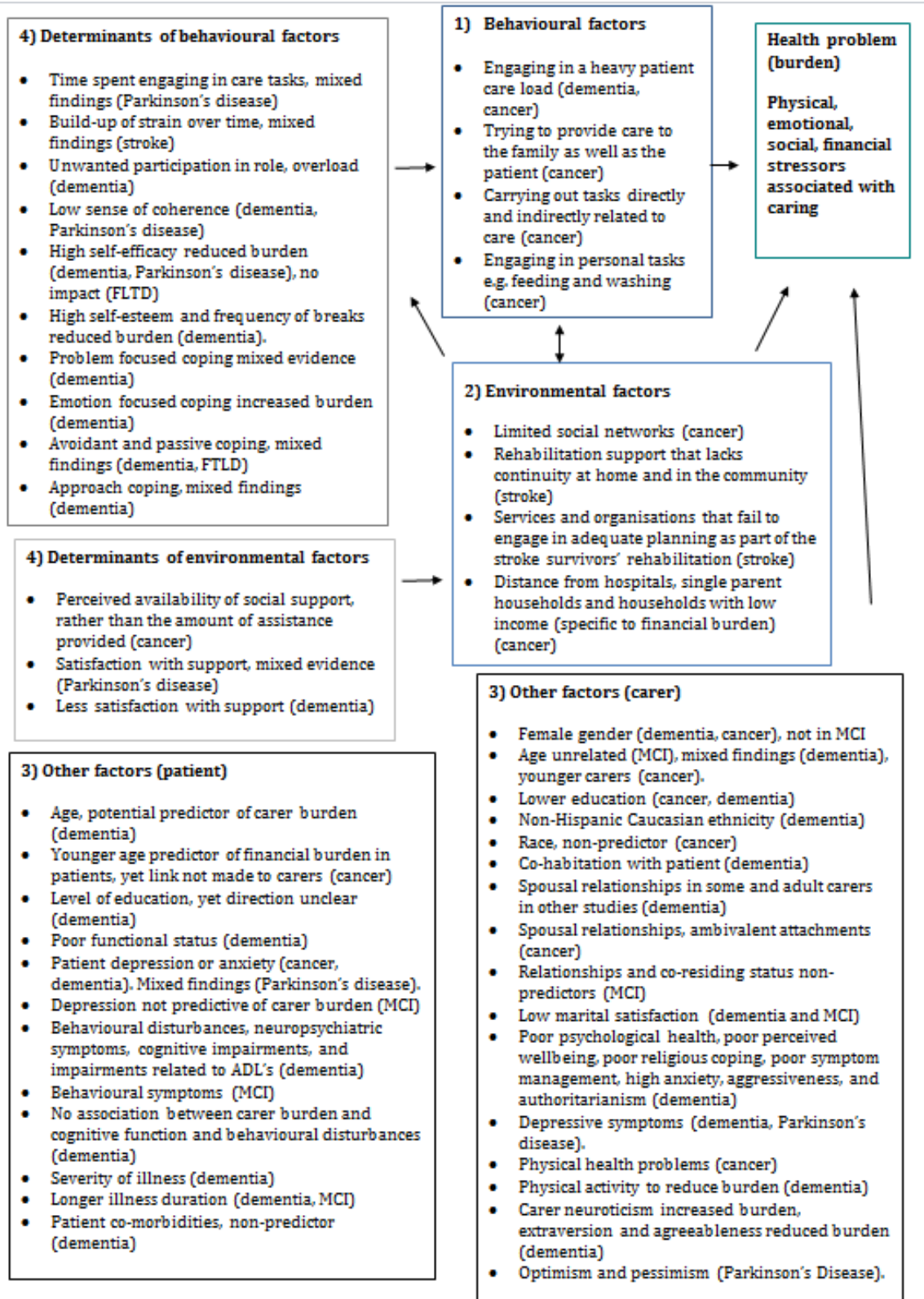


Figure 19: Logic model of the problem (carer burden)

## **5.7. Discussion**

### **5.7.1. Summary of evidence**

This systematic review of 14 systematic reviews presents evidence relating to the factors that influence burden in carers of stroke survivors and other longer-term conditions. Findings are important for informing the 'logic model of the problem' which informs a broader 'overall logic model of burden' together with other evidence contributing to the needs assessment as IM progresses (Bartholomew et al., 2011).

Gaining a greater understanding of burden and its contributory factors is essential to ensure that this is reduced as carers continue to provide care in future. However, examining carer burden is complex and these findings support the notion that there is no single agreed definition of burden (Bastawrous, 2013). The term 'carer' is also applied in different circumstances, where experiences are not always comparable. As highlighted in chapter two, a consistent definition of 'carer' is also lacking in the literature. The evidence is further complicated by the different types of studies included in the reviews and the different methods for synthesising these studies. Therefore, establishing the best evidence for understanding burden can be problematic. However, despite these considerations, the findings from 612 studies across a wide range of conditions are still informative for the subsequent stages of IM.

Unsurprisingly, these findings present burden as a complex, multifaceted construct. Few reviews identified behaviours associated with carer burden, as this was rarely examined from a behavioural perspective. The behaviours that were identified consistently related to the tasks associated with care and a heavy care load. However, more must be learned about behavioural factors that influence burden in stroke carers, given that these were evident in carers of individuals with cancer and dementia. Comparatively, more reviews addressed environmental conditions, but only a few factors were identified. These related to support and financial circumstances in carers of stroke survivors and cancer patients.

More evidence was available about the 'other' carer and patient factors, reflecting how burden is commonly studied. Previously, risk factors have been examined across conditions in terms of demographic factors e.g. age, gender, and educational attainment (Adelman et al., 2014). Many of the findings outlined in the review by Adelman et al. (2014) are consistent with findings in the current review, as risk factors for carer burden included female sex, low education, residing with the care recipient and depression. These are useful to some extent in terms of targeting specific groups of carers that may be at greater risk of burden. However, factors such as gender and age cannot be changed.

Reducing burden is more likely if behavioural and environmental factors are addressed, given that they are more amenable to change. Furthermore, it is likely that interventions would be complex, taking in to account both behavioural and environmental factors, focusing on internal strategies within the individual and external support to alleviate burden.

Outlining determinants for the behavioural and environmental factors extended current evidence, to consider why some carers are more likely to experience burden. The determinants of environmental factors provided valuable insights in to factors that influence whether support will reduce burden in three conditions (cancer, Parkinson's disease, and dementia). Findings indicated that it is not just the presence of support that is important. Perceptions and satisfaction with support are influential in whether carers experience burden. This suggests that the provision of support alone is not enough, if it cannot meet carers' needs and lead them feeling satisfied. There is more to be learned regarding this, as the reviews provided little information about the context of support and when or what may be useful to carers.

The determinants of behavioural conditions highlighted evidence about different coping types including problem focused, emotion focused, avoidant and approach coping. The findings were based on dementia carers and produced mixed findings. It would be insightful to learn more about the specific coping strategies that carers of stroke survivors use to reduce burden, in addition to required support. This would determine whether the findings highlighted in this overview are applicable across conditions.

Many determinants were taken from theories and models outlined in the table in section 5.6.4. In two of the 14 reviews (Gaugler, 2010; Hesamzadeh et al., 2015), theoretical models were applied to understand stroke caring. These provided a valuable contribution to our understandings of burden and coping with care. However, they do not incorporate *how* to change behaviours to reduce burden. Behaviour change theories would be more appropriate for this purpose to inform behaviour change interventions.

### **5.7.2. Strengths and limitations of the review**

This review identified evidence using a comprehensive search strategy. A narrative approach to synthesis ensured that data could be drawn from a broad range of both quantitative and qualitative studies in a way that can inform the later stages of intervention design. This approach also overcame difficulties drawing together findings from different study types that could not be synthesised using alternative methods e.g. meta-analysis.



However, the review is not without limitations. In some sections, the review lacks detail or depth about the context of burden, as many reviews included quantitative studies, often favoured for establishing the risk factors associated with burden (Honea et al., 2008). Relying upon the commentary provided by authors of included reviews also reduced depth. Some qualitative studies were included in the findings however more qualitative research about burden would produce rich, descriptive accounts of individuals' experiences (Jungbauer et al., 2003). This research could also be improved by using supplementary strategies in addition to searching electronic sources to identify additional reviews. These could provide the detail and depth that is lacking in parts of this review.

Furthermore, it is important to be aware of the distinctions between different types of burden. Across the reviews, some studies referred to objective burden, others referred to subjective burden and some did not make this distinction at all. This is commonly the case when multi-dimensional burden measurements are used (Call et al., 1999; Clair et al., 1995). This awareness has implications for understanding burden and how it should be alleviated, as there may be different influential factors associated with the two types of carer burden. With greater understanding, interventions can be tailored to individuals based on their experiences and the factors that influence burden.

This overview of systematic reviews could also be criticised as none of the included reviews were rated as high quality using the AMSTAR checklist (Shea et al. 2007). Instead, nine reviews were low quality and five were rated as medium quality. Problems with the AMSTAR checklist were outlined in section 5.5.3. Allocating a 'yes' response was difficult when multiple criteria had to be met within item. The other responses 'no', 'can't answer' and 'not applicable' were all scored as 0, therefore this may account for some of the low scores. The inclusion criteria related to 'systematic reviews' could also account for the low- quality scores. Many of the reviews were included because the authors specified that they were a 'systematic review', yet they did not always meet the systematic review criteria outlined by Pope, Mays and Popay, (2007). Therefore, they were at risk of being lower in quality.

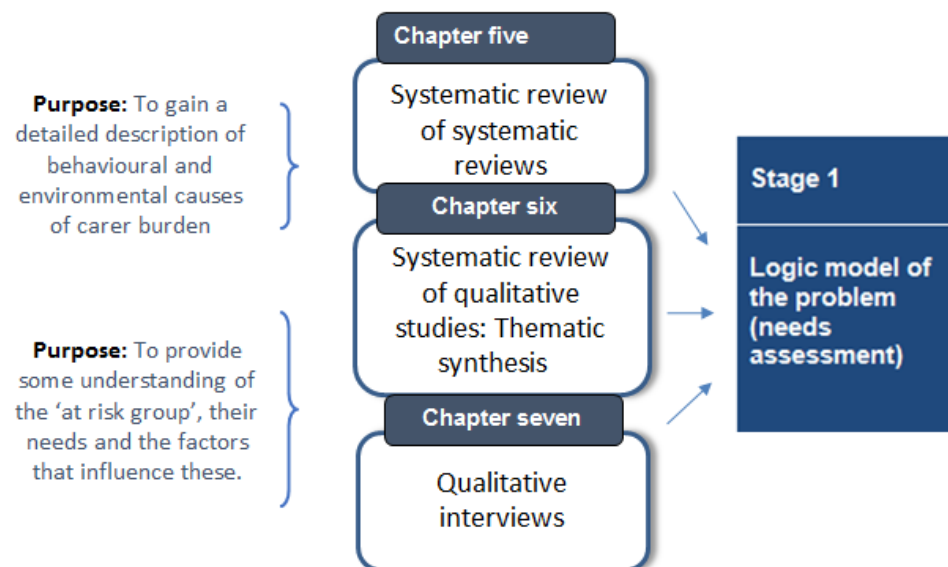
This review has provided a comprehensive account of the factors that influence burden that may not have been gained from the stroke literature alone. However, it is questionable whether these findings are generalisable. Therefore, this must be managed carefully when moving forward with this approach, to avoid assuming experiences are shared across conditions.

## **5.8. Conclusions**

The review has highlighted complexities attached to carer burden across a range of longer-term conditions. However, it is interesting to note that few of the included reviews focussed on carers of stroke survivors. This indicates that limited evidence is available about the factors that lead to carer burden in this population, particularly with a theory-based understanding. This may account for why interventions for stroke carers are not always developed with a comprehensive theory-and evidence- based understanding of a problem such as burden, before seeking solutions.

Nevertheless, this is an informative overview of the complexities attached to carer burden. Further research is required to gain a more in-depth, contextual understanding of stroke carers' experiences, with attention to their needs in different circumstances. Following further research, findings can be drawn together to develop an intervention to reduce carer burden that is grounded in carers' experiences. The subsequent IM stages will guide this process (Bartholomew et al., 2011).

As documented at the beginning of section two, chapter six that follows is the 'systematic review of qualitative studies: thematic synthesis.' This contributes to the needs assessment by understanding the 'at risk' group, their needs and the factors that influence these.



**Figure 20: Overview of the needs assessment**

## **6. Chapter six: Identifying the needs of carers of stroke survivors and the barriers and facilitators to addressing needs: A thematic synthesis**

### **6.1. Introduction**

This systematic review is the second of three components of work contributing to the 'needs assessment.' It updates a review of qualitative studies regarding the experiences of carers after stroke (Greenwood et al., 2009a), establishes the needs experienced by carers and the behavioural and environmental barriers and facilitators they face in addressing these needs, and how and whether they change over time. A thematic synthesis (Thomas and Harden, 2008) is presented, starting with descriptive themes then analytical themes where needs, barriers, facilitators and implications for intervention development are outlined. Then a logic model including behavioural and environmental barriers and determinants of carer and professional behaviours is presented. This will add to the finding presented in the previous chapter and inform the overall logic model of burden. In the discussion section, findings are summarised and considered in the context of current literature and the IM process.

### **6.2. Rationale for review**

Chapter five addressed the first aim of the needs assessment. To address the second aim, of the needs assessment and inform the overall logic model of burden, research was required to understand in more depth the 'at risk' group, their needs and the factors that influence these. This led to the need for this systematic review of qualitative studies.

A systematic review is an appropriate method for drawing qualitative research together to understand the caring experience. However, the notion of synthesising qualitative research has been subject to debate and methods are less developed compared with quantitative systematic reviews (Ring et al., 2011; Thomas and Harden, 2008). Some authors criticised syntheses of qualitative studies for lacking generalisability (Campbell et al., 2003; Sandelowski et al., 2007), yet others value their potential to inform policy and practice (Newman and Benz, 1998; Popay et al., 2006).

An existing, relevant systematic review by Greenwood et al. (2009a) was identified. This included 17 studies summarising qualitative research from 1996-2006, focusing on experiences of caring for stroke survivors and their challenges, satisfactions, and coping strategies. Key findings related to emotional responses, uncertainty, role and relationship changes, coping strategies, and information and training needs.

Greenwood et al (2009a) highlighted the importance of understanding carers' experiences to develop successful interventions for carers. However, the authors recommended considering both positive and negative aspects of caring in future research, as just focussing on difficulties or 'needs' can promote a negative view of caring, reducing the chances of providing appropriate support. Understanding the barriers and facilitators to addressing needs is also important for building upon previous research and for informing IM. Greenwood et al. (2009a) also identified difficulties in establishing the most appropriate time point for an intervention due to a lack of longitudinal studies and authors omitting time post stroke in their studies. They recommended that future research to inform interventions should consider the dynamic nature of the stroke experience in relation to time post stroke.

Greenwood et al. (2009a) adopted a narrative approach to summarising their findings. This provided a valuable insight into carers' challenges, satisfactions and coping strategies, however a method which captured a richer, nuanced understanding of the caring experience was necessary gain an in-depth understanding of the population of study (Bartholomew et al., 2011). The use of qualitative synthesis for informing health related policy and practice has increased (Mays et al., 2005) as have the variety of methods, examples include: meta-ethnography (Noblit and Hare, 1988), grounded theory (Eaves, 2001; Kearney, 2001), meta-narrative synthesis (Greenhalgh et al., 2005), critical interpretative synthesis (Dixon-Woods et al., 2006) and thematic synthesis (Thomas and Harden, 2008).

Meta- ethnography, grounded theory and critical interpretive synthesis methods produce a synthesis of findings that are often complex and conceptual, and further interpretations would be required to inform policy, practice, or recommendations for intervention development (Barnett-Page and Thomas, 2009). Thematic synthesis has been developed and adapted from meta-ethnography and grounded theory and has been applied to several reviews addressing needs, barriers and facilitators, and experiences in public health, including children's healthy eating (Harden et al., 2004; Thomas et al., 2003). However, instead of attempting to draw together data to form a 'whole' or generate new theory, it enables a synthesis of findings that can contribute to recommendations for policy, practice and intervention development. Given the focus and purpose of this review, a thematic synthesis approach was considered the most appropriate method for synthesising findings.

### 6.3. Aims and review questions

Aim: To update the existing review by Greenwood et al (2009a) to illustrate the experience of carers of stroke survivors between 2005-2015.

Research questions:

- What are the needs of carers of stroke survivors?
- What is known about how and whether needs change over time?
- What is known about the barriers and facilitators to addressing needs?

### 6.4. Methods

The review adopted a similar approach to Greenwood et al (2009a), including identifying relevant studies, assessing methodological quality of studies and summarising the evidence. However, data was synthesised using thematic synthesis methods (Thomas and Harden, 2008). Barriers and facilitators to addressing needs were considered within a socio-ecological model (McLeroy et al., 1988) to inform the overall logic model of burden used in later stages of IM (Bartholomew et al., 2011).

#### 6.4.1. Thematic synthesis

The thematic synthesis approach includes three stages which overlap to some degree (Thomas and Harden, 2008):

**Table 19: Stages of Thematic Synthesis (Thomas and Harden, 2008)**

Stages of thematic synthesis (Thomas and Harden 2008).
• 1. Line by line coding of findings from primary studies.
• 2. Generation of descriptive themes through organising free codes.
• 3. Organisation of 'analytical' themes using the descriptive themes.

The output is a synthesis of findings, which moves beyond a descriptive understanding of primary studies, towards an analytical interpretation of findings in accordance with a specific research questions, through development of 'descriptive' and 'analytical' themes. These are comparable to 'second' and 'third order' interpretations, developed using a meta-ethnographic approach (Barnett-Page and Thomas, 2009). Descriptive themes provide an interpretation of experience and are necessary for providing an overall description of the carers' experiences. Analytical themes provide further interpretation,

including implications for policy and intervention development (Thomas and Harden, 2008). In the current review these focus on carers' experiences with attention to their needs, barriers and facilitators to addressing needs, and implications for intervention development.

#### **6.4.2. Inclusion and exclusion criteria**

##### ***Inclusion criteria:***

- Qualitative studies focussing on a) carers' experiences and/or b) carers' needs.
- Studies involving informal as opposed to paid carers of stroke survivors defined as "a person who is providing help and support (practical and/or emotional) to a stroke survivor at least once a week."
- Studies where carers were providing support to stroke survivors in their own homes i.e. not inpatients or those in institutionalised care.
- Studies published between 2005-2015.
- Studies written in English Language.

##### ***Exclusion criteria:***

- Quantitative studies with no qualitative data; reviews or discussion papers without primary data; studies which were not peer reviewed e.g. dissertations.
- Studies where carer data could not be separated from stroke survivor data.
- Personal accounts of caring for stroke survivors with no analysis.
- Studies based on small data sets (two or less).

#### **6.4.3. Study identification and data extraction**

The following databases were searched from 01.01.2005 - 05.02.2015 to identify studies for inclusion: AMED, CINAHL, Cochrane Library, HMIC, Medline, PsycInfo, Social Work Abstracts and Web of Science. A refined search strategy based on input from an information specialist ensured a comprehensive strategy was used (Appendix F).

JH and another reviewer independently screened all titles and abstracts from the original search to assess their eligibility. Studies that did not meet the inclusion criteria were excluded. Full text publications were obtained for potentially relevant studies. Where articles could not be obtained, authors were contacted to request copies. JH applied the inclusion and exclusion criteria to this list; a second reviewer independently assessed 20% of this list against the criteria. Disagreements were resolved through the involvement of a third reviewer.

Data extraction was shared between a team of three researchers. Data was extracted for each study including carer gender, age, ethnicity, time spent caring, relationship to the stroke survivor and use of theory to understand the caring experience. Data regarding needs (how and whether they change over time), barriers and facilitators faced by carers were also extracted initially to gain a sense of whether they were documented within the literature, before conducting the thematic synthesis.

Double data extraction was carried out by JH on 20% of the articles that had previously been reviewed by the two other researchers. Disagreements were resolved through consensus.

#### **6.4.4. Assessment of methodological quality**

Assessing quality in qualitative research is an area of debate. There is little consensus on how this should be assessed, whom should be assessing quality, and whether it is possible to assess this at all (Seale and Silverman, 1997; Walsh and Downe, 2006). Different criteria for assessing quality have been used among researchers from different theoretical backgrounds, adding to the lack of consensus (Sandelowski et al., 1997).

Examples of appraisal tools and checklists used for assessing the quality of studies, include: the Critical Appraisal Skills Programme tool (CASP, 2006); the Quality Framework (Spencer et al., 2003) and the National Institute for Health and Care Excellence (NICE) Public Health guidance qualitative appraisal checklist (National Institute for health and Care Excellence, 2012). These tools vary in their included questions for assessing quality, for example the CASP (2006) is comprised of ten questions that relate to rigour, credibility, and relevance, whereas both the Quality Framework (Spencer et al., 2003) and the NICE Public Health guidance qualitative appraisal checklist (National Institute for health and Care Excellence, 2012) are more comprehensive and include a broader range of questions.

In this review, the NICE Public Health guidance qualitative appraisal checklist (National Institute for health and Care Excellence, 2012) was used. This was considered appropriate given that it was developed based on the other two checklists/ tools outlined above, together with broadly accepted principles that characterise the conduct of qualitative research and may influence its validity. These are included in six sections: theoretical approach; study design; data collection; trustworthiness; analysis and ethics.



The assessments of methodological quality were shared between the same three researchers. Following assessment using the checklist, each article was allocated a score using the system outlined in the guidance (++, +, -) (table 20).

**Table 20: Checklist scoring system for NICE qualitative appraisal checklist**

<b>Checklist scoring system (NICE, 2012)</b>
<ul style="list-style-type: none"> <li>• ++ All or most of the checklist criteria have been fulfilled; where they have not been fulfilled the conclusions are very unlikely to alter.</li> </ul>
<ul style="list-style-type: none"> <li>• + Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.</li> </ul>
<ul style="list-style-type: none"> <li>• - Few of no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.</li> </ul>

These scores were used to assess whether the studies should contribute to the overall synthesis. Including or excluding studies based on their quality remains a contested area, but regardless of the decision to include or exclude studies of lower quality; researchers must preserve transparency through clear documentation of methods and decisions throughout the process (Hannes, 2011). A judgement was made to initially include only those scored as (++) or (+) in the synthesis. The lower quality studies (-) would be compared with higher quality studies following the conduct of the synthesis. This was to establish whether the lower quality studies were consistent with those included in the synthesis of findings, and to ensure core findings were not influenced by poor quality research.

If findings were consistent with the overall synthesis; excluding them would not alter the findings, therefore nothing additional would be gained from including these articles. Alternatively, if the findings contradicted those from the overall synthesis, they would be examined to assess whether those findings had emerged for a reason e.g. they are unique to a particular group of study. If these were considered valuable, they would be scrutinised to assess whether they would provide a relevant contribution to the overall aims and purpose of this review. Furthermore, if there was a reoccurring theme (or themes) across the low-quality studies, these would also be considered to see if they should provide a contribution to the overall synthesis; findings would be refined on this basis.

#### **6.4.5. Synthesis of findings**

This section outlines how the synthesis of findings was conducted and applied based on the three stages outlined by Thomas and Harden (2008). JH primarily conducted the

synthesis of findings; however, efforts were made to ensure rigour and trustworthiness where possible, in accordance with the following criteria in table 21:

**Table 21: Lincoln and Guba's criteria for trustworthiness**

<b>Lincoln and Guba's criteria for trustworthiness (Lincoln and Guba, 1986)</b>
<b>Credibility:</b> confidence in the 'truth' of findings
<b>Dependability:</b> showing that findings are consistent and replicable
<b>Transferability:</b> applicability of findings across contexts
<b>Confirmability:</b> the extent to which findings are shaped by respondents not research biases, motivations and interests

These included using an appropriate and well recognised research method and checking sections of analysis to ensure consistency of interpretation (credibility); and use of diagrams to provide an in-depth methodological description (dependability, confirmability). Regarding transferability, the method of thematic synthesis allows for a contextual understanding of experience which determines how whether findings can be generalised.

#### **6.4.5.1 Stage one: Line by line coding of findings from primary studies.**

Before coding commenced, articles were either imported in electronic form (PDF) or scanned into NVivo qualitative data analysis software (version 10) (NVivo, 2012) in folders according to their methodological quality, and review questions were temporarily set aside. This was to produce a synthesis grounded in the study findings, as opposed to using a pre-defined framework to address needs, barriers and facilitators which may not take context into account. This is consistent with Thomas and Harden's approach in their review about children's healthy eating (Thomas and Harden, 2008).

Line-by-line coding involved coding each line of text within the 'study findings' according to meaning and content. Study findings are all text labelled as 'findings' or 'results,' including quotations from carers themselves and commentary from authors within 'results' and 'findings' sections (Thomas and Harden, 2008). Codes were developed that remained close to the data and new codes were continually developed, rather than generating a smaller 'bank of codes' that were used repeatedly. This ensured a nuanced understanding across different studies and avoided reducing the data too early in a way

that lacked richness and diversity. As coding progressed, consistency of interpretation was checked with a facilitated PhD student group (n=6) and codes were revised and developed where necessary.

#### **6.4.5.2 Stage two: Generation of descriptive themes through organising free codes.**

Researchers should identify similarities and differences between the initial line-by-line codes and create descriptive themes by grouping codes. However, interim steps were required to make this process more manageable.

All the codes created in stage one were printed and notes were documented to establish similarities and differences between them. These were grouped into themes in NVivo, and then refined to capture the essence of what was presented in the themes. This led to a further reduction in themes that were grouped with others according to their similarities and presented in a colour-coded diagram. A large document of memos outlining the focus of each theme and a description of similarities and differences across themes supported this process.

Then, descriptive themes were developed by capturing the experiences of the colour-coded grouped themes. This was achieved through returning to the original data within these grouped themes to ensure that the descriptive themes remained close to the text. A draft summary of the descriptive themes was reviewed by a facilitated PhD student group including six members. Group members checked the titles against the content of themes to assess whether these were appropriate, and identified any overlaps between similar themes. JH also reviewed and discussed coding and analysis with other qualitative researchers within the research department including supervisor DJC. Feedback and further refinements led to the final set of descriptive themes. Memos were made again, documenting what should be included in each theme.

#### **6.4.5.3 Organisation of 'analytical' themes using the descriptive themes**

At this stage, a descriptive synthesis of findings was provided, however progression to analytical themes was required to address the research questions for this review. Thomas and Harden (2008) had difficulty describing this progression, due to reliance on the reviewers' judgements as they moved further from the original data. However, they provided an account of how they created analytical themes in their review of children's healthy eating. The descriptive themes were used as a basis for inferring barriers and

facilitators to healthy eating in children and implications for intervention development. These analytical themes were considered appropriate when they were:

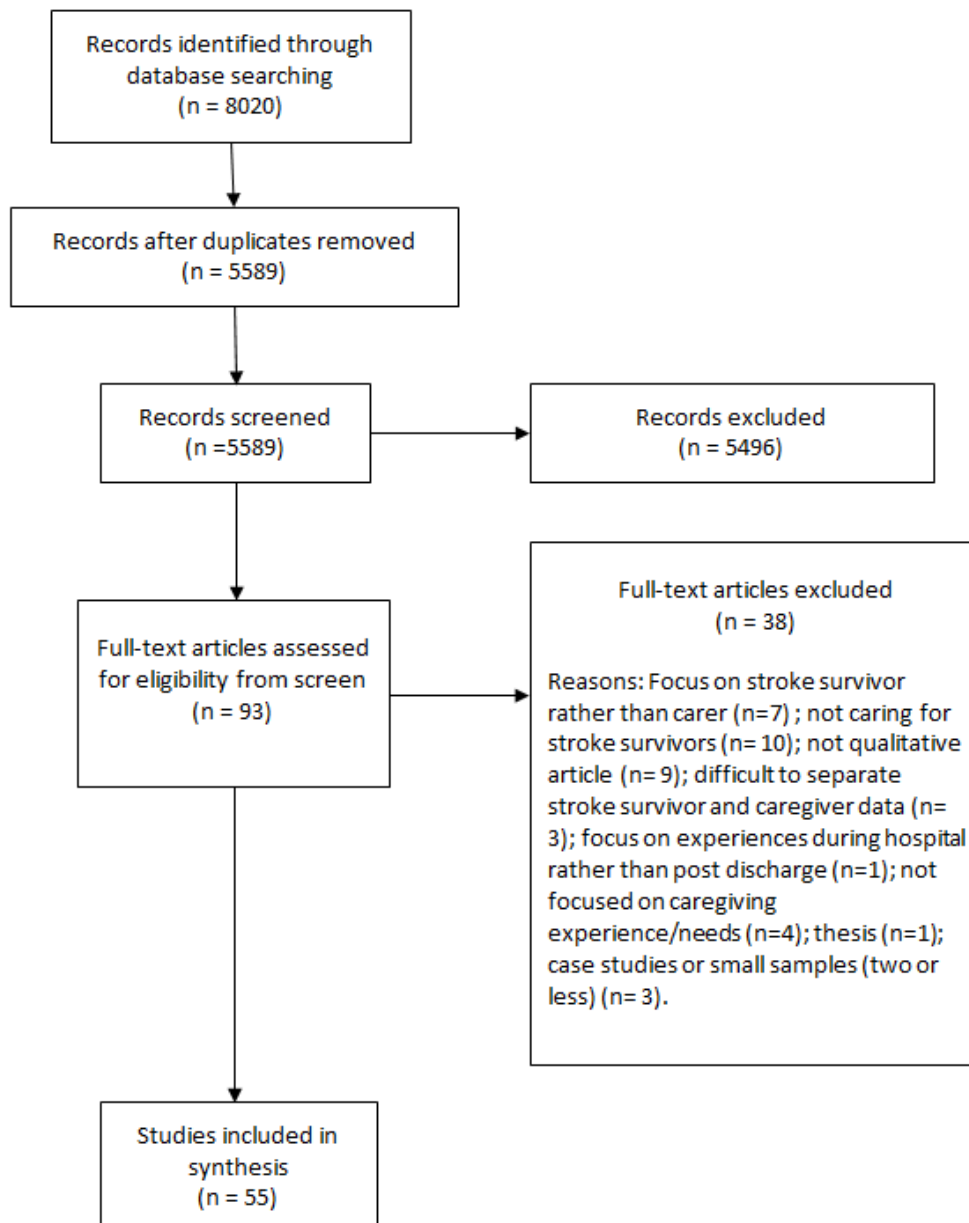
*“Sufficiently abstract to describe and/ or explain all the descriptive themes, inferred barriers, facilitators and implications for intervention development.”* (Thomas and Harden, 2008, pg. 7).

In this review, the process started by examining the descriptive themes to identify ‘inferred needs.’ Then all the codes within the colour-coded themes were checked to ensure that nothing was left unconsidered from the overall findings. This helped confirm that the analytical themes were relevant and important. The same process was carried out to identify the barriers and facilitators to addressing needs. These were also cross referenced with the data extraction regarding needs, barriers and facilitators.

Following Thomas and Harden (2008), findings were tabularised. Tables included needs, barriers and facilitators to addressing needs, which were grouped according to whether they were behavioural or environmental and allocated to relevant levels of the socio-ecological model (e.g. individual, interpersonal and organisational). Non-behavioural and environmental barriers and facilitators were also outlined. A number of descriptive themes were produced, forming an overall description of the carers’ experiences which remained close to the original included study findings; and analytical themes focussing on carers’ experiences with attention to their needs, how they change over time, the barriers and facilitators to addressing needs, and implications for intervention development. A draft summary of these findings was presented to the supervisory team and feedback led to ongoing refinements in the written content.

## 6.5. Results

The search identified 8020 articles, 5589 remained following de-duplication. Ninety-three were considered potentially relevant and full text articles were reviewed. Twenty percent of the 93 articles were randomly selected and screened by a 2<sup>nd</sup> reviewer. Disagreements were resolved through discussion with a third reviewer. Thirty-eight studies were excluded, 55 were included (figure 21).



**Figure 21: Study selection process (using PRISMA guidelines)**

### **6.5.1. Included studies**

Fifty-five studies met the inclusion criteria, all of which were published in English language between 2005 and 2015 (see table in Appendix G). The majority of studies were conducted in the USA, other locations included: Sweden, UK, Australia and Austria.

Participating carers in the studies ranged from three (Van Dongen et al., 2014) to 73 (Pierce et al., 2007). The majority included between eight and 16 participants and in total studies included 833 participants. Carer's ages were reported in most studies as a range and the average was rarely reported. These varied within and between studies. Most studies included spousal carers, other examples of relations to the stroke survivor included daughters, sons, mothers, fathers, siblings, and close friends.

Some studies focused on the overall caring experience, others focused on a specific aspect of care e.g. relationships with the stroke survivor (Bäckström et al., 2010). Some studies focused explicitly on needs, either at a particular phase e.g. the transition from hospital to home, or in one study over time (Cameron et al., 2013). Fewer articles addressed the barriers and facilitators to addressing needs. Only one article aimed to identify these alongside needs (Le Dorze and Signori, 2010).

Face-to-face semi-structured interviews were the most common data collection method. Types of data analysis varied and included: thematic analysis, content analysis and interpretative phenomenological analysis. Less frequently used were framework analysis and grounded theory approaches.

Timing of data collection was reported in most studies. Most reported time since stroke, others used time spent caring or time since stroke survivor discharge. Some studies focused on the first few months of caring, others explored the experience of caring for longer periods e.g. 18 years. Often the time reported varied within studies (e.g. 2-15 years).

### **6.5.2. Excluded studies**

A record of reasons for excluded is outlined in Appendix H.

### **6.5.3. Methodological quality**

Twenty percent of the articles (n=11) were double reviewed (data extraction and quality assessments). Every other paper was selected from the list of studies initially reviewed by DJC and FM and these were reviewed by JH. Discrepancies were apparent within seven of the quality assessments and in some cases the final score differed (++ and +). Following discussions, consensus was reached and the allocated scores were changed.

Overall most articles (n=48) were regarded as good quality (26 + and 22 ++). These articles were included in the synthesis of findings and the lower quality studies (n=7) were compared following the development of the analytical themes. Reasons for assessing these seven studies as lower quality broadly related to unclear links between how the data was collected (process), how this was analysed (reliability) and the findings that emerged as a result. Based on these reasons, the studies remained excluded from the synthesis.

It should be acknowledged that articles not reviewed by a second researcher could have been scored differently, which could influence whether they were retained for the synthesis of studies. However, most of the discrepancies with the results for the assessment (++, +, -) were between those that were scored (++) and (+). This reduced concerns that studies may not have been included in the synthesis through inconsistencies in the assessment of quality among the research team.

Through examination of the lower quality studies, the findings do not contradict those within the overall synthesis. The main themes are consistent with those that were in the descriptive synthesis which formed the basis for the analytical themes. Therefore, excluding these provides confidence that the findings are based on higher quality studies (++, +).

## 6.6. Thematic synthesis findings

Nine descriptive themes and six analytical themes were identified. The following section (6.6.1) details how the descriptive themes were formed using methods outlined in section 6.4.5.2. Nine descriptive themes are outlined in a table. Section 6.6.2 shows the progression from descriptive themes to analytical themes before providing written commentary for each of the six themes.

### 6.6.1. Descriptive themes

The first stage in the thematic synthesis process (line-by-line coding from primary studies) resulted in 1500 codes across the 48 higher quality (++, +) studies. In stage two initial grouping of codes led to 43 themes e.g. ‘the burden of caring’ and ‘changed and additional roles and responsibilities.’ Further refinements were made to these themes following discussions with other PhD researchers, this reduced to 39 themes:

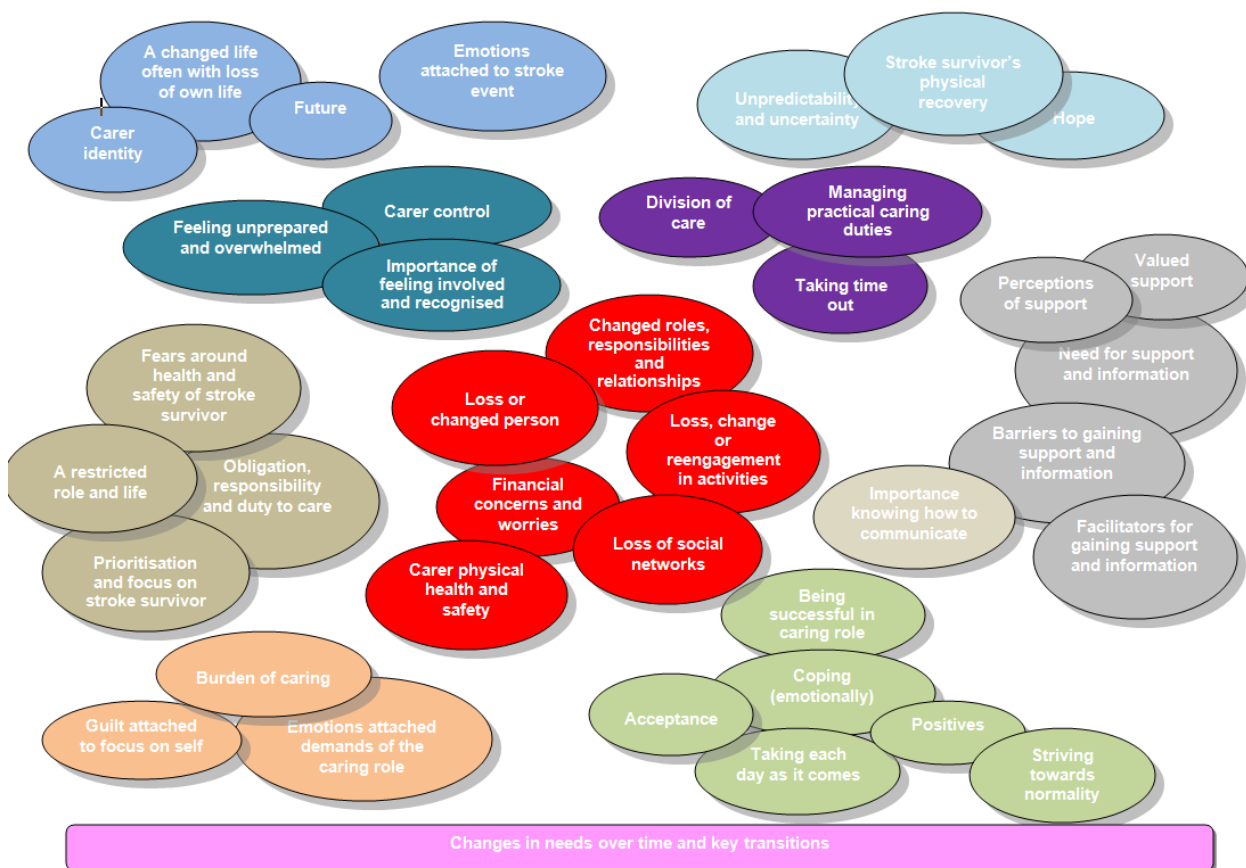


Figure 22: Grouped similar themes for developing descriptive themes



Through capturing the experiences within the colour coded groups, 10 descriptive themes developed. For example, those on the top left of the diagram e.g. ‘carer identity’, ‘a changed life often with loss of own life’, ‘future’ and ‘emotions attached to the stroke event’ were grouped together under the descriptive theme ‘realisation of a changed future.’ When these were refined following feedback from supervisors, a final total of nine descriptive themes were produced about different aspects of the caring experience, including preparing for the role, managing emotionally and physically and the importance of information and support for addressing various needs. These are outlined in the figure 23:



**Figure 23: Nine descriptive themes**

Table 22 provides a summary explanation of the characteristics of each theme.

**Table 22: Nine descriptive themes**

Descriptive theme	Summary
1. The value of hope in light of the unpredictability and uncertainty attached to the stroke survivor's recovery	<p>Hope was important for carers in the initial rehabilitation stage, in light of the uncertainty and unpredictability attached to the stroke survivors' recovery (Bäckström et al., 2010; Bäckström and Sundin, 2007; Creasy et al., 2013; Graven et al., 2013; Greenwood et al., 2009b; Gustafsson and Bootle, 2013; Howe et al., 2012; Le Dorze and Signori, 2010; Lutz et al., 2011; Paul and Sanders, 2010; Saban and Hogan, 2012; Young et al., 2014). Common uncertainties included the level of required care for the stroke survivor following discharge from hospital (Creasy et al., 2013), availability of alternative rehabilitation support (El Masry et al., 2013; Gustafsson and Bootle, 2013), likelihood of recovery, and resultant impacts on their lives (El Masry et al., 2013; Greenwood et al., 2009b).</p> <p>A balance between hope and being realistic was important (El Masry et al., 2013; Howe et al., 2012; Paul and Sanders, 2010; Saban and Hogan, 2012). Carers talked about being hopeful in the context of the stroke survivors being able to improve and engage in activities from their previous lives (Lutz et al., 2011). Carers also perceived activities as milestones for recovery and improvements were recognised in this context (Graven et al., 2013; Lawrence and Kinn, 2013).</p>
2. Navigating feelings of being overwhelmed and emotionally and practically unprepared for the caring role.	<p>For carers, the stroke survivors' transition from hospital to home is a key transitional period. This theme captures the notion that carers must navigate being practically and emotionally unprepared and overwhelmed, at the same time as being unrecognised and neglected by professionals (Bäckström and Sundin, 2007; Bäckström and Sundin, 2010; Cameron et al., 2013; Cobley et al., 2013; Danzl et al., 2013; Howe et al., 2012; Lutz et al., 2011; Niyomthai et al., 2010; Paul and Sanders, 2010; White et al., 2007; Young et al., 2014).</p> <p>Carers often had little time to think about the challenges ahead (Lutz et al., 2011), and they lacked knowledge and skills for managing and providing care (Bäckström and Sundin, 2007; Niyomthai et al., 2010; Young et al., 2014). Carers attributed this to a lack of teaching (White et al., 2007) or poor translation of skills from the rehabilitation facilities to the home (Lutz et al., 2011; Young et al., 2014). Carers felt dismissed when they were not involved in the stroke survivors' rehabilitation (Danzl et al., 2013; Howe et al., 2012; Paul and Sanders, 2010). Where carers were involved, advantages included: being provided with communication, increased expectations, confidence, and an opportunity to ask questions (Cameron et al., 2013; Creasy et al., 2013; Gustafsson and Bootle, 2013).</p>

	<p>Additionally, carers wanted to be recognised as having their own support needs (Bäckström and Sundin, 2010; Cameron et al., 2013; Cobley et al., 2013) and expected professionals to offer required support.</p>
<p>3. Feeling a duty to provide care in a restricted role where the stroke survivor is prioritised</p>	<p>This theme reflects the restrictions carers often faced in their role and the implications of these restrictions, due to their lives being focused on the stroke survivor. The carers' accounts of their experiences were characterised by a sense of obligation and duty to provide care, despite feeling strained or tired, leading to feelings of imprisonment and lack of spontaneity among some carers (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Eaves, 2006; Gosman-Hedström and Dahlin-Ivanoff, 2012; Greenwood et al., 2010; Greenwood et al., 2009b; Niyomthai et al., 2010; White et al., 2007; Winkler et al., 2014).</p> <p>There was a distinction between being restricted through the physical demands of the role and restrictions placed on themselves by being reluctant to spend lengthy periods of time away from the stroke survivors, due to fears of another stroke and guilt (El Masry et al., 2013; Gosman-Hedström and Dahlin-Ivanoff, 2012; Greenwood et al., 2009b; Lawrence and Kinn, 2013). Some carers took the opportunity to leave the stroke survivors for a short period, for essential chores rather than pleasure (Cao et al., 2010; Greenwood et al., 2009b; Silva-Smith, 2007; Van Dongen et al., 2014).</p> <p>Prioritising the stroke survivor had implications for the carer including self-neglect, and a loss their own lives and meaningful activities. Carers had to balance this loss and self-neglect with a sense of guilt, when spending time away from the stroke survivor (Lutz et al., 2011; Silva-Smith, 2007; Van Dongen et al., 2014; Young et al., 2014).</p>
<p>4. Realisation of a changed future</p>	<p>The changes brought by the stroke impacted on both stroke survivors' and carers' lives, leading to a changed immediate and long-term future, where nothing was obvious anymore. The articles reflected a sense of loss, uncertainty, changes to plans, realisation that things would never be the same, difficulties thinking about the future, and a changed place in the world (Bäckström et al., 2010; Bäckström and Sundin, 2007; Bulley et al., 2010; Cecil et al., 2011; Gosman-Hedström and Dahlin-Ivanoff, 2012; Green and King, 2009; Greenwood et al., 2009b; Kniepmann and Cupler, 2014; Lawrence and Kinn, 2013; Saban and Hogan, 2012; Silva-Smith, 2007; Winkler et al., 2014).</p> <p>Realisation of the permanence attached to their changed situations led to emotional responses including "<i>almost choking</i>" (Backstrom and Sundin 2010, pg. 121), grief and despair (Young et al., 2014) and sadness (Bäckström and Sundin, 2007). Some carers held onto their lives before and looked back wondering what could have been (Bäckström and Sundin, 2007). Some engaged in a process of moving forward yet questioned what there was to look forward to in their futures that were considered bleak (Cecil et al., 2011;</p>

	Greenwood et al., 2009b). Others came to terms with a new life, leaving their previous lives behind them (Bäckström and Sundin, 2009). Carers in the study by Young et al. (2014) felt they had little choice but to redesign their lives as part of moving forward.
5. Managing the practical caring duties	<p>This theme attends to the practical aspects of caring, often carried out alongside other commitments, with a focus upon strategies that carers used for managing. At a broader level, some carers negotiated shared care with family members and scheduled time out to organise the practical management that was required of them as part of their caring role (Brittain and Shaw, 2007; Bulley et al., 2010; Eaves, 2006; Gosman-Hedström and Dahlin-Ivanoff, 2012; Grawburg et al., 2014; Greenwood et al., 2010; Greenwood et al., 2009b; Gustafsson and Bootle, 2013; Saban and Hogan, 2012; Strudwick and Morris, 2010; Van Dongen et al., 2014; Young et al., 2014).</p> <p>Daily activities e.g. going to the shops or the pub provide a context for identifying strategies that carers adopted to practically manage. Examples included increased planning and organisation, pre-planning to ensure appropriate facilities were available e.g. toilets, and making plans around increased activities and appointments (Brittain and Shaw, 2007; Bulley et al., 2010; Grawburg et al., 2014; Greenwood et al., 2010).</p> <p>Division of care among family members was achieved through devising rotas and developing routines (Greenwood et al., 2010; Greenwood et al., 2009b). This provided carers with expectations of their involvement. In contrast, the divisions of care were less clear in the study by Strudwick and Morris (2010). The expectations of shared care remained, yet support was not forthcoming.</p>
6. Changed roles, identities and loss of previous relationships	<p>This theme highlights the changes that carers experienced in their roles and the implications of these changes for their own identities and resultant impacts on their relationships. Carers also identified losses in their relationships compared to before the stroke; these had an impact on how the carers perceived the stroke survivors and evoked negative emotions (Bäckström et al., 2010; Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Bäckström and Sundin, 2010; Cao et al., 2010; Jones and Morris, 2013; Lawrence and Kinn, 2013; Quinn et al., 2014b; Winkler et al., 2014).</p> <p>Winkler et al. (2014) identified different roles that carers engaged in; therapists, nurses, counsellors, and administrators. As a result of taking on additional duties around the house, one carer provided an account the changes she perceives in relation to her identity “<i>I used to be a princess but now I am a maid.</i>” (Cao et al., 2010, pg. 38). Another carer faced confusion brought about by taking on multiple roles and identities e.g. mum, caregiver and wife (Bäckström et al., 2010).</p> <p>Carers’ perceived identities impacted on how they continued to engage in their relationships. Carers often identified themselves as</p>

	<p>being in a parent-child relationship, rather than a husband and wife (Bäckström et al., 2010; Bäckström and Sundin, 2007; Quinn et al., 2014b; Winkler et al., 2014). In two studies, carers struggled to engage in the sexual aspect of their marital relationships due to their self-perceptions of being a mother rather than a wife (Bäckström et al., 2010; Bäckström and Sundin, 2007).</p> <p>Other aspects of the relationships were also lost such as the mutual understandings (Bäckström et al., 2010) and emotional support (Quinn et al., 2014b). In these studies, carers also described their relationships as being with a stranger. In the study by Backstrom et al. (2010), this was due to the absence of emotional responses, closeness and tenderness in the relationship leading to disappearance of proximity and intimacy. Carers also described the loss of the person that they knew prior to the stroke and resultant emotions, including dejection, despair (Bäckström et al., 2010) and grief (Bäckström et al., 2010; Bäckström and Sundin, 2009; Jones and Morris, 2013; Lawrence and Kinn, 2013).</p>
<p>7. Coping with uncertainties, feeling overwhelmed and a changed life</p>	<p>Caring includes an element of coping in addition to managing practically. Carers found ways of coping with the uncertainties including the stroke survivors' recovery, the overall changes to their lives, and the overwhelming feelings that were attached to caring. This theme attends to coping with a focus on the strategies that carers devised to manage how they coped. These were varied but included accepting, taking each day as it comes, identifying positives, and changing their perspectives on situations (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Green and King, 2009; Greenwood et al., 2010; Greenwood et al., 2009b; Saban and Hogan, 2012; Van Dongen et al., 2014; Winkler et al., 2014)</p> <p>Carers talked about acceptance with regards to the changes to their lives (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Greenwood et al., 2010; Saban and Hogan, 2012) and more specific aspects of their lives e.g. occupational changes (Van Dongen et al., 2014). Interestingly carers' accounts reflected the idea that they have had little choice but to accept their situation (Bäckström and Sundin, 2009; Eaves, 2006; Graven et al., 2013).</p> <p>'Taking each day at a time' reduced feelings of being overwhelmed and uncertainties in terms of life and the stroke survivors' recovery (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Bäckström and Sundin, 2010; Greenwood et al., 2009b). Carers also coped by making comparisons with others to realise things could be worse, expressing gratitude that their loved ones were alive, and appreciating small gains in the stroke survivors' recovery (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Bäckström and Sundin, 2010; Winkler et al., 2014). Other carers coped by finding joy in their caring situation (Greenwood et al., 2009b; Saban and Hogan, 2012).</p>

<p>8. Importance of information for addressing carer needs</p>	<p>This theme highlights the importance of information among carers of stroke survivors, despite this not always being provided at all, or in a way that is beneficial to carers (Cameron et al., 2013; Cecil et al., 2011; Cecil et al., 2013; Cobley et al., 2013; Eames et al., 2010; Paul and Sanders, 2010; Smith et al., 2008b). This provides an insight into problems associated with information, examples of carers' information needs, including their preferences regarding the format.</p> <p>Carers faced problems with information when this was not applicable, too difficult to understand, or too late following the stroke (Cameron et al., 2013; Cobley et al., 2013; Paul and Sanders, 2010). Carers wanted initial information about the consequences and impacts of the stroke (Howe et al., 2012; Paul and Sanders, 2010), and managing post discharge to provide reassurance and aid preparation and expectations (Creasy et al., 2013; Greenwood et al., 2011; Howe et al., 2012). Once stroke survivors were discharged to home, carers wanted information about community and public resources (Le Dorze and Signori, 2010; Saban and Hogan, 2012). Carers valued a combination of written and verbal information, due to struggling to absorb verbal information in times of stress without having something to refer to later (Cecil et al., 2011; Howe et al., 2012; Paul and Sanders, 2010).</p> <p>The way carers obtained information was influential in whether their needs were met. Professionals in hospitals provided an example of a source of information for carers, however there was an apparent distinction between carers who actively approached professionals for information (Creasy et al., 2013) and those who waited passively for them to provide this (Howe et al., 2012; Silva-Smith, 2007). Carers who took a passive approach expected professionals to teach them what they needed to know, however information was not always forthcoming (Howe et al., 2012; Silva-Smith, 2007).</p> <p>Being active in seeking information was beneficial for some carers, however others were reluctant to seek this, leaving them without information to meet their needs (Cecil et al., 2011; Creasy et al., 2013; Greenwood et al., 2011; Paul and Sanders, 2010). Professionals acknowledged carers' reluctance, however they lacked time to approach carers due to high case-loads, therefore they also took a passive approach to providing carers with information.</p>
<p>9. Importance of informal and formal support for addressing</p>	<p>This theme highlights the different types of support that carers of stroke survivors required and valued (e.g. social, emotional, and practical) with an insight in to the different types of formal and informal support available to meet those needs.</p> <p>Socially and emotionally based support was one of the main support needs. Carers expressed wanting "someone to talk to" (Howe et</p>

carer needs	<p>al., 2012, pg. 517), “<i>someone to phone up and bore</i>” (Greenwood et al., 2011, pg. 9), and “<i>someone to moan to</i>” (Greenwood et al., 2011 pg. 5). There were mixed views about the best provision of this support, as carers suggested counsellors, social workers or someone who has been through the situation (Howe et al., 2012), a helpline (Greenwood et al., 2011) a family therapist (Creasy et al., 2013), a group or therapy (Danzl et al., 2013). Despite the different suggestions for whom should provide this support, the nature of support remained important. There were limitations to receiving this support from formal sources e.g. professionals, as support focused on the stroke survivor and they faced time constraints to approaching carers (Cameron et al., 2013; Greenwood et al., 2011; Le Dorze and Signori, 2010; White et al., 2007).</p> <p>Family and friends were an alternative form of social and emotional support for carers as they showed understanding (Cameron et al., 2013; Cecil et al., 2013; Greenwood et al., 2010; White et al., 2007; Winkler et al., 2014) and were there for carers who wanted to share their deepest fears (Gosman-Hedström and Dahlin-Ivanoff, 2012; Saban and Hogan, 2012). Family and friends also provided practical support including assisting with aspects of therapy, help with adaptations, and help with personal care (Greenwood et al., 2010; White et al., 2007; Winkler et al., 2014). For many carers, family and friends were a reliable source of support, however others experienced loss of this support through either being abandoned or abandoning them as a result of their care demands (Bäckström and Sundin, 2009; Saban and Hogan, 2012).</p> <p>Carers also valued support in from community resources to manage practically and continue in their roles. However, accessibility and availability were limited (Gustafsson and Bootle, 2013; Tellier et al., 2011; White et al., 2007). When formal support for managing practically was more readily available (e.g. support from formal carers), some carers actively rejected this because they wanted to preserve everyday life as much as possible, and did not want to limit the stroke survivors’ independence by accepting this support (Cecil et al., 2011).</p>
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### 6.6.2. Analytical themes

In the third stage of the thematic synthesis, analytical themes were developed from the descriptive themes following methods outlined in section 6.4.5.3. For example, from the themes 'The value of hope in light of unpredictability and uncertainty attached to the stroke survivors' recovery' and 'Navigating feelings of being emotionally and practically unprepared for the caring role' the analytical theme '**Carers need to be supported to feel practically and emotionally prepared before and during the transition from hospital to home**' was developed. Figure 24 provides a representation of how the descriptive themes link to the analytical themes. The descriptive themes are outlined in colours to provide consistency in presentation and the analytical themes are presented in the grey bubbles including bold text.



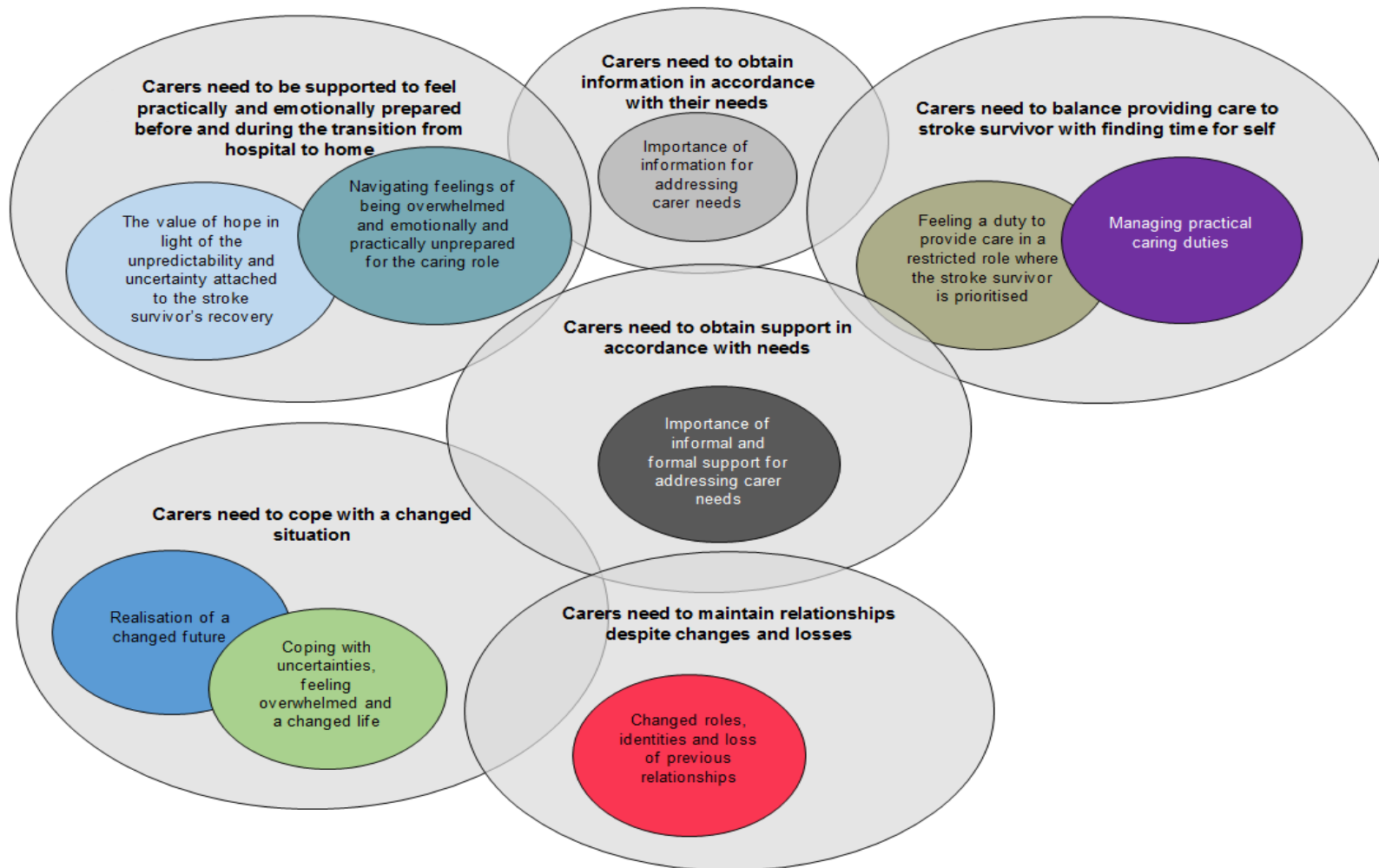


Figure 24: Descriptive and analytical themes

These analytical themes phrased as needs, and the barriers and facilitators for addressing each need and are presented in appendix I. Written commentary for each analytical theme is provided here before outlining the developing logic model.

#### **6.6.2.1 Carers need to be supported to feel practically and emotionally prepared before and during the transition from hospital to home**

Two descriptive themes pointed to the need to support carers to feel 'prepared', both practically and emotionally before and during the transition from hospital to home, these were *'the value of hope in light of the unpredictability and uncertainty attached to the stroke survivors' recovery'* and *'navigating feelings of being overwhelmed and emotionally and practically unprepared for the caring role.'*

Regarding practical support, carers wanted guidance on what they should be doing to increase confidence in their caring skills (Cameron et al., 2013; Cecil et al., 2011; Greenwood et al., 2011; Howe et al., 2012). Regarding emotional support, carers wanted to know what to expect to cope during the transition (Avent et al., 2005; Bulley et al., 2010; Cecil et al., 2011; Cecil et al., 2013; Creasy et al., 2013; White et al., 2007; Young et al., 2014). Barriers and facilitators to carers gaining this were identified across the studies.

Carers avoided approaching professionals for support, due to feeling burdensome. This provides an example of a carer behaviour that was a barrier to gaining support for feeling practically and emotionally prepared (Creasy et al., 2013; Greenwood et al., 2011). In the study by Greenwood et al., (2011), general practice staff acknowledged that carers might *'feel like a burden'* (pg. 6) about asking for support, yet their role perceptions meant that they were passive about seeking out carers to provide support:

*"I guess we could have a supportive role, I mean we wait for people to come to us..."*  
(Greenwood et al., 2011, pg. 6).

This provides an example of an 'interpersonal' barrier, limiting provision of support. Time pressures within organisations also influenced whether professionals approached carers (Cameron et al., 2013; Greenwood et al., 2011). Reliance on professionals to provide support was problematic due to these restrictions. To ensure that carers feel prepared, support should be consistently offered to carers, with a clear indication for who should take on this role. Actively seeking support from professionals facilitated success among carers in some studies (Bäckström and Sundin, 2010; Creasy et al., 2013), however appropriately supporting carers should not rely entirely on carers seeking their own

support. A collaborative approach, involving the carer and a professional (or a different support provider) could ensure that the support is tailored to the carers' needs.

Another example of an 'interpersonal' barrier that influenced whether carers felt supported to feel prepared was poor communication between professionals and carers. Examples included poor delivery of training to carers for supporting the stroke survivor physically (Cobley et al., 2013) and poor communication of carer role expectations (White et al., 2007; Young et al., 2014). Encouraging more effective communication in professionals could be considered in an intervention to ensure that staff members have appropriate skills.

Barriers to communication between professionals and carers were also evident at an organisational level e.g. poorly timed family visiting hours around clinicians working hours (Cameron et al., 2013), limited staff availability (Bäckström and Sundin, 2009; Paul and Sanders, 2010; White et al., 2007), little consideration for the longer-term implications of carers (Cameron et al., 2013; White et al., 2007) and inadequate assessments of whether carers are able to understand the stroke survivors' needs and their role requirements (Young et al., 2014). These barriers have different implications for intervention development and demonstrate the importance of considering changes at both an interpersonal and organisational level to ensure that carers feel supported in being practically and emotionally prepared.

Facilitators for being supported to be prepared were also identified across the articles, including: preparing carers practically by providing opportunities for weekend leave before the stroke survivor returned home (Caap-Ahlgren and Dehlin, 2002; Cameron et al., 2013; Cecil et al., 2011; Gustafsson and Bootle, 2013) and providing carers with opportunities to be involved in the stroke survivors' rehabilitation (Cameron et al., 2013; Creasy et al., 2013; Danzl et al., 2013; Gustafsson and Bootle, 2013). Carers who were more informed felt reassured and had increased confidence for being able to cope (Bäckström and Sundin, 2007; Creasy et al., 2013; Danzl et al., 2013), this therefore had a positive impact on emotional preparation.

Evidence from the studies indicates that carers should be more consistently included as a focus in the preparation phase before returning home to feel practically and emotionally prepared. Providing a more structured approach with a focus on carer involvement and assessment of their needs should be considered within the varied constraints of current services.

### **6.6.2.2 Carers need to balance providing care to the stroke survivor with finding time for self**

The descriptive themes '*feeling a duty to provide care in a restricted role where the stroke survivor is prioritised*' and '*managing practical caring duties*' led to this theme. Carers need to balance losses and restrictions in their lives this with time to themselves. This is important to find an identity aside from caring; engage in their own activities; and gain a break to facilitate coping and opportunities for normality (Bäckström et al., 2010; Bäckström and Sundin, 2009; Cao et al., 2010; Howe et al., 2012; Kniepmann and Cupler, 2014; Le Dorze and Signori, 2010; Winkler et al., 2014).

This was an important ongoing need for carers, however, there were factors that influenced whether this was possible. The demands of the caring role, meant time was a barrier to carers engaging in their own activities (Gustafsson and Bootle, 2013; Silva-Smith, 2007). Support from family or friends would allow for some extra time for carers to spend doing things for themselves, however this was not always forthcoming (Saban and Hogan, 2012; Sjöqvist Nätterlund, 2010; Strudwick and Morris, 2010).

Examples of 'interpersonal' facilitators to carers gaining the required support to take time away from caring were evident in the articles. These included negotiating support with family and wider support networks, and dividing care among family members (Eaves, 2006; Gosman-Hedström and Dahlin-Ivanoff, 2012; Greenwood et al., 2010; Howe et al., 2012; Silva-Smith, 2007; Winkler et al., 2014). In terms of an individual level intervention, carers would need encouragement to take a more active role in obtaining required support. However, this approach is reliant on having an existing support network, which is problematic for carers with limited networks.

Further problems also arise if family and friends do not feel skilled enough to provide support to the stroke survivor. Alternative options for support e.g. day centres, support groups and therapeutic sessions for the stroke survivor may be more beneficial in such circumstances. Carers would need to be aware of these opportunities, through being provided with appropriate information. From an organisational perspective, appropriate and relevant resources would need to be available to enable signposting.

The restrictions that carers faced in finding time away from their roles due to fears and guilt have different implications for intervention development. From an individual perspective, an intervention would aim to increase carers' confidence in spending time away from the stroke survivor, to overcome fears around their safety and reoccurrence of stroke. Carers in some of the studies felt an increase in their confidence over time;

however, this was often dependent on recognising improvements in the stroke survivor (Bäckström et al., 2010; Cao et al., 2010; Silva-Smith, 2007; Van Dongen et al., 2014).

*“I’m fortunate now that my husband is such that I can leave him for a few hours at a time and he is okay.”* (Cao et al., 2010, pg. 40).

Individual circumstances of the carers and stroke survivors need to be considered for an intervention aimed at increasing confidence. Increasing confidence alone, may be unrealistic in cases where it is unsafe to leave the stroke survivor alone, without considering strategies for ensuring the stroke survivors safety in their absence e.g. support from family and friends. Here an intervention would be required to move beyond an individual focus, towards an interpersonal focus, where carers connect with appropriate support networks. Additionally, those responsible for ensuring the stroke survivors’ safety when the carer is not present may benefit from some co-training. Overcoming fears and increasing confidence in spending time away from the stroke survivor could also reduce the guilt experienced by carers. Encouraging carers to recognise their own needs aside from the stroke survivor would also be beneficial.

Evidence from the studies indicates that whilst having support networks in place and strategies for obtaining support is useful, it is also important to ensure that the carer is comfortable spending time away from the stroke survivor for them to find the balance between providing care and finding time to themselves.

### **6.6.2.3 Carers need to be able to cope with a changed life (relates to overall coping)**

Two descriptive themes pointed to carers needing to be able to cope with a changed life, these were *‘realisation of a changed future’* and *‘coping with uncertainties and feeling overwhelmed in a changed life.’* The former provided a sense of how the stroke impacted on carers’ lives, aside from the physical demands of care and some examples of emotions, the latter provided a sense of how carers coped with the changes and impacts upon their lives. Being able to cope remained an important ongoing need from the outset of the caregiving journey.

Barriers to coping with a changed situation related to carers perceptions of their past, present and future. Carers faced difficulties looking back knowing things would be different, and experienced fears looking towards a future of uncertainty (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Bäckström and Sundin, 2010; Cecil et al., 2011; Greenwood et al., 2009b). Coping in the present was also difficult for carers who

faced an ongoing struggle about never having a normal day anymore (Bäckström et al., 2010).

Examples of coping strategies that carers developed were outlined in the descriptive theme '*coping with uncertainties and feeling overwhelmed in a changed life.*' These were varied and included, acceptance, taking each day as it comes, and making comparisons with others. These strategies could be actively encouraged among carers, especially when the changes to their lives were likely to be permanent. Although carers are often unable to change their situation, to some extent they can change their perceptions and coping strategies over time.

In addition to barriers at the level of the individual, regarding their perceptions of their changed lives, further 'interpersonal' and 'organisational' barriers to being able to cope included a lack of formal and informal emotional support, despite this being a need among carers. Professional, emotional support was often not provided to carers (Bulley et al., 2010; Creasy et al., 2013; Howe et al., 2012; Sjöqvist Nätterlund, 2010; Winkler et al., 2014) and informal support from social networks often diminished over time (Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Cecil et al., 2011; Gosman-Hedström and Dahlin-Ivanoff, 2012).

*"No one understands what you're going through. All the crazy things he does from time to time. I have a feeling that people avoid me. They don't understand what it's like. You are so alone"* (Backstrom and Sundin, 2007, pg. 248).

These barriers related to how carers coped daily with their changed lives, so implications in terms of intervention development differ from those outlined above.

When considering implications for intervention development, it is useful to identify the types of emotional support valued by carers and who should provide this. Carers wanted to know what to expect from their new situation to be able to handle the changes and valued support from someone who had experienced and understands their situation (Bulley et al., 2010; Howe et al., 2012).

Professional support would not necessarily be required if alternative informal support could address these needs. Support from caregiving peers was valued in the study by Cameron et al. (2013) and would be appropriate for providing guidance on what to expect and how to handle the changed situation. Furthermore, it would provide carers with an opportunity to engage with similar others who had experienced the situation. Creating groups for carers or linking them to existing groups would encourage this engagement, or if this is not suitable, carers could seek other opportunities e.g. internet blogging. This was

considered a useful outlet for emotion and a place for sharing their *'ups and downs'* in the study by Winkler et al. (2014). Seeking support from similar others may also overcome the barrier of having limited support from family and friends who fail to understand the situation.

In addition to having someone there who could understand, carers valued family, friends, peers, and work colleagues who were willing to listen, even if they were unable to offer any advice or guidance (Bäckström and Sundin, 2007; Cao et al., 2010; Greenwood et al., 2009b).

*"I talk to sisters, I talk to my daughters, you don't want answers, you don't want replies, you want a sounding board and they have all got very good at that."*  
(Greenwood et al., 2009b, pg. 1128).

It is therefore important for carers to develop and maintain different support networks where possible that they can draw upon as situations arise.

#### **6.6.2.4 Carers need to maintain relationships despite changes and losses**

The descriptive theme *'changed roles, identities and loss of previous relationships'* led to the development of this important ongoing need for carers to maintain relationships, despite changes and losses (Bäckström and Sundin, 2009; Howe et al., 2012; Le Dorze and Signori, 2010; Quinn et al., 2014b; Silva-Smith, 2007). The descriptive theme mentioned above highlighted that changes to carers perceived identities impacted on engagements in aspects of their relationships (e.g. sexual relationships). These changes served as a barrier to maintaining previous relationships.

A further barrier to returning to their husband-wife relationship was being unable to rekindle the loss of their identities as a wife when they perceived themselves as a mother, or a maid (Bäckström et al., 2010; Bäckström and Sundin, 2007; Bäckström and Sundin, 2009; Quinn et al., 2014b; Van Dongen et al., 2014). Difficulties with changes to identities and the resultant impact on their relationships also remained in situations where stroke survivors improved over time and less care was required (Quinn et al., 2014b).

Maintaining previous relationships was also challenging for some carers when there would always be a difference (Saban and Hogan, 2012), and they felt there was just nothing left:

*“So, the feelings are...there’s nothing left... I don’t want him to touch me, I don’t want him to be around me...then go to bed every night with a man that you don’t ...want to be there...”* (Backstrom et al., 2010, pg. 120).

Carers struggled with regaining reciprocity and intimacy in this study when they felt this way about their partners. Unsurprisingly carers faced tensions following the losses in their relationships, making maintaining relationships more difficult (Buschenfeld et al., 2009; Green and King, 2009; Jones and Morris, 2013).

Barriers could be addressed by encouraging carers to strive towards maintaining a relationship that is different, yet still meaningful. Facilitators identified from the studies provide examples for how carers found ways to maintain their relationships, despite changes and losses. Instead of focussing on attempting to rekindle the loss of the husband-wife relationship, carers recognised their relationships as being strong in love (Bäckström and Sundin, 2009; Brann et al., 2010; Jones and Morris, 2013; Quinn et al., 2014b). In the study by Backstrom and Sundin (2009), the fundamental love for the person facilitated the maintenance of a relationship that now resembled friendship:

*“You want to be there, still...we’re together as best friends, we’re not much more than are good friends and buddies living under the same roof.”* (Backstrom and Sundin 2009, pg. 1479).

Another example of a facilitator for maintaining relationships included identifying positives such as new closeness, achieved through being there for each other and being able to reflect upon their experiences (Bäckström et al., 2010; El Masry et al., 2013; Grawburg et al., 2014; Green and King, 2009; Silva-Smith, 2007; White et al., 2007). These strategies could also reduce the tensions that carers faced through focussing on losses. In addition, to behavioural strategies such as finding space away from each other (Backstrom et al., 2010) and re-learning to live together again (Silva-Smith, 2007). This emphasises the importance of encouraging carers to find ways around their difficulties in their relationships to enable them to maintain them as well as changing their perceptions and learning to accommodate a changed reality.

Although many carers in the studies overcame the difficulties in their relationships or found new meanings themselves or with their partners over time, others struggled. Formal support may be more appropriate in such cases e.g. family counselling (Young et al., 2014). To ensure that carers have this as an option this type of support would need to be available within appropriate services.



### 6.6.2.5 Carers need to obtain information in accordance with needs

The descriptive theme about *'the importance of information for addressing carer needs'* highlighted reasons why carers needed information, their preferences for how this should be provided and how carers obtained information. However, gaining information in accordance with their requirements was often met with difficulties, meaning carers were left without the information that they needed. As evidence from the descriptive theme suggests information needs can change over time, it is important for carers to have strategies for obtaining this.

In addition to approaching professionals, behavioural strategies included seeking out other sources of information from resources in the community and on the internet (Avent et al., 2005; Creasy et al., 2013; Greenwood et al., 2009b; Le Dorze and Signori, 2010; Paul and Sanders, 2010; Saban and Hogan, 2012; Smith et al., 2008b; White et al., 2007). In the study by Saban and Hogan, (2012) one of the carers used a range of strategies for obtaining information:

*"I learned a lot from the internet and asking questions and taking notes to refer back to"* (Saban and Hogan, 2012, pg. 8).

The internet was something carers could use regardless of organisational restrictions in terms of access or availability of resources. However, successfully obtaining information on the internet is dependent on having access to the internet in addition to some knowledge about what they would like to search for as different problems arise.

Others faced barriers to gaining information proactively because they were reluctant to bother health care providers and GPs (Creasy et al., 2013; Greenwood et al., 2011). Organisational level restrictions also influenced information provision e.g. short hospital stays and limited interactions with health professionals following the return home (Cameron et al., 2013; Lawrence and Kinn, 2013; Paul and Sanders, 2010).

Encouraging carers to initiate interactions with health professionals by overcoming fears of making a fuss (Cecil et al., 2011; Creasy et al., 2013; Silva-Smith, 2007) is important, however reliance on opportunistic information seeking is not appropriate for ensuring carer information needs are met appropriately. A more consistent approach to considering carers' information needs is required. This would involve allocating time during the hospital stay to provide tailored information to promote effective information delivery and communication between professionals and carers.

Carers were successful at gaining information in the community when they had appropriate knowledge about available and accessible resources. Actively attempting to understand the health care system facilitated knowledge for this carer:

*"I spend time trying to understand the healthcare system so that I am able to access things quickly"* (White et al., 2007, pg. 9).

Other carers were provided with information in hospital and referred to this at a later date (Cameron et al., 2013).

Regarding implications for intervention development, encouraging carers to be active in seeking information in the community would be appropriate, however this is dependent on them being aware of, and having access to required information. Awareness could be achieved through providing information about available resources when carers are preparing for discharge. This would provide them with an option to seek information as difficulties arise and would facilitate proactive behaviours.

Evidence indicates that whilst encouraging carers to actively seek information appears important, resources for information need to be available and carers need to be provided with knowledge about these resources. This is particularly important given that carers have different needs and may require this information at different times. From an organisational perspective, considerations would also need to be made about the appropriateness of the information that is available to carers in terms of content and format, given some of the problems outlined in the descriptive theme.

#### **6.6.2.6 Carers need to obtain support in accordance with their needs**

The descriptive theme about the *'importance of informal and formal support for addressing needs'* led to the focus of this theme. This need is important as carers emphasised the need for ongoing support throughout the caregiving trajectory, even up to many years later (Cameron et al., 2013; El Masry et al., 2013; Howe et al., 2012; White et al., 2007).

Barriers to carers being provided with support from health professionals were outlined in the descriptive theme, these related to organisational restrictions e.g. time and the focus of support being on the stroke survivor (Greenwood et al., 2011; Le Dorze and Signori, 2010; White et al., 2007). Health professionals suggesting carers might want alternative support provided an example of an 'interpersonal' barrier.

*“If I can help sure... so I would like to think they can always call us if needs be, but sometimes they might just want to speak to a non-medical person ...”* (Greenwood et al., 2011, pg. 6).

Ambivalence around providing carers with support due to having a medical role could mean that carers would be without important social and emotional support (i.e. “someone to talk to”) unless they contacted the professionals. Although in some cases, being persistent in asking for support led to success (Bäckström and Sundin, 2009; Le Dorze and Signori, 2010), carers could benefit from alternative ways of gaining this support in the community for addressing other needs e.g. coping, gaining time to self and maintaining relationships.

Carers could be signposted to support as part of an intervention. This could extend beyond emotional and social support to other types e.g. practical, financial. However, the success of an intervention of this nature would be dependent on support being available and accessible, which was not always the case (Saban and Hogan, 2012; Smith et al., 2008b). To overcome this barrier, professionals or carers could make active attempts to set up support for carers e.g. groups with support from services and organisations (Cameron et al., 2013).

Maintaining existing support networks that carers can draw upon for support as required e.g. family and friends is an alternative to gaining formal support in the community. Availability of this support facilitated carers gaining support in accordance with their needs (e.g. emotional, social, practical) (Cecil et al., 2011; Greenwood et al., 2010; Greenwood et al., 2011; Saban and Hogan, 2012). However, maintaining a network of support was problematic for some carers when support diminished over time, despite them wanting this to continue (Bäckström and Sundin, 2007; Bulley et al., 2010; Cameron et al., 2013; Gosman-Hedström and Dahlin-Ivanoff, 2012).

Reasons for this varied and therefore have different implications for enabling carers to maintain such support. In some cases, this was due to the actions of their family and friends as carers felt that they no longer kept in touch because they felt uneasy around the changes to the stroke survivor (Bäckström et al., 2010; Bäckström and Sundin, 2009; Cecil et al., 2011). A carer in the study by Saban and Hogan (2012) was left disappointed: *“My friends have kept their distance, this is very disappointing”* (pg.7). In this instance, there was an expectation that friends should maintain contact with them rather than them proactively keeping in touch.

It would be important to encourage carers to be proactive in contacting friends and family for support, however this was met with reluctance, either due to not wanting to disturb

them (Le Dorze and Signori, 2010) or feeling uncomfortable approaching them (Saban and Hogan, 2012).

*“Family members are great, but most of the time we have to call and ask for their help. I wish they would come on their own and do some things. They know what I can’t do, but I still have to ask or do them myself”* (Saban and Hogan 2012, pg. 7).

An intervention should encourage carers to overcome this reluctance and support carers and families together, to ensure that they gain required support.

Approaching professionals for support is useful to some extent as is being active in negotiating support from family and friends. However actively seeking support is not enough if there is no reciprocal interaction between the carer and the ‘support provider.’ Additionally, it is important for carers to be provided with knowledge and access to appropriate support to ensure that carers increase their opportunities for gaining support that meets their needs.

### **6.6.3. A developing logic model of the problem**

The logic model presented in figure 25 adds to the information included in the logic model in chapter five and will continue to develop in chapter seven. Together the findings will form the overall logic model of burden, included in chapter eight. The logic model here was developed based findings outlined in appendix I that have been discussed throughout the analysis of descriptive and analytical themes. More specifically, behavioural and environmental barriers informed the behavioural and environmental factors boxes. Where relevant some of the non-behavioural barriers outlined in appendix I informed the determinants boxes. These are factors that influence the behavioural and environmental factors.

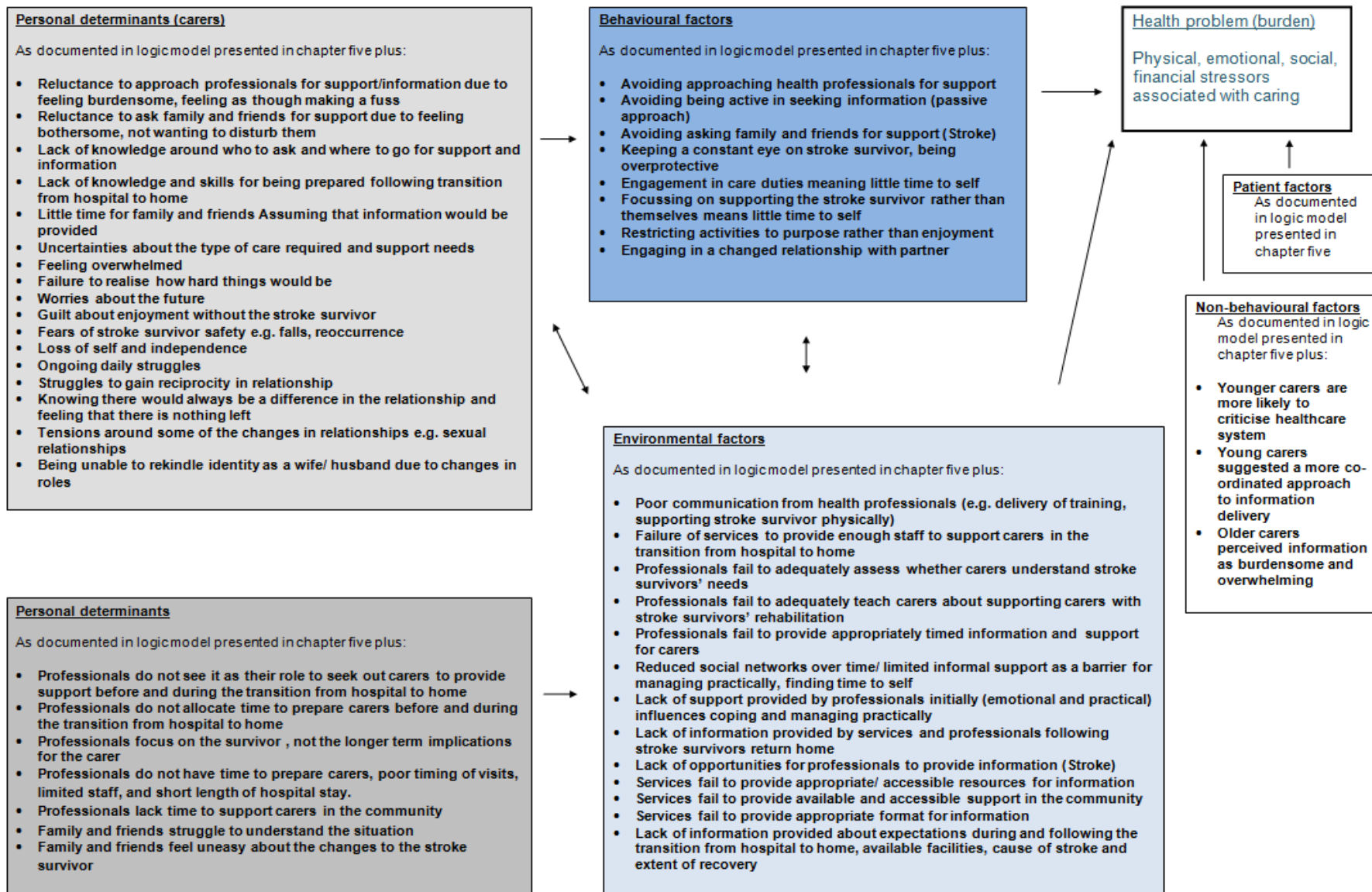


Figure 25: A developing logic model of the problem

## **6.7. Discussion**

### **6.7.1. Summary of evidence**

This review updated the qualitative literature concerning the experiences of caring for stroke survivors since the review by Greenwood et al. (2009a) to include qualitative literature concerning the experiences of caring for stroke survivors published between 2005 and 2015. This is the first synthesis of qualitative evidence that has examined the caregiving literature from a needs perspective; adopted a socio-ecological perspective for identifying barriers and facilitators to addressing needs; and identified implications for intervention development. This has provided additional insights, to those identified by Greenwood et al (2009a) and enhanced understandings of the caring experience. The findings contributed to the logic model which is used as part of developing an intervention to reduce burden among carers.

Following the synthesis of findings from 48 studies, nine descriptive themes and six analytical themes were identified; providing a rich insight in to the whole caring experience. The analytical themes identify that carers have needs relating to different aspects of caring, including the emotional and physical consequences of providing care. These needs changed over time, some were more apparent earlier in the caregiving trajectory, yet others remained consistent. For example, the need to be 'supported to feel practically and emotionally prepared before and during the transition from hospital to home' was important in the initial period following the stroke. Once carers engaged in their roles, coping with a changed life remained important, as did maintaining their relationships, despite changes and losses, and finding time to themselves. Support and information remained important throughout the carers' experiences.

Previous reviews have also highlighted the importance of adequate preparation for carers in the initial period following stroke (Camak, 2015; Pringle et al., 2008). The other needs identified resonate with some experiences and needs outlined in the previous review by Greenwood et al. (2009a). Similarly, carers experienced role and relationship changes, uncertainties about the future, a lack of freedom and time away from caring, and needed information and support over time. This review builds upon these findings by gaining a more in-depth understanding of the caring experience from a needs perspective and identifying factors that influence whether needs are addressed. For example, the current review provides more detail about specific information and support needs and the factors that influenced whether these were addressed (e.g. service constraints, reluctance to approach professionals). These factors underpinned implications for intervention

development. This synthesis of findings has taken a further step towards using findings from qualitative studies to develop an intervention for carers.

It was difficult to determine specific time points for different needs, however the findings indicate that carers have different needs over time, reflecting phases of the Timing It Right (TIR) Framework (Cameron and Gignac, 2008). Cameron and Gignac describe five phases: event/diagnosis, stabilisation, preparation, implementation and adaptation. Need for support to prepare before and during the transition from hospital to home spans phases two to four. The other needs reflect experiences included in the implementation and adaptation phases, when carers experience and respond to the consequences of caring following the transition from hospital to home (changed life, relationships, time to self). Support and information remained important throughout, although the nature of this differed according to needs.

Some of the current review findings are also consistent with Cameron et al's (2013) study which used the TIR Framework to analyse interviews exploring key support providers, carers' support needs, and how these change over time from the perspectives of 14 HCPs and 24 carers. Similarly, HCPs, families, friends, and peers were key sources of support, and carers valued emotional, practical, and informational support throughout the care trajectory from different sources, despite this not always being provided.

However, this synthesis extends these findings by providing a more comprehensive account of needs beyond support needs. For example it has enhanced understandings of the emotional aspects of caring. Carers in Cameron et al's (2013) study experienced stress and required care throughout the care trajectory. In the current review, carers wanted early support to know what to expect as they prepared for their role, and a distinction was apparent between coping with managing care, and coping with the changes to their lives. The TIR Framework places more emphasis on the practical aspects of preparation and emotional support needs attached to managing care, rather than the changes to carers' lives. Emotional needs are more complex than is presented in the TIR Framework (Cameron and Gignac, 2008; Cameron et al., 2013), which has important implications for how those working with carers approach carers' emotional needs.

The synthesis has also provided a more comprehensive account of experiences compared to Cameron et al. (2013) by examining the barriers and facilitators to addressing needs, rather than just identifying when different types of support are needed at different times. Barriers and facilitators were central to understanding how carers addressed different needs, using the socio-ecological model (McLeroy et al., 1988) these were established at an

individual, interpersonal, and organisational level. Individual level barriers and facilitators largely related to whether carers 'coped,' by finding time away from their caring roles and constructing a new life, self, and relationships; and their approach towards gaining information and support. Environmental level barriers and facilitators related to whether carers were provided with the appropriate support and information, due to how available and accessible this was within an organisation or informal support network (e.g. family and friends) and how this was communicated or negotiated between the carer and 'another' from the start of the caring experience, before the transition from hospital to home. Support and information were identified as needs, and barriers and facilitators to addressing other needs.

It is evident that some needs were influenced by multiple levels of the socio-ecological model. For example, taking time out involved overcoming fears, and having support in place for when the carer is not there to provide care to the stroke survivor. This has implications for how behaviours would be encouraged and who should be the target of an intervention. In some instances, it may be appropriate to focus on changing carers' thoughts and behaviours; in other cases it may be more appropriate to change behaviours of individuals responsible for providing support and information to carers. Both may be beneficial. This evidence highlights the complexities associated with developing interventions for carers and emphasises the importance of understanding the factors that are influential in shaping whether these are addressed. Findings can be considered in the context of relevant theory and evidence, below.

Following preparation for their roles, many carers needed to be able to cope with a changed life and maintain their relationships, despite changes and losses. This was important given that carers faced changes to different aspects of their lives, challenging their taken for granted assumptions. Their new roles impacted on their relationships with the stroke survivor, and their perceived identities. In the context of chronic illnesses such as stroke, the concept of 'biographical disruption' (Bury, 1982) has been advanced to describe disruptions to normal rules or reciprocity and the individuals' envisaged plans for their future. However, this concept is more commonly applied to understanding experiences of chronic illness, focussing on the 'sufferer' rather than the carer. Despite this, the concept is applicable to many of the carers' experiences in the reviewed articles, particularly when they faced barriers to overcoming challenges.

However, as time progressed, some carers found ways of coping with their changed lives and relationships. Biographical disruption also includes an element of response to disruption, where the strength of one's social network, and ability to mobilise resources is



crucial to how the illness and its impacts are experienced. For many carers, their own internal resources were important for responding to disruptions to their lives. Coping strategies included accepting, making comparisons with others, finding positives and taking each day as it comes. These findings reflect some of the basic assumptions of this theory, including the importance of mobilising resources. However they suggest that the theory which seeks to describe responses to illness, must acknowledge factors that influence the extent of disruption to different carers lives.

Faircloth et al. (2004) argued that biographical disruption may be inadequate for describing and explaining the impacts of illness because the lives of stroke survivors are not inevitably disrupted. They developed the term 'biographical flow' as an alternative way of understanding illness as part of an ongoing life, arguing a new biography could be constructed that flows with time and space. This is applicable to some of the review findings; particularly in relation to coping and the way carers perceived their lives, relationships and imagined futures. In some cases, carers addressed their needs and lived a life with less disruption.

Although the findings can be explained by elements of 'biographical disruption' and 'biographical flow' neither theory can adequately account for the complexities of carers' experiences. The initial period following the stroke event is typically disruptive and characterised by uncertainty, yet their experiences following this period are varied, where some lives remain more disrupted than others. Carers are vulnerable to further disruptions throughout their care experience as their support networks become fragmented over time, or if changes occur in their circumstances. Therefore, their experiences could be considered as a series of temporary disruptions that can be addressed with appropriate resources (internal and external) and be accommodated in a 'biographical flow.'

As part of coping, findings from the current review also indicated that carers needed to balance providing care with time away from their caring roles. Strang et al. (1999) described this as a type of emotion focussed coping, where carers 'allow' themselves space from caring. However, carers faced barriers to 'allowing' themselves this space, including time, lack of support, and negative emotions e.g. fear and guilt. Merely 'allowing' time to themselves seems simplistic, given that the reasons for providing care and continuing to provide care are bound with complexities such as perceived duties or obligations to fulfil expected responsibilities, including ensuring the stroke survivors' safety (Engster, 2005). Such obligations may make taking time away from this role more difficult.

Reasons for these obligations have been provided in sociological literature. Goodin (1995) suggested we have a special moral obligation to care for family and friends because of their vulnerabilities. Alternative theories have been developed based on the need to provide care due to the dependency of others (e.g. a stroke survivor) (Baier, 1997; Fineman, 2004). Consistent with this argument based on dependency, we are more likely to feel obligated to provide care to those individuals who cannot without difficulty, satisfy their own needs, or develop or sustain their capabilities (Engster, 2005). This would apply to many carers in the included studies, given many stroke survivors were dependent on their support to meet their needs.

Considering the moral aspects of care, achieving the balance between providing care and finding time to themselves is often more than 'allowing' time away from their role. Carers may need to temporarily set aside their obligations to care by distributing their care duties to trustworthy others. This dependency on others to assist in providing support is termed 'derivative dependency' (Fineman, 2004) and has been considered necessary for making caring possible (Engster, 2005). However, it was clear from the findings that maintaining an extensive web of support, for this need and other needs can be problematic. There were often negotiations involved in gaining this support (and information) and this was not always forthcoming or available.

As support and information appear to be important across the needs, considerations need to be made about *who* provides support and information, *what* is made available to carers, and *when* this is provided in the care trajectory. House (1981) regarded these as important decisions for translating evidence in to practice. Based on the evidence from the current review, it would also be useful to consider *how* this is made available to carers to ensure that it is tailored to their needs. Each will be considered in turn.

As carers valued support and information for addressing many of their needs it is important to consider who is best placed to provide this. Thoits (1995) proposed a theory about establishing effective support; if this is provided by a similar other, they are likely to have 'empathic understanding' that ensures they can meet the needs of the recipient. This is relevant to emotional support and other support e.g. instrumental and informational. This is consistent with findings within the analytical theme around coping, as it was established that professionals do not necessarily need to provide support if someone else could provide this. Carers also appreciated support from those who had experienced their situation, which may relate to their abilities to be empathic and understanding.

Seeking alternative providers of support in addition to health professionals could be valuable given the findings in this review that indicated numerous barriers to gaining their support from both a professional and carer perspective. Further barriers can also occur as relationships are not typically reciprocal due to differences in power relations and there can also be a lack of 'empathic understanding' that is regarded as important. Previously such barriers have been overcome by recruiting volunteers and providing training to ensure that can provide appropriate informational support whilst maintaining 'empathic understanding' (Friedman, 2005). This would be appropriate for addressing some of the identified needs, particularly if volunteers had experiences of providing care.

The findings also indicated that it would be appropriate to ensure that support and information are tailored to carers' individual needs and their diverse experiences by taking in to account their preferences in terms of what, when, and how these are provided. To address when and how, a consistent approach to ensuring that carers are provided with information and support would be appropriate at an early stage in the care trajectory. It would also be important to make sure that carers are aware of where they could gain this even if it wasn't needed at an early stage. This may also involve maintaining or developing support networks that they can be accessed as required.

Four categories of social network and social support type interventions have been outlined to establish how this could be achieved (Heaney and Israel, 2008; Israel, 1982). These include: enhancing existing social network linkages; developing new network linkages; enhancing networks using natural helpers and enhancing community networks through participatory problem solving. When moving forward with the intervention development, if such strategies for enhancing and developing support are considered, their applicability in different circumstances and contexts must also be acknowledged. To overcome difficulties, these strategies could be combined, yet further research is required to examine the efficacy using multiple strategies in the translation of evidence to practice (Heaney and Israel, 2008).

With regards to what tailored support and information may involve, decisions would need to be made by the intended intervention participants, hence the importance of stakeholder involvement in the IM process.

### **6.7.2. Strengths and limitations of the review**

The review was conducted systematically using a comprehensive search strategy, consistent with methods outlined by Greenwood et al. (2009a). A thematic approach to synthesising findings ensured an in-depth understanding of the positive and negative

aspects of the caring experience, appropriate for informing IM. Furthermore, the synthesis was based on a diverse range of high quality studies. Publication of this review would provide an important contribution to this field of interest; however, some limitations are acknowledged.

Although 55 studies were included as part of the review (and 48 were retained for the synthesis), restricting the inclusion criteria to articles written in English and excluding carers of stroke survivors in institutionalised care meant that some potentially relevant articles may not have been identified for inclusion. The review restricted to peer reviewed, published studies and did not include grey literature searches. Given that the initial search revealed a large amount of studies based on published, peer reviewed articles; it was not deemed necessary to carry out further searches to locate grey literature. This decision was supported by the notion that it is not necessary to include every single study for a thematic synthesis approach (Thomas and Harden, 2008). Furthermore, it was unnecessary for IM, given that the intervention is developed based on other evidence in addition to this work. Due to the iterative nature of the approach there are also opportunities to locate further evidence at different stages of the process.

Exclusion of studies based on their quality could also be considered as a limitation, as seven of the 55 included studies were not included within the synthesis. However, a strategy was used to consider these papers regardless of their quality, meaning nothing was lost through not including these studies. It is acknowledged that in future research of this nature, an alternative would be to include all the studies within the synthesis regardless of their quality and weight these in terms of importance (Boeije et al., 2011).

However, accepting these limitations, 55 studies were included in the review and 48 of these were synthesised in a manner that added to the depth of data presented by Greenwood et al. (2009a). In the previous review, the frequency of challenges, satisfactions and coping strategies were equated with importance. Using a thematic synthesis approach provided a nuanced and contextualised understanding of the caring experience, added to meaning to the frequency of occurrence issues, ensuring findings are based on importance for carers.

Strengths and limitations can also be considered regarding the conduct of the thematic synthesis. Not all phases of the analysis included involvement from the research team (e.g. line-by-line coding of studies) because no additional funding for this support was available. However, as discussed in section 6.4.5 efforts were made where possible to involve others in the conduct of the analysis and the development of themes that

contributed to the analysis were explicitly recorded using NVivo and diagrams where appropriate.

Although an in-depth understanding of caring has been gained, drawing upon both positive and negative aspects of care, the nature of thematic synthesis, means that findings are often drawn together based on their similarities. Therefore, it is less likely that the experiences of those that differ greatly are considered in a larger review of findings. This could have implications for this study, given that the 'needs assessment' provides a large contribution to IM. However the needs assessment is based upon other evidence aside from this review, meaning a broader understanding of experiences can be gained.

### **6.7.3. Summary and conclusions**

Findings from this review will inform subsequent stages of IM to develop a proposed intervention to reduce burden in carers of stroke survivors. Promoting an active role of the carer as well as ensuring that appropriate support and information is available (if carers need this) would be valuable for addressing the identified needs. Ensuring that an intervention is tailored to the differing needs of carers would also be appropriate, in addition to considering multiple levels of intervention. This is supported by the argument that interventions are more likely to be effective if they are developed and implemented within an ecological framework that considers different levels of intervention for different needs e.g. individual, interpersonal, organisational (McLeroy et al., 2001).

As the intervention development progresses it would be important to learn more about how carers understand burden, and how they attach these understandings to 'needs,' given that carers rarely used the terms 'burden' and 'burdensome' in their narratives, despite their roles being described as demanding and challenging. Some 'needs' may be more important than others for reducing burden; involving stakeholders to prioritise needs on this basis should be considered.

Overall, these findings are pertinent to intervention programmes for carers of stroke survivors because they highlight the need to consider the complexity of factors that could be influential in developing an intervention aimed at reducing burden.

As documented at the beginning of section two, chapter seven that follows is the qualitative interview study. This also contributes to the needs assessment by understanding the 'at risk group', their needs and the factors that influence these.

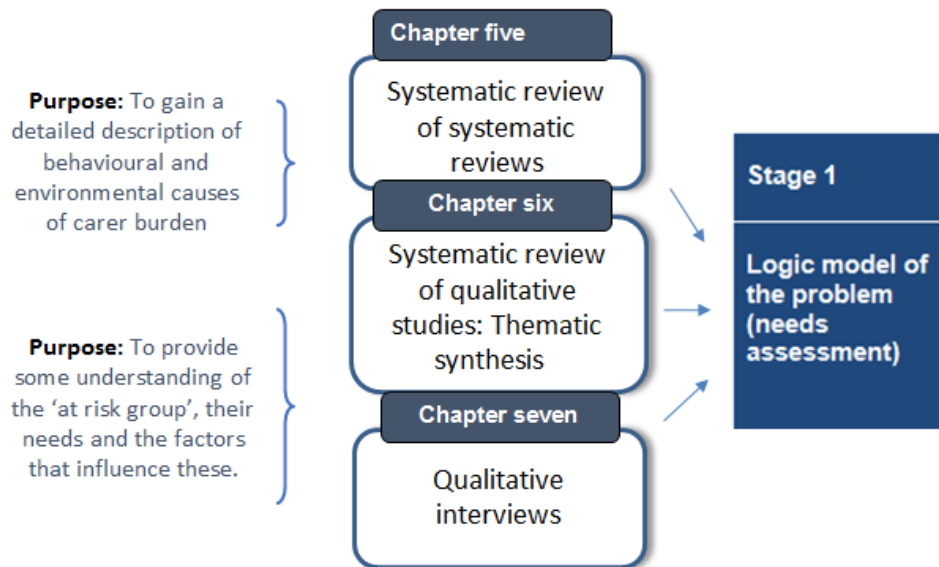


Figure 26 Overview of the needs assessment

## **7. Chapter seven: The experience of carers of stroke survivors at different time points following discharge from hospital: A thematic analysis**

### **7.1. Introduction**

This empirical study is the third and final component of work contributing to the needs assessment. This builds upon the review evidence presented in chapter six, maintaining a focus on needs, barriers, and facilitators. This study explored the experiences of two groups of carers of stroke survivors residing in the community, using qualitative semi-structured interviews. The focus was upon exploring the barriers and facilitators carers face in addressing their needs over time; and the role of social support networks in addressing their needs. Interview data were analysed using thematic analysis (Braun and Clarke, 2006). This chapter presents methods, then findings from both groups of carers. Then a developing logic model is presented including behavioural and environmental barriers and relevant determinants of carer and professional behaviours. In the discussion section, findings are summarised and considered in the context of current literature and IM.

### **7.2. Rationale for study**

Evidence presented in chapter six provided a substantial contribution to the needs assessment. However, this contribution was based on inferred needs, barriers, and facilitators because few studies included in the synthesis explicitly focused on needs or the barriers and facilitators to addressing needs. None of those that addressed needs were longitudinal studies. These either focused on a specific type of need e.g. support (Cameron et al., 2013) or information (Avent et al., 2005); a specific population e.g. carers of individuals with aphasia (Paul and Sanders, 2010); or a specific phase e.g. rehabilitation (Smith et al., 2008b), the transition from hospital to home (Young et al., 2014), and six months post discharge (Lutz et al., 2007). White et al. (2007) and Eames et al. (2010) identified barriers and facilitators to caring, and accessing stroke information. However, only one study in a specific population of carers with aphasia explored needs, and barriers and facilitators to addressing needs (Le Dorze and Signori, 2010).

Further longitudinal research was required to gain a more accurate and contemporary understanding of how carers' needs change over time, as well as the barriers and facilitators to addressing these. Further research was also necessary to understand more about carers' support networks to understand how support networks may change with

time, and to determine how these could be enhanced and mobilised as part of addressing carers' needs.

Qualitative, semi-structured interviews, including a social network mapping tool (Antonucci, 1986) were utilised. Including this empirical work alongside review findings as part of the needs assessment is important, as relevant stakeholders (e.g. carers) should be included at all stages of IM to avoid relying on a solely expert driven approach (Bartholomew et al., 2011).

### **7.3. Aims and research questions**

Aims:

- To explore carers' experiences over time in two groups of carers using qualitative, semi-structured interviews (Group one: a first interview shortly following discharge then two more interviews, each separated by three months; Group two: interviews conducted between nine and 36 months since the stroke).
- To explore the carers' social support networks, using the social network mapping activity (Antonucci, 1986).

Research questions:

- What are the needs of carers of stroke survivors (at each time point)?
- What are the barriers and facilitators to addressing needs?
- How do needs, and barriers and facilitators to addressing needs change over time?
- What can we understand about carers social support networks?

### **7.4. Methods**

#### **7.4.1. Research design**

The study has National Health Service (NHS) permission and was approved by the Yorkshire and the Humber – Bradford Leeds Research Ethics Committee (Ref No: 15/YH/0073) (Appendix J).

The study is qualitative and used semi-structured interviews with carers of stroke survivors at different time points. One group carers (group one) were interviewed at three different time points in a longitudinal study. The first interview was conducted shortly following the stroke survivors' discharge from hospital; the subsequent two interviews were each separated by three months. A second group of carers (group two) were interviewed at one-time point in a cross-sectional study between nine and 36 months



since their friend/relative's stroke. Interviews with group one provided an understanding of the emerging needs of carers and barriers and facilitators to addressing needs over time. Interviews with group two provided a reference point for making comparisons with earlier caring experiences reported by group one participants.

I conducted all interviews between April 2015 and July 2016. These were recorded and transcribed verbatim and analysed using thematic analysis (Braun and Clarke, 2006).

#### **7.4.2. Thematic analysis**

Some approaches to analysis attend to the language of participants and how this is used in social interactions e.g. discourse analysis (Parker and Burman, 1993; Potter and Wetherell, 1987); and narrative methods (Riessman, 1993); some attend to experiences and meanings e.g. interpretative phenomenological analysis (Smith et al., 1997); and others seek to develop theory, derived from the data e.g. grounded theory (Glaser, 1992; Strauss and Corbin, 1994). These approaches are associated with particular disciplines, and are underpinned by philosophical perspectives that influence the conduct of analysis (Crotty, 1998).

Rather than using an approach that provides discursive or phenomenological accounts of experience, or generation of a substantive theory, the chosen analysis method needed to meet the requirements of the needs assessment component of IM. This included gaining a rich, detailed account of the carers' needs and the factors that influence these to produce findings that could inform the developing logic model. Therefore, flexibility was important which is a key strength of the 'thematic analysis' approach (Braun and Clarke, 2006).

Thematic analysis is not aligned with any philosophical, epistemological, or theoretical approach. This approach is widely-used for developing themes and patterns across a data set, which attends to similarities and differences in experiences (Boyatzis, 1998; Roulston et al., 2001). It also provides the opportunity to understand an issue more widely (Marks and Yardley, 2004), it can be used to detect the factors that influence an issue generated by participants, and facilitates comparison between participants at different times. Furthermore, the participants' interpretations are significant in terms of giving the most appropriate explanations for their behaviours actions and thoughts (Hatch, 2002). All these points are important for the broader IM process, therefore a thematic analysis approach was adopted for this study.

The analysis was largely guided by the six stages outlined by Braun and Clarke (2006). However, adaptations were made to the traditional methods to ensure that the data was analysed in accordance with the research questions. A secondary analysis (described on

page 188) was applied to move from a thematic description of experiences to understanding carers' needs and the barriers and facilitators to addressing needs.

### **7.4.3. Sampling**

#### **7.4.3.1 Study populations**

Defining the 'parent population' from which the sample would be drawn was necessary prior to recruitment (Ritchie et al., 2013). Although this study intended to primarily focus on the carers' needs, stroke survivors were included in the interviews across time points at the discretion of the carer. The stroke survivors' presence was to aid understandings of the nature and the context of the carer and stroke survivor relationship. However the focus of the interviews remained on the carers' experiences and perceptions of their own needs in relation to providing care to the stroke survivor.

#### **7.4.3.2 Sampling frame**

Different approaches for generating sampling frames were used to gain a population of carers suitable for both groups. In group one; the sampling frame was generated from a 'flow population.' Carers were approached from two stroke wards (acute and rehabilitation) in a Teaching Hospitals Trust (THT). In group two, the sampling frame was based upon existing sources; a research register, an organisation for carers, and a stroke group.

The research register is an established database of stroke survivors, held by the Academic Unit of Elderly Care and Rehabilitation (AUECR) at the Bradford Institute for Health Research (BIHR). At the time of recruitment, the database held information on over 150 stroke survivors between 0 and 24 months post stroke. Stroke survivors consented to inclusion in this database whilst they were in hospital and agreed to be contacted regarding participation in future research at AUECR. Using this database, carers are contacted via the stroke survivor.

#### **7.4.3.3 Sampling methods**

Qualitative studies are based on non-probability samples, where the characteristics of a group provide a basis for selection, making them well suited to being small scale and in-depth (Ritchie et al., 2013). Different sampling approaches have been developed for use in qualitative research e.g. purposive sampling (Mason, 2002; Patton, 2002); theoretical sampling (Glaser and Strauss, 1967; Strauss and Corbin, 1998) and opportunistic and convenience sampling (Patton, 2002). Each has a different definition and purpose.

Purposive sampling, involves selecting individuals within a population to represent a key criterion e.g. age, socio-demographic characteristics or specific roles. Theoretical sampling is a type of purposive sampling, mainly associated with grounded theory approaches, where people are selected in a sample to develop and test theoretical constructs. Patton (2002) draws a clear distinction between opportunistic and convenience sampling. Opportunistic sampling involves taking advantage of unforeseen opportunities. Convenience sampling lacks a clear strategy; therefore researchers select samples based on ease of access (Ritchie et al., 2013).

Purposive sampling is valued as a pre-defined and systematic approach (Mason, 2002; Patton, 2002). The intention was to use this to provide a heterogeneous sample based on factors such as: degree of stroke survivor impairments including language, physical and cognitive abilities, age of carer, and ethnicity of carer, relationship to stroke survivor (e.g. spouse or other). However, there were some challenges in adopting this approach.

Purposive sampling was possible to some extent when recruiting carers for group one from the stroke wards, as they could be selected based on characteristics outlined above. However this was more difficult in other recruitment approaches (e.g. the carers organisation, stroke group, and the research register) because there were not enough potential participants to be selective about inclusion based on particular characteristics. Therefore, carers in group two were selected based on convenience sampling.

#### **7.4.3.4 Sample size**

Compared to quantitative studies, the sample sizes used in qualitative research can remain small to do justice to the rich data that is gained, yet a balance is required to avoid this being too small, as this could jeopardise the transferability of findings (Ritchie et al., 2013).

I planned to recruit 15 carer and stroke survivor dyads in each group, leading to a total of 60 interviews, as those in group two were interviewed across three time points. However, once the interviews commenced this became unmanageable within the time constraints and recruitment targets were revised in each group (10 in each). This led to a planned total of 40 interviews. This decision was justified based on the notion that richness of data takes precedence over incidence and prevalence in qualitative research (Ritchie et al., 2013). The amount of evidence these interviews would provide was also deemed appropriate for informing the subsequent intervention development.

#### 7.4.4. Inclusion and exclusion criteria

The inclusion and exclusion criteria outlined in table 23 were applied for all recruitment strategies. The only difference was the timing of the interviews in each group as outlined in section 7.4.2.

**Table 23: Inclusion and exclusion criteria for qualitative study**

<b>Inclusion criteria</b>
<b>Carers are eligible for study if they:</b>
Are aged over 18 years
Care for a stroke survivor who is (or will be) residing in the community
Provide (or will provide) help and support (practical and/or emotional) to a stroke survivor at least once a week.
Can provide written informed consent and Consultee Declaration for the stroke survivor (where appropriate)
<b>Stroke survivors are eligible for study if they:</b>
Are aged over 18 years and have a confirmed primary diagnosis of stroke
Reside in the community and being supported by a caregiver who provides support (practical and/or emotional) at least once a week.
Can provide written informed consent (or be consented via a consultee)
<b>Exclusion criteria</b>
<b>Carers are not eligible for study if they:</b>
Are aged less than 18 years
Care for a stroke survivor with palliative care needs
<b>Stroke survivors are not eligible the study if they:</b>
Are aged less than 18 years
Have palliative care needs
Have a carer who refuses to provide written consent to take part.

#### 7.4.5. Participant recruitment (Participants with capacity)

##### 7.4.5.1 Group one (carers recruited from stroke wards)

The researcher attended stroke wards during visiting hours; this was the most appropriate time for contacting potential participants who were visiting their relatives. At every visit, the researcher consulted with clinically based staff (e.g. nurses) to identify friends and relatives of stroke survivors that would be providing care to the stroke survivor once they returned home. As per protocol, the clinically based staff introduced the researcher to the families and asked their permission to speak about the study. If the families and or friends were willing to speak with the researcher, the study was explained and any questions were answered. The anticipated outcome of the study was also explained and that the standard of care the stroke survivor receives would not be affected

by their decisions regarding participation. Participant information sheets (PIS) were left with potential participants whilst they considered participation. These included information about the purpose of the study, how the participants can contribute to the study, and how the data would be used following their participation. It was also made clear that potential participants had the right to withdraw at any point (appendix K).

Once potential participants had considered participation, the researcher returned (usually at least 24 hours later) to see if they were willing and interested. Willing carers were asked if they would like the stroke survivor to take part in an interview with them. If they wanted the stroke survivor to take part, the researcher discussed the study with the stroke survivor and provided information (separate PIS for stroke survivors). Consent was obtained from both the carer and (where relevant) the stroke survivor in hospital. In cases where stroke survivors were unable to read or sign the consent form due to impairments, but who had the capacity to consent and would like to take part, the PIS was read aloud and the consent procedure had to be witnessed.

Participants provided the researcher with their contact details, so an interview could be arranged via telephone following the stroke survivors' discharge. First interviews were usually arranged about two weeks following discharge, to allow families to begin to adjust to their roles once they returned home before being contacted again. Second interviews were arranged at a later date (see section 7.4.7.).

#### **7.4.5.2 Group two (a) Carers recruited via organisations and groups**

To access carers in receipt of services up to three years post stroke, posters were displayed at a carers organisation and a stroke group. These summarised the study and included the researcher's contact details.

Potential participants contacted the researcher via telephone or email to express their interest. The researcher then provided verbal or written information about the study purpose and what their involvement would entail. If potential participants were interested, they were asked if they wished the stroke survivor to take part in the interview, should they agree to take part in the study. PIS were posted to potential participants (and stroke survivors where relevant) and sufficient time was provided to consider participation. The researcher agreed to contact the potential participants (via email or telephone) to see if they remained interested after reading the further information. If they were willing to take part in an interview, these were arranged via email or telephone. Appropriate consent for carers and where relevant, stroke survivors

was obtained during the visit prior to conducting the interview (in their own homes). Again, participants were informed of their right to withdraw at any stage.

#### **7.4.5.3 Group two (b) Carers recruited via established research register**

In group two, carers were also recruited via a research register. Contact with carers was made via the stroke survivors. Before contact was made, the researcher checked eligibility for inclusion in the study and living status, using the summary care record on the NHS spine portal system. When stroke survivors had died, an out of study request was added to the database so they would not be contacted for future studies.

Following checks for eligibility, the stroke survivors were sent a covering letter asking them to pass information to a friend or relative that provides help or support to them (practical and/or emotional) at least once a week, study information sheet and 'consent to further contact form'. Interested carers returned the consent to contact form in the stamped addressed envelope provided. Following receipt of the form, the researcher telephoned carers who consented to being contacted and explained the study. If participants were willing, to take part they were asked if they would like the stroke survivor to take part in the interview. A decision was made and the interview was arranged. If the carer wanted the stroke survivor to take part, information was sent via post for them to consider prior to the interview. As above, appropriate consent was obtained during the visit prior to conducting the interview (in their own homes). Again, participants were informed of their right to withdraw at any stage.

#### **7.4.6. Participant recruitment (Participants without capacity)**

The study aimed to be inclusive, therefore stroke survivors with communication and cognitive impairments to participate were provided with an opportunity to participate. This ensured that carer needs and experiences were understood in varying situations. Consent procedures were adapted to comply with the Mental Capacity Act (2005) to ensure that these participants could be included.

Consultee declaration was required in circumstances where stroke survivors lacked capacity to consent. The researcher assessed capacity in conjunction with a discussion with the carer. Where the carer acted as a consultee, she/he was advised to set her/his own views aside and provide advice on the participation of her husband/his wife, taking in to consideration his/her wishes and interests.

The right of potential participants to refuse consent without giving reasons was respected at every stage of the research process. In all cases, regardless of capacity, original consent forms were stored centrally at the AUECR and participants were each provided with a copy.

#### **7.4.7. Interview topic guides**

The study utilised qualitative, semi-structured interviews. This method captures understandings required to answer the research questions in a way that cannot be accommodated in a formal questionnaire or captured as effectively through focus groups (Silverman, 2013). Topic guides were required to provide a framework for all the interviews; these are discussed in the following sections.

##### **7.4.7.1 Initial semi structured interviews**

An initial interview topic guide was devised from the themes in the existing literature, discussions with carers and stroke survivors and previous research. This was informed by IM and the broader aims of the doctoral study to gain an understanding of caring with attention to aspects of the experience that may relate to carer burden and also carer needs and the barriers and facilitators faced in addressing needs.

The same topic guide was used in the first interviews for carers in group one and group two interviews. The topic guide ensured all carers were asked similar questions, enabling comparisons during the analysis, but was used flexibly based on carers' responses. Further questions were asked to gain richer, detailed accounts of their experiences.

The topic guide was structured to put the participants at ease, starting with questions such as 'could you tell me a little bit about yourself?' and 'how would you describe yourself before the stroke happened?' Following these, questions were asked about the impact of stroke from the point of returning home, to life at the point of interview then thoughts about the future. The domains of burden (social, physical, emotional, financial) from George and Gwyther's (1986) definition of burden are reflected in questions throughout the topic guide.

Although carers do not commonly use the term burden in their narratives, they do experience difficulties that can be considered burdensome, therefore these questions were deemed appropriate for exploring some of these issues. The IM approach indicated a focus on behavioural and environmental factors that influence carers' needs and more broadly carer burden. Carers were asked directly about their needs e.g. 'what were your needs at

this point?' and 'how have your needs changed?' They were also asked less directly in questions such as 'what do you need support with?' To attend to the barriers and facilitators, questions such as 'what has helped the process of adapting to changes?' and 'what has hindered this process?' (see appendix L).

The social networking map was included at the end of each interview; this is discussed in section 7.4.7.3.

#### **7.4.7.2 Follow up semi structured interviews**

The topic guides for the second and third interviews with group one participants were developed prior to these interviews. Questions focused on changes in carers' experiences since the previous interview(s) e.g. 'has anything changed for you since we last spoke?' and 'have you encountered any problems or challenges since last met?' However, to some extent, the emerging themes from the earlier interviews informed the line of questioning in the second and third interviews. The researcher adapted questions and where relevant introduced new questions to understand in more depth the aspects of carers' experiences that they had shared previously (appendix M).

#### **7.4.7.3 Social network mapping as part of the semi structured interviews**

A social network mapping tool, adapted from a Hierarchical Technique (Antonucci, 1986) was included in the topic guides for all interviews. This tool has been used previously to explore support networks in individuals with longer term conditions e.g. chronic obstructive pulmonary disease, diabetes (Morris, 2015). The mapping tool was considered an appropriate framework for stroke carers to describe their support networks.

The tool serves as a way of understanding the importance carers place upon certain people and services at a given time. Whilst hierarchical in nature, carers are not forced to rank support if they consider two types to be of equal importance. In discussions around this activity, carers can indicate where potentially beneficial support is lacking; therefore, a more accurate representation of support networks and how they change over time can be gained. Although IM uses theory and evidence to guide decisions, findings from the social network mapping tool can guide decisions about those involved in delivering interventions at different times in the care trajectory.

#### **7.4.8. Data collection**

Interviews were conducted face-to-face at the carers' homes. Prior to commencing interviews, the purpose of the study was explained again and participants were asked if



they had read the information sheets. They were also given the opportunity to ask any questions about anything that was unclear at this stage.

Participants were reminded of their right to withdraw, terminate or pause the interview and anonymity of their data (Appendix K). Group one participants provided consent during the stroke survivors' time in hospital; but were reminded of the above prior to each interview. Consent was obtained from group two participants once they had read information sheets, asked relevant questions and expressed willingness to take part.

Once carers (and in some cases, stroke survivors) provided consent or consultee declaration, interviews started with opening questions then more general questions, followed by the social network mapping exercise and some closing questions. In all cases, regardless of whether the stroke survivors were present, the questions remained focused on the carers. However, the stroke survivors were free to contribute as they wished. To facilitate this process, and ensure that stroke survivors were given the opportunity to express their views, interviews were adapted for stroke survivors with communication difficulties by writing down key words and adapting questions in accordance with their needs.

At the end of each interview, participants were thanked for their time and asked whether they had any further questions. The researcher also ensured that they were provided with contact details in case they had any further questions or wanted to withdraw from the study. Where participants were invited to take part in three interviews over time (group one), the researcher asked if they would be willing to take part in another interview, approximately three months later. Where participants agreed, they were advised the researcher would be in touch a few weeks before then to arrange an appropriate time for the interview. At each time point, carers were given the option to decide if they would like the stroke survivor to be present.

#### **7.4.9. Ethical considerations**

In sections 7.4.6 and 7.4.8, ethical considerations were outlined regarding capacity to consent, right to withdraw and participant anonymity. Other key considerations regarding the ethical conduct of the study were participant confidentiality and storage of personal data.

The researcher had access to personal details including names, date of births, addresses, and telephone numbers. These were and continue to be stored securely (on paper and electronically) at the AUECR in Bradford. All participants were given pseudonyms and

identifiable and non-identifiable data have been stored separately using participant identifiers. The researcher complied with all aspects of the Data Protection Act (1998) and continues to do so whilst the data is stored at the AUECR. At the end of the study, data will be securely archived at the AUECR for a minimum of three years.

#### **7.4.10. Data analysis**

Interview data from carers and stroke survivors (where present in the interviews), including responses to questions attached to the social network mapping exercise were analysed using thematic analysis, drawing upon phases proposed by Braun and Clarke (2006): 1) familiarisation, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report. However, adaptations to the traditional analysis process were made between phases four and five to allow for an understanding of carers' needs and the barriers and facilitators to addressing needs, rather than a thematic description of experiences. The secondary analysis that was conducted to achieve this is described on pg. 188. The social network mapping tool is also additional element in this data collection and analysis. Section 7.4.10.7 provides further details about diagrams created following the social network mapping exercise.

Interview transcripts were analysed at each time point. In group one, data analysis was ongoing between the three interviews that took place between April 2015 and July 2016. Between the first and subsequent interviews I conducted some interim analysis (initial categories with associated supporting memos) which meant I was sensitised to the carers' circumstances before the follow-up interviews. However, full summaries of themes and needs at each time point were not completed until all the data collection was complete.

In group two, the interviews at one static time point were conducted over a shorter period of time from April 2015 to August 2015. The analysis commenced alongside these interviews. However themes (conceptualised as needs with barriers and facilitators) were reviewed against the group one themes that were produced after the three interviews were analysed. This contributed to an iterative process of establishing the main themes that are presented in this chapter.

The sections that follow provide further details about how the analysis was conducted.

##### **7.4.10.1 Phase one: familiarisation**

Riessman (1993) argued that transcribing your own data is an excellent way of becoming familiar with the data. I transcribed the first three interviews; however this took an

excessive amount of time. Therefore, with a confidentiality agreement in place, the remaining interviews were transcribed externally. There is no, one set of guidance for how spoken words should be transformed into written texts, but at minimum an 'orthographic' transcript is required (Braun and Clarke, 2006). Consistent with this approach each transcript provided a verbatim transcription, remaining true to the participant's account, including utterances e.g. coughs, sighs, and laughs. On receipt of each transcript, I corrected any inaccuracies and misinterpretations and addressed any aspects that the transcriber could not understand e.g. where included stroke survivors had communication difficulties. Identifying text e.g. place names and people were also removed and participants were given pseudonyms.

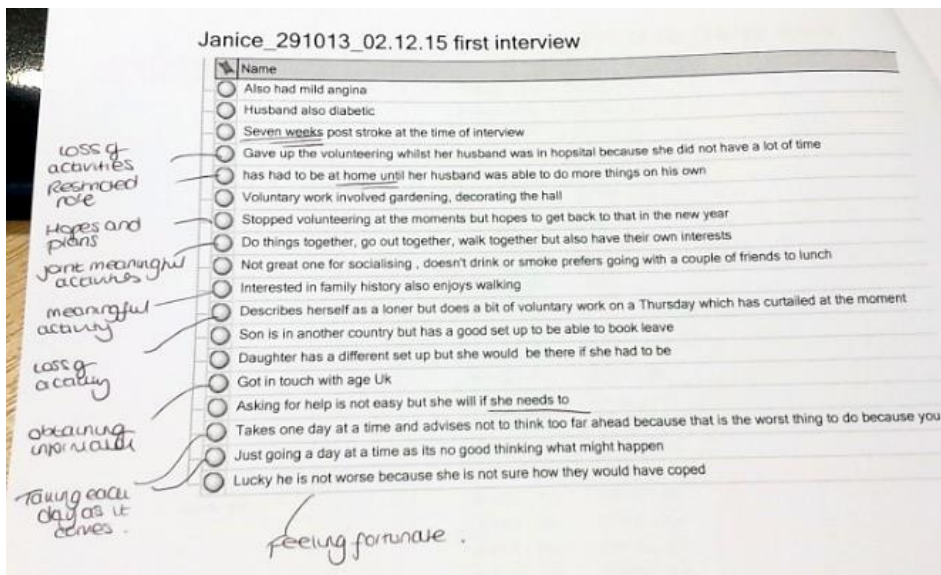
#### **7.4.10.2 Phase two- generating initial codes**

The term 'code' is used to describe a feature of the data that appears interesting to the analyst (Braun and Clarke, 2006). This process of coding contributes to the overall analysis, as coded data is initially organised in to meaningful groups (Tuckett, 2005).

Before applying codes to the data, decisions were made about whether codes were 'theory driven' or 'data driven.' 'Theory driven' codes are developed with key questions in mind, whereas 'data driven' codes are derived inductively from the data. Although the aims relate to specific questions around needs and the barriers and facilitators to addressing needs, a data driven approach was adopted to avoid losing a contextual understanding of the experience. Line-by-line coding was conducted on each transcript, using an active voice to ensure codes remained close to the text. If a 'line' lacked meaning, larger sections of data were coded to capture context. As previously, NVivo 10 qualitative data analysis software was used throughout the analysis process (NVivo, 2012).

#### **7.4.10.3 Phase three: searching for themes**

This phase involved collating all the relevant coded data extracts and, considering how different codes might be combined to form an overarching theme (Braun and Clarke, 2006). Line-by-line codes for each transcript were printed and notes about emerging ideas were written alongside these:



**Figure 27: Example of note taking, searching for themes**

This helped to establish where codes were linked within the data set and where differences were apparent. Following this, codes were organised in to themes. Hand-written memos were documented for each participant. A number of themes were developed, but it was not clear initially which were sub-themes and which would become main themes.

This process was documented on NVivo; however, themes were transformed into diagrams, as recommended by Braun and Clarke (2006). Different colours were used to highlight different aspects of the caring experience and similar colours were applied for similar concepts. Using diagrams helped establish interrelationships between the themes, an example is provided in Figure 28:



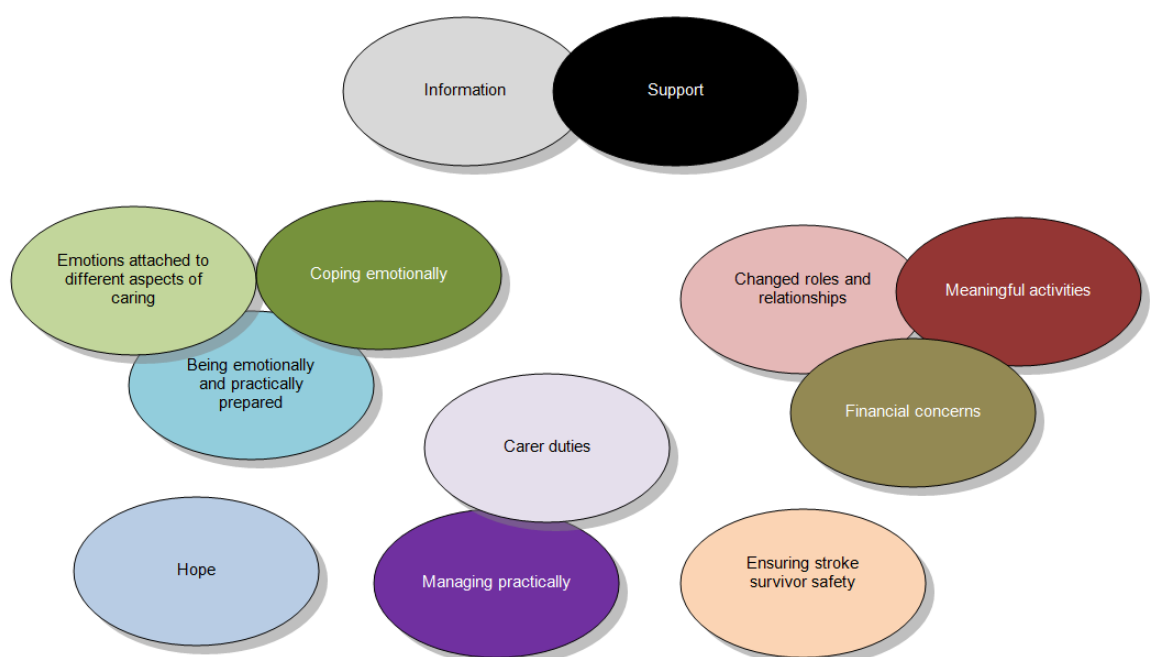
**Figure 28: Representation of themes for Janice's interview at time point one (T1)**

#### 7.4.10.4 Phase four: reviewing themes

This phase involved refining the themes created previously. This did not happen in a linear fashion, as suggested by Braun and Clarke (2006). Rather, this was conducted as part of an iterative process in the translation from codes to themes and then representing these visually in diagrams. For example, the theme 'hopes and plans' became 'hope attached to being able to return to activities and normality' once the themes were refined in the process of developing the diagrammatical representations (figure 28).

At this stage, Braun and Clarke (2006) argued that the data in a theme should cohere together in a meaningful way, yet there should be clear distinctions between the themes that have been developed. Initial codes were revisited to consider whether they formed a coherent pattern. In some cases, codes were moved and changed when this was not the case. Themes were also considered in terms of whether they captured the essence of what was within them and refinements were made where appropriate. In addition to this, another researcher examined 20% of transcripts and noted ideas about emerging themes. These were discussed and themes were refined accordingly.

Level two of this phase of analysis involved a similar process but with the entire data set (across case analysis). Therefore, I looked across the data from each interview participant to develop a thematic map representing data from all participants. An overall thematic map was developed for each time point (the three interviews in group one and the interviews conducted in group two). Similarities and differences across themes were represented based on how they were grouped on the diagrams. See below for an example of the overarching themes at T1.



**Figure 29: Overarching themes for all carers at T1**

At this stage, researchers traditionally move towards defining and naming themes (phase five) before writing the report (phase six). However, a 'secondary analysis' was conducted to establish the needs and barriers and facilitators to addressing needs at each time point, to ensure research questions were addressed.

The analysis in phases one-four was used to develop the needs, barriers, and facilitators. To capture the findings from this perspective, it was inappropriate to simply re-name the themes already developed in a way that reflected a 'need,' instead it was important to review the data to ensure nothing was left unconsidered. Therefore, for each participant, the codes, developed in NVivo were re-examined to identify needs, barriers, and facilitators. To provide an example, using Janice's first interview, the themes 'unsure what to expect initially' and 'ensuring practical arrangements in place' were captured in the need 'feeling prepared and knowing what to expect.' Ensuring practical arrangements were in place to aid stroke survivors with physical difficulties became a facilitator for this need. By looking back at the data from Janice's interview, she expressed that she was emotionally prepared, which also became a facilitator for this need. These are outlined in figure 30:

**Key:**

- Needs
- Behavioural barriers
- Environmental barriers
- Behavioural facilitators
- Environmental facilitators
- Barrier (not behavioural or environmental)
- Facilitator (not behavioural or environmental)



**Figure 30: Example of needs, barriers, and facilitators. Interview 1, Janice**

Tables were created after looking across the data set that included needs, barriers, and facilitators (for each time point). Within these tables, the researcher noted which participants' experiences were related to each of the needs for assisting with the later analysis process. Although this part of the analysis is not traditionally incorporated into methods by Braun and Clarke (2006), it was considered important for avoiding drawing conclusions across the data set based on few participants. An example of part of one of these tables is provided in table 24 for interviews at time point one.

**Table 24: Needs, barriers and facilitators at time point one (T1)**

Carer needs	Indication of needs at particular time (interview time point)	Barriers to addressing needs (behavioural and environmental)		Facilitators to addressing needs (behavioural and environmental)	
1. Managing and coping with a changed relationship	T1		- Lack of support (Amanda)		
				- Maintained emotional relationship (Lucy)	
2. Seeking explanations to understand the cause and consequences of the stroke	T1		- Lack of information provided in hospital about cause of stroke (Paddy)	- Actively obtained information from internet (Paddy) - Actively obtained information from staff in hospital (Paddy, Nadia) - Actively sought information from records in hospital (Paddy) - Established own cause for stroke (Paddy)	- Explanations from staff in hospital (Nadia)

Following this, the final needs, barriers, and facilitator diagrams were developed at each time point to capture the experiences across participants. Capturing these in a diagrammatical form makes comparisons over time more manageable. These are presented throughout the findings sections (7.5.1, 7.5.2, 7.5.3).

#### 7.4.10.5 Phase five: defining and naming themes

It is important at the end of this stage to be able to define what the themes are and what they are not (Braun and Clarke, 2006). Names were therefore selected that provided the reader with a sense of what the theme is about, but from a needs perspective. Each theme (need) was accompanied by a textual description with attention to how changes were apparent over time before proceeding with the final written analysis.

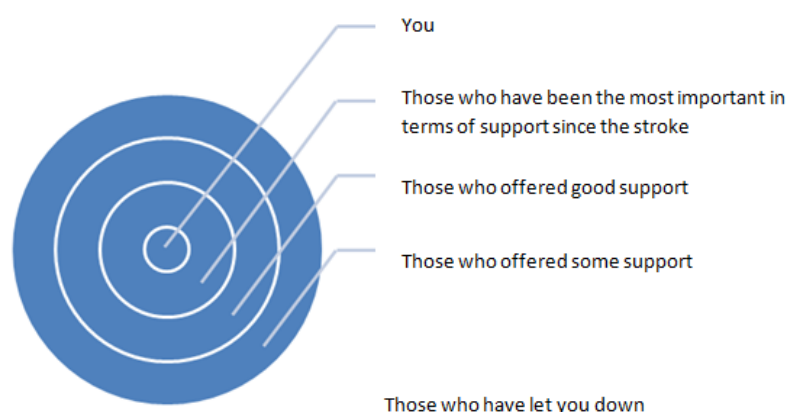


#### 7.4.10.6 Phase six: producing the report

The final analysis (section 7.5), starts with a comprehensive account from the first interviews in group one, then data from time points two and three and data from group two interviews are compared. Participant characteristics are outlined and summarised for each group of carers prior to the written analysis.

#### 7.4.10.7 Documenting findings from the social network mapping exercise

As documented in section 7.4.10, the detailed responses from the social network mapping exercise during the interviews were integrated into the analysis, therefore these were included and are reflected within the themes developed from the analysis processes outlined throughout this section. During the social network mapping exercise, participants were asked to state examples for each of the points outlined in the diagram; their responses were documented on the diagram included in the topic guides at each interview (figure 31).



**Figure 31: Social network map**

To draw together the responses from participants at each time point, four separate diagrams were created (one for each interview in group one and one for interviews in group two). These show a range of support providers, represented in different colours that carers valued to varying degrees. These are presented in appendices N-Q.

#### **7.4.11. Trustworthiness and quality**

To demonstrate trustworthiness and quality in qualitative research, the four criteria (credibility, dependability, transferability, and confirmability) outlined by Lincoln and Guba (1986) were utilised. These included using an appropriate and well recognised research method and checking sections of coding on 20% of the transcripts with another researcher to ensure consistency of interpretation (credibility); clear documentation of the research process and use of diagrams to provide an in-depth methodological description of the analysis process (dependability, confirmability). Regarding transferability, the themes generated in thematic analysis allow for a contextual understanding of experience, which determines whether findings can be transferred to similar groups and contexts.

NVivo was used to store, organise, and code the data. Memos concerning coding and emerging themes recorded throughout the analysis process. Throughout the analysis, data, codes, and emerging themes were also presented to and discussed with a PhD student group (n= 6) in the AUECR. Comments received were considered alongside the on-going analysis.

#### **7.4.12. Reflexivity**

Reflexivity involves the assessment of a researcher's background, perceptions and interests that influence the qualitative research process (Krefting, 1991). To enhance the credibility of the study it was also important to approach the research reflexively to manage biases and assumptions resulting from my life experiences or interactions with research participants. This involved analysing myself in the context of the research, reflecting on my own characteristics and previous experiences and considering how these may have influenced the interviewing experiences and subsequent data gathering and analysis.

This can be achieved through documenting thoughts in a journal as this allows researchers to describe and interpret their own behaviours and experiences in a research context (Lincoln and Guba, 1985). In addition to memos that were documented throughout the analysis process, notes were made to record personal reflections such as feelings about the interviews. These reflections are considered in the discussion section of this chapter (7.6.3). The following section presents the qualitative interview findings from both groups of carers.

## **7.5. Findings**

Thirty three interviews were conducted. Twenty-two were conducted across three time points in group one (T1= 9; T2= 7; T3= 6) and eleven were conducted in group two. Interviews lasted between 28 and 105 minutes, (mean 60 minutes). All carers spoke English; however, this was not always their first language.

Four stroke survivors were present across interviews in group one, and six were present in group two. In all cases they provided minimal input, especially in group two where the majority had communication difficulties following their strokes. Often stroke survivors were present due to the extent of their disability, as carers were unable to leave them for the time required to participate in the interview. The stroke survivors' contributions to the interviews were considered in the analysis process. However, their input was largely confirmatory about the carers' perceptions of their experiences, rather than a rich insight into their own experiences. For this reason and the importance of remaining focused on the carers' needs, the stroke survivors' accounts have not been captured in the findings that are presented.

In group one, nine needs were identified at T1, eight at T2 and six at T3. In group two, nine needs were identified. Section 7.5.1 outlines needs from the T1 with the barriers and facilitators that carers faced in addressing these needs. In the following section (7.5.2), findings from the second and third interviews are considered together and are compared to the findings outlined at the first interviews. In section 7.5.3 findings from group two are contrasted with findings from group one. Findings from the social network mapping are integrated and discussed where relevant throughout these sections. Anonymised direct quotations have been used where appropriate for illustrative purposes.

The characteristics of carers within each group were varied, summaries of these characteristics are provided before discussing findings within each group.

### **7.5.1. Qualitative Interview analysis T1 (group one)**

This section presents a summary of the characteristics of carers in group one (presented in table 25), then diagrammatical representations of needs, barriers and facilitators, followed by written commentary for each need. Pseudonyms have been used to preserve anonymity.

In the analysis, carers' needs and the barriers and facilitators to addressing needs were explored in carers with different circumstances and varied demographic factors (as

demonstrated in table 25). Compared to group two, the sample of carers in group one is more varied. A range of ages, as well as differences in gender, ethnicities, living circumstances and relationships to the stroke survivor were included. Most carers in this group were providing care to stroke survivors with a range of impairments. Only one stroke survivor (Paddy's partner) had no physical impairments.

As anticipated, there were some variations in experience in accordance with demographic factors. Nahida and Nadia are examples of deviant cases due to their cultural differences that influenced some aspects of their experiences compared to other carers within the sample. Both were both from Asian communities and both lived within a family home where the social support networks were more immediate compared those of other carers. There was also a sense of implicit, culturally determined obligation that they would take on some of or all the caring role alongside other family members. Amanda, aged 42 also provides an example of a deviant case. She articulated her experiences of caring in the context of her age. As evident in the findings that follow, she expressed concerns regarding the lack of psychological support as a younger carer for adjusting to life following her husband's stroke. The change to her relationship with her husband was something she found particularly difficult to come to terms with compared with other carers.

Despite these nuances in how caring was experienced, the analysis did not reveal any substantial differences in the overall needs in group one as a consequence of varied demographic characteristics. The findings that follow indicate that caring is complex and different demographic factors cannot solely account for variations in carers' experiences. Instead, this is influenced by a combination of factors that influence how carers' address their needs.

**Table 25: Characteristics of carers, group one**

<b>Pseudonym</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Relationship to stroke survivor</b>	<b>Time post-stroke of 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> interview in weeks</b>	<b>Time spent caring (following hospital discharge, 2<sup>nd</sup> and 3<sup>rd</sup> interviews) in weeks</b>	<b>Living circumstances</b>	<b>Stroke survivor impairments (initial and ongoing)</b>	<b>Number of interviews</b>	<b>Interviewed alone or with the stroke survivor</b>
Nahida	32	Female	Asian	Daughter caring for father	10 28 45	3 21 28	Living with husband and children, away from family home where father lives.	- Memory loss - Initial speech problems but improving - Weakness in left leg and arm - Emotional following stroke	Three	Alone
Lucy	71	Female	White British	Wife	12 30 47	5 23 40	Living with husband	- Physical problems with arm and leg	Three	Alone

								- No speech or memory problems - Not affected emotionally		
Nadia	46	Female	Asian	Daughter caring for mother	10 28 49	7 25 46	Living with mother and other family members	- Narrowed vision in left eye - Slurred speech initially but improved - Weakness in left arm and leg - Fatigue - Not affected emotionally	Three	With mother
Daisy	66	Female	White British	Sister caring for twin sister	14 31 48	5 22 39	Living with sister	- Weakness in left arm and leg - No memory problems - Vision problems	Three	With sister

Janice	70	Female	White British	Wife	7 26 36	5 24 34	Living with husband	- Balance problems - Memory loss	Three	Alone
Gail	58	Female	White British	Daughter caring for mother (sharing care with sister)	16 38 54	10 32 48	Living with husband, not in same house as mother who has suffered the stroke	- Physical problems with right arm and leg - Speech problems (dysarthria) - No memory loss	Three	Alone (sister who shares care attended second interview)
Paddy	63	Male	White British	Caring for long term partner	3 17	2 16	Living with long term partner	- Memory loss - Aphasia - No physical impairment	Two interviews (unable to contact at third interview)	With partner in first interview
Craig	61	Male	White British	Son caring for mother	10	6	Living with wife and children, not in same house as mother who has suffered the stroke	- Vision problems - Memory loss - Physical problems with legs	One interview (withdrew when mother entered a care home)	With mother
Amanda	42	Female	White	Wife	20	9	Living with	- Physical	One interview	Alone

			British				husband and one dependent adult	impaired including numbness in legs - No speech and memory problems - Cognitive difficulties including spatial awareness	(withdrew due to personal circumstances and stress)	
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**Key:**

- Needs
- Behavioural barriers
- Environmental barriers
- Behavioural facilitators
- Environmental facilitators
- Barrier (not behavioural or environmental)
- Facilitator (not behavioural or environmental)





**Figure 32: Time point one (T1) nine needs identified in carers between three and ten weeks post discharge**

The nine needs outlined in the diagrams above are presented in this section, in the following order:

**Table 26: Carer needs, group one T1**

1) Maintaining relationships, despite changes
2) Seeking explanations to understand the cause and consequences of the stroke
3) Feeling prepared and knowing what to expect before and during the transition from hospital to home
4) Using strategies to ensure stroke survivor safety
5) Continuing meaningful activities
6) Devising strategies for managing practically
7) Devising strategies for coping with the demands of care and changes to life
8) Working towards improvements in the stroke survivors' recovery
9) Obtaining information and support as required

### **7.5.1.1 Maintaining relationships, despite changes**

At T1, most carers did not reflect upon changes in their relationships. However, this theme reflects a need evident in two carers' accounts; to maintain relationships with their husbands, despite changes to either the dynamics of relationships or specific aspects of relationships e.g. social, sexual, and physical. It also identifies factors influencing whether these carers could maintain their previous relationships.

Amanda and Lucy recognised that the stroke had and would continue to impact upon their relationships to varying degrees. They differed in the way they talked about changes. Amanda identified the changes to their social, sexual, physical, and emotional relationship. She also expressed that the changes to her relationship were particularly significant due to being a younger carer. Instead, Lucy discussed the changes to the dynamics of her relationship with her husband, following changes to their roles after the stroke.

In Lucy's case, retaining the emotional aspects of her relationship with her husband facilitated the maintenance of their relationship, despite role changes. She did not mention any support for being able to cope with changes; however, Amanda expected this to be provided:

*“ nobody talked about sex after stroke or physical relationship with your husband after stroke...that's something that you'd work through with a [carer] the physical and emotional aspects of your relationship as a marriage, when you suddenly become a carer” (Amanda).*

Amanda reported feeling alone in maintaining a relationship with her husband, in the absence of professional support for coping with the changes to her relationship. She did

not provide any indication for how she would seek to overcome this difficulty in future in response to little support, therefore this could be considered as a barrier to maintaining their relationship at this stage. These experiences suggest that differing circumstances and perceptions of relationship changes may be may be influential in the initial support that carers may require regarding their changed relationships, however this was not provided for these carers.

#### **7.5.1.2 Seeking explanations to understand the cause and consequences of the stroke**

Carers focussed on understanding the cause and consequences of the stroke and how these would impact on their own and the stroke survivors' lives. This was important for avoiding reoccurrence of stroke and knowing how to manage difficulties e.g. physical, cognitive and speech problems. A need to seek these explanations was often a reaction to limited information provision during the stroke survivors' hospitalisation. This theme highlights some of the factors that influenced whether this need was met.

Paddy was particularly focussed on the cause of his partner's stroke because he wanted to avoid this happening again by reducing any influential factors:

*“If we had an answer, say like if it was stress that caused, you know we would make sure she didn't get stressed” (Paddy).*

A barrier to understanding the causes of her stroke was limited information from staff in hospital, aside from a list of possibilities (e.g. smoking and high cholesterol). Despite Paddy's partner being a smoker, he continued to make alternative suggestions throughout the interview to account for the cause of her stroke e.g. genetic influences. Establishing such alternative explanations facilitated some understanding for him in a way that would remove his partner's responsibility for the cause of the stroke, as did concluding that there is probably no right answer as to why it happened.

Carers also appreciated explanations from staff during the time when the stroke survivor was in hospital to understand the consequences of the stroke. Some carers were provided with this information (e.g. Nadia, Lucy), others were active in approaching staff for this information, particularly when insufficient explanations were provided (e.g. Paddy, Amanda, and Gail). Some carers also actively obtained information from the internet during the time when the stroke survivor was in hospital and when they returned home. All these methods for obtaining information facilitated carers' understandings of the stroke and its consequences.

### 7.5.1.3 Feeling prepared and knowing what to expect before and during the transition from hospital to home

The period before and during the transition from hospital to home was characterised by mixed emotions including relief, happiness, and uncertainty. Most carers described being ill-prepared and unsure what to expect. When carers had expectations, these were not always met in reality once they commenced their caring roles; some carers' roles were less demanding than imagined, yet others were more demanding. Common uncertainties among carers, regardless of their differing characteristics and expectations, included the extent of the stroke survivor's abilities once they returned home, their specific role requirements, and the resultant impact of stroke survivor impairments and caring on the carers' lives. Carers only recognised the importance of initial preparation once they had entered their roles, hence this need to ensure that carers feel prepared and know what to expect before the transition to home and beyond this point.

At T1 carers mostly talked about the preparation for the stroke survivors return home in a practical sense. This included two elements; preparing the home environment and preparing for their required caring duties. Few carers talked about preparing mentally i.e. their thoughts attached to the preparation process. However, Lucy talked about her husband's time in hospital as an opportunity to think about how different her life would be:

*“well he was in hospital seven weeks... that's quite a while, to start thinking this is different and it's all going to be different..” (Lucy).*

In many cases, with guidance from physiotherapists and occupational therapists, carers ensured practical arrangements were in place at home including wheelchairs, ramps for wheelchairs and other physical aids, which allowed them to feel prepared to some extent. As carers were often uncertain about what their role would involve, it was difficult to leave the hospital feeling prepared regarding the requirements of their role. However other barriers to being equipped to take on their role included a lack of skills and knowledge, related to not being provided with the desired information and support.

Gail and her sister were unable to spend time learning practical skills, due to their work commitments, therefore support was limited:

*“They showed us the insulin injection, they said you wind it up, stick it in, count, press it down, count to 10 that was it. That's very useful [laughter]. So we've been shown how to get my mum onto the hospital bed once” (Gail).*

This left them feeling unprepared for aspects of care such as transferring their mother from her wheelchair to her bed. This was not necessarily the fault of the staff; however

other carers were more critical of staff. For example, Amanda criticised staff when she was not provided with adequate knowledge and solutions to overcome some of the practical problems that she expected to face when she returned home e.g. assisting her husband with toileting. Both these carers thought that being able to have home visits to prepare for the return home would be worthwhile.

Although there was a sense that carers were often stepping in to the unknown, some carers benefited from previous experiences of providing care (Gail, Nadia). As Nadia was already caring for her mother she, felt prepared for the role. However, Gail's experiences of providing care to her haemophilic sons were only beneficial for realising broadly what the demands of care could involve rather, than the specific skills that would be required.

#### **7.5.1.4 Using strategies to ensure stroke survivor safety**

All carers were conscious of ensuring stroke survivors were safe, however the reasons for their concerns varied. Many carers were anxious or fearful of the stroke survivor falling, particularly when they had physical difficulties following the stroke, or problems with balance. Others were concerned about stroke survivors with physical difficulties or cognitive impairments coming to harm if they engaged in activities of daily living where they were exposed to risks such as burning themselves. Therefore, carers needed different strategies to ensure the safety of stroke survivors when they were with them and when they could not be present.

Carers could protect the stroke survivors' safety within the home by taking on additional roles. Amanda does all the cooking to protect her husband's safety and the safety of the wider family:

*"I worry about things like him handling chicken because he can't wash his hands properly, and I worry about that, you know, so I take over a) because of the hygiene, I don't want us poorly, and I want to make sure things are properly cooked."* (Amanda)

Carers also maintained close proximity to the stroke survivor to ensure their safety within the home. Some carers spent lengthy amounts of time with stroke survivors (e.g. Paddy, Nadia and Daisy), whereas Nahida and Craig had other commitments e.g. dependent children and work which meant this was not possible. However, they had a heightened awareness of safety for the stroke survivor when they were present.

Carers made changes to their homes e.g. safety alarms and safe keys emergencies when they were unable to be there. This was important for carers' peace of mind, particularly when they were regularly spending long periods of time away from the stroke survivor. Additionally, carers relied on trustworthy others e.g. family and friends to spend time with

the stroke survivor when they didn't want to leave the stroke survivor or they were out for a more significant length of time than normal:

*“Last Saturday I went to the theatre but it was a matinee... So it was longer than I would have left him so my friend's husband came and stayed with him, not all the time, just for a couple of hours in the middle” (Lucy).*

Other carers were more comfortable leaving the stroke survivor alone, without relying on support. However, they were reluctant to leave the stroke survivor for long time and went out locally so they could be contacted if necessary. These outings were also for more purposeful activities, rather than activities of enjoyment. On these occasions, carers also ensured additional strategies were in place e.g. leaving the stroke survivor with a phone in case they needed to make contact. However, this was only possible in cases where stroke survivors could communicate with the carer.

#### **7.5.1.5 Continuing meaningful activities**

The importance that carers placed on engaging in meaningful activities either with or without the stroke survivor was varied. In some cases, carers did not talk about their own activities, yet in other cases these had been and were an important part of their lives for various reasons e.g. independence or enjoyment, and a break from caring. Joint activities with the stroke survivor were important for those who engaged in activities together prior to the stroke. The barriers and facilitators to being able to continue meaningful activities differed for their own activities in comparison with joint activities with the stroke survivor. These are therefore discussed in turn.

The demands of the caring role and carers' reluctance to leave the stroke survivor alone were examples of barriers to being able to engage in their own activities away from the stroke survivor. This reflects findings from the previous theme, because carers were more comfortable leaving stroke survivors when activities were brief and purposeful rather than for their own enjoyment.

The loss of activities affected carers in different ways; this could be due to the meaning that they placed on these activities and their perceived permanence of this loss. Janice had set aside her volunteering; however, she was hoping to return to this activity at some stage. However, Amanda became tearful about the changes to her activities:

*“And my independence now, we'd just got to the point with the children being older that I could go away for weekends with friends and I tended to have a holiday away with my daughter [sounds upset] but I don't think Graham is going to be well enough to leave overnight.” (Amanda)*

This quote suggests that her independence was the meaningful aspect of this activity and this has been lost to a point where she cannot foresee that she will be able to continue with this activity in future.

Interestingly, activities became important for Gail and her sister *after* their mother's stroke for gaining respite from their shared caring roles. However, their mother was reluctant to accept respite care, limiting time for such activities to once a month:

*"I only go out once a month with my sister and we've only started that since mum had the stroke because I think we both need just that little bit of time away."* (Gail)

Re-engagement in joint activities with the stroke survivor was important for Lucy and Daisy. They had both started this re-engagement and hoped it could continue in future. They made plans for future activities to facilitate these hopes. However, the stroke survivors were using wheelchairs, limiting activities to environments with wheelchair access. Overcoming this barrier involved pre-planning activities and allowing extra time to set up facilities:

*"I've got to allow sort of quarter of an hour extra to set the ramp up and take it away. But he can get into the car okay."* (Lucy)

Therefore, despite some barriers, carers could still engage in some activities with the stroke survivor.

#### **7.5.1.6 Devising strategies for managing practically**

Once stroke survivors returned home from hospital, caring required practical management, in some cases around other priorities e.g. dependent children and work. This included continuing to ensure that the home was set up appropriately, supporting the stroke survivor in various aspects of care e.g. managing medication, providing encouragement, and assisting with activities of daily living. Regardless of their characteristics and differing circumstances, carers needed to find ways to manage, in some cases with the support from others, and in other cases on their own.

Many carers relied on both formal and informal support for managing. Gail and Craig benefitted from paid carers to assist with care for their mothers, due to their own working commitments; other carers had informal support from neighbours, family members and friends. Neighbours and friends often assisted with taking the stroke survivor out. Family members provided this support in addition to assisting with practical care, and monitoring the stroke survivors. Some carers benefitted from knowing that support was available from professionals, family, and friends even if this was not consistently needed. This is



reflected in the social networking map at T1 (appendix N) as many carers valued a variety of different support providers. The following quote provides an example of Nadia's experiences:

*"She [specialist stroke nurse] gave a number in case we need to contact somebody. If there are any concerns or anything at least I know that there is somebody there."*  
(Nadia)

Other carers experienced difficulties with support where this was either lacking or expensive. Carers developed behavioural strategies that facilitated how they managed in their roles. Developing a new routine was common for many carers, regardless of the extent of their care requirements to provide order and make care less difficult:

*"Yeah, it was harder than I thought at the beginning, but now we've got into a routine it's not as bad now is it?"* (Daisy)

Learning through trial and error was also common in cases where carers were providing practical care to the stroke survivor. As documented in the theme around preparing for home, carers were often left with little knowledge and skills for the practical demands of their caring role, therefore this approach allowed them to develop skills and knowledge as situations occurred. Other strategies included '*getting on with things*' engaging in role changes, juggling care with other commitments, and actively seeking solutions to problems where support was unavailable.

#### **7.5.1.7 Devising strategies for coping with the demands of care and changes to life**

At T1, following the transition from hospital to home, carers' general role requirements were clearer, yet carers were often still realising the extent of the stroke survivors' abilities. Carers acknowledged their changed lives, yet their futures often remained uncertain and difficult to comprehend. Carers were faced with providing care and its demands, as well as the changes to their lives following the stroke. They needed ways of coping with these two aspects, hence the importance of this as a need.

Carers experienced emotions attached to the demands of providing care. Lucy experienced initial fears and anxieties about her abilities to manage when her husband returned home. Daisy also lacked confidence in her abilities to manage initially. Lucy's feelings passed when she found she could manage the demands of care. Daisy hoped that she would be able to manage, however she experienced feelings of being '*depressed*' when things got on top of her initially. She called upon one of the friends for informal support, this facilitated coping with providing care to her sister.

*“I got a bit depressed at the start, it got a bit on top of me and that’s why I phoned that Shirley, ‘cos she said, “If ever it gets,” when she come off holiday, “just ring me,” I thought I’m going to ring her.” (Daisy)*

The value of initial support for coping with the demands of caring is also reflected in Amanda’s early experiences. She faced low moments when professional support from the ESD team was not around at the weekends, although she noticed that with time she was getting better in terms of coping in this respect. This type of support did not remain an ongoing need for Amanda, however she did emphasise the lack of psychological support for coping with the changes to her life following the stroke, rather than the demands of caring. She thought that nurses lacked positivity and they did not discuss coming to terms with a sudden onset of a disability and the sudden changes to life that this brings.

As a younger carer, she emphasised the changes to their social life, working situations and their relationship. Amanda emphasised the need for psychological support for coming to terms with her changed life more than other carers. Her friends also lacked understanding; therefore, she had limited formal and informal support for coming to terms with the changes to her life. She proactively overcame these difficulties by maintaining contact with carers that she met whilst her husband was in hospital, and searching websites for younger carers in a quest for some hope and positivity. These were things she would recommend to others:

*“Make contact with people who are in a similar situation. Do try and look at, you know, positive things that are happening, I started writing things down even though it was hard to see how things are changing, because it’s still, it is hard to stay positive, it’s really hard...just look at the good news stories” (Amanda).*

Amanda’s experiences of drawing upon different types of support in the absence of others to meet her varying needs demonstrates the complexities of coping with and adjusting to caring experience at this stage. The social networking map (T1) (appendix N) highlights the importance of carers having the opportunities to draw on different types of support, depending on their circumstances and needs.

There were also other strategies that were identified across the interviews that allowed carers in diverse circumstances to cope with such change. Paddy, Gail, Nadia, and Janice approached caring for the stroke survivor by ‘taking each day as it comes’ to manage the immediate caring situation and the uncertainties attached to their changed lives by avoiding thinking about an unpredictable future:

*“Just to go one day at a time and don’t think too far ahead because I think that’s the worst thing you can do because you don’t know what to expect.” (Janice)*

Maintaining some hope was also important for other carers at this point, given that the extent of change was unknown.

Although looking to the future was difficult in some cases, acknowledging change and realising that things would be different facilitated coping with the changes to life for some of the carers. Whilst being able to foresee changes was common, acceptance of changes at this stage was less common; interestingly only Lucy talked about this. She felt she had to do this, otherwise *'that's the way to rack and ruin.'* The seven weeks whilst her husband was in hospital allowed her to see that life was changing for them both. This facilitated her acceptance of the situation. Other carers (e.g. Janice and Gail) were grateful that the stroke survivor was alive and they acknowledged that things could have been worse.

#### **7.5.1.8 Working towards improvements in the stroke survivors' recovery**

The scope for improvements in the stroke survivor remained uncertain for carers, the stroke survivor, and professionals at this stage; however, carers were still focused on this aspect of the stroke survivor's recovery. Improvements were often acknowledged by carers in the context of what the stroke survivor could do particularly physical improvements. Carers recognised recovery in the context of meaningful activities and activities of daily living.

Carers attached different meanings to the stroke survivor being able to do more and improvements were important for different reasons. Gail, Amanda and Nahida valued the independence that the stroke survivor would gain from improving physically. These carers perceived the stroke survivor to be independent prior to the stroke so it remained important to maintain this to some extent.

*"I think just, , we think he will improve, he will become more independent because he's not one of those people, he doesn't like relying on others, he just doesn't, he wants to be able to do it all himself."* (Nahida)

Alternatively, Lucy and Janice wanted their husbands to improve to regain some normality. For both carers, normality meant being able to do what they want including things that they enjoy as a couple. Lucy felt she and her husband were already working towards being a *"normal couple,"* as they could do more. However, Janice still hoped for some normality, depending on her husband's recovery:

*"Well I'm hoping that things will be slightly more normal, that all depends on how Mike gets on obviously but life is easier now than it was six weeks ago, so..."* (Janice).

Other carers commonly expressed hope about seeing general improvements, and being able to do activities with the stroke survivor. This was the case where the stroke survivors were physically affected and also in Paddy's case, where his partner had memory problems following her stroke:

*“Well hopefully Mavis is better than what she is. Maybe not a 100% but I suppose nobody knows if her memory is gonna come back or not.”* (Paddy)

Hopefulness was important for carers for managing the unpredictability and uncertainty around different aspects of the stroke survivors' recovery. Although the extent to which the stroke survivors would improve remained uncertain, some carers recognised improvements in the stroke survivors' physical recovery since they returned home, and attributed these to the continued support from the physiotherapy team. Many carers valued this support, as indicated on the social networking map (T1) (appendix N). The following quote from Lucy provides an example:

*“...they've brought him on, they've improved him so much. I thought that he'd be just laid in a bed permanently.”* (Lucy)

Some carers were also keen to work towards improvements aside from allocated physiotherapy sessions, and actively encouraged the stroke survivor with their physical recovery, based on guidance from the physiotherapy team. This allowed the carers to feel as though they were doing what they could for the stroke survivor, despite uncertainties.

#### **7.5.1.9 Obtaining support and information as required**

Evidently support and information were important for addressing the eight different needs. Different types of support, both formal and informal, were valued for different purposes. This is also reflected in the social networking map (T1) (appendix N) as carers often regarded more than one type of support as highly important. For carers, being able to obtain support and information as required remained an important 'need.' The factors that influenced whether carers could obtain information and support in accordance with their needs are considered below.

Barriers and facilitators to obtaining support and information varied. For some needs e.g. understanding the cause and consequences of the stroke, preparing for home, and coping with care, changes to life and relationships, carers expected professionals to provide support and information during the stroke survivors' stay in hospital, however this need was not always met.

Barriers included a lack of support as part of service provision, and a lack of (staff) time to provide support and information to prepare carers for the return home. Furthermore, even when carers gained information, often more was required to fulfil their different needs. Nahida's account reflects her need for more information regarding her father's recovery:

*"I think we would have preferred more information but I think even in terms of his situation we had to keep asking them, you know "how long do you think it's going to be before he comes home?" or "how much longer before he improves?" and they basically said "as he improves then we'll know." (Nahida)*

Being active in obtaining required support and information facilitated this need e.g. approaching staff, using the internet, or alternatively drawing upon other sources of support e.g. friends, peers. Amanda for example took a resourceful approach to finding the support and information that she needed that was appropriate for her age and circumstances:

*"Well I'm quite resourceful because of the job that I do and you know, in terms of self-help, I came away and Googled a lot of things, so like different strokes, which support group for younger stroke survivors, nobody told me about that, I found it myself." (Amanda)*

However, resourcefulness is dependent on being aware of the types of support that are available, or being prepared to look for them independently. Amanda benefited from knowledge as a nurse, however Paddy was uncertain about where to go to access support in the future.

In addition to formal support, having informal support networks to draw upon as required was beneficial to carers for addressing emotional and practical needs. Barriers to this type of support included a lack of understanding from friends about the situation and reluctance to approach friends and family for support. Amanda found it much easier to accept support from her friends when this was offered:

*"I've found that and my friends say, you know, "If there's anything we can do just ask", well you don't ask, you don't ask. The biggest help was somebody ringing saying "I'm coming round and I'm going to wash the cars." (Amanda)*

Being open to seeking support as required would also be beneficial where support networks are available, if this is not offered.

Proximity of family and friends was also influential in the amount and type of support that was provided to some of the carers. Nahida and Nadia had very immediate support networks within their family homes that they could draw upon for support. Others had

friends and family close by. However, distance can be considered as a barrier to some support from family and friends, however some carers still considered them as supportive, Janice provides an example:

*“You know, friends and family who live away and support you in as much as they phone up a lot whereas they can't always visit.” (Janice)*

This again identifies the importance of having different support for different needs.

### **7.5.2. Qualitative Interview analysis T2 and T3 (group one)**

Many needs remained broadly similar over time and others were no longer apparent as time progressed e.g. maintaining relationships, despite changes. This may be because this theme was relevant to only Amanda and Lucy at T1, however Amanda withdrew before the second interview and Lucy did not talk about this in later interviews. Whilst it did not remain a need in the case of these carers, this could be a continuing need for other carers after stroke based on findings presented in chapter six. Barriers and facilitators to addressing needs changed to some extent over time. The diagrams below outline eight needs identified across T2, then six needs across T3. Diagrams include barriers and facilitators to addressing needs.

Figure 33: Time point two (T2) eight needs identified in carers between 21 and 38 weeks post discharge

Key:

- Needs
- Behavioural barriers
- Environmental barriers
- Behavioural facilitators
- Environmental facilitators
- Barrier (not behavioural or environmental)
- Facilitator (not behavioural or environmental)



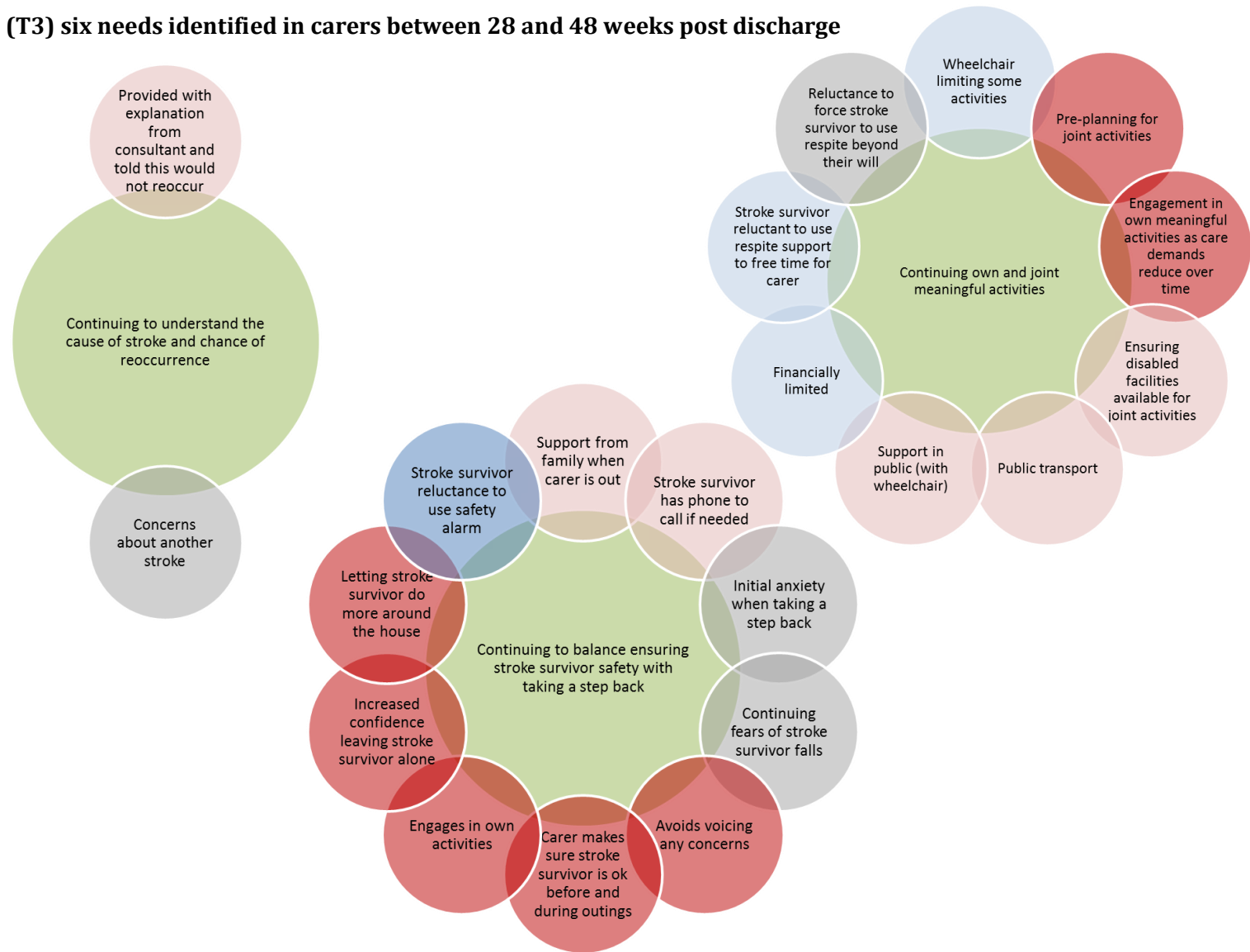




**Figure 34: Time point three (T3) six needs identified in carers between 28 and 48 weeks post discharge**

**Key:**

- Needs
- Behavioural barriers
- Environmental barriers
- Behavioural facilitators
- Environmental facilitators
  
- Barrier (not behavioural or environmental)
- Facilitator (not behavioural or environmental)





Eight needs were identified at T2, six of which were still evident at T3. These time points are discussed together here and compared with T1. The table below outlines the needs discussed in this section. Those that were no longer evident at T3 are written in bold text.

**Table 27: Carer needs, group one, T2 and T3**

1) making sense of the stroke, its consequences and chance of reoccurrence
2) <b>reassurance about caring abilities</b>
3) balancing ensuring stroke survivor safety with taking a step back
4) continuing own and joint activities, often beyond expectations
5) continuing to develop and use strategies for managing practically
6) continuing to develop and use strategies for coping with a changed situation
7) <b>importance of physical improvements and developing independence in the stroke survivor</b>
8) continuing to develop strategies for obtaining information and support as required

#### **7.5.2.1 Making sense of the stroke, its consequences and chance of reoccurrence (continuing need at T3).**

At T1, some carers were *'seeking explanations to understand the cause and consequences of the stroke.'* By time points two and three, fewer carers focused on this; however, making sense of the stroke and its consequences and the likelihood of reoccurrence was still important for some carers.

By T2, Paddy was less concerned about seeking explanations for the cause of his partner's stroke. His thinking was similar to some of the other carers at T1 as he was focused on the impacts and consequences of stroke. Interestingly, Daisy only recognised the lack of information about stroke and its cause at T2 when she thought it would be beneficial to know if her sister was at risk of having another stroke. Daisy sought information from books as to make sense of the stroke. Alternatively, Paddy developed his own understandings around the impacts of his partner's stroke as a result of the support from the Speech and Language Therapy team ending:

*"I put it like when you're using your mobile phone and texting if the word's not in your dictionary; you've got to type it in properly."* (Paddy)

Paddy was unable to take part at T3; therefore his experiences were not captured. Daisy remained concerned about her sister having another stroke:

*"I know she's had the tablets but you wonder will she have another one, he said you wouldn't didn't he, Dr X. So you wouldn't have another stroke"* (Daisy)

Her concerns were addressed through a consultation with a consultant who reassured her that the stroke would not reoccur.

### **7.5.2.2 Reassurance about caring abilities**

At time point one, carers focussed on *'feeling prepared and knowing what to expect before and during the transition from hospital to home'*. By T2, some carers needed reassurance about their caring abilities. Whilst this was not a need for all carers, it remains important because it reflects the perceived lack of support and guidance for preparing for caring following the transitional period from hospital to home. It also indicates how feeling unprepared can impact upon how carers feel about their caring abilities as they continue in their roles.

At T2, carers reflected on their situations and Gail reiterated the importance of having initial guidance. She and her sister had managed the care at this stage, but questioned whether they were providing care as they should:

*"Yeah, and are we doing it right? We don't know."* (Gail)

Daisy was also left in a situation of uncertainty at time point two; however, she hoped that she was doing things as she should for her sister because there was nothing more that she could be doing.

*"And it's a lot me for to take on too, I think, well I hope I'm doing enough and there's nought more I could be doing."* (Daisy)

Daisy also shifted towards recognising her own needs as a carer and the lack of support that she'd had for herself:

*"...they look in on you and say, "are you alright?", when she first had her stroke, but then it wears off and then they don't bother any more."* (Daisy)

Interestingly at the third time point, carers no longer needed reassurance in providing care; therefore this was not captured as a need.

### **7.5.2.3 Balancing ensuring stroke survivor safety with taking a step back (continuing need at T3)**

In the initial interviews, carers focused on *'using strategies to ensure stroke survivor safety'* within and away from the home. This remained important for carers across time points, however, carers progressed towards *'taking a step back'* whilst continuing to be aware of protecting the stroke survivor from falls, that could potentially lead to setbacks. Taking a

step back involved letting go of some of the jobs around the house that were initially taken on to protect the stroke survivors' safety, and letting themselves be away from the stroke survivor beyond the home. Regardless of the extent of improvements, at all three time points carers were still conscious of balancing this with ensuring strategies were in place to protect the stroke survivors' safety to the best of their abilities. This reduced their anxieties to some extent about the stroke survivor coming to any harm.

Across the three interviews, many strategies remained similar e.g. maintaining close proximity to stroke survivor, safety measures e.g. alarms and safety keys, support from family and friends. At T2, Daisy and Janice provided new examples of strategies to ensure stroke survivor safety in their absence e.g. making sure that the stroke survivors had eaten or been to the toilet before leaving them, to reduce the chances of them needing to move around the home in an attempt to reduce the risk of falls.

By the second interview Janice had re-engaged in her own volunteering activities again and the time spent there increased by the third interview, due to being less fearful about her husband's safety:

*"I was just doing nine 'til one, well half twelve really and I've only upped it this last couple of weeks really."* (Janice)

**That's good. So what sort of changed? (Interviewer)**

*"...I don't worry so much."* (Janice)

This is an interesting contrast in comparison with the initial interviews, given that carers often limited time away from the stroke survivors to more purposeful tasks.

#### **7.5.2.4 Continuing own and joint meaningful activities, often beyond expectations (continuing need at T3)**

Over time carers continued to value their own and joint meaningful activities. At T1, there was a greater sense of loss attached to the carers' own activities, due to being reluctant to leave the stroke survivor alone, or being too busy with the demands of the caring role. At T2 some carers were re-engaging in some of their own activities e.g. Janice and Paddy. Family support facilitated some of this activity for Paddy and being less fearful facilitated this for Janice (as outlined in the previous theme).

Over the three interviews, Lucy and Daisy continued to engage in joint activities with the stroke survivor. Lucy recognised that they could do things beyond what she expected by

T2, as part of making plans for a normal life e.g. attending events that they had previously enjoyed:

*“And we're able to do things that we couldn't do before... 'cos I was quite negative really, and there were a lot of things that I thought we'd never be able to do again but we can.” (Lucy)*

Daisy recognised that she and her sister could do things as part of activities beyond their expectations by T3 e.g. going on a train together.

Over time, these carers faced the same limitations with regards to wheelchair access, yet pre-planning their activities helped to overcome this barrier. Lucy and her husband had fitted a hoist in the car following the first interview, which facilitated future outings together. Making use of public transport also enabled Daisy and her sister to visit more places over time. By T3, Daisy and her sister gained support from people in public who offered them practical assistance.

Gail and her sister continued to be limited in activities over time, due to their mother's reluctance to use respite care and their own reluctance to place their mother in to respite against her will. Financial difficulties also contributed to the barriers that they faced in doing their own activities away from caring, therefore, at T2 and 3, their time away from caring was limited.

#### **7.5.2.5 Continuing to develop and use strategies for managing practically (continuing need at T3)**

As the carers continued in their roles, the practical demands remained to varying degrees. Over time there were differences in how carers perceived their roles, some carers felt that their role had become easier over time, whilst other carers recognised the continued physical strain attached to caring. Whilst carers' perceptions of their roles often changed over time, the need for developing and using strategies for managing remained.

Family, friends, and neighbours continued to be a reliable source of support for many carers. For some, e.g. Nadia and Nahida, this was more consistently required; however others e.g. Janice and Lucy called upon this when it was needed. Daisy fluctuated in how she experienced caring as at T2 she expressed the burden associated with supporting her sister and also recognised a reduction in formal and informal support, leading to feelings of isolation:

*“I'm not bothered about doing it all for her, I look after you and you help me, but you do feel a bit isolated then.” (Daisy)*

This is reflected in the social networking map (T2) (appendix O), as she felt let down by family and friends. However this was less problematic by the third interview, consistent with the perception that her role had become easier over time because she was not getting up in the night as much with her sister. Interestingly, no carers expressed being let down by any support network members by T3 (appendix P).

Ensuring practical arrangements were in place around the home in accordance with the stroke survivors physical needs continued to be important for many carers. Being financially fortunate facilitated whether this was possible in some cases. Furthermore, many of the behavioural strategies that the carers previously developed that facilitated how they managed in their roles also remained over time.

#### **7.5.2.6 Continuing to develop and use strategies for coping with a changed situation (continuing need at T3)**

As carers continued in their roles over time, they needed ways of coping with the demands of care, as well as the changes to their lives. Although the need remained the same, the factors that influenced whether this was addressed varied slightly across time. As highlighted above, perceptions of their roles also changed, as did their outlook on their situations.

Carers continued to experience emotions attached to the demands of providing care; however, feelings of anxiety about abilities to cope diminished over time. As highlighted above, Daisy's experience of caring fluctuated in her emotions over time and she became isolated by the second interview. These feelings of isolation were made worse for Daisy by the reduction of support from one of her close friends. There was an expectation that her friend should be there to provide support, yet she was reluctant to approach her for support, despite needing this.

Interestingly this experience did not compare with other carers and by time point three, carers did not identify any barriers to being able to cope. In some cases, where required, carers benefitted from support from family and friends (Janice, Nadia and Nahida) and in other cases carers coped through continuing to develop strategies and changing their outlook on the situation. Carers continued to use the 'taking each day as it comes' strategy across all time points. New strategies for coping were also apparent at T3 time e.g. patience, avoiding worrying about other things and adopting a more 'easy going' approach towards the situation. These approaches allowed Daisy and Janice to concentrate on supporting their loved ones, without worrying about other concerns in their lives:

*“I don’t worry quite as much about other things and my main concern is sort of us at the moment.” (Janice)*

Over time there were some differences in how the carers reflected on their situations in terms of acknowledgement, realisation and acceptance of changes. Previously, only Lucy had reportedly reached a point of acceptance about the changes to her life. She made a conscious decision to do this as part of avoiding the way to ‘*rack and ruin.*’

Carers at T2 and T3 (e.g. Janice, Gail and Nahida) talked about acceptance relating to different aspects of their experience including care requirements, their changed situation, and the stroke survivors’ abilities. Given the diversity of these carers’ experiences in relation to their age, ethnicity, and relationship to the stroke survivor, reaching acceptance did not appear to be associated with particular characteristics or circumstances for this group. The following is an example of Nahida accepting what her father would be able to do in future (T3):

*“Especially if it’s been this long you just need to sort of accept what’s happened and accept that, you know, there will be some things that they won’t be able to do and just be grateful for at least the progress that they have made” (Nahida).*

Expressions of gratefulness remained for carers. They also continued to compare themselves to others as a way of acknowledging that there are others ‘*worse off*’ than themselves. Gail felt grateful in terms of what her mother was still able to do and Daisy felt lucky that her sister had all her ‘*brain faculties.*’ By T3, carers reflected on their situations and realised what they do have, despite the changes to their lives following the stroke. Interestingly, the carers who faced more struggles than others over time (e.g. Daisy and Gail) still remained positive. This outlook is not limited to carers who had an easier experience. This highlights that although the caring situation may not change greatly over time, carers’ outlook can change and lead to effective coping strategies.

#### **7.5.2.7 Importance of physical improvements and developing independence in the stroke survivor**

The likelihood of physical improvements remained uncertain for carers at T2, yet the focus on improvements remained. Carers also continued to acknowledge improvements in the context of meaningful activities and activities of daily living. Previously, carers talked about the importance of independence and normality because of the stroke survivor being able to do more; this also continued.



Independence was conceptualised as the stroke survivor being able to carry out some of the tasks of daily living that they engaged in prior to their stroke e.g. eating alone, making a cup of coffee. However, the reasons why independence was important for carers varied. Gail placed value on her mother becoming more independent because she was an independent woman prior to the stroke. Nahida also talked about the family being happier that her father had become closer to what he used to be, however she also talked about the importance of his increasing independence for making things easier for them in terms of providing care (particularly for her mother as his main carer):

*“...being more independent, being more mobile, it just sort of eased, it just made things easier for us I think, and especially like things like him being able to eat, himself, so it does help that she can just make him the food and leave it and he can eat.”* (Nahida)

These accounts reflect the contrasting perspectives of carers regarding the value placed on becoming independent due to improving physically.

At T3 some carers were still hopeful that the stroke survivor would improve but they acknowledged that things could take time and that the stroke survivor would be more limited, despite attempts to regain some normality and engage in tasks from prior to the stroke. Some carers reached a point where they either saw a lack of improvement in the stroke survivor (Gail), or some physical regression in the recovery (Nadia) and became less focused on independence. Over time Gail could see that her mother was not interested in making attempts to strive towards independence, therefore she took a more relaxed approach to the situation:

*“The bottom line is mum’s not going to live forever and if her last years are what she wants to do and making her happy...”* (Gail)

Here Gail reflected on the importance of her mother being happy rather than striving towards her being the independent woman she was prior to her stroke.

#### **7.5.2.8 Continuing to develop strategies for obtaining information and support as required (continuing need at T3)**

It remained evident that support and information are important for addressing different needs among carers over time. This is reflected in the social networking maps across the time points (T1- T3) (appendices N-P). These also demonstrate changes in the support (including information) that carers valued over time. Some support diminished over time because this was only provided for a limited time (Early Supported Discharge), and some was no longer required once a need was fulfilled (support from charities such as Age UK for addressing financial concerns). Carers consistently valued support from family and

friends for addressing many of their needs, as reflected across the social networking maps (appendices N-P). Strategies for obtaining information and support as required remained important, particularly as both the provision of support and information and needs relating to support and information changed over time.

At T2 and 3, some carers still required information about the likelihood of the stroke reoccurring and available support services. Support was required across a wider range of needs, many of which were consistent with those outlined at T1. As time progressed, the key difference was that carers were no longer preparing for their role, therefore support needs in this respect changed. Carers became more concerned about gaining reassurance about their abilities to provide care once they were engaged in their role.

As carers returned to the community, they continued to expect certain types of support that could be provided by professionals. Examples included some support for themselves as a carer to see how they were managing and follow up support for the stroke survivor.

Daisy's account of her experiences provides an example:

*“You know, I don't know what the doctor could do but I'd have thought he could have just come and seen you were alright, or just said, “we'll give you a little mini medical, you know, blood pressure, weight and blood, and test it, but they don't, he hasn't bothered.” (Daisy)*

Being active in obtaining the required support or information remained a facilitator for carers over time. However, as previously, being active was dependent on having some knowledge about where to seek information and support, particularly in cases where they would like formal support or information from professionals. At T2, carers provided examples of how they would go about obtaining the required support or information if a problem arose. Lucy suggested returning to the hospital if necessary or making use of the internet. Nadia, Paddy, and Gail knew that they could call upon the GP or district nurses if required. Carers continued to use such strategies at T3 where necessary. Carers were familiar with these sources of support from their time spent in hospital and contacted them when they needed help to support the stroke survivor, rather than support for their own needs.

Carers were either unaware that support for themselves exists, or unaware where to obtain this support, an example is provided by Janice:

*“Carers, on a Tuesday morning apparently, yeah. Now how long it's been going I'm not sure but just happened to take [husband] up there for something and it was on the screen, but I thought 'well I wish I'd known about that six months, eight months ago.’” (Janice)*

Janice had already 'got through it' by the time she became aware of the support but thought it could have been beneficial earlier on. It is important to inform carers about supports at an earlier stage so they can make choices about its use.

Carers also continued to benefit from having informal support networks to meet their differing needs. Family, friends and in some cases neighbours, remained a key source of practical and emotional support for many carers as part of managing and coping with different aspects of care. However, this support also reduced over time for some carers e.g. Daisy felt let down by both her family and friends, particularly at T2.

Overall, there was a lack of consistency in the attempts provide carers with information following the stroke. The findings across the interviews indicate that it would be beneficial for carers to be informed about where they could obtain support and information as required, given that their needs change to some extent over time.

### **7.5.3. Qualitative Interview analysis (group two, 9-36 months post stroke)**

This group provided a different perspective from some of those carers that participated in the interviews carried out over time. Conducting interviews later in the caring trajectory meant that carers could provide a reflective account of their experiences. The analysis and development of themes proceeded in the same way as group one.

This section starts table 28 outlining carer characteristics in group two. Then the nine needs identified are outlined in diagrams with the barriers and facilitators to addressing these needs. Written commentary to support each of the needs is provided following the diagrams.

As was the case in group one, carers' needs and the barriers and facilitators to addressing needs were explored in carers in different circumstances. Compared to group one, the sample of carers in group two was less diverse, which may partly account for fewer variations across their experiences. All carers were in spousal relationships, their average age was higher, and many were caring for stroke survivors with significant physical and communication impairments.

Despite the overall similarity in carers' circumstances in this group, Paula's experiences regarding time spent caring were different from other carers. Although she was recruited into the study based on the time since her husband's most recent stroke, she had actually been caring for 21 years since his first stroke. She is therefore considered as a deviant

case. She was experiencing a heightened sense of strain over a prolonged period and there was a sense of loss attached to her own life. Interestingly some aspects of her experience still resonated with carers who had been caring for less time. For example, Molly shared the feelings of resentment towards the stroke survivor.

As was the case in the group one analyses, these nuances in carers' experiences did not have a substantial impact on the overall needs identified. It was difficult to separate demographic characteristics from the range of other complex factors that contributed to how carers addressed their varied needs.

**Table 28: Characteristics of carers in group two**

Name	Age	Gender	Ethnicity	Relationship to stroke survivor	Time post stroke at the point of interview	Time spent caring (months)	Person carers is residing with	Stroke survivor impairments (initial and ongoing)	Interviewed alone or with the stroke survivor
Kate	56	Female	White British	Wife	24 months	21	Husband	- Continued speech problems - Physical impairments in arms and legs (Wheelchair user) - Emotionally affected	Alone
Paula	63	Female	White British	Wife	29 months (most recent stroke)	Caring for 21 years since husbands first stroke	Husband	- Unable to speak - Some but little understanding - Physical impairments (Wheelchair user)	With husband
Julie	82	Female	White British	Wife	9 months	Approx. 8 (unclear how long stroke survivor was in hospital).	Husband	- Speech problems (agitation due to speech problems) - Unable to write - Some memory loss - Mobile, able to go out walking locally alone - Fatigue	Alone
Dorothy	75	Female	White British	Wife	36 months	Unclear how long stroke survivor spent in	Husband	- Initial speech loss and continued problems e.g. slurred speech (Frustration through being unable to do things)	With husband

						hospital		- Difficultly writing - Physical impairments	
Jack	79	Male	White British	Husband	28 months	25	Wife	- Physical impairments (right side) - Cannot read more than a few lines - Communication problems - Some emotional impacts, feeling low	Alone
Molly	76	Female	White British	Wife	24 months	Approx. 24/25 (unclear how long stroke survivor was in hospital).	Husband	- Change to personality - Some initial emotional impact - Some memory problems - Left sided weakness	Alone
Gabby	66	Female	White British	Wife	36 months	32	Husband	- Epilepsy -Physical impairments (uses wheelchair) - Communication difficulties (frustration) - Cognitive problems	With husband
Betty	77	Female	White British	Wife	22 months	Unclear how long stroke survivor spent in hospital	Husband	- Initial slurred speech but improved - Cognitive problems including some memory loss - Change to personality- some aggressiveness	With husband
Phil	54	Male	White	Caring for	23	Approx.	Long term partner	- Ongoing communication	With partner

			British	long term partner	months	23/24 (unclear how long stroke survivor was in hospital).		problems, can communicate through writing unable to speak - Some cognitive impairments	
Marigold	84	Female	White British	Wife	13 months	Just under 13	Husband	- Slight weakness in arm - Some memory loss - No physical impairments	With husband
Tony	74	Male	White British	Husband	24 months	Approx. 24/25 (unclear how long stroke survivor was in hospital).	Wife	- Initial speech problems but improved with time - Weakness in leg and arms - Initial emotional impacts	Alone

Figure 35: Group two, nine needs identified

Key:

- Needs
- Behavioural barriers
- Environmental barriers
- Behavioural facilitators
- Environmental facilitators

- Barrier (not behavioural or environmental)
- Facilitator (not behavioural or environmental)







The nine needs outlined in the diagrams above are presented in this section, in the following order:

**Table 29: Carer needs, group two**

1) Coping with a changed partner
2) Overcoming concerns about another stroke
3) Feeling prepared and knowing what to expect during and following the transition from hospital to home
4) Balancing time to self with protecting stroke survivor safety
5) Continuing joint meaningful activities
6) Developing and continuing to use strategies for managing practically
7) Developing and using strategies for coping
8) Managing communication difficulties with the stroke survivor
9) Sustaining a flexible support network to be able to obtain appropriate support and information in accordance with needs

### 7.5.3.1 Coping with a changed partner

Some carers focused on the changes in their partners following the stroke including: changes to their personalities, temperament, and their abilities to concentrate and engage in conversation. This theme reflects some of the emotions and challenges associated with coping with a changed partner and examples of how carers managed these challenges, without specific reference to their overall relationships. This contrast with two carers in group one, as they focused the need to maintain relationships, despite changes to the stroke survivor as a result of the stroke (emotional and physical).

In this group changes to their partners as a result of the stroke left some carers feeling isolated, unappreciated, and uncertain about how to manage changes. Some carers (e.g. Molly and Paula) also perceived their husband as selfish; due to the loss of their previous social and occupational lives now they had become a carer:

*“Sometimes I get the feeling that he thinks there’s only him in the world kind of thing.”*  
(Paula)

These feelings differed from the experiences of carers in group one, where carers were less focussed on the losses to their own lives and more focused on overcoming difficulties in their relationships and working towards managing those.

Carers provided some examples of strategies that they used to manage the changes in their husbands in different contexts. Betty focused on managing her husband’s anger, this involved withdrawing from the situation or providing some distraction:

*“...If I could see it brewing, try to get him involved in something else, you know...”*  
(Betty).

Molly talked about managing her husband in the context of social situations, as her husband was often rude to others due to the changes in his personality following the stroke. She encouraged others to take no notice of him and makes them aware that he has had the stroke.

### **7.5.3.2 Overcoming concerns about another stroke**

Four of eleven carers mentioned either the reoccurrence of stroke, or the cause of stroke. This theme attends to the need for carers to overcome concerns about another stroke as time progresses. The meaning attached to these concerns is also highlighted within as well as examples of factors that influenced whether carers overcame their concerns over time.

Both Julie and Tony talked about the chance of the stroke happening again in a matter of fact manner, Julie became less concerned about this over time because it was difficult to live with continued worries in the longer-term:

*“The worry about that isn’t there from that point of view because I think well if it happens, it happens.”* (Julie)

**Yes, so you’ve perhaps changed the way you think about that? (Interviewer)**

*“Yeah, well it has to, it’s bound to, you can’t live on that level all the time can you, that you’re going to be worried silly.”* (Julie)

Time may be influential in allowing carers to overcome their concerns about another stroke to some extent, as it allows for adjustments in how they perceive their situation.

Two carers, Betty and Marigold attempted to understand the cause of their husband’s strokes, following a lack of information from hospital staff. This finding is consistent with that in group one, where carers were left with little explanation. The need to establish a cause for the stroke also remained consistent in response to little information. Marigold was similar to the carers in group one, as she was still actively seeking some understanding even up to two years post stroke. She was particularly concerned because her husband had suffered multiple strokes with no explanations. She also wanted her husband to be checked regularly by medical staff, given the frequency of her husband’s strokes:

*“The only thing I would perhaps welcome would be the chance of [stroke survivor] having a further set of tests in about six months’ time, because it seems to have been intervals of about a year, 18 months, between them.”* (Marigold)

This provides an interesting account of experience, suggesting carers are not always less concerned over time. Meanings attached to overcoming concerns about another stroke appear important in the context of different circumstances.

### **7.5.3.3 Feeling prepared and knowing what to expect during and following the transition from hospital to home**

Carers reflected on their experiences and identified feeling prepared and knowing what to expect during and following the transition from hospital to home as an important need. This early period following the stroke was characterised as a time of uncertainty and heightened emotions e.g. shock, distraught, stressed and scared. This theme highlights some of the influential factors in this preparation.

Examples of barriers included: a lack of consistency in including carers in the stroke survivor's discharge and lack of carer support. For example, Molly felt that the staff in the hospital did not acknowledge that she and her husband may have needed emotional support:

*“Yeah it was more the practical, not the emotional side. That was just ignored. I'm not saying ignored, I think it was ignorance really that they just didn't know that you'd need that kind of support you know. My husband and myself needed that emotional. Because for them it must be so scary.” (Molly)*

As carers reflected upon their experiences, they provided examples of the facilitators for being more prepared. However, these related to practical preparation as opposed to emotional preparation, including ensuring practical arrangements were in place at home and receiving practical guidance from hospital staff. Consistent with findings in group one, some carers benefitted from previous experiences of caring if the stroke survivor had suffered more than one stroke.

Carers' accounts also indicated what support and information they would have liked to allow them to feel more prepared. Examples included being provided with some expectations about life once the stroke survivor returned home; emotional support for reassurance; and information about where they could seek support that they may require as needs arise. As with group one, practical guidance was also important in cases where the stroke physically affected the stroke survivors. A balance between overcoming problems and having support available was important for Dorothy:

*“You need a period of time for you to sort of be able to sort things out for yourself but to have someone that you can call upon for advice.” (Dorothy)*

This emphasises the importance of ensuring that carers are supported whilst acknowledging that the support that they require may not be consistently needed as they adjust to the emotional and practical demands of the caring scenario.

#### **7.5.3.4 Balancing finding time to self with protecting stroke survivor safety**

Protecting stroke survivor safety was important, as half the carers still experienced fears about falls. However, carers valued a balance between this and finding time to themselves. This became increasingly important for carers, as they recognised their loss of freedom and their own lives. This also helped carers to cope and provided a break from caring. This theme highlights some of the influential factors in whether carers achieved this ‘balance.’

This ‘time out’ could be considered as purposeful activity in the sense that it provided more than just enjoyment, as suggested by those earlier in their caring experience.

However, in many cases such as Julie’s, time out remained limited:

*“Like on a Friday lunchtime which is the only time, I either meet a friend for a sandwich or I potter about or I just sit and read, we’ve switched off completely, you know, from the responsibilities.” (Julie)*

Time out was often limited by a lack of informal or formal support. Conversely, the availability of support from with family members or respite services meant carers could spend some time to themselves aside from their caring duties. Additional strategies included ensuring things were in place to protect the stroke survivor when they were not in their presence e.g. leaving them with a phone. These facilitators are consistent with findings from group one. It seems informal support networks are particularly important for maintaining the ‘balance’ for many carers in diverse circumstances. This social networking map (appendix Q) reflects the value that carers placed upon informal support at this later stage in the care trajectory.

#### **7.5.3.5 Continuing joint meaningful activities**

Carers valued joint activities with the stroke survivor, in addition to time away from their caring roles. These activities allowed them to get out of the house and provided a sense of normality.

Although some carers faced restrictions to engaging in such joint activities e.g. difficulties with wheelchair access and unhelpful public transport staff, other carers were receiving support from an information specialist at a carers charity therefore they were offered support to attend joint events together. The quote from Kate provides an example:

*“, I’ve got, I get things from the information specialist and stuff like that, so I do get details of stuff. We’re actually going on a canal trip with them in a couple of weeks’ time...” (Kate)*

Continuing joint meaningful activities remained important for many carers across all time points, emphasising the importance of ensuring that carers are facilitated to continue to engage in activities with the stroke survivor.

### **7.5.3.6 Developing and continuing using strategies for managing practically**

Management of practical caring duties remained a key part of the caring role, often alongside other roles and commitments and the carers’ own health problems. This highlights the need to develop and continue using strategies for managing practically.

Compared with group one, carers experienced a heightened sense of physical strain from their caring duties due to the severity of the stroke survivors’ impairments. Despite this contrast, carers used strategies to facilitate the management of practical caring duties, many of which remained consistent with those outlined by group one participants e.g. developing a routine and taking on additional roles around the home. Carers were also benefiting from practical support from formal carers to assist with providing care to the stroke survivor or informal support from family members if this was required. However, others e.g. Kate and Paula recognised a lack of both informal and formal support. Paula expressed that support *“dwindles off”* over time. The social networking map at this time (appendix Q) indicates that more carers were let down by both informal and formal support compared to carers in group one, mainly because this was not available to meet their needs.

In contrast to earlier experiences of caring, carers used the terms *‘getting on with things’*, *‘plodding on’* and *‘muddling through’* to describe their current situations. They had reached a stage where they had stopped learning new things and had muddled through earlier challenges. As they reflected on their circumstances they wanted to do the best that they could. Paula provides an example of this:

*“All you can do is get on with it the best you can.” (Paula)*

This quote suggests that Paula felt that she had little choice but to continue with providing care even though she described her life as a struggle. This reflects her perceived obligation to provide care to her husband; something that was apparent for other carers:

*“I mean you’ve got to over these things, you can’t just walk out on it can you? Maybe some people do, I don’t know.” (Julie)*

This sense of obligation also provides an interesting contrast to the experiences of carers in group one, as this was not as evident in their accounts of their experiences.

### **7.5.3.7 Developing and using strategies for coping**

Carers continued to need strategies for coping with the demands of caring and their changed situations. Throughout the interviews carers expressed negative emotions that added to difficulties with coping e.g. depression, bitterness, anger, resentment. This theme reflects some of the challenges carers faced and how they differed from those in group one. Barriers and facilitators to developing strategies for coping are also highlighted.

Jack, Paula, and Julie talked about the low and depressed moments that they have experienced since being a carer. The following quote is from Julie’s experiences as she talked about the changes to her life situation:

*“It gets me down, I get very depressed from it all because we just sort of plod on from day to day, you know, what else can you do?” (Julie)*

Some carers in group one talked about low moments; however, these fluctuated more compared to carers in group two. By this stage there was more permanence attached to the changes to their lives and the ongoing requirements of caring. Some carers (e.g. Molly and Paula) also expressed other feelings not apparent in group one interviews e.g. resentment, bitterness, and anger. These feelings were attached to changes to their lives:

*“You see like the person who has had the stroke will say it’s not fair, why me but I could stand there and say, it’s not fair, why me . It hasn’t just happened to him, it’s disrupted other people’s lives as well.” (Molly)*

Despite their difficulties, carers developed and used strategies for coping including going with the situation and getting on with it, taking each day as it comes and being self-reliant. Paula, Tony, and Phil preferred to manage the situation themselves, rather than reaching out to others for support:

*“I’m not the type of person to reach out to others for help. I’d sooner just crack on and get it done myself.” (Phil)*

Some carers were reluctant to seek support and in many cases support was either lacking or had diminished. Some carers coped by managing alone, others (e.g. Gabby, Julie, Molly) were more open to drawing upon support from family members and peer support groups, as demonstrated on the social networking map (appendix Q).

Consistent with findings from group one, carers' outlook on their situation was also important for coping. Carers expressed the importance of being positive and having will power to continue in their roles.

*“Well, you definitely have to be positive, you cannot be negligent really and you can't always think of yourself all the time, and in fact I think it's better if you're thinking about the patient, in this case Jeanette, you feel good that you're doing it anyway, yeah, so it's got its own rewards but you've got to be positive about things.” (Tony)*

It seems Tony felt he has little choice but to be positive as part of coping in a situation that could be considered as negative. Carers were still motivated to carry on in their roles and do their best to cope, despite their struggles. Furthermore, they did not lose sight of the importance of being there for the stroke survivor, despite some of the emotional turmoil in their caring experiences.

#### **7.5.3.8 Managing communication difficulties in the stroke survivor**

For carers supporting stroke survivors with communication difficulties, managing was an important need. Carers reflected on their experiences and provided a sense of how they managed these difficulties over time. Managing communication was important in their daily lives. This was influenced by developing strategies, engaging with support, and the extent of public awareness.

Examples of strategies included using flash cards, breaking down communication in to yes and no responses, developing their own sign language and providing the stroke survivor with choices using fingers. Over time, carers also changed the way that they approached communicating with the stroke survivor by giving them more time and acknowledging that they may need longer to understand what has been said.

*“ I suppose Jeanette being the way she is, if she gets frustrated it makes it worse, you've got to be careful that you don't make it worse for her, and then worse for you then.” (Tony)*

Tony thought that it was important to reduce his wife's frustrations to create a better situation for them both. Gabby's husband was still receiving support from 'Speak With IT.' She sought this support herself and they were provided with input from a volunteer speech and language therapist. She has recognised improvements in her husband's speech since he has been receiving this support over the last few years.

*“But when the speech therapist came, I couldn't believe it, she spent an hour with him, she spent at least an hour with me as well and gave him things to do that were doable and from that, he's now got 16 words, from nothing.” (Gabby)*



This has also been useful for Gabby, as she supports her husband with some of the tasks on the programme. Support from people in the wider community was also beneficial for Phil and his wife as part of managing her communication

*“I mean we don’t go out of our way to publicise the fact that she can’t speak or owt like that...I think when you go to the same shops, I think people get used to the little routine that you have going on anyway.” (Phil)*

This highlights the importance of those in public being aware of communication difficulties that stroke survivors can face to make communication more manageable.

### **7.5.3.9 Sustaining a flexible support network to be able to obtain appropriate support and information in accordance with needs**

As carers reflected on their experiences, they provided examples of different support and information needs since the early period following the stroke (e.g. emotional support), in addition to some of the strategies they used for gaining support and information to meet these needs. In some cases, carers expressed that they did not have any current information and support needs, although they had needed this earlier in their caring role. Support and information were not consistently required, but it was important for carers to be able to sustain a flexible support network to draw upon for support in accordance with their changing needs.

The social networking map (appendix Q) indicates the types of support that carers valued. Family and friends were a key source of support across many of the different needs for many carers. This was often the case as few carers were receiving professional input for either themselves or the stroke survivor at this stage, aside from the formal support from paid carers. Consistent with group one participants, carers took an active approach to gaining support and information throughout their caring experiences. The following quote is from Betty who often called her daughter for emotional support:

*“But I’d just ring [Daughter] up and have a natter and feel better about it, then, you know.” (Betty)*

Consistent with findings from group one, knowledge about where to seek information and support, plus more details about potential support was necessary, particularly in cases where carers wanted formal support.

Barriers to sustaining a support network of this nature included a loss or lack of support over time. Other carers were reluctant to seek support, because they thought it was too

late, or they did not consider themselves as the type of person who would ask for support. Paula felt she was too independent now to call upon others for support.

*“No, I am independent, I’m too independent now.” (Paula)*

These findings indicate that support is particularly important throughout the caring experience therefore carers should be supported in ensuring that they are provided with this in accordance with their needs.

Findings across the two data sets (groups one and two) will be discussed in section 7.6 after the developing logic model.

#### **7.5.4. Developing logic model of the problem**

The logic model presented below builds on those reported in chapters five and six. Together the findings will form the overall logic model of burden discussed in chapter eight. The logic model here was developed based on findings from groups one and two. More specifically, behavioural, and environmental barriers informed the boxes for behavioural and environmental factors. Where relevant, some of the non-behavioural barriers informed the determinants boxes for carers or professionals, family, and friends. These are factors that influence behavioural and environmental factors.

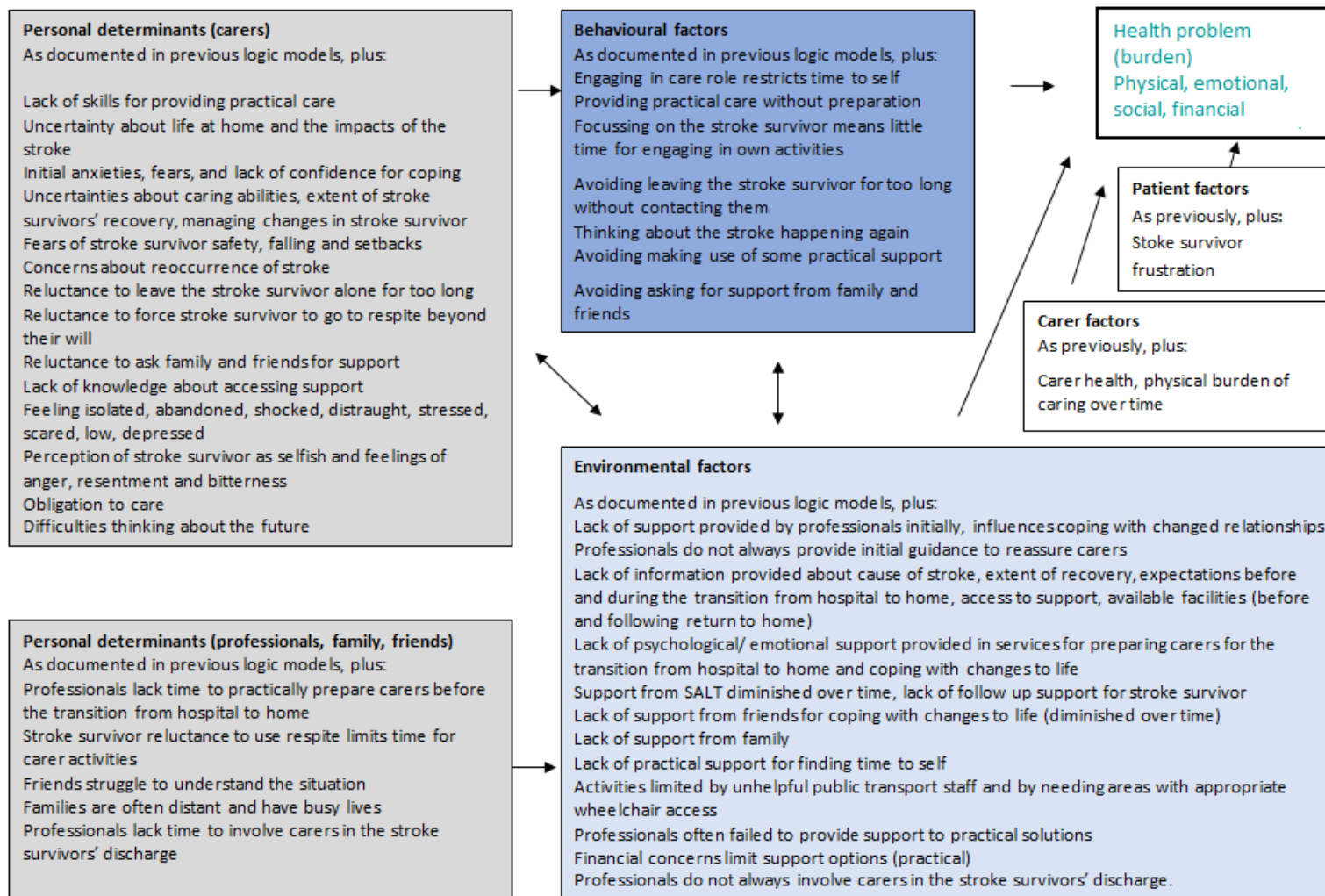


Figure 36: Developing logic model of problem

## **7.6. Discussion**

### **7.6.1. Summary of evidence**

This study examined the experiences of caring for stroke survivors, using semi-structured interviews with two groups of carers. This appears to be the first study which has: examined the caring experience from a needs perspective; identified the barriers and facilitators to addressing needs over time, and explored carers social support networks using a social mapping tool (Antonucci, 1986). The study contributes to understandings of the caring experience post-stroke, and the findings outlined in the logic model can be used in conjunction with the review evidence (chapters five and six) to inform the needs assessment component of IM (Bartholomew et al., 2011).

The evidence across both groups of carers provided a rich insight into carers' needs and the factors influencing whether these were addressed over time. In group one, the number of needs identified reduced over time (T1= 9, T2= 8, T3= 6), in group two, nine needs were identified. Overall, identified needs related to different aspects of caring including: the cause and consequences of the stroke, the stroke survivors' recovery, preparation for the role, coping and managing in the role including gaining reassurance, being able to ensure the stroke survivors' safety, continuing meaningful activities, managing communication, maintaining relationships, and obtaining support and information.

These findings are largely consistent with but also extend the evidence presented in the thematic synthesis (chapter six), particularly regarding changes in needs over time. In the thematic synthesis, some needs were more apparent in the early care trajectory, others remained over time. However, across the review studies, it was difficult to determine exact periods when needs emerged or specific patterns of experience over time. Group one findings built upon these, by indicating how needs diminished, changed, and continued over time in the same carers. Group two findings, based on a different group of carers, provided insight into how needs and the barriers and facilitators to addressing needs compare in the later care experience.

Other research, using the Timing It Right (TIR) Framework has attended to changes in carers' experiences and support needs across the care trajectory (Cameron and Gignac, 2008; Cameron et al., 2013). By using the social network mapping (Antonucci, 1986), this study has advanced our understandings of how support needs change over time by examining the value of different support for addressing specific needs. It also broadens the focus of the TIR Framework by highlighting a range of needs in addition to support needs.

This adds to what is already known about the complexities of the caring experience that influence how carers transition through different stages, and is informative for developing an intervention for carers.

Consistent with findings from the thematic synthesis, some needs (e.g. those related to coping and managing, and obtaining information and support) continued across time. The need to 'maintain relationships, despite changes' diminished after T1, providing an interesting contrast with the thematic synthesis findings where this was an ongoing need. However, some studies contributing to the thematic synthesis focused specifically on the relational aspect of caring, rather than needs and experiences as a whole, which may account for this difference (Bäckström et al., 2010; Jones and Morris, 2013; Quinn et al., 2014b).

Other needs changed over time e.g. carers initially needed to feel prepared before and during the transition from hospital to home, but later became focused on reassurance about their abilities as a result of being ill-prepared for entering the caring role. Consistent with previous studies, some carers felt they did not possess the necessary skills for their caring roles (Bäckström and Sundin, 2007; Niyomthai et al., 2010; Young et al., 2014). Barriers included little time to learn practical skills in hospital due to other commitments, and lack of adequate practical support. This left carers guessing whether they were 'doing things right.' This need for reassurance and guidance is evident in previous studies (Cameron et al., 2013; Cecil et al., 2011; Howe et al., 2012). However, the current study findings highlight how leaving needs unaddressed in the early care trajectory impacts on carers as they continue in their roles. The empirical and review evidence confirms that first six months are particularly important for ensuring carers are prepared and reassured.

Many needs identified in group two around preparation, continuing activities, coping and managing, and obtaining support and information were similar to group one. However there was an interesting contrast in how carers talked about their experiences. In group two, many carers had reached a plateau, they felt there was nothing new to learn and they were '*muddling through*.' Other needs were similar to group one, however, in group two, subtle differences reflecting how needs changed and developed over time were captured. For example, in group one at T2 interviews, carers started to 'take a step back whilst ensuring the stroke survivors safety'; in group two carers were 'balancing ensuring safety with finding time for themselves away from the role.' Carers in group two expressed a felt obligation to care, even when they expressed negative emotions towards caring. This was less apparent in group one, however, some of the carers' accounts (e.g. Daisy, Nahida and

Lucy) reflected an implicit acceptance of a marital or familial obligation to care for their spouse, sibling, or parent. In group two there was a heightened need for freedom away from the caring role.

Carers in previous studies shared a sense of obligation, despite being tired or strained (Bäckström and Sundin, 2007; Eaves, 2006) and a need for time away from caring (Cao et al., 2010; Howe et al., 2012; Kniepmann and Cupler, 2014; Winkler et al., 2014). The focus on finding time away from caring in the later care experience is also consistent with the TIR Framework (Cameron and Gignac, 2008), which suggested carers do not resume their own activities until things have stabilised in the 'adaption phase.' However, findings across the two groups capture a transition from being solely focused on the stroke survivors' safety, to taking a step back and re-engaging in activities, then finding time away from the care role, plus the barriers and facilitators that enable this process to happen. Fears of leaving the stroke survivor and having limited support were common barriers to gaining space away from caring. Facilitators included support from family, friends and respite services and having strategies in place to protect the stroke survivor e.g. leaving them with a phone. Balancing marital or familial obligations with allowing space away from caring was also made more complex by balancing this with marital or familial obligations.

Findings from this empirical study highlight the importance of gaining a comprehensive understanding of the barriers and facilitators to addressing needs and the influence that these have on how needs continue or change over time. As was the case in the thematic synthesis (chapter six), barriers and facilitators were influential in understanding how carers addressed different needs. These were established at different levels of the socio-ecological framework (McLeroy et al., 1988). Individual (behavioural) barriers and facilitators to addressing the identified needs largely related to whether carers 'coped,' and the carers' approach towards obtaining information and support i.e. whether they were passive or active in obtaining this. Environmental (interpersonal and organisational) barriers and facilitators related to whether carers were provided with the appropriate formal and informal support and information, and other factors such as appropriate wheelchair access and financial circumstances.

Consistent with the thematic synthesis findings, many needs were influenced by barriers and facilitators at the individual and environmental level. Some of the environmental factors could not be targeted in a behaviour change intervention e.g. financial circumstances. However, findings emphasise the importance of changing both carer behaviours and behaviours of those responsible for ensuring that their needs are met e.g. professionals, family members, and friends.

Examining the findings in the context of two theories outlined in chapter six: biographical disruption (Bury, 1982) and biographical flow (Faircloth et al., 2004) illuminates the complexities of carers experiences that should be considered in the development of interventions. The theory of biographical disruption is applicable to many carers' experiences across both groups, as they experienced early and ongoing disruptions to their lives, when they faced barriers to overcoming challenges. Their abilities to cope, despite disruption is also consistent with the element of response to disruption included in Bury's (1982) theory. As was evident in the thematic synthesis of studies, carers used their own internal resources for responding to disruptions to their lives and strategies similarly included acceptance and taking each day as it comes. Similarly, these findings acknowledge, with reference to this theory the factors that influence the extent of disruption to different carer's lives.

Examining carers' experiences across time and comparing them with another group has added to understanding how disruption changes with time. Interestingly carers interviewed at T3 in group one reported no barriers to coping because they had developed strategies e.g. taking each day as it comes, realisation, acceptance and patience. Their accounts also reflected elements of positivity and hope as they adjusted over time. Many carers in group two developed similar strategies for adjustment over time; however their lives were comparatively more disrupted. Across the groups, many of the experiences represent how some carers adapt to disruption and are more consistent with elements of biographical flow (Faircloth et al. 2004), where it is argued that a new biography can be constructed which flows with time and space.

However, it was evident from these findings that changes in needs are much more complex than the passage of time alone. Time was influential in how carers adjusted to some extent, as it allowed carers to accommodate the impacts of the stroke as part of an ongoing life and also provided carers with a sense of perspective. However other, factors in combination with time were influential in how carers managed disruption and addressed their needs e.g. different circumstances, extent of stroke survivor impairments, access to available resources e.g. support and information, and the carers' abilities to develop coping strategies. The findings also indicated that demographic characteristics such as age and ethnicity partly shaped some carers experiences (e.g. Nadia, Nahida, Amanda). However these factors did not solely account for the variation in experiences across and within the two groups of carers.

These findings support my previous claim that neither theory can adequately account for the complexities of carers' experiences. Variation in disruption is evident within and across the groups of carers. Findings from group one show carers can experience fluctuations in disruptions to their lives over time, which are influenced by their perceptions of their situations and availability of required support and information. This is consistent with my earlier claim based on findings from the thematic synthesis, that the caring experience is more likely to represent a series of temporary disruptions that can be addressed with appropriate resources (internal and external) to accommodate a 'biographical flow.'

These findings have implications for how we should seek to meet carers' needs in the context of their support networks and current services. The diversity and complexity of carers' experiences requires recognition and consideration. Supporting carers is more complex than providing support to match particular characteristics e.g. age, ethnicity, and gender. The findings highlight that different carers may have different expectations which influence their information and support needs. For example, Amanda (group one), articulated her experiences of caring in the context of being a younger carer. She expressed the difficulties with the changes to her imagined future and relationship with her husband. She expected support to be available to her as a younger carer to cope with these particular issues. However this expectation was not expressed by all younger carers.

Considering this example in the context of intersectionality theory (Crenshaw, 1991), it can be argued that Amanda's experiences and expectations were shaped by her identity as a younger carer, combined with other categories of identity that are interwoven and inseparable e.g. being white and female. This provides a plausible explanation for why other younger carers did not share the same experience, as their age was combined with a myriad of differing factors which shaped their identities and experiences. These findings highlight that it is important to be mindful of differing characteristics but researchers must sufficiently capture the complexities associated with how these characteristics interact and ensure interventions are tailored to differing circumstances and needs.

Given the significance of information and support for addressing needs and overcoming disruptions, it is also important for carers to obtain this in accordance with changes in needs over time. The same considerations highlighted in chapter six regarding *who* provides information and support, *what* is available to carers, and *when* and *how* this is provided are relevant for translating findings into developing an intervention (House, 1981).



The social networking map findings indicated carers' value different and often multiple formal and informal support and information providers at different times in the care trajectory, depending on their needs. Carers required information and support from professionals in the early trajectory to understand the cause and consequences of the stroke, and feel prepared before and during the transition from hospital to home, and feel reassured. However they often received less support than expected, reflecting findings from a previous study (Cameron et al., 2013). Following the stroke survivors' return home, carers still valued support from professionals, however this often diminished within the first few months. After this, carers mostly relied on family and friends. As documented in previous studies, they provided some emotional support and typically assisted carers to manage the practical aspects of care, engage in meaningful activities, and find time to themselves (Eaves, 2006; Greenwood et al., 2010; Saban and Hogan, 2012). However they were not best placed to meet all needs e.g. understanding the cause and consequences of stroke and preparing for home.

Selecting '*who*' provides information and support throughout the care trajectory is dependent upon the support required at a given time. Given the variation in carers' needs, and the likelihood of having different needs at the same time, a range of flexible informal and formal support networks would be beneficial. Consistent with previous studies, many carers actively sought support and information from different informal and formal support networks to address their needs (Creasy et al., 2013; Le Dorze and Signori, 2010; Paul and Sanders, 2010). However, this depended on carers having knowledge about different sources of information and support, therefore there were inconsistencies in whether needs were addressed.

Findings from a review of information provision for stroke survivors and carers, including 21 trials indicated a lack of clarity for the best strategies for providing information (Forster et al., 2012a). However it was recommended that strategies that actively involved carers, including opportunities for follow up and reinforcement should be used in routine practice. Eames et al. (2010) similarly emphasised the importance of involving carers in information provision based on a qualitative study focus on carers' perceptions of accessing stroke information. They recommended a two- way, interactive process between carers and health professionals to facilitate opportunities for carers to be involved in their own care. This important shift towards carers being more involved in the stroke survivors' care and having their needs recognised was something carers valued. Considering these recommendations in the context of Twigg and Atkin's models of how carers are perceived by services, this approach is a way of achieving a focus of support provision that is more in

line with the 'carers as co-workers' and 'carers as co-clients' models, rather than a 'carers as a resource' model (Twigg and Atkin, 1994).

To address, when, what and how, introducing a consistent approach to providing information and support to carers, which considers these recommendations would be appropriate earlier in the care trajectory. This could involve structured opportunities for communication with professionals alongside support and written information provision to address needs at the time. Professionals could also signpost carers to other support networks that they can draw upon as their needs change over time. This knowledge and awareness of other sources of support is important for promoting a proactive carer and contributes to ensuring information and support is tailored to their needs.

These empirical findings also have implications for the content and management of conversations with carers. The relevant information and support providers would need to be skilled in approaching carers about their needs, adopting a focus of care appropriate for the carers. Health professionals and carers typically engage in conversations around the stroke survivors' recovery whilst they are in the hospital setting, however there appears to be a distinction between how health professionals, and carers talk about recovery, which may be problematic for ensuring that they meet carers' needs.

Carers attach meaning to stroke survivors being able to do more as part of their 'recovery' and improvements in physical recovery are important in the context of their pre-stroke lives. Health professionals talk about recovery in terms of the stroke survivors 'rehab potential,' and attach recovery to goals set in the rehabilitation setting that may not be applicable to life beyond this (Burton et al., 2015). Providing carers with realism regarding what the stroke survivor may be able to achieve, beyond just a 'rehab potential' focus without damaging too much 'hope' would be appropriate at an early stage, given that carers in other studies also valued this hope (Howe et al., 2012; Paul and Sanders, 2009; Saban and Hogan, 2012).

Meeting varied needs may mean adequately training professionals (e.g. nurses, physiotherapists, occupational therapists) to engage in conversations with carers, or introducing different professionals that are not typically involved in the stroke survivors' care (e.g. staff from carers' organisations or volunteers). A combination may be appropriate for involving carers consistently and addressing their diverse experiences.

Although suggestions have been made regarding these findings, further decisions about who should be providing support and information and what, when and how this is

provided would need to be made by the intended intervention participants, hence the importance of stakeholder involvement in the IM process, discussed in chapter eight.

### **7.6.2. Strengths and limitations**

Although the focus of this study was similar those in the thematic synthesis in chapter six, it was a necessary for conducting a comprehensive 'needs assessment' for IM (Bartholomew et al., 2011). This empirical study adds to the findings from the thematic synthesis, providing more contemporary detail around how needs, and barriers and facilitators to addressing needs change over time. The second group of interviews provided a point of comparison to establish whether needs and the barriers and facilitators to addressing needs continue to change with time later in the care trajectory.

Chapter six and previous research (Greenwood et al., 2009a) noted that considering time points more consistently in future studies could make experiences more comparable. In group one; this was addressed by recruiting carers from the point of discharge. The consistency in transitions at this stage meant experiences were comparable, even though there were slight variations in the time that stroke survivors spent in hospital, which could influence carers' 'preparation' time.

It is acknowledged that the carers' responses could differ if stroke survivors were present in the interviews, hence the decision to allow carers to decide whether the stroke survivor should be involved. If carers wanted to share experiences that could be considered as upsetting for the stroke survivor, they were free to do this by choosing not to be interviewed with them.

I had anticipated that the presence of the stroke survivor would have more impact on the carers' accounts of their experiences than was evident in this study. Their presence did not appear to have a significant impact. In group one Daisy and her sister took part in all the interviews as a dyad, yet she still expressed the difficulties she had faced over time. In group two, Paula still expressed that she perceived her husband to be selfish following the stroke, and some carers talked openly about the low moments they had experienced as a result of caring. However, looking at this from the alternative perspective, it is possible that not having their mother present meant that Gail and her sister could be more open about the conflicts they faced around encouraging her to use respite care. Overall, the combination of dyadic and single interviews provided an interesting insight into the carers' varying experiences.

Different sampling frames were selected to gain an understanding of different carers' experiences at different time points. To recruit carers in group one, carers were recruited from both acute and rehabilitation wards in a THT. It is a strength of the study to recruit carers at this early stage, considering research indicates this is a difficult time for carers (Camak, 2015; Plank et al., 2012).

To recruit carers between nine and thirty-six months post their relatives/ friends stroke (for group two), alternative sampling frames were selected including a carers organisation, a carers group, and a research register. Identifying longer-term carers can be met with difficulties, especially if they are not connected with any services. The research register was used to contact carers who may not otherwise be included in research. However, as the carers were contacted via the stroke survivor, there was no way of knowing which of these stroke survivors had a carer; this may account for the small number of participants recruited using this method (n=5). Recruiting carers from organisations and groups in addition to this ensured that more carers could be included in the sample. Many of these carers were involved to some extent with a carers organisation or group, therefore it was insightful to hear that they experienced difficulties, even when they had contact with support services.

A purposive sampling approach, valued by many qualitative researchers was intended (Mason, 2002; Patton, 2002). Recruiting carers from hospital wards in group one provided scope to purposively approach carers with particular characteristics including: a range of ethnicities, ages, relationship to the stroke survivor, and gender. Compared to group two, the characteristics of carers were more varied and the sample included more deviant cases. Amanda's experiences as a younger carer have been emphasised throughout the chapter and provide a key example of a more unique caring experience. Nadia and Nahida's experiences were also very interesting and provided some insight into how cultural differences can influence how care is negotiated and managed with others to accommodate the stroke survivors' needs. Despite the sample being relatively small, the variation provided valuable insights into the diversity of caring experiences, which are valuable for developing an appropriate intervention which considers the complexities of different circumstances.

In group two, there were not enough potential participants to adopt a purposive sampling approach within the time-frame. This may account for why the characteristics of group two were less varied, they were all spousal carers and of a relatively similar age. Nevertheless, more of those in group two were caring for a stroke survivor with a range of different impairments following the stroke including communication difficulties. Not being

able to purposively sample participants in the same way as group one posed some limitations of being able to understand a diverse range of experiences according to the characteristics outlined above. Fewer deviant cases were outlined compared to group one; however these findings provided an important insight into providing caring in the later stage of the care trajectory. Many of the needs were consistent with those in group one, thus highlighting some of the shared care experiences regardless of the influence of different demographic factors. In future studies, where resources allow, it may be more appropriate to draw upon different sampling frames.

The sample sizes are not as large as initially intended. Time and resources made continuing with recruitment difficult, particularly as one element of the study involved capturing carers' experiences over time (group one). In this group, some carers with more difficult circumstances were lost before the interviews could be arranged or withdrew from the study before taking part in all three interviews. For example, Amanda was experiencing a stressful time by the time she was due to take part in the second interview. Her initial interview represented a complex experience that would have been interesting to follow over time. Nevertheless, the study highlights the difficulties that carers can face and provides a real-life reflection of some of the additional problems that can occur alongside having to manage care. Future research with larger sample sizes would provide more opportunities for considering the impact of particular characteristics on how caring is experienced. The possible influence of intersectionality of participant characteristics could also be considered in more depth, to explore how characteristics such as gender, age and ethnicity simultaneously impact upon how care is experienced after stroke (Bowleg, 2012).

Strengths and limitations can also be considered regarding the timing of the data collection in relation to the timing of the qualitative analysis, particularly in the longitudinal study (group one). In this group, all interview topic guides were developed in advance of the interviews. Consequently, the interviews at time point one did not influence the development of later topic guides, impeding the scope for a more iterative approach to collecting data. To address this limitation, the topic guide was still used flexibly in subsequent interviews and where relevant my line of questioning changed based on the initial codes from the previous interviews. The questions were also broad enough to allow carers to talk about what was important regarding their needs and the barriers and facilitators to addressing needs at a given time.

As documented by other researchers (Calman et al., 2013), managing the timing of the data analysis also proved challenging. Due to the overwhelming amount of rich data, only

interim analysis was conducted between the interviews which included initial codes, categories, and supporting memos. In retrospect it may have been better to have completed the analysis at one time point before preceding with the subsequent interviews at time points two and three. This could have allowed for opportunities to guide conversations by presenting initial themes to participants, subsequently making the interview data more focused and manageable with regards to how their needs changed over time.

Despite acknowledgement that the analysis could have been conducted differently data that has been gained is rich and informative for the next stages of IM. Including both groups of carers in this study provided an interesting contrast between how needs change with time, and how needs can be identified retrospectively. It was particularly interesting to see how carers adjust the way they talk about and approach their situation over time.

Although this study has provided an insightful understanding of the carers' experiences, the staff perspective on some of these issues is lacking. This is in the next stages of IM by involving a stakeholder group (chapter eight).

### **7.6.3. Reflexivity**

I am a white female, aged 28, with a background in psychology and previous experiences of doing qualitative research. In this section I consider myself as a researcher and the extent to which my previous experiences and interactions during the interviews influenced the research process.

Something that I had perhaps not acknowledged prior to the interviews was that some carers would perceive find me as difficult to place in terms of my role. This was despite introducing myself as a PhD student, and explaining that I was interested in their experiences but was not a trained professional who could provide any medical advice. I expect this difficulty placing me was due to my contradictory signs of status. Carers in group one who had met me in the hospital setting prior to the interviews often believed that I was associated with the hospital and interested in their experiences in a caring rather than research capacity. The materials that I arrived at their homes with (an audio-recorder, interview topic guide and notebook), and my appearance as a young researcher served as a subtle reminder of my role as a PhD student. However, for some carers, I seemed to remain an 'unknown quantity' (Richards and Emslie, 2000, pg. 74).

Consistent with the assumption that who people *think* you are affects what you get told (Richards and Emslie, 2000), carers appeared comfortable expressing any unfavourable concerns about medical professionals due to my perceived neutral professional status.

Many carers also described the engagement in the interview as therapeutic, as it was the only opportunity they had been given to reflect on their experiences and make sense of how things had changed over time. It is possible that they were very open in sharing their experiences because they perceived me as someone who was there to see how they were doing.

During the interviews I had to be mindful of my responses to what I was told and my line of questioning to ensure that this was not driven by my own interests and previous academic experiences. I was aware that my academic background in psychology means I am drawn understanding the emotional aspects of experiences. To overcome this potential issue I made sure my interviews covered the range of topics included in the guides (appendices L and M), which is reflected in the range of needs identified across the interviews.

Despite my interests, I had some initial apprehensions about questions that were likely to evoke emotions such as “how did you feel at this time?” My initial apprehensions were partly driven by my assumptions that carers would find it very difficult to talk about their relatively recent experiences; and knowing I was listening to carers in a research, not a caring capacity.

I have previously worked in varied support worker roles where it was natural for me to try help individuals and their families to overcome their difficulties. Therefore listening to carers about their difficulties knowing there was little I could do to help, aside from signposting them to relevant services (e.g. Stroke Association) was challenging. These feelings of helplessness resonate with researchers’ accounts in previous research (Greenwood, 2009) and were emphasised when carers became tearful during the interviews. Nevertheless, my previous experiences helped me manage in these circumstances and ensured I remained sensitive to carers’ feelings throughout the interviews.

Although these interactions differed from my previous support worker roles, I still built up a good rapport with carers. However, this made departing from carers very difficult, especially those in group one who I had met three times over the course of a year. Despite being there in a research capacity, it is difficult to separate the genuine interests and concerns that develop through engaging with these individual’s lives over time. Similarly from the participant’s perspectives, it is difficult for some participants to engage with researchers about very sensitive and personal accounts of their lives, without some degree

of emotional attachment; especially in interviews conducted over time. I was conscious that I was 'abandoning' carers in the way that they often share when they were describing their experiences with varied health and social services. To overcome these feelings of abandonment, I reminded the carers at each interview that our research relationship would be coming to an end after the three interviews. I also sent each carer a thank you card to mark the end of their involvement in the process.

This departure from participants is often too readily dismissed (Greenwood, 2009). As researchers we need to be careful in how we manage engagements and be aware that the participants' understandings of our presence are likely to influence how parting from the study is experienced. As we are increasingly placing more emphasis on patient and public involvement in research, this is an avenue that could be explored further to avoid unnecessary negative feelings for participants.

#### **7.6.4. Conclusions**

This qualitative study including two groups of carers one of which were interviewed three times (group one) and the other at a single time point (group two) provided evidence that carers of stroke survivors have varied needs across the care trajectory. Some needs continue and some change over time, however it is evident that changes in needs are more complex than the passage of time. These are influenced by a range of factors including the circumstances and characteristics of different carers, extent of stroke survivors' impairments, access to available resources e.g. support and information, and the carers' abilities to develop coping strategies. These barriers and facilitators have important implications for how carers are supported.

Findings from the social networking mapping exercise (Antonucci, 1986) indicated that carers value different and often multiple support and information providers at different times in the care trajectory, depending on their needs, suggesting having a range of informal and formal support networks throughout the trajectory would be beneficial. In addition to findings presented in chapter six, these findings emphasised the importance of introducing a consistent approach to providing information and support, combined with encouraging carers to actively seek information and support, to enhance the likelihood that carers can develop and maintain support networks to meet their needs as they arise.

These findings also align with my previous suggestion that it would be important to understand more about how 'needs' relate to carers' perceptions of 'burden.' Consistent with the findings from the thematic synthesis and the review by Greenwood et al.,

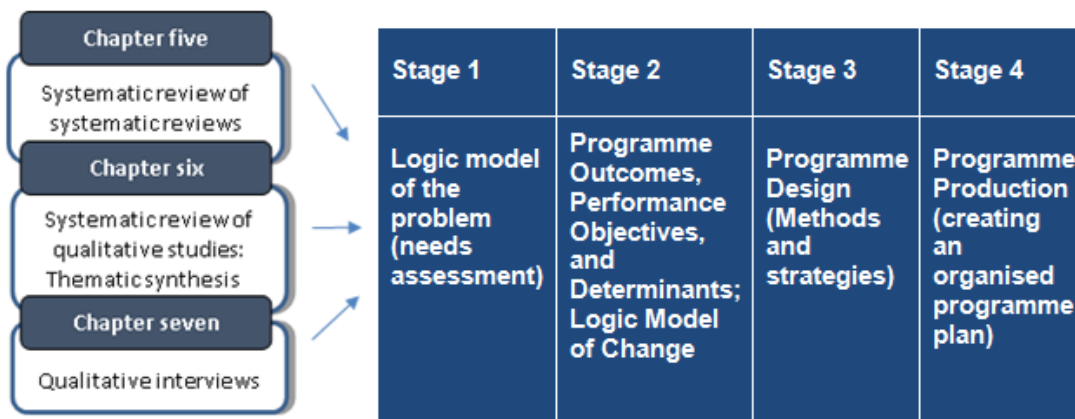


(2009a), carers infrequently used the term burden, yet their narratives from the interviews reflected a role that was at times very difficult and could be considered as burdensome. In the previous chapter, I suggested prioritising needs based on their importance for reducing burden may be important. The needs from the thematic synthesis and this study are similar; therefore, it is important to find a way of drawing these together, whilst paying attention to the time aspect, before prioritising these in relation to burden. These suggestions are considered when drawing the findings together from the needs assessment for the subsequent stages of IM.

Overall, the evidence emphasises the complexities attached to developing an intervention to reduce burden in carers of stroke survivors. Given that numerous barriers and facilitators to addressing needs were identified at different levels of the socio-ecological framework (McLeroy et al., 1988), developing an intervention that addresses multiple levels remains important. More clarity will be gained regarding how this will be achieved as the intervention development progresses.

## Section three: Developing and designing the intervention

The previous section (chapters five to seven) focussed on the first stage of IM. This section includes the final chapters (eight and nine). Chapter eight outlines the methods and outputs for the rest of stage one and the subsequent stages of IM (two-four) presented in figure 37.



Chapter eight: Applying an Intervention Mapping approach to develop and intervention for carers of stroke survivors

**Figure 37: Overview of the Intervention Mapping stages**

The outcome of the IM process is a programme plan of an intervention to reduce burden in carers of stroke survivors. This includes a detailed description of the components of the intervention and the program materials, rather than a fully developed intervention.

Chapter nine includes an overall discussion of the research presented in the thesis.

## **8. Chapter eight: Applying an Intervention Mapping approach to develop an intervention for carers of stroke survivors**

### **8.1. Introduction**

This study aimed to develop a proposed intervention to reduce carer burden using IM (Bartholomew et al., 2011). In section one, chapter four introduced the IM approach and outlined how each stage is conducted within the process. Section two, (chapters five to seven) reported on three components of work contributing to stage one, the 'needs assessment.' This chapter starts with methods including ethical considerations, recruitment of stakeholders, timelines and project management, then how IM methods were applied in stages one to four of the process. The latter part of the chapter outlines the outputs corresponding with each stage outlined in the methods. Stakeholders were heavily involved in shaping the intervention. Details about their involvement are integrated throughout. A critical overview of findings is also presented in the discussion section.

### **8.2. Methods**

The first four stages of IM were used to develop a proposed intervention to reduce carer burden: 1) Logic model of the Problem (needs assessment); 2) Programme Outcomes and Performance Objectives; Logic Model of Change; 3) Programme Design (selecting methods and strategies); 4) Programme Production (creating an organised programme plan).

### **Ethics**

The empirical study (chapter seven) was granted ethical approval by the Yorkshire and Humber – Bradford Leeds Research Ethics Committee (Ref No: 15/YH/0073). A substantial amendment was made to recruit carers to stakeholder groups from the research register. The ethics committee regarded stakeholder involvement as consultation work, therefore no additional approval was required to conduct groups and use audio-recorders.

### **Intervention stakeholder group**

I conducted the intervention development with guidance from a stakeholder group and other researchers (TC, RM). To include individuals relevant to the focus of the doctoral study, different methods were used to approach different stakeholders (table 30). Health professionals and staff from carer support services were either known to the research team at the AUECR or contacted through carer organisations; carers were approached at

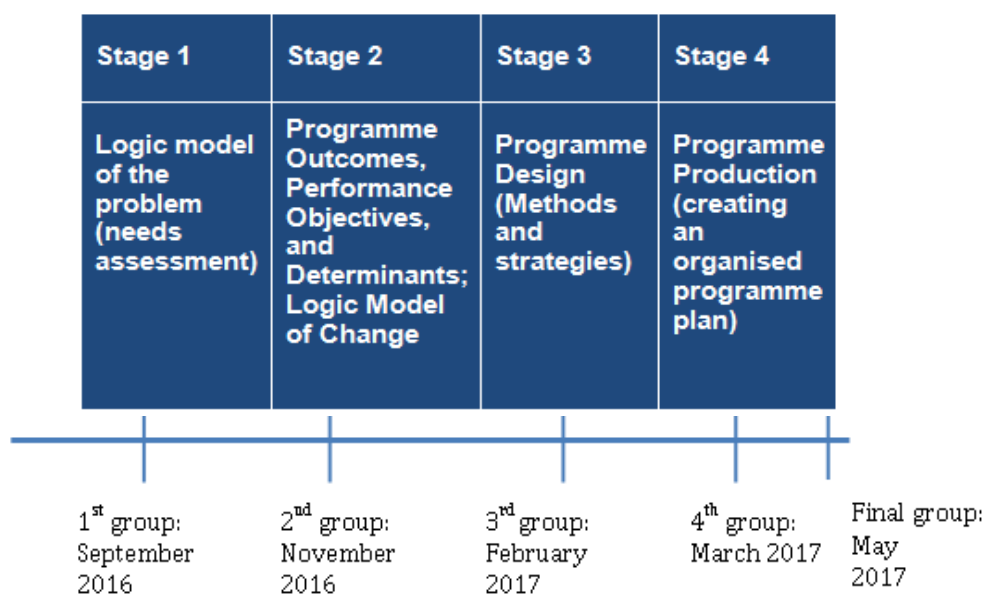
carers groups or via the research register; and researchers were approached at the AUECR, based on their knowledge and expertise. In all cases, I told them the focus of the project, the purpose of the stakeholder groups, planned dates, times and locations for meetings, and their duties throughout the process. I made it clear to potential stakeholders that their time commitments did not extend beyond the scheduled groups.

**Table 30: Stakeholders included in the Intervention Mapping process**

Stakeholders
➤ Six carers (two withdrew from process at meetings one and two, due to personal circumstances).
➤ Three researchers (senior researcher, PhD student, programme manager), with experience of developing interventions for stroke survivors or carers, drawing upon behaviour change techniques and methods e.g. Intervention Mapping and Behaviour Change Wheel.
➤ Three health professionals (therapy co-ordinator, physiotherapist, stroke nurse specialist).
➤ Two professionals from carer support services (carer support and secondary care worker; information Specialist).

### Timelines and project management

I led five group meetings between September 2016 and May 2017, linked to stages one to four:



**Figure 38: Timeline of Intervention Mapping groups**

Throughout the process, stakeholders were included in key decisions and contributed to structured tasks throughout the meetings. Feedback was recorded and included where appropriate. An overview of each group meeting is presented below:

**Table 31: An overview of stakeholder groups and tasks**

<b>Meeting 1: 19<sup>th</sup> September 2016</b>
<p>Task 1: Mind-map of factors that contribute to burden in carers of stroke survivors and other longer-term conditions</p> <ul style="list-style-type: none"> <li>• Stakeholders split into two groups and presented with mind-map</li> <li>• Asked for feedback to establish how they understand and experience burden</li> </ul> <p>Task 2: Prioritising carer needs</p> <ul style="list-style-type: none"> <li>• Stakeholders split in to two groups: 1) carers; 2) staff and researchers, and presented with 11 carer needs cards at different stages in the care trajectory (from the qualitative interviews and thematic synthesis of studies).</li> <li>• Asked which need(s) should be prioritised to reduce carer burden.</li> </ul>
<b>Meeting 2: 8<sup>th</sup> November 2016</b>
<p>Task 1: What is the problem?</p> <ul style="list-style-type: none"> <li>• Stakeholders were asked to discuss the prioritised need from a problem perspective. This involved discussing the ways in which the need was unaddressed.</li> </ul> <p>Task 2: What factors contribute to this problem?</p> <ul style="list-style-type: none"> <li>• Stakeholders asked to discuss and write down the factors that result in the need being unaddressed.</li> </ul> <p>Task 3: What can different individuals do to reach the intervention goals and outcomes?</p> <ul style="list-style-type: none"> <li>• Stakeholders were asked to consider and write down on a worksheet what different individuals and services (e.g. carers, professionals, family, friends, and peers) could do to reach the intervention goals and outcomes. The worksheet provided a framework of responses informed by the socio-ecological framework.</li> </ul>
<b>Meeting 3: 6<sup>th</sup> February 2017</b>
<p>Task 1: Clarifying contextual factors for the intervention</p> <ul style="list-style-type: none"> <li>• Stakeholders asked questions to clarify contextual factors related to the intervention (e.g. where, how, who, what and when).</li> <li>• Stakeholders provided feedback and noted ideas on a worksheet developed for the task</li> </ul> <p>Task 2: Ideas regarding programme, scope, and sequence</p> <ul style="list-style-type: none"> <li>• Stakeholders were asked to note ideas on another worksheet about the design and content (programme), setting (scope) how this might be delivered (scope and sequence), resources and materials (programme, scope, and sequence).</li> </ul> <p>Task 3: Selecting determinants</p> <ul style="list-style-type: none"> <li>• Stakeholders were presented with a condensed grouping of determinants on nine cards.</li> <li>• Stakeholders discussed determinants that could potentially be targeted as part of the intervention.</li> </ul>
<b>Meeting 4: 22<sup>nd</sup> March 2017</b>
<p>No structured tasks</p> <ul style="list-style-type: none"> <li>• Feedback on elements of the intervention</li> </ul>
<b>Meeting 5: 2<sup>nd</sup> May 2017</b>
<p>No structured tasks</p> <ul style="list-style-type: none"> <li>• Celebration event to thank members for their participation</li> </ul>

I made a conscious decision to avoid using complex terms in the groups e.g. performance objectives, determinants, and matrices. However, using carefully designed stakeholder materials meant that stakeholders' ideas could be integrated into development work carried out aside from the stakeholder meetings. Separate meetings with other researchers (TC, RM) facilitated the more complex development work. Further details about how stakeholders were involved are provided in the following methods and results sections.

### **8.2.1. Stage one: Logic Model of the Problem (Needs assessment)**

Stage one involved varied steps, outlined in this section. Firstly an understanding of carer burden was developed, contributing to an overall logic model of burden; secondly a need was prioritised based on its importance for reducing burden; thirdly this was discussed with stakeholders; and finally a programme goal was identified.

The developing logic models of the problem presented throughout needs assessment section of the thesis (chapters five-seven) formed an overall logic model of burden. This includes the factors influencing burden and their determinants identified in the review of systematic reviews, and the barriers (both environmental and behavioural), and determinants identified in the thematic synthesis of qualitative studies and the empirical study.

Following development of the overall logic model of burden, the intervention focus was narrowed by establishing priorities based on two tasks in meeting one. For task one, I developed a mind-map of factors contributing to burden in carers of stroke survivors and other longer-term conditions, based on the overview of systematic review evidence. I split stakeholders into two groups (mix of staff, researchers and carers) and presented them with this mind-map to stimulate their thoughts on burden. I asked for verbal and written feedback to gain an insight into how they understand and experience burden, before participation in the next task. In task two, I split carers into two groups: 1) carers; 2) staff and researchers, and presented them with 11 cards including needs drawn from the thematic synthesis of qualitative studies and the empirical study. I asked each group to order and prioritise needs based on their importance for reducing burden. Through discussions in small groups and as a whole, one need was prioritised.

Tasks one and two in meeting two focused on gaining a greater understanding of this need from a problem perspective. I asked stakeholders to discuss and write down the ways in which the need was unaddressed (task one) and the factors that result in the need being unaddressed (task two). Contributions from stakeholders were used to develop the

programme goal and a different 'logic model of the prioritised problem' about the prioritised need. This logic model provided the foundations for subsequent stages of intervention development, to ensure that the intervention focus was specific to the prioritised need.

### **8.2.2. Stage two: Programme Outcomes, Performance Objectives; Logic Model of Change**

In this stage, the focus shifted from problems to the change process. The logic model of change is the output of this stage; this outlines pathways of the programme effects rather than pathways to identify causes of the problem (Bartholomew and Mullen, 2011). This model includes the programme goal, behavioural and environmental outcomes, performance objectives, determinants of behaviours and change objectives.

#### **8.2.2.1 Behavioural and Environmental Outcomes**

Behavioural and environmental outcomes were created for relevant levels outlined in the socio-ecological model (McLeroy et al., 1988). These were guided by the programme goal and the 'logic model of the prioritised problem' (examples in results section 8.3.2.1, table 33).

#### **8.2.2.2 Performance objectives**

Performance objectives were created for each behavioural and environmental outcome. These are specific behaviours and actions that are carried out to achieve the behavioural and environmental outcomes (examples in results section 8.3.2.2., table 34). Stakeholders contributed largely to the development of the performance objectives. In meeting two, task three, I asked them to consider and outline on a worksheet what different individuals and services e.g. carers, professionals, family, friends, and peers could do to reach the intervention goals and outcomes.

The worksheet provided a framework of responses, informed by the socio-ecological model. These were also guided by the behavioural and environmental factors that were included in the 'logic model of the prioritised problem', the facilitators identified in the thematic synthesis of qualitative studies and the empirical study, and relevant theories identified through rapid scoping of the literature. Together, these contributed to a sequential process, providing a detailed outline of all behaviours that must be carried out to achieve each outcome.

### **8.2.2.3 Determinants**

Theoretical determinants i.e. the factors that influence whether individual behaviours and the behaviours of environmental agents can be changed were identified to develop the matrices of change objectives, based on evidence in the logic model of the prioritised problem. This ensures intervention development is guided by the problem, as opposed to dismissing important factors by prematurely selecting theory.

### **8.2.2.4 Matrices of change objectives and the logic model of change**

Determinants were mapped against performance objectives to create numerous matrices of change objectives. The change objectives state what the intervention should modify to influence performance objectives to achieve the behavioural and environmental outcomes. The matrices of change objectives outline the most immediate change to be addressed by the intervention. Matrices of change provide a basis for selecting theoretical methods and practical applications for the intervention. A matrix was created for each behavioural and environmental outcome, and then a logic model of change was developed.

### **8.2.3. Stage three: Programme Design (Methods and strategies).**

This stage involved generating programme ideas, selecting theory- and evidence-based change methods based on those outlined by Bartholomew et al. (2011), then practical applications.

#### **8.2.3.1 Generating programme ideas**

In meeting three, I updated stakeholders on the project progress since their last contributions to the performance objectives in a manageable, understandable way before asking them to think about programme ideas. I achieved this through presenting stakeholders with a flow diagram based on consolidated performance objectives, in a sequence, where one role interacted with another. This outlined actions and behaviours that must be carried out by different individuals to achieve the overall goal (see section 8.3.3.1, figure 45).

I presented two tasks to stakeholders about programme ideas, first about context (task one), then about the broad structure of the intervention, more specifically the programme, scope, and sequence (task two). In task one, I posed questions to stakeholders to clarify contextual factors of a relevant behaviour change intervention (where, how, who, what and when). Stakeholders provided feedback and noted ideas on the worksheet developed



for the task. In task two, I asked stakeholders to note ideas on another worksheet about the design and content (programme), setting (scope) how this might be delivered (scope and sequence), resources and materials (programme, scope, and sequence). Through completing these tasks, stakeholders shared ideas about the intervention, using a structured approach, without constraining their creativity. The ‘active ingredients’ of these ideas were yet to be established, hence the importance of the next steps.

### **8.2.3.2 Identifying and choosing theoretical methods and selecting and designing practical applications**

For each programme idea, a theoretical process describing how the expected change is going to happen was required. Theoretical methods are general techniques or processes for influencing changes in determinants of behaviours or environmental conditions e.g. ‘modelling: providing an appropriate model being reinforced for a desired action’ to address the determinant, ‘knowledge’. Practical applications are specific techniques used to address theoretical methods in ways that fit the intervention population and the context in which the intervention will be conducted e.g. video clips including role play. The determinant is the linking concept to match a theoretical method with a change objective.

Prior to moving from matrices of change objectives to selecting theoretical methods and practical applications, I grouped determinants based on theoretical methods outlined by Bartholomew et al. (2011) that can be applied to change behaviour. In meeting three, task three, I presented stakeholders with a further condensed grouping of determinants presented on cards, in language to suit the largely non-academic audience. They discussed the determinants that could potentially be targeted as part of an intervention. Change objectives were also consolidated in accordance with the consolidated performance objectives that provided the basis for the flow diagram, as it became clear that the differences between them were redundant.

A table of methods and practical applications was created for each group of determinants, based on guidance by Kok et al. (2015). This included columns for determinants, change objectives, theoretical methods, parameters, practical applications, and how population, context and parameters were considered throughout all these decisions. In each table, change objectives were listed under the relevant step in the flow diagram (based on consolidated performance objectives) and theoretical methods were matched to each change objective from those presented by Bartholomew et al. (2011). Practical applications were developed based on the theoretical methods, taking into account population, context, parameters, and ideas from stakeholders. By considering parameters,

the conditions under which methods are shown to be effective were kept in mind during the translation from methods to applications through to overall programme ideas.

Following this, a new table was created for each flow diagram step (based on consolidated performance objectives), re-using data and columns from previous tables. Unlike previously, multiple determinants were included in each table. This established where the same theoretical methods e.g. modelling for knowledge and skills, and practical applications were used to target different determinants. This provided clarity while drawing together ideas for possible elements of the developing intervention. Working through the process in this way ensured ideas for theoretical methods and practical applications were always considered alongside the change objectives, which remained in the tables at each stage of the process. This ensured that the final practical applications still addressed relevant change objectives.

#### **8.2.4. Stage four: Programme Production (creating an organised programme plan)**

This stage focused on establishing the components of the intervention, including details about content, purpose, and design features. These ideas were used to create an organised programme plan comprised of a 'programme scope and sequence' document and design documents.

##### **8.2.4.1 Establishing programme components**

Following identification of methods and practical applications, components of the intervention were established, with acknowledgement that they must be embedded in a service that supports ideas at an 'organisational' and 'community' level. These broader, organisational considerations were influenced by discussions with stakeholders that occurred alongside tasks in meeting three.

##### **8.2.4.2 Consulting with stakeholders to determine design preferences**

Stakeholders' design preferences also contributed to the proposed intervention. As documented in section 8.2.3.1, stakeholders engaged in tasks that considered their preferences for programme design regarding context, content, and delivery. In meeting four, once intervention components incorporating theoretical methods and practical applications were developed, stakeholders provided feedback including their design preferences. Their preferences and feedback were used to make refinements which influenced the content of design documents.

### 8.2.4.1 Documenting the programme scope and sequence

The 'programme scope and sequence' document was produced using stakeholders' responses to the tasks from meeting three where intervention ideas, context, and delivery were considered (section 8.2.3.1) and feedback from meeting four.

## 8.3. Results

### 8.3.1. Stage one: Logic Model of the Problem (Needs assessment)

This section focuses on outputs from tasks outlined in section 8.2.1 that contributed to prioritising the focus of the intervention. The overview of 14 systematic reviews that contributed to the needs assessment highlighted a range of factors that influence burden in stroke and other longer-term conditions. These were synthesised in five categories:

- Behavioural factors e.g. carrying out a high volume of care tasks
- Environmental factors e.g. lack of informal and formal support
- Patient factors e.g. changes in behaviour
- Carer factors e.g. physical and psychological health problems
- Influential factors (determinants) e.g. coping and extent of stress experienced because of providing care

Findings from the empirical study and thematic synthesis of qualitative studies highlighted numerous, often overlapping needs at different time points in the care trajectory, related to both the physical and emotional consequences of providing care. When drawn together, 11 needs (table 32) were identified and written in a language appropriate for stakeholders:

**Table 32: Carer needs drawn from needs assessment**

• carers need to feel prepared before and during the transition from hospital to home
• carers need reassurance about their abilities to provide care
• carers need to use strategies for managing and coping with practical difficulties
• carers need to encourage the stroke survivors to improve
• carers need to develop strategies for managing communication difficulties
• carers need to find ways of gaining information and support to address their own needs
• carers need to use strategies for coping with changes to their lives
• carers need to understand the cause of the stroke and overcome concerns about it happening again
• carers need to be able to do some enjoyable activities with the stroke survivor
• carers need 'me time' to focus on themselves and gain a break away from caring
• carers need to find ways to manage and cope with their changed relationship

Barriers and facilitators to addressing needs were identified in accordance with levels of the socio-ecological model. Individual barriers and facilitators were associated with coping by finding time away from their caring roles and constructing a new life, self and relationships; and the carers' approach to obtaining information and support.

Interpersonal and organisational barriers and facilitators related to whether carers were provided with the appropriate support and information, how this was communicated or negotiated between the carer and 'another,' and how available and accessible this was within an organisation or informal support network e.g. family and friends.

The overall logic model of burden (figure 39) outlines a range of factors contributing to carer burden, taken from the three components of research contributing to the needs assessment. This is outlined below with a key for the different texts:

**Logic model key:**

Burden review findings: Plain text with an indication of condition or conditions in a bracket

Qualitative review findings: **bold but not italic**

Empirical study findings: *italic*

**Bold and italic**- both empirical study and thematic synthesis of qualitative studies

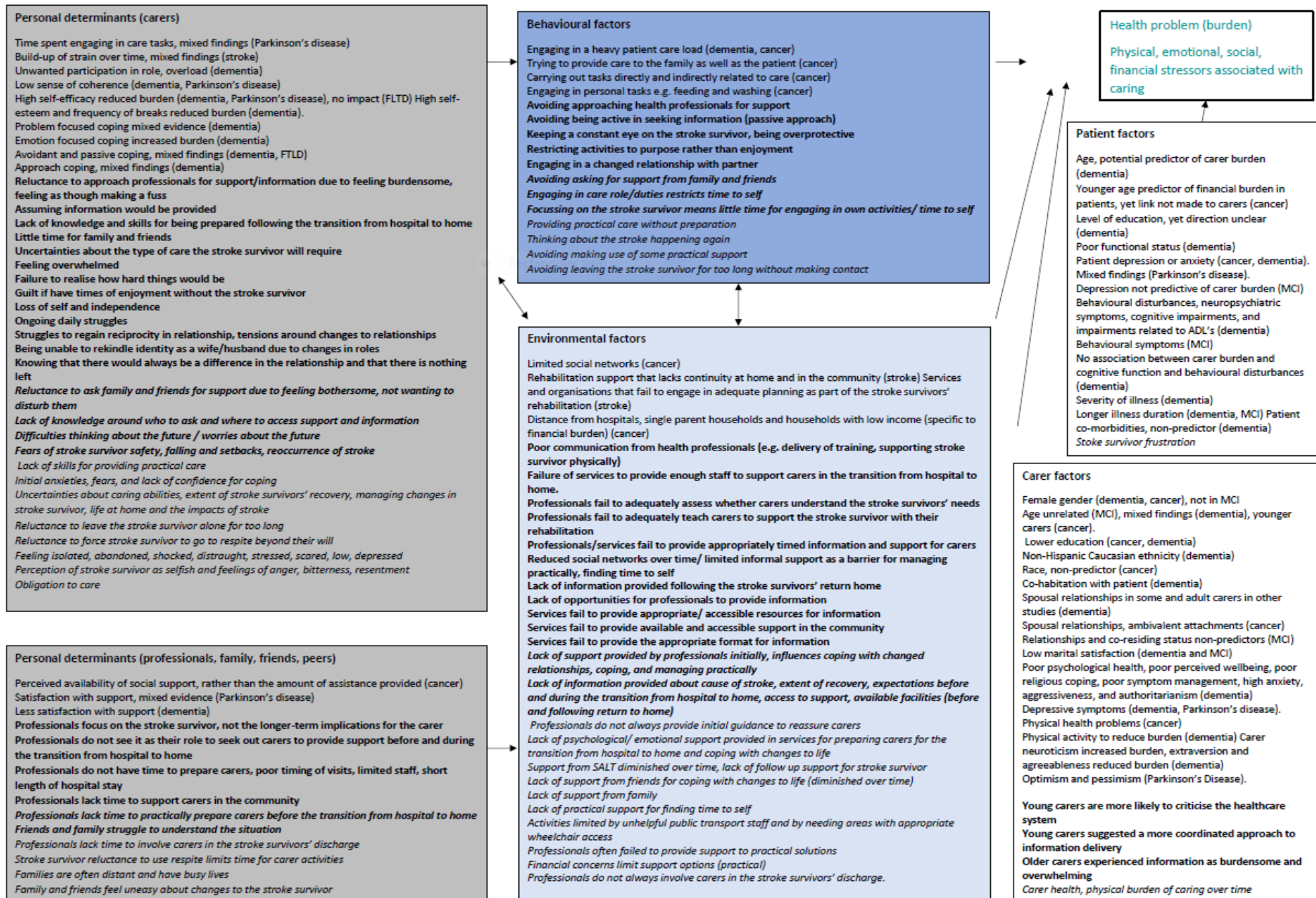


Figure 39: An overall logic model of burden

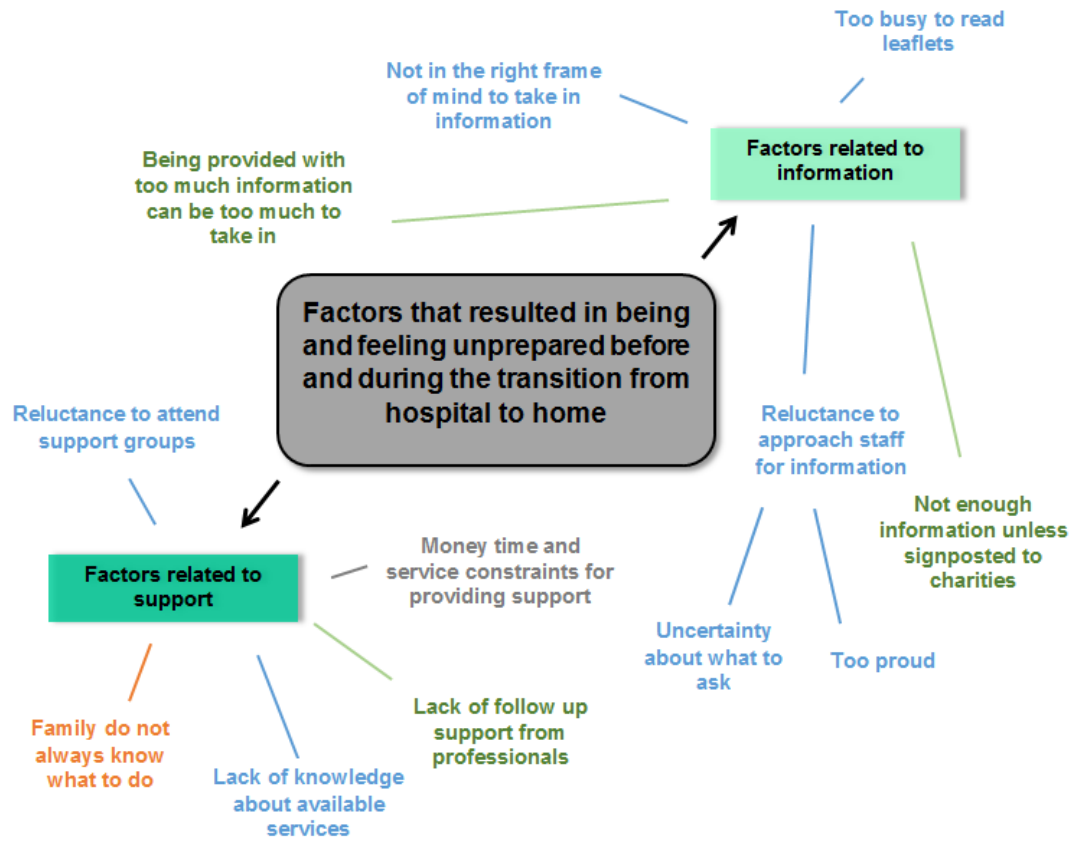
In meeting one, stakeholders agreed with the factors that influence burden presented in a mind map. However they provided additional insights into these factors based on their personal experiences as carers, or working with carers in a stroke specific context, in accordance with the five categories. Examples included: behavioural factors (caring for children alongside care); environmental factors (financial challenges, poor or badly timed support, lack of information); patient factors (loss of the person they knew before, uncertainty attached to stroke survivors' recovery); carer factors (younger carers feeling more burdened); other factors (struggling with their lives being turned upside down and not knowing what to expect). These understandings provided an important basis for the next task where carers prioritised needs based on their importance for reducing burden.

Through ordering needs cards based on highest to lowest priority in separate groups, carers and staff both agreed one key need should be addressed in an intervention aimed at reducing burden: 'Carers need to feel prepared, before, and during the transition from hospital to home.'

In meeting two, stakeholders provided specific examples of being or feeling unprepared before and during the transition from hospital to home. Key findings included practical and emotional struggles, feeling uncertain, and unaware that things would be different. Carers emphasised feeling emotionally unprepared, which was harder to manage than the physical aspects of care. Where carers faced practical struggles, these included: managing medications, and physically getting the stroke survivor up the stairs or moving in and out of bed. Uncertainty around expectations was attached to changes in the stroke survivors and resultant impacts on relationships and roles around the home. Until carers returned home, they lacked realisation that their lives, sense of normality and independence would be different. These findings were important for establishing the nature of an intervention e.g. whether it would involve both emotional and practical preparation. They also provided some context for the task which followed.

When stakeholders considered the factors that resulted in being and feeling unprepared before and during the transition from hospital to home (meeting two, task two), these broadly related to information and support. Examples are provided in figure 40.

- Key:**
- **Blue:** individuals (carers)
  - **Green:** interpersonal (professionals)
  - **Orange:** interpersonal (family, friends, peers)
  - **Grey:** organisational (services)



**Figure 40: Stakeholder feedback about intervention focus**

Establishing the factors that resulted in being and feeling unprepared informed the logic model of the prioritised problem (behaviours and environmental factors and their determinants). This is outlined in figure 41, with a key for the different text styles.

Logic model key:

Burden review findings: plain text with condition or conditions in bracket

Stakeholder meetings: text with\*

Thematic synthesis of qualitative studies: **bold but not italic**

Empirical study: *italic*

Thematic synthesis of qualitative studies and empirical study: **Bold and italic**

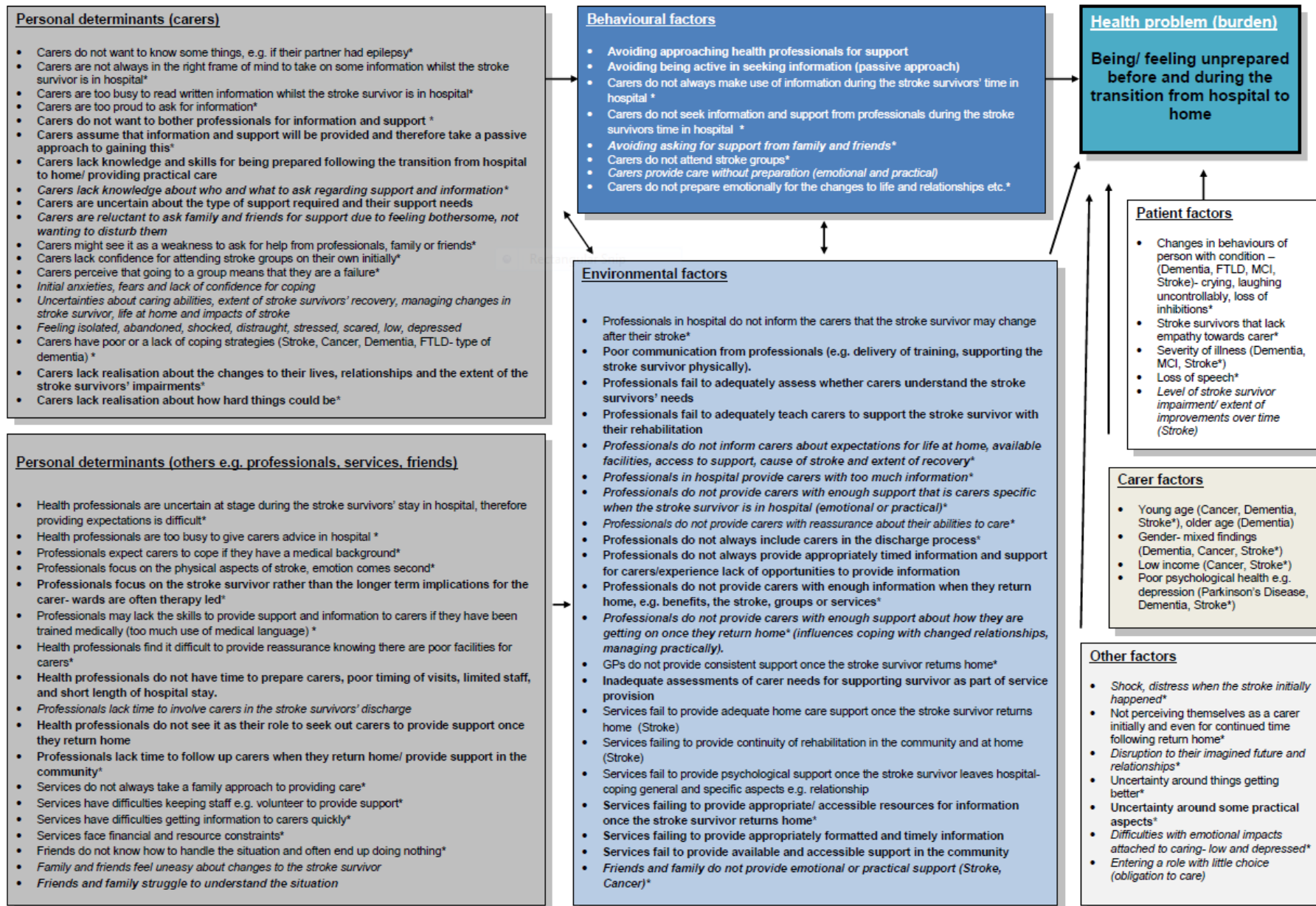


Figure 41: Logic model of prioritised problem



Discussions with stakeholders also indicated that for carers to feel prepared may require intervention beyond the initial transition to home, to the time shortly following this. During this time, carers were still engaging in practical preparation and realised that they were still emotionally unprepared. This was taken into account in the overall programme goal: 'Ensuring carers feel and are prepared, before, during, and following the transition from hospital to home.'

### **8.3.2. Stage two: Programme Outcomes, Performance Objectives, and Determinants; Logic Model of Change**

#### **8.3.2.1 Behavioural and environmental outcomes**

Table 33 outlines 15 behavioural and environmental outcomes informed by different levels of the socio-ecological model. These outcomes were created following the first two meetings and reflect contributions from stakeholders and findings from the needs assessment which indicate that support and information are important for carers' preparation.

At this stage, the timing of the intervention and whether this should focus on support and information (or just one of the two) were unclear. Therefore in the outcomes, the timings were separated e.g. before the transition from hospital to home, and following the transition from hospital to home; and support and information (practical and emotional) were considered separately. Separating these produced a large amount of outcomes, but overcame concerns that something would be missing or unconsidered (table 33).

**Table 33: Behavioural and environmental outcomes, informed by the socio-ecological model (McLeroy et al., 1988)**

<p><b>Overall goal:</b> 'Ensuring carers are prepared before and during (<i>and following</i>) the transition from hospital to home.'</p>
<p><b>Behavioural outcomes:</b>  <b>Individual (carer)</b>            Carer gains information while the stroke survivor is in hospital            Carer gains support while the stroke survivor is in hospital            Carer gains information following the transition from hospital to home            Carer gains support following the transition from hospital to home</p>
<p><b>Environmental outcomes:</b>  <b>Interpersonal (Professionals, family, friends, and peers)</b></p> <p><b>Professionals</b>            Professionals provide useful information to carers while the stroke survivor is in hospital            Professionals provide useful support to carers while the stroke survivor is in hospital            Professionals provide useful information to carers following the transition from hospital to home            Professionals provide useful support to carers following the transition from hospital to home</p> <p><b>Family, friends, and peers</b>            Family, friends, and peers provide useful information to carers while the stroke survivor is in hospital            Family, friends, and peers provide useful support to carers while the stroke survivor is in hospital            Family friends and peers provide useful information to carers following the transition from hospital to home            Family friends and peers provide useful support to carers following the transition from hospital to home</p> <p><b>Organisational (Service)</b>            Services including (hospitals, carer charities, and support groups) promote the involvement of carers to ensure that they are provided with the required information and support during the time when the stroke survivor is in hospital.            Services including (hospitals, carer charities and support groups) promote the involvement of carers to ensure that they are provided with the required information and support following the transition from hospital to home</p> <p><b>Community (relationships among organisations)</b>            Services work together to ensure a continuity of support and information for carers before, during and following the transition from hospital to home</p>

### 8.3.2.2 Performance objectives

There were 168 performance objectives across 15 behavioural and environmental outcomes. Stakeholders shaped these in meeting two, task three by outlining what different individuals and services could do to achieve the intervention goals and outcomes. They wrote responses in behavioural terms. E.g. carers *seek* avenues of support and information; professionals *involve* carers in the discharge process (column two, table 34).

**Table 34: Performance objectives task for stakeholders**

<p><b>What can carers do to be more prepared?</b></p>	<ul style="list-style-type: none"> <li>• Identify questions that need answering</li> <li>• Carers ask friends and family for help</li> <li>• Carers seek avenues of support and information</li> </ul>
<p><b>What can family; friends and peers do to enable carers to be more prepared?</b></p>	<ul style="list-style-type: none"> <li>• Encourage carers to ask for help</li> <li>• Provide support to carers</li> <li>• Offer support to carers</li> </ul>
<p><b>What can professionals do to enable carers to be more prepared?</b></p>	<ul style="list-style-type: none"> <li>• Involve carers in the discharge process and make them more aware of when this is likely to happen in advance.</li> <li>• Inform carers of other services that are available to them - signposting</li> <li>• Encourage carers to ask for help when this is required</li> </ul>
<p><b>What can services do to enable carers to be more prepared?</b></p>	<ul style="list-style-type: none"> <li>• Scale down the information that professionals etc. deliver</li> <li>• Provide services that can support carers once they return home</li> <li>• Make carers and other services aware of the services that they provide</li> </ul>

Performance objectives for each outcome are an expanded list of these behaviours outlined in a detailed sequence. For example, ‘carers seek avenues of support and information’ became the sequence outlined under ‘behavioural objective one’ (relates to information, separate sequence for support). Table 35 includes some examples of performance objectives for outcomes at different levels of the socio-ecological model.

**Table 35: Examples of performance objectives**

<b>Behavioural outcomes</b>
Individual (carer)
<p><b>Behavioural outcome (B01): <i>Carer gains useful information while the stroke survivor is in hospital (before the transition to home)</i></b></p> <p><u>Information within the hospital setting:</u></p> <ul style="list-style-type: none"> <li>➤ PO.1.0: Carers identify questions that need answering (information needs)</li> <li>➤ PO 1.1: Carers access hospital at an appropriate time (during visiting hours)</li> <li>➤ PO1.2: Carers identify staff members in hospital</li> <li>➤ PO1.3: Carers approach staff in hospital to seek information at an opportune time</li> <li>➤ PO1.4: Carers seek or ask for information in an appropriate format (<i>to meet their requirements</i>)</li> <li>➤ PO 1.5: Carers ask further questions about the information provided (<i>to meet their requirements</i>)</li> <li>➤ PO 1.6: Where necessary, carers ask for information about other resources for information</li> <li>➤ PO 1.7: Carers take notes when provided with information (<i>that they can refer back to at a later date</i>)</li> <li>➤ PO 1.8: Carers evaluate whether information is suitable for their requirements</li> <li>➤ PO 1.9: Carers evaluate whether they understand the provided information</li> <li>➤ PO 1.10: In cases where information is inappropriate (format, overload, timing, content etc.) carers communicate this to the provider</li> <li>➤ PO 1.11: Carers seek alternative sources of information if needs are unaddressed</li> </ul>
<b>Environmental outcomes</b>
Interpersonal level
<p><b>Environmental outcome (EO1): <i>Professionals provide useful information to carers while the stroke survivor is in hospital (before the transition to home)</i></b></p> <p><u>Information within the hospital setting</u></p> <ul style="list-style-type: none"> <li>➤ EO 1.0: Health professionals in the hospital setting identify that carers have information needs at this time</li> <li>➤ EO 1.1: Health professionals approach carers at an appropriate time during the stroke survivors' stay to discuss the carers' information needs and come to some mutual agreement about their requirements. <ul style="list-style-type: none"> <li>○ <i>This includes seeking opportunities to involve carers to be able to provide them with this information</i></li> </ul> </li> <li>➤ EO 1.2: Health professionals ask carers about their information preferences (e.g. volume, format, content, timing etc.)</li> <li>➤ EO 1.3: Health professionals provide carers with appropriate information whilst the stroke survivor is in hospital (<i>in accordance with their needs</i>)</li> <li>➤ EO 1.4: Health professionals direct carers to alternative sources of information e.g. leaflets on the ward, relevant websites.</li> <li>➤ EO 1.5: Health professionals ask carers to inform them if information provided does not meet their requirements (e.g. carers struggle to understand this or it is not in an appropriate format etc.).</li> </ul>

- EO 1.6: In cases where information is inappropriate, discuss this with the carers and seek/provide alternative information for carers.
- EO 1.7: Involve carers in the discharge process as a way of providing carers with more information before they make the transition from hospital to home
- EO 1.8: Provide carers with tips and hints to prepare them for their role (practically and emotionally)
- EO 1.9: Health professionals ask carers to contact them for more information if this is required once the stroke survivor returns home

**Environmental outcome (EO 5): *Family friends and peers provide carers with useful information while the stroke survivor is in hospital (before the transition to home)***

- EO 5.0: Family, friends and peers identify that carers have information needs at this time
- EO 5.1: Family, friends and peers approach carers to ask if they require any information
- EO 5.2: Alternatively, family, friends and peers discuss the carers' information needs when/if they contact them seeking answers to their questions
- EO 5.3: Family, friends and peers establish what the carers' information needs are.
- EO 5.4: Family, friends and peers evaluate whether they can answer questions in response to the carers' information needs
- EO 5.5: In circumstances where they are able to assist carers with their questions, they provide information to carers (*likely to be verbal*)
- EO 5.6: In circumstances where they are unable to assist carers without seeking further information, family, friends and peers ask carers what type of information they would like (format etc.)
- EO 5.7: Family, friends and peers seek information for the carer based on their preferences
- EO 5.8: Family, friends and peers encourage carers to tell them if the information is inappropriate (too much, too little).
- EO 5.9: Family friends and peers respond to feedback from carers by seeking alternative information.
- EO 5.10: Family, friends and peers approach professionals (either in hospital or in the community on behalf of the carer to gain useful information).

Organisational (Service) level

**Environmental Outcome (EO9): *Services including (hospitals, carer charities, and support groups) promote the involvement of carers to ensure that they are provided with the required information and support during the time when the stroke survivor is in hospital.***

- EO 9.0: Directors in services identify supporting carers (*with both information and support*) to feel more prepared for their role as a priority.
- EO 9.1: Directors in services adopt a family approach to providing care (*through considering both the stroke survivor and the carer as they prepare for the transition from hospital to home*).
  - *This could include a collaborative approach which involves carers in decision making and other aspects of stroke survivors recovery e.g. rehabilitation.*
  - *Importance of acknowledging that carers have needs that may differ from those of the stroke survivor.*
- EO 9.2: Directors assess adequacy of current services and determine ways to involve carers to be able to provide them with information and support (*hospitals and other support services that carers may use whilst the stroke survivor is in hospital*).

- EO 9.3: Directors assess available resources (*e.g. time, staffing etc.*) for accomplishing inclusion of carers (*in all types of relevant services*)
- EO 9.4: Where resources are available, directors make changes to service provision by allocating time for staff members to provide adequate information and support as part of promoting more effective communication (*not restricted by visiting hours- could include providing opportunities for weekend leave as part of preparing carers*).
  - *This may also involve allocating particular staff members to provide the support and or information.*
- EO 9.5: Where resources are unavailable, directors obtain additional resources/ make changes to resources (*changes to staffing- increase number of volunteers, changes to shift patters to increase staff availability, training for staff*).
- EO 9.6: Directors introduce assessments of carers' understandings of the stroke survivors' needs to determine whether they are prepared for the transition to home.
- EO 9.7: Directors ensure that carers are consistently included in the stroke survivors discharge process as a way of increasing their involvement and opportunities for support and information.
- EO 9.8: Directors ensure that services have appropriate resources for information and support in accordance with the carers' needs (*e.g. information in a variety of formats, support that can meet varied needs including emotional and practical*)
- EO 9.9: Directors ensure that they can facilitate access to useable support and information in alternative services/organisations if it is something that they are unable to provide (*suggestions may include forums for online blogging or support groups*)
- EO 9.10: Directors respond to feedback from carers about their provision of information and support and make changes accordingly (*Can include the design of the information itself or the availability/accessibility of support and information*).
- EO 9.11: In response to feedback, directors create services that are accessible and useful to carers (*Could include opportunities for engaging with similar others as part of preparing for role, opportunities for gaining information*).

Community level (relationships between organisations and networks)

**Environmental outcome (EO 11): *Services work together to ensure a continuity of support and information for carers before, during and following the transition from hospital to home***

- EO 11.0: Directors identify providing consistent support and information as part of preparing carers for their role as important.
- EO 11.1: Directors collaborate with other services for carers to ensure that they are all aware of the different services that are available to carers.
- EO 11.2: Directors collaborate with other services to ensure that the messages provided to cares about preparing them for their roles are consistent.
- EO 11.3 Directors from different services engage in public campaigns about life for carers and stroke survivors in the initial time following the stroke

Theories of information seeking from the perspective of the seeker and provider support these sequences (Gorman, 1999; Wilson, 1999). These theories emphasise the notion of starting by identifying a need then engaging in a problem-solving process to meet needs.

### 8.3.2.3 Determinants

Some determinants included in the overall logic model of burden were taken from conceptual models of stress and burden presented in chapter five e.g. time spent engaging in care tasks in carers of those with Parkinson's disease, based on Goldsworthy and Knowles' stress appraisal model (Goldsworthy and Knowles, 2008). However determinants included in the 'logic model of the prioritised problem' were specific to behaviours and environmental factors identified for the more focused need. These were largely a-theoretical and either based on discussions with stakeholders or findings from studies where authors did not apply theories to understand carers' experiences.

Traditionally theoretical constructs from the literature are selected to create a relevant list of determinants that map onto those outlined in the logic model (in this case logic model of the prioritised problem). The theoretical models identified in chapter five were considered at this stage, however they were inappropriate for this purpose, as they provided a conceptual understanding of stress and burden, but did not incorporate elements of behaviour change required for intervention development using IM. For example, the factors that should be targeted to influence changes in behaviours.

Behaviour change theories such as the theory of planned behaviour (Ajzen, 1985) and social cognitive theory (Bandura, 1989) were also considered but the determinants included in the logic model of the prioritised problem did not map onto a single, unifying theory. However, many determinants in the logic model mapped onto domains included in the Theoretical Domains Framework (Cane et al., 2012). This includes 14 domains from a combination of 33 behaviour change and organisational theories, but it is not uncommon for researchers to select multiple theories at this stage to guide this aspect of the process, and this has previously been applied in the context of IM (Gray-Burrows et al., 2016; Taylor et al., 2013). Given the range of factors influencing behaviours and environmental factors, that were not included in other behaviour change theories, the TDF (Cane et al., 2012) was selected. Table eight, in chapter four outlined the 14 TDF domains (Cane et al., 2012). Figure 42 outlines the domains that mapped onto findings in the logic model of prioritised problem.

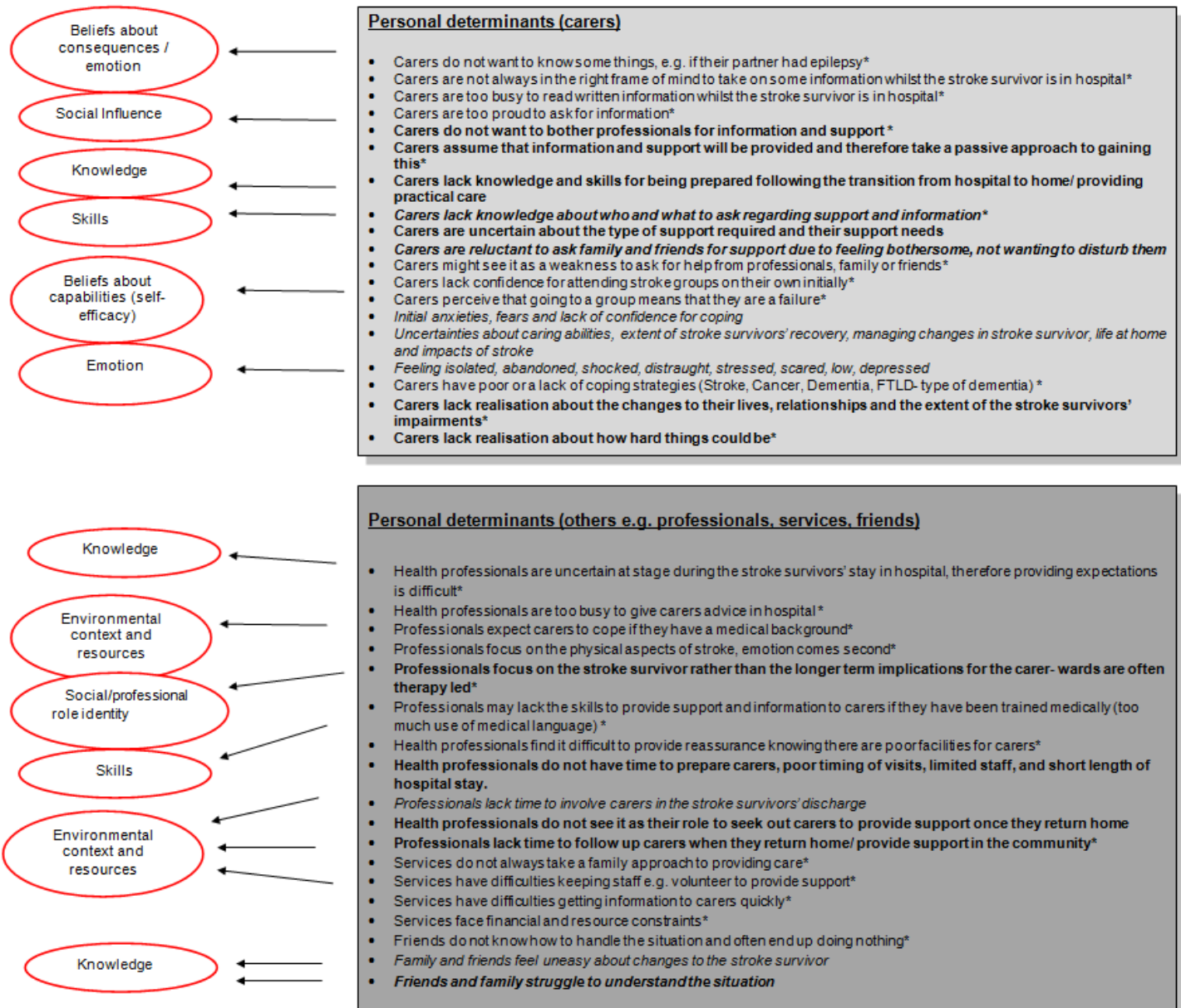


Figure 42: TDF mapped to determinants in the logic model of the prioritised problem



Not all the domains of the TDF were present in the logic model of prioritised problem e.g. reinforcement, intentions, goals, behavioural regulation, memory, attention, and decision-making processes. However, all 14 domains were included in the matrices of change to ensure that they were not discarded prematurely.

#### **8.3.2.4 Matrices of change objectives and the logic model of change**

Fifteen matrices of change objectives were created, addressing all behavioural environmental outcomes (outlined in section 8.3.2.1.). A snap-shot of a 'matrices of change objectives' is provided in figure 43. This is part of the matrices for behavioural objective one: 'carer gains useful information whilst the stroke survivor is in hospital.' Performance objectives are outlined down the left column, determinants (domains of the TDF (Cane et al., 2012)) are listed across the top, and change objectives are outlined at the intersection of each determinant with each performance objective.

<b>(B01) Carer gains useful information while the stroke survivor is in hospital</b>														
<i>Personal determinants (based on domains of the TDF Cane et al. (2012))</i>														
Individual level (carer)														
Performance objectives	Knowledge	Skills	Social/ Professional Role and Identity	Beliefs about capabilities	Optimism	Beliefs about consequences	Reinforcement	Intentions	Goals	Memory, attention and decision processes	Environmental context and resource	Social Influences	Emotion	Behavioural regulation
Information within the hospital setting:														
PO.1.0: Carers identify questions that need answering (information needs).	K.1.0a Carers recognise own information needs  K1.0b Carers know the questions that need answering	S. 1.0 Carers demonstrate their abilities to identify questions that need answering	SPRI 1.0 Carers recognise their role is to identify questions that could be answered	BC. 1.0 Carers believe they are capable of identifying questions that need answering	O 1.0 Carers express positivity about identifying questions that need answering	BAC 1.0 Carers believe that identifying questions that need answering is helpful in gaining information		I. 1.0 Carers intend to/ want to identify questions that need answering	G. 1.0 Carers implement the intention to identify question that need answering	MADP 1.0 Carers remember and use the decision making abilities to identify and think about questions that need answering	ECR 1.0 Carers utilise appropriate resources to facilitate the identification of questions that need answering	SI 1.0 Carers believe that it is socially appropriate to identify questions that need answering	E 1.0 Carers demonstrate emotional capability to attempt to identify questions that need answering	
PO 1.1: Carers access hospital at an appropriate time	K 1.1a Carers state when it would be appropriate to access hospital	S. 1.1 Carers demonstrate their abilities to identify when an appropriate time to access hospital would be.	SPRI 1.1 Carers recognise their role is to access hospital at an appropriate time	BC 1.1 Carers believe they are capable of accessing hospital at an appropriate time	O 1.1 Carers express positivity about accessing hospital at an appropriate time	BAC 1.1 Carers believe that accessing hospital at an appropriate time would be helpful for gaining information	R. 1.1 Carers have an incentive to access the hospital at an appropriate time as this could lead to gaining useful information.	I. 1.1 Carers intend to attend hospital at an appropriate time	G 1.1 Carers implement the intention to access the hospital at an appropriate time	MADP 1.1 Carers use their abilities to identify, think about and remember the most appropriate times for accessing the hospital	ECR 1.0 Carers utilise appropriate resources to facilitate the identification of appropriate times for accessing the hospital	SI 1.1 Carers believe that it is socially appropriate to attend hospital at appropriate times	E 1.1 Carers demonstrate emotional capability to access hospital at an appropriate time	BR 1.1 Carers break usual habits and access hospital at an appropriate time.
PO1.2: Carers identify staff members in hospital	K 1.2 Carers recognise appropriate staff members in hospital setting	S 1.0 Carers demonstrate their abilities to identify appropriate staff members	SPRI 1.2 Carers recognise their role is to identify staff members in hospital	BC 1.2 Carers express confidence about identifying staff members in hospital setting	O 1.2 Carers express positivity about identifying staff members in hospital	BAC 1.2 Carers believe that identifying staff members in hospital is appropriate/ helpful for gaining information	R 1.2 Carers have an incentive to identify staff members in hospital as this could lead to gaining useful information	I 1.2 Carers intend to identify staff members in hospital	G 1.2 Carers implement the intention to identify staff members in hospital	MADP 1.2 Carers use their abilities to identify and think about appropriate staff members	ECR 1.2 Carers use appropriate resources to facilitate the identification of appropriate staff members	SI 1.2 Carers believe that it is socially appropriate to identify staff members in hospital	E 1.2 Carers demonstrate emotional capability to attempt to identify staff members in hospital	

Figure 43: Snap-shot of a matrices of change objectives

After the fifteen matrices of change were created, the shift from problems to change was captured in a logic model of change. Traditionally, this model includes the programme goal, behavioural and environmental outcomes, performance objectives, determinants of behaviours and change objectives. The model presented below (figure 44) includes these factors but these were consolidated to capture the vast volume of data presented across the matrices.

The programme goal identified in stage one is outlined on the left. The four original behavioural outcomes outlined in table 33 are included and the environmental outcomes relating to professionals, family, friends and peers were reduced to avoid repetition. Together these individuals are referred to as 'information and support providers' as at this stage it was unclear who this person may be before further engagement with stakeholders.

It was evident that the performance objectives represented a sequence of behaviours requiring collaboration between a carer and an 'intervention and support provider' to meet the programme outcomes and goals. These were reduced into the six stages presented in the model. The theoretical determinants from the TDF (Cane et al., 2012) and change objectives are included in the boxes on the right. The change objectives state what the intervention should modify to influence performance objectives to achieve the behavioural and environmental outcomes. These were also consolidated to mirror the consolidated performance objectives. In stage three, theoretical methods and practical applications are selected to address the change objectives and relevant determinants.

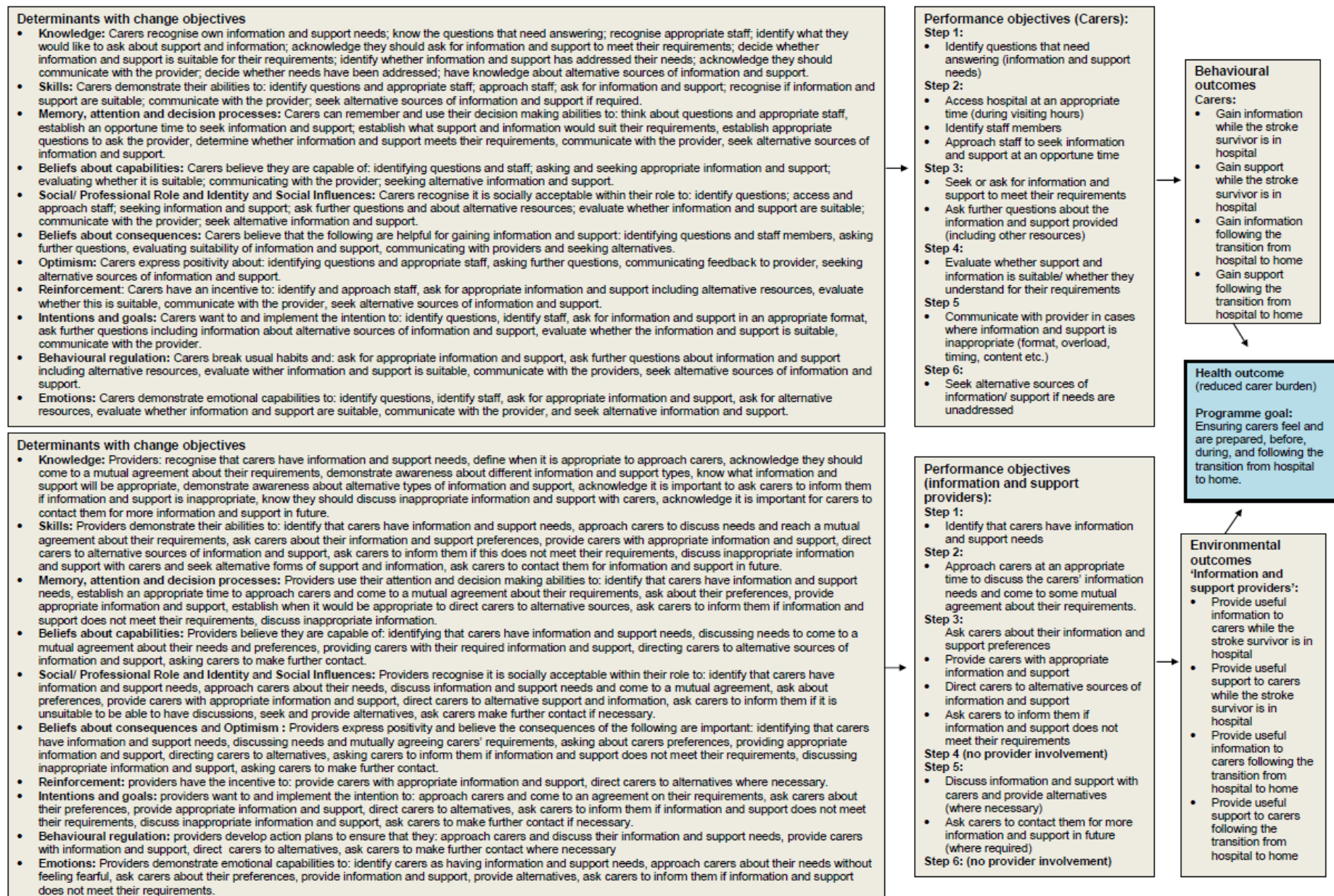
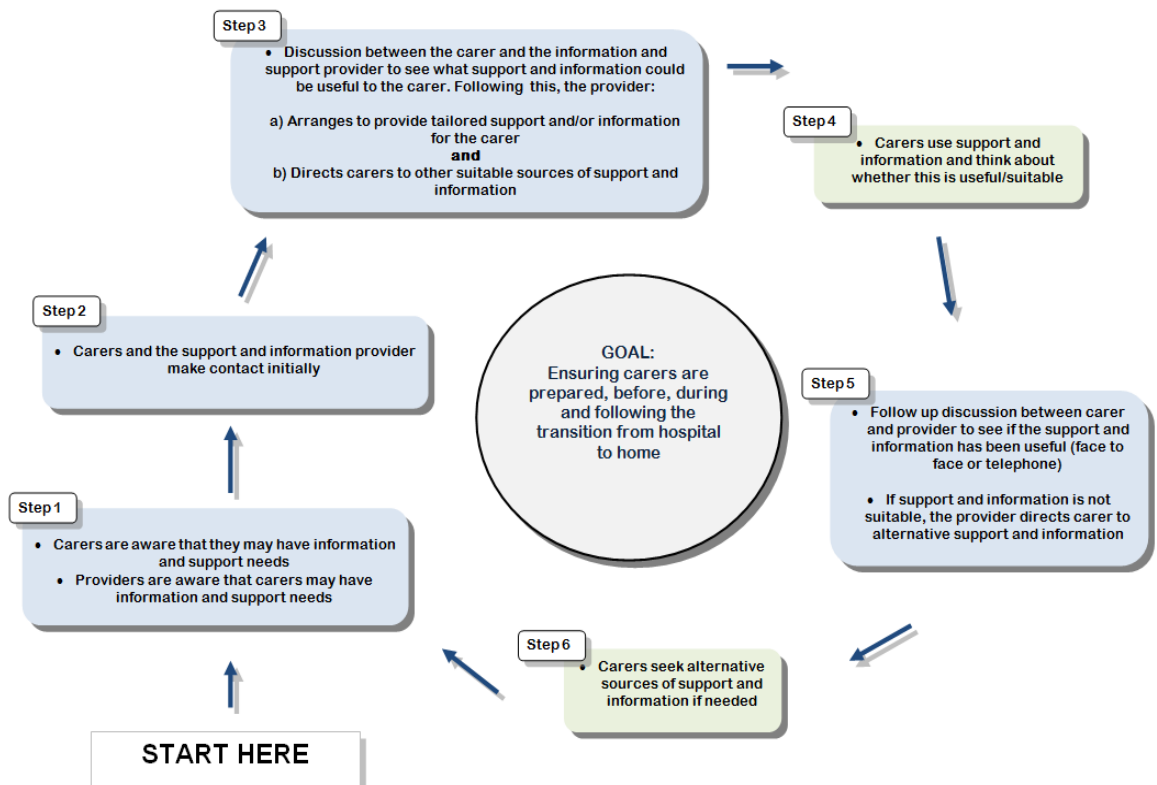


Figure 44: Logic model of change

### 8.3.3. Stage three: Programme Design (Methods and strategies).

#### 8.3.3.1 Programme ideas

The flow diagram presented to stakeholders in meeting three is based on stages of consolidated performance objectives related to both the 'information and support provider' and the 'carer,' to emphasise the collaboration required to meet the goal of the intervention that were outlined in the logic model of change. This flow diagram provided a basis for generating programme ideas.



**Figure 45: Flow diagram based on consolidated performance objectives**

Before engaging in two structured tasks in meeting three, stakeholders provided feedback about the ideas presented, and emphasised the importance of consistency and structure in how support and information is provided to carers as part of their preparation.

In task one, regarding the context and timing of the intervention, stakeholders agreed when, how, and where carers would benefit from input to gain support and information

that they need to feel prepared. They suggested this should be during the carers' time in hospital, continuing across the transition from hospital to home, in face to face discussions at hospital, then either in the carers' own homes or GP surgeries.

They favoured early intervention, starting in the hospital, because this gives the carers time to understand and come to terms with their new role and an ongoing contact is important as new problems arise. They also thought this would be useful for building up a relationship with the carer and the wider family. Face-to-face contact was preferred so professionals could make better judgements about a situation and understand carer needs. Stakeholders recognised some people do not want support all the time, so it is about finding a balance to suit different needs.

It was less clear who should take on the role of the information and support provider. Stakeholders talked about the importance of someone taking on this role to be a carer specific contact, yet they would need to be embedded in a wider team. Stakeholders suggested: someone in the stroke ward, community based staff, GPs, or an additional role. The barriers and facilitators of this person being an existing staff member or creating an additional role, taken from discussions with stakeholders from this meeting and meeting four are outlined in section 8.3.4.3.

Stakeholders ideas about 'what' carers could be given during discussions with the information and support provider to facilitate preparation included: a log of contacts on either a key ring or credit card sized card; access to a helpline, an 'in case of' plan to guide carers through scenarios (e.g. if I struggle, I will do x, y, and z). They emphasised a preference for signposting, rather than being provided with too much information, hence their ideas for facilitating preparation.

In task two, stakeholders contributed their ideas regarding the programme, scope, and sequence of an intervention required to ensure the information and support provider is equipped to help carers feel more prepared by providing them with the right support and information. Stakeholders thought that a training package for the information and support provider was appropriate; this became the focus for ideas.

Their preferences for programme design and content were: a training package including modules with interactive and written content for 'information and support providers' and a session for staff in the wider teams. Delivery preferences included face-to-face training and supervision sessions focused on meeting competencies. Ideas about resources and materials included appropriate funding, training package materials, and resources for

materials provided to carers e.g. key rings. Further details about the stakeholders' ideas are presented in table 36.

**Table 36: Ideas about the programme, scope and sequence of the intervention**

<p><b>Programme : Design and content</b></p>	<p><b>Ideas for programme:</b> Training package including different modules, including advanced modules (where appropriate).</p> <p><b>Key messages:</b></p> <ul style="list-style-type: none"> <li>• Acknowledge carer concerns from the start and support carers to address their needs.</li> <li>• Avoid making assumptions about carer needs and engage in conversations to tailor support and information to their needs.</li> <li>• Reduce the focus on the term 'carer' and ensure that they can be prepared as they can be as a 'family member' or 'friend.'</li> <li>• Gain a balance between supporting carers and promoting proactive-ness.</li> <li>• Ensure carers are aware of their information and support options.</li> </ul> <p><b>Content of modules:</b></p> <ul style="list-style-type: none"> <li>• Providing knowledge about the prognosis of stroke; financial information and legislation and local services for signposting.</li> <li>• Providing skills and knowledge to identify emotional triggers.</li> <li>• Focus on supporting carers psychologically to protect their wellbeing.</li> </ul>
<p><b>Scope and sequence: Delivery</b></p>	<p><b>How</b></p> <ul style="list-style-type: none"> <li>• Face to face training for 'staff' or person/ people taking on a supportive role.</li> <li>• Supervision alongside a formal training package including meeting competencies to demonstrate impacts of working with carers.</li> <li>• Spending time with other agencies as part of the training/ learning.</li> <li>• Package would need to be tailored to each area (e.g. service-hospital) but the overall idea of the training and key messages would remain the same.</li> <li>• All staff members involved require the same or very similar training because you never know when someone is ready for the next support. This would also give the staff a network of support for each other</li> <li>• Different training might be required for the information and support provider then the wider team that are involved in supporting stroke survivors and carers as part of existing practice.</li> </ul>
<p><b>Programme, scope and sequence: Resources and materials</b></p>	<p><b>Resources:</b></p> <ul style="list-style-type: none"> <li>• Package must fit with current resources within services</li> <li>• If existing staff are used they must have capacity to take on the role.</li> <li>• Funding must be available to train someone to take on this 'additional role' as an information and support provider.</li> </ul> <p><b>Materials:</b></p> <ul style="list-style-type: none"> <li>• Training package materials, including competency booklets.</li> <li>• Resources for any materials provided to carers e.g. key rings</li> </ul>

### 8.3.3.2 Theoretical methods and practical applications

Before establishing the active ingredients by selecting theoretical methods and practical applications that are appropriate for varied determinants, stakeholders contributed to discussions about determinants (meeting three, task three). Determinants taken from the TDF (Cane et al. 2012), grouped determinants according to Bartholomew et al.'s (2011) categories of theoretical methods used to target determinants, and reduced language appropriate determinants for stakeholders are detailed in table 37:

**Table 37: Determinants, grouped determinants and reduced determinants**

Determinants based on the TDF (Cane et al., 2012)	Determinants grouped according to categories of theoretical methods (Bartholomew et al., 2011)	Translation for stakeholders
<ul style="list-style-type: none"> <li>Knowledge</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> <li>Methods to increase knowledge</li> </ul>	<ul style="list-style-type: none"> <li>Knowledge</li> </ul>
<ul style="list-style-type: none"> <li>Skills</li> <li>Memory, Attention, and Decision Processes</li> <li>Beliefs about Capabilities</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> <li>Methods to change skills, capability, and self-efficacy to overcome barriers</li> </ul>	<ul style="list-style-type: none"> <li>Skills and Decision Making Abilities</li> </ul>
		<ul style="list-style-type: none"> <li>Confidence in their own capabilities</li> </ul>
<ul style="list-style-type: none"> <li>Social/ Professional Role and Identity</li> <li>Social Influences</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> <li>Methods to change social influence</li> </ul>	<ul style="list-style-type: none"> <li>How they see their role/ professional role</li> </ul>
<ul style="list-style-type: none"> <li>Beliefs about consequences</li> <li>Optimism</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> <li>Methods to change attitudes, beliefs, and outcome expectations</li> </ul>	<ul style="list-style-type: none"> <li>Beliefs and attitudes</li> </ul>
<ul style="list-style-type: none"> <li>Reinforcement</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> </ul>	<ul style="list-style-type: none"> <li>Reasons or incentives for actions and behaviours</li> </ul>
<ul style="list-style-type: none"> <li>Intentions</li> <li>Goals</li> <li>Behavioural Regulation</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> <li>Methods to change habitual, automatic, and impulsive behaviours</li> </ul>	<ul style="list-style-type: none"> <li>Intentions and goals</li> </ul>
<ul style="list-style-type: none"> <li>Emotion</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> </ul>	<ul style="list-style-type: none"> <li>Emotions</li> </ul>
<ul style="list-style-type: none"> <li>Environmental context and Resources</li> </ul>	<ul style="list-style-type: none"> <li>Basic methods at the individual level</li> </ul>	<ul style="list-style-type: none"> <li>Having the Right Context for the Intervention and Resources in Place</li> </ul>



Stakeholders focused on determinants related to the information and support providers, these are outlined in table 38 with further details about context.

**Table 38: Determinants discussed by stakeholders**

<b>Discussed determinants</b>	<b>Context (how determinants could be targeted)</b>
Beliefs about capabilities (self-efficacy)	Staff members on wards do not always have the confidence to deal with certain issues. For example physiotherapists are confident in therapy sessions, yet lack confidence about providing carers with information once they return home.
Social/ Professional Role identity Social Influences	Staff members often think it is someone else's role to support carers, and then it doesn't happen.  Staff members need to feel that it is acceptable to provide support that differs from their medical training.
Emotion	The person taking on the role to support carers would need support through supervision as it could become stressful.
Knowledge	Knowledge about financial aspects; local services and befriending; different types and symptoms of strokes; varied carer needs; emotional support; and identifying triggers.
Skills Memory, Attention and Decision Processes	Skills to: tailor conversations to individuals and their circumstances; provide emotional support; and identify triggers for when people need emotional support.
Environmental context and resources	Staff undertaking role need to see carers in a private place e.g. their own home.

Considering the feedback from stakeholders, in addition to evidence from theories and the logic model of the prioritised problem, all 14 determinants were relevant to some extent. A lack of theory based evidence for these behaviours compared to other 'model' health behaviours (e.g. physical activity) meant it was difficult to prioritise some over others and all determinants were considered.

Seven tables of methods and practical applications were created, one for each group of determinants. These were re-organised into six tables, one for each step in the flow diagram based on consolidated performance objectives (section 8.3.3.1). The seven tables of methods and practical applications are lengthy, instead of including whole tables, snapshots of some of the tables are provided in this section, with annotations.

The first table (39) is a snap-shot of one of the seven tables for one group of determinants (social professional role and identity and social influences). The change objectives listed under step one in the flow diagram 'carers are aware that they may have information and support needs' relate to carers recognising it is their role to identify questions regarding their information and support needs, as well as believing it is socially acceptable to do so. 'Information about others' approval' was selected as an appropriate theoretical method to target the change objectives, given the emphasis on providing information about whether others e.g. information and support providers approve of carers thinking of questions to ask about their needs as they arise. Considering this and the parameters of effectiveness, an initial introduction between the information and support provider and carer, and a brief written information sheet were selected to target the change objectives.

The second snap-shot of table 39 is from the same table, except the change objectives focus on the information and support providers. These relate to the information and support providers': recognising it is their role to identify and approach carers about their needs (social professional role and identity); and believing that these behaviours are socially acceptable (social influences). Two different theoretical methods were selected to target these change objectives: 'modelling' and 'belief selection.' These were considered important given the emphasis on beliefs and role behaviours.

Taking the example of modelling, it was thought that providing information and support providers with video clips of successful interactions with carers as part of training would be appropriate. To ensure that the parameters of effectiveness are considered, videos would include appropriate role models to enhance the likelihood that their behaviour is reinforced.

**Table 39: Example of theoretical methods and practical applications relating to carers and information and support providers**

Determinants and Change Objectives for Carers	Methods	Parameters	Examples	Applications	How population, context and parameters were taken in to account.
Determinants and Change Objectives for 'Information and Support provider'					
<ul style="list-style-type: none"> <li>• <b>Social professional role and identity</b></li> <li>• <b>Social influences</b></li> </ul> <b>Based on methods to change social influence (adapted from methods by Bartholomew et al., 2011; 2015)</b>					
<ul style="list-style-type: none"> <li>• <b>Carers are aware that they may have information and support needs</b></li> </ul>					
<p>Carers recognise their role is to identify questions that could be answered (<i>Social Role and Identity</i>)</p> <p>Carers believe that it is socially appropriate to identify questions that need answering (<i>Social Influences</i>)</p>	<p><b>Information about others' approval</b> (<i>theory of planned behaviour; Reasoned action approach; Social Comparison Theory; Forsyth, 2014; Mollen, Ruiter and Kok, 2010</i>) – providing information about what others think about the person's behaviour and whether others will approve or disapprove of any proposed change</p>	<p>Positive expectations are available in the environment</p>	<p>Something in the hospital environment that allows carers to see that it is socially appropriate to speak to the 'information and support provider'</p>	<p>As noted at in tables re knowledge, skills, MADP and BAC, carers would need to be made aware of staff or the information and support provider by being introduced during the stroke survivors' time in hospital.</p> <p>In this introduction, it</p>	<p>Population: Information and support providers and other staff members in the team would introduce themselves to the carers</p> <p>Context: In the hospital setting, at an appropriate time</p> <p>Parameters: Positive expectations would be available in the environment if carers were approached (<i>it may also be appropriate to provide a brief written material at this stage- with an image of the information and support provider and their role</i>).</p>
				<p>could be made clear to carers that they can ask any questions that arise.</p>	<p>Application based on the theoretical method</p> <ul style="list-style-type: none"> <li>• Introduction between carer and information and support provider</li> <li>• Brief written introduction information</li> </ul>

Recognising the change objectives by determinants:

Included both 'social/professional role and identity' and 'social influences' in the same table because the theoretical methods that can be used such as 'information about others approval' apply to both determinants.

It is essential that methods are identified and parameters are considered in the translation from methods to practical applications

Parameters differ for different methods and influence the practical applications

<p>Information and support providers recognise their role is to identify that carers have information and support needs (<i>Social Role and Identity</i>)</p> <p>Information and support providers believe it is socially acceptable to identify carers as having information and support needs (<i>Social Influences</i>)</p> <p>Information and support providers recognise their role is to approach carers at an appropriate time about their information and support needs (<i>Social Role and Identity</i>)</p> <p>Information and support providers believe that it is socially appropriate to approach carers about their information and support needs (<i>Social Influences</i>)</p>	<p><b>Modelling</b> (<i>Social cognitive theory; Theories of learning; Kazdin 2008; Kelder et al., 2015</i>) – providing an appropriate role model being reinforced for a desired action</p> <p><b>Beliefselection</b> (<i>theory of planned behaviour; Reasoned action approach; Fishbein and Ajzen 2010</i>) - Using messages designed to strengthen positive beliefs, weaken negative beliefs and introduce new beliefs</p>	<p>Attention, remembrance, self-efficacy and skills, reinforcement of model, identification with model, coping model instead of mastery model.</p> <p>Requires investigation of the current attitudinal, normative and efficacy beliefs of the individual before choosing the beliefs on which to intervene.</p>	<p>Trainer finds an appropriate model who will encourage engagement in appropriate discussions with carers.</p> <p>Programme to change the beliefs around being passive in supporting carers to be prepared before and during the transition from hospital to home.</p>	<p>Information and support providers provided with examples of successful interactions with carers where they discuss the carers' having information and support needs (video).</p> <p>This could be included as part of a module focussing on:  <i>"Approaching carers and being there for carers."</i>          As part of discussions</p>	<p>Population: models used within the training</p> <p>Context: formal training sessions including discussions and appropriate materials</p> <p>Parameters: models would be other information and support providers (or other relevant professionals) that are reinforced for the right behaviour.</p> <p>Population: models used within the training</p> <p>Context: formal training sessions including discussions and appropriate materials</p> <p>Parameters: the beliefs of individuals would be explored as part of activities before attempting to encourage</p>
				<p>outlined as part of addressing knowledge, skills etc., can explore current beliefs before engaging in other activities during the training.</p>	<p>them to be less passive around supporting carers to be prepared before and during the transition from hospital to home.</p>

Ideas for modules in the training package.

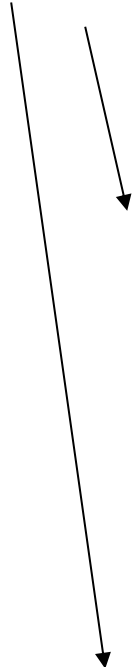
Across the seven tables for each group of determinants, there were many ideas for practical applications based on different determinants and different theoretical methods (but with some overlap). Outlining ideas in each table in the order of stages in the flow diagram based on consolidated performance objectives was helpful for establishing an order in which some of the practical applications may be useful. For example, an initial introduction between the information and support provider (with brief written information) would be important before any further engagement or provision of concrete materials e.g. key rings of contacts.

However, I reorganised the data into six further tables to represent each stage in the flow diagram. These tables established where the same methods and practical applications were used to target different determinants. Again, these tables are lengthy so a snap-shot of the table for the third step in the flow diagram with annotations is presented as an example (table 40). Multiple determinants from different groups are included in this table. For example, modelling was selected as an appropriate theoretical determinant to target all the listed change objectives, despite different determinants. In this case the application: 'an in case of' plan was applicable for addressing all change objectives.

**Table 40: Example of reorganised theoretical methods and practical applications to address multiple determinants**

Determinants and Change Objectives for Carers	Methods	Parameters	Examples	Applications	How population, context and parameters were taken in to account.
Determinants and Change Objectives for 'Information and Support provider'					
<b>All determinants (Based on methods adapted from Bartholomew et al., 2011; 2015)</b>					
<b>Step 3 Discussion between the carer and the information and support provider to see what support could be useful to the carer</b>					
• <b>(Carer focus)</b>					
Carers believe that asking further questions about the information provided is helpful ( <i>beliefs about consequences</i> )  Carers express positivity about asking further questions ( <i>Optimism</i> )	<b>Modelling</b> ( <i>Social cognitive theory; Theories of learning; Kazdin 2008; kelder et al., 2015</i> ) - providing an appropriate role model being reinforced for a desired action	Attention, remembrance, self-efficacy and skills, reinforcement of model, identification with model, coping model instead of mastery model.	Carers could be provided with written information during discussion that includes a role model (another carer) that serves as a model for gaining the appropriate support and information as part of being prepared	This could be part of the 'in case of...' plan.  It could be written in a way that includes a role model (carer)	Population: models selected that are relevant to carers  Context: Information provided to carers within the hospital setting but can be used <del>aside from the</del> hospital setting.  Parameters: models would be carers that are reinforced for the right behaviour.
Carers recognise their role is to seek or ask for information and support in an appropriate format (Social Role and Identity)  Carers believe that it is socially	<b>Modelling</b> ( <i>Social cognitive theory; Theories of learning; Kazdin 2008; kelder et al., 2015</i> ) - providing an	Attention, remembrance, self-efficacy and skills, reinforcement of model, identification with model, coping model instead of mastery model.	Carers could be provided with written information during discussion that	This could be part of the 'in case of...' plan.  It could be written in a	Population: models selected that are relevant to carers  Context: Information provided to carers within
appropriate format (Social Influences)	reinforced for a desired action		carer) that serves as a	model (carer)	hospital setting.

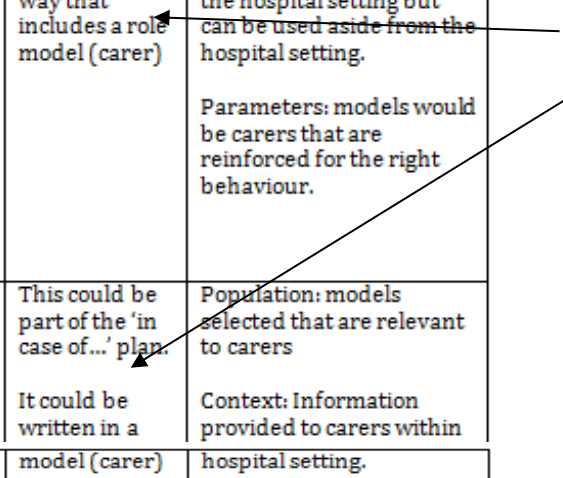
Same method (modelling) used for multiple determinants



Consolidated performance objective (step 3 in flow diagram)



Same practical applications across different determinants



Creating these additional tables and supporting summaries provided clarity while drawing together ideas for possible elements that were incorporated into the proposed intervention.

#### **8.3.4. Stage four: Programme production (an organised programme plan)**

##### **8.3.4.1 Established intervention components**

This stage required the translation of practical strategies into programme components, considering their context, delivery and design features.

Various intervention components incorporating theory based methods were established contributing to the planned intervention titled 'Preparing is Caring.' These include: a training package for the information and support providers working with carers (including an induction plus five key modules and on-going supervision sessions); an additional training session for the wider staff team and elements to support carers to feel prepared. These are presented below with visual representations of each component.

# 'Preparing is Caring' intervention components

## Training package for the 'information and support provider' *'Preparing is caring'*



Interactive training sessions



Some written materials as part of training sessions



## Training for the wider staff team

'One off' session outlining key messages around involving carers and ensuring that they are prepared before, during and following the transition from hospital to home



## On-going learning:

Supervision meetings alongside training modules

Meeting competencies



Initial introduction between the carer and the information and support provider

Brief written document



Face to face discussions between the carer and the information and support provider - on-going from hospital to home

Carers take notes to increase likelihood of preparation



Carers provided with either:

- A key ring

Or

- A key contacts card

These include a number for a helpline that carers can contact

An 'in case of plan' for carers which includes relevant contact numbers (listed in the back) for both practical and emotional needs



The training package for the information and support provider is to equip them to support carers to feel prepared before, during and following the transition from hospital to home. This targets multiple determinants including skills, knowledge and beliefs about capabilities across five different modules. Stakeholders previously suggested that 'information and support providers' should be provided with written materials and engage in different interactive sessions as part of the modules. This idea was maintained and these have been developed further, therefore different modules include content based on varied theoretical methods e.g. modelling, persuasive communication; and practical applications e.g. role plays, discussions following video clips.

The supervision sessions focus on meeting competencies. This idea was favoured by the stakeholders as an opportunity for ongoing learning and to provide evidence for the impacts of working with carers. These sessions target multiple determinants including beliefs about capabilities and skills. Stakeholders' idea to include a shorter training session for the wider staff team was maintained. They valued this idea so that all those involved in supporting carers received key messages about involving carers and ensuring they are prepared. This was also to promote consistency within teams and a culture of supporting carers in addition to stroke survivors. This is a reduced training package based on ideas within the main training package.

The information and support providers would provide carers with additional elements to assist preparation before, during and following the transition from hospital to home e.g. brief written introduction document, key ring or card or key contacts and the 'in case of...' plan (outlined above). Each element is also based on varied theoretical methods that target numerous determinants including knowledge, beliefs about consequences, reinforcement.

Tables 41 and 42 provide further details about each component. Table 41 outlines the training package including supervision sessions and additional training, key messages, determinants, theoretical methods, and practical applications. Table 42 outlines elements of the intervention to support carers to feel prepared, reasons why these are important, determinants, theoretical methods, and practical applications.

**Table 41: Detailed outline of the training package, supervision sessions and additional training**

Training for information and support providers				
Modules	Key messages	Determinants	Theoretical methods	Practical applications
Carers have varied needs	<ul style="list-style-type: none"> <li>• Carers need to be included in conversations about their needs and have the opportunities to build up relationships with appropriate staff.</li> <li>• The distinction between the carers' own needs and their needs in terms of supporting the survivor.</li> <li>• Carers should be considered in their own right and valued by services.</li> <li>• Need for openness to understanding broader carer needs aside from supporting the stroke survivors in their recovery.</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• Discussion</li> <li>• Elaboration</li> <li>• Active learning</li> </ul>	<ul style="list-style-type: none"> <li>• Video clips followed by discussions (with some interactive learning)</li> </ul>
		<ul style="list-style-type: none"> <li>• Skills</li> <li>• Memory, attention and decision processes</li> </ul>	<ul style="list-style-type: none"> <li>• Active learning</li> </ul>	
		<ul style="list-style-type: none"> <li>• Beliefs about capabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Guided practice</li> </ul>	<ul style="list-style-type: none"> <li>• Role plays</li> </ul>
		<ul style="list-style-type: none"> <li>• Beliefs about consequences</li> <li>• Optimism</li> </ul>	<ul style="list-style-type: none"> <li>• Shifting perspective</li> </ul>	<ul style="list-style-type: none"> <li>• Additional interactive learning activity following role plays</li> </ul>
Positive engagement: Approaching and being there for carers in the transition from	<ul style="list-style-type: none"> <li>• The importance of being there for the carer from when the stroke happens throughout the transition from hospital to home (including circumstances where the stroke survivor is entering a home).</li> </ul>	<ul style="list-style-type: none"> <li>• Social role and identity</li> <li>• Emotion</li> <li>• Beliefs about consequences</li> <li>• Optimism</li> </ul>	<ul style="list-style-type: none"> <li>• Belief selection</li> </ul>	<ul style="list-style-type: none"> <li>• Discussions and written scenarios</li> </ul>

hospital to home	<ul style="list-style-type: none"> <li>• Carers needs and worries need to be acknowledged from the outset</li> <li>• The importance of tailoring conversations to individuals and their circumstances</li> <li>• Finding the balance between being there for the carer and encouraging a proactive carer.</li> <li>• Being aware of their own limitations and direct carers elsewhere when appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge</li> <li>• Skills</li> <li>• Memory, attention and decision processes</li> </ul>	<ul style="list-style-type: none"> <li>• Facilitation</li> </ul>	
		<ul style="list-style-type: none"> <li>• Emotion</li> <li>• Social role and identity</li> <li>• Social influences</li> <li>• Beliefs about capabilities</li> <li>• Reinforcement</li> </ul>	<ul style="list-style-type: none"> <li>• Modelling</li> </ul>	<ul style="list-style-type: none"> <li>• Video clips with successful interactions</li> </ul>
Your role and the role of others in your team	<ul style="list-style-type: none"> <li>• It is part of the information and support providers' role to approach the carers at an appropriate time as part of making initial and ongoing contact with carers</li> <li>• Information and support providers should not be passive towards supporting carers to feel prepared before and during the transition from hospital to home</li> </ul>	<ul style="list-style-type: none"> <li>• Social role and identity</li> <li>• Social influences</li> <li>• Beliefs about consequences</li> <li>• Optimism</li> </ul>	<ul style="list-style-type: none"> <li>• Belief selection</li> </ul>	<ul style="list-style-type: none"> <li>• Discussions and written or picture based scenarios</li> </ul>
		<ul style="list-style-type: none"> <li>• Intentions</li> <li>• Goals</li> <li>• Behavioural regulation</li> </ul>	<ul style="list-style-type: none"> <li>• Implementation intentions</li> </ul>	<ul style="list-style-type: none"> <li>• No specific activity, delivered as part of teaching</li> </ul>
Different types of support and information to address carer needs	<ul style="list-style-type: none"> <li>• Signposting carers to the right information is important</li> <li>• Information and support providers need to engage in</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge</li> <li>• Skills</li> <li>• Memory, attention and decision processes</li> </ul>	<ul style="list-style-type: none"> <li>• Active learning</li> </ul>	<ul style="list-style-type: none"> <li>• Written information followed by learning activities</li> </ul>

	<p>discussions with carers around options for support and information that are tailored to their needs</p> <ul style="list-style-type: none"> <li>• Services need to work together the facilitate efficient signposting</li> </ul>	<ul style="list-style-type: none"> <li>• Beliefs about capabilities</li> </ul>		
		<ul style="list-style-type: none"> <li>• Intentions</li> <li>• Goals</li> <li>• Behavioural regulation</li> </ul>	<ul style="list-style-type: none"> <li>• Planning coping responses</li> </ul>	<ul style="list-style-type: none"> <li>• Video clips followed by discussions (with some interactive learning)</li> </ul>
Caring for yourself as part of being prepared to care	<ul style="list-style-type: none"> <li>• Taking on this role can be stressful and at times emotionally exhausting, therefore it is important that you look after yourself to be successful in the role</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge</li> <li>• Skills</li> </ul>	<ul style="list-style-type: none"> <li>• Active learning</li> </ul>	<ul style="list-style-type: none"> <li>• Mind-maps and discussions</li> </ul>
Supervision sessions alongside the training modules				
Key messages		Determinants	Theoretical methods	Practical applications
<ul style="list-style-type: none"> <li>• Ongoing learning aside from the formal training is important for the information and support providers</li> </ul>		<ul style="list-style-type: none"> <li>• Beliefs about capabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Guided practice</li> <li>• Feedback</li> </ul>	<ul style="list-style-type: none"> <li>• Face to face verbal discussions</li> <li>• Document to list competencies relating to different role requirements.</li> </ul>
		<ul style="list-style-type: none"> <li>• Emotions</li> <li>• Skills</li> <li>• Memory, attention and decision processes</li> <li>• Social role and identity</li> <li>• Social influences</li> </ul>	<ul style="list-style-type: none"> <li>• Feedback</li> </ul>	
		<ul style="list-style-type: none"> <li>• Reinforcement</li> </ul>	<ul style="list-style-type: none"> <li>• Reinforcement</li> </ul>	

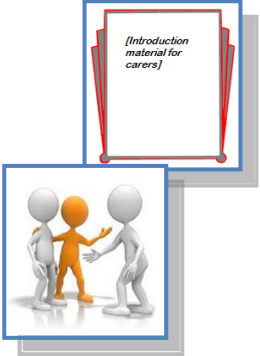
Additional training for other staff in wider team


Key messages



- Provide staff with the skills and knowledge to be able to converse with carers appropriately and acknowledge that they might need support and information to feel prepared.
- Develop and promote a culture that is shared among the information and support provider and the wider staff team.

Shorter version of the main training package.


**Table 42: Elements of the intervention to support carers to feel prepared**

Intervention components	Why is this important?	Determinants	Theoretical methods	Practical applications
<p><b>Element 1:</b> Initial introduction between the information and support provider and carer</p> 	<p>This is important so that carers:</p> <ul style="list-style-type: none"> <li>• Are aware of who they can contact during the time when they need to prepare before and during the transition from hospital to home.</li> <li>• See it as their role to be proactive in seeking support and information with the right support from the information and support provider.</li> <li>• Have reinforced beliefs about being proactive in seeking support and information in the right supportive environment.</li> <li>• Feel positive about the consequences of seeking support, asking questions and engaging in useful discussions about their preferences.</li> <li>• Feel emotionally capable of seeking support and information due to the supportive environment.</li> </ul>	<ul style="list-style-type: none"> <li>• Social role and identity</li> <li>• Social influences</li> <li>• Emotion</li> <li>• Skills</li> <li>• Memory, attention and decision Processes</li> <li>• Beliefs about capabilities</li> <li>• Beliefs about consequences</li> <li>• Optimism</li> <li>• Reinforcement</li> </ul>	<ul style="list-style-type: none"> <li>• Information about others' approval</li> <li>• Facilitation</li> <li>• Belief selection</li> <li>• Modelling</li> </ul>	<p>Face to face verbal introduction between the information and support provider and carer</p> <p>Written material (a4 sized paper based) including image of the information and support provider</p>
<p><b>Element 2:</b> Face to</p>	<p>This is important so that carers:</p>	<ul style="list-style-type: none"> <li>• Knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• Discussion</li> </ul>	<p>Face to face,</p>

<p>face discussions between the carer and the information and support provider</p> 	<ul style="list-style-type: none"> <li>• Can positively engage with the information and support provider.</li> <li>• Have the opportunity to share concerns and to be told that it is normal to feel emotional following their loved ones stroke.</li> <li>• Gain tailored information and support for their needs as they change over time.</li> <li>• Take a proactive approach to seeking alternative support and information through the right guidance.</li> </ul> <p>(Many of the points outlined in element 1 also apply here).</p>	<ul style="list-style-type: none"> <li>• Skills</li> <li>• Memory, attention and decision Processes</li> <li>• Beliefs about capabilities</li> </ul>		<p>verbal discussions between the information and support provider that are ongoing from the transition from hospital to home</p>
<p><b>Element 3:</b> Carer takes notes away from the hospital setting to increase likelihood of</p>	<p>This is important so that carers:</p> <ul style="list-style-type: none"> <li>• Can write down any questions that they would like to ask the information and support provider</li> <li>• Can keep a record of whether information and</li> </ul>	<ul style="list-style-type: none"> <li>• Intentions</li> <li>• Goals</li> <li>• Behavioural regulation</li> </ul>	<ul style="list-style-type: none"> <li>• Facilitation</li> <li>• Implementation intentions</li> </ul>	<p>Note taking by hand using paper based materials</p>

<p>being prepared by gaining the appropriate information and support</p> 	<p>support was useful or not and whether they understand this. These behaviours could be encouraged as part of discussions outlined above.</p>	<ul style="list-style-type: none"> <li>• Skills</li> <li>• Memory, attention and decision Processes</li> <li>• Beliefs about capabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Self-monitoring of behaviour</li> </ul>	
<p><b>Element 4:</b> Materials to support carers to gain the information and support that they need to feel prepared before and during the transition from hospital to home</p> 	<p>This is important so that carers:</p> <ul style="list-style-type: none"> <li>• Know how they can seek alternative sources of support and information and who they can contact</li> <li>• Have another opportunity to share their concerns aside from face to face contact with the information and support provider</li> <li>• Believe it is socially acceptable to seek alternative support and information, without fear of bothering professionals.</li> <li>• Are more likely to receive tailored support and information as part of preparation</li> </ul>	<ul style="list-style-type: none"> <li>• Skills</li> <li>• Memory, attention and decision Processes</li> <li>• Beliefs about capabilities</li> </ul> <hr/> <ul style="list-style-type: none"> <li>• Emotion</li> </ul> <hr/> <ul style="list-style-type: none"> <li>• Social role and identity</li> <li>• Social influences</li> </ul> <hr/> <ul style="list-style-type: none"> <li>• Knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• Individualisation</li> </ul> <hr/> <ul style="list-style-type: none"> <li>• Chunking</li> </ul>	<p>Access to a helpline</p> <p>Key ring of contacts or credit sized card of contacts including catchy phrases</p>



<p><b>Element 5:</b> An ‘in case of...’ plan to support carers to gain the information and support they need to feel prepared before and during the transition from hospital to home.</p> 	<p>This is important so that carers:</p> <ul style="list-style-type: none"> <li>• Are assisted in gaining the right support and information they need in addition to discussions with the information and support providers.</li> <li>• Can be proactive in seeking information and support following guidance from the information and support provider (consistent message across materials).</li> <li>• Can see the positive consequences of being proactive as well as having the right support to gain tailored information and support</li> <li>• Can see the benefits of engaging with professionals, asking for support and information in their preferred format, evaluating whether this is appropriate, and communicating with the information and support provider in cases when this is inappropriate.</li> <li>• Can see the benefits of alternative forms of information and support as their needs change</li> <li>• Can develop skills and decision making processes to seek solutions to their problems and needs with the right guidance.</li> </ul>	<ul style="list-style-type: none"> <li>• Reinforcement</li> <li>• Social role and identity</li> <li>• Social influences</li> <li>• Emotion</li> <li>• Beliefs about consequences</li> <li>• Optimism</li> <li>• Intentions</li> <li>• Goals</li> <li>• Behavioural regulation</li> <li>• Skills</li> <li>• Memory. Attention and decision processes</li> <li>• Beliefs about capabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Modelling</li> <li>• Belief selection</li> <li>• Elaboration</li> <li>• Planning coping responses</li> </ul>	<p>A written, paper based document in the style of a booklet titled ‘in case of ...’ plan.</p> <p>This includes: Flow diagrams to guide carers through different scenarios and how to respond in these scenarios (including carers as role models)</p> <p>Key contacts in the back of the booklet as the number of contacts on the key ring/cards are limited.</p>
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#### **8.3.4.2 Stakeholder design preferences**

Stakeholders contributed to the ongoing design of the intervention by expressing their preferences and constraints regarding the intervention context and the programme, scope, and sequence (meeting three). They also provided feedback about each element of the complex intervention outlined in the previous section (meeting four). In some cases, they provided feedback on new ideas that had emerged following the process of selecting theory based methods and practical applications e.g. the brief written information to introduce the information and support provider and note taking alongside discussions. In other cases, they made suggestions about ideas raised in earlier groups, such as scenarios that should be included in the 'in case of' plan e.g. making adaptations to the home and obtaining information and support about benefits.

Regarding the training element, they provided detailed feedback on the training package modules. Stakeholders agreed with the content of the modules and that supervision alongside training in all cases is important. Overall, feedback was positive, as stakeholders were heavily involved in shaping ideas. Useful considerations were also made about potential constraints that could influence implementation of ideas and potential solutions. For example they suggested that the wider staff team should be trained during handovers to ensure enough staff remained on the wards.

Their preferences influenced design documents created for each element of the intervention, based on guidance by Bartholomew et al (2011). The design document for the training package includes module titles, activities, and design features (including interpersonal features e.g. conversations, teaching approaches). The design document for the elements to support carers to feel prepared includes a description for each element and their design features. These add to details provided in table 42 regarding the design of different elements and are available from the author as supplementary information.

#### **8.3.4.3 Programme, scope, and sequence**

The programme, scope and sequence document for the training package element of the intervention (including training for the information and support providers, ongoing supervision sessions and the additional session for the wider staff team) outlines the sequence of five key modules, key messages and the scope of activities included in each module, adding to information provided in table 41. This is also available from the author as supplementary information.

This section highlights some key considerations discussed with stakeholders regarding the delivery and organisational context of 'Preparing is Caring.' Stakeholder's suggestions regarding who should deliver the training to information and support providers included: NHS trainers or staff from other relevant services e.g. Carers Resource and Stroke Association. However, decisions would be dependent on available funding. Their suggestions regarding how this could be delivered to information and support providers and the wider team included: face-to-face by releasing staff during handover times, or online. They considered time spent training in terms of the trainees' abilities to take in information and the time available to release staff. Ideally this would be delivered over at least two days, given the depth of content. However, considerations regarding time and resources within services are necessary.

Given the ambiguity around who would be best placed to take on the role of the information and support provider, stakeholders discussed the barriers and benefits to existing staff members or an additional role. Table 43 outlines an overview of their responses.

**Table 43: Barriers and benefits of existing staff members vs an additional role**

<b>Existing staff member</b>
<p><b>Barriers</b></p> <ul style="list-style-type: none"> <li>• Nurse training may not provide the skills to take on other problems that carers may face (e.g. financial difficulties).</li> <li>• Retraining existing staff could be difficult.</li> <li>• Can become confusing for carers and staff if existing staff are trying to take on the role of providing carers with support and information.</li> <li>• Health professionals often think that they already support carers, making changes to their practice difficult.</li> <li>• Stroke survivors continue to take priority and carers are dismissed when staff face time constraints.</li> <li>• Some carers would slip through the net if they are supported as part of a service that supports the survivor.</li> </ul>
<p><b>Benefits</b></p> <ul style="list-style-type: none"> <li>• Band 3 support workers already exist in the community and have generic knowledge that is appropriate (note: may be trust specific)</li> <li>• Funding may be more likely if existing staff are utilised</li> </ul>
<b>Additional role</b>
<p><b>Barriers</b></p> <ul style="list-style-type: none"> <li>• Hard to prove to that a service is valuable to commissioners to gain funding</li> <li>• The person would potentially be supporting someone with significant psychological trauma; not everyone would be suitable.</li> <li>• Funding difficulties (different authorities have different limitations).</li> </ul>
<p><b>Benefits</b></p> <ul style="list-style-type: none"> <li>• Someone could be well trained to learn all required skills</li> <li>• A carer specific contact is beneficial because carers know the time is for them, not for the patients.</li> <li>• Having an additional person would still be valuable to ensure that carers are considered in their own right rather than as an 'add on' to stroke survivors</li> <li>• Could provide continuity across care transitions if they were not assigned to being on a ward as an existing member of staff.</li> <li>• There could be a conflict of interest using an existing members of staff so there is value in having an additional role.</li> <li>• Using volunteers similar to dementia champions would overcome funding difficulties.</li> <li>• A network of 'information and support providers' could support each other and engage in mentoring/ supervision.</li> </ul>

Overall, stakeholders favoured an additional role but this would be highly dependent on funding and resources within a service. This leads to the importance of wider organisational considerations, presented in table 44:

**Table 44: Organisational considerations for the intervention**

<b>Environmental stressors e.g. competing tasks and time constraints</b>
Time for: <ul style="list-style-type: none"> <li>• Undertaking training (information and support provider and the wider team)</li> <li>• Introductions and on-going discussions with carers, despite competing tasks</li> <li>• Managing the helpline</li> </ul>
<b>Material resources</b>
<ul style="list-style-type: none"> <li>• Available staffing if others are attending training</li> <li>• Material resources for training sessions</li> <li>• Available resources to assist carers in feeling more prepared (e.g. written introduction document, key rings/ cards of contacts, in case of plan)</li> <li>• Access to helpline</li> </ul>
<b>Person x environment interaction (necessary resources available to those expected to undertake behaviours)</b>
<ul style="list-style-type: none"> <li>• An appropriate environment to deliver training sessions</li> <li>• An appropriate environment for engaging with carers e.g. family room with comfortable chairs</li> </ul>
<b>Organisational culture/ climate</b>
<p>Services promote the importance of preparing staff to support carers to feel prepared before, during and following the transition from hospital to home. This ultimately promotes a culture which:</p> <ul style="list-style-type: none"> <li>• Adopts an approach to care which considers families, friends and carers.</li> <li>• Values carers in their own right</li> <li>• Considers broader carer needs aside from supporting the stroke survivor in their recovery.</li> <li>• Promotes effective communication</li> <li>• Promotes collaboration with other services to tailor information and support to carers' needs; and facilitate efficient sign posting</li> <li>• Is open to feedback and change to enable better provision of information and support</li> <li>• Promotes continuity in care</li> <li>• Has an open door policy so carers can re-contact services when required</li> <li>• Maintains a balance between being there for the carer and encouraging a proactive carer</li> </ul>
<b>Critical incidents/ salient events e.g. unexpected or negative events that occur as part of a service</b>
<ul style="list-style-type: none"> <li>• Training staff remains a priority even when unexpected and negative events occur</li> <li>• Supporting carers to feel prepared remains a priority even when negative events occur</li> </ul>
<b>Other barriers e.g. financial constraints</b>
Costs for: <ul style="list-style-type: none"> <li>• Training resources</li> <li>• Staffing to deliver training</li> <li>• The 'information and support provider role'</li> <li>• Resources e.g. written introduction document, key rings/ cards of contacts, in case of plan)</li> </ul>

These considerations highlight potential challenges when translating the intervention ideas into practice. These need to be considered in future research to develop the work presented in this chapter. Compliance with the IM process beyond this stage involves completing the remaining steps in stage four: developing and refining intervention components, and overseeing the production of materials, then plans for implementation and evaluation (stages five and six). A more detailed outline of further research is presented in chapter nine (section 9.6.2). The discussion that follows summarises the proposed intervention, and highlights some of the challenges that IM posed at different stages.

#### **8.4. Discussion**

This chapter described in detail the process of using IM for developing a proposed theory- and evidence-based intervention aimed at reducing burden in carers of stroke survivors ('Preparing is Caring'). To the researcher's knowledge, this is the first complex intervention for carers of stroke survivors developed using IM, incorporating evidence from empirical work, review data, behaviour change theories and collaboration with a stakeholder group. The intervention was developed using an approach consistent with guidance outlined in the MRC framework (Craig and Petticrew, 2013) and has the capacity to provide a valuable contribution to this field.

Stakeholders prioritised a need based on its importance for reducing burden, which led to a more specific programme goal to 'ensure carers feel prepared before, during and following the transition from hospital to home.' Using the socio-ecological model (McLeroy et al., 1988) to frame specific outcomes highlighted the importance of looking beyond the individual (carers) in interventions to change behaviours. Ensuring preparation was considered as an 'interpersonal activity' between the carer and the 'information and support provider.' This interaction is emphasised in the on-going discussions included in the developed intervention. Multiple intervention components were also developed to target carer and provider behaviours.

The intervention includes a training package, comprised of five modules for the information and support providers, with ongoing supervision sessions; and a shorter training session for the wider staff team. The training is to equip the information and support providers for on-going discussions with carers as part of their preparation. To facilitate preparation, additional components have also been developed that would be provided to carers. All outlined components were developed, selecting appropriate practical applications to address theoretical methods.

Training to target behaviours of 'information and support providers' is important for promoting inclusion of carers in the focus of care provision. Evidence contributing to the needs assessment indicated that professionals perceive their role is to focus on stroke survivors rather than carers, limiting opportunities to support carers in their preparation. Additionally, their medically focused training meant a lack of skills, knowledge, and confidence to support carers. These factors and other determinants are targeted in the developed intervention.

On-going discussions between carers and information and support providers provide an opportunity to influence carer behaviours. Additional components targeting varied determinants including knowledge, beliefs about consequences, and reinforcement were included to facilitate preparation, aside from discussions. These were based on evidence from the needs assessment, indicating carers often take a passive approach to gaining support and information, due to their reluctance to 'bother' professionals or uncertainties about what to ask. Stakeholders emphasised the importance of being signposted to appropriate information and support for practical and emotional needs, to facilitate a more proactive approach. Through appropriate guidance, using the contacts provided and the 'in case of ...' plan to seek solutions, carers can be encouraged to meet their needs, reducing time spent in discussions with the 'information and support providers.'

Organisational limitations around training professionals and increasing their involvement in supporting carers were acknowledged, as constraints were discussed with stakeholders throughout the process. Training the 'information and support providers' is a priority, however stakeholders valued wider team involvement, hence providing an additional training session to the wider staff team. This is expected to be beneficial for promoting a culture which supports carers and providing clarity to staff about their role boundaries and responsibilities. Supervision sessions for ongoing learning could be regarded as time consuming, yet they were considered a valuable contribution towards reaching the programme goal.

Resources and costs regarding the materials provided to carers require consideration. Had the intervention taken a different focus, it is possible that this may have been less resource-intensive. However, the developed components were deemed necessary, given the needs of carers at the early stage in the care trajectory. This was developed on the premise that it would reduce the risk of later burden, potentially reducing the need for intensive input later in the care trajectory.

Despite potential limitations translating this work in to practice, this work demonstrates how IM can provide a structure for addressing a complex construct, 'carer burden' which is related to different aspects of care and has multiple contributory factors. This was partly managed through prioritising the focus to one need that should be addressed to reduce burden. Collaboration with this stakeholder group exemplified the importance of developing an intervention that is grounded in how carers understand and experience burden. This was an important contribution, given previous qualitative review (Greenwood et al., 2009a) findings and those presented in chapters six and seven indicated that carers rarely use the term 'burden' in their narratives about caring experiences.

Stakeholders were integral to intervention development, which was a key strength of this research as they are valued for providing a greater breadth of skills, knowledge, and expertise beyond a solely expert driven approach (Bartholomew et al. 2011). However, involving stakeholders is not without its challenges. Bartholomew et al (2011) provided little guidance on how to involve them in decisions, and little clarity for how much weight should be given to their responses in addition to evidence, theory, and researcher judgements. Authors of IM papers often omit details about how stakeholders contributed, so little can be learned from previous research in this field.

To overcome the challenges regarding how to involve stakeholders, I made a conscious decision to avoid using complex IM terminology (e.g. performance objectives, determinants, matrices of change) in stakeholder meetings. In structured tasks, using carefully designed stakeholder materials, I phrased questions to address particular concepts. For example in the task related to performance objectives I asked what different individuals could do to enable carers to be prepared to elicit responses which included behaviours. These tasks provided a structure for collating stakeholders' responses to weave in to the process where necessary, and avoided overwhelming them with the complexities of IM. Before creating tasks, I made judgements about what parts of the process would be appropriate for involving stakeholders, then decided how these could be translated to maintain interest and commitment. These decisions are dependent on those involved in the groups, however it is hoped that other researchers can learn from this more detailed account of collaboration with stakeholders.

I also faced challenges aside from the stakeholder groups, despite IM being presented as a structured process, guiding researchers from a problem towards a solution. In addition to the complex needs assessment, researchers are required to review literature at various stages (e.g. to check performance objectives are consistent with the literature and to select



theoretical constructs relevant to behaviours of interest for the determinants). This suggests that there is always a large volume of literature and that researchers have time to engage with this at numerous times throughout the process.

Selecting a theory to establish the determinants to underpin the intervention proved challenging, as evidence in the logic model did not map on to a single behaviour change theory. Furthermore, the target behaviours (gaining or providing information and support) were not health behaviours that are heavily theorised in comparison with other health behaviours e.g. those associated with physical activity. This meant drawing upon limited literature about information and support seeker and provider behaviours (Gorman, 1999; Wilson, 1999). With more time, a more comprehensive search could be conducted. However, Bartholomew et al (2011) provided little clarity about how literature should be reviewed i.e. whether this should be done systematically, or whether scoping is enough.

The TDF (Cane et al., 2012) was introduced to overcome these challenges. This is a widely-used framework for mapping the factors that influence behaviour change as part of intervention development and has been used previously in the context of IM (Gray-Burrows et al., 2016; Taylor et al., 2013). Using this framework meant that theory based determinants were relevant to evidence from the needs assessment. However, including all 14 domains as determinants across 15 matrices of change produced an overwhelming amount of work for the subsequent stages of intervention development. This also meant that the developed intervention components target multiple determinants and include multiple theoretical methods.

Adaptations were made to manage a process that could have become unwieldy. Multiple matrices of change, including determinants at multiple levels (individual, interpersonal, and organisational) were useful for mapping required behaviour change. However, as Heaney (1998) argued, this is likely to impede linkages in how behaviours interact across levels. To acknowledge the interaction required between individuals (carers and providers) to achieve the programme goal, a flow diagram based on consolidated performance objectives from different matrices was developed. This provided the foundations for generating intervention ideas and a structure for creating tables to map theoretical methods and practical applications. This deviated from the traditional process where matrices would be considered separately, but the principles for selecting the 'active ingredients' (theoretical methods) were maintained. These were still matched to change objectives for different determinants and practical applications were still selected with consideration of parameters for effectiveness. This adaptation to the process was also

advantageous as the context of this 'interaction' was considered, which was influential in the emergent ideas.

This example illustrates the flexibility of this approach for overcoming difficulties or managing the extensive work that is created at each stage. However, it also highlights that additional advice would be helpful, as researchers are often required to manage such issues in a restricted time-period. Other authors (Greaves et al., 2016) have similarly acknowledged that 'best solutions' are not always available and are highly dependent on available evidence, expertise, instincts and knowledge, consequently claiming IM is as much an art as a science. Through thorough engagement with IM, I would agree with this notion and other researchers embarking on this process would benefit from being mindful of this.

### **8.5. Summary**

This chapter has demonstrated how stages one to four of Intervention Mapping were applied to develop a proposed theory- and evidence-based intervention aimed at reducing carer burden: 'Preparing is Caring.' In the next and final chapter, 'Preparing is Caring' is compared with other interventions for carers of stroke survivors and a more critical examination of challenges using IM is provided.

## **9. Chapter nine: Discussion**

### **9.1. Introduction**

This thesis reports the first UK study to use Intervention Mapping (Bartholomew et al., 2011) to develop a proposed intervention aimed at reducing burden in carers of stroke survivors, based on a prioritised need. This chapter provides a summary of the key findings, comparison of findings with published intervention literature, a critical examination of the challenges using IM and critical reflections on addressing and measuring burden. Implications for policies and practice related to carer support, and the ways in which the intervention can be developed and evaluated in future research are considered. The chapter concludes by reviewing the strengths and limitations of the research conducted.

### **9.2. Summary of key findings**

#### **9.2.1. Context and methods overview**

Research has indicated that burden is highly prevalent among carers of stroke survivors, and can occur at different phases in the care trajectory (Hung et al., 2012; Jaracz et al., 2015; Visser-Meily et al., 2008). This was considered the most appropriate focus for the intervention because without strategies to reduce this, carers are at risk of negative health consequences and adverse effects in social, psychological and physical functioning (Adelman et al., 2014; Greenwood et al., 2009a; Rigby et al., 2009).

The systematic review reported in chapter three, which updated a Cochrane review by Legg et al. (2011), ensured understanding of recent developments in intervention research for carers of stroke survivors, before developing a new intervention. This included 20 randomised controlled trials of interventions targeted at reducing negative outcomes, including carer burden. The review found no conclusive evidence for the effectiveness of a single intervention type (teaching procedural knowledge, support and information, psycho-educational) for reducing negative carer outcomes. The London Stroke Carer Training Course, tested in a single centre was identified by Legg et al. (2011) as having the most potential (Kalra et al., 2004). However, a later and much larger multi-centre trial of the same intervention reported no significant effect on carer outcomes (Forster et al., 2013). A single study (Bakas et al., 2009) in the updated review reported reduction in depression for a Telephone Assessment and Skill Building Kit compared with an attention control (MD; -2.12 95% CI - 2.91 to -1.33, P= 0.00001). This intervention included elements of all three intervention types.

Based on this evidence, it was important to ensure that the proposed intervention addressed limitations of existing interventions.

Although the MRC guidance (Craig et al., 2008; Craig and Petticrew, 2013) advocates the use of theories in intervention development for establishing the causal assumptions that underpin an intervention, and in the evaluation to understand how it works in practice, nine of the 20 interventions reviewed lacked a theoretical basis or framework. Of the 11 that utilised theory, most provided vague descriptions of its use, and limited information about the content of interventions, including the active ingredients that would determine their effects. Inadequate use or lack of theory in existing interventions made it difficult to establish why they were ineffective, limiting understanding about how future interventions could be refined and improved. A review of more recent evidence just prior to submission did not change these conclusions.

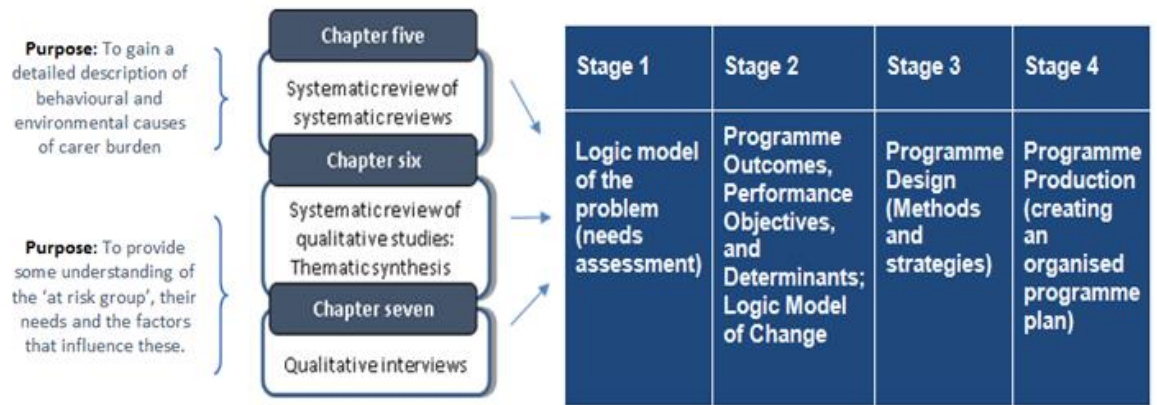
Appropriate choice and application of theories can prove challenging, as MRC guidance does not specify *how* to incorporate theories into intervention development. Therefore it was necessary to use a systematic method that facilitates appropriate theory selection to develop an intervention underpinned by theory.

Following consideration of theories, frameworks and models contributing to behaviour change research for example, the Theoretical Domains Framework (Cane et al., 2012; Michie et al., 2005) and the Behaviour Change Wheel (Michie et al., 2014; Michie et al., 2011), IM was adopted for this study. This fulfils criteria recommended in the MRC framework and provides a logical process for effective decision making, including how to integrate theory and evidence throughout intervention development, implementation and evaluation; maximising the likelihood that the intervention is feasible, acceptable, effective, and sustainable.

To develop a proposed intervention aimed at reducing burden in carers of stroke survivors, the first four stages of IM were used.

### **9.2.2. Development work: Needs assessment**

A systematic review of reviews, a thematic synthesis of qualitative studies, and qualitative interviews were conducted to address the key aims of the first stage in IM (figure 46).



**Figure 46: Overview of Intervention Mapping**

Findings contributed to an overall logic model of burden (chapter eight) and provided important foundations for subsequent stages of intervention development. This section summarises key findings from these three components, with attention to how these informed the developing logic models of the problem, which, when combined became the overall logic model of burden.

### 9.2.2.1 Systematic review of systematic reviews

The systematic review of 14 systematic reviews, including 612 studies (chapter five) contributed to the first aim of the needs assessment (figure 46). This established the factors that influence burden in carers of stroke survivors and other longer- term conditions. Factors included behavioural and environmental conditions and their determinants, and patient and carer characteristics. Other studies have identified risk factors and determinants of burden in carers of stroke survivors including greater stroke survivor disability, disturbances in the stroke survivor and carer emotional health, increased time spent caring, and low sense of coherence and anxiety (Jaracz et al., 2015; Rigby et al., 2009). However, this review of reviews is the first to systematically identify factors to inform the development of an intervention.

Interestingly, few reviews identified behaviours associated with carer burden, suggesting this is rarely examined from a behavioural perspective, especially in carers of stroke survivors. The environmental factors associated with burden in stroke survivors and cancer patients e.g. support and financial circumstances were an informative contribution, as these were less evident in previous research by Jaracz et al. (2015). Findings suggested that interventions may need to target both behavioural and environmental factors, because carers' experiences are influenced by their own behaviours and the external environment, including the behaviours of others responsible for the provision of support.

The determinants of behavioural and environmental factors also had implications for intervention development. Carers' perceptions and degree of satisfaction with support influence carer burden, suggesting the importance of ensuring support meets their needs. Evidence for different coping types that reduce burden was mixed and based on carers of people with dementia. However, this suggested the possibility of carers protecting themselves from experiencing burden by developing coping strategies, if encouraged with the right support.

All the factors identified in the review of reviews contributed to the logic model of the problem (page 124), outlining behavioural and environmental causes of carer burden, and their determinants, yet few of these factors related to carers of stroke survivors. This work informed the decision to conduct further qualitative research which addressed the second needs assessment aim (figure 46) and continued to inform the developing logic models of the problem; adding to the behavioural and environmental factors and their determinants, necessary for intervention development.

#### **9.2.2.2 Systematic review of qualitative studies: thematic synthesis**

The update of the Greenwood et al (2009a) review included a thematic synthesis of forty-eight studies. The nine descriptive themes and six analytical themes identified indicated carers have varied needs, relating to different aspects of care. Findings confirmed experiences and needs reported in previous reviews (Camak, 2015; Greenwood et al., 2009a; Pringle et al., 2008). However, this thematic synthesis contributed to development of an intervention for carers by gaining a more in-depth understanding of their needs, the factors that influence whether they are addressed, and implications for intervention development.

It was difficult to determine specific time points for different needs, findings indicated that carers needs differ over time, reflecting phases of the Timing it Right (TIR) Framework (Cameron and Gignac, 2008). Consistent with later work using the TIR Framework (Cameron et al. 2013), findings indicated carers value emotional, practical and informational support throughout the care trajectory, from different sources (HCPs, families, friends and peers). The synthesis progressed beyond establishing support needs evident at different time points in the care trajectory and identified barriers and facilitators to addressing these needs.

Examining the caring experience in context of biographical disruption (Bury, 1982) and biographical flow (Faircloth et al., 2004), theories typically applied to those experiencing chronic illness, illuminated the complexities associated with developing interventions for

carers. Findings from the thematic synthesis of studies could be explained by elements of each theory, but these did not account for the variability in disruptions to carers' lives and their vulnerabilities to further disruptions as circumstances change over time. The extent to which carers could overcome barriers and develop appropriate strategies for coping influenced the extent of disruption to their lives.

Barriers and facilitators were identified at different levels of the socio-ecological model (McLeroy et al., 1988). This was instrumental in highlighting how carers addressed different needs. Behavioural (individual) barriers and facilitators related to whether carers 'coped,' by finding time away from their caring roles and constructing a new life, self, and relationships; and their approach towards gaining information and support. Environmental (interpersonal and organisational) barriers and facilitators related to whether carers were provided with appropriate support and information. Many needs were influenced by barriers and facilitators at multiple levels of the socio-ecological model. Conclusions in chapter six suggested a tailored intervention, targeting multiple levels of the socio-ecological model could be appropriate for addressing carers' needs; in addition to gaining a balance between promoting a proactive carer and ensuring that appropriate support and information is available.

Findings from this thematic synthesis built upon the evidence presented in chapter five, added to the developing logic model of the problem (pg.163), and provided a more in-depth understanding of the caring experience in carers of stroke survivors. More specifically, the needs identified provided a contextual understanding of experience and a potential basis for prioritising the intervention focus in later stages of IM. Behavioural and environmental barriers e.g. avoiding asking professionals for support, and reduced social networks over time informed the logic model. Facilitators provided a full picture of the experience and provided potential solutions to be considered later in the intervention development e.g. assisting carers to develop support networks.

Although the review findings provided a valuable contribution to the evidence required to develop an intervention, it was difficult to determine exact time periods when needs emerged or how these and the barriers and facilitators to addressing needs changed with time. This was addressed in the empirical study.

### **9.2.2.3 Qualitative interviews**

The empirical study (chapter seven) including a thematic analysis of 33 semi-structured interviews in two groups of carers extended the review evidence presented in chapter six

by adding to understandings about how needs, barriers and facilitators change over time. Including the social network mapping exercise (Antonucci, 1986) also advanced understandings of how social support needs change over time, again adding to previous research using the TIR Framework (Cameron and Gignac, 2008; Cameron et al., 2013).

In group one, the number of needs identified differed with time (T1= 9, T2= 8, T3= 6), in group two, nine needs were identified, all of which related to different aspects of caring. Findings from group one provided a nuanced understanding of how needs change over time in the same group of carers, highlighting implications for when some needs should be addressed. Group two findings, based on a different group of carers, provided insight into how needs and the barriers and facilitators to addressing needs compare in the later care experience.

Examining and comparing carers experiences across the two groups in the context of biographical disruption (Bury, 1982) and biographical flow (Faircloth et al., 2004) added to insights gained from the thematic synthesis and highlighted further complexities associated with developing interventions for carers, given the changes in disruptions over time. As previously, neither theory could completely account for the complexities of carers' experiences. Variability in disruptions to carers lives were evident within and across the groups and examining the experiences of carers over time provided evidence to support my previous claim that caring often represents a series of disruptions over time, that are managed with appropriate internal and external resources.

It was evident that changes in needs are much more complex than the result of the passage of time alone. Carers in group one experienced some positive adjustment over time, as they experienced fewer barriers to coping by interviews at T3. Carers in group two similarly adjusted over time; however their lives were comparatively more disrupted. These empirical study findings indicated that time, in combination with carers' different circumstances and characteristics, the extent of stroke survivors' impairments, access to available support and information resources, and the carers' abilities to develop coping strategies were influential in managing and addressing needs. Other studies have established the importance of such resources for coping (Green and King, 2009; Greenwood et al., 2009b; Saban and Hogan, 2012).

These empirical findings re-iterated the importance of gaining a comprehensive understanding of the factors that influence how needs are addressed and their influence on how needs change over time. Similar individual and environmental barriers and facilitators to those identified in the thematic synthesis were established at different levels



of the socio-ecological framework (McLeroy et al., 1988) e.g. individual, interpersonal, environmental. These remained influential in how carers' addressed different needs and confirmed the need for an intervention which targets multiple levels.

The social network mapping exercise (Antonucci, 1986) demonstrated carers valued different and often multiple support and information providers at different times in the care trajectory, depending on their needs. The value placed on support was partly influenced by its availability. Professional support diminished within the first few months leading carers to seek support from more informal sources thereafter.

Together these findings had important implications for developing an intervention to meet varying needs and circumstances of different carers. Consistent with those in the thematic synthesis, conclusions suggested introducing a consistent approach to providing information and support, combined with encouraging carers to actively seek information and support to enhance the likelihood that carers can develop and maintain support networks, would be necessary to meet needs as they arise.

This empirical work added to the developing logic model of the problem (pg. 241) and enhanced the depth of understanding gained in the thematic synthesis by attending to how needs, barriers and facilitators to addressing needs, and support networks change over time. Similarly, the needs identified provided a contextual understanding of experience and a potential basis for prioritising the intervention focus in later stages of IM. Behavioural and environmental barriers informed the logic model e.g. providing practical care without preparation, and professionals do not always provide initial guidance to reassure carers. Facilitators provided a full picture of the experience and potential solutions to be considered later in the intervention development e.g. encouraging carers to actively seek support.

The overall logic model of burden (pg. 267), was developed using findings from all three components of the needs assessment and presented a complex picture of burden and needs. This highlighted a range of behavioural and environmental factors, and their determinants that could lead to carer burden, related to numerous and varied carer needs. Clarity regarding which needs should be addressed to reduce burden was required; this was considered before progressing with subsequent stages of intervention development. Stakeholder meetings (reported in chapter eight) were a key element of this clarification process, as discussed in the following section.

### **9.2.3. Subsequent stages of Intervention Mapping to develop the intervention**

Stakeholders including six carers, three researchers, three health professionals and two professionals from carer support services attended a series of meetings which commenced following completion of the needs assessment and overall logic model of burden. As highlighted in chapter eight, guidance on how to involve stakeholders in decisions and how much influence they should have on the intervention development using IM is limited (Bartholomew et al., 2011). Learning from others who have used IM is difficult, as details about how stakeholders contributed are often lacking, or poorly described (Durks et al., 2017).

As little guidance is available, I chose to avoid complex IM terminology in stakeholder meetings and developed structured tasks relevant to IM stages, which fed into complex and more detailed intervention content and process development work, which I conducted aside from the meetings. This section provides commentary on the IM process and outcomes, including how I balanced stakeholder input with use of theory, and evidence generated in the needs assessment to develop the intervention components.

In stage one of IM, Bartholomew et al. (2011) stated priorities must be established about the intervention focus following the initial analysis of a problem in the needs assessment. They specified that this should be achieved by identifying groups at greater risk of the health problem, or considering the magnitude between 'what is and what could be' (Bartholomew et al., 2011 pg. 226). This guidance is abstract and provides little indication for how to do this, particularly with involvement from stakeholders. So I asked stakeholders to prioritise 'needs cards', developed from my qualitative findings, based on their importance for reducing carer burden. Presenting findings in this accessible way was necessary, as carer burden spans a wide range of issues and intervention development needed to be manageable and focused on what is important for carers and those working with carers.

Stakeholders prioritised the need 'to feel prepared before and during the transition from hospital to home,' which subsequently influenced the whole intervention focus. This prioritisation was informed by detailed work presented to stakeholders. However, with a different group of stakeholders, the focus may have differed. Nevertheless, the prioritised need is consistent with research which highlights the early care trajectory as a difficult time for carers and a pressured time for staff members (Luker et al., 2017; Lutz and Camicia, 2016).

Other needs are at risk of being unaddressed, particularly those requiring intervention beyond the initial transition to home e.g. finding time away from caring. However, the focus on the specific need prioritised by stakeholders provided an opportunity to address needs earlier to overcome later difficulties, including for example, carers' concerns about changes in their partner that could impact on whether they can maintain relationships.

The prioritised need influenced the behaviours that required change as part of the intervention. Preparing carers for the transition from hospital to home places responsibility primarily on professionals, partly because carers valued professional support at this time and perceived professionals were well placed to assist carers with aspects of this need. This included assisting with practical preparation and helping carers to understand what to expect during their transition from hospital to home.

Exploring this prioritised need in more detail in the second stakeholder meeting helped inform the more focused logic model of the prioritised problem (page 270). Including a range of professionals from hospitals and carers support services in the stakeholder groups was important, as few studies in the thematic synthesis focused on carers' experiences from a professional perspective.

In stage two of IM, where the focus shifted from problems to the change process, I involved stakeholders in tasks that provided the foundations for more complex work, but continued to avoid IM terminology. In meeting two, task three, carers identified what different individuals could do to prepare carers. Their responses provided the foundations for the development of 168 performance objectives which influenced the fifteen matrices of change and the logic model of change. However, to develop performance objectives, it was important to balance stakeholder involvement with appropriate theory and evidence from the needs assessment.

In stage three of IM, the process for selecting theoretical methods and practical applications required that I complete numerous lengthy tables, specifying how parameters for effectiveness were considered in the translation from theoretical methods to practical applications. Stakeholders were heavily involved in the initial ideas for the intervention (practical applications) but I selected theoretical methods (active ingredients) for intervention components aside from the groups during the process of completing the tables. This ensured that I allocated sufficient time to this time consuming process and generated ideas to match the reality of the target populations and contexts. Lack of stakeholder involvement in part of this process could be criticised. However I judged that review and validation of my selected methods by researchers with behaviour change

experience was more appropriate than stakeholder involvement in what is a challenging and complex theory driven process.

The resultant intervention components (established in stages three and four) targeting carer, information and support provider, and other staff behaviours were developed using a combination of evidence from the needs assessment, theories and theory based methods, and stakeholder input. IM provided structure to guide these decisions to produce a coherent intervention named 'Preparing is Caring.' This involves ensuring carers are provided with relevant information and support for practical and emotional needs, before, during and immediately after the stroke survivors' transition from hospital to home by an 'information and support provider' taking on a single point of contact role. The main elements are a training package for information and support providers working with carers; an additional training session for the wider staff team; and various elements to support carers to feel prepared.

### **9.3. Comparison of findings with interventions included in the updated review by Legg et al. (2011)**

The following two subsections compare the previous 20 interventions included in the updated review (chapter three) with 'Preparing is Caring', focusing on how the interventions were developed, and the nature and delivery of the interventions, including their components. Then four trials of interventions published since the updated review are considered regarding how they impact upon, challenge, and inform my proposed intervention.

#### **9.3.1. Development of interventions**

Little detail was provided about the methods used to develop the 20 interventions included in the updated review. Descriptions were often vague or in four cases, not provided (Kalra et al., 2004; Larson et al., 2005; Marsden et al., 2010; Shyu et al., 2010). As documented in section 9.2, theory was either lacking or in many cases used without establishing the links between theories and intervention components (Bishop et al., 2014; King et al., 2012; Pfeiffer et al., 2014; Pierce et al., 2004b; Pierce et al., 2009c; Smith et al., 2012). These were developed without specifying the active ingredients that would determine their effects. It is possible that little detail was provided about the methods used to develop interventions, due to word limits in journals. However, it is difficult to refine existing interventions if little detail is provided about how they were developed and how they intend to have an effect.

IM addresses some of the limitations and criticisms of previous interventions and meets the MRC requirements for developing complex interventions, by providing a structured framework for systematically gathering appropriate evidence, theories, and stakeholder input throughout the process of intervention development. It also facilitates clear documentation of the intervention development process, by providing guidelines and tools in the format of tasks, matrices and tables (Schaalma and Kok, 2009).

A particular strength of IM is the ongoing stakeholder involvement which ensured the intervention was grounded in the experiences and needs of carers and relevant professionals, yet still based on a large body of current evidence (at the point of intervention development), gathered through a range of rigorous methods including qualitative interviews and systematic reviews, as recommended in MRC guidance (Craig et al., 2008; Craig and Petticrew, 2013).

The 'needs assessment' stage in IM provided more clarity on how needs were determined compared to previous studies that provided little indication about the evidence used to understand carers' needs or how intervention materials addressed needs (Bakas et al., 2009; Mant et al., 2000; Pierce et al., 2004b; Pierce et al., 2009c; Shyu et al., 2010). Prioritising the intervention focus to one need meant materials were designed with a more specific purpose.

Utilising IM in this study also overcomes previous criticisms regarding theory in intervention development. IM uses a clearly defined and structured process to guide adequate theory and application, enhancing the likelihood of an effective intervention (Craig and Petticrew, 2013), and explicit links are made between intervention change objectives, determinants, theoretical methods, and intervention components, which are used to articulate the causal assumptions underpinning an intervention (Schaalma and Kok, 2009). More can be learned about interventions developed using IM, beyond just a measure of effectiveness and interventions can be refined where necessary following evaluations. Therefore, this has the potential to advance knowledge in this field regarding how interventions aimed at carers of stroke survivors can be developed and refined in future.

The next section focuses on the nature of the intervention, its delivery, and components compared to previous interventions.

### **9.3.2. Intervention design, delivery and components**

The nature of 'Preparing is Caring' is different from all 20 existing interventions which typically involve providing carers with either a web-based or an intervention using a workbook or guidebook, combined with face-to-face or telephone interactions with a health professional (in groups or one to one sessions). However, the timing of its delivery in the early part of the care trajectory is similar to the majority of interventions. Of these, it is most comparable to three interventions, due to their focus on supporting carers according to their individual needs through initial face to face interactions and supplementary information. These are: Stroke Association Family support in Oxford (Mant et al., 2000); Discharge Preparation Programme (DPP) (Shyu et al., 2010) and Timing it Right Stroke Family Support Programme (TIRSFSP) (Cameron et al., 2014a).

Although carers had opportunities for interaction with professionals in these similar interventions, the main difference in 'Preparing is Caring' is the focus on changing how professionals support carers in the transition from hospital to home. IM acknowledges that behaviours and interactions are part of a complex system, influenced by multiple levels (Hawe et al., 2009; Kok et al., 2014). Consequently, 'Preparing is Caring' targets carer 'information and support provider', and wider staff behaviours with the training packages and various components for carers based on theoretical methods and practical applications to target relevant determinants that differ greatly from materials provided in existing interventions.

Other initiatives aimed at training health professionals in stroke settings have been developed by partnerships in Scotland (Chest, Heart and Stroke Scotland), and NHS Scotland and NHS Education for Scotland: Stroke Core Competencies, Stroke Training and Awareness Resources (STARS), and the Stroke Competency Toolkit Framework (SCoT). However, the delivery, focus and content are different from 'Preparing is Caring.' The outlined resources are all available as e-learning and seek to improve knowledge and skills of staff working with stroke patients. The modules in 'Preparing is Caring' seek to train professionals to work with carers of stroke survivors and explicitly address factors in addition to knowledge and skills e.g. social role and identity and emotional capabilities. These modules are a novel addition to these resources and extend the focus of care beyond the stroke survivor.

The training component of 'Preparing is Caring' is better suited to face-to-face delivery due to the interactive elements such as role plays that target particular theoretical methods (e.g. guided practice) and determinants (e.g. beliefs about capabilities). I acknowledge there are possible barriers to delivering the training face-to-face regarding

costs, staff time and resources, particularly in a resource challenged NHS. However the proposed intervention was developed with input from professionals working in NHS settings, who were mindful of resource implications throughout the process. An appropriate balance needs to be gained between delivering the proposed intervention in a cost and resource effective manner and ensuring it maintains the elements that are likely to lead to its effectiveness. Further research is required to examine what needs to occur for this complex intervention to be delivered in the NHS. Plans to progress the work presented in this thesis are outlined in section 9.6.2.

### **9.3.3. Current evidence context**

This section reflects on emerging evidence of interventions aimed at carers of stroke survivors since those identified to update the Legg et al. (2011) review in February 2015. As documented in chapter three, an updated search in August 2017 identified four additional studies (Forster et al., 2015; İnci and Temel, 2016; Kuo et al., 2016; Lindley et al., 2017).

Two studies showed significant improvements in carer outcomes: knowledge and self efficacy (Kuo et al., 2016) and carer burden (İnci and Temel, 2016). However, there are still no definitive conclusions about the best strategies for reducing negative outcomes. The study indicating a significant difference in carer burden in the support programme group compared to control was based on a small sample, limiting generalisability of findings (İnci and Temel, 2016). The four studies are briefly considered here regarding how they impact on, challenge, and inform my proposed intervention.

Both interventions that showed some significant improvements in carer outcomes were guided by theory. İnci and Temel (2016) used the resilience model of family stress, adjustment and adaption (McCubbin et al., 1996). Kuo et al (2016) used the PRECEDE-PROCEDE model (Green and Kreuter, 2005) underpinned by behaviour change theories. These indicate some benefit of developing an intervention with appropriate application of theory, which is promising for my proposed intervention.

Larger trials aimed at meeting the longer term needs of stroke survivors and their carers (Forster et al., 2015) and training family members in a simplified version of evidence based rehabilitation (Lindley et al., 2017) both showed no significant differences in burden in the intervention and control groups. These highlight potential problems for the current intervention given the similar focus on needs and the training component. However, authors outlined factors that could account for these findings: difficulties

determining whether changes in practice occurred, failure to address needs when treatments were unavailable (Forster et al., 2015), ineffective training components and time spent training (Lindley et al., 2017).

These factors are informative and can be considered in future plans to develop the 'Preparing is Caring' intervention. Although its effectiveness is yet to be determined, my proposed intervention has the potential to provide valuable contributions to the developing evidence and has incorporated recommendations made in previous studies. Examples include: tailoring interventions to meet carers needs (Forster et al., 2015), and incorporating behaviour change theories and evidence (Lindley et al., 2017).

#### **9.4. Critical examination of challenges using Intervention Mapping**

IM is a well established, widely used framework for developing interventions. It is often presented as an unproblematic, clearly structured approach, including a series of stages, guiding researchers from a problem towards a solution. Despite its complexities it has been considered as a practice-friendly process (Tortolero et al., 2005).

Broadly similar strengths and limitations have been identified among those who have used IM to develop interventions to target varied behaviours. Researchers, including the IM authors have criticised IM for being an overwhelming, time and resource intensive process (Bartholomew et al., 2011; Gray-Burrows et al., 2016; McEachan et al., 2008). Greaves et al. (2016) suggested that the replicability of interventions may be affected by the complexity of the process, despite a transparent audit trail.

Wheeler et al. (2013) challenged these criticisms and described IM as a very useful planning tool for setting time frames and expected accomplishments and producing a clear outline of how the programme will work to achieve the outcomes. IM is consistently valued for being able to fulfil MRC recommendations for developing complex interventions. Its structured and systematic nature for incorporating theory, evidence and stakeholder involvement in the planning, development, implementation and evaluation of interventions is one of its key strengths.

Despite the common criticisms and complex terminology, before embarking on this research, I was enthused by the IM process that appeared to flexibly apply to a variety of health problems. Having used the approach, I can appreciate some of its strengths, some of which were highlighted in sections 9.3.2 and 9.3.3 when comparing 'Preparing is Caring' with existing interventions. I would also regard this as a useful process as the emphasis



from working from a problem towards a solution avoided jumping straight to solutions that were based on little evidence.

However, it soon became apparent that 'carer burden' is a more complex health problem than those traditionally targeted using IM methods e.g. health screening, physical activity. This presented challenges, many of which were highlighted in chapter eight (section 8.4). These included difficulties: reviewing new literature at varied stages throughout the process when available literature and time are limited; selecting a theory for the determinants of behaviour change; and managing large volumes of data produced in the matrices of change.

Managing and prioritising the data collected in the needs assessment to incorporate this into subsequent stages of the process was challenging. A large amount of data was obtained in the needs assessment because of the broad focus on carer burden. In many cases, researchers identify specific health problem(s) or target behaviours and the 'type of intervention' prior to embarking on the IM process e.g. back pain and a return to work programme (Ammendolia et al., 2009). This leads to a more focused needs assessment, making progression from the needs assessment to the next stage easier (identifying outcomes and performance objectives). This may account for why research using IM is often presented as unproblematic if a well-defined problem is the target of the intervention.

The nature of carer burden as a complex concept means that it is not as readily associated with one, or just a few specific behaviours, therefore, narrowing the intervention focus from the outset was not possible here. As documented in section 9.2.3, prioritising a need based on its importance for reducing burden narrowed the focus for the next stages, however this provided an example of what Greaves et al. (2016) considered as managing when 'best solutions' were available, because Bartholomew et al. (2011) did not provide guidance on how this could be achieved.

There was also little acknowledgement from Bartholomew et al. (2011) that some of the language and processes involved in selecting theoretical methods and practical applications (stages three and four) could be confusing for stakeholders who are unfamiliar with IM. To overcome these challenges, I allocated considerable amounts of time to ensure group materials were appropriate for each stage. This included avoiding complex terminology and using appropriate graphics. Other researchers must be mindful of the time required for this, in an already time-consuming process. Suitability of materials

for different groups must also be considered. Although strategies adopted in this study encouraged successful engagement, these may not be transferable across all groups.

These examples, and those presented in chapter eight demonstrate that it was possible to overcome challenges, demonstrating the flexibility of IM, but this often involved intuitive and creative thinking. In cases where adaptations were made to the process, it was important to comply with the key principles of IM. For example, I managed large volumes of data in the matrices of change by creating a flow diagram based on consolidated performance objectives from different matrices. This provided the foundations for generating intervention ideas and a structure for creating tables to map theoretical methods and practical applications. This deviated from the traditional process, where matrices would be considered separately, but the principles for selecting the 'active ingredients' (theoretical methods) were maintained. These were still matched to change objectives for different determinants and practical applications were still selected with consideration of parameters for effectiveness.

I acknowledge that many of the challenges are likely to have arisen due to the focus of the research, and it could be argued that this method is more applicable to other health problems. However, the nature of the process, focused on working from a problem towards a solution means it can take unexpected turns, posing difficulties that researchers may not have anticipated, regardless of the focus.

Additional advice on parts of the IM approach such as prioritising need, working with stakeholders, and managing large volumes of data would be useful to make this more 'user-friendly.' Until this is available, it is important for researchers to enter a project knowing that creativity and flexibility, combined with drawing upon expert knowledge and advice is necessary for successfully incorporating theory, evidence and stakeholder views into relevant stages of IM.

### **9.5. Critical reflections on addressing and measuring burden**

The work contributing to this thesis has confirmed that 'carer burden' is a complex construct. Its overwhelming nature makes it difficult to address and limitations of measures such as the Carer Strain Index (Robinson, 1983) and the Carer Burden Scale (Zarit and Zarit, 1983) make demonstrating the effectiveness of interventions such as 'Preparing is Caring' more difficult. Measures of burden have been criticised for neglecting the cultural and contextual factors that contribute to diverse caring experiences and the extent to which carers become burdened (Thornton and Travis, 2003). It is also possible that some carers only experience burden in few of the numerous domains presented in

measures of carer burden. Therefore, it may be unrealistic for an intervention to demonstrate a marked reduction in burden, if this is measured as an all-encompassing construct. The inclusion of only the negative aspects of caring is also problematic as this does not necessarily reflect the complexities of caring experiences that are often demonstrated in qualitative studies, including the findings presented in chapter seven.

To address this issue, it would be useful to select measures that attend to both the positive and negative aspects of caring. Al-Janabi et al. (2010) incorporated positive aspects of caring into the Caregiver Strain Index. Using this measure could help to determine whether interventions have had a positive impact, even in cases where carers were not burdened prior to receiving an intervention. This leads to an important consideration about which carers should be targeted in an intervention designed to reduce burden.

It is questionable whether interventions should be offered to all carers, as previous studies indicated that approximately 60% of carers do not experience prolonged burden (Hung et al., 2012; Visser-Meily et al. 2008; Tooth et al., 2005). Common sense dictates that targeting carers who are most 'at risk' of burden would provide the best hope of reducing burden. However identifying 'at risk' carers is not straightforward. The scope of factors that contribute to the diversity in caring experiences make it difficult to establish who is most likely to become burdened at different stages in the care trajectory. 'Preparing is Caring' has been developed with these complexities in mind, by providing carers with continuing opportunities for support, as and when this is required. It accounts for the notion that some carers are not 'ready' for support initially, yet the option is still available if this is required later.

I acknowledge that avoiding targeting 'at risk' carers reduces the likelihood that a change in burden will be evident, as some carers may not be burdened prior to receiving the intervention. However, numerous carers in the interviews and stakeholder groups valued feeling prepared in the transition from hospital to home and could benefit from the 'Preparing is Caring' intervention. Additionally, selecting 'at risk' carers prematurely in the care trajectory may dismiss changes in burden over time. Attention would be better focused on ensuring the selected outcome measures reflect the complex reality of carers' circumstances after stroke. It may also be important to consider other relevant outcomes in addition to burden e.g. carer preparedness, with the ultimate aim of achieving and demonstrating a more positive caring experience. These issues require further consideration in future developments of this proposed work.

## **9.6. Implications**

### **9.6.1. Implications for policies and practice**

For decades, carers have been a feature of policy documents by virtue of their relationships with the cared for. As documented in chapter two, it is becoming increasingly common for government strategies and policies to emphasise a 'carer centred approach' which considers carers as equal partners in care and recognises their unique knowledge and expertise in addressing their own needs.

The National Clinical Guidelines for Stroke (ISWP, 2016) provided specific recommendations about how to support carers with an educational programme, an assessment of their own needs, appropriate practical and emotional support, and guidance about seeking further help as problems arise with support from a stroke-coordinator. Recent policies and guidelines are more in line with Twigg and Atkin's 'carers as co-workers' or 'carers as co-clients' models, rather than the 'carers as resources' model (Twigg and Atkin, 1994). However, evidence presented in this thesis indicates some disparity between what current policies and guidelines aim to achieve, and what happens in reality. Often, policies and guidelines discount some of the complexities surrounding how carers are perceived by health and social care systems and the resultant implications associated with the ambiguous position of carers within services (Sadler and McKeivitt, 2013). They also lack detail indicating how supporting carers can be achieved in practical terms.

The prioritised focus of this intervention suggests many carers are not adequately supported to meet their needs before, during, and shortly following the transition from hospital to home. Evidence from the thematic synthesis of qualitative studies indicated why this may be, as professionals focus on stroke survivors, not the longer-term implications for carers for numerous reasons including lack of time, role perceptions and limited staff capacity. The 'Care Act, 2014' (Department of Health, 2014) has contributed to carers being recognised by policy makers as legitimate recipients of support in their own right. However, a need for a consistent approach to supporting carers with appropriate and tailored support to meet their needs remains. This would help carers to be recognised as 'co-workers' or 'co-clients' rather than 'resources' (Twigg and Atkin, 1994).

The proposed intervention, 'Preparing is Caring' is in keeping with recent policy recommendations and also incorporates some of the more specific recommendations outlined in the National Clinical Guidelines for Stroke (ISWP, 2016) e.g. a single point of

contact for carers and assisting carers with problems as they arise. It was developed with acknowledgement that wider, organisational factors influence behaviours. A range of organisational considerations were presented in chapter eight, regarding the provision of training and how carers are supported once staff members are trained. These are important and may influence whether this type of intervention can be implemented in hospital settings. However, such considerations may differ across trusts due to variations in staff capacity, service structures, and available funding. This leads to the need to consider the cost implications of an intervention of this nature.

Examining the costs of interventions is particularly important in the current health and social climate, where the demand for care is increasing faster than the supply of resources (Kings Fund, 2017). Examples of specific costs associated with introducing 'Preparing is Caring' include: employment costs for the 'information and support provider' and trainer roles; time costs (e.g. staff time spent in the delivery and engagement in training, engaging with carers following the training, and in ongoing supervision sessions); and material costs (e.g. key rings, the 'incase of plan,' information sheets, and training materials).

A systematic review of the economic evidence of existing interventions for carers of stroke survivors found limited evidence that interventions are cost-effective compared to existing alternatives (Heslin et al., 2016). The variation in intervention types combined with methodological limitations undermined the conclusions that could be drawn in their review. The authors suggested that higher quality full economic evaluations are required to extend the current evidence base (Heslin et al., 2016). To assess the cost-effectiveness of 'Preparing is Caring' a comprehensive economic evaluation is required. The exact methods will be established in collaboration with a health economist. However, this will be carried out from a societal perspective to avoid any cost shifts between relevant sectors (e.g. NHS services and other relevant support services). The opportunity costs to the carer, such as the loss of employment and leisure time and the costs that arise from taking on the caring role will also be considered (Arksey and Glendinning, 2007).

It is hoped that adequately preparing carers with the 'Preparing is Caring' intervention will mean they are well-equipped for their role, reducing the number of stroke survivors requiring institutionalised care. It is also hoped that the costs of 'Preparing is Caring' will be offset by savings in the provision of more intensive therapies and medications that may be required if carers are not provided with the intervention and continue to experience burden. If it can be delivered in a cost-effective manner, 'Preparing is Caring' has the potential to meet policy recommendations and may be a promising addition for supporting carers.

In the context of recent developments in stroke care, it is an opportune time to seek to adopt an intervention of this nature into health and social care services. With support from NHS England, the Stroke Association are developing the National Plan for Stroke to build upon the success of the National Stroke Strategy which came to an end in 2017. The Stroke Association's new ambitions specified in their 'New Era for Stroke' campaign include building research and knowledge to support stroke care, expanding the networks of available support in the UK, and ensuring a well-trained workforce (Stroke Association, 2017); all of which are relevant to the proposed intervention and ultimately improving support for stroke survivors and their carers.

Successfully implementing 'Preparing is Caring' into practice requires collaboration between policy makers, NHS trusts and third sector partners e.g. the Stroke Association to foster an environment which ensures that lessons are learned and experiences are shared. However, further work is required before it is possible to translate 'Preparing is Caring' into practice, as discussed in the next section.

#### **9.6.2. Implications for future research**

Post-doctoral research is required progress the work presented in this thesis. To complete IM stage four, current intervention plans need to be developed into draft materials that can be refined following feedback from stakeholders in focus groups. Once intervention materials are finalised, compliance with IM stage five involves following procedures outlined in chapter four (section 4.6.5) to develop detailed implementation plans, produced with stakeholder involvement.

In this study, implementation plans would provide further clarification about elements of the intervention delivery that were raised in chapter eight, by specifying the person taking on the 'information and support provider' role (an existing health professional or a new, additional role); and details about the training component including location, number of days required for delivery, and the person responsible for delivery. More broadly, these plans would outline how the intervention would be successfully adopted and maintained when it is translated into practice. Further work would be required to assess whether intervention ideas and plans for implementation established in stage five would be sustainable in an NHS setting.

A case study approach could be adopted with the proposed intervention delivered in three services. This would enable exploration of the barriers and enablers for implementing staff training in NHS settings, compliance with, and adherence to the training programme, and the level of system change needed to integrate the intervention into existing NHS

services. These findings in addition to staff members' views of the intervention would inform necessary refinements to the intervention content, materials, and how they are implemented. Following any required further refinement, a feasibility trial could be undertaken prior to a large-scale cluster RCT with embedded process evaluation and cost-effective analysis.

These plans for refining and evaluating the proposed intervention are consistent with IM stage six and adhere to MRC guidance which recommends testing complex interventions using smaller-scale studies, before conducting a larger full-scale evaluation (Craig et al., 2008).

### **9.7. Strengths and limitations of research presented in the thesis**

This research provides a novel contribution to intervention development in carers of stroke survivors, in both methods used to develop the proposed intervention and the design and content. Evidence, theories, and stakeholder involvement were incorporated throughout the process, producing different intervention components based on theoretical methods that address relevant determinants. In the translation from theoretical methods to practical applications (intervention components) parameters of effectiveness were also considered, ensuring they were suitably tailored to the population and context. These steps are crucial to achieving desired behaviour change and practice change (Kok et al., 2016).

The socio-ecological model was applied in numerous ways throughout this work. In chapters five to seven (the needs assessment), the model was used as a framework for identifying behavioural and environmental factors at different levels e.g. individual, interpersonal, organisational. Findings from each chapter contributed to developing logic models, which when brought together became the overall logic model of burden (presented in chapter eight). In subsequent stages of IM, the socio-ecological model was used to frame outcomes, objectives, and matrices (stage two) and informed thinking throughout the development of the intervention (stages three and four). This, in addition to drawing upon different methods to gain evidence for the 'needs assessment', as recommended by Bartholomew et al. (2011) provided a more complete picture of the changes required to address a complex problem e.g. carer burden, highlighting that interventions should consider the nature of interactions between professionals and carers and acknowledge wider environmental influences on behaviours.

Stakeholders were influential throughout intervention development. This is a strength in any research and in the context of IM. Guidance is available to researchers about achieving

public involvement in all phases of the research cycle (INVOLVE, 2012). This guidance informed this study, however, researchers could benefit from more specific guidance about how to involve stakeholders in IM, with recognition of a need for flexibility and creativity.

Despite the strengths of stakeholder involvement, the generalisability of the proposed intervention to different healthcare trusts and organisations may be limited, given that some of the ideas were influenced by empirical work undertaken in West Yorkshire and the stakeholders were from a similar area. Carers involved in the groups had experiences based on their time involved with certain hospitals and services and professionals brought their perspectives from their work within specific hospital trusts and carer organisations. However, findings were not solely based on the input from stakeholders and were grounded in the evidence from the needs assessment. Therefore, it is anticipated that some of the decisions made by stakeholders and the factors need considering when implementing this type of intervention e.g. constraints in staff capacity and financial resources would be transferable to other settings.

Chapter six is the first systematic review to synthesise evidence from qualitative studies of carers' experiences using thematic synthesis (Thomas and Harden, 2008) to explore needs, barriers, and facilitators to addressing needs, and how and whether they change over time. This highlighted important implications for intervention development regarding needs and the factors that influence whether they are addressed. These findings may be informative for establishing how current policy initiatives outlined in the Care Act (Department of Health, 2014) can be achieved e.g. supporting carers' needs and providing entitlements to assessments and support, and may be useful to others who wish to use existing literature as a basis for intervention development in this population. A transparent and detailed account of the thematic synthesis approach is provided, with additional steps that were taken to manage the large volume of studies. This could provide learning for others wishing to use this method, if they are similarly working with numerous studies.

The qualitative interview study (chapter seven) is the first study to explore not only the changes in needs over time, but also the barriers and facilitators to addressing needs. Given the limited longitudinal research in this area with this specific focus, it is a valuable contribution to this field and indicates how we should seek to address carers' needs in an intervention aimed at reducing burden. Findings from chapters six and seven also provide further support for the use of the socio-ecological model as a framework for identifying



the barriers and facilitators to addressing needs. In chapter seven, the secondary analysis where this was incorporated provided a greater understanding of the data, going beyond a descriptive list of themes that would not be obtained using thematic analysis alone.

Due to time and resource constraints, I conducted much of the work as a sole researcher, which has potential for researcher bias. However, this was overcome by engaging in discussions with my supervisors and the PhD group including six researchers with a range of valuable experiences. Regular meetings were also held aside from stakeholder groups with other researchers with experience of using IM (RM and TC). This ensured that ideas were developed with feedback from those with required expertise. Research processes were also clearly documented, showing transparency throughout decisions.

## **9.8. Conclusions**

This study used Intervention Mapping, underpinned by a socio-ecological model to develop a proposed intervention aimed at reducing burden in carers of stroke survivors. The research presented in this thesis highlights the complexities of developing an intervention in this population, illustrated by the range of factors that can influence burden and the needs that carers experience throughout the care trajectory. 'Preparing is Caring' represents the first attempt to systematically apply theory and evidence in the development of an intervention of this nature, and has been designed with a view to ensure that carers are included in care provision, before, during and following the transition from hospital to home.

On reflection, IM is a useful approach but was not without its challenges. Much can be learned from this experience regarding the need for creativity, flexibility, and adequate time to manage unexpected endeavours when developing complex interventions. Further research to continue this work includes developing and refining intervention materials, establishing plans for implementation and assessing what is required for the delivery of the proposed intervention within the NHS. Ultimately a cluster randomised trial of the intervention, with embedded process evaluation and cost-effective analysis would demonstrate the extent of its effectiveness. It is hoped through additional research that the impacts of this work will be evident in future.

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## **List of abbreviations**

AMSTAR: Assessment of Multiple Systematic Reviews

AUECR: Academic Unit of Elderly Care and Rehabilitation

BCT: Behaviour Change Taxonomy

BCTs: Behaviour Change Techniques

BCW: Behaviour Change Wheel

BIHR: Bradford Institute for Health Research

CBS: Carer Burden Scale

CES-D: Centre for Epidemiologic Depression Scale

COM-B capability, 'opportunity,' 'motivation' and 'behaviour'

CSI: Caregiver Strain Index

EOD: Early Onset Dementia

EQ-5D: Euro-Qol 5-D

FTLD: Frontotemporal lobar degeneration

GHQ 28: General Health Questionnaire 28

HADS: Hospital Anxiety and Depression Scale

HCPs: Health Care Professionals

HRQoL: Health Related Quality of Life

IM: Intervention Mapping

JBIMAStARI: Joanna Briggs Institute-Meta Analysis of Statistical Assessment and Review Instrument

ISWP: Intercollegiate Stroke Working Party

LSCTC: London Stroke Carer Training Course

MCI: Mild Cognitive Impairment

MRC: Medical Research Council

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

PHQ 9: Patient Health Questionnaire 9



PIS: Participant Information Sheets

RCTs: Randomised Controlled Trials

SCoT: Stroke Competency Toolkit Framework

SF- 36: Short Form 36

SIS: Stroke Impact Scale

STARS: Stroke Training and Awareness Resources

TDF: Theoretical Domains Framework

THT: Teaching Hospitals Trust

TIR: Timing it Right Framework

TIRSFSP: Timing it Right Stroke Family Support Programme

TRACS: Training Caregivers After Stroke

## Appendices

### Appendix A: Search strategy for updated Legg et al. (2011) review

Ovid Medline:

- 1 cerebrovascular disorders/
- 2 exp basal ganglia cerebrovascular disease/
- 3 exp brain ischemia/
- 4 exp carotid artery diseases/
- 5 stroke/
- 6 exp brain infarction/
- 7 exp cerebrovascular trauma/
- 8 hypoxia-ischemia, brain/
- 9 exp intracranial arterial diseases/
- 10 exp intracranial arteriovenous malformations/
- 11 exp "intracranial embolism and thrombosis"/
- 12 exp intracranial hemorrhages/
- 13 vasospasm, intracranial/
- 14 vertebral artery dissection/
- 15 aneurysm, ruptured/ and exp brain/
- 16 brain injuries/
- 17 brain injury, chronic/
- 18 exp carotid arteries/
- 19 endarterectomy, carotid/
- 20 \*heart septal defects, atrial/ or foramen ovale, patent/
- 21 \*atrial fibrillation/
- 22 (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vascul\$ or cerebral vascul\$ or cva\$ or apoplex\$ or isch?emi\$ attack\$ or tia\$1 or neurologic\$ deficit\$ or SAH or AVM).tw.
- 23 ((brain\$ or cerebr\$ or cerebell\$ or cortical or vertebrobasilar or hemispher\$ or intracran\$ or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal ganglia) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$ or hypox\$ or vasospasm or obstruction or vasculopathy)).tw.
- 24 ((lacunar or cortical) adj5 infarct\$).tw.
- 25 ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or subarachnoid or putamen\$ or putamen\$ or posterior fossa) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.
- 26 ((brain or cerebral or intracranial or communicating or giant or basilar or vertebral artery or berry or saccular or ruptured) adj5 aneurysm\$).tw.
- 27 (vertebral artery dissection or cerebral art\$ disease\$).tw.
- 28 ((brain or intracranial or basal ganglia or lenticulostriate) adj5 (vascular adj5 (disease\$ or disorder or accident or injur\$ or trauma\$ or insult or event))).tw.
- 29 ((isch?emic or apoplectic) adj5 (event or events or insult or attack\$)).tw.
- 30 ((cerebral vein or cerebral venous or sinus or sagittal) adj5 thrombo\$).tw.
- 31 (CVDST or CVT).tw.
- 32 ((intracranial or cerebral art\$ or basilar art\$ or vertebral art\$ or vertebrobasilar or vertebral basilar) adj5 (stenosis or isch?emia or insufficiency or arteriosclero\$ or atherosclero\$ or occlus\$)).tw.
- 33 ((venous or arteriovenous or brain vascul\$) adj5 malformation\$).tw.
- 34 ((brain or cerebral) adj5 (angioma\$ or hemangioma\$ or haemangioma\$)).tw.
- 35 carotid\$.tw.
- 36 (patent foramen ovale or PFO).tw.
- 37 ((atrial or atrium or auricular) adj5 fibrillation).tw.
- 38 asymptomatic cervical bruit.tw.
- 39 exp aphasia/ or anomia/ or hemiplegia/ or hemianopsia/ or exp paresis/ or deglutition disorders/ or dysarthria/ or pseudobulbar palsy/ or muscle spasticity/
- 40 (aphasi\$ or apraxi\$ or dysphasi\$ or dysphagi\$ or deglutition disorder\$ or swallow\$ disorder\$ or dysarthri\$ or hemipleg\$ or hemipar\$ or paresis or paretic or hemianop\$ or hemineglect or spasticity or anomia\$ or dysnomia\$ or acquired brain injur\$ or hemiball\$).tw.
- 41 ((unilateral or visual or hemispacial or attentional or spatial) adj5 neglect).tw.
- 42 or/1-41
- 43 caregivers/ or friends/ or exp parents/ or spouses/ or visitors to patients/
- 44 exp home nursing/ or community networks/ or exp parent-child relations/ or exp interpersonal relations/
- 45 family/ or exp family characteristics/ or family relations/ or intergenerational relations/
- 46 family therapy/ or family nursing/ or family health/
- 47 (carer\$ or caregiv\$ or care giv\$).tw.

48 (family or families or spous\$ or parent or parents or father\$ or mother\$ or friend or friends or husband\$ or wife or wives or partner or partners).tw.  
 49 ((home or communit\$) adj5 (caring or care\$)).tw.  
 50 (home-based or homebased or community-based or communitybased).tw.  
 51 home nursing.tw. (1094)  
 52 ((non-professional or nonprofessional or informal or unpaid) adj5 (care or nursing)).tw.  
 53 (next of kin or relatives).tw.  
 54 or/ 43-53  
 55 42 and 54  
 56 community networks/ or social support/ or social isolation/ or social welfare/  
 57 (community adj2 network\$).tw.  
 58 (community adj2 support\$).tw.  
 59 patient education as topic/ or professional-family relations/  
 60 (patient adj3 (feedback or education)).tw.  
 61 altruism/ or helping behavior/ or social adjustment/  
 62 adaptation, psychological/  
 63 stress, psychological/  
 64 anxiety/ or depression/  
 65 emotions/  
 66 family/px  
 67 respite care/  
 68 day care/  
 69 ((attitude\$ or perception\$ or belief\$ or expectation\$ or satisfaction or emotion\$ or relationship\$ or support\$ or control or adjust\$ or guid\$ or information or advi\$ or help\$ or train\$) adj3 (carer\$ or caregiv\$ or care giv\$)).tw.  
 70 (anxiet\$ or stress\$ or fatigue\$ or resent\$ or burden\$ or cope\$ or coping).tw.  
 71 (support\$ adj2 conversation\$).tw.  
 72 (moral\$ adj3 (oblig\$ or duty or duties or responsibilit\$)).tw.  
 73 ((social or psychosocial or practical or group\$) adj3 (information or advice or help or support or network)).tw.  
 74 (post discharge or postdischarge).tw.  
 75 respite.tw.  
 76 day hospital\$.tw.  
 77 "quality of life"/  
 78 ((health or problem\$ or mood\$) adj3 (carer\$ or caregiv\$ or care giv\$)).tw.  
 79 self-help groups/  
 80 ((self-help or selfhelp) adj group\$).tw.  
 81 /or 56-80  
 82 55 and 81  
 83 randomized controlled trial.pt.  
 84 controlled clinical trial.pt.  
 85 randomized.ab.  
 86 placebo.ab.  
 87 drug therapy.fs.  
 88 randomly.ab.  
 89 trial.ab.  
 90 groups.ab.  
 91 exp animals/ not humans.sh.  
 92 90 not 91  
 93 82 and 92  
 94 limit 93 to yr="2009 -Current"  
 95 remove duplicates from 94

**Appendix B: Characteristics of included studies table (updated Legg et al. (2011) review)**

Authors	Type of trial	Sample size and no. assigned to intervention /control	Country	Age (mean)	Gender (% female)	Intervention /control	Timing of delivery and length of intervention	Data collection and follow up	Outcome measures
Bakas et al. (2009)	RCT	40 I: 21 C: 19	America	I: 56.43 (9.61) C: 57.84 (11.8)	I: 62% C: 84%	Telephone Assessment and Skill Building Kit (TASK) intervention vs Attention control (brochure on family caregiving and 8 weekly calls from the nurse).	Early post-stroke period (exact time not specified)  8 weeks	Baseline 4 weeks (half way through intervention) 8 weeks (end of intervention) 12 weeks (4 weeks after end of intervention)	- <b>Optimism:</b> The Revised Life Orientation Test (LOT-R) - <b>Perceived difficulty with tasks:</b> Oberst Caregiving Burden Scale Difficulty Subscale (OCBS) - <b>Threat appraisal:</b> Appraisal of Caregiving Threat Subscale - <b>Depressive symptoms:</b> Patient health Questionnaire Depression Scale (PHQ-9) - <b>Carer life changes:</b> 15 - item Bakas Caregiving Outcomes Scale (BCOS) - <b>Health perceptions:</b> SF-36 Health Survey General Health Subscale (SF-36GH)-
Bishop et al. (2014)	Randomised trial	49 dyads I: 23 dyads C: 26 dyads	America	Combined for intervention and control  56.8 (16.4)	Across both groups: 65.3%.	Treatment as usual plus the telephone intervention (Family Intervention Telephone Tracking FITT) vs treatment as usual (medical follow up)	Hospital-transition to home  6 months	Baseline 3 months 6 months  (post stroke)	- <b>Psychological functioning:</b> The 13 item Geriatric Depression Scale (GDS) Short form (uses dichotomous yes/no scaling). - <b>Family functioning:</b> Family assessment device (FAD) and perceived criticism scale (PCS)

Cameron et al. (2014a)	Single blind explanatory mixed methods RCT (feasibility)	31 C: 10 Self directed intervention: 10 Social support person directed intervention: 11	Canada	C: 55 (10.9) Self directed intervention: 57 (14.9) Social support person directed intervention: 57 (19.4)	C: 80% Self directed intervention: 80% Social support person directed intervention: 73%	Intervention (the timing it right stroke family support program) offered in two formats, self directed by the caregiver or stroke support person- directed over time vs standard care.	Hospital-transition to home  6 months	Baseline 1 month 3 months 6 months	<ul style="list-style-type: none"> <li>- <b>Perceived social support:</b> 20-item Medical Outcomes Study Social Support Scale</li> <li>- <b>Psychological wellbeing and depression:</b> 10-item Positive Affect Scale and 20-item Centre for Epidemiological Studies Depression Scale (CESD)</li> <li>- <b>Sense of control over life:</b> Pearlin's 7-item Mastery Scale</li> <li>- <b>Stroke Knowledge:</b> Stroke Knowledge Test</li> <li>- <b>Carer participation in valued activities:</b> 14-item Caregiving Impact Scale</li> </ul>
Eames et al. (2013)	Multisite, RCT	61  I: 31 C: 30	Australia	I: 55.2 (16.7) C: 61.4 (12.7)	I: 39 % C: 36%.	Standard care and the intervention (Education and support package) vs standard care (control)	Hospital-transition to home  3 months	Baseline 3 months	<ul style="list-style-type: none"> <li>- <b>Stroke knowledge:</b> Stroke Knowledge 25 item Knowledge of stroke questionnaire</li> <li>- <b>Self efficacy:</b> Lorigs Self efficacy to Perform Self management behaviour measures for chronic disease</li> <li>- <b>Anxiety and Depression:</b> 14 item Hospital Anxiety and Depression Scale (HADS).</li> <li>- <b>QOL:</b> Stroke and Aphasia Quality of Life Scale 39 Generic (SAQOL-39g)</li> <li>- <b>Carer Burden:</b> Caregiver Strain Index</li> </ul>
Forster et al. (2013)	A pragmatic, multicentre, cluster RCT	928 dyads  I: 450 dyads C: 478	UK	I: 61.1 (14.64) C: 60.8 (13.91)	I: 68.9% C: 68%	London Stroke Caregiver training course (LSCTC) vs control (Care as usual based on the National Clinical guidelines for	During time in hospital  Varied	Baseline 6 months 12 months	<ul style="list-style-type: none"> <li>- <b>Carer Burden:</b> Caregiver Burden Scale (CBS)</li> <li>- <b>Self-report measures of social restriction:</b> [Frenchay Activities Index (FAI)]</li> <li>- <b>Mood</b> (HADS)</li> <li>- <b>Health state</b> (EQ-5D)</li> <li>- <b>Cost effectiveness and cost utility:</b> Costs were combined with the NEADL score and quality-adjusted life-years (QALYs) for patients and the CBS and QALYs for caregivers.</li> </ul>

						stroke).			- <b>Resource use:</b> Client Service Receipt Inventory.
King et al. (2012)	Randomised control two-group design	255 I: 136 C: 119	America	I: 54.5 (15.1) C: 54.6 (13.3)	I: 76.5% C: 80.7%	Caregiver problem solving intervention (CPSI) vs a wait list control treatment.	Hospital-transition to home  12 weeks	Baseline Post intervention 6 months 12 months	- <b>Depression:</b> Centre for Epidemiologic Studies-Depression scale (CED-S). - <b>Perception of life change:</b> Bakas Caregiving Outcomes Scale (BCOS) - <b>Preparedness:</b> Preparedness for caregiving scale - <b>Anxiety:</b> Tension Anxiety 5 item subscale of the Profile of Moods Scale short form - <b>Family functioning:</b> General Functioning Scale of the McMaster Family Assessment Device (FAD).
Marsden et al. (2010)	Randomised, assessor blind, crossover, controlled trial	17 I: 9 C: 8	Australia	I: 66.3 (10.1) C: 69.6 (11.5)	I: 100% C: 75%	Community Living After Stroke for Survivors and Carers' (CLASSic) programme. Following completion control group crossed over to receive intervention.	Community (exact time unspecified)  7 weeks	Baseline 9 weeks (once intervention complete) 21 weeks (post intervention follow-up)	- <b>Health related quality of life:</b> The Health Impact Scale, an adapted version of the Stroke Impact Scale - <b>Carer burden:</b> Caregiver strain index
Perrin et al. (2010)	Experimental design with random assignment	61 dyads  Unclear how many in intervention and control	America	Combined for intervention and control  58.5 (12.0)	Combined for intervention and control  56%	Transition Assistance Programme (TAP) vs standard care	Hospital-transition to home  6 weeks	Baseline 1 month 3 months 6 weeks later	- <b>Carer strain:</b> Caregiver Strain Index - <b>Depression:</b> Short 10-item version of the Center for Epidemiologic Studies Depression (CESD-10) scale. - <b>Caregiver satisfaction:</b> 5 point Likert scale
Pfeiffer et al. (2014)	RCT	122	Germany	I: 66.7 (9.9)	I: 76.7% C: 79%	Problem solving intervention	Early post-stroke period	3 months 12 months	- <b>Depression:</b> 20 item Centre for Epidemiological Studies-Depression Scale (CES-D)

		I: 60 C: 62		C: 65.6 (10.1)		(PSI) vs information only control	12 months		<ul style="list-style-type: none"> <li>- Sense of <b>Competence</b> Questionnaire SCQ</li> <li>- <b>Social problem solving</b>: Short version of the Social problem Solving Inventory- Revised (SPSI-R:S)</li> <li>- <b>Physical complaints</b>: Giessen Subjective Complaints List (GBB-24)</li> <li>- <b>Satisfaction with Leisure Time</b>: Leisure Time Satisfaction (LTS) questionnaire.</li> <li>- <b>Spiritual beliefs</b>: Beliefs and Practices subscale of the Systems of Belief Inventory (SBI-15R)</li> <li>- <b>Informal support</b>: German Social Support Questionnaire (F-SozU)</li> </ul>
Pierce et al. (2009c)	Randomised, two group repeated measures design	103  I: 51 C: 52	America	I: 54 (12.2) C: 55 (13.1)	I: 69% C: 81%	Caring Web internet based intervention vs no web	Community setting (exact time unspecified)  12 months	3 months 6 months 9 months 12 months	<ul style="list-style-type: none"> <li>- <b>Depression</b>: CES-D scale</li> <li>- <b>Satisfaction with Life</b> Scale (SWLS)</li> </ul>
Shyu et al. (2010)	Randomised experimental design	201 dyads  I:97 C: 104	Taiwan	Combined for intervention and control  47.9 (13.7)	Combined for intervention and control  60.8%	Routine hospital discharge services consisting of in-hospital health education and occasional discharge referrals and the discharge preparation programme consisting of both in hospital and post hospital components vs	Hospital-transition home  1 month	1 month 3 months 6 months 12 months  After discharge	<ul style="list-style-type: none"> <li>- <b>Health related Quality of Life</b>: Medical Outcomes Study Short Form (SF-36), Taiwan version, SF-36.</li> <li>- <b>Quality of Care</b>: Family Caregiving Consequence Inventory (FCCI)</li> </ul>

						control (routine hospital discharge services).			
Smith et al. (2012)	Randomised clinical trial	38 dyads I: 19 C: 19	America	I: 55.3 (6.0). C: 59.9 (8.2).	Not reported	Internet intervention vs control (where minimal support was received and individualised access to relevant online information).	Community setting (exact time unspecified)  11 weeks	Baseline Post-test 1 month follow up post test	<ul style="list-style-type: none"> <li>- <b>Depression:</b> The 20-item CES-D and PhQ-9</li> <li>- <b>Mastery</b> Scale ,</li> <li>- 10-item <b>Self-Esteem</b> Scale</li> <li>- MOS <b>Social Support</b> Survey</li> <li>- <b>Treatment credibility, reported effort, and perceived benefit:</b> Credibility/Expectancy Questionnaire</li> </ul>



## Appendix C: Search strategy for systematic review of systematic reviews

Ovid Medline:

1. caregivers/
2. ((family or families or relative\* or parent\* or spouse\* or partner\* or husband\* or wife or wives or significant other\* or child\* or friend\* or neighbor\*) adj2 (care\* or caring)).tw.
3. or/1-2 [caregiver terms]
4. Stress, Psychological/
5. Depression/
6. exp depressive disorder/
7. exp Suicide/
8. (distress\* or stress\* or burnout or suicid\* or emotion\* or depressed or depression or depressive or psycholog\* or cope or coping or burden).tw.
9. or/4-8 [caregiver burden]
10. long-term care/
11. chronic diseases/
12. ((longterm or long term) adj (disease\* or condition\*)).tw.
13. or/10-12 [long term conditions]
14. stroke/
15. (stroke\* or post stroke or poststroke or post-stroke).tw.
16. exp dementia/
17. Alzheimer\*.tw.
18. exp cognition disorders/
19. ((cognit\* or memory or mental\*) adj5 (declin\* or impair\* or los\* or deteriorat\*)).tw.
20. (cognit\* adj2 (abnormal\* or defect\* or disorder\*)).tw.
21. Neurodegenerative Diseases/
22. exp Parkinsonian Disorders/
23. exp Neoplasms/
24. (cancer\* or tumor\* or tumour\* or neoplas\* or malignan\* or carcinoma\* or adenocarcinoma\* or choriocarcinoma\* or lymphoma\* or leukemia\* or leukaemia\* or metastat\* or sarcoma\* or teratoma\*).mp.
25. or/14-24 [specific long term conditions]
26. 13 or 25 [long term conditions and specific long term conditions]
27. 3 and 9 and 26 [care givers AND caregiver burden AND longterm conditions]
28. limit 27 to (english language and yr="2010 -Current")
29. limit 28 to "review articles"

#### Appendix D: Characteristics of included studies table for systematic review of systematic reviews

Author s, date	Aims	No. of included studies	Included study types	Condition of person in receipt of care	Relationship to cared for	Time spent caring	Gender	Age	Ethnicity
Azzani et al. (2015)	To assess the prevalence of perceived financial difficulty among the cancer patients and their families and identify the risk factors related to this targeted group.	10	Cross sectional	Cancer	Not reported, referred to as family members	Not reported			
Chiao et al. (2015)	To identify the main factors of caregiver burden among the informal caregivers of people with dementia living in the community	21	16 cross sectional 4 longitudinal 1 respective records review	Dementia.	Spouses, children adult children, other relatives, friends, daughter in laws, son in laws, descendants, extended family.	Not reported		Not reported in all studies. Reported in some studies:  233 white family caregiver/patient dyads. 74 black family caregiver/patient dyads (Skarupski et al., 2009)  67 African American caregivers. 74 non- Hispanic White family caregivers (Sun et al., 2010)	
del-Pino-Casado et al.	To analyse the effect of coping strategies on subjective burden in informal caregivers of disabled older adults.	10	9 cross sectional 1 longitudinal	9 dementia 1 non-trauma induced cognitive	Majority of studies reported as relatives Some studies more	Unclear, not reported for all	Not reported		Reported in some studies: 95 Afro- Americans and 65 whites (Kim

(2011)				impairment	specific: Wives and daughters (Artaso et al., 2003), husbands (Kramer, 1997) and spouses (O'Rourke and Wenaus, 1998).	studies.  Caring for at least four hours per week (Cooper et al., 2008).  Caring for at least four hours per day and caring for 12 months (Chou et al., 1999).			et al., 2007).  89 Hispanic and 96 non- Hispanic Caucasian (Montoro-Rodriguez and Gallagher-Thompson, 2009).
Gaugler (2010)	To determine how time influences important stroke caregiving outcomes (e.g., caregiver stress, burden, caregiver mental health).	117	Cross sectional, longitudinal, qualitative	Stroke	Not reported		Varied across studies	Range 41.2 to 76 years	Not reported
Greenwell et al. (2015)	To summarise and evaluate the evidence on all the factors which predict psychosocial outcomes for carers of people with Parkinson's disease.	29	26 cross sectional 3 longitudinal	Parkinson's disease	Mainly spouses.. Other relationships included offspring, siblings, daughter/son in-laws, niece/nephews, friends, and neighbours.	Four studies reported duration of caregiving (range 3.8-8.1 years) . One reported daily caregiving hours	Predominantly female	Mean age across studies ranged from 45.8 to 70.8 years	87.8-98.9% white  Different ethnicities (including: North America, Europe, Asia (2 from Japan, 2 from South Korea), Australia.

						(mean 3.3 h).			
Hesamzadeh et al. (2015)	To bring together the voices of family members of stroke survivors based on adaption to care tasks and to determine the extent to which their experience can be accommodated within the Double ABCX Model of family crisis.	18	All qualitative designs using different types of analysis e.g. grounded theory, content analysis, thematic analysis, phenomenological analysis.	Stroke	Not stated but focus broadly on family members of stroke survivors	Not reported			
Nunne mann et al. (2012)	To systematically review studies analysing (1) burden, problems, and needs of caregivers of Frontotemporal lobar degeneration (FTLD) patients, and (2) the feasibility and efficacy of caregiver interventions in FTLD.	10	Unclear, study designs specified in inclusion criteria included: RCTs, observational studies, care series and case reports.	Frontotemporal lobar degeneration (FTLD)- a type of dementia	Not reported				
Orgeta and Miranda-Castillo (2014)	To systematically review the effects of physical activity in improving psychological well-being in carers of people with dementia	4 studies met criteria and were included in quantitative synthesis, 3 studies meeting criteria are	RCTs	Dementia	Not reported for all studies. 47 adult children and 53 spousal carers (Castro et al., 2002). Spouses only (Connell and Janevic, 2009).	Not reported for all studies Providing at least 10 hours of unpaid care per week (Castro et al., 2002).	Not reported	Age: Reported in two studies: Average age 62 years (Castro et al., 2002). 50-75 years of	Ethnicity: Reported for one study: White/Caucasian (Connell and Janevic, 2009).

		ongoing.						age (King and Brassington, 1997).	
Seeher et al. (2013)	To establish whether there was published evidence to support the stress process model by Pearlin and colleagues in the context of Mild Cognitive Impairment (MCI)	10	All cross sectional	MCI	Majority of carers were spouses across studies	Not reported	Majority of carers female, not reported by all	Carers had a weighted mean age of 65.1 (pooled SD 5 12.60) years.	Not reported
Stenberg et al. (2014b)	Specific research questions: - Family caregivers' experiences and their caregiver burden over time; - Family caregivers' depression, sleep disturbance, and fatigue over time; And - Social and health care professionals' experiences and descriptions of family caregivers' situation.	108	65 studies used quantitative methods with experimental, quasi-experimental or descriptive designs. 40 used qualitative methods 3 used mixed methods	Cancer (most common: breast prostate, gastrointestinal, colon and lung).	The family caregiver was a spouse/partner, adult child (mostly daughters), parent, sibling, son-/daughter-in-law, grandchild, niece, or friend of the patient.	Not reported			

Stenberg et al. (2010)	<p>Summarise the state of knowledge on the following</p> <p>1 What physical and psychosocial health problems do Family Carers (FCs) of cancer patient's experience, as reported in the literature? Similarly, what burdens do they carry due to their caregiving responsibilities?</p> <p>2 How do FCs describe their problems and responsibilities?</p>	192 studies	164 research based studies, 12 systematic reviews, 6 more general reviews, 10 expert opinions.	Cancer (same common types as above)	Most frequently spouse/partner, adult child (mostly daughters), parent, sibling, son/daughter-in-law, grandchild, niece, or friend.	Not reported	10 222 (63.5%) were women and 5871 (36.5%) were men. Gender was not reported in 12/163 (7.3%) studies, representing a total of 3373 (17.3%) carers of unknown gender	Mean age 54.1 years. Eight studies (4.8%) did not report FC age	Race or ethnicity reported by 83/164 (50.6%) studies.
van der Lee et al. (2014)	Research question: Which patient and caregiver characteristics are significant determinants of subjective caregiver burden or burden related concepts like caregiver mental health or depression in the different models?	56	Unclear, not reported for all. Examples included: Prospective studies, cross sectional design, pre-post design, cohort studies, qualitative designs,	Dementia	Not reported				

			RCT effectiveness, longitudinal studies.						
Van Vliet et al. (2010)	To systematically investigate the literature on the psychosocial impact of Early onset dementia (EOD) on patients' informal caregivers, including their children.	17	All cross sectional studies	Early onset dementia (EOD)	Relationships included: spouses, children, daughter in law, parents as well as more formal care settings such as at home, long term care, care ward.	Not reported	Gender of carers included in 8/17 studies analysed. Of these 8 there is a mix of male and female of different proportions	Mean age or age range of carers stated in 8/17 studies. Ages varied but were predominantly middle aged carers	Not reported
Wolfs et al. (2012)	Explore the literature regarding the predictive factors of objective burden in terms of the amount or costs of informal care provided for elderly patients suffering from dementia or other cognitive impairments.	10	Studies were either longitudinal (n=4) or cross sectional (n=6).	Dementia	Not reported				

**Appendix E: Excluded studies table (systematic review of systematic reviews)**

<b>Reason for exclusion with references</b>
<b>n= 19: Not systematic review</b> (Adelman et al., 2014; Brandon, 2013; Cipriani et al., 2015; Dean and Wilcock, 2012; Emanuel et al., 2010; Fletcher et al., 2012; Fowler, 2014; Grant et al., 2014; Li et al., 2013a; Lippa, 2011; Mc Donnell and Ryan, 2013; Northouse et al., 2012; Pellerin et al., 2011; Piiparinen and Whitlatch, 2011; Robinson et al., 2010; Sansoni et al., 2013; Siemens and Hazelton, 2011; Stenberg et al., 2014a; Wu and Harden, 2015)
<b>n = 2: Unable to obtain text from library or author</b> (Lauritzen et al., 2014; Leow and Chan, 2011)
<b>n= 30: Included intervention studies where there was no attention to behaviours, environmental factors or determinants of burden, even if this was an outcome</b> (Applebaum and Breitbart, 2013; Boots et al., 2014; Candy et al., 2011; Chan Raymond et al., 2011; Cheng et al., 2014; Cheng et al., 2012; Chien et al., 2011; Diaz and da Cruz, 2015; Dugmore et al., 2015; Elvish and et, 2012; Forster et al., 2012a; Godwin et al., 2013; Hopkinson et al., 2012; Hu et al., 2015; Hurley et al., 2014; Jensen et al., 2015; Jones et al., 2012; Kaltenbaugh et al., 2015; Lang and Lim, 2014; Legg et al., 2011; Li and Loke, 2014b; Li et al., 2013b; Li et al., 2012; Lins et al., 2014; Marim et al., 2013; McKechnie et al., 2014; Regan et al., 2012; Schoenmakers et al., 2010b; Van't Leven et al., 2013; Waldron et al., 2013)
<b>n = 1: Individuals less than 18 years</b> (Crespo et al., 2013)
<b>n = 3: Not published in English</b> (Delalibera et al., 2015; Martin-Carrasco et al., 2014; Santos et al., 2011)
<b>n = 30: Not focussed on carer burden and associated behaviours, environmental conditions and/or theoretical determinants in stroke and other longer-term conditions</b> (Allison et al., 2011; Bailey and Grenyer, 2013; Cabote et al., 2015; Cooper et al., 2012; Corbett and et, 2012; Danielsen et al., 2013; de Bruin et al., 2012; Demaerschalk et al., 2010; Dias et al., 2015; Ellis et al., 2010; Glasdam et al., 2010; Greenwood and Mackenzie, 2010; Hall and Shelton, 2012; Harmell et al., 2011; Innes et al., 2011; Kotronoulas et al., 2013b; Kotronoulas et al., 2013a; Li and Loke, 2013a; Li and Loke, 2013b; Li and Loke, 2014a; Maayan et al., 2014; Mackenzie and Greenwood, 2012; Ornstein and Gaugler, 2012; Park and Schumacher, 2014; Quinn et al., 2010; Quinn et al., 2014a; Schoenmakers et al., 2010a; Tungpunkom et al., 2013; Vernooij-Dassen et al., 2011)



## Appendix F: Search strategy for updated Greenwood et al. (2009a) review

Ovid Medline strategy:

- 1 cerebrovascular disorders/
- 2 exp basal ganglia cerebrovascular disease/
- 3 exp brain ischemia/
- 4 exp carotid artery diseases/
- 5 stroke/
- 6 exp brain infarction/
- 7 exp cerebrovascular trauma/
- 8 hypoxia-ischemia, brain/
- 9 exp intracranial arterial diseases/
- 10 exp intracranial arteriovenous malformations/
- 11 exp "intracranial embolism and thrombosis"/
- 12 exp intracranial hemorrhages/
- 13 vasospasm, intracranial/
- 14 vertebral artery dissection/
- 15 aneurysm, ruptured/ and exp brain/
- 16 brain injuries/
- 17 brain injury, chronic/
- 18 exp carotid arteries/
- 19 endarterectomy, carotid/
- 20 \*heart septal defects, atrial/ or foramen ovale, patent/
- 21 \*atrial fibrillation/
- 22 (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vascul\$ or cerebral vascul\$ or cva\$ or apoplex\$ or isch?emi\$ attack\$ or tia\$1 or neurologic\$ deficit\$ or SAH or AVM).tw.
- 23 ((brain\$ or cerebr\$ or cerebell\$ or cortical or vertebrobasilar or hemispher\$ or intracran\$ or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal ganglia) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$ or hypox\$ or vasospasm or obstruction or vasculopathy)).tw.
- 24 ((lacunar or cortical) adj5 infarct\$).tw.
- 25 ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or subarachnoid or putamen or putamen or posterior fossa) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.
- 26 ((brain or cerebral or intracranial or communicating or giant or basilar or vertebral artery or berry or saccular or ruptured) adj5 aneurysm\$).tw.
- 27 (vertebral artery dissection or cerebral art\$ disease\$).tw.
- 28 ((brain or intracranial or basal ganglia or lenticulostriate) adj5 (vascular adj5 (disease\$ or disorder or accident or injur\$ or trauma\$ or insult or event\$))).tw.
- 29 ((isch?emic or apoplectic) adj5 (event or events or insult or attack\$)).tw.
- 30 ((cerebral vein or cerebral venous or sinus or sagittal) adj5 thrombo\$).tw.
- 31 (CVDST or CVT).tw.
- 32 ((intracranial or cerebral art\$ or basilar art\$ or vertebral art\$ or vertebrobasilar or vertebral basilar) adj5 (stenosis or isch?emia or insufficiency or arteriosclero\$ or atherosclero\$ or occlus\$)).tw.
- 33 ((venous or arteriovenous or brain vascul\$) adj5 malformation\$).tw.
- 34 ((brain or cerebral) adj5 (angioma\$ or hemangioma\$ or haemangioma\$)).tw.
- 35 carotid\$.tw.
- 36 (patent foramen ovale or PFO).tw.
- 37 ((atrial or atrium or auricular) adj5 fibrillation).tw.
- 38 asymptomatic cervical bruit.tw.
- 39 exp aphasia/ or anomia/ or hemiplegia/ or hemianopsia/ or exp paresis/ or deglutition disorders/ or dysarthria/ or pseudobulbar palsy/ or muscle spasticity/
- 40 (aphasi\$ or apraxi\$ or dysphasi\$ or dysphagi\$ or deglutition disorder\$ or swallow\$ disorder\$ or dysarthri\$ or hemipleg\$ or hemipar\$ or paresis or paretic or hemianop\$ or hemineglect or spasticity or anomi\$ or dysnomi\$ or acquired brain injur\$ or hemiball\$).tw.
- 41 ((unilateral or visual or hemispacial or attentional or spatial) adj5 neglect).tw.

42 / or 1-41  
 43 caregivers/ or friends/ or exp parents/ or spouses/ or visitors to patients/  
 44 exp home nursing/ or community networks/ or exp parent-child relations/ or exp  
 interpersonal relations/  
 45 family/ or exp family characteristics/ or family relations/ or intergenerational relations/  
 46 family therapy/ or family nursing/ or family health/  
 47 (carer\$ or caregiv\$ or care giv\$).tw.  
 48 (family or families or spous\$ or parent or parents or father\$ or mother\$ or friend or friends or  
 husband\$ or wife or wives or partner or partners).tw.  
 49 ((home or communit\$) adj5 (caring or care\$)).tw.  
 50 (home-based or homebased or community-based or communitybased).tw.  
 51 home nursing.tw.  
 52 ((non-professional or nonprofessional or informal or unpaid) adj5 (care or nursing)).tw.  
 53 (next of kin or relatives).tw.  
 54 or/ 43 - 53  
 55 42 and 54  
 56 community networks/ or social support/ or social isolation/ or social welfare/  
 57 (community adj2 network\$).tw.  
 58 (community adj2 support\$).tw.  
 59 patient education as topic/ or professional-family relations/  
 60 (patient adj3 (feedback or education)).tw.  
 61 altruism/ or helping behavior/ or social adjustment/  
 62 adaptation, psychological/  
 63 stress, psychological/  
 64 anxiety/ or depression/  
 65 emotions/  
 66 family/px  
 67 respite care/  
 68 day care/  
 69 ((attitude\$ or perception\$ or belief\$ or expectation\$ or satisfaction or emotion\$ or  
 relationship\$ or support\$ or control or adjust\$ or guid\$ or information or advi\$ or help\$ or train\$)  
 adj3 (carer\$ or caregiv\$ or care giv\$)).tw.  
 70 (anxiet\$ or stress\$ or fatigue\$ or resent\$ or burden\$ or cope\$ or coping).tw.  
 71 (support\$ adj2 conversation\$).tw.  
 72 (moral\$ adj3 (oblig\$ or duty or duties or responsibility\$)).tw.  
 73 ((social or psychosocial or practical or group\$) adj3 (information or advice or help or support  
 or network)).tw.  
 74 (post discharge or postdischarge).tw.  
 75 respite.tw.  
 76 day hospital\$.tw.  
 77 "quality of life"/  
 78 ((health or problem\$ or mood\$) adj3 (carer\$ or caregiv\$ or care giv\$)).tw.  
 79 self-help groups/  
 80 ((self-help or selfhelp) adj group\$).tw.  
 81 or/ 56 - 80  
 82 55 and 81  
 83 animals/  
 84 humans/  
 85 83 and 84  
 86 83 not 85  
 87 82 not 86  
 88 limit 87 to yr="2005-current"  
 89 remove duplicates from 88

## Appendix G: Characteristics of included studies for updated Greenwood et al. (2009a) review

NB: the seven excluded low quality studies are highlighted in Grey.

Authors, date	Country of origin	Sample size, strategy and recruitment location	Time post stroke	Aims and topics	Data collection methods and details (timing, location, etc.)	Data analysis	Gender	Age	Ethnicity	Relationship to survivor
Avent et al. (2005)	USA	16	1.10 to 13 years, (average 5.5)	To determine what information family members need during each of three phases (hospital, rehab, chronic) of aphasia.	Three focus groups lasting 2 hours, conducted in two different clinics.	Framework analysis	15 females, 1 male	Not reported	Not reported	12 spouses, 2 children, 1 parent, 1 long term partner.
Bäckström et al. (2010)	Sweden	4 Consecutive sampling	Within the spouse's first year after stroke	To illuminate the meanings of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke during the first year after their partner's discharge from a rehabilitation clinic.	Longitudinal design: Narrative interviews conducted 1, 6 and 12 month post discharge (total of 12 interviews), audio-taped and transcribed verbatim to a text. Open-ended questions.	Phenomenological-hermeneutic interpretive approach.	All females	40-58	Not reported	All spouses-length of relationship 8-36 years
Bäckström and Sundin (2007)	Sweden	10	1 month after discharge from rehab clinic ( 12-33 weeks)	To illuminate meanings in the lived experience of being a middle-aged close relative of a person who has suffered a stroke.	Longitudinal design: Narrative interviews conducted 3 to 4 weeks after discharge from the rehabilitation clinic.	As above	8 females 2 males	23-5)	Not reported	2 spouses, 5, common law partners, 2, mothers, 1 'lives apart
Bäckström and Sundin (2010)	Sweden	9	6 months discharge from rehab clinic	To illuminate the experiences of being a middle-aged close relative of a person who has suffered a stroke 6 months after being discharged from a medical	Narrative interviews were conducted 6 months after discharge from the rehabilitation clinic.	Content analysis	7 females, 2 males	40-64	Not reported	6 spouses or partners, 11 partners

				rehabilitation clinic.						not living together, 2 mothers
Bäckström and Sundin (2009)	Sweden	9	12 months after discharge from 1 rehab clinic	To illuminate the experiences of being a middle-aged close relative of a person who has suffered a stroke 12 months after being discharged from a medical rehabilitation clinic.	Narrative interviews conducted 12 months after discharge from the rehabilitation clinic.	Latent content analysis approach	7 females, 2 males	41-65	Not reported	6 spouse or partners, 1 partner (but not living together), 2 mothers (living in the same household as the stroke sufferer)
Brann et al. (2010)	USA	16	1 month to 12 years	To identify any dialectical tensions prominent in the relationships between stroke survivors and their spouses from the spouses' perspective.	Semi-structured interviews (n = 9) or via telephone (n = 7).	Dialectical perspective	10 females, 6 males	21-93	Not stated	Spouses
Brittain and Shaw (2007)	UK	20 carers recruited from a Medical Research Council (MRC) Incontinence Study and a locally based Family Support Officer.	7 months to 18 years	To explore bounded body and dirty work in light of the role of informal carers looking after someone with incontinence.	Interviews conducted in the home of the stroke survivor and lasted approximately 1 h45 mins	Inductive approach to data collection: Constant comparative method and deviant case analysis.	13 females, 7 males	51-86	Not reported	Majority spouses or partners, 1 daughter caring for mother.

Bulley et al. (2010)	Scotland	9	2-7 years	Experiences explored as part of a larger study to explore the impact of a clinic for people who have dropped foot after stroke and potential to benefit from an electronic orthotic called functional electrical stimulation.	Interviews varied in length from 23 to 68 min (mean 43 min; median 39 min). Interviewees selected the interview location – all took place in their homes.	Interpretative phenomenological analysis	7 females, 2 males	40-44 to 70-74	All white British	Spouses
Buschenfeld et al. (2009)	England or Wales	7	-	To develop understanding of the experience of partners of young stroke survivors and explore the processes through which caring influences psychological wellbeing.	Semi-structured interviews conducted in the participants' home (n=6) or at the interviewer's place of work (n=1), and lasted *90 min.	Interpretative phenomenological analysis	3 females, 4 males	49-62	All white British or European origin	'Described as 'partners.'
Cameroon et al. (2013)	Canada	24 Purposively sampled from three sources: (1) an inpatient rehabilitation centre; (2) a community based aphasia program and (3) a community care organisation serving a rural population.	1 month and 1 year	To explore support needs over time from the perspective of caregivers, (2) explore the support needs over time from the perspective of HCPs, and (3) compare and contrast caregivers' and HCPs' perspectives.	Caregivers and HCPs each participated in one interview either in-person or by telephone.	5 stages of qualitative framework analysis	17 females, 7 males	36-77	Not reported	18 Spouses, 6 daughters/ sons
Cao et al. (2010)	USA	10 Convenience sampling,	-	To explore the perceptions and experiences of caregivers of persons with	Semi-structured individual, in-depth, face-to-face (n=6) or telephone	Constant comparative method	Females	45-73	Not reported	Spouses

		recruited from stroke exercise class in urban rehabilitation centre		stroke with respect to their own health and their participation in physical activity.	interviews (n=4), each lasting approx. 1 hour					
Cecil et al. (2011)	Northern Ireland	10 Recruited through the community stroke staff of a health charity.	Within 8 years post stroke	To explore the personal experiences of carers of stroke survivors and to elicit their views and opinions of what constitute the major issues and concerns of people in their situation.	Semi-structured interviews conducted with four carers (two individual interviews and one joint interview with two carers); interviews were followed by a focus group with six carers. The study was based at two research sites in Northern Ireland: interviews conducted in rural north of the country, focus group in suburban hinterland of its capital city.	Unclear-inductive approach used	All female	"Middle aged or older"	Not reported	Spouses
Cecil et al. (2013)	Northern Ireland	30 Approached by community-based staff (of the charitable organisation 'Northern Ireland Chest, Heart and Stroke'), either shortly before or shortly after hospital	Following discharge from hospital (within first few months post stroke)	To explore the lives of carers of stroke survivors in terms of caring and coping and identify the factors that had an impact on their lives.	Interviews conducted in own homes (stroke survivors sometimes present)	Unclear Qualitative, descriptive design	23 females, 7 males	Wives age range: 36–83, husbands age Range : 73–84. Other carers' age range	White, British or Irish	19 Spouses, no further details

		discharge.						39-66.		
Cobley et al. (2013)	UK	15 Carers and patients referred to ESD and those meeting Cochrane criteria but not referred.	Mean (SD) days of interviews completed post-hospital discharge: 69.5 ± 40.5 days.	To investigate patients' and carers' experiences of Early Supported Discharge services and inform future Early Supported Discharge service development and provision.	Semi-structured interviews ranged from 30 to 45 minutes. All interviews conducted in the patients' usual place of residence within one and six months of hospital discharge.	Thematic analysis	13 females, 2 males	Mean (SD) age: 72.79 ± 14.10.	Not reported	Spouses
Coombs (2007)	Canada	8 recruited from the discharge patient list of a rehabilitation unit in an institution in Eastern Canada.	1.5 to 5 years (average time caring, 3.4 years)	To gain an understanding of the holistic lived experience of spousal carers	Data collected through audiotaped interviews. Each participant engaged in two separate interviews, each lasting approx. 60-120 minutes.	Phenomenological approach	5 females, 3 males	57-81	Not reported	Spouses, same homes
Creasy et al. (2013)	USA	17 Recruited during a rehabilitation stay and post-discharge.	Within first four months post discharge	To explore carers' perceptions about interactions with providers in rehabilitation, and how these experiences affected caregiver preparation.	First interview conducted while patient still in rehabilitation or as close to discharge as was convenient for the carer. Second interview conducted within four months of discharge.	Grounded theory	10 females, 7 male	43-83	2 black, 15 white	13 spouses, others adult children
Danzl et al. (2013)	USA	13 Purposeful, criterion	Not reported	To explore experiences of stroke survivors and their caregivers in Appalachian Kentucky, including	Semi-structured, open-ended interviews conducted with the person with stroke,	Qualitative content analysis	5 females, 7 male	38-75	White	Spouses and adult children

		sampling		onset of stroke, the healthcare continuum and rural community reintegration post-stroke	the carer, or both as determined by participant preference					
de Leon Arabit (2008)	USA	5 Theoretical sampling	2-9 years	To generate a theory explaining the process of caregiving coping strategies from the perspective of Latino women spouses of stroke survivors.	Interviews and guide form, no further detail. Note: interviews were not audio-taped; notes were handwritten on the interview guide form.	Constant comparative analysis, grounded theory	Females	57-85	All Latino	Spouses
Eames et al. (2010)	Australia	18 Recruited via hospital acute stroke unit in Brisbane, Australia.	Within three months post discharge	To identify patients' and carers' perceived barriers to accessing and understanding information about stroke	Data were collected via face-to-face interviews and review of the patient's medical chart. Prior to discharge and three months following discharge	Qualitative content analysis	13 females, 5 males	26-77	Not reported	Not reported
Eaves (2006)	USA	26  Initially, purposeful sampling then theoretical sampling	Four months post stroke	To examine rural African American family caregiving for older adult stroke survivors	Data generated through interactive interviews and focused observations.	Grounded theory	19 females, 7 males	18-70	Not reported	Sisters, brothers, daughters, nephews, and, in one instance, great-granddaughter.
El Masry et al. (2013)	Australia	20 carers of stroke survivors admitted to a metropolitan hospital neurology unit, a speech pathology department	At least three months post stroke	To explore the psychosocial aspects of carers' experiences	Little details. Semi-structured interviews, lasting approx. 60 minutes	Interpretive phenomenological analysis	Not reported	Not reported	Not reported	Not reported



		and a nearby rehabilitation hospital in Sydney.  Purposive, maximum variation and theoretical sampling.								
Gosman-Hedström and Dahlin-Ivanoff (2012)	Sweden	16 Recruited from the Stroke Association in Gothenburg. Purposive sampling	2 to 15 years	To explore and learn from the older women how they experience their life situation and formal support as carers of their partners after stroke and to suggest clinical implications.	Focus groups, little detail	Analysis conducted according to the method developed by Krueger.	Females	Median age 74 years	Not reported	Spouses
Graven et al. (2013)	Australia	14 Convenience sampling	3-15 months	To explore the way in which stroke survivors and their carers view the concept of recovery, the factors that influence recovery and perspectives about community-based health rehabilitation services delivered after discharge from inpatient stroke rehabilitation.	Data obtained via focus groups using semi-structured questionnaires. Focus group sessions were digitally recorded and additional notes documented to accurately identify speakers. All data collected were transcribed verbatim.	Qualitative interpretative analysis	Not reported	49-75	Not reported	All spouses with the exception of one carer who was a daughter
Grawburg et al. (2014)	Australia	20	Aphasia post-onset time (years) 7.5 Std Dev 10.91 Range 1-40	To describe the impact of aphasia on family members in the context of changes to their functioning and disability using the framework of the International Classification of Functioning	Mixed methods study. Individual in-depth semi-structured interviews.	Qualitative content analysis. Research codes generated were	14 females, 6 males	13-80	Not reported	5 daughter, 4 wives, 3 sisters, 2 sons, 1 brother, 1 brother in law, 1

						mapped to the ICF.					father, 1 granddaughter, 1 husband, 1 mother
Green and King (2009)	Canada	28 Recruited from a larger study examining the recovery trajectory following minor stroke.	One year post discharge	To explore perceptions of factors that impacted patients' quality of life and wife caregivers' strain over 12 months following minor stroke.	Semi-structured individual telephone interviews undertaken with participants at 1, 2, 3, 6, 9 and 12 months following the index hospital discharge. Men and wife-caregivers interviewed separately when possible.	Qualitative content analysis	Females	33-75	Caucasian	Spouses (wives)	
Greenwood et al. (2010)	UK	31 Purposive sample of Recruited from one acute ward and two rehabilitation stroke units in South West London.	Within three months post discharge	To explore the changes in carer autonomy and control and on the strategies they developed over the first 3 months after discharge	Interviews carried out by two experienced researchers. Carers interviewed three times (just before discharge and at 1 and 3 months after the survivors' discharge). Interviews were audio-taped and transcribed verbatim. Second and third interviews tailored to individual carers to follow-up specific topics they had mentioned in earlier interviews."	Ethnographic approach	22 females, 9 males	77% aged 66 and over with the remainder (except for one) aged between 40 and 65 years.	Over half described themselves as White British.. Other groups included Other White, Asian and Black.	16 Spouses/partners, 13 adult children, 2 siblings.	
Greenwood et	UK	13 carers 10 members	?	To explore both the support stroke carers would like from general	Semi-structured, face-to-face interviews were conducted	Content analysis	8 females,	< 60 years	Not reported	6 Wives, 5 husbands,	

al. (2011)		of general practice team  Purposive sampling from an acute stroke unit, a rehabilitation centre and a general practice in South West London.		practice and their reactions to the community based support proposed in the New Deal. Secondly, perceptions of a general practice team were investigated covering similar topics to carer interviews but from the practice team's perspective.	with carers and the general practice team using topic guides. Interviews were recorded and transcribed verbatim.		5 males	3 > 60 years 10		2 daughters.
Greenwood et al. (2009b)	UK	31 Purposive sample From one acute and two rehabilitation stroke units in South-West London.	Within three months post discharge	To investigate experiences of informal carers of stroke survivors over time- close to discharge, 1 month and approximately 3 months after returning home.	Semi-structured interviews at three time points: close to discharge, 1 month and approximately 3 months after returning home. Interviews were audio-taped and transcribed verbatim as soon as possible after the interviews.	Ethnography	2 females, 9 males	Age < 65: 8 Age > 66: 23	White British 18 Other white 4 Asian/mixed Asian 4 Black 2 Other ethnicity 3	16 spouses/partners. 13 adult children, 2 siblings.
Gustafsson and Bootle (2013)	Australia	5	One month following discharge from stroke rehabilitation	To enhance our understanding of the transition experience for clients with stroke and their carers during discharge and the first month at home.	Semi-structured interviews conducted in a 26 bed inpatient rehabilitation unit in a major metropolitan hospital. Baseline demographic data collected from all participants at recruitment (age, gender and	Demographic data were entered into STATA and summaris	4 females, 1 male	36-79	Not reported	1 Friend 1 Daughter 1 Wife 2 Spouses

					hemisphere affected, stroke type).	ed. Inductive thematic analysis				
Howe et al. (2012)	Australia	48 Nominated by relatives with aphasia who had taken part in a complementary investigation. Maximum variation sampling	1-195 months	To identify the rehabilitation goals that family members of individuals with aphasia have for themselves.	Individual semi-structured in-depth interviews conducted with the family members in their homes or other location of their choice. Interviews audio-recorded and then transcribed verbatim.	Qualitative content analysis	36 females, 12 males	24-83	Not reported	28 spouses / partners, 5 siblings, 4 daughters, 3 sons, 2 parents and 6 other relatives
Jones and Morris (2013)	Wales	11 Recruited via UK charity 'Different Strokes' using web and paper adverts.	At least 12 months post stroke	To examine particular, and potentially unique, aspects of the parent-adult child caring relationship in stroke.	Semi-structured interviews, guided by interpretative phenomenological analysis conducted in each participant's home, lasted approximately 45 minutes (range 21-59 minutes) and were audio-recorded for transcription	Interpretative Phenomenological Analysis	6 females, 5 males	55-76	1 British-Indian. All other British-White.	Mothers and fathers
Kniepmann and Cupler (2014)	USA	12	At least 6 months post stroke	To explore how carers of spouses with stroke and aphasia experience occupational changes, and how these changes are described	Mixed methods exploratory study combining quantitative description and statistical comparisons of the participants with qualitative narratives of their lived experiences. Three graduate student researchers	Quantitative data: Descriptive analysis, non-parametric statistics,	10 females, 2 males	37-73	7 Caucasian, 4 African American (one did not disclose)	Spouses or 'significant others.'

					conducted face-to-face study sessions either at the medical school campus, in the carers' home, or in a community location. Study sessions took 40 to 90 minutes.	Mann-Whitney U tests (independent samples). Qualitative data: Content analysis				
Lawrence and Kinn (2013)	Scotland	11 Purposive sampling	Between 3 months and two years post stroke	To explore, over an extended period of time, the experience of being a family member of a young adult who has had stroke, and to determine specific needs, priorities and outcomes of family members throughout the stroke recovery trajectory	Longitudinal interview study. Participants were invited to take part in one-to-one, face-to-face interviews, in a location of their choosing, usually their own home. Participants were interviewed alone, with the exception of two sisters who chose to be interviewed together.	Phenomenological approach	9 females, 3 males	17-71	White	2 mothers, 1 father, 1 sibling, 3 spouses/partners, 4 daughters
Le Dorze and Signori (2010)	Canada	11 Recruited with the help of several community associations of aphasic people. Convenience sampling	The time elapsed since the onset of aphasia was, on average, 6 years and 8 months	To better understand the process that spouses of people with aphasia engage in, over time, to satisfy their needs and any encountered facilitators and barriers when needing help.	Each semi-structured group interview included between two and four participants and lasted between 90 and 120 mins.	Unclear	9 female 2 male	51-68	Not reported	Spouses
Lin (2010)	USA	20 carers (community one)	Not reported	To explore the self-reported needs and concerns of the family caregivers of stroke survivors	Little details provided: Twenty carers interviewed with a semi-structured	Not reported	Community one: 17	Community one:	Primarily Chinese-American	Community-1 7 Parents,

		20 carers (community two)		soon after discharge to the home setting.	questionnaire as pre-test study (community-1) and 20 carers interviewed with a structured questionnaire (community-2).		female 3 male  Community two: 18 female 2 male	56-70  Community two: 51-87	carers and two Caucasian carers	12 spouses, 1 friend Community-2 5 parents, 12 spouses, 3 friends
Lutz et al. (2007)	USA	12 Purposive sampling	?	To identify post-discharge needs of veterans recovering from stroke and their caregivers and to identify how a CC/HT program could be designed to address these needs.	Semi-structured interviews were 1 to 2 hours in length, audio-taped, transcribed verbatim by a research assistant, and verified by the primary author/interviewer. Questions in initial interviews were open and unstructured. Veterans and caregivers were interviewed together.	Grounded dimensional analysis	Females	57-86	Not reported	Spouses
Lutz et al. (2011)	USA	19 Inpatient rehabilitation facility	Within 6 months of stroke survivor's discharge from rehab setting	To explore the experiences of stroke patients and their family caregivers as they moved from acute care to inpatient rehabilitation to home and to identify needs as they transitioned through the care continuum.	1st Interviews: Interviewed when in inpatient rehabilitation or as close to discharge as was convenient for the caregiver. 2nd interviews: Conducted 6 months post discharge usually in participants homes.  Group interviews: 3 case managers at 1 site and 1 case manager at another	As above	Not reported	Not reported	Not reported	14 spouses 1 mother

					site.					
Sjöqvist Nätterlund (2010)	Sweden	14 Recruited via asking aphasic people from an earlier study if they could interview one of their close relatives. Convenience sampling	Between 2 and 11 years after the onset of aphasia	To investigate the close relatives' experiences of the influences of aphasia on their own life situation and their perceptions of everyday activity for the person with aphasia and support for the family in daily life.	Interviews with close relatives of people with aphasia were performed in a conversational form. Nine interviewed in own homes, 5 interviewed in centre for rehabilitation research. Interviews lasted between 45 minutes and two hours.	Content analysis	7 females, 7 males	Not reported	Not reported	7 spouses/partners, 4 parents, 1 sibling, 1 child, 1 close friend
Niyomthai et al. (2010)	Thailand	16	Between 13 and 168 months (approx. 1-14 years)	Explored the meaning of family strength when caring for a stroke member at home.	Semi-structured Interviews	Thematic analysis	11 females, 5 males	24-67	Not reported	13 married, others daughters.
Nyström (2011)	Sweden	17  Purposefully chosen via aphasia associations.	Not reported	Understanding existential consequences of being closely related to a person with aphasia.	Interviews - followed principles of an open lifeworld approach	Life world approach	6 females, 11 males	25-88	Not reported	10 spouses, 6 children, 1 parent.
Paul and Sanders (2010)	USA	9  Five healthcare networks, a home health agency, and two private rehabilitation	0.5-24 months (mean 11)	To explore the education experiences and needs of communication partners of individuals with aphasia within two years post onset of aphasia.	One-on-one semi-structured interviews were audiotape recorded for later transcription. General initial questions were followed by more specific key questions related to education received about aphasia.	Bronfenbrenner's ecological model	7 females, 2 males	37-68	Not reported	1 friend, 4 spouses, 3 sons/daughters, 1 significant other.

		agencies distributed information on the study. Two area stroke support groups, word of mouth, and snowball technique garnered additional participants.								
Pierce et al. (2007)	USA	73 Recruited from rehabilitation facilities in northern Ohio and southern Michigan	Within first year post stroke	To gain an in-depth, theory based description of the experience of caring, that is, problems and successes adult caregivers new to the role expressed in the first year of caring for stroke survivors.	Bimonthly telephone interviews (trained interviewers).	Guided by Friedemann's framework of systemic organization, data analysed using content analysis.	55 females 18 males	55 years (average)	62 white, 9 African American, 1 Hispanic, 1 American Indian	34 wives, 16 husbands, 13 daughters 1 son and 9 other relatives and friends.
Pierce et al. (2006)	USA	9 Enrolled in the web based education project	Within first 3 months	To examine perceived problems reported in caring	Bi-monthly telephone interviews to collect data over a 3 month period.	Unclear	4 females 5 males	51-68	8 reported ethnicity as white, one did not answer	male carers included husbands and friends, female



										carers included wives and adult children
Quinn et al. (2014b)	UK	8 Recruited through two charitable organisations for stroke survivors and two independent Facebook groups.  Opt in approach	Between 1 and 9 years post stroke	To qualitatively explore couples shared experiences when one partner had a stroke at a young age and to explore how this experience may have impacted on their relationship	Semi-structured joint interviews were conducted, most lasted approximately 1 h 30 min	Interpretative Phenomenological Analysis	7 females 1 male	36-59	Not reported	Spouses
Robinson et al. (2005)	UK	14  Selected from the North Tyneside General Hospital Stroke Review Clinic, and Newcastle Stroke Discharge Team	Between two and four years post stroke	To develop an intervention that followed these phases of the MRC framework, to facilitate coping skills in carers of people with stroke	Qualitative interviews - (either at home or at the hospital)	Grounded theory	Not reported	38-74	Not reported	wife, husband, daughter, son
Saban and	USA	46 Purposive	Within 3 and 12	To conduct a qualitative study to describe the experience of female	Qualitative descriptive design- open ended	Content analysis	All female	18- 73	38 white, others not	24 wives 18

Hogan (2012)		sample Recruited nationally via recruitment flyers distributed at stroke caregiver support groups, social networking internet sites, and several neurology/neurosurgical outpatient clinics	months post stroke	caregivers who care for an adult family member who has experienced a stroke within the previous year.	questionnaire Participants received packets of written study materials in the mail, including written questionnaire containing open-ended questions exploring the experience of female caregivers of stroke survivors and how they coped with changes in their lives during the first year				reported	children, 2) as either significant other to the survivor or mother of the survivor.
Silva-Smith (2007)	USA	12 Purposive, consecutive sampling, from inpatient rehabilitation units of one suburban hospital and two urban hospitals located in a large Midwestern city.	Within first month	To generate a grounded theory to describe the experience of preparing for and beginning a new caregiving role following a family member's stroke.	Pre-discharge audiotaped interviews -occurred during the stroke survivor's hospitalisation. The second -4 weeks after the stroke survivor's hospital discharge. Twenty three interviews conducted with 12 participants.	Grounded theory	9 females 3 males	38-78	6 African American, 6 Caucasian	4 wives, 3 husbands, 2 sisters, 1 mother, 1 daughter, and 1 fiancée
Smith et	Canada	9	Within first	To learn about family caregivers'	Semi structured interviews at	Content	6	Mean	Not	Spouse:

al. (2008b)		Recruited from inpatient and outpatient clinics of the stroke rehabilitation program of the Toronto Rehabilitation Institute.	6 months	experiences and support needs during the rehabilitation phase to inform program development.	the rehabilitation unit, approx. 40- 60 minutes.	analysis	females (2 younger, 3 older) 3 males (two younger 1 older)	age (range younger carers - 45.6 years (36-52)  Older carers - 68.8 years (58-77)	reported	younger carers 3 (60%) older carers 3 (75%) Adult child: younger carers 2 (40%) older carers 0 (0%) sibling/ other: younger carers 0 (0%) older carers 1 (25%)
Strudwick and Morris (2010)	UK	9 From three urban locations in southern England. Convenience sampling	6 months-11 years post stroke.	To explore the experiences of African-Caribbean informal stroke carers in the UK	Semi structured interviews, lasted between 40 and 80 minutes.	Thematic analysis	8 females, 1 male	30-72	All African Caribbean	5 Spouses, 1 Cohabiting partner, 2 daughters, 1 niece
Tellier et al. (2011)	Canada	8 Recruited from rehabilitation unit	3 months after the discharge of stroke survivor from acute	To explore the QOL of spouses after a mild stroke	Interviews 3 months after the discharge, without stroke survivor present.	Content analysis	6 females 2 males	45-69	Not reported	All spouses

			care							
Tunney and Ryan (2014)	Ireland	10 Volunteer sampling from a local carers' support group	2-5 years	To explore how members of a stroke carers' support group perceived that services for stroke patients and their carers could be improved.	Experience-based design approach  Experience questionnaire and listening labs used in this study.	Thematic content analysis	All females	64.5 years (mean )	Not reported	Not reported
Van Dongen et al. (2014)	Austria	3 Recruited via Occupational therapists working at two different stroke rehabilitation centres in Austria	5-14 months	To explore how some working Austrians experience and handle their changing daily occupations after becoming carers of a relative who has had a stroke.	Two semi-structured interviews for each participant.	Interpretative Phenomenological Analysis	Females	49-59	Not reported	2 wives, 1 daughter
White et al. (2007)	Canada	14 Recruited via medical records of stroke survivors discharged to the community or to a rehabilitation centre from acute care urban hospitals in	"About half of the group had been in the role less than six months and the other half, on average, for one year."	To explore the perceptions of caregivers of persons with stroke regarding the barriers and facilitators to undertaking the caregiving role, particularly related to the health care system, to identify potential strategies that could be implemented within the health care	Focus groups and individual interviews, between 2-4 members in each focus group. Lasted 2-2.5 hours	Content analysis procedure	7 females, 7 males	"majority over 50 years"	Not reported	Spouses

		Montreal, Canada								
Winkler et al. (2014)	UK	10 Recruited via blogs located by searching key words e.g. aphasia	-	To explore the impact of stroke and aphasia on the carer and their relationship with the person with aphasia.	Publicly available data were gathered from the Internet and analysed without investigator interaction with participants.	Framework analysis	9 females, 1 male	Not reported	White Caucasian	6 spouses, 1 mother; 3 daughters (co-authors of one blog).
Young et al. (2014)	USA	14 Recruited from two inpatient rehabilitation facilities.	In period from discharge to home	To understand needs of spousal carers of stroke survivors during the transition from rehabilitation to home.	Carer participated in one to two interviews depending on availability, scheduled as follows: (1) a few days prior to discharge to a few weeks post-discharge from the IRF and (2) within 3 to 6 months post-discharge. Eight participated in both interviews and six participated in one post-discharge interview for a total of 22 interviews-approx. 60 to 90 minutes	Grounded theory	8 females, 3 males	49-82	3 black, 10 white and 1 Native American	Spouses

## Appendix H: Excluded studies table for updated Greenwood et al. (2009a) review

Reasons for exclusion with references
<b>n= 7: Focus on stroke survivor rather than carer</b> (Allison et al., 2008; Ellis-Hill et al., 2009; Goetz, 2011; Halle et al., 2011; Norris et al., 2012; Robison et al., 2009; Salisbury et al., 2010)
<b>n= 11: Not qualitative article (or primarily)</b> (Cameron et al., 2014b; Grant et al., 2006b; Jones-Cannon and Davis, 2005; Le Dorze et al., 2009; Mackenzie et al., 2007; McGurk et al., 2011; Perry and Middleton, 2011; Rodgers et al., 2007; Sieminski et al., 2005; Wachters-Kaufmann et al., 2005; Yaffe and Jacobs, 2008)
<b>n= 2: Case studies or small samples (two or less)</b> (Ekstam et al., 2011; Lefebvre et al., 2008)
<b>n = 9: Not caring for stroke survivor</b> (Gan et al., 2010; Giosa et al., 2014; Minnes et al., 2010; Rand and Malley, 2014; Turner et al., 2007; Turner et al., 2011a; Turner et al., 2009; Turner et al., 2011b; Williams et al., 2014)
<b>n = 4: Not focused on caregiving experience/ needs</b> (Gillespie et al., 2010; Grawburg et al., 2013; Greenwood and Habibi, 2014; Pierce et al., 2009a)
<b>n = 1: Thesis</b> Kitzmüller et al. (2012)
<b>n = 3: Difficult to separate stroke survivor and caregiver data</b> (Pereira and Botelho, 2011; Pringle et al., 2013; White et al., 2014)
<b>n= 1: Focus on inpatient experiences during hospital rather than caring in own homes</b> (Morris and Morris, 2012)

Appendix I: Table of needs, barriers and facilitators identified in the updated of the Greenwood et al. (2009a) review

Analytical themes reflecting carer needs	Barriers		Facilitators	
	Behavioural	Environmental	Behavioural	Environmental
1. Carers need to be supported to feel practically and emotionally prepared before and during the transition from hospital to home	<p><b>Individual:</b> - Avoiding approaching HPs for support</p>	<p><b>Interpersonal:</b></p> <ul style="list-style-type: none"> <li>- Poor communication from HPs</li> <li>- Professionals fail to adequately assess whether carers understand stroke survivor's needs</li> <li>- Professionals fail to adequately teach carers about supporting stroke survivors with rehabilitation</li> <li>- Professionals not providing appropriately timed information and support</li> </ul> <p><b>Organisational:</b></p> <ul style="list-style-type: none"> <li>- Poorly timed family visits</li> <li>- Failure of services to provide enough staff to support carers</li> </ul>	<p><b>Individual:</b> - Approaching providers with needs</p>	<p><b>Interpersonal:</b> Collaboration from healthcare providers to provide reassurance and increase confidence</p> <p><b>Organisational:</b></p> <ul style="list-style-type: none"> <li>-- Weekend leave for preparing practically</li> <li>- Involvement in rehabilitation</li> </ul>

	<b>Non-behavioural and environmental barriers</b> <ul style="list-style-type: none"> <li>- Reluctance to approach professionals for support/information (feeling as though making a fuss)</li> <li>-- Professionals do not see it as their role to seek out carers</li> <li>- Lack of knowledge and skills for being prepared following the transition from hospital to home</li> <li>- Lack of knowledge about who to ask and where to go for support and information</li> <li>-Lack of time to prepare, poor timing of visits, limited staff, short hospital stays</li> <li>- Focus on survivor not long-term implications for carer</li> <li>- Uncertainties about care required</li> <li>- Feeling overwhelmed</li> <li>- Lack of realisation of how hard things would be</li> <li>- Younger carers more critical of health system</li> </ul>		<b>Non-behavioural and environmental facilitators</b> <ul style="list-style-type: none"> <li>- Hope (rehabilitation)</li> <li>- Younger carers rated support services highly</li> <li>- Older carers positive about staff</li> <li>- Training in transfers at an appropriate time important for young carers</li> </ul>	
<b>2. Carers need to balance providing care to stroke survivor with finding time to self</b>	<b>Individual-</b> Keeping a constant eye on the stroke survivor <ul style="list-style-type: none"> <li>- engagement in care duties meaning little time for self</li> <li>- focussing on supporting the stroke survivor rather than themselves</li> <li>- Restricting activities to purpose</li> </ul>	<b>Interpersonal:</b> <ul style="list-style-type: none"> <li>- Support from family not forthcoming</li> </ul>	<b>Individual:</b> <ul style="list-style-type: none"> <li>- Scheduling and planning</li> </ul> <b>Interpersonal:</b> <ul style="list-style-type: none"> <li>- Negotiating support with family</li> <li>- Dividing care among family members</li> <li>- Devising rotas to share care</li> <li>- Putting themselves first without guilt</li> </ul>	<b>Organisational:</b> <ul style="list-style-type: none"> <li>-Stroke survivors spending time at club/therapy sessions</li> <li>- Family and friends supporting the stroke survivor.</li> <li>- Shared care</li> </ul>
	<b>Non-behavioural and environmental barriers</b> <ul style="list-style-type: none"> <li>- Little time for family and friends</li> <li>- Family and friends feel uneasy about changes to stroke survivor</li> <li>- Family and friends struggle to understand the situation</li> <li>- Feeling guilty enjoying themselves without stroke survivor</li> <li>- Fears of stroke survivor safety</li> <li>- Loss of self and independence</li> </ul>		<b>Non-behavioural and environmental facilitators</b> <ul style="list-style-type: none"> <li>- Finding selves and own identities aside from being a carer</li> <li>- Improved situation facilitated engagement in activities</li> <li>- Increased confidence leaving stroke survivor alone</li> </ul>	
<b>3. Carers need to be able to cope with a changed</b>		<b>Interpersonal/ Organisational:</b> <ul style="list-style-type: none"> <li>- Lack of emotional/ psychological</li> </ul>	<b>Individual:</b> <ul style="list-style-type: none"> <li>Venting in an internet blog</li> </ul>	<b>Interpersonal/ Organisational:</b> <ul style="list-style-type: none"> <li>Support from family who will listen</li> </ul>



situation (relates to more overall coping).		support - Reduced support from family and friends		- Peers as an emotional outlet - Support from other external support.
	<b>Non-behavioural and environmental barriers</b> -- Family and friends struggle to understand the situation - Worries about the future - Daily struggles		<b>Non-behavioural and environmental facilitators</b> - Taking each day as it comes - Acceptance - Comparing with others - Appreciating life - Working towards normality Sense of humour	
4. Carers need to maintain relationships despite changes and losses	<b>Individual:</b> Behaving differently in relationship		<b>Individual:</b> Creating space away from each other - Relearning to live together	<b>Organisational:</b> Family counselling
	<b>Non-behavioural and environmental barriers</b> -Struggles to gain reciprocity in relationship - Knowing there would always be a difference - Tensions around some of the changes - Unable to rekindle identity as a wife/ husband following role changes		<b>Non-behavioural and environmental facilitators</b> - Finding positives (new closeness) - Searching for new meanings in the relationship and focussing on what remains	
5. Carers need to obtain information in accordance with needs	<b>Individual:</b> - Passively waiting for information	<b>Interpersonal:</b> - Little interaction with health professionals once home <b>Organisational</b> - Lack of opportunity for communication with health professionals - Lack of appropriate and accessible resources of information - Lack of information provided by services and professionals following stroke survivors' return home	<b>Individual:</b> - Seeking knowledge from the internet, asking questions, making notes - Approaching professionals for information	<b>Interpersonal:</b> Appropriate information delivery by professionals

	<b>Non-behavioural and environmental barriers</b> <ul style="list-style-type: none"> <li>- Reluctance to approach professionals for support/information (feeling as though making a fuss)</li> <li>- Short hospital stay limits opportunity for gaining appropriate information</li> <li>- Assuming information is provided</li> <li>- Lack of coordinated approach to information delivery - area of improvement (younger carers)</li> <li>- Information among older carers- overwhelming</li> </ul>		<b>Non-behavioural and environmental facilitators</b> <ul style="list-style-type: none"> <li>- Younger carers proactive in gaining information</li> <li>- Information important for young carers</li> <li>- Focus on information content in young people</li> <li>- Knowledge about available and accessible resources.</li> </ul>	
<b>6. Carers need to obtain support in accordance with their needs</b>	<b>Individual:</b> -Avoiding asking/ approaching family, friends and HPs for support	<b>Interpersonal/ organisational</b> <ul style="list-style-type: none"> <li>- Decreased support from family and friends over time</li> </ul> <b>Organisational:</b> <ul style="list-style-type: none"> <li>Lack of available/ accessible support in community</li> </ul>	<b>Individual:</b> <ul style="list-style-type: none"> <li>- Proactive in asking for help</li> <li>- Devised own peer support groups</li> </ul>	<b>Organisational</b> - Available support from friends, family and professionals <ul style="list-style-type: none"> <li>- Access to resources</li> </ul> <b>Interpersonal</b> <ul style="list-style-type: none"> <li>- Awareness from HCPs that support groups are important</li> <li>- Provided with knowledge about available resources</li> </ul>
	<b>Non-behavioural and environmental barriers</b> <ul style="list-style-type: none"> <li>- Reluctance to ask family and friends for support (not wanting to disturb them).</li> <li>- Reluctance to approach professionals for support/information (feeling as though making a fuss)</li> <li>- Professionals lack time to support carers in community</li> <li>- Professionals' ambivalence towards proactively supporting carers</li> <li>- Little time for friends</li> <li>- Younger carers more likely to criticise health system</li> </ul>		<b>Non-behavioural and environmental facilitators</b> <ul style="list-style-type: none"> <li>- Younger carers rated support services highly</li> <li>- Older couples enjoyed company of paid carers</li> </ul>	

## Appendix J: Ethical approval letter



### Health Research Authority NRES Committee Yorkshire & The Humber - Bradford Leeds

Room 001  
Jarrow Business Centre  
Viking Industrial Park  
Rolling Mill Road  
Jarrow  
NE32 3DT

Telephone: 0191 428 3384

09 March 2015

Miss Jessica F Hall  
PhD student  
University of Leeds  
Academic Unit of Elderly Care and Rehabilitation  
Bradford Institute for Health Research, Temple Bank House  
Bradford Royal Infirmary  
BD9 6RJ

Dear Miss Hall

**Study title:** An exploration of the experiences of carers of stroke survivors, their unmet needs and the health, social and emotional consequences of caring across different time points: A qualitative study.

**REC reference:** 15/YH/0073

**IRAS project ID:** 166761

Thank you for your submission of 3<sup>rd</sup> March 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 27 February 2015

#### Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster for recruitment in voluntary organisations and groups]	v.2	03 March 2015
Other [Research Summary ]	Word doc.	03 March 2015
Participant consent form [Carer consent form]	v.3	03 March 2015
Participant consent form [Consultee declaration form]	v.2	03 March 2015
Participant consent form [Stroke survivor consent form]	v3	03 March 2015
Participant information sheet (PIS) [Carer information sheet]	v.3	03 March 2015
Participant information sheet (PIS) [Patient information sheet]	v.3	03 March 2015

## Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster for recruitment in voluntary organisations and groups]	v.2	03 March 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds conformation of Liability]		02 February 2015
Interview schedules or topic guides for participants [Initial Interview Topic Guide]	v.2	08 December 2014
Interview schedules or topic guides for participants [Second topic guide]	v.1	08 December 2014
Letter from sponsor [Letter from sponsor ]		02 February 2015
Letters of invitation to participant [Invitation letter]	v.1	09 January 2015
Other [Research Summary ]	Word doc.	03 March 2015
Participant consent form [Stroke survivor consent - aphasia friendly version]	v.1	09 January 2015
Participant consent form [Carer consent form]	v.3	03 March 2015
Participant consent form [Consultee declaration form]	v.2	03 March 2015
Participant consent form [Stroke survivor consent form]	v3	03 March 2015
Participant information sheet (PIS) [Aphasia friendly information sheet for patients]	v.2	09 January 2015
Participant information sheet (PIS) [Consultee information sheet]	v.1	09 January 2015
Participant information sheet (PIS) [Carer information sheet]	v.3	03 March 2015
Participant information sheet (PIS) [Patient information sheet]	v.3	03 March 2015
REC Application Form [REC_Form_04022015]		04 February 2015
Research protocol or project proposal [Protocol]	v.7	02 February 2015
Summary CV for Chief Investigator (CI) [Curriculum Vitae - J.Hall]	v.1	09 January 2015
Summary CV for supervisor (student research) [CV Supervisor - A.Forster]	v.1	12 January 2015
Summary CV for supervisor (student research) [Supervisor CV]	J. Dickerson	
Summary CV for supervisor (student research) [Supervisor CV]	D. Clarke	

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/YH/0073	Please quote this number on all correspondence
------------	--

Yours sincerely



**Sarah Prothero**  
REC Assistant

A Research Ethics Committee established by the Health Research Authority

E-mail: [nrescommittee.yorkandhumber-bradfordleeds@nhs.net](mailto:nrescommittee.yorkandhumber-bradfordleeds@nhs.net)

Copy to: Mrs Jane Dennison, Bradford Teaching Hospitals NHS Foundation Trust

## Appendix K: Participant information sheet

Participant information booklet for carers/significant others  
V.3 03.03.15

### Introduction

We would like to invite you to take part in a research study. This leaflet tells you about the study and what your participation would involve. Please read this carefully and ask us if anything is not clear or if you would like more information.

### What is the purpose of the study?

This study aims to understand your experiences of life after your friend/relative had a stroke. We hope to gain a better understanding of unmet needs after stroke so that we can improve services and the support offered to the carers of people who have had a stroke.

### Why have I been invited to take part?

You have been chosen because you are a carer /significant other of someone who has had stroke. Your views are important in understanding the experiences of carers of people who have had a stroke.

### Do I have to take part?

No, it is up to you whether you would like to take part or not. The standard of care and support received by your relative/friend or yourself will not be affected in any way.

### What will be involved if I agree to take part?

Taking part would mean being interviewed by a trained researcher to talk to you about your experiences of life after your friend/relative had a stroke.

This interview would take place at a time and a location that is convenient for you (probably your own home) and take about an hour. We would like to record the interview so that we can accurately

recollect what you say but all your data will be anonymous. You may be asked to take part in a follow up interview at a later date to understand your experiences over time.

### Will my taking part in the study be kept confidential?

All your personal information (name, address and telephone number) will be kept confidential and securely stored at the Academic Unit of Elderly Care and Rehabilitation in Bradford. However, if we have concerns that your friend/relative are at risk of harm, then we will break confidentiality and tell the relevant professional services, for example their GP, hospital or social services.

You will be given a pseudonym (false name) and only researchers involved in the study will be able to identify you from your pseudonym. The actual recordings of the interview will be destroyed once the study is completed. At the end of the study, your information will be securely archived for 3 years.

### What are the possible benefits of taking part?

Taking part is unlikely to benefit you directly, however, it may help improve future services and support for carers of people who have had a stroke.

### What are the possible disadvantages and risks of taking part?

We do not anticipate that there will be any disadvantages or risks if you take part.

You may find some of the topics covered in the interview upsetting. You do not have to answer any questions you do not wish to and you may pause or stop the interview at any time.

### What will happen if I do not want to carry on with the study?

Participant information booklet for carers/significant others  
V.3 03.03.15

You are free to withdraw from the study at anytime. If you withdraw, the information already collected from you will be included in the final study analysis. If you withdraw consent for your information to be used, it will be confidentially destroyed.

**What will happen to the results of the research study?**

The results of this study will be published in a PhD thesis. We also hope to publish the results in an academic journal. If you wish to obtain a copy of the report, you can request one from the researcher.

It is also possible that the results and extracts from the interviews may be presented at conferences. You will not be identified in any report/publication.

**What if I need more information or there is a problem?**

If you need further information or have or have any concerns about any aspects of the study, please contact the researcher Jessica Hall on 01274 38 2818 or [Jessica.Hall@bthft.nhs.uk](mailto:Jessica.Hall@bthft.nhs.uk)



**INFORMATION LEAFLET FOR CARERS / SIGNIFICANT OTHERS**

Study Title: The experiences of carers of people who have had a stroke.

**TAKE PART IN AN INTERVIEW**



Bradford Teaching Hospitals   
NHS Foundation Trust

  
UNIVERSITY OF LEEDS

This study is organised and run by the Academic Unit of Elderly Care and Rehabilitation at Bradford Teaching Hospitals NHS Foundation Trust. This study is funded by the University of Leeds. The sponsor for the research is the University of Leeds. The study has been approved by a NHS Research Ethics Committee.

## **Appendix L: Interview topic guide (first interviews group one, all interviews group two)**

### **General opening questions:**

Could you tell me about yourself?

Who are you caring for?

How long has it been since their stroke?

### **Life before your relative's stroke**

Could you tell me what your life was like before your relative's stroke?

### **Your relative's stroke**

Could you describe what happened at the time of your relative's stroke?

How did your relative's stroke affect you at this early stage?

- (physically, functionally, emotionally, social consequences)?

How did you feel ?

Could you tell me about your relative's and your own experience in hospital?

- support/information given in hospital
- What were your needs at this point?

### **Coming home**

Could you tell me about what it was like for you and your relative coming home from hospital?

- Involvement, preparation, expectations
- Support/ information
- What were your needs ?

### **Recovery and adjustment**

Could you describe how things have been since returning home?

- Process of stroke recovery over time (what has helped/hindered this process)
- Formal support/informal support received (both)
- Information/advice received (both)

Have your needs changed? (how/why)

### **Life now**

Could you describe a typical day now? (what do you do, how and why)

What activities/events do you now find meaningful/important/enjoyable?

- Experiences of resuming activities

### **Managing impacts of new role**

Could you tell me how the stroke affects you now?

- Challenges/needs

How have things changed over time?

- What has helped/hindered this process?

What, if any, formal support do you still receive?

- What support offered/available (how this has changed over time, any new engagements?)
- What do you think of this support?

What, if any, support do you receive from family and friends? (how changed over time)

### **Problem solving / resolving issues (including barriers/facilitators)**

What do you feel you manage/cope with well?

Have you encountered any problems/challenges following discharge home?

- Management for problems now and in future

### **Unmet needs / ongoing problems/issues (including barriers/facilitators)**

What do you find particularly difficult to manage/cope with?

What do you feel you could do with extra support with?

- Health, social, emotional?

What information has been most useful to you/ do you need?

- what kind, what format, when, why and how
- At what time point do you feel information would be useful for you?

### Future

What are your hopes/plans for the future?

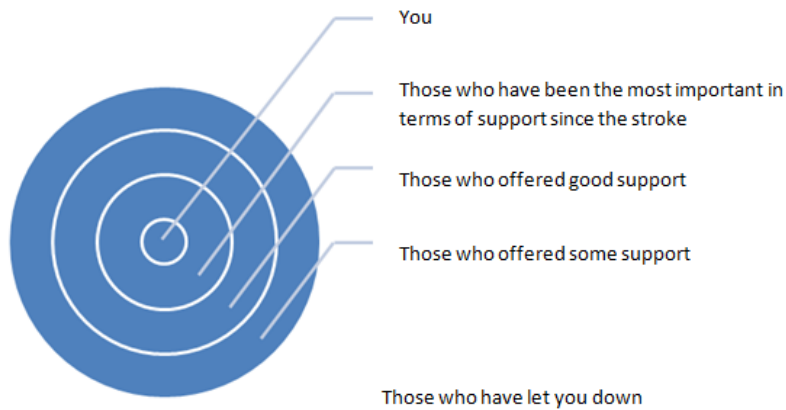
- Where do you see yourself in 6 / 12 months time?

What do you feel your needs are?

### Exploring social networks

- Discuss map – could you tell me a little about each of the people/services identified. What kinds of help have they provided? Why have you placed them where you have on the diagram?
- Who was the most helpful when your friend/relative first returned home from hospital? Is there anyone/any service who you expected to be more helpful for you personally?
- How did you manage to access support from ...?
- Who is particularly helpful now?
- Have you grown closer or apart from anyone since your friend/ relative's stroke?
- Have you asked anyone for help? Did people offer to help you?

An example of the social network mapping tool that will be used:



### Closing questions

What advice would you give to others?

Do you have anything to add or questions for me?



## Appendix M : Interview topic guide (second and third interviews, group one)

### General opening questions:

- How have you been since I last saw you?
- Has anything changed for you since we last spoke? Have things got easier/ more difficult?
- How do you feel about these changes?
- Are there things that you still struggle with?

### Exploring changes in health (physical and mental health)

- Have there been any changes in your health?
- How have you managed these changes in your daily life? Could you give me an example?
- How do you feel about these changes?
- Has anyone / anything in particular helped / hindered the changes?

### Exploring changes in daily life

- Could you describe a typical day now?
- Have you encountered any problems/challenges since we last met? Could you give me an example of how this has impacted on your daily life?
- What have you stopped doing that you did before? What has stayed the same?
- Has anyone been helpful to you as a carer? How did you access this support?
- What additional help do you still need for yourself?
- Have there been any key moments or turning points in your caring role since I last saw you?
- What do you feel your needs are?

### Exploring changes in understanding / coming to terms

- (If relevant) Do you feel you have a better or a different understanding of your situation than when we met before?
- Have you had any insights or started to think differently about anything?
- How have you adapted? Are there things you feel you've learned to cope better with since we last met?
- Are there things that worry you?
- Do you need emotional support?

### Exploring social networks

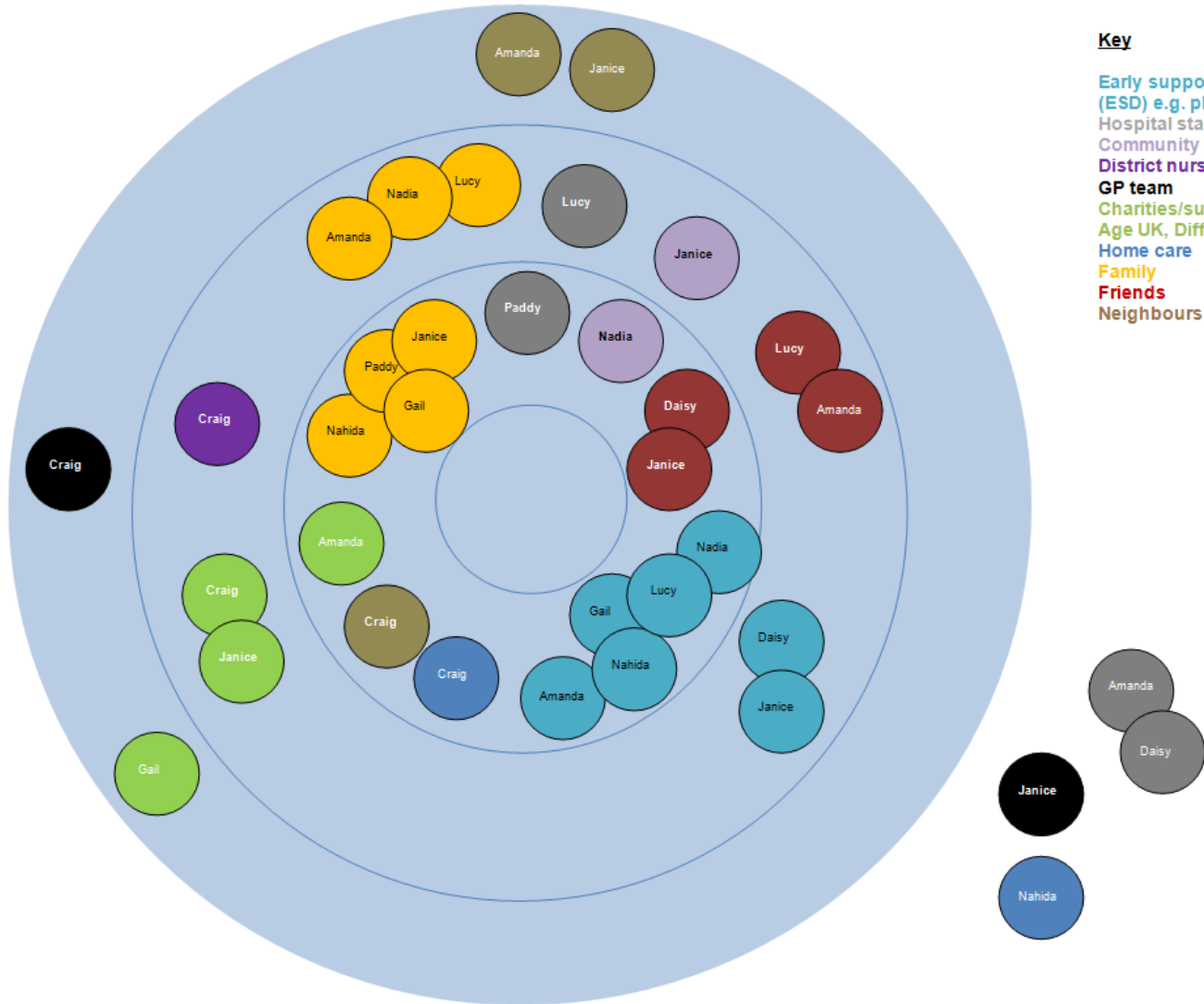
- As before

### Closing questions

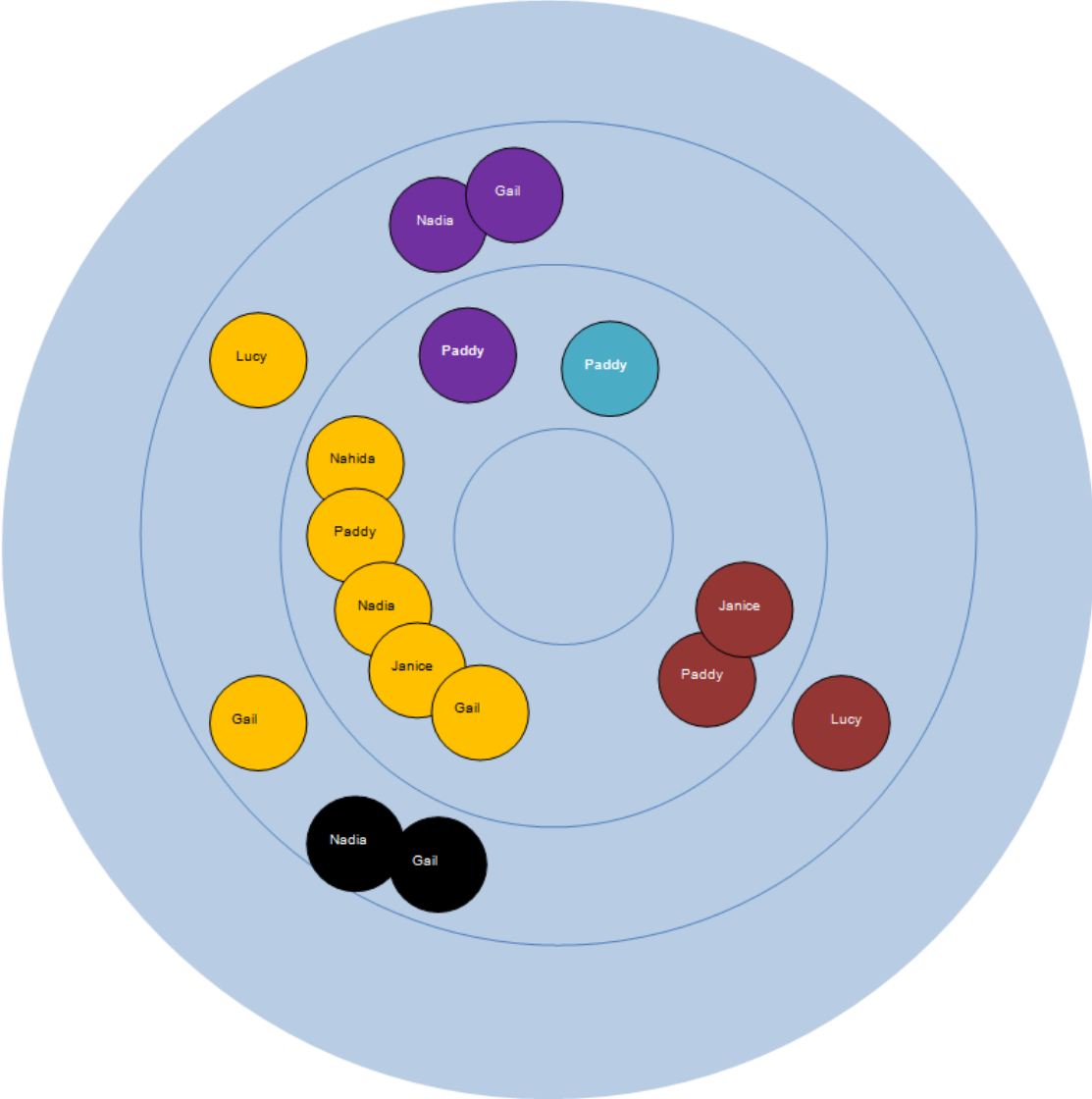
When you reflect on the last few months, is there anything you've learnt? Any advice you'd give to others?

Any questions for me?

**Appendix N: Social networking map, group one (T1)**



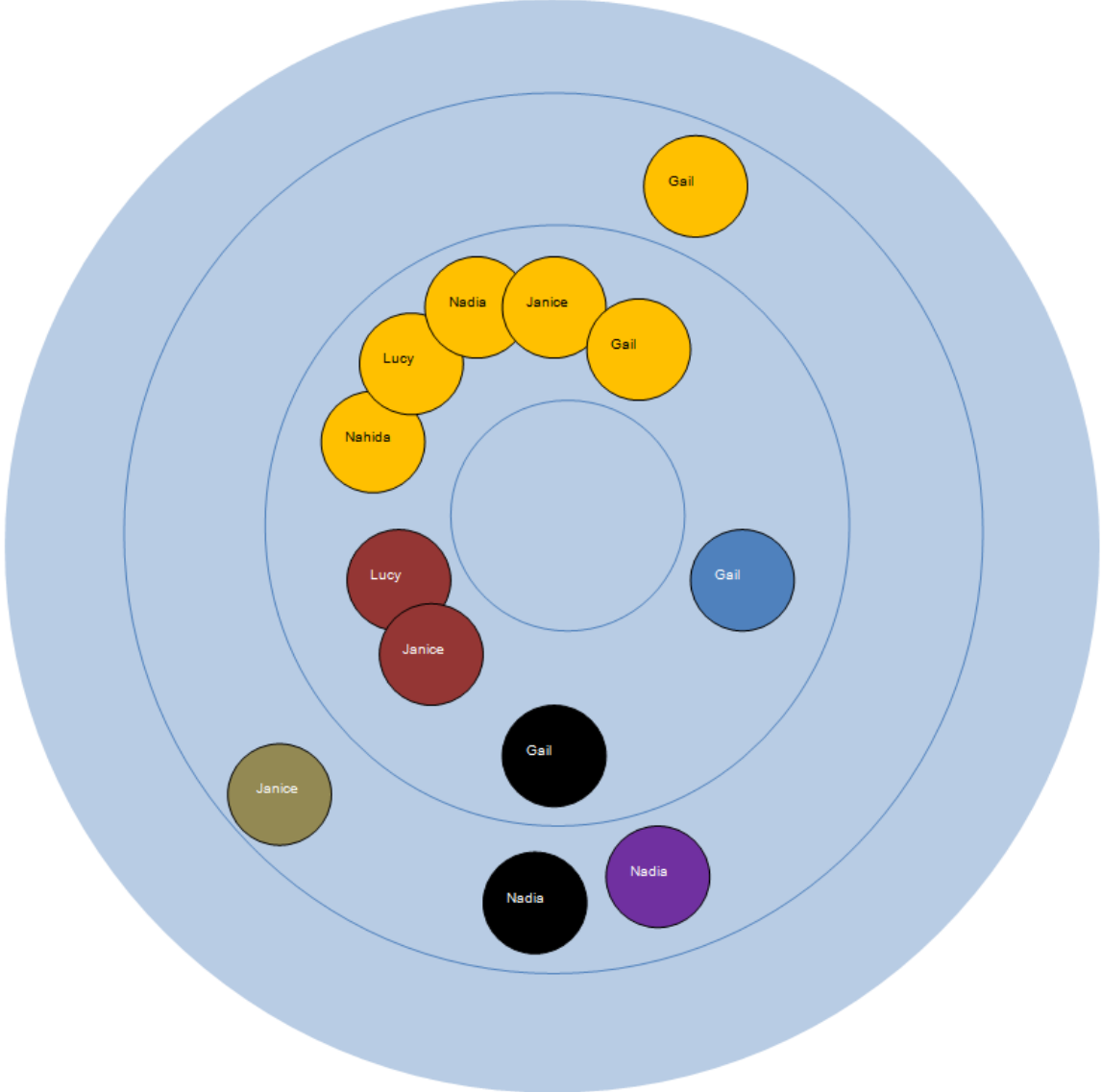
**Appendix O: Social networking map, group one (T2)**



- Key**
- Early supported discharge team (ESD) e.g. physiotherapists
  - Hospital staff e.g. nurses
  - District nurse
  - GP team
  - Family
  - Friends



Appendix P: Social networking map, group one (T3)



- Key**
- District nurse
  - GP team
  - Home care
  - Family
  - Friends
  - Neighbours

**Appendix Q: Social networking map, group two**

