

“It made me see him in a different light.”

**The use of life story work with older people who
have dementia in health and social care practice.**

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ABSTRACT

“It made me see him in a different light.”

The use of life story work with older people who have dementia in health and social care practice

Background: Life story work (LSW) is used within health and social care and has the potential to provide people with: the opportunity to talk about their life experiences; record relevant aspects of individuals' lives in some way; and in doing so use this life story to benefit them in their present situation. Empirical evidence to support LSW use with people with dementia remains scant and most work draws on the perspectives of care staff.

Aims: To examine critically the process of undertaking LSW in health and social care; to explore the impact of using LSW on the delivery and outcomes of care for older people with dementia; and to investigate the experience of using LSW with people with dementia from the perspective of care staff, persons with dementia and family carers.

Methodology and Methods: After gaining ethical approval, four in-depth case studies involving twenty participants were undertaken employing a constructivist approach. The study was conducted within a large mental health and social care NHS Trust in the North of England. Process consent was taken to recruitment, consent and ongoing involvement. Data were gathered using in-depth semi-structured interviews, formal and informal discussion, observation and a research diary. Data analysis was guided by a framework approach which employed an evolving theoretical framework to interrogate the data.

Findings: The findings reveal an enhanced understanding of the process of undertaking LSW and the conditions required for its implementation in health and social care practice. The LSW process and product were found to be of equal importance. A clear link between the use of LSW and the delivery of person-centred care was demonstrated. Family carers valued LSW as a means of upholding the personhood of their relative with dementia; care staff were less able to recognise embodied manifestations of personhood.

Conclusion: The empirical evidence on the use of LSW has been extended. A constructivist approach and process consent were found to enable people with dementia to become actively and ethically involved in the research. LSW should be

implemented within a planned and systematic approach to reduce any difficulties and to enhance the care offered to people who have dementia and their family carers.

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CHAPTER ONE

POSITIONING THE LIFE STORY WORK RESEARCH IN THE CONTEXT OF CLINICAL PRACTICE

1.1 Introduction

This thesis presents the findings of a qualitative study exploring the meaning of life story work (LSW) with four older people with dementia, their family carers and health and social care staff (I will subsequently refer to this as the LSW research).

The focus for the research originated from my own clinical practice with people who have dementia in a mental health and social care NHS Trust. I observed that we often provide care for people with dementia, with very little knowledge of the person we are caring for and without an understanding of who that person is or has been in the context of his or her whole life.

A thesis often marks the end of a piece of research that commenced with the development of a research protocol and concludes with the submission of the thesis and a successful viva leading to the attainment of a Doctor in Philosophy. This thesis is different in that it is a part of a process that began in practice many years before the research protocol was developed and will continue in practice long after the thesis is complete. McCormack (2003a) highlights the irony that much research into person-centred care does not adopt a person-centred approach to the research process. Such a process involves the researcher having a long-term vision for their research: *'from the design through to implementation and beyond.'* (McCormack 2003a:182). This first chapter places the thesis in the context of being one part of an endeavour that seeks to enable people with dementia to be seen as people and not merely patients.

The chapter begins by introducing myself: the author; the person; the trainee researcher; and the nurse, whose interest in LSW has developed over the past ten years and has been undertaking this PhD for the past seven years. I will describe how my clinical journey has intertwined with my academic and my personal

journeys to generate an interest in LSW. I concur with Webster (2007) who writes a similar opening chapter to this in his thesis; the style of this opening chapter is not intended to be self-indulgent or inward looking. It is intended to set the study in the real life context of nursing practice, to demonstrate its evolution. The primary aim of which is to improve the understanding and the delivery of care for older people with dementia and their family carers.

1.2 The practice background to the study

Reed and Proctor (1995) argue that when practitioners undertake research, the characteristics of the researcher can have a profound effect on the ways that a study is conducted; as such, it seems important to give the reader some insight into these characteristics at the outset. Since the study is concerned with the nature of person-centred care and the methodology adopts a humanistic approach, it would seem inappropriate to neglect my status as a person in the role of nurse and researcher. McCormack (2003a) challenges researchers undertaking research into person-centred care to be 'upfront' about their own skills, knowledge and values. As Chamberlayne *et al.* (2000:7) state:

'To understand oneself and others, we need to understand our own histories and how we have come to be what we are. We make our own history but not under conditions of our own choosing, and we need to understand these conditions of action more, if our future making of our own history is to produce outcomes closer to our intentions and projects.'

My interest in the care of people with dementia gradually developed throughout my career experiences (see Table 1.1 for a summary of my career path). I worked on an assessment ward for people with dementia and became aware of 'good care' and 'not such good care'; the impact that this had on the mood and the behaviour of people with dementia and the influence individual care staff could have on the quality of care. When I moved to practice in the community, I spent time at a Day Centre for people with dementia and had the opportunity to talk and reminisce with the patients; something I rarely had managed when working on the ward. I often found my assumptions about individual's abilities challenged.

Table 1.1: Summary of my career path

Year	Developing interest in LSW in health and social care practice
1983 - 1987	RMN training in Leicester at Charles Frears School of Nursing
1987 - 1988	Moved to Sheffield worked as staff nurse on an Adult Mental Health Ward
1989 - 1990	Travelled to Australia on working holiday – older adult nursing homes
1991	Returned to Sheffield; worked on older adult dementia assessment ward. Became interested in assessment tools and awareness impact of care on dementia
1992	Staff nurse on functional mental illness older adult assessment ward Commenced BA Social Studies part time
1993 - 1994	Staff nurse then community sister – CPN older adults. Worked a day a week in a dementia day centre; particularly enjoyed listening to memories of attendees and reminiscing with them.
1995	CPN Course at Sheffield Hallam University – Diploma Community Mental Health Nursing. Introduced to the work of Tom Kitwood; was inspired by the idea that good care could potentially impact on the course of a person’s dementia.
1996 – 1998	CPN for Nursing and Residential Homes – offering consultation and advice to general homes on mental health, became interested in education of others also how living in a home could rob people of their identity. Dementia Care Mapping Training with Tom Kitwood the year before his death. Became a mother.
1999	Returned from maternity leave to role as lecturer / practice development nurse with focus on older people. Course leader for older adult mental health units. Completed BA Health Care Practice
2000 - 2002	Practice development project developing ‘Life Diaries’ with people with dementia. Dementia care mapping / person-centred care taking off in the Trust. PG Diploma in Health Care Education.
2002	Lecturer secondment ended, continued as practice development nurse with older adult services; continued interest in LSW.
2003 - 2005	Commenced MPhil at University of Sheffield with a focus on LSW; undertook review of LSW literature leading to publication (McKeown, Clarke and Repper 2006). Worked closely with ward with people with dementia and challenging behaviour where began to develop research protocol in collaboration with staff and carers.
2006	Upgraded to PhD. In an organisational review Practice Development role moved out of older adults to Trust Wide remit.
2007	Obtained research governance and ethical approval; research commenced. Engaged staff and carers in research reference group
2008 - 2009	Ongoing data collection. Delivered LSW workshop to care staff which evaluated positively; presented to student nurse conference at Sheffield Hallam University. New roles in Clinical Governance Dept. and then as Senior Nurse for Service User and Carer Involvement.
2010	Published articles on involving older people with dementia in research (McKeown et al 2010a) and LSW and person-centred outcomes (McKeown et al 2010b). Attended LSW Conference in Leeds. Writing up thesis. Working with nursing home to develop LSW.
Ongoing Plans	Complete PhD; develop ‘practical resources’ for using LSW; present at National Conference; further article on “Whose story is it anyway?”; explore possibilities of writing thesis into a book; retain links with Sheffield University

Whilst studying for a diploma in community nursing I was introduced to the work of Tom Kitwood (Kitwood 1990; Kitwood and Bredin 1992) and felt inspired by his challenge to the medical and nihilistic models of care I had sometimes experienced and the move towards a 'new culture' of dementia care (Chapter Two in this thesis highlights the changes that have taken place in dementia care over past years and considers the concept of person-centred care). Kitwood's work, although unique in the field of dementia care, felt familiar to me and reminded me of my mental health nurse training based on a curriculum heavily influenced by humanistic principles and in particular the work of Carl Rogers. I have found Rogers (1951) six necessary conditions relevant to both my work as a mental health nurse and to my relationships in life more generally, these being:

- Two persons are in psychological contact (relationship).
- The first, whom we shall term the client, is in a state of incongruence, being vulnerable or anxious.
- The second person, whom we shall term the therapist, is congruent or integrated in the relationship.
- The therapist experiences unconditional positive regard for the client.
- The therapist experiences an empathic understanding of the client's internal frame of reference and endeavours to communicate this experience to the client.
- The communication to the client of the therapist's empathic understanding and unconditional positive regard is to a minimal degree achieved.

Jones and Butman (1991:257) argue that the:

'Core assertion of [Rogers'] personality theory is that there is but one single motivational force for all humanity: the tendency toward self-actualisation'.

I was able to associate self-actualisation with what Kitwood termed 'personhood' (personhood will be explored in more detail in Chapter Two) and what I believe is the essence of who we are as people when our roles and social facades are stripped away. For me 'personhood' can be threatened when people (both with and without dementia) do not feel respected, when they feel they are being judged and if they feel misunderstood by others.

When I worked as a link community psychiatric nurse for general nursing and residential homes, I became interested in the education and support for staff to help them to improve the care they offered to people with dementia. I also attended a basic Dementia Care Mapping course which was facilitated by Tom Kitwood shortly before he died.

More specifically, the LSW research can be traced back to 1999 when I commenced a new role as a lecturer/practice development nurse. At that time practice development, as an approach, was relatively new but has since become a feature of 'how I work' and my understanding of practice development will be explored later in this chapter.

My first role as a practice development nurse involved working with staff on a ward for people with dementia to support care staff to develop an area of practice. The staff felt that they would benefit from knowing more about the life history of the people they cared for and a project was developed that focused on 'Patient Diaries'. I, together with the deputy manager and an occupational therapist, discovered that Life Story Work more accurately described our work (LSW is explored in Chapter Two). We drew on the early work of Charlie Murphy (1994) and succeeded in acquiring a small grant from the Foundation of Nursing Studies to purchase some materials and initiate the project. Five life story books were developed with the patients on the ward. We undertook a small evaluation seeking the views of all concerned and wrote an article for our Care Trust magazine. However, when the project ended the work was not sustained, despite having been enjoyable and beneficial to those staff, relatives and patients who took part.

My work moved on to other projects and yet my interest in LSW remained; I had experienced its potential in understanding more about the people with dementia with whom I worked. From my working experiences I had developed a particular interest in:

- Improving the care offered to people with dementia; particularly in an in-patient / residential setting.
- The importance of biographical knowledge; the need to understand the person in order to offer the best care and yet the apparent difficulty areas

seem to have on collating this information and then using this knowledge in everyday practice.

- The education of health and social care staff and an awareness of a significant number of staff continuing to believe 'person-centred care' is not meaningful to the older people with dementia for whom they care.

At this time in the UK health care policy was also recognising the significance of care approaches to older people. Government policy, for example placed an increasing emphasis on involving people and patients in service development and research (DH 1997) and *Forget Me Not* (Audit Commission 2000) began to move towards involving people with dementia far more in decisions about their care. Additionally the National Service Framework for Older People (DH 2001) made person-centred care a central feature.

My interest in LSW with people who have dementia and person-centred care was an obvious focus for my MPhil and this allowed me to undertake a systematic review on current use of LSW in health and social care setting, which was subsequently published (McKeown *et al.* 2006). This work formed the basis for my PhD upgrade proposal. I took a participatory approach to developing the proposal and drew on the experience of care staff and family carers on a ward for people with dementia and complex needs, culminating in the proposal that was accepted for undertaking my PhD (this process is explored in Chapter Three).

A research focus was identified which aimed to:

'Explore the use of LSW with older people with dementia in health and social care practice.'

More specifically four research questions were formed, these being:

- What helps or hinders the process of implementing LSW?
- What are the benefits and/or difficulties in undertaking LSW?
- How does LSW effect the care the person with dementia receives?
- How is LSW experienced by all who participate?

A constructivist methodology was adopted and the rationale for this is presented in more detail in Chapter Three along with a discussion on how my personal values and constructivism were complementary to one another.

This thesis presents the findings from this work and details the attempt to understand these cumulative observations from the viewpoint of the staff, carers and older people with dementia receiving care in an NHS Health and Social Care Trust.

1.3 Positioning the researcher as a practitioner and a person

Undoubtedly, who I am as a person and the values I hold have impacted on the way in which the research was undertaken and my choice of methodological approach. It is relevant to consider my values more formally in relation to an ontological and epistemological position.

My ontological position could be described as 'relativist' in that I do not accept one objective social reality, or single 'truth' but rather see that reality is an individual construction based on a variety of personal and social constructions. I would concur with Guba and Lincoln (1994) in accepting that 'multiple knowledges' can exist together and, consequently, a range of views may emerge. I find this position especially relevant in my clinical practice as a mental health nurse. It is difficult to imagine that a patient, their family carer and care staff could all accept one reality when each is viewing a situation based on their individual experience, knowledge and the 'position' they hold. This ontological position seems particularly relevant in the field of dementia care, where imposing our own reality on a person with dementia can cause distress. As this thesis will argue the subjective experience of the person with dementia is increasingly being recognised as a cornerstone of person-centred dementia care. Guba and Lincoln (1994:110) argue that from a relativist ontological position: *'Constructions are 'alterable' as are associated realities.'* I accept that people's realities may change as they are exposed to different experiences and viewpoints. This perspective is essential for me in my role within practice development and nursing; it is what motivates me to work with people to enable improvements to practice.

From an epistemological standpoint my values are based on collaboration and partnership working where possible. I have always been interested in listening to different view points, and, in debates I find myself as the 'person in the middle'; that is the mediator, reflecting the views from each side back to into the discussion.

In teams or groups, I find myself bridging groups, being in an often unofficial liaison role. I rarely take a polar position and tend to see many shades of grey in any debate. I have learned that working 'with' people is essential when looking at change. Previously in this chapter I referred to practice development as 'the way I work' which, in many ways, sums up the epistemological position I prefer to take.

Practice development as a concept has been under constant development and refinement in the literature over the past fifteen years and a range of papers have contributed to the development of the concept (for example, McCormack *et al.* 1999; Unsworth 2000; Garbett and McCormack 2002; Manley and McCormack 2004; Manley *et al.* 2008). Manley *et al.* (2008) argue that the focus of practice development is on increasing the effectiveness in person centred practice through impacting on workplace culture. The role of practice development in integrating knowledge into practice has been highlighted (Dewing *et al.* 2009).

A simple and easily communicated definition of practice development remains elusive and debates surrounding practice development, similarly to person-centred care are predominantly in the academic literature. Garbett and McCormack (2002:2) offer the definition:

'Practice development is a continuous process of improvement designed to promote increased effectiveness in patient-centred care. It is brought about by enabling healthcare teams to develop their knowledge and skills and, in doing so, transform the culture and context of care.'

However since that time further developments in the understanding of the concept have taken place. I would argue that, although the concept may have become more refined, the challenge to articulate its meaning to a practice audience has not been overcome. Manley *et al.* (2008) present a nine point framework of the principles of practice development (see Table 1.2).

The methodology of practice development with an emphasis on inclusion, participation and collaboration and an interaction with all key stakeholders is consistent with my own values.

Table 1.2: Practice Development Framework

	Principles of Practice Development	Focus
1	It aims to achieve person-centred and evidence based care that is manifested through human flourishing and a workplace culture of effectiveness in all healthcare settings and situations	Purpose
2	It directs attention at the micro-systems level – the level at which most healthcare is experienced and provided, but requires coherent support from interrelated mezzo-and macro - systems level	Level
3	It integrates work-based learning with its focus on active learning and formal systems for enabling learning in the workplace to transform care	Learning
4	It integrates and enables both the development of evidence from practice and the use of evidence in practice	Evidence use and development
5	It integrates creativity with cognition in order to blend mind, heart and soul	Creativity
6	It is a complex methodology that can be used across healthcare teams and interfaces to involve all internal and external stakeholders	Methodology and methods
7	It uses key methods that are utilised according to the methodological principles being operationalised and the contextual characteristics of the practice development programme of work	
8	It is associated with a set of processes including skilled facilitation that can be translated into a specific skill-set required as near to the interface of care as possible	
9	It integrates evaluation approaches that are always inclusive, participative and collaborative.	

Manley *et al.* (2008:5)

Practice development theory has remained largely although not exclusively within the domain of nursing and McCormack (2010) reports the accusations made against him perpetuating his own 'cottage industry'. Certainly the advancement of practice development as a concept appears to be driven by a small group of academics mainly in the UK and Australia. In response Dewing *et al.* (2009) draw attention to the growing number of publications in peer reviewed journals both

within and beyond a nursing audience, opening practice development up for scrutiny within the wider academic and practice communities.

Clarke and Proctor (1999) believe that understanding the differences between practice development and research provides a challenge in defining the concept of practice development. Recent debates have focussed on whether practice development should be situated firmly in academia or practice, with Thompson *et al.* (2008a:222) questioning its: '*legitimacy as an academic pursuit*'. In their response Dewing *et al.* (2009) argue the existence of practice development on a continuum; at one end practitioners engaging reflexively with practice, along to practitioners working to transform practice cultures and at the 'academic end' practitioner/researchers developing new understandings and theories from the practice development process. At the commencement of my PhD these debates were less well developed and adopting practice development as a research methodology would have presented too much of a risk to the academic rigour of the study. The principles of practice development, however, guide my practice and will inevitably have influenced the way in which the research design was developed and executed.

My interest in LSW has also become personal. Whilst I was first involved in 'patient diaries' in my post as a new practice development nurse, a work colleague died. She was a similar age to myself and, in the preparation for her death, she prepared memory boxes for her three children so that they had something by which to remember her. As a new mother myself, this had a profound effect on me. At the same time, my Grandfather died, and he left behind his 'memoirs' which he had been writing for a number of years. I had found him a difficult person to understand and sometimes even to like, yet reading his memoirs allowed me to understand more about why he was the person he was. As my son was growing up I told him about the year I spent travelling in Australia and some of the adventures I had; I could tell he was able to see a different person in me, the Mother he saw, probably more cautious and responsible as a result of my parenting role. As my parents become older and experience health problems, I am find my research and my practice become intertwined with my life. These experiences have contributed to my interest in LSW.

1.4 The research / practice interface

A constant challenge that has faced me throughout the development and undertaking of the LSW research has been to meet the academic requirements of a PhD whilst also 'staying true' to clinical practice, so that the findings can be meaningful to care staff, family carers and people with dementia. The importance of keeping true to this aim is reflected in the words of a staff nurse, who was involved in the development of the research proposal, during one of our discussions about how the research might take place:

'That's all very well Jane but keep it practical it's got to be practical to make a difference.'

McCormack (2003a) highlights the difference in academic and practice focussed endeavours and draws on the work of Welldon (1987) to describe Aristotle's distinction between *poiesis*; which means 'making action' and could be described as this PhD endeavour resulting in an academic outcome and *praxis*; which means 'doing action' and considers the process of achieving a quality change to practice. The research methodology and methods employed for this study were carefully chosen to achieve both the theoretical aims and the development of LSW in practice. Chapter Three presents the methodological rationale behind this decision.

It seems important to state my position in relation to the tension of attending to both the needs of academia and practice. This seems best discussed with reference to the practitioner research literature. The call for 'practitioner research' is not new and a number of authors have identified the need to pursue it (Reed and Proctor 1995; Brooker and MacPherson 1999; McCormack 2003b; Rolfe 2003). However, McCormack (2003b) points out, since there is no consistent framework or model, a range of approaches to practitioner research have evolved. An adapted definition by Brooker and MacPherson (1999) is offered by McCormack (2003b:89) and allows for such diversity of approaches:

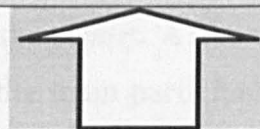
'Practitioner research is a formal and systematic attempt made by practitioners' alone, or in collaboration with others, to understand practitioners' work with the intended purpose of transforming self, colleagues and work contexts and the development of new understandings of practitioners' work.'

Researcher/practitioner roles have been explored by Reed and Proctor who describe three researcher positions, that of: 'outsider'; researching into practice where the researcher has no professional experience, 'hybrid'; the researcher is a practitioner researching the practice of others, and 'insider'; the researcher is researching their own practice and that of their colleagues (Reed and Proctor 1995).

I positioned myself somewhere between the 'hybrid' and 'insider' categories. Although undertaking research into the practice of others, I had previously worked, and will subsequently work, in practice, albeit in a slightly distanced role as a senior nurse. Reed and Proctor (1995) describe the hybrid and outsider roles as having the singular temporary role of researcher, whereas the insider researcher often holds different roles concurrently. At the time of the research, my primary visits were as a researcher, but my role within the organisation meant I might also have cause to intervene as a senior nurse if required; for example, if I needed to comment on an aspect of practice. I argue for a further category, proposing myself as a 'semi-insider' and have amended the model proposed by Reed and Proctor (1995:10) to include this additional category (see Figure 1.1):

Figure 1.1: Reed and Proctor's amended researcher positions

Outsider	'Hybrid'	Semi Insider	Insider
A researcher undertaking research into practice with no professional experience	A practitioner undertaking research into the practice of other practitioners	A practitioner undertaking research into practice that they support or facilitate	Practitioner undertaking research into their own and their colleagues practice



J. McK

Recognising the position of 'semi-insider' has helped me to consider both of my roles. The need to meet academic needs cannot be neglected when completing a PhD and clearly adhering to a robust design strengthens the quality of the research. In order to keep the research relevant to practice I convened a research

reference group, comprised largely of practitioners and carers (Chapter Three will detail the full role of this group). This group helped to ensure that the LSW research remained meaningful to practice. The differing roles and the practice knowledge I brought to the research influenced the way I chose to write the thesis.

1.5 The thesis style

The style of this thesis has emerged from a deliberate decision to integrate my own thoughts and feelings within the data and existing literature. There are three main reasons for this.

Firstly an aim of the research is to impact on and develop clinical practice. Monchamp (2007) points out that despite fieldwork often being very interesting academic reports are often inaccessible to the lay person. If I want practitioners to read my research then I need to draw them into the work and certainly not exclude them. A more personal style of academic writing is reported to make it more accessible to an audience other than academia (Richardson 1994; Foster *et al.* 2006) although, there is a risk to taking such an approach which is not always accepted as a credible method of disseminating scholarly work.

Secondly, as I have argued earlier in this chapter, I am involved in the research as a PhD student, as a practitioner and as a person and it would feel disingenuous to not reflect this. As Cotterill and Letherby (1993:74) argue:

'any inclusion of the researcher's self into the research process involves some 'weaving' of biographies of researched and researcher.'

In discussing the emotions evoked in undertaking research that requires the development of relationships in order to gather the data, Monchamp (2007) argues that such emotions need to be reflected in the report. A risk of an autobiographical approach to writing is that the voices of the main participants can get pushed to the margins (Edwards and Ribbens 1998) and a measure of whether I have been successful is how well I am able to present myself whilst also keeping the research participants' voices central to the thesis.

Thirdly, Reed and Proctor (1995) argue that the insider knowledge which is used to determine research projects in practitioner research is often built up over many

years and can be hard to put aside or even properly articulate and recognise. The reflexive style adopted in this thesis aims to integrate and provide a running commentary on my own reflections and knowledge with the research data and the academic literature. Reflexivity has been defined as:

'The continuous process of reflection by the researcher on his or her own values, preconceptions, behaviour or presence and those of respondents, which can affect the interpretation of responses.'
(Parahoo 2006:327).

The use of reflexivity to enhance rigor is demonstrated throughout and the style adopted for this thesis is aimed at being as transparent as possible about my own values and motivations, which will have undoubtedly impacted on the research.

1.6 Aims of this thesis

The aims of this thesis are to report:

- The process of undertaking LSW
- The impact of using LSW on the delivery and outcomes of care for older people with dementia
- The experience of using a LSW approach with people with dementia from the perspective of all concerned

1.7 Thesis outline

I will now outline the structure of the thesis in order to provide the reader with an overview and reference point.

Chapter Two offers a critical analysis of the concepts underpinning the research and it focuses on the theoretical concepts around the use of LSW. It explores the debates around person-centred care, at the centre of which is the concept of personhood. The chapter also appraises the challenges with person-centred care being implemented into health and social care practice. The chapter then evaluates the concept of LSW and draws on the theoretical literature around reminiscence and narrative in order to place LSW within a historical and theoretical context. The chapter concludes with a conceptual framework that seeks to explore the ways in which LSW can be implemented into practice and its potential in enabling person-centred care.

Chapter Three provides the rationale for the methodology chosen to undertake the research. The chapter sets the research within a constructivist paradigm and offers a multiple case study design as a complimentary approach to constructivism. The methods chosen to answer the research aims are presented and issues impacting on both rigor and ethics are discussed.

Chapter Four explores the issues around entry into the field and describes the context of the case study sites. Chapter Four also explores what proved to be a significant area of learning for both the research and my practice; that is the involvement of people with dementia in the research through the use of a process consent framework.

Chapter Five provides the link between the first part of the thesis and prepares the reader for the findings chapters. It introduces the case studies and individual participants and provides an overview of the findings. The links between the thematic framework used in the data analysis and the findings are made explicit. Each case study is summarised, providing an 'in-case' and individual participant presentation of the findings. The chapter provides a reference point for the finding chapters.

Chapters Six to Nine present the findings from the research; each chapter addresses one of the four research questions detailed on page 6 of this thesis.

Chapter Six explores the process of undertaking LSW and presents what helped and what hindered the implementation of LSW into practice. The chapter draws on the values and culture of individuals and organisations and considers how these may have influenced how LSW was understood. This chapter also considers what practical assistance was needed for LSW to be successfully implemented.

Chapter Seven considers the benefits and outcomes of the process of spending time with the person with dementia and gathering their life story information. The chapter also explores the LSW product where the LSW is collated and presented for wider dissemination and compares the process with the product, drawing out the significance of both for the person with dementia, family carers and care staff. The chapter concludes by offering some practical considerations for staff undertaking LSW.

Chapter Eight explores the person-centred care outcomes that were observed though using LSW. It provides evidence for a range of ways in which LSW enabled relationships and communication to be supported and also considers how the 'voice' of the person with dementia was heard, literally and through embodied action. The chapter concludes by proposing a range of processes required to enable staff to become more person-centred in their practice.

Chapter Nine investigates the experience of using LSW for all participants. It considers some of the challenges in gathering a person's story and considers the different ways the people with dementia and others contributed to their story. The chapter highlights some of the challenges when people disclose private information and considers issues of consent and confidentiality.

Chapter Ten summarises the LSW research and in particular offers a synthesis of the findings and a re-conceptualisation of LSW and person-centred care. The chapter and thesis conclude by making recommendations for future research, practice, education and policy.

1.8 Conclusion

Through the use of reflection, discussion and drawing on relevant literature I have positioned myself as a researcher/practitioner/person and discussed how the research both evolved from and is grounded in practice. I have provided a rationale for the style in which this thesis is written and have described this thesis as part of a journey to enable the improved understanding of people with dementia in health and social care. The next chapter begins to critically appraise the concepts that are central to this research.

CHAPTER TWO

CRITICAL ANALYSIS OF KEY CONCEPTS

2.1 Introduction

This chapter explores the condition of dementia and considers the changes that have taken place over the past thirty years in the care offered to older people living with dementia and their families. The chapter emphasises the importance of undertaking research into the care of people with dementia due to the projected numbers of new cases expected over the next forty years and the potential impact a diagnosis of dementia can have on the person and their family. A critical analysis of the concept of person-centred care is offered before exploring the challenges of implementing such an approach in health and social care practice. The meaning of LSW is appraised together with an evaluation of its theoretical underpinnings. Finally, the conceptual model developed at the outset of the research is presented alongside the theoretical propositions and research questions that guide the subsequent study design.

2.2 Literature review search strategy

The concepts critically analysed in this chapter are diverse and a range of approaches to appraising the literature were taken within the different sections.

A narrative integrative review of the literature focussing on the use of LSW within health and social care practice was undertaken early in the study which was subsequently published in a peer reviewed journal (McKeown *et al.* 2006). A variety of search methods were employed to ensure that all relevant literature was identified. The health and social science databases searched were: CINAHL, Medline, Assia, PsycINFO, British Nursing Index, Social Science Citation Index. Citations were followed up from the reference lists and bibliographies of retrieved articles. The grey literature was searched through internet search engines such as Google. Communication with key people was used to reveal any ongoing work.

The search strategy consisted of a combination of thesaurus and free text search

terms. For LSW 'intervention' search terms (e.g. life stor*, biograph*, reminisce*) were combined with 'population' search terms (e.g. client*, user* patient*). For person-centred care, search terms that were used were 'patient-centred', 'client-centred', 'person-centred', these were combined with the term 'care' and 'service'. No date, language or study type restrictions were applied at the searching stage, although in reality any references that were not in English or translated into English were disregarded due to limited resources for translation. These terms were then periodically entered into databases and up until the present day in order to capture the most recent literature.

Since the review was intended to inform evidence-based practice the retrieved literature underwent a process of critical appraisal. A number of critical appraisal tools and checklists exist, but there is no generally agreed appraisal tool for qualitative research (Popay *et al.* 1998; Dixon-Woods *et al.* 2001). Popay *et al.* (1998) and Jones (2004) propose a set of reflective questions to facilitate rigour in this process, and these were adapted to appraise the selected papers (see Appendix 1). These questions interrogate studies across a range of aspects, including focus, ethical issues, ability to illuminate the subjective experience of those being researched, and the responsiveness of the research design.

The search strategy for other concepts was thorough, though selective, in that not all possible references were appraised, however an interrogation of a variety of databases took place, most commonly CINAHL, Medline, Assia and PsycINFO.

2.3 Dementia

It is estimated that over 750 000 people have some form of dementia in the UK with numbers expected to increase to 940 000 by 2021 and to 1.7 million by 2051 (Alzheimer's Society 2007). It is currently estimated that 1 in 14 of people aged 65 or over in the UK have dementia and by the age of 80 this rises to 1 in 6. The numbers of people with dementia worldwide is expected to increase and double every 20 years; by 2040, it is estimated 81.1 million people will be affected by dementia globally (Ferri *et al.* 2005). The need to find effective ways of supporting people with dementia and their family carers is therefore a global issue.

Dementia is often discussed within the paradigm of the medical model. The term

dementia describes a range of conditions affecting memory, thinking and communication. Stephan and Brayne (2008:11) report that dementia is:

'A group of syndromes characterised by progressive decline in cognition of sufficient severity to interfere with social and /or occupational functioning, caused by disease or trauma, and often associated with increased aging.'

Within the medical paradigm each type of dementia is characterised by differences in the course and the nature of the cognitive impairment experienced, largely due the area of the brain that becomes damaged, although not all individuals with any one type of dementia will present in exactly the same way. Table 2.1 shows the different types of dementia and their prevalence offered by Alzheimer's Society (2007).

Table 2.1: Type and prevalence of dementia

Type of Dementia	Percentage of all dementias
Alzheimer's Disease (AD)	62%
Vascular Dementia (VD)	17%
Mixed (AD & VD)	10%
Dementia with Lewy Bodies	4%
Fronto - Lobe Dementia	2%
Parkinson's Dementia	2%
Other dementias	3%

The medical model is not the only paradigm used to explain dementia, its signs and symptoms and consequences for the individual. It can be argued that a number of different social and psychological processes, political and historical factors might be used to explain why the condition has emerged. Sabat (2008:71) highlights increasing research to demonstrate that the behaviour of people with dementia can be understood by at least four factors encompassing biological, psychological and social responses, these being:

- Brain damage
- The person's reaction to the effects of the brain damage
- The ways in which the person is treated by healthy others
- The reactions of the diagnosed person to the ways in which he or she is treated by others

Harding and Palfrey (1997) offer a social constructionist perspective and argue that dementia is 'medicalised' in order to meet the needs of society. Dementia is often depicted in the media in frightening terms as if it were a threat to society itself, 'the demographic time-bomb', 'an epidemic'. In framing dementia as an illness, Harding and Palfrey (1997) argue that it reassures society and offers the hope of a cure. An implication of a medical diagnosis is that aspects of the person's life and behaviours they exhibit become defined as 'symptoms' of the disease, often to be controlled by medication. Tresolini and Pew-Fetzer Task Force (1994) comment on the prevalent medical paradigm that separates bodily conditions from other factors such as mental state, life events and relationships; they call for a more integrative paradigm that considers dementia within the wider context of relationships and community.

2.4 Caring for people with dementia

Adams (2008) illustrates the influence of the medical model and institutional approach towards the care of people with dementia in the first part of the twentieth century with a tendency towards therapeutic nihilism. Baines *et al.* (1987) describe how, in the past, good quality care for people with dementia equated to providing good physical care. During the 1970s and early 1980s reality orientation (Taulbee and Folsom 1966; Holden and Woods 1995) followed shortly by reminiscence (Baines *et al.* 1987) emerged, offering a new and more positive way of working with people with dementia. At the time, these were considered as 'stand alone' interventions rather than being linked to a coherent new way of looking at the care of people with dementia.

During the late 1980s the work of Kitwood (1989) promised to offer a more comprehensive alternative to the medical model to dementia, offering a new emphasis on recognising the subjective experience of people with dementia. Kitwood (1990) described a complex interplay between neurological, physical and psycho-social factors that impact on the course and experience of dementia that he termed a 'dialectic'; whilst recognising that the disease process may have some influence he argued it was not enough in itself to explain the range of peoples' experience of dementia. He explored the effect of malignant social psychology (MSP) on people with dementia; that is negative communications that undermine

the person. Whilst not intentional or malicious, Kitwood (1990) argued that such interactions that include ignoring, infantilisation and intimidation could impact in a negative way on a person's well being and sense of self. The implications of Kitwood's work were that quality care could potentially reduce the impact that dementia might have on a person. This is summarised by O'Connor *et al.* (2007:122) who report that:

'There is growing evidence to indicate that at least some of the negative consequences associated with dementia may be mitigated or delayed by an approach to care that supports each individual's personhood, and that facilitates its transformation and development throughout the disease.'

More recently medical advances in drug treatments, such as those offered by cholinesterase inhibitors, have offered hope of improving the impairment experienced by dementia. These drugs work by preventing an enzyme, known as acetylcholinesterase, from breaking down acetylcholine in the brain, which may in turn temporarily improve or stabilise the symptoms of Alzheimer's disease. At present these drugs are not a panacea and as Sabat (2008) notes they are unlikely in the near future to impact on people with dementia with more complex needs who are more likely to access health and social care services. The most effective interventions remain in the development of services to support people with dementia and their carers (Nolan *et al.* 2002). The provision of such services is therefore one of the most significant issues facing policy makers and care providers today.

2.5 Dementia and 'behaviours that challenge'

Assisting a person to maintain their identity, in a condition such as dementia where identity is systematically eroded, is a key role for healthcare staff (McCormack 2004). This seems especially pertinent for people with dementia and 'challenging behaviour', whose identity maybe become obscured by behaviours that challenge others.

Terms used to describe this include 'challenging behaviour' 'disruptive behaviour' and 'complex needs' but more recently the National Collaborating Centre for Mental Health (2006) propose 'behaviours that challenge' as a more acceptable term. Such behaviours are reported to include: *'aggression, agitation, wandering,*

hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting' (National Collaborating Centre for Mental Health 2006:219). People with dementia and behaviours that challenge are more likely to: require hospital admission, institutionalised care, or be moved between care homes (Donaldson *et al.* 1997; National Collaborating Centre for Mental Health 2006).

The behavioural difficulties that some people with dementia exhibit can be a major challenge for staff working in care settings (Moniz-Cook *et al.* 1998) and can impact on the quality of life for the person with dementia, family carers and care staff (Mace 1990). Behaviours that challenge are influenced by factors both intrinsic and extrinsic to the person (Stokes 2000) and are not an inevitable consequence of having dementia (Moniz-Cook *et al.* 2001). Person-centred models of care have encouraged the move towards behaviours that challenge in people with dementia to be seen as an expression of unmet need (Stokes 2000; Moniz-Cook *et al.* 2003; James *et al.* 2006, 2007; Cohen-Mansfield 2008). Needs-led approaches to both understanding and intervening with such behaviours have been developed and include the 'Newcastle Model'¹ (James *et al.* 2006). There still remains an over reliance on psychotropic medication to manage such behaviours (Audit Commission 2000; Banerjee 2009) and my own observations as a senior nurse suggests that care staff working with this client group need to develop a wider range of skills for intervening in behaviours that challenge. This is despite National Collaborating Centre for Mental Health (2006) guidance for non-pharmacological treatments to be the first line treatment for such behaviours.

Gibson (1991; 1994) demonstrates that LSW could potentially be an intervention that may be of benefit to the care of older people with dementia and behaviours that challenge. The understanding of a person's biography is central to current needs-led approaches (Keady and Jones 2010).

The following sections in this chapter present a critical analysis of the concepts of personhood and person-centred care. Chapter One identified these as key

¹ The Newcastle Model is based on a 'needs perspective' and considers behaviours that challenge from a range of factors including: life history, physical, mental and cognitive status, including the type of dementia, personality and coping styles, context and environment. This understanding combined with the precise nature of the behaviours that challenge results in an identification of need and a plan of care.

concepts in the development of the LSW research and also identified them as key to my own personal and professional value system

2.6. Personhood

The debate on what constitutes a person is complex and according to Erde (1999:141) much literature lacks: *'a satisfying moral and intellectual consensus of personhood'*. Early explanations of personhood tended to focus on traits that reward intellectual skills and independence, with autonomy and rationality remaining as the two most valued 'qualities'. Quinton (1973), for example suggests five criteria which determine whether or not one is a 'person', namely: consciousness of self; rationality, particularly the ability of abstract reasoning; agency, the ability to determine numerous choices and act upon the ones made; morality, the ability to live within a set of principles and be accountable for one's actions accordingly and; capacity, to form and hold relationships and, in doing so, understand and recognise the needs of others. Locke (1964) argues that a 'person' has to display psychological continuity and connectedness since thought, intelligence, reason, reflection and consciousness are seen as essential attributes of being a person. Parfit (1984) contends that a person's identity is maintained by the links that join the past to the present. Such an emphasis on cognitive abilities and continuity clearly has implications for people who have cognitive impairments such as those with dementia. This cultural influence is examined by Post (1995:314), who criticises the tendency of Western personhood theories to present a *'hyper-cognitive culture'* that exclude people with dementia by reducing their moral status; he contrasts this with Chinese culture where cognitive abilities do not define personhood.

Harrison (1993) draws on the work of MacIntyre (1981:471) in highlighting some of the deficiencies in the commonly held beliefs about psychological continuity; she develops a concept of self where: *'unity resides in the unity of a narrative which links birth to life to death as narrative beginning to middle to end'*. This narrative approach to defining personhood reinforces the notion that personhood is greater than simply cognitive abilities and characteristics and places a person in a context of family relationships, social roles, personal triumphs and grief. For people with dementia, it provides an opportunity where understanding the person's history

helps them to be seen within the context of their whole lives.

Kitwood (1997) supports the Kantian belief that all humans should be afforded supreme and equal value and intrinsic worth. Kitwood's oft quoted definition of personhood summarises this as:

'a standing or status bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.'

(Kitwood 1997:8).

This clearly highlights the importance of relationships in maintaining personhood and also suggests a person's worth should not be based on their usefulness to society. Kitwood's definition of personhood is largely accepted uncritically and Dewing (2008a) notes that by stating that personhood is 'bestowed' by another person, Kitwood is unintentionally deferring people with dementia to a secondary status. In extending the work of Sabat and Harré (1992), Sabat and Collins (1999) also recognise the importance of 'others' in maintaining personhood. The authors identify three types of self. Self 1 exists in narratives and is akin to personal identity articulated through the terms 'I' and 'Me'; Self 2 consists of past and present individual attributes and ones beliefs about these; Self 3 is the public personae presented that is made up of a multitude of social roles a person holds. Sabat and Harré (1992) report that a person's social personae may be misinterpreted by carers in the light of a diagnosis of dementia. Sabat (2008:79) observes that a person with dementia may be prevented from maintaining Self 3 due to:

'(a) the lack of cooperation from healthy others in the social milieu, and the intimately related (b) tendency of others to view the person with Alzheimer's disease increasingly in terms of his or her deficits.'

A further perspective supporting the inclusion of people with dementia in the personhood debate is proposed by Meilaender (1995), who offers a concept of embodied personhood. This involves a 'natural trajectory of bodily life' that needs to run its course. This is summarised by Fleischer (1999:318) as:

'tragic though it may be, individuals achieve moral status by living out the destiny of the body. We may also learn that those who have lost or never had cognitive abilities offer the gift of their frailty and vulnerability to members of the human community with whom they live in interdependence'.

Taking this debate a stage further, in challenging Western cultural perceptions and reductionist approaches to personhood, Hughes (2001) argues for a 'situated embodied agent' view; he argues that a person is 'situated' by their life history, family, societal and culture contexts, an agent in that they can choose how they act, but this too is 'situated' and that a person's bodily movements and behaviours can only be understood within the context of their whole life. Kontos (2005) claims that understanding embodied selfhood can extend the understanding of personhood and its manifestations even when a person has cognitive impairment. More recently Kontos (2004; 2005) develops the notion of embodied intentionality through drawing on the work of Merleau-Ponty (1962), who claims the body acts 'primordially' in that it can act without the need for cognition or reflection and Bourdieu (1990) who argues that socio-cultural factors influence bodily movements resulting in the concept of 'habitus'. Embodied selfhood as defined by Kontos *et al.* (2010:160) as:

'bodily expressions of vocation and class distinction; the spontaneity of actions; and the often subtle attentiveness to appearance, cleanliness and social etiquette by persons with dementia'.

It can be seen, therefore, that the concept of personhood is not orderly, precise or systematic in a way that supports one general philosophical theory to the exclusion of another. This initial exploration of the debates about personhood will continue to be developed throughout this thesis; having a greater understanding of the philosophical debates surrounding personhood, allows for a better understanding of person-centred care in practice, which is explored in the next section.

2.7 Person-centred care

Since the early work of Kitwood (1990, 1993) debates about the nature of person-centred care have been further developed and explored at a theoretical and conceptual level (Brooker 2004; Dewing 2004; McCormack 2004; Nolan *et al.* 2004). Definitions of person-centred care have been the subject of critical debate (c.f. Brooker and Nolan 2007) and alternatives offered to the initial use of the term in dementia care offered by Kitwood (1997).

Three current concepts of person-centred care stand out as having been developed

beyond their initial conceptualisation and tested in the realities of clinical practice. These are: the 'Senses Framework' within the context of relationship-centred care (see Figure 2.1); the 'VIPS Framework' (see Figure 2.2) and the 'Person-Centred Nursing Framework' (see Figure 2.3). This next section will offer a critical analysis of these frameworks. I will commence with a summary of each of the frameworks and detail their development, before offering an appraisal of their key similarities and differences.

Nolan *et al.* (2004; 2006) offer the concept of relationship-centred care as an alternative vision to person-centred care and describe the Senses Framework as a means of enabling an inter-relational approach to practice. The framework was developed in response to a perceived lack of therapeutic direction in the care of older people with long term conditions and as a challenge to the prevailing emphasis on individual autonomy and independence as measures of successful ageing and quality of care. The Senses emerged from a distillation of key themes following an extensive literature review on the quality of care for older people (Nolan 1997; Nolan *et al.* 2001). The Senses were employed as a theoretical framework in subsequent empirical research exploring dignity in hospital care (Davies *et al.* 1999) and investigating the educational needs of nurses working in the care of older people (Nolan *et al.* 2002). Nolan *et al.* (2004:51) report the Senses to be meaningful to nurses, student nurses, older people and their family carers and: *'spoke to them in a language that they understood and related to'*; these groups participated in adapting and further developing the framework. A key tenet of the Senses, following the work of Tresolini and the Pew Fetzner Task Force (1994) on relationship-centred care, is the focus on a network of relationships that extend beyond the person to include family members, care workers and the wider community and so recognising the value of 'interdependence'. The Senses Framework does not appear to have involved people with dementia or their carers in its development, although data from studies with such groups of people has been applied in a meaningful way to the framework (Ryan *et al.* 2008). Through their empirical work Nolan *et al.* (2006) identified 'enriched' and 'impoverished' care environments which could be impacted on by factors such as the physical environment, staff attitudes and care practices. An 'enriched' environment it is claimed is more likely to prevail if all the Senses were met for all stakeholders.

Figure 2.1: Senses Framework



Figure 2.3: Person Centred Nursing Framework

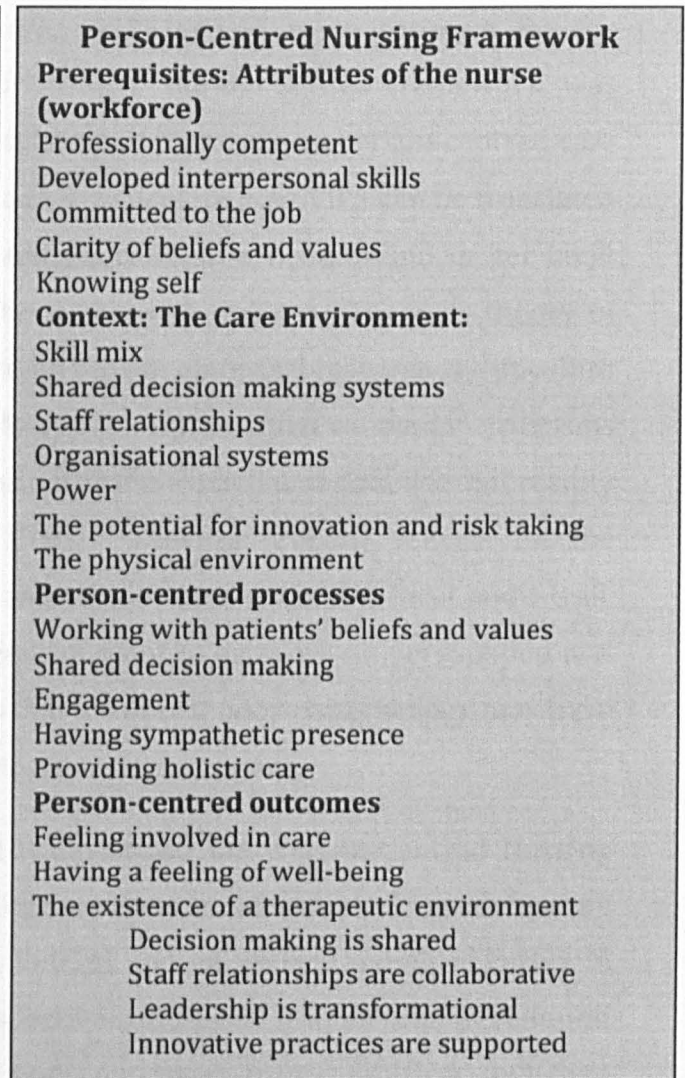
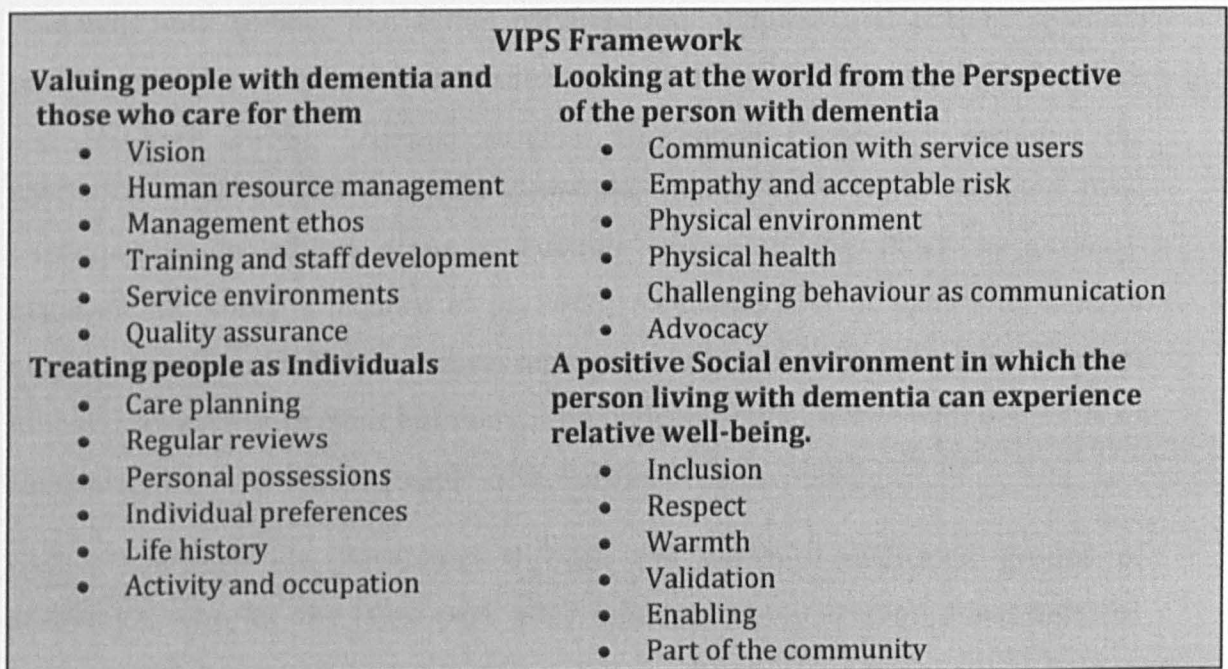


Figure 2.2: VIPS Framework



Brooker (2004) has extended the 'Positive Person' work of Kitwood (1997) in the relevance and subsequent application of person-centred care to people with dementia through the VIPS Framework. VIPS serves as an acronym for the essential components of the framework which, like the Senses Framework, was conceived through a synthesis and distillation of literature on person-centred care (Brooker 2004). Progress has been made to articulate how VIPS can be translated into practice through organisational and educational processes and in her book Brooker (2007) demonstrates how the framework links to Kitwood's theory of dementia care. The development of the VIPS from empirical research is difficult to audit and the work of Brooker (2004; 2007) may be open to similar criticisms made of Kitwood that an audit trail was not made explicit and data was not readily available for peer review (Adams 1996). Dewing (2008a) reflects on the unfinished nature of Kitwood's work and the absence of an empirical audit trail. She also reveals the consistency and development of his work on personhood and understanding of dementia and argues that his unorthodox methodology may have been appropriate but failed to demonstrate academic rigour.

McCormack and McCance (2006; 2010) developed the 'Person-Centred Nursing Framework' (PCNF) through integrating previous empirical work on autonomy and older people (McCormack 2001a, 2001b) and an understanding of caring in nursing (McCance *et al.* 2001). The respective conceptual frameworks were found to have complementary constructs, both emerging from empirical inductive research, both seeking the active participation of nurse and patient research participants and complimented by the synthesis of current literature (McCormack and McCance 2006). Neither original conceptual framework included the participation of people who had dementia; indeed they were excluded from participating on ethical grounds. Further testing of the PCNF in a quasi-experimental study (McCance *et al.* 2008; McCormack *et al.* 2008) took place across a number of different clinical settings including older people, intensive care unit and sexual health clinic but there is no indication that people with dementia or specialist nurses caring for people with were actively involved.

Each framework has developed through the work of dedicated groups of academics, who for the large part, after initial conceptualisation, have invested

their work in developing and demonstrating the utility of their particular framework. There is an absence of commentary on how each was similar or different to other frameworks. There has been little critique of the frameworks from an 'independent' perspective.

Having presented each of the frameworks and explored their origins and theoretical background, I will now critically appraise their commonalities and differences.

All three frameworks are values based and humanistic principles underpin each of them. These principles are more openly discussed in relation to the PCNF and VIPS with reference to the work of Kitwood and links with personhood and identity. The Senses refers to respecting, rather than maintaining personhood and has an emphasis on improving the quality of care.

A critical empirical evaluation has not, to date, occurred with the VIPS Framework compared to that achieved in the Senses and PCNF through recent publications. The VIPS Framework developed initially through scholarly work within the Bradford Dementia Group which is held in high regard by many practitioners working in the field of dementia care. The impact that Kitwood had on challenging existing cultures of dementia care and the offer of a therapeutic approach cannot be denied and his untimely death has no doubt made those who worked closely with him wish to continue and develop his work. A weakness of VIPS, compared to the Senses and PCNF is the absence of a clear audit trail demonstrating empirical testing, however whether this makes it any less valid for use in practice is debatable.

The VIPS is the only framework that purposively and specifically focuses on the care of people who have dementia. Brooker (2007) clearly situates the development of VIPS from the seminal work of Tom Kitwood and maintaining 'personhood' remains a central outcome of the VIPS framework. McCormack (2004) has contributed to the debates around care and older people, exploring person-centredness relating to older people rather than specifically to older people with dementia, although he often refers to the considerations of people with dementia. Similarly Nolan *et al.* (2004) developed the notion of relationship-centred care and the Senses Framework in relation to older people, although it has

since been applied with older people with dementia in a community setting (Ryan *et al.* 2008). What is absent from the Senses and PCNF to date is a search for any inadequacies in their frameworks when applied with people with more complex needs and dementia. Dewing (2004) questions the lack of evidence about how dementia impacts on relationship structures and notes that some existing person-centred frameworks may be better suited to particular contexts and yet the literature to date does not make this explicit. Indeed both the Senses and PCNF seem to require more empirical testing with range of people with dementia to assess their utility with this service user group.

The Senses Framework refers explicitly to the Senses being applicable to older people, family carers and care workers alike and perceives this as an advancement on person-centred care. Approaches to the care of people with dementia have previously privileged the experience of the family carer or the person with dementia and in so doing marginalised the experience of the other (Adams 2008). Whether the relational aspects are significant enough to develop an alternative concept to person-centred care is debatable and person-centred care has been subsequently been defended as recognising the importance of relationships wider than the person with dementia and the staff (Dewing 2008a). However, an emphasis on relationships beyond the nurse/patient domain may potentially contribute to reducing the stigma of dementia highlighted by Brooker (2004) when the relational aspects of the Senses encompass the person's wider community. VIPS refers to the need for person-centred care to be experienced by all and not just the person with dementia. Brooker (2007) does not attempt to provide a framework that applies to all equally, but draws out some of the unique needs of people who have cognitive impairment so keeping the needs of the person with dementia central. There is some lack of clarity in the PCNF about who the framework applies to at different stages particularly in the processes and outcomes, adding to its complexity. The Senses focus largely on interpersonal interactions, seeing the person within a context of a wider community. Whilst there are advantages to this there is also a risk that the subjective experience of the person with dementia may not be recognised. Section 2.6 of this chapter identified the concerns raised by Dewing (2008a), that people with dementia can be offered secondary status as persons if personhood is bestowed upon them by others.

Kitwood (1997) does define personhood as a 'status' but is perhaps reflecting the current care culture where the personhood of people with dementia can be either upheld or undermined by others who do not have cognitive impairment. Sabat (2008) also recognises that 'healthy others' may define a person with dementia based on their deficits and so prevent their maintenance of self. If the Senses are equally relevant to all stakeholders, including family carers and care staff, it is possible the needs of the person with dementia may be subsumed by the needs of others. Taking such a relational position may underestimate the difficulties of maintaining personhood when a person has a diagnosis of dementia.

A strength of the PCNF is in its comprehensive attention to the multi-factorial influences that may impact on the delivery of person-centred care, including the context of care and individual attributes of staff. More recent work has explicitly linked the implementation of the PCNF into clinical practice with the use of a practice development methodology (McCormack and McCance 2010) offering a complete model that may influence organisational and cultural issues that impact of the delivery of person-centred care. Whilst the Senses has utility for assessing care environments it is unclear how the Senses may be achieved when environments are 'impoverished' or how to move from an 'impoverished' to an 'enriched' environment. In this aspect the framework does not appear as well developed as the PCNF, for example.

In assessing their utility for practice each framework has its strengths and weaknesses. Dewing (2004) draws attention to the expert knowledge needed by nurses to work with some of the more conceptual elements of person-centred care frameworks. Of all the PCNF, whilst appearing perhaps the most comprehensive in terms of structure, process and outcomes, equally presents as the most complex with the person-centred process terms such as 'engagement', 'sympathetic presence' and 'shared decision making' needing a degree of translation and understanding. The Senses are well explained and in a language that is understandable, but as previously reported the framework may not yet be comprehensive enough to address the contextual and cultural aspects of care settings. Brooker (2007) offers a framework that is translated into practitioner's language and by offering an approach similar to clinical benchmarking may be

familiar to clinical staff.

This thesis does not seek to preference one framework over another but will appraise their relevance based on the findings from the LSW research in the concluding chapter.

2.8 Understanding person-centred care in practice

The literature offers a broader understanding of person-centred care than purely the three conceptual frameworks appraised in the previous section. A range of characteristics central to the concept of person-centred care are offered and in a summary of the literature McCormack (2004) suggests that recurring themes that feature in models of person-centred care practice with older people are: Knowing the person, values, biography, relationships, seeing beyond the immediate needs and authenticity. In my own review of the literature four key themes that seem relevant across current person-centred concepts and applicable to the care of people with dementia can be discerned. These emphasise the importance of:

- Understanding and valuing the individual
- Developing relationships
- Understanding the subjective experience of the person with dementia
- The context of care

2.8.1 Understanding and valuing the individual

Valuing people with dementia and the people who care for them is reported as a key element of person-centred care with people with dementia by Brooker (2004), who highlights the particular difficulties that arise when people with dementia are not valued as a person. Understanding the uniqueness of the individual is particularly important when caring for people with dementia and complex needs. Stokes (2005) proposes that such an understanding includes awareness of the person's fears, insecurities and superstitions.

Biographical approaches to the assessment of older people that make use of narrative and story are one way of understanding and valuing the person, and these approaches help in respecting the intrinsic worth of the person (Kitwood 1997; McCormack and McCance 2010). Nolan *et al.* (2004) promote the use of the past to contextualise the present to achieve relationship-centred care. The value of

understanding life history is, according to Hughes (2001), that it provides the context for understanding a persons' bodily movements and behaviours.

Despite the reported value of undertaking biographical work in order to understand and value the older person, attempts to adopt such an approach have sometimes been met with resistance or have not been sustained (Clarke *et al.* 2003; McKeown *et al.* 2006). Care staff working with older people with dementia in residential care report that 'knowing the person' needs to be translated into practice (Edvardsson *et al.* 2010) if it is to impact on person-centred care.

Valuing the individual extends to an organisational and societal responsibility and Brooker (2004) argues that person-centred care needs to recognise when shortfalls in service result from the discrimination of people with dementia. Valuing the individual is also described as relevant to the treatment of care staff and family carers (Brooker 2004; Nolan *et al.* 2006).

2.8.2 Developing relationships

The importance of the 'therapeutic relationship' and its potential to enable growth and change extends back the work of Rogers (1961), a major influence on the subsequent work of Kitwood (1997). Since people exist in relationships with others and not in isolation, a significant role for nurses working with older people is to nurture these relationships in order to help maintain the connections between the person and their social world (Dewing 2004; McCormack 2004). Relationships with the person with dementia have been described as central to care and as the place where personhood can be upheld or diminished (Kitwood 1997; Woods 2001).

Relationships are a feature of all person-centred concepts. This is reflected in the PCNF through the person-centred processes of 'engagement' and 'sympathetic presence' (McCormack and McCance 2010). The VIPS Framework also considers the importance of relationships within the care environment and the possible negative interactions that can impact on the experience of dementia (Brooker 2004). Tresolini and the Pew-Fetzer Task Force (1994) draw attention to the significance of a relational approach to support a more integrative paradigm to healthcare than the purely medical approach. They argue that practitioners need to focus on the skills and knowledge to develop relationships not only with the

patient and their family, but also with the wider community and with other practitioners. The significance of these network of relationships is fundamental the 'Senses Framework' (Nolan *et al.* 2004; 2006).

2.8.3 Understanding the subjective experience of the person with dementia

Brooker (2004), in exploring care practice, argues the subjective experience of the person with dementia needs to be understood as a starting point in explaining behaviours and planning approaches to care. Goldsmith (1996) first initiated the discussions on 'hearing the voice of the person with dementia'. He proposed that many 'challenging behaviours' observed in people with dementia were as a consequence of them feeling unheard. Understanding the subjective experience of the person with dementia has increasingly become a dominant theme in the literature around personhood and dementia research. McCormack (2003c:204) uses the term 'authentic consciousness' to explain this approach (although not specific to people with dementia) and suggests that in caring for older people there needs to be: '*A consideration of the person's life as a whole in order to help sustain meaning in life*'. It seems logical that we cannot look at the world from the perspective of a person unless we can appreciate their individual values and beliefs. The use of biography and narrative as a way to respect and understand a person can assist them to make decisions based on their whole lives (McCormack 2003a).

Kitwood (1997) proposed seven routes to access the subjective experience of people with dementia, these being: through the accounts that have been written by people who have dementia; by careful attention to what people with dementia say in individual or group-work; by careful attention to what people with dementia say in the course of their everyday life; to learn from the behaviours of people who have dementia; consulting with people who have recovered from illnesses with dementia like features; and through the use of our own poetic imagination and through the use of role play. Killick (1997) and Killick and Allan (2001) have contributed greatly to understanding the use of metaphor, poetry and the arts to enable people with dementia to express their experience. The past twenty years have also seen the publication of first hand accounts from people who have dementia, (c.f. Friel-McGowan 1994; Bryden 2005).

Whilst it is encouraging that both research and practice models are considering the subjective experience as being of importance that the research to date tends to largely overlook the experiences of those with more severe dementia. There appears to be a challenge in supporting health and social care staff to understand the subjective experience of people with dementia when they are unable to articulate this verbally.

2.8.4 Context of care

'Being in place' is identified as a concept at the heart of person-centredness with older people (McCormack 2004). He contends that context has the greatest potential to enhance or limit person-centred care; for example, systems of decision making; power differentials; the potential to support innovative practices and risk taking, can all promote or stifle person-centred care. Nolan *et al.* (2002) identify the characteristics that define 'impoverished' and 'enriched' care settings for older people. They propose the use of the Senses Framework as a way of enhancing care environments. Both the physical environment and more subtle issues relating to staff attitudes and care practices are seen as important factors (Nolan *et al.* 2004). A positive social environment is identified as fundamental to the concept of person-centred dementia care (Brooker 2004); a place where a person can experience relative well-being and which promotes helping relationships. Nevertheless, Dewing (2004:39) contends that:

'Being person-centred within the context of contemporary and performance driven health care systems brings tensions and challenges.'

Nurses, for example, work in organisations where person-centred care is espoused and yet the organisation demands a whole gamut of risk assessments and screening that may result in dehumanising rather than enabling a person. Kitwood (1997) also discusses context at the social, cultural and economic level, radically suggesting that over time failures to meet the needs of a person with dementia can contribute to their cognitive impairment.

The concept of person-centred care continues to be debated in the literature and yet there remain challenges in implementing person-centred care into health and social care practice.

2.9 The challenges of implementing person-centred care into practice

Person-centred care means different things to different people and observations from the clinical setting suggest that the theoretical discussions have limited impact on everyday care in practice (Talerico 2003; Martin 2009). My own observations lead me to believe that nurses may work in a person-centred way but not recognise it; they may want to work in a person-centred way but not know how to or, as McCarthy (2006) reports, nurses may be sceptical about person-centred care working in practice. Translation of theories of person-centred care to practice may well be hindered by staff perception that it is an abstract notion, a euphemism that has little to do with the day to day realities of working with older people who are often severely cognitively and physically disabled. It would appear that much of the rhetoric of person-centred care fails to have an impact on front line staff. This view is supported by Dewing (2004) who argues that most of the frameworks have not yet developed from a conceptual level into care practice.

More recently, studies have begun to explore the use of person-centred frameworks in health and social care practice, and this has led to the development of indicators and checklists for the delivery of person-centred practice (Fossey and James 2008; McCance *et al.* 2008; Edvardsson *et al.* 2009). In developing the 'Senses Framework' Nolan *et al.* (2004) report the Senses as indicators for quality care practice with older people. Brooker (2007) and McCormack and McCance (2010) also present systems by which their frameworks may be best implemented into practice. Debates have extended to include bodily manifestations of personhood as indicators of person-centred care (Kontos 2005; Kontos and Naglie 2007). Despite the existence of these indicators, many still remain largely in the academic domain and are not widely accessible to health and social care staff. Dewing (2008a), for instance, draws attention to the lack of expert gerontological practitioners needed to implement person-centred practice.

Additional barriers to achieving person-centred care at a societal level include the unrelenting double stigma that surrounds older people with dementia. Brooker (2004) attaches the label of 'dementia-ism' to this stereotypical culture, a culture that pervades health and social care services as well as society in general. This stigma has arisen because of society's attitude towards ageing and the social

construction of dementia, a process that has been heavily influenced by the medical profession (Adams and Manthorpe 2003), and reinforced by the pharmaceutical industry (Bender 2003).

A range of models are emerging that purport to be the most relevant framework for working with older people such as 'person-centred care' and 'relationship centred care'. Although these models share some characteristics there are also subtle but important differences. A comprehensive person-centred framework remains elusive.

2.10 Life story work

LSW is a term given to biographical approaches within health and social care. It is claimed that LSW provides people with the opportunity to talk about their life experiences; record relevant aspects of individuals' past and present lives in some way and then use this life story to benefit them in their present situation.

McKeown *et al.* (2006) identify a range of similar and overlapping terms to describe LSW and some attempts have been made to clarify such definitions. Table 2.2 provides a description and summary of some of the commonly used terms. A number of authors use the term life history work synonymously with LSW (Bruce and Schweitzer 2008).

For the purposes of this thesis I use the term LSW. Life history can indicate the area of interest is the past, whereas LSW indicates the inclusion of contemporary aspects of a person's life and is purposively used with the person in their care. As I will discuss in this chapter, life history suggests a collation of facts, whereas life story opens up wider opportunities for hearing the person with dementia.

In their systematic review of intervention studies on the use of LSW with people with dementia, Moos and Bjorn (2006) extend their search terms to include life review, music therapy and life history. Our narrative review of the use of LSW (McKeown *et al.* 2006) adopted a more limiting range of terms and adheres to the definition of LSW provided at the beginning of this section. Consequently our review identifies a contrasting body of literature to the Moos and Bjorn (2006) review, further reflecting the complexity of the concept of LSW.

Table 2.2: Terms commonly associated with the use of life story work

Term	Description
LSW	An intervention undertaken to elicit some aspect of a person's life that goes beyond routine health assessment. It implies collaboration with another/others to gather and record information and usually results in a 'product' and aims to have an impact on the care a person receives. (McKeown <i>et al.</i> 2006)
Life Review	A planned 1:1 structured intervention (Haight and Haight 2007) often evaluating a person's life and used for therapeutic gain
Biographical Approaches	An approach taken to provide older people with opportunities to talk about their life experiences – family, friends, work, hobbies – often using photographs and personal belongings as triggers to discussion (Elipoulos 1997)
Oral History	The recording, preservation and interpretation of historical information, based on the personal experiences and opinions of the speaker.
Life History	All that has happened in a person's life, their background, events in their life and how they felt about it (Bruce and Schweitzer 2008)

The comprehensive update I have taken to the search undertaken in 2006 reveals that LSW has been reportedly been used with: older people (Heliker 1997; Adams *et al.* 1996, 1998; McKee *et al.* 2002; Clarke *et al.* 2003; Wills and Day 2008; Bakken *et al.* 2009); older people with dementia (Gibson 1991, 1994; Caron *et al.* 1999; Hansebo and Kihlgren 2000; Murphy 2000; Batson *et al.* 2002; Keady *et al.* 2005; Russell and Timmons 2009; Gibson and Carson 2010; Kellett *et al.* 2010; Thompson 2010) and; people with learning disabilities (Hewitt 1998, 2000; Moya 2010).

An emphasis on the use of LSW with older people using a person-centred care philosophy links many of the studies. All of the identified studies adopted a qualitative methodology. This review categorised studies based on the work of Polit and Hungler (1999) to include: research papers (where the research process was explicitly used to inform the study) and evaluations (where there was evidence of a systematic approach but no evidence of adherence to the research process).

The review classified four of the studies relating specifically to people with dementia as 'primary research' (Hansebo and Kihlgren 2000; Keady *et al.* 2005; Russell and Timmons 2009; Kellett *et al.* 2010). Meanwhile six were classified as 'evaluations', (Gibson 1994, 1991; Caron *et al.* 1999; Murphy 2000; Batson *et al.* 2002; Gibson and Carson 2010; Thompson 2010), either because their stated aim was evaluation or because the paper did not have enough detail to assess the research process.

Improving care for the person with dementia (Gibson 1994, 1991; Hansebo and Kihlgren 2000; Murphy 2000; Batson *et al.* 2002; Gibson and Carson 2010; Thompson 2010); offering family support (Caron *et al.* 1999; Kellett *et al.* 2010) and enabling a reflection on services received (Keady *et al.* 2005) are the most commonly articulated aims.

Of the research studies only one (Keady *et al.* 2005) had an explicit aim of involving the person with dementia in the research and actively seeking their experience of participating in LSW. The methodological choice of constructivist grounded research demanded an approach that involved all participants. Three of the evaluations (Murphy 2000; Batson *et al.* 2002; Gibson and Carson 2010) made some attempts to elicit the views of the person with dementia, albeit in a limited way. None attempted to involve them in the research process. This may reflect the perceived ease of seeking the views of people with dementia in the frame of an 'evaluation' in comparison to a research study with its stricter adherence to ethical approval.

In their review of LSW intervention studies Moos and Bjorn (2006) identify three aims of LSW, these being changes in: self esteem and self integration; quality of life; and behaviour. Our review of the literature (McKeown *et al.* 2006) identifies that the studies fail to explain precisely how LSW works but that in the care of older people with dementia, LSW appears to:

- be an enjoyable activity for patients
- provide a basis for individualised nursing care
- improve understanding of the person with dementia and can challenge staff attitudes
- develop the skills and job satisfaction of staff caring for people with

dementia

- can be therapeutic for family members
- can enhance relationships
- can enable the person with dementia to comment on their experience of health and social care services

In addition to the reported benefits our review (McKeown *et al.* 2006:246) identifies a number of gaps in the LSW literature, these being:

- an assessment of the different goals of LSW and the most effective methods in achieving given goals
- investigating the experiences of people with dementia in using LSW
- the impact of LSW on staff attitudes and subsequent care provided
- the impact of LSW on relationships between staff patients and relatives.

As this section demonstrates, LSW has an emerging knowledge base, although a number of gaps are evident in the empirical literature. In addition to the reported gaps there persists a lack of clarity over precisely what LSW means. The concepts of reminiscence and narrative are most commonly referred to in the literature as informing LSW. What adds to the confusion is that life story, reminiscence and narrative can all be used as a research method and an intervention and some authors refer to the use of both (Haight and Hendrix 1995; Keady *et al.* 2005, 2007a; Koch and Crichton 2007). The next section seeks to explore the ambiguity through a critical analysis of the distinct features of LSW, reminiscence and narrative, primarily as interventions rather than research methods.

2.10.1 Reminiscence

Reminiscence as an approach is often attributed to the work of Butler (1963) who challenged the hitherto view that reminiscence was a symptom of mental ill health in older people. Butler's work reframed reminiscence, and more precisely life review, as a normative and healthy process that all people undertake towards the end of their lives. Merriam (1980), however, challenges Butler's assertion that life review is a universal process; similarly Bornat (1989) and Coleman (1994) both note that reminiscence is not beneficial to all older people. For many people life-review is considered to be a private matter (Coleman 1986). Despite the challenges to the work of Butler (1963), it remains central in literature pertaining

to reminiscence.

The wide range of reported functions and characteristics of reminiscence have made comparison of reminiscence outcomes difficult (Gibson 2004). A clearer definition of the concepts and processes of reminiscence in research are called for. A review of reminiscence studies (Woods *et al.* 2005) report a lack of quality in existing research and call for more rigorous studies to establish the efficacy of reminiscence with older people with dementia. Similarly, Coleman (1994) calls for reminiscence to be explored across a wider range of contexts and cultures.

The reported value of reminiscence is extensive. A range of different aims and benefits of reminiscence have been purported and Gibson (2004) provides a composite summary of studies exploring the functions of reminiscence and concludes that reminiscence can:

- Provide a sense of coherence and continuity
- Encourage sociability and open up new relationships
- Confirm personal identity and encourage feelings of self worth
- Assist the process of life review
- Change the nature of caring relationships and contribute to staff development
- Aid assessment of present functioning and inform managed care plans
- Help to transmit knowledge, values and wisdom and to bear witness
- Be accessible and enjoyed by most people
- Contribute to social inclusion and community development

That is not to say that all functions are evident in all reminiscence interactions but will depend on the people involved and will vary over time and in practice. Moreover, Cohen and Taylor (1998) point out that reminiscence may serve several different functions at the same time

A range of categorisations of reminiscence have been put forward. Coleman (1974) for example, describes three types of reminiscence: simple, that is non-directed and often automatic reminiscence; narrative, that is a recollection of past experiences as in day-dreaming; informative, that is reminiscence that teaches or entertains others; and life review, which is a more planned and evaluative exercise.

Wong and Watt (1991) distinguish six types of reminiscence: integrative, instrumental, transmissive, escapist, obsessive and narrative and argue that in their study people who displayed greater amounts of integrative (acceptance and coherence of their life story) and instrumental (using past experiences to cope with current situations) reminiscence appeared more well adjusted and people who were less well adjusted tended to display more obsessive reminiscence. Adams (1994) is cautious about the use of such taxonomies and their attempt to pigeonhole individual responses, but suggests that their real value is in reminding us of the range of different ways in which people reminisce, some of which may be less adaptive.

Through using reminiscence with older people Gibson (1994:47) describes 'general' reminiscence that is more often used with people without dementia and includes group activities focussed on a generalised recall of the past; and 'specific' reminiscence which she argues is more relevant for use with people with dementia and describes as:

'Carefully selected, highly focussed consistent efforts to stimulate recall and conversation using carefully selected triggers known to closely approximate the detailed life history of the participant'

LSW has been described as a structured form of reminiscence (Gibson 2004) and I would agree that reminiscence, in one or more of its categorisations, is often evident in LSW. An understanding of the reminiscence literature can offer practical guidance to those undertaking LSW, particularly warning against an uncritical use of reminiscence. Coleman (1994) for example, emphasises the importance of finding positive memories, dealing with difficult memories and recognising when to challenge ways of thinking and memories that are unhelpful to the person and their relationship with others. Reminiscence alone is not a sufficient theoretical base to LSW and I will explore the literature on narrative in order to substantiate this claim.

2.10.2 Narrative

Personal stories or narratives are the means that people use to construct past events and actions that go on to shape identities (Rosenwald and Ochberg 1992). Concepts of narrative have developed from stories seen as a functional means of expressing our experience of the world to more recent accounts in which

narratives are seen as defining who we are. Baldwin (2008a:223) argues:

"We are indeed narrative beings who find our Selves in the stories we tell about ourselves and the stories that others tell about us."

Narratives are not accounts that describe the real world but rather are:

"constructed, creatively authored, rhetorical and replete with assumptions and interpretive" (Reissman 1993:5).

The links between narrative and identity have been well documented and McAdams (2003:187) contends that *'identity is itself a life story'*. Ricoeur (1984) argues that identity is embedded in time and as such can give meaning can be given to past in terms of based on present experience. This notion can be extended to consider that narratives are not fixed and can be *'restoried'* (Kenyon and Randall 1999:2), indeed this is often necessary when personal narratives are disrupted by life events or illness. Becker (1994) highlights the complexity in maintaining continuity when disrupted lives fail to conform to perceptions of normality. The condition of dementia can be described as a disruption to life and narrative has been extended to understandings of personhood with people with dementia (Mills 1997; Vittoria 1998; Cheston and Bender 1999; Surr 2006; Beard *et al.* 2009).

Narratives can take a diverse range of forms although are often reported to follow certain rules. For example the historical continuity of characters has been described as an essential element of narrative alongside the need for sufficient structure and grammar (Polkinghorne 1995; Herman 2002). Whether such rules are relevant for people with dementia is contested. Crisp (1995) for example, noted that if she listened carefully to the stories her mother who had dementia told, they adhered to rules of narrative. Similarly Mills (1997) demonstrates the use of narrative with people with dementia, although notes the possibility that over time the dissolution of narrative can occur. In his work Baldwin (2006:105) argues that people with dementia may become *'narratively dispossessed'* if the usual rules of narrative are applied. He describes narrative agency as a combination of being able to express oneself in narrative form and having the opportunity to express one's narrative. Opportunities for expression are not always available to people with cognitive impairment because of difficulties in communication or because the person is not invited or enabled to tell their story. Narrative has been described as giving a voice to those whose voices are not

always heard (MacKinnon 1996) and this seems relevant to the experience of older people with dementia, but clearly this only becomes a reality if there is an audience prepared to listen.

2.10.3 Clarifying the meaning of life story work

The analysis of the concepts of LSW, reminiscence and narrative demonstrate their similarities and differences. Reminiscence and narrative both have distinct and yet sometimes overlapping characteristics and purposes; both have formed the theoretical underpinning to the use of LSW with people with dementia over recent years.

Reminiscence places an emphasis on the recall of past memories. It may be a spontaneous activity or it may be planned and often visual and verbal prompts are used to stimulate past memories. Reminiscence is a familiar concept to many staff working with people with dementia.

The focus of narrative is on telling one's story which may enable the voices of those 'less heard' to be told and may support the maintenance of a person's identity. In my experience narrative is less commonly used and understood concept in the care of people with dementia.

Either or both concepts may also be evident in use with older people with dementia without this being termed LSW. In calling for 'narrative care' Randall (2009:323), argues that reminiscence can be an aid to the continuation of narrative development with people with dementia.

In their work exploring the narratives of people with dementia and their carers, Williams and Keady (2006) draw on the work of Somers (1994) in urging people to not only '*turn on*' to the narratives of people with dementia but also to '*tune in*'. Reminiscence can be initiated simply through spontaneous conversations, this may serve as a focus for staff to '*turn on*' to using LSW with people with dementia by listening to their stories of the past. By also considering narrative and its links to identity formation it is more possible to also '*tune in*' to what the person with dementia is actually saying and 'who they are' beyond merely the sharing of memories.

For the purposes of this research LSW is defined as:

'LSW is a form of intervention carried out in health or social care practice. It is usually undertaken to elicit an account of some aspect of a person's life or personal history that goes beyond a routine health assessment undertaken to plan care and treatment, and aims to have an impact on the care the person receives. LSW implies collaboration with another/others to gather and record information, and it usually results in a "product", for example a story-book, collage, notice board, life history/biography summary, or tape recording. It is an ongoing, dynamic process rather than a task to be completed and is usually planned and purposeful, although it does not need to be carried out systematically.'

(McKeown et al. 2006:238)

The final section will make explicit the conceptual framework constructed at the commencement of the research and will detail the research questions developed to guide the study design.

2.11 Conceptual framework and research questions

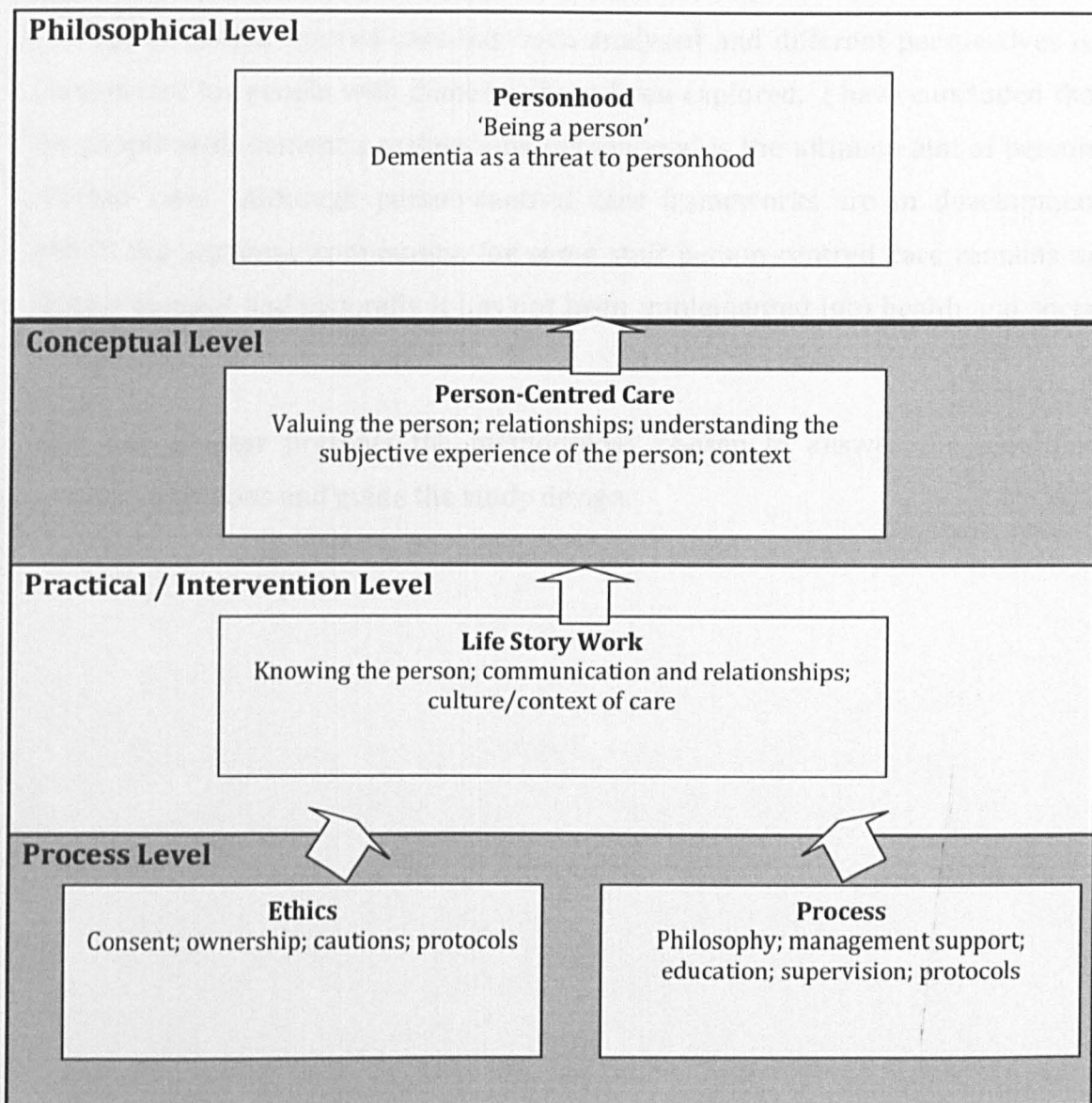
This chapter has provided a critical analysis of key concepts relevant to this thesis. This has provided the justification for undertaking research into the care of older people with dementia. The analysis, combined with my own practice experience and values (made explicit in Chapter One of this thesis) informs the conceptual framework that was developed to reflect current understandings of LSW (see Figure 2.4).

Fundamental to this study is the belief that a primary aim of the care of people with dementia is the maintenance of their personhood and yet having dementia can provide a threat to personhood. The concept of person-centred care provides the means of upholding personhood through valuing the person, relationships, understanding their subjective experience and paying attention to context. There can also be challenges in the implementation of these aims into everyday practice.

Research into LSW has been linked with the use of person-centred care philosophies and there are similarities between features of person-centred care and reported outcomes of LSW. The practical application of LSW may enable features of person-centred care to be implemented into practice; although to date LSW has been reported largely from the perspective of care staff and less so from the person with dementia or their family carers. Furthermore, the process of

undertaking LSW is under-developed in the literature, although there are reported cautions and concerns with using LSW these are not explored in any detail.

Figure 2.4: Conceptual framework to life story work study



The conceptual framework described above lead to the following research questions:

- What helps or hinders the process of implementing LSW?
- What are the benefits and/or difficulties in undertaking LSW?
- How does LSW effect the care the person with dementia receives?
- How is LSW experienced by all who participate?

2.12 Conclusion

This chapter has offered a critical analysis of the key concepts that relate to the care of people with dementia. The chapter has considered the development of explanations of dementia as a condition and subsequent care practices. The concept of person-centred care has been analysed and different perspectives on personhood for people with dementia have been explored. I have concluded that for people with dementia maintaining personhood is the ultimate aim of person-centred care. Although person-centred care frameworks are in development within the academic community, for some staff person-centred care remains an illusive concept and generally it has not been implemented into health and social care practice.

The next chapter presents the methodology chosen to answer the identified research questions and guide the study design.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

In this chapter I present the rationale for adopting a constructivist paradigm as the guiding framework for this study. I explain how it allowed me to gain a deep understanding of participants' experiences of LSW; whilst also involving participants in the creation and development of the research process and findings. I also discuss some of the achievements and the challenges faced in adhering to the key tenets of constructivism including the aspiration that research and practice inform one another. I then discuss the use of a multiple case study design and how that enabled me to investigate the use of LSW in the context of health and social care practice within a complex organisation.

The ethical considerations of LSW, methodology and methods used to collect the data are presented. In doing so, I demonstrate how they were consistent with the chosen approaches to research; the process taken to analyse the data and the steps taken to maintain involvement of participants and maintain transparency in the transition from the raw data to the findings. Finally, I outline the approach taken to ensure the rigour of the study.

3.2 Deciding on a research approach

Qualitative approaches are indicated where exploratory or descriptive knowledge is the aim of the study (Draper 2004). A starting definition of qualitative research is offered by Denzin and Lincoln (1994:2):

'Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means qualitative researchers study things in their natural settings, attempting to make sense of or interpret, phenomena in terms of the meanings people bring to them.'

These espoused values are consistent with the approach required to answer the

research questions in the present study. The research was conducted in the applied setting of clinical practice where the use of LSW was explored from the perspective of a range of key stakeholders; the alternative meanings these stakeholders held about the approach were central to understanding the processes taking place in practice. A positivist approach, with the emphasis on taking an objective and reductionist stance (e.g. Crossan 2003), would not have achieved the aims of this study. The next section explores the considerations informing the identification of the most appropriate qualitative research approach.

3.3 Identifying a particular qualitative approach

Had the research been purely about developing new knowledge then a range of qualitative approaches could have been considered. However, as described in Chapter One, I was equally interested in ensuring the research would change practice. For this to be realised and sustained it was essential to engage care staff, family carers and people with dementia in the research process. As such it was important to consider an approach that both embraced the active involvement of all participants and enabled the development of practice.

Participatory approaches to research have developed in response to health and social care policy requirements and over the past ten years the debate on user participation has gathered pace (Nolan *et al.* 2007). Involving service users in research is commonly described as a hierarchy ranging from: consultation; where consumers are consulted but with no sharing of power, to collaboration; which involves an active partnership between consumers and researchers through to user controlled research; where users may commission and indeed conduct the research (Telford *et al.* 2002). According to INVOLVE (2007:2) active public involvement in research would involve people other than researchers:

- helping researchers to identify and ask the right questions in the right way
- making sure that health and social care research is relevant to patients, people using services and the public
- getting involved in the research process itself, whether designing, managing, undertaking or disseminating research.

In health and social care, Beresford (2005) identified that service user and practitioner knowledge has traditionally been marginalised. An additional challenge in this study was how to actively involve people with dementia in the research process. In the past, people with dementia were largely excluded from participating in research (Dewing 2002) and, until the 1990s, research tended to overlook the perspectives and subjective experiences of older people with dementia (Hubbard *et al.* 2003). The person with dementia was viewed as a 'disease entity' and not someone who was able to contribute directly to an understanding of the illness (Cotrell and Schulz 1993). There is now a growing consensus that people with dementia should be included in research as active participants and not purely as subjects (Cotrell and Schulz 1993; Downs 1997; Dewing 2002; Hubbard *et al.* 2003; Hellstrom *et al.* 2007) and the issue is no longer *whether* we should involve people with dementia but *how* we can best involve people with dementia (Hellstrom *et al.* 2007).

For people in the early stages of dementia it is possible that their involvement in research can be facilitated through conventional involvement frameworks. However, some groups of people may not be able to participate as fully or in the same way as other groups in society (Tetley and Hanson 2000) and it is unrealistic and indeed undesirable to expect the participation of people with more advanced dementia under the frameworks designed for wider society. This study aimed to provide opportunities for people with dementia to become actively involved in research as participants and not purely subjects (Dewing 2008b). By this I mean ensuring that people with dementia are included in all decisions about choosing to participate, ensuring research methods are acceptable to the person with dementia and providing the opportunity for their voice to be heard about the actual research topic as well as their continued involvement. The precise way that people with dementia were involved is discussed in Chapter Four, but the choice of research approach was fundamental to achieving this.

Action research was initially considered as an approach to the LSW study, although after careful consideration this methodology was rejected for the reasons I now discuss.

In my desire to make the research meaningful to practice I had been attracted to the description by Waterman (2001:12) that the emphasis on '*research on action*' was seen as highly relevant with its potential to '*overcome the separation of theory and research from practice*'. On initial assessment this methodology appeared to be consistent with my research questions and desired approach. In particular emancipatory action research (EAR) was appraised in its relevance for the LSW study as it aims specifically to increase the closeness between the actual problems encountered by practitioners and the theory used to explain and resolve the problem (Masters 1995); and to assist practitioners in identifying and making problems explicit by raising their collective consciousness (Holter and Schwartz-Barcott 1993).

As I gained more understanding of action research I began to doubt its relevance for the LSW research. EAR seeks to empower participants and be truly egalitarian (Lincoln 2001); there was some doubt from myself whether this was possible in an organisation where financial constraints and management structures did not always support empowerment and freedom. Additionally, participatory action research is framed by the assumption that the researcher should share the same goals and values as group participants and indeed the research focus would emerge from co-construction. In reality I had a research focus in mind, and although it was perceived as meaningful to participants they may have had more pressing questions to focus on which I was not in a position to act upon. Further reading on research approaches suggested that a constructivist approach might be more relevant.

In the next section I discuss how a constructivist paradigm enabled me to answer my research questions whilst also developing practice and enabling the active involvement of all participants.

3.4 The Constructivist Paradigm

The constructivist paradigm is developing in popularity in health research inquiry (Appleton and King 1997) and a number of recent nursing studies have employed constructivist approaches (Appleton 1995; Scammell 1996; Davies 2001; Ross

2002; Brown Wilson 2007; Tetley 2007; Laker 2008). One of the reasons for this trend is the drive towards more collaborative, user led approaches to developing services and the move to service user involvement in health and social care research (Hanley *et al.* 2004). Nolan *et al.* (2003) define the goals of constructivist research are to promote action and change and also to develop knowledge and understanding. This was precisely what I wanted to achieve in my PhD to ensure that the development of practice was synonymous with developing new understanding. It was also important that participants were involved meaningfully throughout the process. As previously discussed in Chapter One this approach was consistent with my own values and the way I prefer to work and I believed it would increase the likelihood that any changes to practice would be sustained. In describing the work of the Aldre Vast Sjuharad Research Centre in Sweden, Nolan *et al.* (2003:23) describe a philosophy that aims to:

- Promote co-operation and partnerships in shaping health and social care and medical treatment
- Enhance the sharing of perspectives between older people, their families, professionals, voluntary organisations, health and social care providers and researchers.
- Increase the opportunities for older people and their families, together with professionals working with older people to initiate, participate in and evaluate new research-based interventions and service developments
- Raise the awareness and competence of care professional to ensure the future quality of health and social care and medical treatment through their involvement in programmes of research, development and education.

This described what I hoped the LSW study might achieve. The aims described above resonate with the aims of a practice development approach explored in Chapter One.

Guba and Lincoln (1994) describe a constructivist paradigm as a basic belief system or world view that guides the researcher comprising three components. These are:

- Ontology - Questions about the nature of reality

- Epistemology - Questions about the nature of knowledge and the relationships between the inquirer and the known
- Methodology - The best ways of gaining knowledge about the world.

Constructivism holds a 'relativist' ontology; that is it recognises the existence of multiple and intangible realities (Appleton and King 2002; Rodwell 1998). This accepts that 'multiple knowledges' can exist together and, consequently, a range of views may emerge (Guba and Lincoln 1994). The constructivist research study primarily aims to illuminate these different constructions (Lincoln 2001) and the iterative development of the research method through stakeholder involvement at every stage. This was particularly relevant since the views and experiences of the people with dementia, family carers and care staff were pivotal to the study's aims. Indeed, a review I had published earlier demonstrated that the perspective of all key stakeholders involved in LSW had not been explored (McKeown *et al.* 2006). As I previously discussed in Chapter One such an ontological position was consistent with my own values and beliefs as a mental health nurse and as a person.

The constructivist epistemology is directly related to the ontological position, in so much as the only way of gaining access to multiple realities within an environment is by interacting with participants in the natural setting. The 'researcher' and 'researched' develop a relationship based on mutual concern, trust and sharing of interests (Lincoln 2001). Taking a more participatory and relational approach to the research was complimentary to the theoretical model of person-centred care that the study was exploring and this supports the appeal from McCormack (2003a) that research exploring person-centred care should in itself consider person-centred principles. Epistemologically, constructivism adopts a '*subjectivist and transactional approach to examine the phenomena under investigation*' (Appleton and King 1997:13) in which the knower and the researcher create understanding jointly (Rodwell 1998). This is in contrast to positivist paradigms where objectivity is highly valued or even post-positivist research, where partial objectivity is aspired to. My own preferred way of interacting and working with people seeks to adopt a collaborative and participatory stance and I found the

constructive epistemology was consistent with my own professional and personal values.

The failure of Guba and Lincoln to appreciate the asymmetries of power is identified by Pawson and Tilley (1997); they suggest some people will always have their ideas and voices heard above other people. My experience was that in the early stages care staff and family carer participants were unused to participatory approaches; indeed in the proposal development stage where time was invested to gather staff and carer views on the important areas for study, one staff nurse became impatient with the length of time this was taking and requested: *'Just tell us what you want us to do and then we can all just get on with it'*. Stoeker (1999) proposes that participation cannot be forced and that communities and individuals have their own activities to attend to. Tetley and Hanson (2000) emphasise the importance of recognising the power dynamics, skills and knowledge of all participants before agreeing how they might be empowered to participate. Other authors suggest that Guba and Lincoln do accept the existence of power differentials and hold a moderate relativist stance; nevertheless, they are unable to describe clearly a process for resolving these issues of imbalance that are perpetuated by social structures and status (Appleton and King 2002).

Inequalities of power did exist in this study; similarly in her study of older women with dementia Proctor (2001) also highlights the subjugation of age, gender and disability of participants. In the LSW research inequalities of power existed between myself having the status as a senior nurse and a researcher, and other participants of care staff, family carers and people with dementia. Although I tried to minimise the power differentials by taking a person-centred and participatory approach it would be naïve to state that power issues were eliminated. Additionally people with dementia and family carers were service users whereas I was a part of the organisation that provided these services. In clinical practice Adams and Gardiner (2005) argue that people with dementia can struggle to secure strong positions in relationships that include family carers and health professionals, partly due to the respect and deference that society ascribes to

health professionals and partly due to the impairment from dementia; one can assume similar challenges occur in research relationships.

The LSW research does not make claims to be truly emancipatory; it did not seek to empower participants, indeed as Steel (2005) describes the idea that we can ‘empower’ others is a contradiction in terms. Proctor (2001) also appreciated that her research was not emancipatory, as there were no self-organised activists groups for people with dementia and the participants in her study were unable to empower themselves however this did not prevent her from taking a participatory approach. Like me she made attempts to allow her participants’ voices to be heard but also was honest that the person who benefited most from the research was herself in gaining a qualification.

Rodwell (1998) proposes a number of methodological considerations for a constructivist inquiry (see Table 3.1 below) each of equal importance and every one necessary: if one aspect is missing the inquiry process cannot be named constructivism.

Table 3.1: Rodwell’s methodological considerations for constructivist inquiry

Aspect of Inquiry	Methodological Element
Entry	Natural setting Prior knowledge
Research Design	Emergent design Problem-determined boundaries Purposive sampling
Data Collection	Qualitative methods Human Instrument Tacit knowledge
Data Analysis	Inductive data analysis Grounded theory
Rigor	Trustworthiness Authenticity
Inquiry Product	Negotiated results Idiographic interpretations Tentative applications Case study reporting

This methodological framework may appear attractive to the novice constructivist researcher in it’s ‘how to do’ approach, however, it has the potential to be rigid and prescriptive and could potentially inhibit the development of the application of

constructivism. My proposed study concurred with Rodwell's (1998) criteria in that the research was:

- a) Undertaken in the natural setting, of health and social care practice in this case of which I had prior knowledge of both the subject matter and the context.
- b) The research design was emergent and purposive sampling was employed.
- c) Qualitative methods were applied and I, the researcher, gathered the data in order to understand the meaning in the interactions of participants.
- d) Tacit as well as propositional knowledge was used and is reflected in the reflexive account of the study employed throughout this thesis.
- e) Data analysis was inductive in nature, although there was a slight departure from Rodwell's methodology at this point in that tentative *a priori* conceptual propositions were brought to the research as will be described in the data analysis section later in this chapter. Rodwell (1998) and other commentators on naturalistic inquiry promote a grounded theory approach. The traditional approach to grounded theory has been developed by Charmaz (2000) to reframe it as 'constructivist grounded theory' with the aim to more explicitly evidence participant voices in the resulting grounded theory. However this has not been uncritically accepted and the debates continue with Glaser (2002) criticising what he perceives as the erosion of grounded theory in Charmaz's desire to tell descriptive stories. In the LSW research a conceptual framework was used as a starting point for the study, consequently neither grounded theory or even constructivist grounded theory methods were employed yet I remained true to a constructivist approach.
- f) The approach to the study was rigorous in terms of Rodwell's criteria of trustworthiness and authenticity. This will be demonstrated throughout the thesis and summarised in Chapter Ten when considering the limitations to the LSW research. The findings are reported in a case study format and findings were presented in a style to maximise accessibility to participants and a range of stakeholders.

Rodwell (1998) argues that the emergence of a constructivist research design is a planned process comprising three successive phases, the contents of which will be unknown until the completion of each phase. She describes these phases as:

- Phase 1: Orientation and overview
- Phase 2: Focused exploration
- Phase 3: Comprehensive member check.

Phases 2 and 3 will be discussed in this chapter largely in relation to the research design, including data collection, analysis and the research product. However, Phase 1 will be considered below as a discreet stage, which was undertaken prior to the formal research approval processes of research governance and ethics had been granted. Without adopting a constructivist approach this phase may not have been detailed in the methodology chapter, when it was a fundamental part of demonstrating the use of the constructivist paradigm and also illustrates the stage where practice informed the research design.

Rodwell (1998:61) describes this phase of orientation and overview as the point where the researcher has a notion about what needs to be understood or known; she states:

'this idea comes from prior experience, exposure to the literature or some other situation that has shaped an intellectual puzzle.'

This perfectly describes the phase when I completed the literature review for my MPhil and was preparing the proposal to upgrade to PhD. My previous practice experience, the literature review and my current practice development work, assessing staff development needs on a ward for people with dementia and complex needs, had all drawn my thoughts towards how taking a LSW approach may improve care in some way (this is detailed in Chapter One).

It was at this point that I commenced a 'pre PhD' journal, recording events, decisions thoughts and feelings (Rodwell 1998) and began to develop ways of sharing my early thoughts, or foreshadowed questions (McMillan and Schumacher 1993) with care staff and carers on the ward I was working with. Rodwell (1998) describes this as 'hanging out'; this was a process I was familiar with due to my practice development role. I would sit in the day room, speak to staff, attend handovers, chat to family carers; fortunately these were all legitimate activities in my combined nursing and research role. I had approached the research department to ascertain if I needed any formal approval for this process but was

informed that this was pre-research activity. I sent letters to care staff and family carers inviting them to share their thoughts, experiences and ideas about finding out more about the people with dementia cared for on the ward and also displayed an information flyer inviting participation (see Appendix 2 for an example). A time limited group was organised for people who had responded and I facilitated three formal sessions where group participants were asked to comment on my ideas in order to develop them (see Appendix 3 for an example of notes from these meetings). It was sometimes difficult for ward staff to attend these sessions and so I would feedback at ward hand-over, or with staff individually where possible and noted their contributions. It was during one of these conversations that the previously reported difficulties for care staff in embracing a participatory approach were voiced. I also sent a letter to the local Alzheimer's Society inviting them to participate, asking whether there were any suitable groups for people with dementia who may wish to comment of the research protocol (see Appendix 4), unfortunately they were unable to participate at that time. An ethical issue arose at this point. I had spent a lengthy period with staff and carers to develop the research proposal; however it took longer than expected to obtain research governance and ethical approval. In addition the organisational structure of the Care Trust changed and my role moved away from having purely an older adult focus, to a Trust Wide remit. I did try to provide regular e-mail and written updates (see Appendix 5) for staff and family carers who had been involved but to them it must have felt as if I had left the service. It was 12 months before I had the necessary research governance and ethical approvals to commence the research (see Appendices 6 a and b) and it took my communication skills and a sense of humour to re-gain access to the field and contact with interested parties (see Chapter Four for more detail). Some of the care staff and one of the family carers who had participated in this process agreed to join the research reference group. The aims of this group were to: help guide and support the research; collaborate in data analysis and; improve the likely-hood of the research findings being implemented in practice.

The next section will describe the reasons for adopting a case study methodology and how this complemented the constructivist paradigm.

3.5 Case study methodology

Case study is a research strategy with a focus on the in-depth understanding of a single entity. Jones and Lyons (2004:72) highlight the confusion that exists between case study being seen as a design or a method; they conclude by describing case study as '*a comprehensive research strategy*'. It has further been described as a 'methodological frame' within which individual techniques of data collection are situated (Hakin 2000) and this is the frame in which case study was used in the LSW research. Case study research is defined as:

'an empirical enquiry that investigates a contemporary phenomenon [LSW] within its real-life context [Health and Social Care practice], especially when the boundaries between phenomenon and context are not clearly evident' (Yin 2009:18).

The chosen design allowed LSW to be applied within everyday practice; exploring both the experiences of the people involved and the processes taken for LSW to be implemented. Furthermore, case study can have an advantage over other methods when:

'a 'how' or 'why' question is being asked about a contemporary set of events over which the investigator has little or no control' (Yin 2009:9)

Case study research has the capacity to be flexible and sensitive to different contexts and meanings (Stake 1995) and I would argue is therefore consistent with the tenets of constructivist inquiry. As previously discussed it was essential that the study developed theoretical understanding and provided a sound theoretical rationale for the choice of method. However, for the study to be meaningful in the clinical arena pragmatic decisions also support the choice (McDonnell *et al.* 2000). Platt (1988) contends that case study material provides 'aesthetic appeal' by its humanistic mode of presentation; as such this widens the appeal beyond academia to the practice arena and non-academic audiences. Case study is a tangible and familiar concept to practitioners and the choice of a case study methodology offered the potential for the research to progress with practitioner collaboration.

Hakin (2000) describes case studies as the most flexible of research designs. Research involving person-centred phenomena often follows an unpredictable path (Jones and Lyons 2004), making case study research an appealing strategy. It

has also been described as an appropriate method for studying nursing (Pegram 1999; Bergen and White 2000; Zucker 2001) and a mechanism to transform practice. Keen (2006:113) rather simply summarises:

'Case studies are most valuable where a planned change is taking place in the messy real world setting, and when it is important to understand why such interventions succeed or fail.'

There are debates as to whether case study should be linked to a particular paradigm. Yin (2009) resists linking the strategy with either a qualitative or quantitative paradigm and recommends that data collection and data analysis develop as a logical response to the questions asked. Conversely, Lincoln and Guba (1985) argue that case study has many links with qualitative research. In practice, Repper (2000) concurs with Yin in that, the selection and application of method is dependant on the aims of the study.

Yin (2009) identifies the development of theory prior to the conduct of any data collection as a point of difference between other methods such as ethnography and grounded theory. As already discussed I had been developing an understanding of LSW in clinical practice for a number of years before commencing my PhD; additionally I had conducted an in-depth literature review and had been considering the potential role of LSW in achieving outcomes of person-centred care. Care staff and carers participated in the development of the research proposal and so by the time the research commenced a considerable amount of knowledge had already been gained about LSW and there were already 'sensitising concepts' emerging. These have been described as constructs derived from participants' perspective that sensitise or alter the researcher to possible lines of inquiry and in qualitative research Blumer (1954), who first described 'sensitising concepts', emphasised the importance of not prematurely closing down definitions of concepts. Van den Hoonaard (1997) further likens these to 'half way houses' where data is stored temporarily and made ready for further analysis.

The next section of this chapter will detail the steps taken to ensure the research was conducted in an ethical way.

3.6 Ethical considerations

This section explores the ethical considerations guiding the research, primarily in terms of the research methodology and subject of the research. Chapter Four details the additional ethical considerations that were given to researching people with dementia, family carers and care staff.

Fundamentally ethical research aims to do no harm to participants and LSW is generally a safe and enjoyable activity, although not everyone enjoys reminiscing and sometimes painful memories can be evoked (McKeown *et al.* 2006). Providing that protocols for good practice in using LSW are employed then the research is unlikely to be unpleasant or harmful to participants. Staff collating the LSW information received awareness training and I also provided support and supervision. Access to an experienced practitioner or clinical psychologist had been negotiated prior to the commencement of the study in-case of any participants being especially affected by life story disclosures, but in the event this was not required.

Ethical issues relating to the research process included the maintenance of confidentiality and anonymity of participants as an inherent difficulty in new paradigm research. Rodwell (1998) identifies that strict confidentiality protections are not possible in constructivist inquiry where face-to-face negotiations and understandings of the data are integral to the research process. Participants were made aware of the difficulties in maintaining anonymity and their responsibility for what they disclosed was emphasised. However, further safeguards were put into place to maintain confidentiality and anonymity in the final case report and sensitivity employed where it was felt that disclosure moved beyond what is required for the research.

The ethical behaviour required on the part of the researcher has been compared to the concept of 'professional morality' (Rodwell 1998; Williamson and Prosser 2002). As a registered nurse, governed by the Nursing and Midwifery Council Code of Professional Conduct (NMC 2008) I was accountable for maintaining the well being of the people with whom I work. The research reference group, PhD supervision and my professional mentorship all acted as an additional safeguard.

The study received approval from the local Research Ethics Committee (REC) on two occasions; initially, when the study commenced and then re-submitted in light of the enactment of the Mental Capacity Act 2005 (see Appendix 6b for ethical approval letters). Dewing's (2007) process consent framework was used to ensure maximum involvement of the person with dementia in the continual assessment of their agreement to participate. The detail of this process is discussed in more depth in Chapter Four. The ethics committee commended the approach taken in involving people with dementia and felt such an approach should be considered in all ethical submissions to the committee when people with dementia were participants. The application of the process consent framework to the LSW research has subsequently been published in a peer reviewed journal (McKeown *et al.* 2010a)

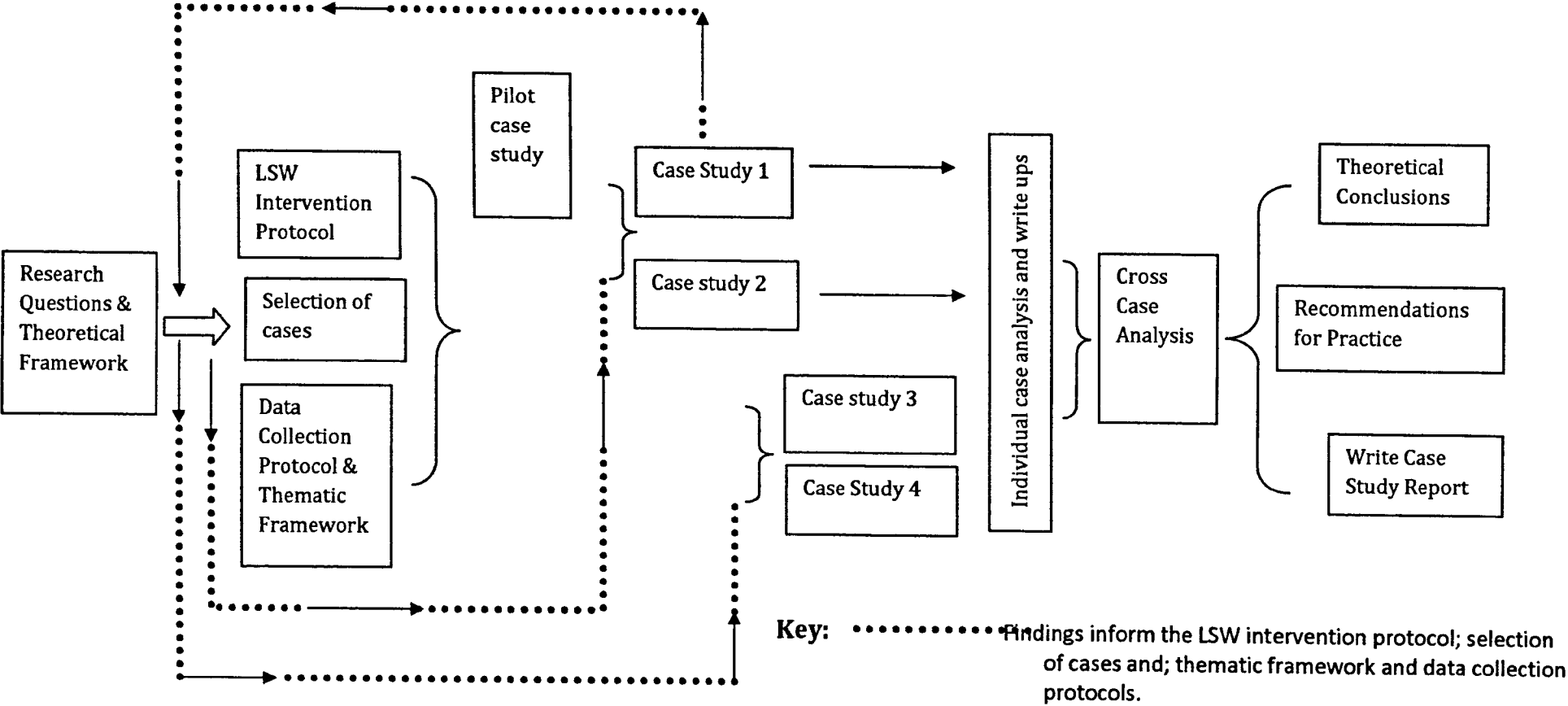
The next section of this chapter will explore the research design and how this adhered to the tenets of constructivism and case study methodology.

3.7 Research design

3.7.1 Sample

Each case and all participants were purposively selected and four case studies were undertaken. Stake (1995) describes case studies as either intrinsic, when the case itself is of primary importance; or instrumental, when the case is selected to gain an understanding of a particular aspect or phenomenon; and collective or multiple case studies, where an instrumental study might be extended to several cases when it is believed that understanding them will lead to an improved understanding of the phenomena. The present study adopted the latter design and what is described by Yin (2009) as multiple case study design. Figure 3.1 is adapted from Yin (2009) and provides a visual representation of the research design, it demonstrates that the pilot case study helped to refine the thematic framework and LSW intervention protocol and similarly case studies one and two influenced the choice of subsequent case studies.

Figure 3.1: Life story work case study research design



3.7.1.1 Case study sample

Case studies 1 and 2 were chosen for 'literal replication' (Yin 2009:54); that is each case study replicating the same or similar results for predictable reasons. Rodwell (1998) describes the 'typical case' as helpful at the beginning of constructivist research to understand the depth and the range of the issue under investigation.

The case studies did produce some similar but rather un-predictable outcomes. I had been un-prepared for the slow progress with both case studies; gaining entry to the field had been extremely time-consuming and a number of unexpected challenges emerged, each impacting on the research, the exact nature of these circumstances is detailed in Chapter Four. Case study 1 was ended abruptly as the ward closed far earlier than planned and the case study had to be re-commenced on a new ward. The data collected from this aborted study, comprising six interviews, were re-categorised as pilot data and early analysis confirmed the relevance of the thematic framework developed for data analysis whilst also extending it. There were also insights into the lack of progress in initiating LSW. Case study 2 also took time to progress and the person with dementia at the centre of the case study fractured his leg and was transferred to a nursing home, effectively slowing down the progress of the research, whilst also offering new opportunities to follow up the study in a different care environment. This, however, necessitated a time consuming revision of the research protocol and a re-submission to ethics and a lengthy negotiation to gain entry to the nursing home. Appendix 7 shows the time line of the LSW research from ethical approval to final data collection.

Eisendhart (1989) describes the utility of sampling decisions in case study research. Far from seeking to achieve a representative sample, cases are selected to explore specific issues or hunches, or to test a conceptual framework. In the present study, case studies 3 and 4 were chosen as 'theoretical replications' (Yin 2009); that is predicting contrasting results (i.e. a speedier implementation of LSW) for predictable reasons. Case study 3 was chosen with an OT as the lead implementer compared to nurses in case studies 1 and 2. Case study 4 was chosen as a Beacon site case study, an environment where LSW was already being used

and where person-centred practice was reputed to be embedded. It was predicted that important learning could be uncovered from both of these studies by considering what conditions might be necessary to ensure LSW is embraced and sustained in practice.

Eisendhart (1989) states there is no ideal number of cases but numbers between four and ten usually work well; less than four can make it difficult to generate theory with much complexity, whilst more than ten can make it difficult to cope with volume and complexity of the data. Yin (2009) describes the simplest multiple design as having two or more cases believed to be literal replications, whilst a more complicated design can result from the number and type of theoretical replications. Yin (2009:58) offers little specific guidance on numbers required beyond stating the researcher:

'should think of this decision as a reflection of the number of case replications – both literal and theoretical – that you would need or would like to have in your study.'

The literature does not appear to adequately consider the complexity of the case study and range of data sources when considering 'how many is enough'. For example six or more case studies that are very straight forward might yield less meaningful results than fewer cases that explore a wider range of complexity in terms of data sources and types. It is fair to say the complexity of case studies 1 and 2 in particular was not anticipated at the outset of the research. Case study 1 for example, continued far longer than could have been anticipated, this allowed for a more longitudinal approach, so producing a richness and greater level of detail in the data than was initially envisaged. The precise details of activity undertaken in each case study are shown in Appendices 8 a, b, c, d and e.

Taking this evidence, both from the literature and from experience in the field, the considered decision to stop data collection after four case studies was made. Lincoln and Guba (1985) propose that data collection should cease when: all sources of information have been exhausted; all identified categories have been defined; each construct developed appears to be a regular occurrence or an anomaly and new information gathered stretches beyond the boundaries of the study. In discussions with my supervisory team we agreed that although it could

not be stated that no new data would emerge, consistent connections between themes were emerging and all areas of the thematic framework had been populated. There was confidence that there was adequate data to address the research questions.

Eisendhart (1989) concurs with this idea of data saturation, but also suggests that in practice the decision is often combined with pragmatic considerations such as time and money. Pragmatic reasoning strengthened the decision to cease collecting data. Far more data had been collected from a wider range of sources than had been anticipated at the outset of the study and this had at times placed demands on staff and carers in terms of time commitments and personal investment. As in other qualitative research the dataset had the potential to become unwieldy and the inclusion of more cases would add to that. Additionally a thorough range of care settings for people with dementia had been explored from community health and social care day centres, through to an intermediate care ward, an assessment ward and finally nursing home care.

3.7.1.2 Participant sample

An information flyer was displayed on each ward (see Appendix 9) and information sheets detailing the exact nature of the research were given to all potential participants (see Appendices 10 a, b and c). At the centre of each case study was a person with dementia who was selected by care staff based on set criteria to ensure that the 'cases' helped to answer the research questions and to address ethical considerations; purposive sampling is consistent with constructivist approaches. Table 3.2 details the inclusion criteria.

Multi-professional staff, working with the selected people with dementia, were asked if they would volunteer to participate. In case studies 1 and 2 the ward manager identified staff members they thought would be interested, on one occasion the family carer recommended a particular staff member whom she felt had developed a rapport with her husband. In case studies 3 and 4 staff were recruited to enable theoretical replication. The research design was extended for the person to be followed up in other care environments; for example, when they moved to a nursing home or if they received day care in another setting.

Table 3.2: Inclusion and exclusion criteria for the life story work research

Inclusion Criteria
The person must have complex behavioural needs; the research is focusing on people with 'challenging behaviour'
The person is likely to be on the ward for at least 12 weeks to assess the impact of the LSW approach.
With carers (if any) who may be willing to participate
Exclusion Criteria
The person is purely physically frail.
The person is towards the very end of their stay on the ward.
The carer is unwell or especially distressed

Three family carers agreed to participate. In case study 2 the person with dementia and his wife and both initially seemed interested in becoming involved. However after having read the information sheets and considering her circumstances the wife decided not to participate, her husband stated his wish to remain involved and his wife supported his decision (see Chapter Four for a detailed discussion on the active involvement of people with dementia in the LSW research).

All participants were asked to sign a consent form (see Appendices 11 a, b and c). The approach to seeking the consent of the person with dementia is discussed in more depth in Chapter Four. Table 3.3 illustrates the total number of participants.

Table 3.3: Total number of participants

Participant	Total Number
Person with dementia	4
Family carer	3
Registered Nurse	6 (5 RMN 1 RGN)
Support Worker	4
Occupational Therapy Assistant	2
Student Nurse	1
Total	20

3.7.2 Data collection

The methods of data collection were chosen to answer the research questions and also were consistent with commonly used methods in case study research (Yin 2009) and included: interviews, conversations, observation, rating scales, filed notes and some documentary analysis. The precise detail for each case study is shown in Appendix 12.

3.7.2.1 Interviews

Interviews were conducted using a semi-structured topic guide (see Appendices 13 a, b, c and d for copies). Topic areas were chosen to interrogate the research questions, but also provided the flexibility and opportunity for each participant to bring their own experience to the research interview. The strengths of such an approach is that it provides a systematic framework to the information collected for each respondent and the interview remains fairly conversational and situational (Patton 1980), there is however the potential for salient topics to be missed. The skill of the interviewer is important here in using active listening to know when to ask for more detail or clarification on a subject.

The initial plan was to interview each person at least twice or three times, initially before the LSW commenced in order to elicit their understanding of the approach and their knowledge of the person with dementia; then again after their involvement in LSW to understand their experience of participating and finally after six months in order to assess if LSW was still being used. In reality this was not achievable due to the nature of the research design; factors such as staff leaving, the person with dementia moving care environments, the LSW commencing before consent had been gathered for the research all influenced the design and the appropriate timing of the interviews. All staff and family carer participants were interviewed once and sometimes twice when it was identified that this would extend the understanding of emerging concepts. Interviews lasted between twenty minutes and fifty minutes. Twenty-one interviews were conducted in total (see Appendix 12). When it was not possible to follow up on a case after six months, other forms of data collection such as conversations and care plans were used, as detailed later in this section.

Interviews were highly consistent with a constructivist approach and as Kvale (1996) notes the researcher is the research instrument. With that comes not only the need to be knowledgeable about the subject but equally an expert in communication and interaction; skills I possessed through an interest in the subject area and experience as a mental health nurse.

The realities of undertaking interviews in 'real life' are worthy of some comment. For example Field and Morse (1989) identify the conditions for an interview to proceed comfortably; these include: avoiding interruptions and minimising distractions. Although efforts were made there were circumstances where interviews were conducted in less than satisfactory conditions and these were reported in my research diary. One example was the planned interview of a staff nurse on a busy ward; on arrival it was evident he was the only qualified nurse on duty, and although I suggested postponing he wished to proceed. We undertook the interview in the ward office with him eating a slice of toast and drinking a coffee I had made, as he had not had time to eat. The recording was paused, once whilst he took a phone call and again when interrupted by a support worker and was finally cut short when he needed to attend to a clinical matter and resumed at the end of his shift. The resulting data was rich and coherent and provided valuable data although it was clearly not ideal. Perhaps it was significant that I knew the participant and already had a degree of rapport with him, something Clarke (2006) identifies as important in qualitative interviewing. On another occasion a family carer requested that the interview was conducted with her mother (a participant) present. I was able to adapt the style of the interview so that her mother felt involved and there were a number of digressions where we attended to her mother's need for information and reassurance regarding her condition. MacDonald and Greggans (2008) identify the lack of guidance in the literature in preparing for the realities of undertaking research in the field. In relation to interviewing children and families they argue that multiple interruptions reflect the complex reality of research into social phenomena and this was consistent with my experience.

Opportunities to talk to care staff participants that could not have been identified at the start of the research were utilised; these included care staff from nursing or residential environments that the person with dementia moved to and also chance meetings and follow up conversations that took place with participants outside of the interviews. A more informal topic guide was developed (see Appendix 14) for the conversation with each participant and a record of each encounter was maintained and consent established. Patton (1980) categorises this as an 'informal conversational interview' in which questions emerge from the immediate context and are asked in the natural course of things.

3.7.2.2 Conversations

The views of people with dementia were gathered in a less formal way than with other participants. Structured interviews or inflexible methods have limitations with people with dementia (Hubbard *et al.* 2003). Opportunities were therefore taken to adopt dementia specific interview methods, and these required me to be aware of the nature of communication and dementia and being able to respond to verbal and non-verbal communication and utterances. Killick (2001) contends that a direct approach of asking questions can be counterproductive in gathering the views of people with dementia as it can increase anxiety and confusion; in advocating a 'hit and miss' approach Killick (2001) recognises the potential reduction of rigour, but the improved opportunity person to voice their views at their own pace in an atmosphere of intimacy and relaxation. This approach was taken and permission to write down what is said was negotiated at the time of the interaction and interactions were recorded in detail and used as data. Communicating with people with dementia requires skill and experience and researchers can lack these skills (Hubbard *et al.* 2003); as a senior nurse my skills enabled me to facilitate this process. Conversations usually revolved around the life story book or pen picture which served as prompts for the topic under discussion.

3.7.2.3 Observation

Informal observation was undertaken whenever the opportunity arose and the details were recorded in my research diary. Observations included the person

with dementia using their life story book and were also noted during the process of assessing consent. These include obvious engagement or disengagement with LSW, verbal and non-verbal behaviours and gestures, all of which were detailed in field notes either directly from observation of the person or through reports of staff observations.

I found it difficult to categorise my observer role following Gold's (1958) typology. Was I a 'participant as observer' gaining access to a setting by virtue of having a natural and non-research reason for being part of the setting and part of the group being studied? As a senior nurse in the organisation this could describe my role; but as I no longer worked for the Directorate into which I was researching perhaps I was an 'observer as participant'. Such a role means having only minimal involvement in the social setting being studied; there is some connection to the setting but the observer is not naturally and normally part of the social setting. This seems to better sum up my position, but it did not fully reflect my dual role as researcher and facilitator of the LSW initiative. This role and its implications for the research were discussed in more detail in Chapter One.

3.7.2.4 Rating scales

Two rating scales were identified in the research protocol as data collection methods. The first of these was the Challenging Behaviour Scale (CBS) (Moniz-Cook *et al.* 2001) (see Appendix 15). This validated scale was developed as a measurement of behaviour that staff in care homes found difficult: it has potential for the evaluation of psychosocial interventions for people with 'challenging behaviour'; it can indicate potential quality of life issues for the person with the challenging behaviour; it provides an indication of staff perception of the behaviour (Moniz-Cook *et al.* 2001). The other scale was the Wellbeing profile (Bruce 2000; BDG 2001) (see Appendix 16). Wellbeing profiling attempts to understand the subjective experience of a person with dementia (BDG 2001); it:

"is a way to record observations of people with dementia, and to assess how they are faring at an emotional level" (Bruce 2000:26).

The profile provides a numerical score of wellbeing whilst also providing information that can be transferred into the care planning process. The intention

had been to observe any changes in the scoring of these scales before and after the use of LSW. As the research emerged it became evident that their use following the intervention would not be possible, partly because in two cases the person with dementia had moved care environments and it would be difficult to compare the scores and also because the use of the scales in this particular way was not consistent with the research design. The rating scales were used on one occasion in all cases to provide demographic and descriptive detail to the studies.

3.7.2.5 Field notes

Field notes were recorded alongside my own reflections and observations in the form of a research diary which spanned two volumes. The use of a research diary can help to maintain rigour in qualitative research as well as help to clarify thoughts and feelings (Koch 1994). For ease of data analysis a different colour highlighter pen was used to identify notes and reflections specific to each case study. Clarke (2009) describes how her research diary allowed her to demonstrate transparency by documenting her thought process through the analysis stage whilst also being a useful reflection of her own learning as a researcher.

3.7.2.6 Other

In one case the care-plan of the participant with dementia was copied before and after the use of LSW. This was not possible across all cases due to the person with dementia moving care environments. In one case where the person was unable to articulate his opinions on the LSW approach an observation sheet was developed (see Appendix 17). This had a dual role of assessing his response to the use of LSW to assess continued assent to continuing and also as a data collection method to record his responses to using LSW. Additionally, and not anticipated at the outset of the research, a number of opportunities arose to test out developing ideas and these were reported in my research diary and used as data. Notes were kept of all research reference group minutes (see Appendices 18 a, b and c for record of meetings and examples of notes maintained).

3.7.3 Data analysis

In this section I explain the rationale for using Framework Approach (Ritchie and Spencer 1994) to manage and analyse the interview, observation and documentary data and how it was consistent with a case study design. I will also explore some of the challenges I faced with this approach and how they were overcome.

Qualitative research typically generates large volumes of data that need to be analysed and has been criticised for not being transparent in the analysis process (Murphy *et al.* 1998). Yin (2009) asserts that the analysis of case study evidence is the most complex and underdeveloped aspect of case study research; however he recommends the strategies developed by Miles and Huberman (1994) as a starting point for analysis. They propose a three stage approach of: reducing the data, displaying the data and conclusion drawing and verification. These are evident in Framework Analysis (Ritchie and Spencer 1994) and it is this approach that was used for the LSW study and is characterised by the following distinct and interconnected stages: familiarisation; identifying a thematic framework; indexing; charting and finally mapping and interpretation. This approach utilised the conceptual framework that had been developed prior to data collection and is consistent with case study research which:

'benefits from the prior development of theoretical propositions to guide data collection and analysis' (Yin 2009:18).

Framework analysis provides a systematic and visible structure to the analysis process in order to produce analyses with *'potential for actionable outcomes'* (Ritchie and Spencer 1994:173). The Framework approach can help to maintain an audit trail, since it is possible to observe the stages by which the results have been obtained from the data (Lacey and Luff 2001) and the process and interpretation can be assessed by people other than the primary analyst (Pope *et al.* 2000). The method is increasingly being used in policy related and applied research (Pope *et al.* 2000) and is also pragmatic and follows a common sense approach making it understandable to practitioners who are likely to be an audience for the results.

Framework has been criticised for being too prescriptive and Donovan and Sanders (2005) suggest that Framework removes certain aspects of traditional qualitative analysis such as induction of themes, flexibility in design and sampling and an iterative approach to data collection and analysis. I aim to demonstrate in the next section that it is possible to overcome these perceived weaknesses of the approach. The use of Framework in the LSW research will be discussed in relation to each of the five stages previously outlined.

3.7.3.1 Familiarisation

This phase took place over many months and involved transcribing and reading the data. I transcribed all the interviews and although this was a timely process it allowed me to listen back and initial familiarisation of the data took place. It was surprising how poor my recall of some of the interview data was and a reminder of what data may have been lost had notes alone been maintained. The data was collected over an 18 month period and so the familiarisation phase was a continuous process throughout the life of the research; initial familiarisation of the pilot interview data helped to develop the initial thematic framework .

3.7.3.2 Identifying a thematic framework

Themes emerging from the pilot data were combined with themes from the conceptual framework to develop an initial thematic framework and this was refined throughout the study. Appendix 19 details the development of the thematic framework and this process is presented in more detail in Chapter Five. This is consistent with the observations of Swallow *et al.* (2003) and Lacey and Luff (2001) who argue that Framework analysis allows for *a priori* as well as emergent codes to be used in the analysis (Lacey and Luff 2001). This stage departed from the methodological considerations for constructivist inquiry described by Rodwell (1998) in so far as a grounded theory approach was not used. The conceptual framework had been in formation since my interest in LSW in practice began in the year 2000. A review of the literature conducted in 2006 further began to inform on themes that were emerging from research, and my early conceptual framework (see Chapter Two) was tested with the pilot interview data and organised into an index as described by Ritchie *et al.* (2003).

Pope *et al.* (2000) argue that Framework, with its focus on the aims and objectives already set for the study, starts deductively, however it can also develop inductively as the findings are grounded in the original accounts and observations of participants. My initial propositions were that LSW potentially had a role in enhancing outcomes of person centred care; but equally there were difficulties in its wholesale implementation in health and social care. Additionally I was interested in the experience of those participating in LSW. These propositions demonstrate the dual deductive and inductive processes required to answer the research questions

The thematic framework continued to be adapted and refined as new data was collected and also through sharing of the Framework in formal and informal ways with different audiences. In particular the members of the research reference group participated in some of the coding and adaptation, this confirmed the choice of Framework which, with some explanation, could be understood by care staff and family carers in enough detail for them to be able to participate in the data analysis process.

3.7.3.3 Indexing

When the data collection was completed the transcribed data was transferred into Microsoft Excel spreadsheet programme; this approach had been used successfully by Swallow *et al.* (2003) who found it an alternative approach to dedicated 'code and retrieval' qualitative software programmes. A page was assigned for each theme of the framework and to aid data management and subsequent abstraction fields were developed; these included the number of the case study, participant, where in the data the quote was located and the sub theme in the thematic framework it related to (see Appendix 20 for an example of the spread sheet). This process was arduous and felt like it was taking too much time but the final result was a spreadsheet I could easily interrogate and that could support my aim for transparency in the data analysis process. Notes were made as patterns or connections were noted; both on the excel spreadsheet and also in my research diary.

Ritchie *et al.* (2003) predict the need for refinements after initial application of the data and this became necessary in the LSW study. For example, initial themes of 'relationship' and 'communication' were merged, but the data suggested the development of sub-categories that necessitated separating the themes and consequently data that had initially been difficult to index was found to have more meaning than originally anticipated.

It was around this time that I had started to question the use of Framework and had wondered if the process may be too mechanical and may be inhibiting the creativity, perhaps reflecting the concerns of Donovan and Sanders (2005) that Framework can constrain what is to be studied and can suppress complexity. This proved frustrating and I was concerned that emerging patterns and associations may be lost by adhering to a strict framework. However, I began to use the approach more flexibly to follow up on connections and cross case themes; whilst having a robust and transparent process to demonstrate how the data could be traced back to its source.

3.7.3.4 Charting

Charting commenced when the decision had been taken to work with the most recently adapted version of the thematic framework as the data appeared to fit; the process of charting served to further clarify the relevance of the thematic framework and gave confidence to the indexing structure and vindicated the decision to stop amending the thematic framework. I charted each case study against each theme and subsequent sub themes (see Appendix 21 for an example) and then charted each theme against all the case studies (see Appendix 22 for an example). I then proceeded to write a descriptive narrative of each theme; which I gradually refined to become more analytical as connections emerged. I also summarised each individual case study across all themes along with the salient points relating to the specifics of each case and across each participant. Charting is consistent with the approach to data display developed by Miles and Huberman (1994) who promote the use of charts, matrices and diagrams in addition to the traditional narrative approach to presenting qualitative findings.

Interview data, notes from discussions and conversations and reflections from my research diary specific to each case study were analysed in this way. It was more of a challenge to incorporate observational data less specific to each case study. Rodwell (1998) supports the use of observational data more as 'background' data rather than in the same way that interview raw data is used for analysis.

3.7.3.5 Mapping and interpretation

The charts were laid out and connections, similarities and differences were noted which helped to identify explanations and begin to draw conclusions. At this point I decided Framework had fulfilled its use and began to think more creatively and freely about the findings to identify themes more inductively whilst also referring back to charts and raw data to begin to confirm or dis-confirm emerging ideas. A further dimension to the process occurred when I reflected on what the findings meant for practice and how I might share the findings with participants and care staff, for whom the importance of the findings was their relevance to inform practice. It was at this stage I became more confident in being able to articulate the analysis. Chapter Five details more specifically how the findings emerged from the final thematic framework. The chapter also demonstrates how the final four themes emerging from the analysis address each of the research questions and form the basis of Chapters Six, Seven, Eight and Nine

3.8 Rigour

Issues of rigour in qualitative research differ from the positive paradigms and the criticisms of rigour in constructivism are extensions of the paradigmatic discussions (Rodwell 1998). There is no one agreed single set of criteria to assess quality or rigour in qualitative research; nor should there be, according to Rolfe (2006) who argues that each methodology (and possibly each study) should be assessed on its own merits considering the range of ontological and epistemological characteristics of different qualitative methodologies.

Rather than discuss rigour as a discrete stage in the research process, I aim to demonstrate its presence throughout this thesis. I will critically appraise the

extent to which I achieved rigour in Chapter Ten when I consider the limitations to the study and how I minimised these.

3.9 Conclusion

This chapter has explained the rationale for a qualitative approach and for the specific choice of paradigm and methodology. The data collection methods have been detailed and the process for analysis explained. The ethical issues explored. Chapter Four will describe entry into the field and detail the context in which the research was undertaken; the chapter will also consider how people with dementia were actively involved in the research process.

CHAPTER FOUR

SETTING THE SCENE

4.1 Introduction

This chapter will firstly outline the context in which the LSW research was undertaken before discussing entry to the field. The challenges of actively involving the people with dementia within the research process will then critically analysed in relation to the use of a process consent model.

4.2 The organisational context of the study

The LSW research was undertaken in a mental health and social care Trust in a large city in the north of England with a population of 547, 000. There are estimated to be over 6000 people living with dementia in the City (Jackson 2009). The Trust comprises six service directorates: adult acute and community; rehabilitation and recovery; learning disability; substance misuse; older adult functional mental health and community; and the dementia directorate in which the LSW research was undertaken.

The Trust employs over 3000 staff and in 2008 gained status as a Foundation Trust. The service directorates are supported by the service development directorate which includes clinical governance, risk, patient experience and practice development, where I currently work as a senior nurse. Throughout the duration of the study the organisation underwent two major re-organisations (see Table 4.1 for a timeline of the changes and their impact on dementia services and the LSW research). The first re-organisation was a leadership review in which the service directorates were re-organised into their current configuration. This re-organisation resulted in the dementia directorate emerging from a previously generic older people's directorate. At this time my role as practice development nurse moved from an older adult focus to a Trust Wide remit. During this change,

three other senior nursing posts were lost and a newly appointed assistant clinical director took on a lead nurse role.

Table 4 1: Timeline of the impact of organisational changes on the life story work research

Year	Event	Impact on Dementia Directorate / Research
2005		Older Adult Directorate existed and my role as Practice Development Nurse located within older adults
2006	Development of research proposal.	My role working with ward and developing research proposal as agreed part of work remit
	Trust Leadership Review	Older Adult Directorate split, some jobs changed and managers had to apply for new jobs in either the Dementia Directorate or FMI and Community. Practice development nurse moved out of older adults to a central Trust Wide remit. New Leadership structure for Dementia Directorate
2007	Research Governance permissions received	On gaining research governance I had to re-negotiate with new set of managers and gain permission for entry to field.
	Dementia Service Reconfiguration	My role moved into audit department The ward where pilot Cs commenced closed earlier than had been anticipated; staff and patients moved to different wards. Some staff felt the process had been poorly managed and there was some resentment. Cs1 commenced on ward where patient moved to Cs2 commenced on ward where staff moved to New 'model of care' 'Newcastle Model' introduced to Cs2, LSW seen as complementary to this.
2008	Trust Gained Foundation Trust Status	No impact on research
	Two existing dementia wards closed and patients and staff moved to new purpose built ward. New community rapid response teams developed.	Follow up of Cs1 on new ward New role as Senior Nurse with Focus on Service Users and Carers

A year later the dementia directorate underwent a re-configuration and consequently three in-patient wards went through a planned process of closure, a new ward was commissioned and resources were invested in a new community service aimed at reducing hospital admissions by supporting people with dementia in crisis and their families in their own home. The dementia directorate now comprises; two specialist community services; an intermediate general hospital

based team; an assessment ward; an intermediate care ward; two memory clinics; four social care resource centres offering day care and short term respite care; and the directorate provides the staff for two nursing homes owned by local housing associations.

4.3 Negotiating access to the case-study sites and participants

Gaining access to the research field was a gradual process that took place over many months and was both helped and hindered by my 'semi insider' role in the organisation. Hellstrom *et al.* (2007) and Sherratt *et al.* (2007) describe 'several layers' of gatekeepers who have to be negotiated in order to access older people with dementia for research; examples include: practitioners, managers, research ethics committees and carers. Overprotective gatekeepers may deny older people with dementia the right to decide whether to participate in research and recruiting participants may be dependant on how the gatekeeper perceives the research, the type of relationship they have with potential participants and their personal judgement about who should be involved (Bartlett and Martin 2002). Access to commence the research was negotiated with key managers and practitioners within the dementia directorate and was largely welcomed with little need to consider the 'gatekeeper challenge', this was achieved through presenting to the directorate 'planning and practice development group' and positive face-to-face meetings that were detailed in my research diary and through frequent e-mail communication.

In the time it took from agreeing the LSW research proposal and receiving research governance the previously described 'leadership review' took place; consequently before recruitment could commence I had to communicate with newly appointed managers who were largely unaware of my research and I was no longer employed exclusively to work within dementia services. The need to adapt to changing circumstances is well documented within the domain of 'real world' research (Robson 2002; Payne *et al.* 2007). I re-negotiated access through a face-to-face meeting with the newly appointed clinical director and was able to recruit a service manager onto the research reference group.

Within case study research it is important to describe in some detail the context of the case studies so that readers can assess the relevance of the findings for their own areas of work (Yin 2009). Table 4.2 describes the context of the four case study sites.

Table 4.2: Description of case study site context

Case Study	Description of Context
1	A 24 bedded assessment ward for people with dementia living in the North of the City; was due to close within 6 months due to service reconfiguration. Recent changes of staff with some patients being admitted with 'challenging needs' who had previously been cared for on another ward. The ward was moving from a task orientated culture to one embracing a person-centred approach.
2	A 24 bedded assessment ward for people with dementia living in the South of the City; was due to close within 6 months due to service reconfiguration. Recent changes of staff with some patients being admitted with 'challenging needs' who had previously been cared for on another ward.
3	A 24 bedded intermediate care ward for people with dementia from across the City who had been physically unwell and were well enough for discharge from a medical ward but were not ready to go home. The ward was staffed by an established multi-professional team of staff.
4	A day centre offering care for people with dementia in the South East of the city. Staffed by joint health and social care experienced staff and supported by volunteers. The centre had a reputation for strong leadership and an emphasis on person-centred care for people with dementia and their family carers.

The next section focuses on the challenges of gaining consent and the process of actively involving all eligible participants.

4.4 Challenges in actively involving person with dementia

An important aspect of the LSW research was the active involvement of all participants in the research process but as Chapter Three highlights, there are particular challenges in involving people with dementia. This section details the processes that were followed and the associated learning that took place for me.

A diagnosis of dementia does not necessarily indicate incapacity to give consent to be involved in research; capacity to consent is largely situational (Dewing 2007)

and dependant on the complexity of the decision to be made. This view is reinforced by the Mental Capacity Act. As dementia progresses, however, it is accepted that abilities of comprehension, making judgements, reasoning, communicating and remembering may become increasingly impaired (Hubbard *et al.* 2002) and thereby capacity to informed consent may be affected and it is at this stage that proxy consent is commonly employed.

Proxy consent is based on the belief that the proxy, most often a relative or close carer, knew the person before they developed dementia and will base the decision on their best interests, taking into consideration past desires and values. Communication with carers of people with dementia during the development of the LSW research proposal, demonstrated that they are often surprised at the everyday choices their relatives make compared to the past, so it is difficult to ensure that other values and preferences remain the same with the experience of dementia (McKeown *et al.* 2010a). A number of studies have highlighted the potential conflict that can exist between people with dementia and their proxies when consenting to research (Buchanan and Brock 1990; Sachs *et al.* 1994; Stocking *et al.* 2006). A further concern regarding the use of a proxy is that the person with dementia becomes excluded from the process as the attention is on the researcher and proxy responsibilities (Dewing 2002) so disempowering a person who has made their own decisions throughout life.

Much research with people with dementia tends to use an extension to traditional competency based informed consent methods or rely on proxy consent (Dewing 2008b). A 'one-off' act of attaining consent is inadequate for people with dementia (Dewing 2002; Hubbard *et al.* 2003); this is particularly relevant within qualitative research where consent is rarely viewed as a single event but a continual, ongoing process between the researcher and participant (Kayser-Jones and Koeing 1994; Reid *et al.* 2001). McCormack (2003a) and Dewing (2007) believe researchers need to present a range of alternative approaches to ethics committees and consent must move towards methods that fully engage the person lacking in capacity in the research process. Terms used to describe ongoing processes towards consent include: process consent (Usher and Arthur 1998; Reid *et al.*

2001; Dewing 2007, 2002); ongoing negotiated consent (Crossan and McColgan 1999) and narrative based approach to consent (McCormack 2002).

Dewing (2007) proposes a model where consent is seen as a process running through the whole research project, incorporating the key characteristics of process consent models and considers: background and preparation; establishing the basis for consent; initial consent; ongoing consent monitoring and feedback and support. Table 4.3 summarises the key tasks and processes in each stage.

Table 4.3: Dewing's (2007) process consent framework

Stage	What is involved
Preparation and Background	Gaining 'permission' from gatekeepers to access the person. Finding out about the persons' biography and indicators of wellbeing
Establishing basis for consent	Understanding the person's capacity to consent. Establishing usual ways of expressing consent and signs of well being and ill being
Initial Consent	Considering consent and assent Using a range of written and visual prompts/information to enhance understanding Maintaining extensive notes as evidence to account for methods/decision
Ongoing Consent Monitoring	Revisiting consent on each research encounter with the person and responding accordingly
Feedback and Support	Providing feedback to care staff/ family carers following research encounter (respecting confidentiality of person with dementia) Assisting the person's transition from research encounter back into care environment Identifying issues to take to lead investigator/research supervisor

This model appeared highly relevant to the LSW research for two reasons. Firstly, it provided a structured framework which was attractive to a novice researcher; secondly, it provided an opportunity to assess the LSW research design against an established model of process consent.

The next section explores how Dewing's model of process consent (Dewing 2007) was employed to maximise the active involvement of people with dementia within the LSW research, this was published in a peer reviewed journal (see McKeown *et*

al. 2010a). Process consent, as I will demonstrate, is also relevant to assess the active and ethical involvement of the care staff participants and case study sites.

4.5 Actively involving participants with dementia in the life story work research

An important element of Dewing's method (Dewing 2007) is to discover something about the person's biography and, in particular, develop an awareness of signs of wellbeing so that the researcher can then assess this in research interactions. For some studies this may prove a challenge for the researcher, however in the LSW research understanding biography and wellbeing were integral to the project, which was based on listening to the individual's life story. A well-being profile (Bradford Dementia Group 2001) was used as part of the data collection and its use required discussions with care staff, allowing me to find out about the person with dementia's usual state of wellbeing. I met all the people with dementia prior to their involvement and all volunteered information about some aspect of their life story. This information enabled communication with the person and highlighted significant people in their life. In view of the research topic additional questions were asked of the person with dementia to further improve the likelihood that the person with dementia may wish to participate; these were:

- Has the person been someone happy to talk about their life to others?
- Have there been any past indications of distressing or unpleasant memories the person may prefer not to relive?
- Do you think the person would have liked care staff to know more about their life to assist in their care?
- Is the person someone who was happy to share their views and opinions with others if given the opportunity?

It is important for researchers to understand the usual ways the person would communicate consent or non-consent and be able to support any decisions made with detailed notes (Dewing 2007). Pre-meetings may be helpful to get to know the person and to assess their abilities. Participants with dementia in the LSW research were seen alone if they were comfortable with this and if they had some

understanding of what was being asked. Timing was particularly important; in the case of one participant who had very few 'good days' where he was able to communicate; the researcher needed to be able to seize the opportunity to meet with him on a 'good day'. This was made more possible by my role in the organisation and may be something more difficult for an 'outsider' researcher to achieve.

A deliberately flexible approach was taken to describe the project to the person with dementia. In her study with people with dementia Cowdell (2008:32) explained: *'trying to find the right words without being patronising was challenging'*. My experience of working with people who have dementia allowed me to adapt the way information was provided to each person and assess their response to that information. In the absence of relatives, the Mental Capacity Act offers guidance to help ensure people with dementia are not exploited or railroaded into participation. Cowdell (2008) discusses the importance of maintaining an audit trail explaining what decisions have been made and the actions taken. Detailed field notes were made in the LSW research about interactions with participants and their family and were discussed in supervision (see example of notes from research diary in Appendix 23). Conversations with care staff helped to establish whether the person was assenting to participation. All of the people with dementia were recruited before the enactment of the Mental Capacity Act and in all cases their relatives were asked to agree for them to take part and sign an agreement form (see Appendix 11c), however where possible the person with dementia was also asked to sign their own 'consent form'. Since the enactment of the Mental Capacity Act relatives are asked to act as a 'consultee' and although I prepared new information sheets and consent forms no new participants with dementia were recruited.

Providing relevant information in a way that is understandable to the person is important in facilitating their decision whether or not to consent to the research. This can be challenging as research ethics committees often require adherence to a specified framework, with standard information sheets that may not always be accessible for people with dementia or their relatives. One relative became

overwhelmed with the information sheets which had followed a template required by the ethics committee. She clearly stated that she was happy for her husband's participation (and it was clear he was assenting); however, she thought that it was 'too much' for her to get involved and did not wish to sign anything. With hindsight, a range of more illustrative information sheets may have helped but the best tool was skilled face to face communication. Dewing (2007) emphasises the importance for the researcher employing process consent to have the ability to engage in critical reflection while also having the skills to interact with the person with dementia.

Fundamental to process consent is the need to continually assess the person's choice to continue in the research and such approaches to consent rely on the researcher's conscience in ensuring that the person is consenting to continue with each research encounter (Reid *et al.* 2001). In the LSW research, consent was continually assessed for both the practice and the research aspect of the work. One person could clearly articulate his desire to remain involved by his verbal comments and enthusiasm in all interactions. Another participant was at times very angry and frustrated with any situation, be it care interventions or research. On other occasions he could express his pleasure at the same things that had previously evoked anger. Staff monitored his verbal and non verbal behaviours on a simply designed recording form following any encounter (see Appendix 17). Hellstrom *et al.* (2007) illustrate the realities of responding to the changes in consent to participation with people with dementia, describing a participant who changed their mind on a number of occasions throughout their study. This demonstrates the complexity of assessing consent in practice and research.

The morality of building up the trusting relationships required for engaging people with dementia in research, when these are ultimately going to end is questioned (Hellstrom *et al.* 2007), highlighting the process of disengagement from research with people with dementia. A number of suggestions are put forward in the literature as a way of facilitating this 'ending'. A celebratory event may mark the completion of the work McCormack (2003a) and research participation may be followed up with a 'Thank you' card which serves as a reminder of the research

encounter (McKillop and Wilkinson 2004). The approach taken in the LSW research varied depending on the amount of direct contact I had with the person and their family. My engagement with two participants and their families was relatively minimal as staff participants provided the main point of contact. When one participant subsequently died I sent her daughter a card and a letter, expressing my sadness whilst also validating their contribution to the research. I maintained some occasional contact with another participant's wife and would see her occasionally at Trust events. When her husband also died I attended the funeral and followed up contact a few weeks later with a card and letter. I developed a closer relationship with the daughter of another participant, and maintained e-mail contact with her beyond the research ending.

The process consent approach was consistent with the LSW research design and methods. Furthermore, my role as researcher/practitioner enabled the continual assessment of consent and active involvement of people with dementia in the research; either through my own actions and observations or through those of the care staff with whom I worked closely.

4.6 Process consent applied to care staff and case study settings

Equally important in the LSW study was consent monitoring with the ward areas and the staff where the research was occurring. The organisational re-structure previously described not only had implications for my research design, but perhaps more importantly had implications for staff, patients and family carers. McCormack (2003a) believes that those not directly involved in the actual research, for example all patients, ward staff and visitors, must still feel involved. In one ward area, a staff nurse acted as the '*principal liaison person*' (Payne *et al.* 2007:241) and kept others up-to-date with information and facilitating access, this was not always possible to replicate as successfully in other areas. Care staff participants were kept involved and updated on the progress of the research by face-to-face contact, telephone and e-mail.

Care staff were able to consent or decline to take part in the study and when the research ended some staff requested testimonies of their participation for their

professional development portfolios whilst others reported to have enjoyed the involvement and to have learned from it, highlighting reciprocity. McCormack (2003a:185) uses examples of the offer of clinical supervision, seminars and supporting action from findings as possible '*pay back*' to participants.'

At times, difficult circumstances, such as an unexpected death or high clinical activity meant the LSW research was temporarily put on hold and I negotiated an appropriate time to restart. Sometimes planned visits were cancelled at the last minute; it would have been easy to express irritation, but was more important to understand the reasons why and re-arrange another visit. This helped maintain relationships with staff and maintaining the research, albeit at a much slower pace than anticipated and is consistent with McCormack's belief that researchers undertaking person-centred research need to be: '*sensitive to the practice setting and the variety of unpredictable challenges that may arise.*' (McCormack 2003a:185). This responsive style was possible within the constructivist research approach used within the LSW research. Additionally it enabled me to remain true with my own values and preferred way of working and this may have been more difficult to achieve had a more rigid design been chosen.

I would argue that the principles of the process consent framework presented by Dewing (2007) can equally be applied to care staff and care settings to enable an ethical and sensitive approach to research in complex organisational environments.

4.9 Conclusion

This chapter has explored in detail the context in which the LSW research was undertaken. The chapter has reported how access to the field was negotiated and how participants were recruited and where possible actively involved throughout the research process. The utility of process consent framework has been demonstrated not only for use with people with dementia but also with care staff and case study site.

The next chapter will introduce the participants and the individual case studies and provide an overview and introduction the LSW research findings.

CHAPTER FIVE

AN INTRODUCTION TO THE PARTICIPANTS AND AN OVERVIEW OF THE FINDINGS

5.1 Introduction

The previous four chapters have outlined the background to the LSW research. A rationale has been provided for both undertaking the study and the choice of methodology. The challenges in entering the field have been explored and the approach taken to overcome these has been explained. This chapter provides a link between the preparatory work for the study and the findings. I will begin by introducing the participants before providing an overview of each of the case studies. The chapter presents an overview of the research findings for each case study and demonstrates how the findings emerged from the thematic framework and how these inform the findings chapters.

5.2 Introducing the participants

This section introduces the individual participants and case studies and provides background information in order to appreciate the characteristics to each case (see Table 5.1).

Table 5.1: Summary of each case study

Cs	Person and age	Diagnosis and Length of Diagnosis	Life Story 'Product'	Care Setting	Duration of Cs
1	Male George 87	Vascular Dementia 4 Years	Life story book	Assessment Ward	23 months
2	Male Harry 80	Dementia with Lewy Bodies 1 Year	Pen picture	Assessment Ward	21 months
3	Female Rachel 88	Alzheimer's Disease 4 months	Life story book	Intermediate Care Ward	13 months
4	Female Eileen 83	Alzheimer's Disease 5 Years	Life story book	Day Centre / Group	10 months

Table 5.1 presents a summary of each person with dementia at the centre of each case study, (a pseudonym has been used to protect their anonymity and confidentiality). The table displays the details of their age, diagnosis, the type of life story product that was completed for each person, the type of care environment and the duration of each case study.

Table 5.2 details all of the participants in each of the case studies. The LSW research data will be referred to by the pseudonym given to the person with dementia. The other participants will be referred to by the case study number and the title indicated in the table below, for example Cs2 RMNb will refer to the male staff nurse participant in case study 2. This key will be a useful reference point when considering the four subsequent findings chapters.

Table 5.2: Key to participants

Case Study	Person with Dementia	Other Participants	How they will be referred to
1	George	RMN deputy ward manager Wife Support worker Occupational therapy assistant	Deputy manager George's wife Support worker OT assistant
2	Harry	Female RMN who subsequently left the study Male RMN Female newly qualified RMN RGN from nursing home	RMNa RMNb RMNc Nursing home RGN
3	Rachel	OT Assistant Daughter Support Worker Care assistant from nursing home	OT assistant Rachel's daughter Support worker Nursing home care assistant
4	Eileen	RMN Nurse manager Daughter Student nurse Outreach worker in social care facility.	Nurse manager Eileen's daughter Student nurse Outreach worker

5.3 Profile of the case studies

By way of a more comprehensive introduction, the key participants (cases), their social situation and their service use are summarised for each case study. These accounts provide additional detail on how the person with dementia was chosen to participate, the roles each of the participants assumed, how the life story work was

collated and what each product comprised of. The details of the methods of data collection for each case study are reported.

Figure 5.1: Case study One

Case One - George

George is an 80 year old man who participated with his (second) wife of 17 years. George has a son and daughter who were not involved in the research. At the time of the research George resided on an assessment ward for people with dementia.

Staff on the ward suggested that George get involved as they felt it might help them to understand him better. The staff who were involved in the LSW included: the deputy manager who was a RMN and assumed a link role with me and a co-ordinating role; an OT assistant; and a support worker whom his wife had requested be involved in the research; both worked closely with George's wife in gathering the life story information and collating it into a life story book.

A life story book was presented in a photograph album, it contained: photographs from when George worked in the mines, certificates, some photos of his family, a testimony from his step daughter, a story from one of his Grandchild's school projects and more recent photographs of his garden and hobbies. At the front was a pen picture summary of his life with clip art illustrations.

Interviews were conducted before and after the project with the deputy manager and wife. Interviews were conducted with the OT assistant and support worker after the project. Notes were maintained from observations and visits to the ward including a follow up meeting with the wife 6 months after the project had been completed. Observation forms were completed by the wife or staff when the book was used with George. Copies of care plans before and after the project were taken.

Figure 5.2: Case study Two

Case Two - Harry

Harry is an 80 year old man. Harry's wife chose not to be involved in the research due to other commitments but was supportive of Harry's participation, he had no other family. At the time of the research Harry resided on an assessment ward for people with dementia and subsequently moved to a nursing home.

Staff chose Harry to participate as they felt he had an interesting life and they wanted to understand him better. The staff who were involved in the LSW included: a female staff nurse who withdrew from the research after the first interview for personal reasons; a male staff who had suggested Harry become involved, he undertook LSW with Harry in a spontaneous and ad-hoc manner, he provided an initial link between me and the ward and encouraged other staff to get involved ; a newly qualified female staff nurse who was on preceptorship part time and working as a support worker part time, she undertook planned work with Harry resulting in the writing of a pen picture; and a nurse who was an RGN in the nursing home Harry moved.

The pen picture was a two sided A4 sheet with the details of his life chronologically typed in a narrative; there was a paragraph at the end describing Harry as he was known on the ward by staff. The pen picture was printed on a background picture of a canal barge as this was relevant to Harry's interests.

Interviews were conducted before and after the project with two staff nurses and before the project with a staff nurse who subsequently withdrew from the research. Notes were maintained from observations and visits to the ward including the visit to Harry in his nursing home. Notes were kept from a visit to an RGN in the home Harry moved to.

Figure 5.3: Case study Three

Case Three - Rachel

Rachel is an 88 year old woman who participated with her daughter who lives away but visits regularly. Rachel has a step son and daughter who live locally but did not take part in the LSW. At the time of the research Rachel resided on an intermediate care ward for people who have dementia and she subsequently moved to a nursing home.

Occupational therapy staff suggested that Rachel might be involved as they noticed she seemed to enjoy talking about her life. Staff who participated in the LSW included: an occupational therapy assistant who was the main link with me, she undertook the LSW with Rachel; a support worker who was chosen as a potential 'sceptic' and someone not be afraid to be honest about her views whose main role was to comment on how LSW was received by the ward; and a care worker in the nursing home Rachel moved to.

A life story book was produced, this was a scrap book with photographs that had been scanned and cut out and stuck in by the OT assistant and Rachel. Rachel had said what each photo was and the OT assistant typed this up. Rachel chose the cover from a selection of papers and materials the OT assistant had offered to her.

Interviews were conducted before and after the project with the OT assistant, support worker and daughter. Notes were maintained from observations and visits to the ward including meetings, with all participants to share the book and from a discussion with a care worker at to the nursing home where Rachel eventually moved to.

Figure 5.4: Case study Four.

Case Four - Eileen

Eileen is an 83 year old woman who participated with her daughter. Eileen lived at home alone and at the time of the research she attended a health and social care day centre for people with dementia, as well as occasionally having respite at a social care resource centre.

Staff suggested that Eileen participate as they thought it was something she would enjoy and that she would like to have a life story book. Staff who participated included: the day centre manager who was an RMN and my main link and supervised the student nurse; a second year student RMN who undertook the LSW with Eileen and an outreach worker at the social care centre where Rose attends for day care and respite.

A life story book was produced, this was a folder with plastic inserts; the photographs were scanned into a computer and printed on A4 sheets with some explanation typed under each photograph.

Interviews were conducted before and after the project with the nurse manager, after the project with Eileen's daughter, before the project with the student nurse and then e-mail communication was made after as she had finished her placement (although the project was well underway at the time of the initial interview). Notes were kept from observations and visits to the day centre including a meeting with Eileen to share the book and a discussion with the outreach worker at the social care day centred Eileen attended.

5.4 Overview of the findings

Chapter Three details the development of the thematic framework and Appendix 19 presents a visual representation of these developments. The thematic framework can be traced back to the early understandings of LSW that emerged from my clinical practice. The review of the LSW literature (McKeown *et al.* 2006) extended my understanding of LSW and revealed some common emergent themes and these were considered in the development of the LSW research protocol. The pilot study data and the development work informed the initial thematic framework, which was refined through the process of applying data from the case studies. The final thematic framework that was used to chart the LSW data is shown below in table 5.3. Tables 5.4 – 5.7 provides a summary of the findings for each case organised by the key themes of the final thematic framework. This affords an appreciation of each case in its entirety.

Table 5.3: Final thematic framework

LSW Thematic Framework 4 - September 2009	
1.0 UNDERSTANDING THE PERSON 1.1 Knowledge of life history information 1.2 Seeing the person behind the illness 1.3 Understanding the person in the present from the past 1.4 Improved empathy	2.0 COMMUNICATION 2.1 Providing prompts and trigger to conversation 2.2 Hearing the voice of the person 2.3 Making interactions easier/more possible
3.0 RELATIONSHIPS 3.1 Developing a bond 3.2 Finding common ground 3.3 Moving the person into the limelight 3.4 Changed / complex relationships	4.0 IMPACT ON CARE 4.1 A trigger for memories 4.2 Providing a resource / legacy 4.3 Providing cues for activities 4.4 Helping with assessment and care planning 4.5 Impact on mood / behaviour
5.0 THE PROCESS 5.1 The need for support and guidance 5.2 The time factor 5.3 Personal values 5.4 Culture and continuity 5.5 Involvement	6.0 ETHICAL ISSUES/DIFFICULTIES 6.1 Distressing memories 6.2 Personal disclosures 6.3 Ownership and consent 6.4 Overuse of LSW
7.0 THE EXPERIENCE OF PARTICIPATING IN LSW 7.1 Feeling proud and valued 7.2 Emotional aspects 7.3 Learning something new 7.4 Enjoyment and pleasure 7.5 Suggested improvements	

Table 5.4: Case Study One Overview of Findings

Case Study One Findings	
Understanding the person	Staff already knew quite a lot of information about George but all felt the work added more depth to their knowledge. His wife especially felt this was helpful for new staff. Staff were able to get glimpses of the person behind the illness and see more of George the funny, loving, family man and understand he had not always been aggressive and resistive. His wife was reminded of good memories; something she had been forgetting. The OT assistant felt sad and could appreciate what George had lost through developing dementia.
Communication	The use of the life story book allowed George to interact more both verbally and non-verbally. He was able to name people in the photographs, respond to the questions of who were in the photographs; he was seen to express emotions and took control in turning the pages of the book. His wife and the staff all described a lovely afternoon sharing his book and observation sheets detailed other instances of interactions when using the book. His wife described an instance where his book facilitated interaction with other patients; she seemed in tune with how he was able to communicate and show his real self through using the book through non-verbal behaviours.
Relationships	The support worker described how George called her name on the corridor; something that was unusual. Otherwise there is little evidence of changes in the relationship with George particularly when he was having a <i>'bad day'</i> and was resistive to care.
Impact on care	Staff felt there had been little benefit to George in his everyday care and suggested it had not lessened his <i>'bad days'</i> in anyway; although they vividly described the lovely afternoon they shared with him and his wife with his book and how his wife had been able to cut his hair and nails. The deputy manager spoke of the value in knowing what to talk to George about or showing him a video and she thought that combined with the new approach to care the way staff approached him was more consistent. The OT assistant thought life story books were useful if someone goes to another care setting. The initial care plan referred to <i>"his challenging behaviour"</i> and the care plan after LSW had been completed still talked of problems and apart from a small section on ideas for social interaction did not reflect George as a person. RMNb (see case study 2) described being able to assist George alone with his care needs by talking to him about life history compared to needing 2 or 3 staff which was usual. This raised the issue of manipulation; achieving an aim by using what you know of the person. RMNb thought if someone saw this as an ethical issue then the person <i>'is too far up their ethical backside!'</i>
The Process	The deputy manager took on a co-ordinating role whilst the OT assistant and support worker worked with George's wife in gathering and producing the life story book. Staff found it difficult to involve George due to his behaviour and communication difficulties and all the staff felt a little disappointed the story was more from his wife's perspective than Georges. There were some concerns on <i>'how to do life story work'</i> initially and there was some reassurance needed that they had <i>'done it right'</i> . Time was an issue but they managed to find the time and George's wife felt supported throughout and felt her ideas were listened to and acted on but the final book had been a real collaboration. The support staff appreciated the collaboration with one another. All staff felt that life story work would have <i>'worked better'</i> with a person who could have contributed more. His wife continued to update the book and use it with George.
Ethics / Difficulties	His wife was mindful that some of the photographs of things George used to enjoy may upset him and she was prepared to change photographs if needed. His wife described not wanting some photographs to go in the book as they were personal between her and George. The first time the book was used George became agitated and his wife felt they had learned to not <i>'over do it'</i> on future occasions.
Experience of All Concerned	His wife gave vivid examples of George's posture and behaviour to suggest he felt proud when using the book. For her it had been an emotional journey with a mix of sadness and happiness and she thought it similar with George by observing his reactions. I found it emotional looking though George's book. The OT assistant, support worker and wife all described the experience as enjoyable and worthwhile. Staff would like to have seen more in the book about George's wider family; the wife thought the balance was about right. Suggestions made by his wife about improving the quality of the book were acted upon.

Table 5.5: Case Study Two overview of findings

Case Study Two Findings	
Understanding the person	Superficial knowledge about Harry was turned into more in-depth knowledge. RMNb had a genuine interest in 'digging' for information. RMNc was aware that some of the life story information may not be 'true' but she appreciated it was what Harry wanted her to know. The pen picture did not enable the nursing home nurse to gain new information. RMNs b and c were able to see Harry beyond his dementia and also how his life had made him the person he is today. RMNb in particular was able to appreciate how being a soldier in Palestine had made Harry the person he was and understand and identify with his core beliefs and values. RMNc showed an understanding of the impact Harry's stroke had on his life.
Communication	Information could be used as a topic for conversation or to get Harry to expand on a subject. The time given to listen to Harry's story allowed him to speak about his life, whereas he was usually a quiet man, other staff not involved in the LSW would not have heard what he had to say which RMNc felt was a shame. He received more individual time and RMNb and Harry found shared topics of conversation. The nursing home did not use the pen picture to talk to Harry.
Relationships	Both RMNs b and c felt a bond was formed and that Harry was more likely to seek them out over other staff, there was something satisfying about that; standing out from other nurses, being a confidant, a friend. RMNb found shared interests and thought you needed to share of yourself; they had interactions that were exclusive ' <i>something between me and him</i> '. RMNb was challenged by Harry when he had to break a promise about going out because of staffing; he felt he had let Harry down and made arrangements for the outing to go ahead which he felt was important to maintain relationship, RMNb felt he was tested by Harry and felt their relationship was more equal.
Impact on care	Evidence that interventions in terms of time spent and talks about interests gave Harry more 1:1 time; the well-being scale before the research showed that he had been lacking in activities and was bored. Shared interests and experiences were discovered between RMNb and Harry. RMNc felt LSW gave her <i>permission</i> to spend 1:1 time. RMNc used her knowledge of his life story to distract Harry if he was getting into arguments with other patients.
The Process	The structure provided for gathering life story information was valued by RMNc; I acted in supervisory capacity in view of RMNc's lone working and the ethical issues that arose. Knowing that I was visiting motivated / put pressure on RMNc to progress the work. Time to undertake the work was an issue and there were competing priorities for RMNs, LSW was achieved by taking planned approach and getting management support. RMNb felt a spontaneous approach to LSW was more achievable for ward areas. RMNa described how tasks were seen as a priority, LSW gave ' <i>permission</i> ' to spend time talking with the person; staff sickness and staff attitude were potential barriers. RMNb thought the ' <i>end result</i> ' such as a book was not important and thought that people might not read a book; he saw the process and the individual interaction more important. The nursing home did not make use of the pen picture due to Harry's ' <i>confusion</i> '. Harry validated the content of the pen picture but was not involved in its development, although provided all the information. His wishes of where it be kept were disregarded in the nursing home.
Ethics / Difficulties	Some sadness was expressed by Harry comparing how he was to how he is now; but RMNb feels there is more to be gained by using life story work than is lost and that upset should not stop LSW being undertaken. Harry made some intimate disclosures to RMNc about his life, this had to be managed and his story was edited to protect him and his wife. Harry described feeling he might be judged. RMNb learned about some of Harry's core beliefs and values. Although Harry consented to sharing his story cannot be sure he understood full implications of use of information. The pen picture was not used with him when he moved to nursing home.
Experience of All Concerned	Harry seemed proud of his pen picture and wants <i>10,000 copies</i> ; however remembering his life also evoked emotions. RMNb seemed to value the enhanced relationships and how he could influence care through the relationship. RMNc learned new things from Harry about the past; facts about the war, what wages were, how early TVs worked. All participants seemed to enjoy being involved and Harry seemed to like the pen picture.

Table 5.6: Case Study Three overview of findings

Case Study Three Findings	
Understanding the person	As Rachel had recently been admitted there was initially not a lot known about her personal history, through LSW, new details were learned and valued by staff. Rachel herself was reminded about things she had done with her life. There was some evidence that she was seen beyond the dementia but sometimes her anxiety made that difficult all the time. There was not evidence of staff understanding her in the context of her whole life and although I believe staff did understand her more there was not evidence of greatly linking her past with the present.
Communication	The life story information was used to help focus the conversation; it was used during care activities such as assisting Rachel to get dressed and was a way to stimulate conversation. This was particularly useful when distracting her from the repetition and anxiety and need for reassurance. There was good description of how the use of the book had helped stimulate conversation with other service users and staff both on the ward and then in the nursing home. The support worker describes talking around common interests.
Relationships	The OT assistant noted that Rachel recognised her as the person that worked with her on her life story; she could not always remember her name but knew she knew her. The OT assistant felt trust had been built between them. It was similar when I visited. Friendships and bonds seemed to develop with other service users though sharing the book.
Impact on care	The daughter thought the life story book was good for plumbing the depths of the mind and it helped to stimulate memories for Rachel. The OT assistant particularly valued the fact she had helped Rachel make something tangible that could go with her when she moved and the support worker thought if anything happened to Rachel in the future her family would value the book. The book was valued by the nursing home staff and it helped them to develop Rachel's care plan. Knowing about past interests helped plan for activities such as knitting and sewing and the book was also used as an activity to share with her daughter when she visited. The support worker used the information to talk to Rachel when getting her up and she also started to do this with other service users she cared for. Talking about the past helped distract Rachel from feeling anxious and she was observed to look more relaxed and happy; the OT assistant thought it raised Rachel's self esteem as it challenged her negative view of herself.
The Process	The support worker valued a workshop she attended on using life story work and felt it had helped her to value the approach over other staff who had not attended. The OT assistant was relatively self sufficient in undertaking the life story work approach and although she found it difficult to find the time but she managed to make the work a priority with the support of her manager. The support worker felt she could not have given the same amount of time. Initially Rachel's daughter felt the work may not be relevant as her Mum had dementia; as the work progressed she felt she had learned things about dementia and how to respond to her Mum from watching me interact with her Mum. Rachel felt she was not interesting and her life was not interesting - LSW challenged this. The support worker used the approach with another service user and felt everyone should have a book but she did not think there would be the time to make them. Rachel was involved with the whole process; the daughter contributed parts of the story and photographs but felt these contributions were not fully used and she may make her own book.
Ethics / Difficulties	None noted, the family were open and honest and described having 'no skeletons'. My awareness of over- using the life story book and potentially tiring the person.
Experience of All Concerned	Many of examples given from the OT assistant and support worker and my own observations of Rachel appearing proud. No evidence of it being emotional. The daughter felt upset when I left, I too felt sad as we had developed a relationship and I had been a support through a difficult time, we maintained e-mail contact. The support worker seemed to learn new ways of interacting with service users and everyone enjoyed the approach. There were spelling and grammar errors in the life story book, I noted in my diary, Rachel and her daughter commented on them when I met them in the nursing home, as did the carer there. The daughter later e-mailed me saying grammar and spelling were important to her Mum and they had since made corrections to the book.

Table 5.7: Case Study Four overview of findings

Case Study Four Findings	
Understanding the person	Although staff already knew a lot about Eileen they learned much more depth and could begin to understand the person she is today through understanding what she has been though in her life, the photographs were seen as powerful in this. Eileen's daughter would have liked the staff to have met her Mum before she had dementia to really see what she was like. The nurse manager demonstrated true empathy and respect for Eileen.
Communication	The book and the photographs provided a trigger to conversation and gave staff something to talk to Eileen about. The nurse manager felt it helped Eileen, a quiet person, to move into the limelight and provided more opportunities for her voice to be heard. It allows Eileen to take more of a lead in conversations. The student nurse found that photographs provided prompts for conversations. The nurse manager noticed that volunteers, who had previously taken less notice of Eileen as she was quiet, were more interested in spending time with her.
Relationships	The nurse manager already had a good relationship with Eileen and her daughter, this was confirmed by her daughter, but the life story book helped to strengthen the relationship between Eileen and other students and volunteers, though them getting to know her better as a person. The nurse manager believes to develop a relationship you need to share something of your own life and by being privileged to information about the person it makes the relationship more equal.
Impact on care	The photos in the book remind Eileen of the things she did in her life and her family, they also provide memories of family members who have died. Having the book, something physical, was seen as being important when Eileen moves between care settings. The book is used in a group setting with other service users and staff. The outreach worker gave an example where he used the knowledge of another person's life history in order to distract him and encourage him to have a bath. The student nurse felt Eileen's mood could change for the better by looking at the book.
The Process	The student nurse identified finding the time to undertake the LSW as a pressure with working part time and being on placement. The nurse manager believes time difficulties can be challenged by breaking the process down into gathering small pieces of life story information and acting on them; she was passionate about life story work and believed it was 'magical' and essential for working with people with dementia. She also thought an end result such as a life story book was important to broaden out the knowledge of the person to the wider team. The nurse manager was also very reflective and thoughtful and not afraid of having her beliefs about the abilities of people with dementia to be challenged. The outreach worker at the respite centre had a personal interest in finding out about life history in his own family and with the people he cared for. The nurse manager could see why busy wards might struggle to use life story work due to staffing levels and the way they are managed, she herself had a person centred and 'can do' attitude that meant LSW was used. She also believed the photographs were particularly important for continuity within and beyond the care setting. Eileen was fully involved in the development and use of the book.
Ethics / Difficulties	The nurse manager was mindful that other service users may become distressed if Eileen shared some of her sad memories with them, but this did not occur in reality. The nurse manager felt that personal disclosures occur when the person feels they trust and have a relationship with the worker. Eileen decided what went into her book but the daughter would have liked some extra photos. There is potential for the book to be overused with the person and tire them.
Experience of All Concerned	Eileen was proud and pleased to have been asked to participate and her daughter was proud of how her Mum has lived her life. The process did not appear overly emotional for anyone. The nurse manager felt her views on Eileen and people with dementia were challenged throughout the process. The student nurse learned about life story work and also had her beliefs about dementia challenged and she understood more about what it would have been like bringing up children with learning disabilities, I also learned that. Everyone enjoyed the work. Eileen and her daughter noticed spelling mistakes and commented on them. On looking back the student nurse would have been more creative in developing the life story book and Eileen's daughter would like to have seen some more photographs in. Eileen liked having the photos of her life all together in one book.

The data from all the case studies were applied to the thematic framework and Table 5.8 displays the key emergent themes.

Table 5.8 Themes emerging when data applied to thematic framework

Final Themes and Sub Themes
<p>1.0 UNDERSTANDING THE PERSON Depths of knowledge gained <ul style="list-style-type: none"> • Seeing person beyond the patient / Seeing person beyond behaviour • Glimpsing values / beliefs of person Continuity /Discontinuity <ul style="list-style-type: none"> • Person in context of their whole life • Noticing the person then and the person now /Sadness in what was lost </p>
<p>2.0 COMMUNICATION The value of photographs A Topic of Conversation <ul style="list-style-type: none"> • Making conversation and interactions more possible • Permission for 1: 1 time Hearing the voice of the person <ul style="list-style-type: none"> • Literally and Non verbally </p>
<p>3.0 RELATIONSHIPS Development of bonds between patients and staff More equal / authentic relationship <ul style="list-style-type: none"> • Changes in power – staff sharing of selves • Staff learning from patient • Facing challenges Use of relationship to achieve care aims</p>
<p>4.0 IMPACT ON CARE Recall of memories and benefits of that for person and for family Potential for use in transition /Potential legacy Care planning Permission to spend 1:1 Time – links with process/culture Benefits to care/person <ul style="list-style-type: none"> • Staff if helps achieve a care aim • Personal on the spot benefits to person's self esteem </p>
<p>5.0 THE PROCESS What helps and what hinders the use of LSW? <ul style="list-style-type: none"> • Different levels of support – or same level organised in different way • Competing priorities • Contradictions • Organisational / Cultural v Personal Process v Product <ul style="list-style-type: none"> • Different roles of each Ways in which people were involved; Collaboration</p>
<p>6.0 ETHICS Distress and Personal disclosures <ul style="list-style-type: none"> • Understanding and consent of what is taking place Whose story is it? <ul style="list-style-type: none"> • Big theme – person / family • Consent monitoring – good practice and issues Balance of use of the product</p>
<p>7.0 THE EXPERIENCE OF PARTICIPATING Pride and emotional for some Learning and enjoyable for all Quality of the end product Differing perceptions of who to involve and when – linked to product</p>

A further stage of analysis (see Chapter Three for details) distilled the themes (see table 5.9).

Table 5.9: Final themes and sub-themes

Final Themes and sub-themes
<p>Exploring the process of undertaking LSW: What helps and what hinders?</p> <p>6.2 The context of care</p> <p> 6.2.1 A lack of time to undertake LSW</p> <p> 6.2.2 Task over person</p> <p> 6.2.3 Care environment</p> <p>6.3 Personal attributes of care staff</p> <p>6.4 Practical factors that helped or hindered life story work</p> <p> 6.4.1 Preparing to undertake life story work</p> <p> 6.4.2 Supporting the implementation of life story work</p>
<p>From process to product: From individuals to communities.</p> <p>7.2 Process</p> <p> 7.2.1 A focus on the individuals concerned</p> <p> 7.2.2 Learning something new from the person with dementia</p> <p> 7.2.3 Challenging care staff and family carer attitudes</p> <p>7.3 From process to product</p> <p>7.4 Life story work product</p> <p> 7.4.1 A prompt for memories</p> <p> 7.4.2 Use in transitions of care and as a legacy</p> <p>7.5 Considerations of using LSW product in practice</p> <p> 7.5.1 Under and over-use</p> <p> 7.5.2 The significance of photographs</p> <p>7.5.3 Content and quality of the life story work product</p>
<p>From patient to person: Person-centred outcomes.</p> <p>8.2 Communication</p> <p> 8.2.1 A topic of conversation</p> <p> 8.2.2 A communicative community</p> <p>8.3 Relationship</p> <p> 8.3.1 Making a connection</p> <p> 8.3.2 Relationships with family carers</p> <p> 8.3.3 Using the relationship to achieve care aims</p> <p>8.4 Understanding the person</p> <p> 8.4.1 From patient to person</p> <p> 8.4.2 S/he wasn't always that type of person</p> <p> 8.4.3 Developing a more equal relationship</p> <p>8.5 Hearing the voice of the person</p> <p> 8.5.1 Can you hear me?</p> <p> 8.5.2 Embodied personhood</p> <p>8.6 Personhood upheld</p> <p> 8.6.1 Pride and enjoyment</p> <p> 8.6.2 Making their wishes known</p>
<p>Whose story is it anyway?</p> <p>9.2 Differing contributions to the life story</p> <p>9.3 Personal disclosures</p> <p>9.4 Confidentiality</p> <p>9.5 Who is the story for?</p> <p>9.6 Consent</p>

These final themes are organised in relation to the research questions and form the themes for the following four findings chapters.

- Chapter Six: Exploring the process of undertaking LSW: What helps and what hinders?
- Chapter Seven: From process to product: From individuals to communities
- Chapter Eight: From patient to person: Person-centred outcomes
- Chapter Nine: Whose story is it anyway?

5.5 Conclusion

This chapter provides a link between the first part of the thesis, that details the background, rationale and methodology to the LSW research and the second part of the thesis that presents the findings and recommendations from the LSW research. The complete findings across all of the case studies are presented in the following Chapters Six to Nine. Each chapter will commence with a presentation of the LSW data across all themes. This will then be followed in each chapter with a critical analysis of the findings from the LSW research in relation to the current evidence on life story work and person-centred care.

CHAPTER SIX

EXPLORING THE PROCESS OF TAKING A LIFE STORY WORK APPROACH: WHAT HELPS AND WHAT HINDERS?

6.1 Introduction

Figure 6.1: Chapter Six themes and sub-themes

Exploring the process of undertaking LSW: What helps and what hinders?

6.2 The context of care

6.2.1 A lack of time to undertake LSW

6.2.2 Task over person

6.2.3 Care environment

6.3 Personal attributes of care staff

6.4 Practical factors that helped or hindered life story work

6.4.1 Preparing to undertake life story work

6.4.2 Supporting the implementation of life story work

This chapter explores the issues that helped and hindered the implementation of LSW in health and social care practice, offering insights relevant for both research and for care staff considering a similar approach.

The discussion focuses on three main emergent themes and these along with the sub-themes are presented in Figure 6.1. The chapter concludes with a discussion of the conditions in which LSW can best be implemented and sustained.

6.2 The Context of care

The importance of the context of care in developing person-centred practice was explored in Chapter Two. The findings presented in this section explore the factors evident within the context of care that can both help and hinder the implementation of LSW.

6.2.1 A lack of time to undertake LSW

A consistent theme from the care staff participants in the LSW research was the challenge in finding the time to undertake LSW. In Cs2 RMNc, reported difficulty in finding time to spend with Harry gathering his life story information:

"Making time because I think it was an issue ...because I was the only one that was able to collect the information because ... there were no staff around or ... other things sort of took a bit of priority." Cs2 RMNc.

Similarly the OT assistant reported insufficient time to collate Rachel's life story book:

"The difficulties with it is just the time making sure I've just got that bit of time to ... spend with Rachel and putting it altogether really I think that's just been difficult with being so busy." Cs3 OT assistant.

In Cs3 finding the time to meet Rachel's daughter was a challenge for the OT assistant who worked part-time. The OT assistant in Cs1 described difficulties in finding time to meet with colleagues, the person with dementia and family carers due to shift patterns:

"It'd just be because [the support worker's] only working for 2 or 3 days a week while I'm here ...I don't do weekends and then if I happen to have had something on, a meeting or a training session or anything, we've just kept missing each other or there was one day when we was going to sit down and do it and it were quite busy so our priorities lie with patients." Cs1 OT assistant.

Despite the concerns that staff expressed over finding time they all managed to find ways of undertaking LSW, at least for the purposes of the research.

6.2.2 Task over person

It appeared that LSW was not generally a priority compared to other activities as can be interpreted through interview excerpts. Two RMNs in Cs2 reported the situations they faced:

"As a nurse you get so preoccupied with the running of the ward and the practicalities and the staffing issues and if you haven't got enough staff around it's easier to put these things [LSW] on the back burner than it is to put the drug round - you can't." Cs2 RMNa.

"As a qualified nurse you're pulled around and that's even if you're well staffed but if you're the only qualified then you are pulled around." Cs2 RMNb.

As the support worker in Cs3 reflects, the demands are as great for support staff as they are for registered nurses:

"It's not feasible for me to be able to sit for two hours and talk to somebody for an hour because there's always somebody that wants to go to the toilet, there's always somebody that wants a cardigan so you're always having to leave that person then by the time you've come back we've lost that." Cs3 Support worker.

This seems significant as particularly in care homes support workers spend more face-to-face time with people with dementia than the registered nurses. The deputy ward manager in Cs1 described her thoughts on the care George received and described an emphasis on physical over psychological care:

"I think he gets very good physical care... I think we've got a problem sometimes with... engaging with him for his social and mental health care." Cs1 Deputy manager.

LSW was an integral part of the care provided in Cs4 and consequently it received a high priority and the only concern over time was raised by the student nurse who wanted to complete Eileen's life story book before her learning placement at the day centre ended. In reflecting why LSW seemed easier to implement in the day centre compared to the wards the nurse manager in Cs4 was sympathetic to the difficulties and competing priorities faced by ward staff:

"It is hard work and you do have to slot time and I think if you're in in-patient services and you've arranged for a carer to come in with the photographs and they you're short staffed and you have to say "I'm sorry" I can see why that might be ... you'd rather not do that." Cs4 Nurse manager.

This observation was significant and the importance of completing LSW once it has been promised is affirmed by George's wife who described:

"They started off really with such gusto ... and then ...I didn't know whether they was going to continue with it...I'd just like to say is I'm glad it went ahead and I'm glad it got finished...I would have hated it to have been started and not finished, I think that would probably have eaten away." Cs1 Wife.

6.2.3 Care environment

The LSW research reported observations in the physical and emotional aspects of the care environment. I report in my research diary and detail in the individual case study reports (see Chapter Five) the differences in the physical care environments. Cs1 and 2 were both low ceilinged and cramped. Cs1 appeared dark and I found it difficult to navigate when I visited. Cs2 could get very hot and all the rooms were situated along one long corridor and very often patients walked up and down the corridor sometimes upset or restless. The environment was far more attractive for Cs3, with a circular lay out and light and airy with a feeling of space. Cs4 was situated an old church hall with high ceilings and one central room that was used for meeting and eating with a large table or a circle of chairs which seemed aimed at facilitating interaction between attendees. How much the environments impacted on how LSW was implemented was not possible to assess, but combined with other factors may have had an impact.

Additionally the pressures staff were under were evident particularly in Cs1 and I had doubts over whether to proceed with the research due to the high levels of clinical activity and seemingly poor staffing levels and at times low staff engagement. My diary reports the early stages of engaging with staff when George moved wards part way through the research:

“Visited ward to meet with deputy to re-establish research; when I arrived she was not there ... spoke with two other staff about attending a staff meeting: ‘Staff meeting – what staff?’ suggesting poor staffing at the moment. Was informed clinical activity was high and ward closed to admissions. Left with doubts about being able to re-establish research but also concerned over [George’s] wife who we had planned this with.” Research diary.

Cs1 and 2 were both undertaken on wards that were part of the service re-configuration described in Chapter Four. Some patients and staff had moved wards and further moves were planned as both wards were due to close. These circumstances no doubt impacted on how enthusiastic staff were to embracing new initiatives. The nurse manager from Cs4 considered that emotions could be a factor impacting on the uptake of LSW:

“I wonder if part of it is because you have to give so much of yourself to it and we already give a lot don’t we? I don’t think you

can do this book without being affected personally and perhaps that might be just too much for some people when you're already stretched to the limit and working really hard." Cs4 Nurse manager.

I summarise my frustrations in my research diary at a cancelled meeting that I had travelled across the city to attend and the respectful approach I took to maintain progress:

"After handover it was apparent the meeting was not going to take place, I felt irritated and annoyed but managed to contain it and show empathy, suggesting we need to meet to catch up and even discuss whether the work was feasible...shows how time consuming process is just as practice development job used to be, have to go with the flow, be patient, be quietly persistent." Research diary.

To summarise, the context of care where the LSW was undertaken were all very different. The value placed on completing tasks over spending time interacting with patients became evident in some environments and this may have contributed to the challenge of implementing LSW. Similarly the environment, high clinical activity and disruption due to service re-configuration may also have impacted on how care was delivered and LSW was received.

6.3 Personal attributes of care staff

The context of care did not appear to be the only factor that helped or hindered the implementation of LSW; the personal attributes of care staff emerged as significant and are explored in this next section.

LSW seemed relevant to staff who had a genuine interest in finding out more about people generally. The outreach worker who worked with Eileen had not seen her life story book but already knew a lot about her life from the conversations he had with Eileen and her daughter. He had a genuine interest in finding out about people and the past and described how he was travelling to France to retrace the steps of his Grandfather who had died in World War One. I noted in my research diary:

"For me it shows it is the type of person he is – interested in building relationships with service users and families." Research diary.

The care worker at the nursing home where Rachel moved to seemed to value the personal knowledge she gained about Rachel from her life story book. I met with her to seek her opinion of Rachel's life story book and noted my observations in my research diary:

"I felt as though I really liked the woman, she was clearly very compassionate ... examples she gave such as being moved when she played music to a non-communicative woman, who cried - noticing that and appreciating its significance; like caring for a woman who never spoke, only for her to say thank you after the carer had bathed her." Research diary.

I contrasted this with my experience of the RGN in the nursing home that Harry had moved to who had spoken so positively about LSW but then not used it with Harry due to him being 'confused'. I reflected that some staff appeared to believe that personhood persisted in the person with dementia:

"I am considering that perhaps those people who really embrace LSW believe that 'the person is still in there' and those that don't embrace it don't believe that (consciously or not)." Research diary.

The two care staff participants who seemed the most confident in undertaking LSW were the nurse manager in Cs4 and RMNb in Cs2. They shared similar personal attributes of both being over fifty years of age with a wealth of life experience and seemingly comfortable with 'who they were' as people. They both appeared confident in their work role and able to articulate their experiences of LSW (both of their research interviews following the use of LSW were the longest in duration). They did not appear to need 'permission' to undertake LSW and indeed RMNb in Cs2 in many ways was a 'maverick' and was not afraid to challenge the culture or take calculated risks, he appeared to have developed a certain amount of freedom to practice with an emphasis on the person over the task.

6.4 Practical factors that helped or hindered life story work

Getting started with undertaking LSW was a challenge for some of the participants in the case studies and despite preparation with staff, LSW did not proceed as planned.

6.4.1 Preparing to undertake life story work

When the pilot case study ended prematurely due to the ward closure I had time to reflect on the lack of progress in undertaking LSW:

"I always had an uneasy feeling of how things would get off the ground (in the LSW gathering). I had hoped that by having a common aim the team would find their own way ... I was reluctant to tell staff what to do. However I am beginning to think that is exactly what I have to do. The support worker reported 'Nothing got going', I know the OT tried to co-ordinate meeting 2 or 3 times but on each occasion other priorities got in the way. The OT started a file with a structure to it but no-one added to it - why? Just don't have the time? Ward closure no doubt had some impact. No-one took the lead or the person who did, did not really have the authority? The MDT really not used to negotiating? Just not a priority? It's like I was expecting staff to do something they were not equipped, skilled, familiar with doing." Research diary.

I discussed my role in both the research and the practice with my supervisors and concluded that I would need to employ my senior nurse role as a practice development facilitator in order for LSW to be implemented; as such I had become in effect a participant in my own research. I also became aware that I could not expect staff to have the same understanding and motivation of undertaking LSW work as I had as I reflect in my research diary:

"Seems like perhaps I need to model how to work, set up a system, allocate roles, give them [the staff] 'tasks'. It feels uncomfortable but necessary. At one point I felt a bit foolish for not knowing this and another level feels this is already something emerging from the research which will influence the next stage." Research diary.

Certain preparation was required so that the care-staff were able to commence LSW. A training session lasting one hour was offered to any staff who had not previously undertaken LSW. This comprised: an introduction to what LSW involved; a discussion on the possible benefits for people with dementia, family carers and care staff; a consideration of some of the difficulties that may arise; and information on possible LSW 'products'. Additionally, the support worker in Cs3 attended a day long workshop facilitated by me and my academic supervisor. This covered the same aspects as the hour long session, only in far more depth and the delivery of the workshop was more interactive, using a range of verbal, visual and active learning methods.

A structure of suggested topic headings for gathering LSW information was developed (see Appendix 24) and validated by the LSW reference group. There is no definitive structure recommended in the LSW literature but the themes chosen were derived from other examples and from clinical experience. The topic headings followed a lifespan approach beginning with childhood and ending in old age whilst also enquiring about current preferences and needs. A suggested structure of roles (see Appendix 25) was also developed and these were discussed with staff during subsequent training and offered as a resource if staff were unsure how to get started. The use of these materials and further reflection on the difficulties of 'getting started' were reflected in subsequent case study data. RMNc working with Harry valued the structure provided:

"I think definitely them questions you provided helped, the prompts and the different sections, I think if I didn't have them it would have stagnated for a lot longer Yeah definitely [having a structure helped] yes especially with the time constraints ...we did a section per time." Cs2 RMNc.

The deputy manager in Cs 1 described that even though information can be provided, staff still have to work out their own way to proceed with LSW:

"You try and give us as much information as you can as to what you want ... but actually getting going with something like that is quite difficult ... it's one of those things you look at as quite a big thing and where do I start? and who do I ask? where do I go to find out this information? and I think once you get going it's kind of easy and you find your way and you find your paths." Cs1 Deputy manager.

It is interesting that these difficulties were not discussed by the staff in Cs 3 and 4 and neither made use of the topic headings I had developed; both case studies had undertaken LSW before and so had awareness of what they wanted to achieve.

6.4.2 Supporting the implementation of life story work

I took on a facilitator role in the implementation of the LSW, particularly in Cs1 and 2. In the LSW research facilitation involved supporting staff to implement LSW into practice, helping them to problem solve any organisational or personal challenges, ensuring they had the necessary emotional support and supervision and motivating them when things were difficult. Appendices 8 a, b, c, d and e reflect the considerable time and activity that was involved in this process. The

deputy manager in Cs1 described that she took on a co-ordinating role but she was also aware of keeping progress maintained when I was due to visit:

"I mean in my experience it was just getting everybody together and making sure things were getting done and going 'Oh Jane's coming soon [laughs] has this been done has that been done' [laughs] really but just co-ordinating it ... when it were near time for you to come and [Laughs] 'Oh no we've not got anything yet.'"
Cs1 Deputy manager.

RMNc in Cs2 felt some pressure around my visits, feeling she was letting me down personally, even though I intended visits to be supportive and motivating:

"I felt like it stagnated a little bit at the beginning you know of actually you know I felt like I haven't done anything you know every time you came to see me I felt like 'Oh my God I'm letting her down' [laughs] 'I haven't done anything' but then all of a sudden it just sort of like came together." Cs2 RMNc.

These responses reflect the difficulties in Cs 1 and 2 with independently progressing LSW, Cs 3 and 4 appeared more self-sufficient in taking LSW forward. I felt my part in the process was in Cs3 a link between the carer and the OT assistant and I had no role in Cs 4, suggesting that the needs for support, motivation and driving the project forward were integral to the team.

Leadership and management support was important for LSW to be implemented and subsequently sustained. The nurse manager in Cs4 saw LSW as central to the work undertaken with attendees at the day centre and not only did she show commitment but she was able to facilitate the implementation of LSW. The day centre where she worked had a long history of working with a person-centred focus; there was an emphasis on partnership working with people with dementia and their carers and the necessary support in terms of supervision and learning for the paid staff and volunteers.

The OT assistant's manager in Cs3 was extremely supportive and despite time pressures enabled LSW to be integral to the OT assistants work. In Cs2 the difficulty in RMNc being able to plan time to spend with Harry was noted in my research diary:

"Issues of 'permission' to spend time; the need for validation from 'up high' ... empowerment of staff – interesting. I felt it would help

if [RMNc] asked ward manager to give her some time.” Research diary.

This diary entry reflected my observations that RMNc did not appear to feel empowered to request or take the time to spend with Harry and I had to prompt her to request this from the ward manager. This was in contrast to RMNb who, as previously described, was confident in undertaking LSW without seeking permission. Similarly Cs1 received management support for the LSW research rather than LSW *per se*, suggesting that LSW may not be sustained beyond the research project. The support worker in Cs1 had previously worked on a ward where LSW was promoted and valued but the practice subsequently ceased. She reported her insights into why this had happened:

“I think it all depends on the ward manager and ...we did it before on that same ward but then it changed ... I think it’s just the ward manager a different views and what they’re wanting.” Cs1 Support worker.

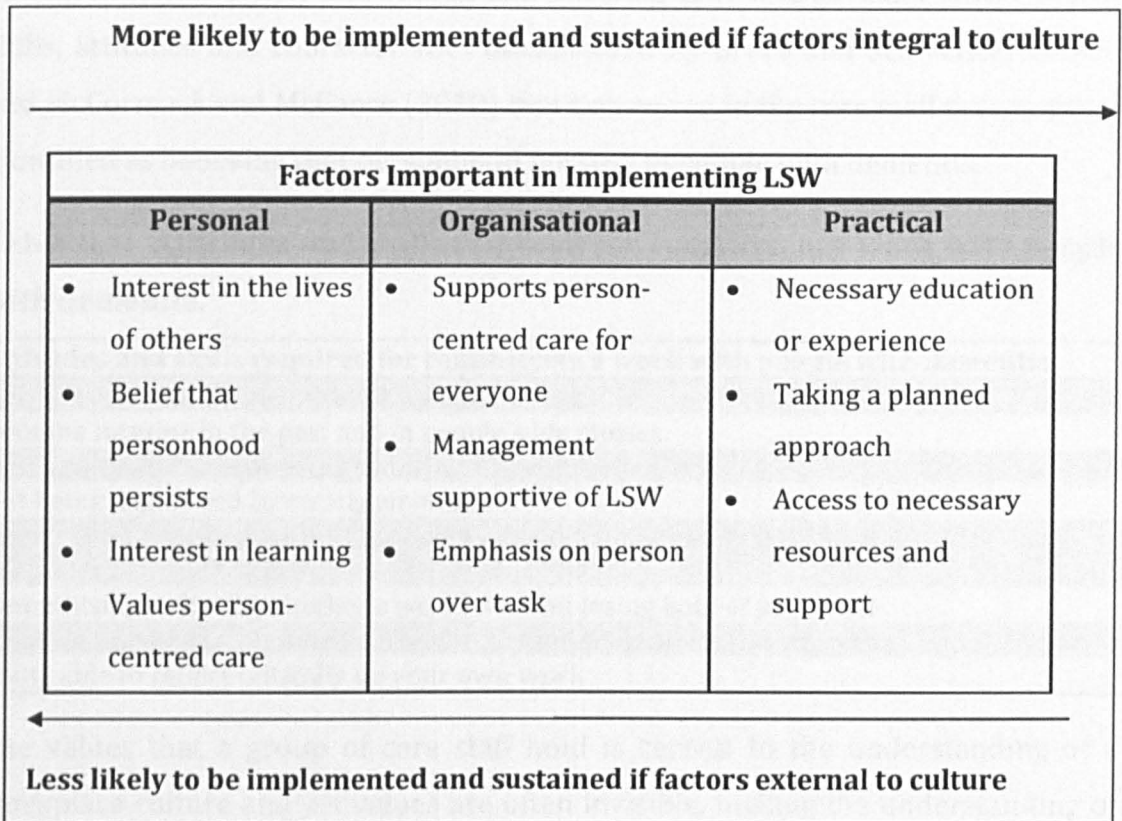
6.5 Discussion

The context of care is used to describe the care environment in the LSW research and is consistent with the definition of context offered by McCormack *et al.* (2002:96) as the: ‘*environment or setting in which people receive health-care services*’. Kitson *et al.* (1998:152) report that:

‘Context implies an understanding of the forces at work which give the physical environment a character and a feel.’

The features of context that emerged from the LSW study included the culture of care (characterised by values and beliefs at an individual, collective and organisational level), management and leadership, the physical environment and resources (educational, emotional and practical). In their work on the factors that influence the implementation of research into practice, Kitson *et al.* (1998) identify context as comprising three elements of leadership, culture and measurement. Whilst there is some merit in these elements I found it meaningful to explain the findings from the LSW research in terms of personal, organisational and practical components of context. Figure 6.2 summarises the findings from this chapter and discussed in relation to existing research.

Figure 6.2 Summary of findings from Chapter Six



The personal attributes of care staff appeared significant in the way in which life story work was embraced and sustained. The findings highlight that some care staff demonstrate a genuine interest in the lives of other people and embraced the use of life story work. I questioned whether some staff were more able than others to recognise that personhood persists in people, even those with more advanced dementia. In discussing person-centred care, Sheard (2010:4) argues that: *'staff who 'get it' do so because of who they 'are' rather than what they 'do.'* and as such training programmes need to develop staff self awareness and emotional intelligence rather than competencies. Gibson (1998) also notes that the attitudes and skills needed for working with life history are not always obtained through programmes of training but may be more inherent to the individual. The attitudes and skills that are needed for reminiscence work with people with dementia are summarised by Bruce and Schweitzer (2008:177) (see Table 6.1).

A range of attributes of staff are identified by McCormack and McCance (2010) as significant in achieving person-centred care, these are: being professionally

competent; having developed interpersonal skills; being committed to the job; having clarity of beliefs and values; and knowing self. It is perhaps some of these skills, attitudes and characteristics documented by Bruce and Schweitzer (2008) and McCormack and McCance (2010) that I observed in the care staff that could be identified as believing that personhood persists in people with dementia.

Table 6.1: Attitudes and skills required for reminiscence work with people with dementia.

Attitudes and skills required for reminiscence work with people with dementia
Respect and valuing people as unique individuals
Genuine interest in the past and in people's life stories
Willingness to listen to both painful and happy memories
Not being frightened by strong emotions
Giving good attention with active listening and a sense of being genuinely available to people
Empathising – sharing another's world without losing hold of your own
Relating sensitively – not being a bull in a china shop or over-interpreting
Being able to reflect critically on your own work

The values that a group of care staff hold is central to the understanding of a workplace culture and yet values are often invisible, making the understanding of and subsequent change in culture complex (Kotter and Heskett 1992). 'Values clarification' is a vital part of any practice development initiative (Manley 2004) and although no formal values clarification exercise was undertaken the LSW research enabled some of the values of the individual participants to emerge and make them visible. The value placed on finding out about the lives of people who have dementia was highlighted by some care staff, and the value in sharing aspects of one's own life was seen as significant for a few care staff. Similarly the collective values within the individual case study sites were illuminated. A clear tension was evident for some care staff, between an espoused organisational person-centred culture and the actual culture where value was placed on completion of care tasks.

Previous research has cited lack of time as a factor that may prevent LSW being implemented in practice (Adams *et al.* 1996; Clarke 2003; Gibson and Carson 2010) and the LSW research findings suggest that gathering life story information is not part of routine practice but in effect an 'add on' to current care processes. A study in a Norwegian nursing home (Bakken *et al.* 2010:14) reports that LSW was

not time consuming, rather: *'It is just a question of prioritising.'* It is possible the skill mix, culture and organisation of Norwegian nursing homes offer a more conducive context to implementing LSW than in the UK. LSW was prioritised in all the case studies in the LSW research, but in Cs1 and 2 was perhaps prioritised as part of research activity rather than an everyday clinical practice activity. Thompson *et al.* (2008b) explored the 'lack of time' in relation to the utilisation of research amongst nurses and noted the absence of inquiry into the meaning of the 'lack of time'. Their study highlighted a *'culture of busyness'* (Thompson *et al.* 2008b:545) where performance tasks of caring were valued over time spent reading or reflecting on research. This seemed relevant to the LSW research where tasks such as managing the ward, undertaking the medicines round and meeting physical care needs were seen as priorities. A study into student nurse experiences of the care of older people (McGarry *et al.* 2009:20) referred to a similar culture where *'getting through the work'* was valued over spending time with patients. Brown Wilson and Davies (2009:1749) equate individualised task-centred care with *'getting the job done'* and found that nursing home staff working in this way appeared less motivated to develop personal relationships with residents; the authors report that the staff believed it to be the best way of caring for residents with complex needs. In extending this observation a concern about implementing LSW in a task centred as opposed to a person-centred culture is that the process of LSW may itself become perceived as a 'task that must be done'.

A person-centred culture is espoused in the organisation where the LSW research was undertaken, however in ward areas in Cs1 and 2 there was evidence of values that were less person-centred and more task centred. Anthony (1994) identifies the gap that can exist between the organisational espoused culture and the actual culture that exists in practice, with the recognition that within any organisation a series of sub-cultures exists between different areas; this seemed evident between the different case study areas. In the current economic and political climate care is influenced by a range of political, policy and financial forces and as Johns (1999) reports it is not always easy for nurses to fulfil their moral obligation to the patients when competing external obligations also exist. Kemmis (2005) argues that organisations can feel threatened when the very values that are espoused are

brought into action as this often requires extra resources such as the necessary 'space' where practitioners can engage reflexively.

The implications of the care environment and the service re-configuration must be considered in how values and beliefs were formed, the impact on care delivery and on how much energy staff had for undertaking LSW. In their Senses Framework, Nolan *et al.* (2006) describe a 'Sense of Security' as important to not only patients and family carers but also care staff. The service changes and subsequent staff and patient relocation would have made a 'Sense of Security' difficult to experience for all concerned.

A support worker in the LSW study identified management support as key to whether an initiative became embedded into practice or failed to be seen as a priority. The two case studies that proceeded with little facilitation from myself were well supported, whilst the two case studies needing more of my time received less commitment from the managers. Commitment from managers was reported by Gibson and Carson (2010) as a key tenet of initiating LSW in their trust-wide project. Commitment and facilitation, however, are two different things and Bevan (2010) points out that not all managers and leaders have skills in facilitating change.

The LSW research findings report how training was delivered to care staff in Cs 1 and 2 who had not previously undertaken LSW. The literature reports the importance of providing the necessary training to allow care staff to undertake LSW (Clarke *et al.* 2003; Bakken *et al.* 2009; Gibson and Carson 2010). Case studies 3 and 4 developed LSW fairly independently and the staff leading the LSW had previous experience of using LSW and did not take up the offer of training. The use of LSW gathering prompts were also valued particularly from the staff nurse in Cs2. Similarly Bakken *et al.* (2009) reported that cue words and questions provided to staff were valued in initiating conversations with patients about their life story.

In addition to educational resources required the LSW research demonstrated the practical support required for LSW to proceed in some cases. Rycroft-Malone

(2004) highlights the naïve view often held that providing professionals with evidence and the skills to appraise it will automatically lead to changes in practice. Although far from naïve in the field of practice development I was still surprised that staff appeared unable to implement the approach, even when they were enthusiastic and had volunteered to participate. I have since reflected on how I may have underestimated my own expertise and knowledge of implementing LSW into practice and perhaps expected that staff would have shared the same skills, knowledge and motivation. In addition the influence of the culture of care with an emphasis on 'getting through the work' may have taken precedence over the staff's initial enthusiasm and willingness to participate. The findings from the LSW study detail how I had to adopt a facilitative role, particularly in Cs 1 and 2. Quite simply facilitation is described as: '*a technique by which one person makes things easier for others*' Kitson *et al.* (1998:152). Shaw *et al.* (2008) place the emphasis in enabling others to grow and develop by supporting them through change. Care staff who took part in a LSW project facilitated by specialist community nurses were positive towards the facilitation, motivation and mentorship offered (Thompson 2010). In particular they valued the knowledge the community nurses held about using LSW. Staff in Cs 1 and 2, although finding my support helpful also described the 'pressure' of knowing I was visiting and ensuring that they had undertaken what they had agreed to do.

The support needed to implement LSW was provided externally by me to Cs1 and 2 and was internal to the contexts of Cs3 and 4. As these findings demonstrate, there appeared to be varying degrees of being able to prepare, plan and implement LSW; sometimes the resources were available internally to the case study area and in these cases LSW proceeded swiftly and was more likely to be embedded in practice. A review of diffusion of innovation literature (Greenhalgh *et al.* 2004:21) describes certain features associated with receptivity to change and these include: Strong leadership, clear strategic vision, good managerial relations, visionary staff in key positions, a climate conducive to experimentation and risk taking, and effective monitoring and feedback systems. It seems evident that for a variety of reasons Cs1 and 2 were further from having all these features in place and as such LSW was slow to be implemented and is unlikely to be sustained. Cs 1 and 2 in

particular required the support from external sources and implementation was more challenging and seemed unlikely to be sustained beyond the research project.

The context of care where the LSW was undertaken appeared significant in how easily it was implemented and in particular the values held by the organisation and individual care staff had the potential to help or hinder implementation of LSW. However I would concur with Dopson and Fitzgerald (2005) who describe care context as multi-faceted and in a constant state of flux and the LSW findings do not claim to provide one single explanation for the differences in the uptake of LSW across individuals and case studies.

The three conceptual frameworks presented in Chapter Two all identify the context of care as an important factor in understanding and implementing person-centred care in practice. Of the three frameworks McCormack and McCance (2010) perhaps offer the most integrated consideration of contextual and cultural factors into their PCN framework. Their recommendations to implement the PCN framework within a process of practice development affirms the importance they place on addressing personal and organisational values, learning and culture change.

The VIPS framework (Brooker 2007) explicitly refers to values of organisations, staff and management in influencing person-centred care. The VIPS framework has been coupled with Dementia Care Mapping to ensure that the experience of the person with dementia is considered and that necessary change in care practice can be enabled.

The Senses Framework, as currently published (Nolan *et al.* 2006) integrates contextual factors less explicitly than the other two frameworks. Whilst the existence of 'enriched' and 'impoverished' environments are recognised, to date the complexity of contextual, cultural and environment factors are not summarised within the framework. The authors have presented their intention to support implementation through education and profiling, but their plans in this area are

less well developed and have less developmental history than practice development and Dementia Care Mapping.

In summary a complex range of personal, organisational and practical factors appear to either support or hinder the implementation and use of LSW in practice. LSW appeared to be implemented more effectively if these factors were internal to the practice setting as was demonstrated in Cs3 and 4. When these factors were not internal to the culture of care, or where facilitation was necessary, LSW seemed to proceed more slowly and with more uncertainty.

The next chapter will present the findings relevant to the process of undertaking LSW in health and social care practice.

CHAPTER SEVEN

FROM PROCESS TO PRODUCT: FROM INDIVIDUALS TO COMMUNITIES

7.1 Introduction

Figure 7.1: Chapter Seven themes and sub-themes

From process to product: From individuals to communities
7.2 Process
7.2.1 A focus on the individuals concerned
7.2.2 Learning something new from the person with dementia
7.2.3 Challenging care staff and family carer attitudes
7.3 From process to product
7.4 Life story work product
7.4.1 A prompt for memories
7.4.2 Use in transitions of care and as a legacy
7.5 Considerations of using LSW product in practice
7.5.1 Under and over-use
7.5.2 The significance of photographs
7.5.3 Content and quality of the life story work product

This chapter focuses on the process of gathering the LSW information and the 'end result' or LSW product. Data from the LSW research is presented and then I present a critical appraisal of the findings in relation to the existing empirical literature on the use of LSW.

The process of gathering a person's life story is a pre-requisite to developing a LSW product. This chapter appraises the different functions of both the process and the product of LSW and argues their equal importance. The chapter also critically reflects on the considerations of using the LSW product in practice. The themes and sub-themes presented in this chapter are summarised in Figure 7.1.

7.2 Process

This section appraises a range of features that were observed during the process of gathering LSW information with the person with dementia.

7.2.1 A focus on the individuals concerned

The process of gathering LSW information provided the participants with a unique opportunity to share time together and, potentially, to form a relationship, often slightly different from the usual care relationship. RMNc who had worked alone with Harry was able to describe how she had valued the process and the individual time spent with him:

“So maybe that one to one you know just one person all the time ... it got a bit more ... of a better relationship I think rather than just sharing it with any old person.” Cs2 RMNc.

RMNb from Cs2 simply describes the process:

“That’s where the good stuff is.” Cs2 RMNb.

By this, he implied that the individual time spent getting to know interesting aspects of the person’s life was valuable and enjoyable. Certainly, the OT assistant in Cs3 valued the individual time she spent with Rachel:

“She says ‘Oh you’re that lady that has been doing something with me’ but not recalling what but she did know we’d been doing something and then sometimes she calls me by my name ... (laughs) so she knew who I was but not what I was doing. But it’s a nice feeling that you know what I mean ...It’s like putting trust in you really isn’t it?” Cs3 OT assistant.

The deputy manager in Cs1 raised the issue of the timing of gathering life story information, believing it was important to undertake this within the context of a relationship:

“I mean you first come into contact with somebody and they don’t know you from Adam, you don’t know them from Adam and it’s like there’s not the trust there ... its about building up relationships and getting their trust with people to be able to delve that little bit further.” Cs1 Deputy manager.

The LSW process provided opportunities for the key aspects of person-centred care that were identified in the LSW research, to be observed; these include: opportunities for improved communication and relationships; getting to know the

person; enabling the voice of the person to be heard and upholding personhood. These person-centred outcomes will be the focus of Chapter Eight.

7.2.2 Learning something new from the person with dementia

The process of undertaking LSW enabled some staff to gain new knowledge, not only about the person with dementia but also more broadly about the lives of older people within a social and historical context. This was the case for RMNc working with Harry who described:

"It's been really interesting just to finding outthere's things I never knew about during the war and just information you just think 'Oh I never knew that' just general information ... like working in the electrical shop, I never knew that TV remote controls were attached to the TV I never knew that ... and telling me about his wages ... I just never realised how little they were compared to nowadays just things like that so I got quite a lot from that." Cs2 RMNc.

RMNb, who worked with George in the pilot case study, described a conversation they had about a Yorkshire cricket player who died in the war. RMNb knew some facts about the player, but through talking to George he was able to learn much more about the circumstances of the player's life and death, something that he found personally interesting.

Similarly, the student nurse, through listening to Eileen's life history became aware of her experience of having children with a learning disability:

"I think she had to somehow protect them [Eileen's twin daughters] from people because they were like stigmatised ... because of this learning disability they had so she had to fend for her children she talked about that a lot it was quite interesting." Cs3 Student nurse.

Eileen's story was pertinent to my own role as I had recently taken on a new job which included working with people with learning disabilities. Through talking with Eileen and her daughter I felt I was better able to understand the challenges facing older family carers and older people with learning disabilities.

7.2.3 Challenging care staff and family carer attitudes toward people with dementia

The LSW research provided opportunities for negative attitudes towards people with dementia to be challenged. Rachel's daughter was sceptical that her mother would be suitable to participate in the LSW research when I telephoned her to ask her views on her mother's involvement. I reported her response in my research diary:

"It sounds good, but you do know she has dementia don't you, perhaps it won't be relevant." Research diary.

I was able to inform Rachel's daughter that it was relevant and she was able to appreciate the benefits as the research progressed, possibly challenging her earlier assumptions that Rachel might not be suitable to participate.

The student nurse working with Eileen found her beliefs about the abilities of people with dementia being challenged:

"Every photo we took out she could tell you what happened ...I thought that way cos of her dementia maybe ...[she would not remember] 'Ahh that's interesting that she can still remember all those things.'" Cs3 Student nurse.

The potential for the process of LSW to challenge negative stereotypes was just as relevant for more experienced staff. There were examples when I found my own views on the abilities of the person's with dementia challenged. Eileen, for example, surprised me with how up-to-date she was with a current news story and Harry challenged my assumptions by being able to recall that he had shared private memories with RMNc as she gathered his life story information. Similarly, the nurse manager working with Eileen in Cs4 commented:

"And I think as well we're all, well I'm certainly a victim of prejudice, I think you work for a long time with people with dementia and have certain expectations and I think we're ... pulled up sharp about that one. You think 'Oh she won't remember that' ...but she clearly did so I think those ... negative things that you have are constantly challenge." Cs4 Nurse manager.

7.3 From process to product

The different functions of both the process and the product are described by the nurse manager in Cs4, who had a clear view on the need for both the process and the end product:

"I think the process is fantastic for the people that are doing it but I think it's very difficult to then debrief that to somebody else think it's very difficult to take someone's life history which'll be fantastically moving and brilliant but then on third telling it will have lost something and your interpretation of it as well will have changed it whereas I think the physical photographs can't be changed. ...When you have a physical book it can then extend through the work team." Cs4 Nurse manager.

Perhaps her leadership skills allowed her to appreciate the needs of the team, whereas RMNb, working with Harry, tended to focus on what he personally gained from being involved and as such was less convinced of the value of a LSW product:

"I mean essentially I don't care about producing a book because my experience is that people will probably not read it. If you've got it and you can pass it on then to other people then that's ok and I think sometime doing it verbally's better." Cs2 RMNb.

RMNc in Cs2 described how Harry's sudden transfer to a nursing home had meant that she had been unable to share his pen picture with other staff and, consequently, they did not learn about Harry's life beyond his care needs:

"As for the more in depth things about his life you know being in the army, building his boats with his friends, how the stroke you know was a big part of his life I don't think that many people would have known that which is quite sad really, it was such a big part of his life ...Maybe it would have benefited him a bit more had more people known about what I'd done." Cs2 RMNc.

The LSW research did not provide evidence of the LSW product being integrated into case conferences, care plans or supervision.

The next section explores the format and characteristics of each of the LSW products and presents the outcomes that were observed from the use of the product.

7.4 Life story work product

As was previously reported in Chapters Three and Five, life story books were produced with three of the case studies and a written pen picture in one case.

Participants seemed content to use conventional ways of displaying LSW information and it is difficult to know whether this is what they thought would work best or whether they did not have the confidence or knowledge to try alternative approaches. Staff in Cs1, 3 and 4 all used a style they were familiar with (a life story book) and a pen picture was chosen in Cs2 due to Harry's unexpected transfer to the nursing home.

The different ways of involving people with dementia and family members and the range of purposes of using LSW are discussed at some length in Chapter Nine. The LSW product had two particular outcomes, in addition to the person-centred outcomes which are discussed in Chapter Eight.

7.4.1 Use of the life story product as a prompt for memories

The LSW product when used with the person with dementia appeared to prompt the person to remember aspects of their life. George's wife observed this when George looked through his life story book:

"It was nice to see his face as well as much to say 'Well I think I do remember that'...it was also sad as well because obviously some of the photographs I don't know whether there's good memories to him I don't know what he was thinking at that particular point."
Cs2 Wife.

RMNc visited Harry in the nursing home to talk though his pen picture and noted that his memories resulted in an emotional response:

"It was quite an emotional thing I felt for him you know reading back about his life and about meeting his wife again." Cs2 RMNc.

Certainly, for Rachel's daughter visits could be difficult and she seemed to value being able to help stimulate her mother's memories:

"I've enjoyed it and it's always useful to look at it because it stimulates memories." Cs3 Daughter.

When asked what had been the main benefit of participating in LSW, Rachel's daughter described:

"Well just really to plumb the depths of the mind ... so that she can be involved in talking about it." Cs3 Daughter.

This seemed important to her and the memories then aided conversation between them. This was noticed by the OT assistant who reported:

"Her daughter looking though it and saying it was nice to see her Mum looking through the book and recognising people or friends and family members" Cs3 OT assistant.

Harry spoke about his time as a soldier, his work as a successful television salesman and the time when he met his wife. Eileen chose photographs that reflected her family life and she was clearly proud to recall memories of her achievements as a hard working wife and mother. Rachel's life story book reflected her friends, family and her holidays; although interestingly, focused more on her years from forty upwards when she had trained to be a school teacher and learned to drive and a time when she seemed to have developed more confidence and life experience.

7.4.2 Use of the life story product in transitions of care and as a legacy

The life story product appeared to be valued in transitions for the person with dementia. The term 'transition' is used in the LSW research to denote a move between care environments; for example, when the person moved from a ward to a nursing home, or from home to a respite service. The nurse manager working with Eileen, uses the example of transitions to support her belief that a LSW product is as important as the process of undertaking LSW:

"I think also people move into different care settings and get different workers and the book will remain, whereas information that is passed on mightn't be or might be changed or misinterpreted and as people's needs change the verbal or written accounts might change as well mightn't they? I think the book is an essential you need something physical at the end of it." Cs4 Nurse manager.

The value of the life story book that accompanied Rachel when she moved to the nursing home was reported by the care worker:

"It arrived with some notes, her belongings, the past history book and photo albums. The carer sat with her when she came in and looked though her book - this helped Rachel to settle and also allowed carer to fully complete the care plan as she felt she knew her." Cs3 Nursing home care worker.

However, the use of an existing life story product in a new care setting is not universal as will be described in the case of Harry in Chapter Eight.

There was also the suggestion that a life story book may provide a legacy for the person with dementia:

"I think also if anything does, God forbid, happen to Rachel then her daughter's got all this down in black and white what her daughter can look back on and her Grandchildren can look back on and Great grandchildren...if it's not down in black and white they can't, they can just pass things on but everyone can look back on Rachel's life now." Cs3 Support worker.

Two of the people with dementia who participated in the LSW research have subsequently died but it would have been insensitive to enquire with the family how the book was viewed following their death for research purposes. I attended George's funeral and was struck that his life story was so integral to the service and the sharing and passing on of memories of George. In my recent clinical practice, LSW was undertaken with a female resident in a nursing home who died soon after it was completed. I spoke to her husband who described that the life story book had provided comfort after her death and it was given to her eldest son to keep as an heirloom.

7.5 Considerations when using the LSW product in practice

The LSW data provided insights into considerations that need to be taken into account when using the LSW product in practice.

7.5.1 Under and over use

In Cs2, it seems likely that Harry's pen-picture will remain hidden in his case notes rather than being used with him (the possible reasons for this will be debated in Chapter Eight). An unexpected finding from this research is that, at least initially, there is the potential for the life story book to be overused with the person with dementia. The nurse manager reflected this in her experience of working with a range of volunteers with Eileen:

"I think you also have to be aware that she tires very easily and I think what we've had to watch out for is that she's not actively engaged for the full day...Eileen is a very polite person and I don't think she would say 'can you stop talking I'm getting bored' I think

she would go along with it so I think it's our job to look for signs that she's wanting a bit of a rest." Cs4 Nurse manager.

Similarly, George's wife felt the same thing happened when the OT assistant, support worker and herself all shared George's life story book with him for the first time:

"There was a time in the early days when he got agitated but there were a lot in the room with him and I think there was 'overkill' as it was new. Now it is usually used on a 1:1 – we learned by early mistakes." Cs1 Wife.

George's wife, however, was confident that George would demonstrate he had 'had enough' by closing the book, although it would require staff to recognise this as a demonstration of his agency in order to respond to his non-verbal request. I report in my research diary that I felt we had spent too long with Rachel and her book when it was first completed:

"[The OT assistant] joined us and to be honest I think we spent a little too long. Rachel became more distracted and [her daughter] looked tired." Research diary.

Conversely, Rachel's daughter described how when she reached the end of the book, Rachel picked it up again and asked what it was and looked through the book afresh as if she had not seen it before.

7.5.2 The significance of photographs

The photographs displayed in the life story books appeared to assist in enhancing communication. The day centre manager describes this potential:

"I think the photographs are so powerful that somebody can tell you 'Yes I worked in the cutlery / furnace' and tell you a bit about that but once you see a photograph then the detail becomes so intense I think..We put the text in which the person whose book then approves...the photographs speak for themselves." Cs4 Nurse manager.

Some of the people with dementia had an opinion about the use of photographs. Rachel, for example, disliked a recent photograph that had been taken of her and was included in her life story book. When I enquired what exactly she did not like she said: *"I look old"*. Her daughter noted that in the photograph, Rachel's hair was unkempt, something that would have been unusual for her, also she liked to wear bright lipstick and would not have liked to have been photographed without

lipstick. I discuss this further in Chapter Eight making links to embodied personhood. There were other photographs in Rachel's book of her with family and friends that she appeared to value.

Eileen reported that she liked her life story book with all her photographs in one place but she stated that the more recent photographs in the book did not look like her as she 'looked old'.

George's wife was extremely mindful of which photographs should appear in his life story book as she felt more recent photographs may upset him:

"I know quite early on in George's illness when he would look in the mirror obviously he would see something different and he would go 'rubbish, rubbish' so he wasn't see what we were seeing so I don't know how he would react to photographs like that". Cs2 Wife.

George did not appear upset at seeing any of the photographs in his book, but this may have been due to his wife's careful consideration of what to include.

Harry did not have any photographs available for use. The background image on Harry's pen picture was of a canal barge and it had been carefully chosen to reflect his interests. The image clearly struck a chord and Harry believed it to be his own boat.

7.5.3 Content and quality of the life story product

Different views were expressed about the content and quality of the life story books. George's wife was pleased with the overall balance of George's life story book and she describes a collaborative approach to its development between herself, the OT assistant and support worker.

"So I think it worked pretty well, I think we all complimented each other ...I think we got the balance right in the book." Cs1 Wife.

Although George was unable to verbalise his opinion on the book, observations of him using it indicated that he appreciated it.

By being involved and collaborating closely with staff, George's wife described how she was able to influence the quality of the book. She also arranged for the photos

that had been printed on ordinary paper, to be scanned onto photographic paper and felt that staff appreciated the difference in quality:

"Small things like I wanted each photograph labelling up not just writing on the back but I didn't want it just scribbled on a piece of paper, so I just wanted to do it so that was nice...Even they [staff] passed comment that they was better." Cs1 Wife.

I noted in my research diary:

"Was really lovely, mixture of pictures and captions ...it was lovely." Research diary.

Rachel and Eileen's life story books both contained typing errors. I observed Eileen's reaction when she shared her book with me:

"Throughout the book there were some spelling mistakes on family names ...on one occasion Eileen had corrected it in pen, on each occasion she pointed it out with mild irritation or disappointment however she did not voice her displeasure even when asked if she would change anything about the book." Research diary.

I was not alone in observing this; Eileen's daughter commented that her niece had noticed the mistakes when looking through Eileen's book.

The care worker in the nursing home commented on Rachel's reaction to the spelling errors in her life story book:

"I noticed Rachel spotted spelling mistakes so it shows she is reading it and taking notice." Cs3 Nursing home care worker.

I sum up some of these contradictions in my research diary after a meeting with Rachel and her daughter:

"Re the content of the book I feel mixed, typos, stuck in pictures, not polished – or how long it will last? But the great thing is it was done in collaboration with Rachel ... spelling mistakes, bad grammar does it matter?" Research Diary.

Clearly to Rachel and her daughter it did matter, as an update e-mail sent to me by Rachel's daughter after the research had ended indicated:

"Mother and I look at it quite often and every time she comments that things are not spelt correctly etc; she and I have always been very fussy about the correct use of English ...Of course it does not matter very much but it is just an observation!" Cs3 Daughter.

Eileen's and Rachel's daughters felt the life story book was not exactly how they would have wished them:

"I think it's good, I would probably like to have seen a bit more writing, but that's just me, I think it's fine." Cs4 Daughter

"I just wish it was more comprehensive and more photographs had been used that I had put though and I suppose I could have put more into it" Cs3 Daughter.

Both daughters made these comments to me with almost an apology – *"It doesn't matter very much it is just an observation"*; *"But that's just me I think it's fine"* *"I suppose I could have put more into it"*; but I believe they both felt as if they would like to have been more involved. Rachel and Eileen's daughters were less involved in producing the life story books than George's wife who, interestingly, described being able to influence the quality of the book throughout. The issue of whose voice is privileged is discussed more fully in Chapter Nine. The life story book used in Cs4 was a set format and structure that was used with all the people with dementia who attended the day centre. The student nurse reflected on her lack of awareness of alternative ways of presenting the LSW information:

"This folder that we use, I didn't know we could use something different I didn't know I could write the life story book in different formats ... I could buy one of those [photograph album] and write in it, I didn't know that. I thought that everything was supposed to be like computer based you know scanning in typing and printing ... I didn't know I could be creative." Cs4 Student nurse.

A member of the research reference group indicated that past experience had taught him the need for an 'editorial' meeting with all the necessary people to be involved in negotiating and agreeing the final product. He felt this was particularly important as sometimes the book would become almost a legacy or testimony to the person when they passed away. I noted in my research diary that a poor quality book almost detracts from the personhood of the person with dementia.

7.6 Discussion

This next section will now critically analyse the findings from the LSW in relation to the current knowledge base on the use of LSW. In particular the discussion will emphasise the how the LSW research findings validate current knowledge and contribute to new understandings of the use of LSW in health and social care practice.

Figure 7.2 summarises the findings from this chapter and the following discussion considers how the findings from the LSW research compare with existing literature.

Figure 7.2: Characteristics and considerations of life story work process and product

Process	Adaptive Functions	Product
It's about individual relationships	Person-Centred Opportunities and Outcomes	Its about the wider community
	Learning about older people and social history	
	Stimulating memories	
	Challenging attitudes	
		Use in transition and a legacy
	Considerations	
	Use within a person-centred philosophy	
	Not a 'hit and run' approach	
		Over use / under use
		Use of photographs
		Content and Quality

The process of undertaking LSW presented the opportunity for staff to develop individual relationships with the person with whom they were working. Clarke *et al.* (2003:703) report that the support workers in their study believed it was important to '*get to know the patient*' before working with them on their life story. This view was held by the deputy manager in the LSW research. Perhaps these views reflect a perception that gathering life story information is a 'one off' event, rather than a process that can enable relationships to develop. In using LSW with older people, Bakken *et al.* (2009) report that trust grew through the personal relationships that developed through using LSW and, similarly, Kellett *et al.* (2010) describe the building of trust and gathering of LSW information as an incremental process. These accounts seem more consistent with the findings from the LSW research and the way that LSW enabled opportunities for staff to offer person-centred care is detailed in Chapter Eight.

The LSW research demonstrated how some care staff gained new knowledge about older people and social history more generally. This finding is consistent with the work of Gibson and Carson (2010) with people who had dementia in Northern Ireland; they report how care staff gained an increased knowledge of local history

through undertaking LSW. McGarry *et al.* (2009) state that student nurses in their study learned more about older people through listening to their life history. The LSW research demonstrates this is also the case for more experienced staff. Relationships with people with dementia can be viewed as a one way process where care staff 'give' care and the person with dementia is the recipient (Duffy *et al.* 2009). The process involved in LSW has the potential to allow staff to learn from the experiences and knowledge of the older people with dementia; potentially, reducing the power imbalances that traditionally exist in caring relationships. This issue will be explored in more detail in Chapter Eight.

LSW has previously been reported to challenge negative assumptions held by care staff about older people. Clarke (2000) and Wills and Day (2008) in their studies of using life story books report that stories served to challenge ageist attitudes and negative stereotypes of older people and also demonstrate the contribution of older people to society. The LSW research demonstrates that through engaging with the stories of the older people with dementia staff did have their assumptions challenged and this is consistent with existing literature on LSW and people with dementia (Gibson 1991, 1994; Batson *et al.* 2002). Additionally the LSW research raises the possibility that family carers may also have their attitudes towards dementia challenged through using LSW, this has not been reported in existing LSW literature. In my clinical practice, care staff have reported that family members are sometimes reluctant to engage in LSW. There will be a number of reasons for this, but it is likely that some relatives, like Rachel's daughter, may need education and support to overcome the therapeutic nihilism that can prevail. An alternative explanation for non-participation in LSW is offered by Kellett *et al.* (2010), who report that some family carers were not always ready to undertake LSW whilst coming to terms with the changes that dementia can bring to all family members.

The LSW research has contributed to the debate on the importance of both the LSW process and the LSW product. An emphasis only on the LSW product could potentially exclude the person with dementia or have no positive impact on person-centred outcomes. Murphy and Moyes (1997) highlight the dangers of life

story books as being synonymous with LSW, rather suggesting the book is just one possible format for containing life story material. The 'number' of LSW products has been used as a means of evaluating the impact of LSW (c.f. Thompson 2010), but such an approach can undermine the true essence of LSW; that is, the interaction that takes place within the process. Gibson (2005) reports the process of engaging with the person with dementia can be overlooked if staff are over-enthusiastic in producing an impressive and comprehensive life story product. She states the process must always be more important than the product, but highlights the considerable significance the life story product can have for the person, family carers and staff. The LSW research demonstrates that the potential risk of not producing a LSW product is that the knowledge remains with one staff member and is not extended to benefit the wider staff team and others, including the person with dementia. As Murphy and Moyes (1997) report, there are filing cabinets full of a wealth of important information about individuals without it ever being used in their care, or pieces of information kept in the heads of care staff. The LSW research findings reveal that the LSW information gathered did not become integrated into care plans. This is in contrast to the experience of Kellett *et al.* (2010), who described their plans to integrate LSW into case conferences and Bakken *et al.* (2009) who shared LSW information through group supervision.

The LSW product has been shown to provide a prompt for memories to be recalled by the person with dementia and enables care staff and family carers to participate in reminiscing. Gibson (2005) describes LSW as an 'aide memoire' to remember the past and encourage further recall and the LSW research validated this finding. Murphy (2000), also reports care staff using the person with dementia's life story book to help stimulate their memories. Some family carers can find visits to their relative with dementia uncomfortable, not always knowing what to talk about. Bruce and Schweitzer (2008) describe how some family carers find it particularly helpful to use past memories as a way to stimulate conversation and take on a role of 'holding' the person's memories for them. In keeping with the experience of family carers in the study by Batson *et al.* (2002), Rachel's daughter in particular valued LSW as a focus for her visits to her mother. In taking on a role that Koch and Crichton (2007) term as a 'memory guide' she was able to prompt Rachel and

assist her to recall memories she was forgetting. Cheston and Bender (1999) discuss a range of ways that staff may help maintain the identity of the person with dementia by stimulating autobiographical memory and prompting them to remember who they are. The memories evoked through using LSW in this research were largely positive, however, care staff and family carers need to be mindful that upsetting and possibly traumatic memories may also surface. This is discussed in more depth in Chapter Eight.

Brooker (2010) reports that the memories that people with dementia recall, often focus on important times in their life when they felt powerful and competent, this often being a time when they were between fifteen and twenty-five years old. George and Harry appeared to value recalling times in their lives when they were active as a soldier in Harry's case or a proficient sportsman and miner as was the case with George. Eileen's memories were focussed on her family, signifying her role as a mother. Interestingly Rachel's memories were focussed more on her life after the age of forty, when she trained to be a teacher and learned to drive. This serves to reinforce the need to understand the story the person with dementia wishes to tell rather than focus on specific periods in their life.

The findings from the LSW research illuminate the LSW product as a valuable resource for transition between care environments. In allowing the life story to be retained and passed on it may also act as a tangible record of the person's life when they die. Bell and Troxel (2001) describe the benefits of having detailed life story information when a person moves into a nursing home and life history information is reported to assist the significant people in a care home welcome and get to know the newcomer more quickly (Forster 1998). This was confirmed by the care staff in the nursing home that Rachel moved to although was not reported by staff at the nursing home Harry was transferred to. Keady *et al.* (2005:211) describe the sharing and documentation of a life story as a: '*living document of choice, experience and history.*' that may support the wishes of a person if they become unable to express them due to dementia. The existing LSW research does not explore the use of life story books in transitions of care, perhaps reflecting the absence of studies adopting a longitudinal design.

Elford *et al.* (2005) report that reminiscing can help to preserve family history and pass on historical memories to future generations and recorded life histories can serve as a family heirloom when the person dies (Kuhn and Gray-Soltys 2007). Meininger (2005:109) makes the link between LSW and spiritual care with a focus on '*experiencing the sense of life*' and questions concerning '*the meaning of life*'.

In his study into the use of LSW Murphy (2000) reports that in some cases, staff were unaware of the existence of life story books and consequently, they were not used with residents. In contrast the life story books that were produced as part of the LSW research were all used with the people with dementia during the life span of the research project. The LSW research revealed the potential 'over-use' of the life story books with George, Rachel and Eileen. Finding the 'correct' balance in using the LSW product can be challenging to care staff and family carers to ensure that the person with dementia is respected and not overwhelmed or over-tired. Murphy (2000) evaluated the use of LSW in three nursing homes, and noted that staff need to ensure they are not asking too many questions of the person with dementia about facts that they may be unable to remember or respond to. Batson *et al.* (2002) report that staff can sometimes find it emotionally draining listening to people with dementia tell the same story over again and staff need to recognise that the experience may be novel each time the person with dementia views it. Rachel's daughter was able to recognise that her mother was able to view her story book as if for the first time each time she opened it.

Photographs in the LSW research seemed particularly significant in triggering memories and evoking emotions. All the participants with dementia appeared to recognise themselves in the photographs. This is consistent with a study by Fazio and Mitchell (2009) who used recently taken photographs to assess the persistence of self in older people with dementia. The authors found that most participants recognised themselves, apart from three people with moderate dementia living in residential care. Hehman *et al.* (2005:121) concluded that with people with more advanced dementia '*self recognition is frozen in time.*' They used the example of an 83 year old participant who was able to recognise photographs of herself in her 20s and 30s but not in her 80s. Rachel and Eileen both voiced

some displeasure at recent photographs of themselves. Fazio and Mitchell (2009) did not explore the feelings evoked by the photographs beyond commenting that one person reported she had 'Always hated that picture'.

The LSW research revealed a finding that has previously been unreported in the literature relating to the content and quality of the LSW product. The quality of Eileen and Rachel's life story books was tarnished by the spelling mistakes and poor grammar, something that both women and their daughters commented upon. In addition, although Rachel was fully involved in the choice and development of her life story book, the scrapbook format meant that could easily be damaged. Eileen's book was robust, in a folder style with plastic inserts, but was less visually appealing than George's book which was collated in a photograph album.

The existing LSW literature does not offer an assessment of the different ways that LSW can be displayed. I have reflected upon my observations and the findings and have summarised the advantages and disadvantages of the different formats in Table 7.1 below.

Table 7.1: The advantages and disadvantages of each life story work product.

Format	Advantages	Disadvantages
Photo Album	Visually pleasant to view Robust Can be changed / added to Can take a range of information Easily useable with the person Can be individualised	Expensive to buy Takes time to collate Requires visual information
Pen Picture	Does not require visual information Is not too time consuming to produce Can easily be used in care records Can be quickly read and assimilated Low cost	Less interesting to view Lacking visual information Less useable with the person
Scrap Book	Can be individualised Low cost Can be used with the person Initially looks attractive	Not very robust – soon looks tatty Can't be easily changed or added to
Folder with inserts	Can be changed and added to Can be used with the person Robust In- expensive	Less visually appealing Less opportunity for individualising

The literature reports a range of ways in which LSW can be recorded. Gibson (2004) states that these are too numerous to detail but she draws three broad

categories under which products of reminiscence can be loosely described: performance, for example audio recordings, recitation, music; visual, for example collage, maps, memory boxes; and written, for example life story book, biography, poetry. A review of the literature (McKeown *et al.* 2006) suggests that at the time the review was undertaken, life story books seemed to be the most used and this proved to be true in the LSW research.

The format for the LSW product is best chosen to reflect the aims of the LSW and this will be discussed in Chapter Nine in relation to the LSW research findings.

The next chapter explores the person-centred care outcomes observed through the use of LSW.

CHAPTER EIGHT

FROM PATIENT TO PERSON: PERSON-CENTRED CARE OUTCOMES

8.1 Introduction

Figure 8.1: Chapter Eight themes and sub-themes

From patient to person: Person-centred outcomes.
8.2 Communication
8.2.1 A topic of conversation
8.2.2 A communicative community
8.3 Relationship
8.3.1 Making a connection
8.3.2 Relationships with family carers
8.3.3 Using the relationship to achieve care aims
8.4 Understanding the person
8.4.1 From patient to person
8.4.2 S/he wasn't always that type of person
8.4.3 Developing a more equal relationship
8.5 Hearing the voice of the person
8.5.1 Can you hear me?
8.5.2 Embodied personhood
8.6 Personhood upheld
8.6.1 Pride and enjoyment
8.6.2 Making their wishes known

In this chapter, I present the outcomes for the care of people with dementia and consider the potential of LSW to enhance person-centred care. This chapter builds on the analysis of personhood and person-centred care offered in Chapter Two and extends this to consider the relevance specifically to people with dementia through engaging in LSW. The LSW research findings are discussed under key themes that emerged from the data (see Figure 8.1)

8.2 Communication

The LSW research illuminated the ways in which staff and the person with dementia were able to communicate with one another through undertaking LSW.

8.2.1 A topic of conversation

RMNa in Cs2 described looking forward to undertaking LSW since she perceived it would allow her time to talk with Harry; something that was currently a challenge where she worked:

“As a nurse you spend half your time running around doing the practicalities it’ll be nice to sit down and talk to him about his life ...we forget these things on busy assessment wards ... it’s awful really cos you don’t – we don’t get the opportunity to do things like that.” Cs2 RMNa.

Clearly there was a tension for RMNa as she reflected that talking to patients could readily be overlooked when dealing with ward practicalities. Similarly, spending time talking with Harry was something that RMNc had previously found a challenge and LSW gave her the permission to do this:

“You’re sitting down and having one-to-one time with the patient that you might never have had one to one time with before....Once I found out about his hobbies it was like a topic of conversation for us, I felt like I could instigate a conversation, we could talk for a while and I could sort of interact with him that way.” Cs2 RMNc.

In Cs3, the support worker described being able to talk with Rachel about shared interests and she found the conversation seemed to distract Rachel from her anxiety:

“Like type of car ‘Oh Rachel I’ve got a new car, you used to have a car’ just silly little things but it did distract her and it did make her feel better you could see it on her face.” Cs3 Support worker.

The support worker explained that working with Rachel in this way helped her to communicate better with other people with dementia, particularly when assisting them with care tasks:

“We’ve got a new lady in and so I’ve started asking her questions ...so I can use that next time I go to get her ready. So just if you’ve got that little bit of information you can bring that person out. I think it’s fantastic for them.” Cs3 Support worker.

The response from the support worker suggests that enquiring about the life of the person with dementia for whom she was caring was not something she had routinely engaged with and by seeing the positive response with Rachel it had helped her see the benefits of taking the approach with other people.

RMNb's conversations with Harry in Cs2 focused on shared interests and experiences which led to prompts for conversation:

"If I can I relate me to them you know like Harry 'I was in the army' 'I was in the army' that sort of thing, he was a jazz listener and I kind of like jazz." Cs2 RMNb.

Rachel's daughter could also appreciate how her mother's life story book helped staff to communicate about common interests:

"Mum liked dogs and so if the staff discover that and the staff has a dog they have a mutual point of contact to talk about and anything else that's there perhaps a building that's mentioned might be familiar to one of the care staff for some reason so any of the topics could be discussed by them if they're familiar with them." Cs3 Daughter.

LSW was not, however, always helpful in initiating conversation with the person with dementia as I discovered when I enquired with the registered nurse at the nursing home Harry moved to. I asked whether the pen picture had been helpful in striking up a conversation with Harry. The nurse responded:

"Not really, Harry is confused and forgets where he is." Discussion notes.

Care staff working with George did not report that LSW impacted on their ability to communicate with him and, indeed, his ability to hold a lengthy conversation was inhibited by the dementia. It is possible that George's care needs and the challenges staff faced in providing his care, overshadowed the subtle communications that occurred and resulted in a perception that he was not amenable much of the time to engaging in LSW.

8.2.2 A communicative community

The improved conversations were not confined to care staff and the people with dementia. A common feature of the three case studies where a life story book was produced was the improved interactions that appeared to occur when other

people with dementia viewed the book. The OT assistant in Cs3 described a time when Rachel shared her life story book with other residents:

"A lot of the clients are quite mobile so they were like hovering over her or stretching their necks thinking 'What's that? Can I have a look?' and Rachel gave permission for them to have a look through and a lot of the clients commented. It was nice to see them interacting together rather than sat apart not saying anything." Cs3 OT assistant.

These interactions between residents did not appear to be the norm and Rachel's life story book enabled communication to occur. The nursing home care worker in Cs3 described a similar scenario:

"Today she had her book with her and another resident, a friend Rachel has made asked to look at it, Rachel was happy to show her. It got conversation going and the other resident was saying 'Aren't you beautiful'; the resident wants her own book." Cs3 Nursing home care worker.

Life story books were commonly used to stimulate group discussions between other attendees and volunteers at the day centre where Eileen attended; this usually took place around a large table where conversations could be more easily facilitated.

The observation that the life story book made some difference to the care community was not confined to staff participants. George's wife described an afternoon where George shared his life story book with another patient on the ward:

"His wife described that day there was a real change in the atmosphere, she can't be sure it was due to the life story book but she felt interactions between everyone were better, the meal time was more chilled and the whole mood on the ward seemed to change for the better." Discussion notes.

George's wife also reported an interaction her husband had with a female patient:

"One day he showed it [the life story book] to other patients and seemed proud of it, other patients said 'Look after those photos' he responded back. Another showed a picture of him without a shirt on in the pit he said 'Look at my physique'." Discussion notes.

8.3 Relationships

LSW appeared to enable different relationships to emerge between participants. These will be explored in this section.

8.3.1 Making a connection

A common description from care staff within the LSW research was the development of a closer 'bond' between themselves and the person with dementia. In Cs2, RMNs b and c noticed that Harry seemed to identify them over other staff. RMNc said Harry recognised her as the person who was interested in his life; something she appreciated:

"There was a link formed and I was like a point of contact almost he knew who I was and so that was quite nice." Cs2 RMNc.

Similarly, RMNb noticed that both people with dementia with whom he had undertaken LSW seemed to seek him out:

"I know that George and Harry used to come to me, more than most staff – they would go to other staff but if I was there they would tend to come to me." Cs2 RMNb.

The OT assistant in Cs3 also noted that Rachel, despite her poor memory, was able to recognise her as the person who was helping her with her life story book. She, too, valued the rapport she developed with Rachel.

It is interesting that developing a closer bond or connection with the person with dementia was valued and appreciated by the staff as if it were somehow affirming their own value and worth as a care worker.

The support worker in Cs1 described a time when George appeared to call her name on the corridor; something so unusual she thought she had misheard until another staff member pointed it out:

"He were walking behind me and he was shouting a name and I thought he shouted 'Kath' and I thought no he can't be and somebody else says "Kath he's shouting you" and I turned round and talked to him and he responded so that's a plus really but that was the only time." Cs1 Support worker.

This encounter appeared to challenge the support worker's assumptions about George's social abilities. The nurse manager in Cs4 observed that the life story

book allowed the volunteers at the day centre to get to know Eileen better and, consequently, develop a better relationship:

"Because Eileen is quiet they [the younger volunteers] tend to gravitate to the people that are a bit more lively or a bit more easy to engage and wanting to join in ... but the book's I think enabled them to question more and talk about what's happening so it's helped them I think establish a better relationship with Eileen cos there was something to prompt Eileen with but also they were genuinely interested in this woman's life." Cs4 Nurse manager.

In Cs2, RMNb and the nurse manager in Cs4, both identified the need to share parts of their own story in order to develop the relationship:

"It's about us it's not just about them it's about us... that's why I always give I always tell them something about me...so it's not a one way street it's actually a conversation." Cs2 RMNb.

"You can work with somebody and get to know their life story and share bits of your own life I think that's as important in building that relationship." Cs4 Nurse manager.

Other staff participants did not refer to sharing their stories with the people with dementia with whom they were working.

8.3.2 Relationships with family carers

The LSW research findings draw attention more to the relationships that developed between the person with dementia and care staff. Less data were available about the relationships between care staff and family carers, although there are some useful observations.

Effective communication between George's wife and care staff already existed, partly due to the length of time George had been within the service, George's wife described having a relationship with staff where she could challenge aspects of George's care and she felt her views were listened to and acted upon. LSW was supported by this relationship. All participants in Cs1 reported how they had valued working in collaboration with one another regarding George's life story book. Similarly, Eileen's daughter already had a good relationship with the day centre manager:

"The care is really good, [the nurse manager] always keeps in touch and lets me know if she has any concerns." Cs4 Daughter.

The LSW research enabled me to develop a relationship with Rachel's daughter. The OT assistant in Cs3 worked part-time and was not always working when Rachel's daughter visited; consequently, because of the initial contact I had made with Rachel's daughter, I became a link person between the OT assistant and Rachel's daughter. This was enhanced by e-mail communication and the visits I made to meet with Rachel and her daughter to gather their experiences of participating in LSW. I would describe a degree of reciprocity in our relationship, as I noted in my research diary:

"I feel my role as nurse and researcher was hard to unravel. I think I provided 'something' certainly for the daughter, at the same time the interactions provided data for my research."
Research diary.

I reflected with the daughter that I felt I was intruding on the time she spent with Rachel; she responded that she appreciated my visits and she had learned from me as I *'knew what to say'* when Rachel was repetitive and anxious. I had been a constant presence through a difficult time from soon after Rachel had been admitted to hospital and diagnosed with dementia, to when she was transferred to a nursing home. The support I offered to Rachel's daughter was confirmed through a subsequent e-mail I received from a family friend who provided feedback on the article I had written about the use of LSW.

The LSW research reflects that existing relationships between care staff and family carers helped to support the process of gathering LSW. In Cs3 the process did enable relationships with family carers, but with me the researcher rather than with the staff participants.

8.3.3 Using the relationship to achieve care aims

A number of care staff referred to the use of LSW in achieving care aims. In Cs2, RMNb described how he felt that a benefit of the relationship developed through helping him to achieve care aims with the person with dementia:

"Sometimes I could get them to do things where people had struggled which made me feel good that I could get something that was needed to be done I managed to get it done without any great problems to do with care ... so sometimes you could achieve things that didn't look like they were going to be achieved without any fuss or a very minimal amount of fuss." Cs2 RMNb.

I reflected with RMNb that this could potentially be seen as using the relationship to manipulate a situation. He used his experience of providing care to George in the pilot case study, describing how it would sometimes require three staff to assist George with his care needs:

"It did happen with George where I managed to get him washed and changed without too much fuss, too much aggression, too much distress... I'd rather be manipulating him than have 3 staff I'd much rather have that and anybody that thinks there is an ethical problem with that well as far as I'm concerned they've got a problem and they've probably got their heads too far up the ethical problem backside ... but essentially that's what you are doing isn't it it's about how we use their life their experiences to achieve something else different it's still manipulation really." Cs2 RMNb.

Certainly, I could see RMNb's point of view, that making an intervention less distressing for everybody concerned was a positive outcome. The outreach worker in the day centre that Eileen attended also described how he had distracted a man, who was reluctant to wash, into having a bath by talking to him about things in the past he enjoyed.

I noted in my research diary how the female staff nurse working with Harry used her knowledge as a way of distracting Harry from arguments:

[The staff nurse] "has also used some of the detail about Harry as distracting conversations if Harry has been getting into any altercations with other patients – 'Here Harry come and tell me about you boating holidays with Tony and Sheila'." Research Diary.

It is an interesting insight that LSW information and the relationships gained through this knowledge can be used effectively to achieve care aims, minimise distress and aid co-operation, and there is nothing to suggest in examples from this research that these relationships were misused. However, it does highlight the potential for relationships to be abused.

The benefits of LSW, particularly in the case of George, were judged by staff in respect to the extent to which it helped them to achieve care aims. The OT assistant felt that nursing staff were still struggling with George's care needs:

"I mean some days they'll go [nursing staff] – like the other day he let one person see to doing half of him but ... most of the time I

think it's still taking 3 people ... he's certainly not stopped with his punching and kicking ... you'll probably find from their point of view it's not done an awful lot for his ordinary basic care." Cs1 OT assistant.

When asked if taking a LSW approach had benefited anyone, the support worker responded:

"There's been a benefit for me but I don't think it had been any benefit for George because he hasn't been responding apart from one day I think that we had a really good day." Cs1 Support Worker.

She continued by describing what sounded like a wonderful afternoon sharing George's life story book with him, his wife and the OT assistant; interestingly, she referred to what his wife was able to achieve that day with George's care:

"She [George's wife] had a lot done for him that day she cut his hair, cut his nails, she did a lot for him that day you know and he was quite responsive to that." Cs1 Support Worker.

Perhaps staff had assessed the success of using LSW against whether there was a reduction in the behaviours that George presented that staff found challenging. In assessing success in this way, maybe staff underestimated the small changes and moments of wellbeing. I discussed this issue with the research reference group who suggested that the use of his life story book with George on his 'good days: *'Made the good days even better'*.

8.4 Understanding the person

All case studies demonstrated that staff gained more depth to the knowledge they possessed about the person, even if they had known the person for some time.

8.4.1 From Patient to Person

Using LSW seemed to help staff to see the person with dementia beyond being merely a patient. Rachel, the person, could sometimes be hidden behind anxiety and agitation. The support worker describes her different understanding of Rachel after learning more about her life history:

"I've learned a lot about her. I mean to me she came in she was a patient she was very confused, very distressed – but when she started opening up you could see the type of person she was." Cs3 Support worker.

It is interesting to see the support worker replace the word 'patient' with 'person', indicating that she was seeing Rachel differently.

The OT assistant similarly felt that LSW had benefited her with new insights into George 'the person':

"It really hits home that this is a person and he's had this life before he came here and done everything that everyone else does and the sort of things you probably take for granted a bit I think so I think it's really good." Cs1 OT assistant.

These accounts suggest that the care staff were not always able to view the person behind the dementia and LSW enabled them to achieve this.

The nurse manager in Cs4 described how she improved her knowledge of Eileen:

"I know Eileen much better than I thought I did ...It has really highlighted the fact that she has had to learn to become a really balanced person and non judgemental person 'cos she has been on the receiving end of such a lot of it." Cs4 Nurse manager.

The nurse manager was able to appreciate that Eileen's qualities were a consequence of her life history; bringing up twins with a learning disability in an era where such disability was poorly tolerated by others. She was able to view Eileen within the context of her life experiences.

8.4.2 S/he wasn't always that type of person

Knowing more about the person highlighted the person beyond behaviours that the staff found challenging. George's behaviour sometimes appeared aggressive. The support worker describes how seeing his life story book challenged her views of him:

"It made me understand more about him ...with his aggression he wasn't that type of person before he was quite friendly helpful he was very helpful apparently ... he loved his grandchildren and he loved his family." Cs1 Support Worker.

The deputy manager felt this understanding changed how staff on the ward perceived George:

"I think seeing George more as a person it makes him less scary doesn't it?" Cs1 Deputy manager.

George's life story book provided an alternative narrative; a loving family man who had a good sense of humour and who was an enthusiastic and proficient

sportsman; nevertheless his care plan still focused on *'his aggression'* and did not reflect his alternative story.

Some staff appreciated the losses the person had encountered; the OT assistant described feeling saddened by the losses in George's life.

"Reading through it I thought it was quite sad to see how much he's – has got lost along the way." Cs1 OT assistant.

RMNb working with Harry also reflected on this:

"He was a paratrooper so this young man you know fit and strong and tanned and here he is..." Cs2 RMNb.

The findings from the LSW study provide evidence of continuity, but also, as in the case of the nurse's awareness of what Harry had lost, hint that LSW may emphasise discontinuity in the lives of people with dementia. This is reflected by the nurse manager who was able to recognise the discontinuity with Eileen and attempt to reassure her and improve her self-esteem:

"I mean Eileen often talks of herself now in a very negative way, that she's dependent on us and her mobility's not so good and she needs help ... I think she sees that as very negative things and she says "I'm a burden" and "I take up too much of your time" and we're very reassuring but I think she does see herself now in a lesser way from the lady that was running a house and working." Cs4 Nurse manager.

The knowledge of Eileen's life story and the skills of the nurse manager offered opportunities for Eileen's negative perceptions of herself to be challenged.

8.4.3 Developing a more equal relationship

The nurse manager in Cs4 and RMNb in Cs2 both appeared to show an appreciation and understanding of the values of Harry and Eileen beyond what was achieved by other staff participants.

The nurse manager spoke of how inspiring she found Eileen and the way she had conducted her life:

"I don't think I quite knew the depth of her character, when you listen to her life story it's been very troubled and traumatic at times and yet she's come out very balanced and non judgemental and I think it's just made me inspired really by how she's handled things." Cs4 Nurse manager.

RMNb was able to describe some of the values and beliefs that Harry held in life and from his time as a soldier:

"I think also ... a degree of forgiveness in Harry as well he didn't seem to have any animosity in who was trying to kill him you know it was part of the game ... he was a soldier and that is how soldiers actually see it it's part of the game." Cs2 RMNb.

RMNb had himself served as a soldier and this may have helped him understand and empathise with Harry.

The nurse manager working with Eileen reflects on LSW:

"It's about your relationship with that person ... it sort of alters that relationship because they've shared so much you're privileged to so much information I think it changes your relationship with them It makes it much more equal I think." Cs4 Nurse manager.

8.5 Hearing the voice of the person

Understanding the subjective experience of the person is a central tenet of concepts of person-centred care for people with dementia. The next section explores how LSW appeared to provide opportunities for the voice of the person with dementia to be heard; both literally and through embodied expression.

8.5.1 Can you hear me?

George's experience of dementia meant it had been difficult for him to contribute to his life story book, which was developed in collaboration with his wife. However, the photographs in his life story book appeared to trigger memories that he could put into words. The OT assistant described an afternoon using the book:

"He went through ... 'and that's me Mum' and Anne says 'who's that' and pointed to dog and he said dog's name and looking at pictures." Cs1 OT assistant.

Observational notes kept by George's wife and care staff reported his comments about the photographs such as: *'That's me and the dog' 'The greenhouse looks the same.'*

Rachel's voice was initially lost behind her anxiety and repetitiveness about her situation but, by using LSW, staff were able to distract her and hear more about her

as a person through her accounts of owning a pub, being a teacher and living in different parts of the country.

Eileen's life story book seemed to raise her profile in the group and allowed her to be seen and heard:

"People were very interested and were saying "who's this" and so we were hearing a lot more from Eileen about ... it sort of pushed her into the limelight a bit." Cs4 Nurse manager.

Eileen and Rachel's choice of what photographs and text went into their life story books and what was left out, was privileged by staff, over their daughters' choices of what they had wanted in the books.

All three family carers seemed to value the opportunity of LSW to allow their relative to be more 'seen and heard' and, possibly, their personhood upheld. This seemed evident with George's wife, who considered carefully which photographs should appear in his life story book in order to challenge staff views of her husband:

"There was one that I did want including in it which is and that's when he was actually dressed up smart because they [staff] see them [patients] as they are now ... they don't realise they was people before. They was smart." Cs1 Wife.

However, her accounts also suggest that LSW helped her to continue to uphold George's personhood when she herself was beginning to lose the essence of who he was:

"At that particular time I was actually losing the good memories of George ... so it was nice actually just to recapture some of those and some of those ... the fact that he is still the person that you married he looks slightly different, he may act differently but it's still the person that you married so I think I needed that little jolt back as well." Cs1 Wife.

When I met Eileen's daughter to explain the research and get her consent, I reported her views towards the researcher in my research diary:

"The daughter is looking forward to it [LSW] and wants to show how hard her Mum worked to bring up her family." Research diary.

Both daughters alluded to wanting more say over the photographs that were included in their mothers' books; perhaps they wished to influence how their

mothers were seen by staff in a similar way that George's wife had been able to by the choice of photographs she chose to represent George's life. Although care staff appeared to have a particularly good understanding of Eileen within the context of her life, her daughter still expressed the view that:

"I just wish they could have seen my Mum a few years ago before the dementia to really be able to see the person she was." Cs4 Daughter.

Maybe this was a reflection of the difficulty Eileen's daughter was having in recognising that her mother was still the same person, in spite of her dementia.

8.5.2 Embodied Personhood

An observation of George turning the pages of his life story book was interpreted in different ways by his wife and by care staff. George's wife appeared to interpret this as an indication of his agency; care staff were more likely to interpret the action that he was agitated and wanted to end the activity:

"That is actually the way that George would look at a photograph album I think it was nice as well for me to see him actually doing that because usually people have turned pages for him." Cs1 Wife.

This was how George had always looked though photograph albums and it demonstrated to his wife evidence of his 'agency' and 'personhood'. However, she felt that simply telling staff what George was like as a person was not effective and they had to experience this for themselves, although she appreciated this was sometimes a challenge and hoped the life story book might help:

"I don't think it matters how much as a carer you express 'Well this was how he used to be, he was so laid back'... I think someone passed a comment to me 'Look at his little finger how he had got that up when he was taking a drink' and he still does that now so obviously they'd never picked up on that so they're the little things I know ... maybe they have trouble just looking beyond that but I hope it [the life story book] helps." CS1 Wife.

The nursing home care worker noted important facts about Rachel from looking through her life story book:

"The fact she had ginger hair and lovely skin." Discussion notes.

This is something I detailed in my notes from our conversation:

"She made links to herself, she likes to look at what hairstyles women used to like – for example she has straight hair and would hate to have a perm, she would like to wear perfume after being washed and dressed in a morning." Discussion notes.

The care worker appeared to tune into embodied manifestations of Rachel's personhood.

There was a photograph at the end of Rachel's life story book which had been taken on the ward. I reported in my research diary:

"Rachel said she did not like it as it made her look old." Research diary.

Her daughter suggested that in the photograph Rachel's hair needed cutting and had not been set and Rachel would not like to be seen in this way. It was clear from the other photographs in Rachel's book that she took pride in her clothes and her hair. The OT assistant did not offer to change the photograph and maybe did not appreciate the significance of this photograph and its potential distraction from Rachel's personhood. Perhaps also Rachel was unable to assert her desire for the photograph to be changed

RMNc picked up on important aspects of Harry's embodied personhood:

"He's a proper gentleman very courteous he's very proud of his image ... he spends a lot of time making sure his hair's just right he likes to have a shave every day he's immaculate and he's self caring still so he's able to make sure he's happy with his appearance. Very smartly dressed, smart trousers, blazer type thing." Cs2 RMNc.

When we visited the nursing home, RMNc felt upset that Harry had not been shaved and his hair was very untidy; she knew he would have hated to have been left like that.

To extend the debate, it is interesting to consider how, for example, Harry was embodied in his experience of how he lived his life and, in particular, of being a soldier. The fact he took extreme pride in his grooming may have emanated from his time in the forces. RMNb, having also been a soldier seemed to make links between Harry's values and behaviours as a consequence of his military training and experience. RMNb had discussed with me how being a soldier himself had helped his connection with Harry and described:

"We are all the same by virtue of being a soldier." Discussion notes.

The nurse manager felt that Eileen's low opinion of herself may have resulted from the distance between herself as a capable mother and housewife and her current situation as an attendee at a day centre. The nurse manager was able to see how Eileen's embodied qualities of being a balanced and non-judgemental woman who brought up children with a learning disability were still evident in the way she interacted with other attendees:

"She says you have to see people as people and not as an illness or a problem and that's stayed with her all her life I think. So now even at the day centre with people who are, to other people, being difficult she sees it as a problem so we need to sort out what it is."
Cs4 Nurse manager.

It seems possible a person can be embodied by their social class, as the deputy manager described in her knowledge about George:

"I mean I get the sense he was a working class man who kind of enjoyed all the things that working class men do – he was a miner so he worked hard and he enjoyed to play hard I think afterwards he liked his pub and he liked his sport and he like all the things that working class men like and I think I've picked that up about him." Cs2 Deputy manager.

The deputy manager described a 'pub evening' the ward previously ran and when she described George it was easy to visualise him relaxed and potentially being 'himself':

"When we used to have the pub group ... he used to like his pint and he used to sit there, I mean he didn't do a lot of chatting, but he used to enjoy that." Cs2 Deputy manager.

It is possible that such social roles, rather than being embodied also have the potential to stereotype people, particularly if the person can no longer define their perceived social role for themselves due to cognitive impairment. Additionally, the findings indicate the need to consider ways to educate staff on the possibilities of personhood being manifested through embodied means.

8.6 Personhood upheld

As previously argued in Chapter Two, it can be difficult for care staff to know when their attempts at delivering person-centred care have been successful. The LSW research offered some glimpses that at any one moment personhood had been upheld.

8.6.1 *Pride and enjoyment*

All care staff in the LSW research refer in some way to their enjoyment in participating in LSW, as do family carers. Although participants with dementia did not overtly express that they enjoyed the activity, the pride they experienced in their life story and other people's interest was evident. Harry's response to seeing his pen picture for the first time was:

"Can I have 10,000 copies made?" Cs2 Harry.

He appeared genuinely moved that someone had taken the time to write up his life story. In Cs2, RMNb shared his observations of undertaking LSW with people with dementia:

"I think they felt valued, respected and ...and I think they felt interesting." Cs2 RMNb.

Although George was unable to articulate directly how he felt about his life story book, his wife describes his behaviours when using the book:

"When he looks at it his face changes, his eyes light up, it's almost as if someone turns a light on, he's like the 'Ready Brek Man', all lit up. His posture alters, he sits up tall. The other day he was walking down the corridor with it, like Eamon Andrews, he was tall and upright." Cs1 Wife.

This was in contrast to a man who had often appeared depressed and withdrawn.

Rachel appeared to have a low opinion of herself and would ask *"Have I lost my marbles?"*; *"Why are you interested in me, I've done nothing special?"* However, these concerns could be offset by sharing with Rachel the things she had achieved and her sense of pride is described by the OT assistant:

"I was noticing her expressions 'Oh yes it was me' when other people comment 'Oh was you a school teacher' and 'I didn't know you ran a pub' and 'Yes it's me' and like shuffling her clothes to...very proud of what she did do." Cs3 OT assistant.

The support worker also commented that Rachel's face 'lit up' when she spent time talking to her about her life history.

The student nurse noted of Eileen:

"When I gave Eileen her book she was very happy and proud to show it to other patients." Cs4 Student nurse.

When Eileen talked through her book with me she appeared proud and confident; as I noted in my research diary:

"I think she enjoyed sharing the book with me and I felt privileged to share part of her life and for her to share some personal memories with me." Research diary.

Staff and the family carer who fully participated in the LSW showed evidence of being proud.

8.6.2 Making their wishes known

Harry appeared to value the opportunity to share his life story and staff felt this enabled him to express his wishes and preferences more clearly. RMNb described how the relationship he had developed with Harry was 'turned back' on him on one occasion; he had promised to go with Harry to the barber's, but when the day arrived the ward was short staffed and RMNb had to tell Harry they were unable to go, the response was unexpected:

"He turned round and he said 'It's just always the same you promise things and nothing gets - nothing happens everything gets cancelled' and he just looked at me and said 'I thought better of you'." Cs2 RMNb.

RMNb described feeling he had let Harry down particularly by the statement 'I thought better of you' and felt compelled to remedy the difficulty for fear the relationship between them would break down:

"But the thing was I was well aware that I had to try and make it happen because just maybe whatever level the relationship was at it could get fractured." Cs2 RMNb

Harry's assertion of will about going to the barbers could have been a manifestation of his personhood. This was recognised and acted upon by RMNb who was able to embrace a more challenging relationship and not hide behind professional boundaries. This highlights the potential challenges that may occur as

relationships become more equal and the greater risk of what could be lost if it is not maintained.

In Cs4, the nurse manager found her own assumptions about Eileen being challenged when it occurred to her that Eileen may have been wondering why she had not been asked previously if she would like to develop a life story book:

“She knew Audrey had got one and she knew other people had got one and I think it had occurred to her that other people had got one and might be thinking ‘Why haven’t I got one?’ Cos these books are on the table so she made me think and the people we work with are constantly doing that to us aren’t they, pulling you up and making you think about what you are doing so I think it perhaps crossed her mind before it crossed ours.” Cs4 Nurse manager.

The nurse manager was willing to reflect on her own practice and its implications for Eileen, affording Eileen with the same thoughts and feelings that a person without dementia may experience if they had felt overlooked or left out.

8.2.3 Discussion

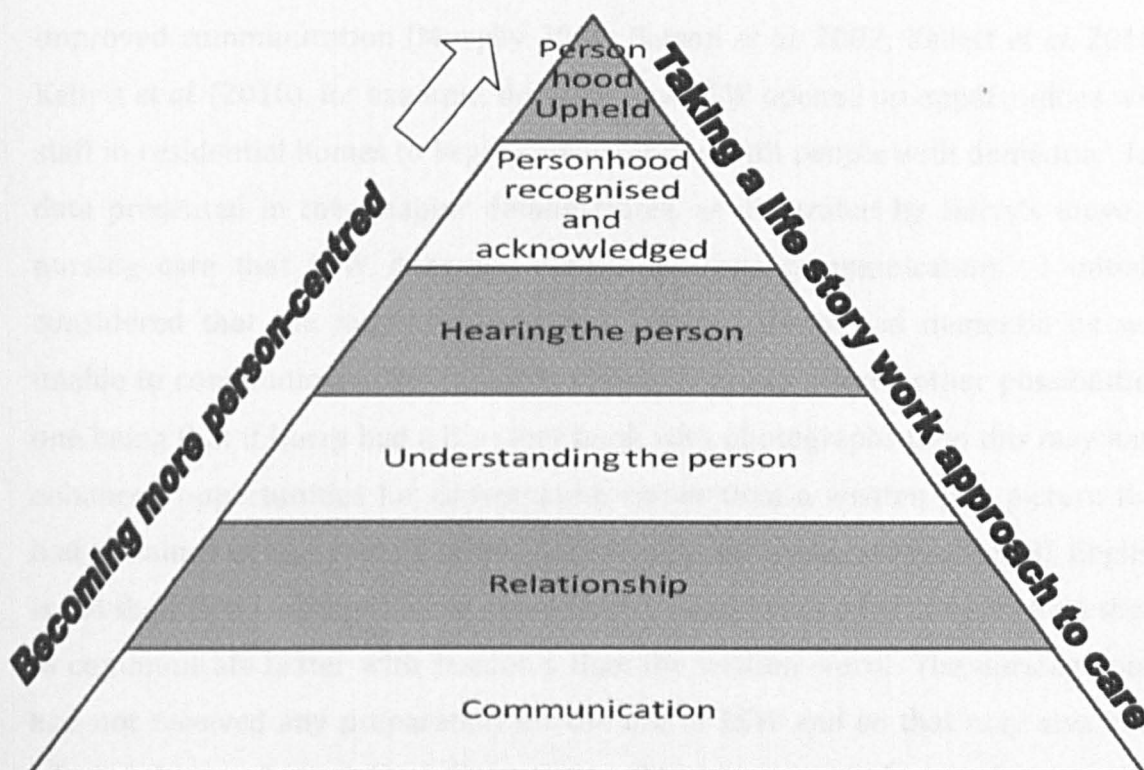
This next section will appraise the findings from the LSW research in light of the existing literature exploring the use of person-centred care and LSW.

Brooker (2010) argues that person-centred care are the processes that maintain personhood. Through analysing the data from the LSW research, there appears to be a hierarchy of necessary processes (see Figure 8.2) needed for person-centred care to be delivered through using a life story work approach. Each process builds on the foundation of the previous process towards the aim of upholding personhood.

Opportunities for communication were enhanced through LSW, initially between individuals during the process of gathering life story information and then opportunities were extended to the wider staff, family and care community through the LSW product. Communication is fundamental to person-centred care and Allan and Killick (2008) remind us that we signal our recognition of the personhood of others through our communication with them. LSW offered opportunities to enhance communication and interaction between participants,

although, as is evident, this data is largely from a care staff position and less from the perspective of the people with dementia or their family carers.

Figure 8.2: The necessary processes for 'personhood' to be upheld through using life story work



The data presented in this chapter demonstrates how LSW provided 'permission' for staff to spend one to one time communicating with the person with dementia about their life. Ward *et al.* (2005), in their UK study of care for people with dementia in residential care settings, found that staff often feel limited in the time they can spend communicating with people with dementia due to the amount of 'task' work that has to be completed and that this causes a 'tension'. This was consistent with the experience of the staff nurses working with Harry. Good communication, according to Ward *et al.* (2005), is the essence of caring for people with dementia and yet the researchers found that only two percent of the day of the person with dementia was spent in communication with care staff. Their findings emerged through interviewing staff, family carers and people with dementia in addition to analysing recordings of care encounters. The LSW study confirms that challenges were just as great in secondary mental health services. It

seemed surprising that spending time talking with patients was not a priority on an assessment ward for people with dementia. LSW appeared to highlight this dichotomy and provide care staff with the permission to converse and interact.

Current literature on the use of LSW presents a largely positive account of improved communication (Murphy 2000; Batson *et al.* 2002; Kellett *et al.* 2010). Kellett *et al.* (2010), for example, describe how LSW opened up opportunities with staff in residential homes to begin conversations with people with dementia. The data presented in this chapter demonstrates, as illustrated by Harry's move to nursing care that LSW does not always improve communication. I initially considered that the nurse believed that because Harry had dementia he was unable to communicate. The research reference group offered other possibilities; one being that if Harry had a life story book with photographs then this may have enhanced opportunities for conversation rather than a written pen picture that had remained in Harry's care notes. Additionally, for some care home staff, English is not their first language and so photographs, rather than pure text may help them to communicate better with residents than the written word. The nursing home had not received any preparation for the use of LSW and so that may also have affected their understanding of its purpose. The importance of preparing care staff to undertake LSW through training and development was identified in Chapter Six and may have been a factor in why the nursing home staff were unable to see the potential of Harry's pen picture in enhancing communication with him. The staff in the nursing home had not been involved in the 'process' of gathering Harry's life story, this also may have influenced their use of the life story 'product'.

The LSW research identified that the use of life story books contributed to communication between other residents and the wider staff group. LSW research has previously identified the potential to connect the common ground between people with dementia (Bruce and Schweitzer 2008). Heliker (1999) reports that the sharing of stories in residential care with older people can help to create a sense of community between residents and care staff. The report from George's wife of his interaction with a female patient regarding his 'physique' surprised me based on the assumptions I had made about his ability to interact formed through

my attention to care staff data. This supports the findings by Offord *et al.* (2006), who study the interactions of six older people with dementia and observe the range of social skills and abilities that people with dementia retain given the opportunity to communicate with one another. Their study was undertaken during structured psychotherapeutic group conditions and the LSW study demonstrates that similar opportunities to enhance interaction and retained social skills can be enabled in less formally organised group settings.

Relationships with between care staff, people with dementia and family carers would struggle to develop without effective communication. This next section explores how the communication developed through the LSW facilitated relationships. McCormack *et al.* (2008) describe the development of therapeutic relationships as fundamental to delivering person-centred care and the development of relationships has been reported as pivotal in upholding identity and personhood (Tester *et al.* 2004). Staff participants in the LSW research describe a range of ways in which they felt their relationship with the person with dementia had been enhanced and this is something that staff valued and felt good about. This seemed significant as study in a Swedish care home reports that care staff can feel hopeless and dissatisfied when they are unable to make 'contact' with the patient (Ekman *et al.* 1991). In their work on the Senses Framework Nolan *et al.* (2006) argue that for quality care to be delivered staff as well as older people and their carers need to experience the Senses. Our own recognition as a person by others is central to Kitwood's concept of personhood and Allan and Killick (2008) suggest that applies equally to care staff. The LSW research supports these observations by previous researchers and LSW appeared to provide a means of working with people with dementia to enhance relationships.

The nurse manager in the day centre reported how Eileen's life story book enabled the younger volunteers to become more interested and improve their relationship with Eileen. Larson and Perlstein (2007) describe a programme of work in America where older European immigrants shared their life stories with college students and this enabled friendships and understanding to develop between the generations. Perhaps for the younger care workers / volunteers LSW enabled

enabled links to be developed between themselves and the older people with dementia in a way that was less required by older and more experienced care staff.

The day centre manager in Cs4 and RMNb in Cs2 discuss the importance of sharing aspects of their own life story when interacting with the person with dementia. This suggests the staff members were sharing of themselves and entering into a more reciprocal relationship that moved beyond a nurse/patient interaction. In the context of using LSW as a qualitative research method, Keady *et al.* (2007a:77) discuss how in their method of co-constructed inquiry the researcher/practitioner shares his own story with the person with dementia in order to identify connections and develop trust, awareness and sharing; he reflects:

'... nurses are used to asking questions and listening to people. To have someone who is interested in you and prepared to listen to your story can be a rewarding experience.'

It is interesting that in the LSW research the younger and/or less experienced care staff did not described sharing their own stories.

I would suggest the understanding and the relationships developed by RMNb and the nurse manager with Harry and Eileen were as reciprocal and equal as it is possible to achieve within current services. Both staff appeared to appreciate the person with dementia in the context of their whole lives and were able to understand the values held by the person and how these developed through their life experiences. Many care staff, according to Duffy *et al.* (2009), perceive that they invest more energy into the relationships with people they care for than is invested in return by the care recipient. The nurse manager described feeling 'inspired' by understanding Eileen's life and RMNb shared similar interests and learned from both Harry and George. Clarke (2000) reports that through listening to the stories of the older people in her study she felt inspired by the lives some of them had led.

Reciprocity is described as a process of 'give and take' (Fyrand 2010). In their study into nursing home residents' definitions of quality of care, Bowers *et al.* (2001) report that residents equate 'reciprocity' with evidence of a good relationship with care staff. Value was placed on care staff sharing of their own

lives with the resident being able to offer 'good advice' in return (Bowers *et al.* 2001:542). Power sharing, along with negotiation, openness and respect are, according to Gallant *et al.* (2002) essential if enabling partnerships are to develop. Davies and Nolan (2008) argue for more equitable relationships based on a sharing of power but also recognise the challenge this presents in pressured care environments. Additionally, Brown Wilson (2008) argues that it is only when care staff recognise and respond to the contributions offered by residents or family members to the relationship that reciprocity can be achieved. Studies of reciprocity are more common in general nursing home for older people rather than with people with dementia more specifically. Nolan *et al.* (1996) highlight the limitations in reciprocal care with people who have more advanced dementia. The LSW research challenges this view and demonstrates that reciprocal relationships are achievable between care staff and older people with dementia although seem to occur more with staff who shared attributes of being older, having a broad life experience, confidence in themselves and their work role and who valued finding out about the lives of the people they cared for.

George's wife and Eileen's daughter described a relationship that already existed between themselves and care staff and this may have helped to support the LSW but did not develop as a result of the LSW. Kellett *et al.* (2010) describe how staff in their study found that developing the life story in partnership with family carers resulted in staff feeling they had become 'part of the family' of the person with dementia. This was not a finding from the LSW research and may be a reflection of the more permanent relationships that occur in residential care settings studied by Kellett *et al.* (2010). Another explanation is that the relationships in the LSW research between relatives and care staff were already strong.

Care staff in the LSW research identify how they used their relationship with the person and their knowledge about their life history to achieve care aims. Such aims include encouraging a person to have a bath, assisting a person with their personal care needs and distracting a person from a potential argument with other residents. McCormack (2001b) highlights the ways in which nurses can influence patient decisions based on use their knowledge of the 'picture' of the patient.

Although not intentionally malicious such practices highlight the power differences between staff who understand the healthcare system and the patient who may not appreciate how their decisions are influenced by care staff. Some staff working with George judged the success of LSW against whether it resulted in him being less resistive to care interventions. I compared their assessment with their powerful accounts of a lovely afternoon spent with George sharing his life story book with him and his wife. This may suggest a reduction in challenging behaviours is valued over increased moments of wellbeing with the person. My reflections concur with those of Pringle (2003), who draws attention to the emphasis often placed on reducing disturbed behaviours in people with dementia in measuring quality of care, rather than the emphasis being on increasing positive experiences for the person. Sabat (2009:166) reflecting on his father's life, concluded that there was great importance in recognising '*good moments*' and that such moments are defined by the person. The importance that is afforded to physical care tasks for people with more severe cognitive impairment is highlighted by Pringle (2003) who argues that the creation of quality moments should receive the same priority. This reflects the cultures of care in Cs1 and 2 reported in Chapter Six where 'tasks' appeared to be given priority over spending time with the person with dementia. Perhaps one role of care staff working with people with dementia is to make these '*good moments*' happen and an appreciation of what this means to the person with dementia may be elucidated from an understanding of their values and life history. This was reinforced by the research reference group who described LSW as making George's '*Good days even better*'.

Through spending more time communicating with the person with dementia and building a relationship, the staff participants in the LSW research gained a deeper knowledge of the person with whom they were working. The findings from the LSW research imply that care staff can begin to see the person behind the patient and are consistent with previous research into using LSW with people with dementia (Murphy 2000; Batson *et al.* 2002; Gibson and Carson 2010) and older people (Clarke *et al.* 2003).

Baldwin (2008b) argues that people with dementia can have narratives constructed about them that focus on deficits and difficulties such as 'challenging behaviour'; this particularly seemed the case for George. George's life story book did provide an alternative narrative which staff could appreciate, however as described this did not become translated into his care plan. Some staff described George as 'less scary' once they knew that he had been a caring family man with a good sense of humour. An alternative to a deficit narrative may be a heroic narrative and in their taxonomy of reminiscence Wong and Watt (1991) refer to escapist or defensive reminiscence which may exaggerate the pleasant aspects of the past or the person. Whilst there was no evidence that this was the case with George, it is a consideration for those working with life stories.

Staff and the people with dementia in the LSW research expressed sadness at who the person with dementia 'was' compared to their current situation. Harry and RMNb for example reflected on Harry's time as a soldier, fit and strong, compared to his present situation as an older person in hospital. Discontinuity in a person's biography is reported as one of the most significant effects of disability and chronic illness (Corbin and Strauss 1988). Although sadness was expressed by participants in the LSW research there is not evidence that their life stories located the person in the past or simplified their story as was reported by Adams *et al.* (1996). Murphy (2000) argues the importance of keeping life history current by including up-to-date experiences as part of the person's story and this was evident in all the LSW research participants' life stories.

The family carer participants in the LSW research appeared to value the opportunity for their relative to be better understood in the context of their whole life. Galvin *et al.* (2005) describe the role of family carers as that of mediators able to facilitate empathy in for example care staff, towards the person with dementia. It is possible that LSW is a tangible way in which family carers can maintain continuity and so uphold the personhood of the person with dementia. In their research of spousal caregivers of people with dementia, Perry and O'Connor (2002) described the preservation of personhood as an essential guiding principle for the spouse participants in their study. This seemed relevant to George's wife

who clearly wanted staff to appreciate George as a person. Perry and O'Connor's work (2002) focuses on spousal relationships and the authors recommend further research to explore the experience of other family members. The LSW research suggests that the daughters of Rachel and Eileen also saw LSW as an opportunity to portray their mothers beyond the current image as older women with dementia.

Bamford and Bruce (2000) state that maintaining a sense of identity was important for the people with dementia in their study; family carers in the same study, rarely reported this as an important outcome for the person for whom they cared. This finding conflicts with the data from the LSW research where maintaining the personhood of the person with dementia seemed important to all family carer participants; however, the family carer participants in the study undertaken by Bamford and Bruce (2000) did not share the same demographic profile as the family carers in the LSW study and, perhaps more importantly, the people with dementia they cared for were living at home and not receiving hospital care. It may be that the need to maintain personhood increases when the person moves into health and social care environments.

George's wife reported that LSW was a reminder to her of the good memories she had shared with George and provided a prompt that he was still the person she married. Her experience is consistent with the findings of Kellett *et al.* (2010) who report that relatives engaged in a series of family biography workshops were able to view their relative with as a 'whole' person and escape from the 'disease saturated context' that dementia had created.

I would argue that it is only when care staff are able to understand the person with dementia within the context of their whole lives they can truly begin to 'hear the voice' of the person with dementia. Care staff were able to 'hear' the person verbally but seemed less 'in tune' to picking up on bodily manifestations of self. This is evidenced by care staff interpreting the way that George turned the pages of his life story book as 'agitation' whereas his wife recognised it as the way he had always looked at a photograph album. Hughes (2001) contests that it is not possible to separate a person from their body; people are 'embodied' and it is their bodies that place them in a historical context of time and place. Kontos (2004;

2005) develops the notion of embodied intentionality; suggesting the 'self' resides in the body which moves, perceives and behaves. She argues that people act with a sense of agency even with severe cognitive impairment. The care worker in the nursing home that Rachel moved to did seem to recognise the importance of the way Rachel liked her hair and her clothes and she described this in terms of how she would feel if her own hair was not styled as she liked it. This is consistent with the work of Kontos and Naglie (2007) who report that staff who make connections between themselves and people with dementia are more likely to recognise embodied personhood. As previously discussed in Chapter Six, it was this care worker who I noted had seemed to 'tune in' to non-verbal communication from other residents with whom she had worked. A recently taken photograph of Rachel in her life story book, which she disliked because of her unkempt hair and lack of make up, remained in the book perhaps because the OT did not appreciate its links with Rachel's identity. Ward and Holland (2010) underline the importance that hair can have on the self image of some older people and draw attention to the links with identity through a quotation from Bennett (2005:12) reflecting on the experience of his mother's admission to hospital:

'She had on admission been bathed, her hair washed and left uncombed and uncurled, so that now it stood out round her head in a mad halo, this straight away drafting her into the ranks of the demented. Yet the change was so dramatic, the obliteration of her usual self so utter and complete, that to restore her even to an appearance of normality now seemed beyond hope. She was mad because she looked mad.'

The staff nurse working with Harry was upset at seeing how his shaving and hair had been neglected when we visited him on the nursing home, perhaps reflecting her awareness of the significance grooming had on how Harry felt about himself. There is evidence of aspects of embodiment related to the jobs and roles the people with dementia held when younger. Kontos and Naglie (2009) describe the socialisation that can occur through the cumulative exposure to a vocation, such as a policeman who insists on checking other residents' rooms looking for anything suspicious or a farmer who rises early each morning to tend to his land.

There is evidence across all the case studies of the people with dementia experiencing pride or pleasure from participating in LSW. This is supported by

Woods (1998) who argues that reminiscence with people with dementia conveys to the person that the care workers respects, values and is interested in them. Sabat and Harre (1992), in their work on self in dementia, note that if others honour or validate the person with dementia and respect their personhood then the person may continue to experience positive feelings toward themselves.

Rachel and Eileen could both have negative views on their self and their situation and the data from the LSW research demonstrates occasions when LSW could challenge these perceptions. Phinney (2008) reports that people with dementia can often feel foolish, useless and unproductive. Some older women with dementia can experience powerlessness and have a low opinion of themselves (Proctor 2001) but equally they can be provided with opportunities to voice their opinions and feel more connected. Rachel's surprise that anyone would be interested in her life is consistent with research by Adams *et al.* (1996) and Clarke (2001), who also found that some older people thought their lives would be boring or of no interest to others. It is difficult to know whether this is linked to low self-esteem or whether older people are un-used to anyone wanting to listen to their story and this may be more likely to be true for people with dementia. An older person with dementia at a workshop I attended however told the audience:

"We've all got a story to tell and very often that story is very interesting if people can be bothered to listen." Keith Turner: Expert by Experience 2009.

Sometimes, it can be difficult for people with dementia to find opportunities, particularly in care settings, to feel proud and value their lives. LSW has the potential to provide this opportunity. In relation to positive person work, Kitwood (1997:91) discusses the significance of *celebration* for the person with dementia where they and caregivers: '*all are taken up into a similar mood*'. The sharing of the life story books and participation in life story work provided the opportunity for such celebration and all who participated appeared to enjoy the activity.

The LSW research revealed that the care staff who developed the more reciprocal relationships with the persons with dementia reported potential challenges to the way they usually worked. The nurse manager working with Eileen found her own prejudices and attitudes challenged, although welcomed this and was able to

reflect on her learning. Tyrrell *et al.* (2006) report that people with dementia can feel that they are excluded in decisions about their care and consequently, can feel 'invisible'. Perhaps that was how Eileen had felt about having no life story book when other people who attended the day centre had one. By participating in LSW the nurse manager had been able to recognise and reflect on this. Jennings (1999) argues that being able to sustain relationships with others enhances person-centred care as it makes it difficult for the person with dementia to feel ignored, abandoned or excluded. RMNb found his authority and decisions challenged by Harry, he too was able to respond in a positive way. The consequences of truly engaging with a patient are explored by McCormack (2003c) who draws attention to dilemmas such as difficult decisions, ethical dilemmas or disagreements that may arise and effect how the nurse and patient can continue to work together. Drawing on the work of Heidegger (1990), McCormack and McCance (2010:98) describe three stances of: 'full engagement', 'partial engagement' and 'complete disengagement'. Full engagement could be described as the relationships experienced by the nurse manager and RMNb with Eileen and Harry. McCormack and McCance (2010) describe this as a care partnership where the values of the nurse and the patient are recognised. 'Partial engagement' is perhaps what RMNb describes as he withdraws to consider options to enable Harry to still attend the barbers. This is explained by McCormack and McCance (2010:98) as a stage where the nurse needs to 'take stock' and 'formulate' the problem. RMNb describes his actions as an attempt to prevent the relationship becoming '*fractured*', or what could be described as 'complete disengagement' to occur.

The LSW research provided glimpses of where personhood was upheld, through the people with dementia appearing proud of the life stories, perhaps illustrating what Nolan *et al.* (2006) would classify as a 'Sense of Significance'. There were also occasions where the person with dementia was able to exert their will or care staff were able to recognise the unspoken wishes of the person.

The next chapter identifies the complexities of taking a LSW approach and considers who the story belongs.

CHAPTER NINE

WHOSE STORY IS IT ANYWAY?

9.1 Introduction

Figure 9.1: Chapter Nine themes and sub-themes

Whose story is it anyway?

9.2 Differing contributions to the life story

9.3 Personal disclosures

9.4 Confidentiality

9.5 Who is the story for?

9.6 Consent

This final findings chapter evaluates the contribution to, and the ownership of, each life story and it also discusses some of the complex and ethical issues that arose. The chapter also presents some of the difficulties that emerged for participants around private and public accounts and proposes some possible solutions. The themes and sub-themes are summarised in Figure 9.1.

9.2 Differing contributions to the life story

The first section of this chapter discusses the ways in which the life stories were told, but also highlighted the potential difficulties of involving people with dementia in telling their own story.

The LSW research uncovered a range of different ways that the person with dementia and their family carers worked with staff to share life story information. Rachel and Eileen were both enabled by their daughters and by the staff working with them to tell their story. Each chose how their life stories were reflected by the choice of the photographs and the accompanying words, although the choice of photographs was influenced by what both daughters were able to find. This was especially limited for Eileen as her daughter explained:

"We didn't have a lot of money and so never had lots of photographs taken." Cs4 Daughter.

The nurse manager described how Eileen was able to take much more of a lead in the process than she had expected:

"She was very definite about what she wanted in and what she didn't want in where [her daughter] had picked photographs that she had thought Eileen would want and quite a few of them, weren't what Eileen wanted at all.... so she very much collaborated, participated in and took the lead ... which I thought was really nice, cos it wasn't what I was expecting." Cs4 Nurse manager.

Similarly, the OT assistant described how she worked in collaboration with Rachel in putting the book together:

"She chose the photos and she cut them out so really I worked closely with her ...she's had a choice throughout her likes it could be the photos and she cut them all out herself and so some are a bit skew wiff and er [laughs] but I just stuck them in so they were kind of straightish but yeah we did parts of it at a time together." Cs3 OT assistant.

The OT assistant seemed to value the collaborative approach she had taken with Rachel. I did, however, note that early in the process my feeling that the daughter may have felt excluded at the expense of the OT assistant taking a very person-centred approach with Rachel:

"[The OT assistant] only engaging with daughter though me, very Rachel centred, good - collaborating with her, I feel uneasy daughter left out?" Research Diary.

Harry was able to author his own story. His wife had chosen not to participate in the research, as was reported in Chapter Four. There were challenges for the staff nurse who listened to his story and these complexities will be explored later in this chapter.

LSW provided the opportunity for Harry, Rachel and Eileen's life story to be told from their perspective. Rachel initially seemed surprised that anyone would be interested in her life and I recorded her response to my invitation for her to participate in the research in my research diary:

"I'm nothing special; I've not got much of interest to say." Research diary.

George's wife provided most of the information about his life story and there appeared to be a real collaboration between her and the staff in developing George's life story book:

"I think the girls [the OT assistant and support worker] they passed comments on what was nice ... I had no negative feedback ...it was very rare that we all met up – we was actually on the ward at the same time, one was either going or coming sort of thing so it was just a case of 'I've done so and so is that OK?' 'Yes that's fine oh I'll bring that down next time that I come down' so I think it worked pretty well...I think we all complimented each other." Cs1 Wife.

Cs1 care staff, although pleased with George's life story book, described their disappointment that his story was largely from the perspective of his second wife whom he had been married to for sixteen years. The deputy manager reflected:

"He's not participated in any of the evidence gathering ...I think there are other difficulties like not being able to get George's point of view as well cos I think that's really important and while we've got quite a good insight we've not got George's insight really I mean we haven't even got any extended family there's really just [his wife]." Cs1 Deputy manager.

The OT assistant felt a similar way:

"I think it would have been nice to have had some more about his life before [his wife] cos he has brought two children up and cared for a wife before his second marriage and you know not taking anything away from [his wife] she's been a marvellous carer and still is but that has been a big part of his life and I would have liked to have got a little bit more of that first bit." Cs1 OT assistant.

George's wife was able to provide a co-authorship to her husband's story that supported and enhanced his personhood but gathering the views of his wider family was more complex. Although he had a son and daughter from his first marriage, family circumstances prevented their contributions.

Staff can feel that the voice of the person with dementia may be overshadowed by that of the family carer, as the nurse manager in Cs4 describes:

"I think you have to be mindful of who's life story it is and you do get carers that they've had a joint life for a long time perhaps 50 years so it's a joint book really but sometimes they'll tell you their life story and if the person can't express a lot or join in you can lose the path." Cs4 Nurse manager.

It is not clear if George's wife was aware of staff views; she had expressed pride at her contributions to George's life story book and was able to understand the challenges for staff:

"I think some of the staff have actually found it difficult to get information out of him but I think that's probably how he's been behaving at the time." Cs1 Wife.

George's wife appreciated the difficulty of reflecting her husband's life, although she felt fortunate that she had been able to include photographs from the times before she was married to George and she could see that they triggered memories for him even if she could not always share them.

It was important for care staff to involve the person as much as possible, but when not possible in conventional ways, as with George, the staff appeared to feel disappointed, even suggesting that George had not been the best choice of person to undertake LSW with; this is reflected by the deputy manager:

"But I think and even with a different person I think we probably could have got so much more out of it – for the staff team and for the person involved really." Cs1 Deputy manager.

Similarly, the OT assistant felt that:

"With other people it might work a lot better I mean George's a case on his own isn't he?" Cs1 OT assistant.

Opportunities for George to contribute to his own story were denied; not out of a wish to exclude him, rather out of a lack of understanding how best to include him. In working with George initially and then Harry, RMNb seemed adept at using snippets of information he knew about their life stories to engage them in conversation and expand the knowledge. He describes how he used the knowledge that George's wife had told him about how George used to play semi-professionally for a local football team:

"I brought the subject up and he told me about he played left back his right back partner was a guy called Charlie Smith and I said 'so what was he like' and he told me he described him as a 'big big lad' and I said 'So there was two hard men at the back then George' and he just laughed and he said "Yeah, yeah" he took no prisoners sort of thing [laughs]...so he actually started talking so I picked up a lot about that from that." Cs2 RMNb.

It appeared that more value was placed on working directly with the person with dementia as in Cs3 and 4 than working with family carers.

9.3 Personal disclosures

In Cs2, RMNc was privy to some private and intimate memories of Harry's life. In the interview she described the circumstances and nature of this information:

"Harry told me some quite personal information that others might not be aware of, including wife and ... I just let him tell me what he wanted to tell me then the conversation moved on. It wasn't uncomfortable but I was very aware of what he was telling me was very, very personal information." Cs2 RMNc.

The nurse manager spoke of personal disclosures taking place within the context of a trusting relationship when using LSW:

"You do access you know family secrets people do tell you things that you would never be privy to because you are using photographs and you know working on a one to one and spending a lot of time doing it people do tell you things that you would never be told, you know private things." Cs4 Nurse manager.

The reflections of the nurse manager caused me to re-assess my own assumption that it had been by chance that Harry had shared the information with a nurse who was sensitive and had integrity; he had most likely shared this information with her *because* of the qualities she had. This challenged my own belief that Harry would not be able to discriminate between staff he could trust and those he could not. I shared these thoughts with the nurse manager as they occurred to me during the interview and she responded:

"I think your relationship with the person is the key that opens those disclosures aren't they so I think if you've got that far with that person that they trust you to tell them something like that then I think you must have the skills and the ability to take it." Cs4 Nurse manager.

In order to maintain the dignity of Harry a decision was made to edit his story. This felt a difficult decision but was vindicated when we met Harry in the nursing home to show him his pen picture, as RMNc described:

"He almost – not looked embarrassed but suddenly the thought of putting things in that he didn't want people to know was quite alarming to him so I think leaving out them bits was a good thing"

cos I think it would have been quite stressing for him if we'd put in all about what he told me." Cs2 RMNc.

The nurse manager working with Eileen had concerns that Eileen's sensitive disclosures may be shared with other volunteers or day centre attendees:

"I was very aware that Eileen talked about personal things that had happened in her lifetime ... and I was a bit concerned about her talking about that at the group and not getting the right level of support...and if she was talking to another member of the group who would not then know quite how to handle it if one of us wasn't around, but that seems to have been unfounded she's not mentioned it she seems to only talk about that when it's on a one to one in a more private setting." Cs4 Nurse manager.

The experiences from this research reflect the complexity of LSW. Personal memories can also relate to photographs, this was evidenced when Georges' wife spoke of choosing not to include some photographs in George's life story book. I asked her to enlarge on her decision and she explained:

"It was about half a dozen that I decided I didn't want to go in... because Bob was such a comic he would actually do things ... just silly things and obviously the camera's caught him on camera they were the ones I wouldn't have wanted, cos they was quite personal to me as well." Cs1 Wife.

Personal disclosures are clearly an issue that need to be considered by anyone undertaking LSW, not only for the people with dementia but also potentially for family carers. The next section explores the associated issue of confidentiality.

9.4 Confidentiality

The experience of working with Harry raises the issue of respecting the confidentiality of others who appear in a story who may not have consented, as in Harry's wife's situation. Some general information relating to George's son and daughter were contained in his life story book; it is unlikely any would have caused offence or harm but its inclusion was not something we were able to check out with George's wider family.

Eileen and Rachel and both their daughters had no concerns over confidentiality and Eileen's daughter described an openness of information within their family:

"We don't have any secrets in the family, we've always been open and honest, that's just how we are. Nothing has ever been hidden away." Cs4 Daughter.

What it means to keep a person's life story confidential is open to interpretation and the support worker working with George interpreted it that his story was not to be shared widely in the team:

"It's just those staff that we've told about it cos it's supposed to be confidential isn't it cos it's in a folder so I don't think everyone knows that it's there." Cs1 Support worker.

This reflects the need to be explicit about what confidentiality means for each piece of LSW.

9.5 Who is the story for?

Clarifying who is the main beneficiary of LSW and its exact purpose in each situation is an issue that has arisen from the LSW research. Although not explicitly raised by participants its importance has become evident through the reflexive process undertaken during the LSW research data analysis.

Eileen kept possession of her life story book and was encouraged to take it and share it with others; she took it with her to the day centre, but staff at the social care resource centre where also attended had no knowledge of the book. It may have been that Eileen forgot to take it with her; that no-one asked to see it or that she chose not to share it; consequently opportunities were lost for staff to get to know more about Eileen.

Rachel's book belonged to her and was kept in the drawers in her room and was shared with family members and care staff. However, as previously discussed it was in scrapbook form and not robust for use by lots of people. Staff had suggested it may become a legacy for Rachel when she eventually died, but it seems likely the poor quality may detract from it being a pleasing tribute to Rachel's life.

Harry's story was told from his perspective but he was not reminded of it and the pen picture remained hidden in care notes once he moved into the nursing home.

George's book probably had the most utility for the widest range of people; it served as a reflection of his life for use with him, it was therapeutic for his wife and was also a resource for care staff. The book was not kept with George for fear of it becoming damaged or lost and was kept in the nursing office for use with George.

9.6 Consent

Consent to participating in LSW is paramount but, as previously discussed in Chapters Three and Four, consent cannot be seen as a one-off event when working with people with dementia.

When previously using LSW in the Trust in 1990, we had devised a consent form; I was reluctant to use such a form for the research as I was concerned a form would indicate a one-off act and I was interested to see how the issue of consent for the LSW was addressed through the research.

RMNc working with Harry was the only participant to explicitly refer to consent; she felt that it was something she had managed to achieve with him:

"...consent I think is quite a big point because obviously I'm talking to Harry and saying ... I'm wanting to get your information and he's saying well why? and getting their consent when they might not be able to give consent I think is a bit of an issue especially around this whole Mental Capacity Act coming out ... I think that was something that was important and I was able to do in this case but it might be a stumbling block if it was to be done another time." Cs2 RMNc.

It would have been difficult to fully assess Harry's ability to understand precisely the nature of sharing his story and what would happen with this. No matter how well a person with dementia has appeared to understand what is involved with LSW the responsibility remains with staff to ensure that this information is not misused. Perhaps there was an assumption that consent to taking part in the research had also included consent to participate in LSW and, on reflection, it would have been prudent to explicitly separate the two and enquire precisely how consent had been achieved.

9.7 Discussion

This next section compares the findings from the LSW research with existing literature. The main findings presented in the previous section are summarised in Table 9.1.

Table 9.1: Summary of Chapter Nine findings

Considerations when using LSW with people with dementia	
Involvement	Whose story? Consider a negotiated product, consider alternative to conventional rules of narrative
Clarity	Clarity on commencement about the purpose of LSW; whose story is it?
Personal Disclosures	Be prepared for any disclosures, ensure adequate supervision and support. Consider what remains private and what becomes public
Confidentiality	Consider everyone involved in the story; negotiate who has access to the story
Consent	An ongoing process; need for consent monitoring increases as increasing levels of life story information are divulged

The different ways the people with dementia and their family carers were involved in the LSW extends the knowledge available from the current evidence. For staff it seemed very important that the person with dementia was the author of their own story and this was possible with Harry, Eileen and Rachel. Where this proved difficult, as with George staff felt that perhaps he had been the wrong person with whom to undertake LSW. There are potential challenges for some people with dementia to contribute to their own life story in conventional ways and this was clearly the experience of care staff working with George. Baldwin (2008a) describes how some people with dementia are denied the opportunities to talk and share their stories because the traditional 'rules' of narrative are not always relevant when a person has a cognitive impairment. The rules of narrative are explained by Baldwin (2006) as:

a: narrative agency; where people have the opportunity to express themselves. This is generally expected by others, to be recognisable as narrative.

b: narrative consistency and coherence; where events, characters and context are held together as an understandable whole and links are made between the past and the future.

c: emplotment; where characters, events and context in a narrative are positioned within a relationship to one another.

George appeared to struggle to conform to such rules due to difficulties with memory, communication and ability to describe situations in a chronological way.

A challenge exists to develop a broader perspective on involving a person with dementia in telling their story and Bower (1999) argues that health care professionals may need to suspend expectations about how older people use narrative. Baldwin (2006) describes some alternative approaches that may 're-possess' the narratives of people with dementia by interpreting the rules of narrative more flexibly. This next section appraises the findings from the LSW research in light of Baldwin's proposed approaches to enabling people with dementia to tell their stories.

The piecing together of smaller stories is one way that Baldwin (2008a) offers to enable a person with dementia to contribute to their own narrative. This process has been described as 'narrative quilting' (Moore and Davis 2002), where staff collaborate with the person with dementia over time in order to re-introduce details and topics from earlier conversations to help the person expand on it. The LSW research data shows how RMNb successfully managed this with George and Harry, although as discussed in Chapter Seven this information did not get shared in any life story product. Crisp (1995) demonstrates that fragments of memory and metaphor can be brought together to construct the identity of the person with dementia.

Joint authorship is another way of supporting a person's ability to contribute to their own story. Phinney (2002) argues that when a person has dementia, the telling of their own story alone becomes impossible and, as stories are jointly lived,

so they should be jointly told. Koch and Crichton (2007:90) describe this co-authorship in their longitudinal research aimed at preserving the self identity of people with dementia living in the community:

'We generate stories with ... people living with dementia, and their significant others, including health care providers. Working with participants we merge their stories into one narrative. The narrative, a composite of stories generated, is written so that it can accompany the person through life and into particular health and social care settings.'

Keady *et al.* (2005) also discuss the value of working alongside people with dementia and their families using life stories not only to document a life history but also to find meaning in their experience of receiving a diagnosis of dementia. The authors further develop this collaborative approach to storytelling through co-constructed inquiry which involves the person with dementia, their family carer and researcher negotiating a life script (Keady *et al.* 2007b). Frank (1995) goes as far as saying that stories told without the involvement of others are bound to fail and similarly, in discussing people with a learning disability, Meininger (2005:109) argues that:

'a life story does not exist outside the intense intertwining with other people's life stories.'

Despite the literature supporting a co-constructed narrative, staff in the LSW study appeared to give precedence to what the person with dementia could contribute and perhaps valued less the contribution of family carers to the story. The staff working with George felt disappointed his story had been mainly from the perspective of his wife, even though she herself was proud of how she has provided a balanced story for George. McAdams (1995) argues that narrative serves to bring purpose and meaning to a persons identity through integrating past, present and future as perceived by the person. In having another person tell his story George was not able to narrate what was important to him about his life and his identity. The nurse manager was concerned that sometime family contributions can overshadow those of the person with dementia. Chapter Seven of this thesis discussed how both daughters would have liked more of a say about what went into their mother's life story books and more influence over the quality of the final product. Baldwin (2008b) warns that when another person takes over

the narrative of a person with dementia, care needs to be taken to ensure that person is not distanced from society. Perhaps the staff felt concerned that if they did not privilege the story of the person with dementia they would be in some way excluding them. The observations from the LSW research may suggest an emphasis on the person with dementia rather than the relational approach advocated by Nolan *et al.* (2006). The findings reflect the complexity for care staff working with people with dementia in successfully being able to incorporate and integrate the views and opinions of both the person with dementia and their family members.

The LSW research reflects the challenges for George's wife, as his second wife, to present a comprehensive life history for George. Sherman and Boss (2007) discuss the complexities in caring for a person with dementia for spouses who have married later in life; there can be little shared family history between the families and sometimes there can be conflict between the spouse and their grown up step children. George's wife was aware that this could have been difficult but described how she overcame the difficulty by including photographs and stories from before she had been married to George. It may be that the perceived challenges for spouses married later in life are over-estimated and in reality few spouses and even fewer child carers can provide a comprehensive life history for the person with dementia dating back to childhood and early adolescence.

An unexpected finding from reflecting on the LSW research data was the lack of clarity about the main purpose of the LSW with each person with dementia. The use of LSW to improve care staff understanding of the person with dementia is well-documented (Gibson 1991, 1994; Hansebo and Kihlgren 2000; Batson *et al.* 2002; Gibson and Carson 2010; Thompson 2010) and appeared to be a significant function of LSW within the research reported in this thesis. The LSW research and the literature have also revealed the potential of LSW as a therapeutic activity for family carers (Caron *et al.* 1999; Kellett *et al.* 2010). Harry and Rachel particularly appeared to benefit personally from sharing their life stories and this was demonstrated by their enjoyment. Rachel's life story book was particularly helpful to care staff when she moved to a new care environment and staff perceived the

life story books may be valuable as a legacy to the person with dementia when they died. The LSW research identified the lack of clarity about the intended use of the LSW product and yet this seems crucial before being able to agree on the format and content of the LSW product. An example from my recent clinical practice highlights the issue:

A support worker developed a life story book with a female resident in a nursing home; the book was produced in collaboration with the resident and her family members. When complete, the support worker showed me the book; it was beautifully collated in a white photograph album, with parchment separating each page and photographs mounted individually. After admiring the book, my first thought was it would be difficult to use with the resident on a regular basis by staff as it would easily become damaged. We agreed that a more robust scanned version would be required, however the resident died quite suddenly and the format and presentation of the book could not have been more suitable for a legacy to the woman's life.

Table 9.2 reflects the learning from this LSW research and recent clinical practice and details a possible range of uses of LSW with people with dementia. In practice, there may be an overlap and the precise use may not always be evident until the process is underway.

Table 9.2: The range of uses of life story work with persons with dementia

Overall aim to benefit person with dementia
For the person with dementia to tell their story – as a way to be heard or for therapeutic benefits
As a tool to use with person with dementia as part of care
Therapeutic for family members – participating and reviewing life
Helping staff to understand and care for the person
As a way of expressing experience of condition / and or services
As a legacy
Assistance in transition between care environment

For whom the life story work actually belongs to is more contentious that might first appear. The care staff working with Rachel and Eileen would firmly say that

their stories belonged with them. At a recent LSW conference, there were fierce assertions that the story belongs to the person with dementia and this was generally unchallenged. In reality, this argument around ownership is more complex than it may initially appear and data from the LSW research demonstrates the range of ways the life story products were stored and who had access to them. Gibson (1998) highlights the importance of agreeing where reminiscence records are stored and subsequently disposed of.

The LSW research demonstrated that private and personal stories were sometimes divulged during the LSW process. It was evident that some of the disclosures were not for public knowledge and were not included in the person's life story product. Clarke *et al.* (2003) highlighted that older people were sometimes pleased to share information verbally but did not always wish it to be recorded. The older people in the study by Clarke *et al.* (2003) did not have dementia and were able to understand the process and clearly articulate their wishes. Gibson (2005) urges staff working with people with dementia to exclude sensitive information from records but not from discussions.

Regarding the range of personal information that may be offered through LSW Brooker (2010) proposes the analogy of a chest of drawers that disclosures can be sorted into; this is represented in Table 9.3. Harry most definitely shared bottom drawer information with the staff nurse within the context of his relationship with her and as such it was correct to keep that private and not public.

Seeking consent is clearly important through all stages of LSW but, when referring to Brooker's (2010) previously described analogy, the need for increasing re-assessment of consent becomes more important when working with 'middle drawer' material and especially that it can be established with whom the person wishes the information to be shared. It was interesting that the staff member who spoke about consent was the staff nurse working with Harry, perhaps reflecting her awareness of the ethical issues faced.


Table 9.3: Analogy of how personal information may be categorised

Drawer	Type of Personal Information
Top Drawer	Information freely available about a person often kept on case notes and that may be collected on admission. May include: demographics, what the person did for a living, family members, basic preferences.
Middle Drawer	Information a person may choose to disclose in the context of a friendship or caring relationship and that might be disclosed when using LSW. May include: Thoughts, feelings, beliefs, significant relationships, more personal memories.
Bottom Drawer	Information that may be private to a person or perhaps a few close others and not for the public domain. May include: Family secrets, private or traumatic memories.

Adapted from Brooker (2010)

Figure 9.2 identified the contexts in which different levels of information might be gathered, the shaded box suggests that there may be a continuum of levels of information that may be disclosed beyond what is anticipated. The model of process consent taken to the LSW research is also highly relevant when undertaking LSW in the context of practice.

Figure 9.2: Consent in the context of level/type of information gathered

Top Drawer	Middle Drawer	Bottom Drawer
Information gathered on admission	Information gathered as part of LSW and within a relationship	Information that may be disclosed as part of psychotherapy / life review
Kept in care records and commonly known to many people	Negotiated how it is displayed and who is able to access it	Most likely kept in confidential records or kept between the person with dementia and the person it is disclosed to
Increasing need to re-visit and re-assess consent using process method 		

The issue of what information about family members should or should not appear in a person's life story book has received little attention in the literature to date but may become more widely reported as LSW is more commonly used. Maintaining confidentiality and seeking consent remains a challenge, particularly with family members who may not wish to be included in the story told by the person with dementia. Gibson (2004), however, notes that a sensible perspective needs to be maintained to the issue of confidentiality in order to enjoy the benefits of reminiscence type work.

The final chapter of this thesis considers the findings from the previous four chapters and synthesises them to propose a re-conceptualisation of LSW in health and social care practice. The chapter will also make recommendations for further research and also for practitioners planning to undertake LSW.

CHAPTER TEN

FINAL DISCUSSION AND CONCLUSION

10.1 Introduction

The focus of this thesis has been the use of LSW with older people with dementia in health and social care. This final chapter assembles the key findings of this thesis and appraises their contribution in understanding LSW and its association with providing person-centred care. The chapter demonstrates the extent to which the study research questions were answered; these being to explore:

1. What helps or hinders the process of implementing LSW?
2. What are the benefits and/or difficulties in undertaking LSW?
3. How does LSW effect the care the person with dementia receives?
4. How is LSW experienced by all who participate?

The chapter appraises the unique contribution of the thesis to the research and practice of the care of older people with dementia. The initial conceptual framework developed at the outset of the study (see Chapter Two) is refined in light of the findings. The chosen research methodology is appraised and the limitations of the study are outlined before finally the plans for dissemination and the recommendations are presented.

10.2 The contribution of this thesis

The thesis makes a unique contribution in four important areas. Firstly, the findings add a unique contribution to the understanding of the process of undertaking LSW which extends the current empirical evidence base. Secondly the thesis offers a re-conceptualisation of the use of LSW and the achievement of person-centred care outcomes with people with dementia and their families in health and social care. Thirdly, the thesis reports an extended understanding of the experience of participating in LSW from a range of perspectives. Finally, the thesis demonstrates the relevance of a process consent approach to actively

involving the participants in the research process. More specifically the LSW research makes the following contribution:

10.2.1 Research

- Demonstrates constructivism as a relevant methodology for investigating multiple perspectives including those of people with more advanced dementia
- Critiques the application of a process consent approach to the involvement of people with dementia in research
- Takes a longitudinal approach to the use of LSW with persons with dementia

10.2.2 Practice

- Reports the nature of factors that may help or hinder LSW to be implemented in practice
- Provides a re-conceptualisation of how LSW can enable person-centred care for persons with dementia
- Highlights the ways that personhood can be manifested in persons with dementia and makes connections between LSW and upholding personhood.
- Presents a critical examination of the particular complexities of undertaking LSW with people with dementia and their family carers

10.2.3 Education

- Offers new insights into the process of undertaking LSW on which future educational programmes may develop to support the implementation of LSW
- Demonstrates the potential of LSW as an educational practice based tool

10.2.4 Policy

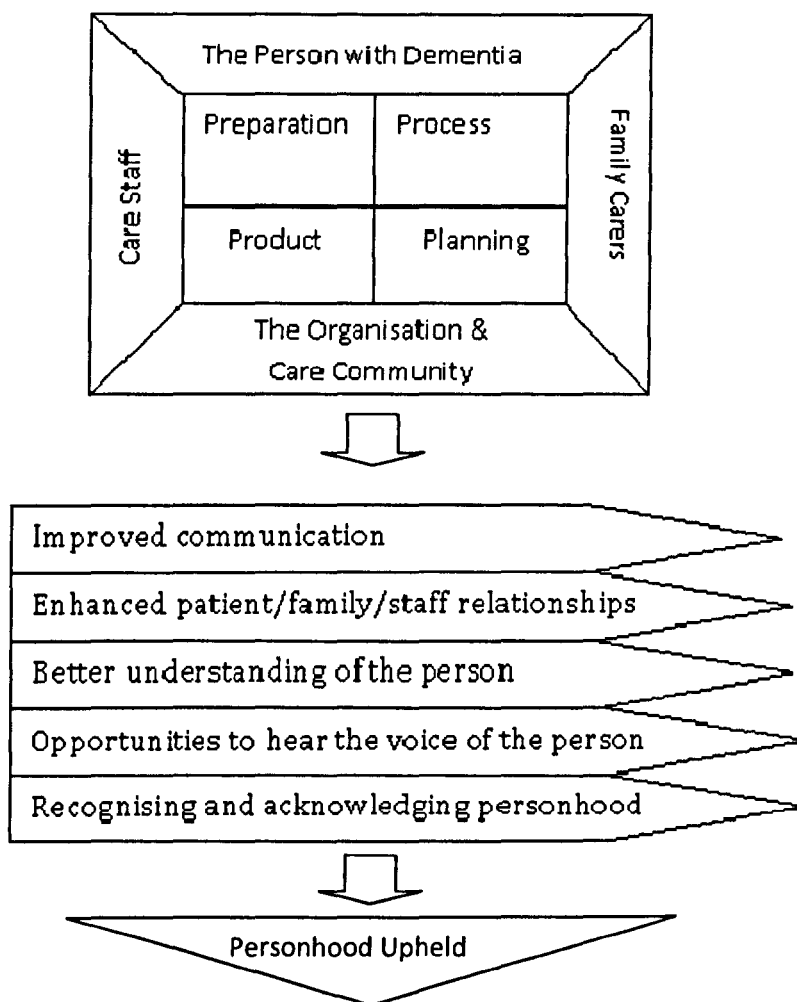
- Provides evidence for policy recommendations advocating the use of LSW to enhance dignity and person-centred care with older people with dementia

10.3 Re-conceptualisation of LSW within the context of providing person-centred care

The findings from the LSW research are reflected in a re-conceptualisation of the relationship between LSW and person-centred care, which is shown in Figure 10.1. This extends the initial conceptual framework I presented in Chapter Two in a number of ways that will now be discussed.

Figure 10.1:

LIFE STORY WORK AND PERSON-CENTRED CARE



The outer square represents the stakeholders that need to be considered and involved when LSW is undertaken and addresses the findings answering the fourth research question of the study. This extends the understanding of the initial conceptual framework which did not clearly articulate different stakeholder

perspectives on LSW. By considering the different needs of all of these stakeholders LSW is more likely to benefit all and more likely to be sustained. The perspective of all stakeholders is discussed in section 10.6.

The divided inner square illustrates four essential aspects of LSW, reflecting the thesis findings on the process of undertaking LSW. This section identifies the considerations needed at each stage when LSW is implemented and addresses research questions one and two. This part of the re-conceptualisation combines the process and ethical elements of the initial conceptual framework. Section 10.4 reflects these findings.

The five arrowed bars below the square represent the person-centred processes that were observed through using LSW. This extended understanding of the initial conceptual framework and more boldly integrates the outcomes from LSW into an understanding of person-centred care for older people with dementia. This is explored in detail in section 10.5 and addresses the third research question. The triangle below the arrowed bars reflects the successful implementing of life story work into practice; that is the upholding of personhood.

10.4 Understanding the process of undertaking LSW

This thesis offers unique insights into the process of undertaking LSW with people with dementia. This section appraises the extent to which the first two research questions were addressed. The process of undertaking LSW as been divided into the four activities observed through the LSW research, these being: preparation, process, product and planning care. The process and the product can be difficult to separate and so are discussed concurrently in this conclusion.

10.4.1 Preparation for undertaking LSW

Current literature has identified the need for adequate preparation before undertaking LSW. This includes the need for training (Batson *et al.* 2002; Gibson and Carson 2010; Kellett *et al.* 2010); and 'templates' or prompts to facilitate gathering of LSW information from the person with dementia have been used (Bakken *et al.* 2010; Gibson and Carson 2010; Thompson 2010). The research

reported in this thesis confirms previous identified need for preparation but also draws attention to the need for ongoing support throughout the LSW process.

The findings presented in this thesis indicate that some staff who had not previously undertaken LSW, valued the structure and prompts developed to guide the gathering of LSW information. Current research has not been explicit about what these entail or how and with whom they were developed. The difficulties that some staff experienced initially in undertaking LSW and the range of complexities that emerged would suggest the need for LSW to be adequately facilitated.

This thesis has identified significant features important in the preparation for undertaking LSW. It is recommended that future evaluations assess the impact of education, training and resources on the successful implementation and use of LSW in health and social care practice.

10.4.2 The process of gathering LSW information and the LSW product

This thesis offers unique insights into both the process and the product and concludes that both are of equal importance, departing from previously held views that the process is the *most* important aspect (Gibson 2005). The process enables individual relationships to develop whilst the product enables opportunities for the person with dementia to make connections with the wider care community.

In contrast to the largely uncritical reports of LSW usage this thesis has highlighted the complexities of undertaking LSW in practice with persons with dementia. The potential for upsetting memories to be evoked has been most commonly reported in previous literature with people with dementia (Murphy 2000) and older people more generally (Adams *et al.* 1998; Clarke *et al.* 2003). This concern was largely absent from the LSW research presented in this thesis. The skills and experience of the care staff participants who work specifically with people with dementia may enable them to interpret and manage distress differently to less specialist care staff participants in previous studies. The complexities detailed in this LSW research are un-reported in existing literature. These include, different contributions to the

story, whose voice to privilege, private memories being evoked, quality and potential under-use and over use of the life story product.

A further, previously unreported complexity is the challenge for staff who develop more reciprocal relationships through using LSW. As partnership working with people with dementia and their family carers becomes more prevalent, then consideration needs to be given to the support systems required. These may include negotiating professional boundaries, codes of professional conduct, emotions and risk factors, all of which are best considered in a supervisory relationship.

The LSW research has identified the need for LSW to be undertaken within a planned and facilitated framework for development. Clarke *et al.* (2003) discuss the implementation of LSW within the context of practice development; however the authors did not explore in detail what this meant and how it might be sustained. More recently evaluative accounts have begun to make more explicit the potential role of practice development in achieving a largely instrumental use of LSW with persons with dementia (Gibson and Carson 2010; Thompson 2010). If LSW is facilitated using a comprehensive approach to its development then this may offer improved opportunities for impacting on culture, developing care staff and improving the quality of care for persons with dementia and their families.

10.4.3 Planning care to incorporate LSW information

Moos and Bjorn (2006) report a dearth of studies that translate the life story into care interactions and that actively encourage resident initiatives. This thesis demonstrates the dichotomy in some of the case studies between an approach to care that had a focus on tasks and LSW which had a focus on the individual. It is not surprising then that in some of the case studies the LSW information collated did not become incorporated into care practice. This is reflected by George's care plan that did not reflect the life history information learned about him. Conversely in the day centre that Eileen attended, LSW was incorporated into everyday discussions and work with the persons with dementia who attended.

In summary, for LSW to be successfully implemented, this thesis demonstrates that there needs to be investment in its preparation in the form of education, resources and ongoing support and supervision. A number of previously un-reported considerations were observed within the use of the product that may contribute to the development of protocols for 'good practice' when implementing LSW. A challenge remains in how to integrate LSW into the person's care and share it more widely and this reflects an area worthy of further research.

10.5 The impact of using LSW on the delivery and outcomes of care for older people with dementia

Previous research into the use of LSW with people with dementia has drawn attention to the connections between LSW and person-centred care (Gibson 1991, 1994; Murphy 2000; Batson *et al.* 2002; Kellett *et al.* 2010; Thompson 2010). To date, the empirical literature has failed to clearly articulate an association between the use of LSW and person-centred outcomes for people who have dementia. My initial conceptual framework combined with a review of the person-centred care literature (see Chapter Two) offers a limited vision of person-centred care. I also questioned a tentative link between the use of LSW to enable person-centred care. The research reported in this thesis has made the connection clear (McKeown *et al.* 2010b).

This thesis has reported the opportunities offered through LSW for the processes of person-centred care to be 'enabled'. Through the analysis of this LSW research data my initial understanding of person-centred care processes with people who have dementia has been extended and observed to be:

- Improved communication
- Enhanced patient/family/staff relationships
- Better understanding of the person
- Opportunities to hear the voice of the person
- Recognising and acknowledging personhood

The ultimate outcome of person-centred care with persons with dementia, I would argue, is the 'upholding of personhood'. This thesis has appraised the LSW

research findings against the three conceptual frameworks for person-centred care identified in Chapter Two. This appraisal confirms the observation of person-centred processes occurring through the use of LSW.

The literature to date has demonstrated that improved communication (Murphy 2000; Batson *et al.* 2002), enhanced relationships (Hansebo and Kihlgren 2000; Kellett *et al.* 2010) and a better understanding of the person with dementia (Gibson 1991, 1994; Murphy 2000; Batson *et al.* 2002; Russell and Timmons 2009) are outcomes from the use of LSW. These themes are consistent with the LSW research reported in this thesis and with current conceptualisations of person-centred care presented in Chapter Two.

The understanding of the person with dementia in the context of their whole life seemed to lead to a deeper relationship, but also raised issues of continuity and discontinuity for the care staff and the people with dementia. This draws attention to the need for LSW to be accompanied with the appropriate facilitation and supervision so that discontinuity can be noticed and, where possible, resolved for the person with dementia and the care staff.

Understanding the person with dementia as a 'person' rather than a 'patient', allows the voice of person with dementia to be heard. In some cases, this was literally and staff were sometimes challenged in their views of the person's abilities. The data from the LSW research on 'hearing the voice of the person with dementia' was consistent with the VIPS model (Brooker 2004), reflecting the more specific features of person-centred care when applied to people with dementia.

Care staff appeared less tuned in to embodied manifestations of the person. The literature on embodiment (Hughes 2001; Kontos 2004) adds to the critical debate on personhood. For the recognition of a range of manifestations of personhood to be realised in practice, care staff (and potentially family carers) will need to develop knowledge and skills to recognise more subtle manifestations of personhood. This may provide opportunities for the personhood of people with more advanced dementia to be recognised by giving significance to some of the basic bodily care interventions.

The LSW findings presented in this thesis observed features that were interpreted as 'personhood being upheld' and included pride, enjoyment and the person with dementia making their wishes known.

The LSW research highlighted the importance of: communication, developing a relationship, understanding the person and hearing the voice of the person with dementia in enabling care staff to recognise personhood. If personhood can be recognised and then responded to then the outcome of maintaining personhood is possible, even if in some cases this was maintained for a few brief moments. Achieving person-centred care is in itself a process and I concur with McCormack's vision for practitioners: *'becoming more person-centred in our practice'* (McCormack 2004:37) rather than aiming for an ideal of person-centredness. In this way, carers can develop their approach to care and not feel they have failed by not achieving some gold standard of being person-centred. LSW provided opportunities for aspects of person-centred care to be facilitated and enhanced and for staff and family carers to experience what it feels like to communicate, be in relationship, understand the person and hear the voice of the person with dementia.

This study indicates that LSW is a practical way of enabling and supporting the processes of person-centred care. Other interventions may also provide such opportunities, but the strength of LSW is its simplicity and practical application and its emphasis on finding out about the person beyond the patient and giving voice to the person with dementia.

10.6 The experience of LSW from the perspectives of all concerned

The major focus of current LSW literature is on the experiences of care staff in using LSW. Previous studies have explored family carer experience of LSW but very few have investigated the experiences of people with dementia. This thesis reports novel understandings of the experience of LSW with people with different stages of dementia whilst also extending the understanding from the perspectives of care staff and family carers.

10.6.1 The experience of the person with dementia

The views of people with dementia in using LSW remains largely overlooked. Where people with dementia have been invited to share their experience of LSW this has usually involved people in the earlier stages of dementia (Keady *et al.* 2005), or in evaluative rather than empirical accounts (Murphy 2000; Batson *et al.* 2002). This may reflect the perceived complexities of obtaining ethical approval for involving people with dementia in research, a challenge that this study successfully addressed.

The choice of research design in the LSW research was critical as it enabled both formal and informal conversations to take place and these generated textual data reflecting the experiences of the participants who had dementia. Such 'text', however, does not reflect the range of ways in which the person with dementia expressed their experience of LSW. My experience was consistent with Booth and Booth (1996), who argue the need for a range of approaches to report the experience of people unable to articulate verbally. Whilst none of the participants in this thesis could be described as 'inarticulate', expecting them to reflect verbally on their experience of LSW was not always feasible or appropriate. Reflecting on experience requires the person to remember that they had been involved in LSW and this was not always possible. Rachel for example, showed bemusement at how her life story book had come into being, an experience consistent with participants in the evaluation undertaken by Murphy (2000). Consequently, data here also included observations made by myself or other participants and seized opportunities to discuss LSW whilst the person was looking at the pen-picture or life story book. These methods were consistent with the constructivist methodology chosen.

Current LSW literature reporting the experience of people with dementia demonstrates that LSW books were valued (Murphy 2000). Participants enjoyed the time spent with them and companionship that was associated with the use of LSW (Murphy 2000; Batson *et al.* 2002). The LSW research data reported in this thesis also reveals the participants with dementia appeared proud of their life story product, or representations of themselves within the product. Harry was

able to verbalise his desire for '10,000 copies' of his pen picture to be printed. Non-verbal evidence is demonstrated by Rachel, George and Eileen 'showing off' their life story book to staff or other residents. Similarly the account of George walking around the ward holding his life story book as if he was 'Eamon Andrews', and the image that evokes, is extremely powerful, even when not witnessed personally.

The participants with dementia were able to share their experiences on the content and quality of the book. Rachel could clearly distinguish between the photographs that she had chosen and that evoked pleasure for her. This contrasted with her notable displeasure of a recent photograph of herself that had been added to her life story book by care staff. George's obvious pride of a photograph showing off his 'physique' suggested that he was pleased it had been included. Personally witnessing Harry's concern, and then immediate relief, when he realised that the private information he had shared with the nurse had not been written into his pen-picture, was a poignant reminder of how LSW has the potential to help as well as harm. Eileen articulated her pleasure at having all of her photographs together in one location and clearly showed pride at talking through the photographs of her family members. Eileen was not, however, entirely satisfied with her life story book and this was reflected by the mild irritation and facial expressions that she displayed when reading the misspelt name of her deceased husband. Her non-verbal communication spoke volumes and was a clear indication of her experience even though it was never put into words. The comments Rachel made about the spelling mistakes in her life story book also reflect her experience.

Previous literature has not investigated the perceived quality of life story products and this novel finding was exposed through the participation of previously unheard stakeholders. There is the potential for future research to explore the impact of photographs, recent and from the past, on the personhood and self-esteem of the person with dementia across different stages of the condition.

10.6.2 The experience of family carers

Current LSW research has not widely reported the experience of family carers in participating in LSW. Where research has explored the family carer experience it has predominantly focussed on family workshop approaches to LSW in long term care (Hepburn *et al.* 1997; Caron *et al.* 1999; Kellett *et al.* 2010). Individual approaches to the use of LSW in secondary mental health services have been evaluated Batson *et al.* (2002) and Thompson (2010) but there is limited reporting of family member's perceptions. A further limitation of existing research is the absence of an exposition of spouse compared to child family member experience of using LSW.

The findings reported in this thesis demonstrate how all three family carer participants appeared to value LSW as a way of 'showing off' the person behind the dementia. Maintaining the personhood of the person with dementia has previously been reported in this thesis as a possible 'caring task' for family carers. This observation has previously been reported by Bowers (1988) and termed 'preservative care'. Such care is characterised by the attempts of the family carer to preserve the dignity and self-esteem of the person being cared for. The use of LSW enabled family carers to undertake this perceived task and is consistent with what Nolan *et al.* (1996), extending the work of Bowers (1988), term 'reconstructive care'. One purpose of this is to: '*rebuild an identity on the foundations of past histories and biographies.*' (Nolan *et al.* (1996:45). Kellett *et al.* (2010) discuss how LSW enabled family carers to appreciate the accomplishments of the person with dementia they cared for and this gave them strength to continue caring. This may explain why both daughters felt in some way that they would have liked more of a say in what went into their mother's life story books. Accounts of individual approaches to LSW do not report the ways in which family members are involved in developing the life story books (Batson *et al.* 2002; Murphy 2000). In comparison the literature on family workshop approaches to LSW detail precisely how family members were involved in the process of LSW (Caron *et al.* 1999; Kellett *et al.* 2010). The findings presented in this thesis highlight that by promoting the choices of the persons with dementia, care staff

may have unintentionally precluded the daughters from fulfilling an essential caring task.

Family members all appeared to value the role of LSW in enabling memories to be shared and all showed examples of coaxing the person with dementia in remembering and conversations focussed around past memories. This is consistent with previous accounts (Murphy 2000; Batson *et al.* 2002; Kellett *et al.* 2010) where family members valued life story books as a way to stimulate memories and conversations with the person with dementia. This reflects the greater involvement of the two daughters in use of the LSW product than in the process of preparing the product.

Previous research has reported the value of LSW in enabling family members to escape from a 'disease saturated context' (Caron *et al.* 1999; Kellett *et al.* 2010) and this was clearly replicated in the LSW research through the experience of George's wife who was pleased to be reminded of the person she married and loved. LSW allowed Rachel to be distracted from a preoccupation with why she was in hospital and enabled her daughter to steer the conversation onto aspects of her life they could both enjoy speaking about. The explicit use of LSW as a therapeutic intervention for family members is an important area for undertaking future research.

10.6.3 The experience of care staff

The LSW literature, to date, has focussed largely on the experience of care staff. Previous accounts report that staff find LSW enjoyable and satisfying (Batson *et al.* 2002; Kellett *et al.* 2010; Thompson 2010); enables them to see the person behind the dementia (Murphy 2000; Batson *et al.* 2002); and provides opportunities and prompts for communication (Murphy 2000; Batson *et al.* 2002). The findings from this research are consistent with these observation and all care staff who participated reported that they had valued using LSW with the person with dementia they cared for allowed staff participants to gain a greater depth of understanding about the person with dementia allowing them to be seen beyond the condition of dementia.

Previous research has detailed the difficulty in finding 'time' to undertake LSW (Adams *et al.* 1998; Clarke *et al.* 2003; Gibson and Carson 2010) but has not explored in depth what this actually means. This thesis contributes to an improved understanding of the tensions that exist for some staff in undertaking LSW in the face of other priorities. The LSW study illuminated the persistence of a task oriented culture in some care settings which creates a dichotomy for care staff who wish to engage more with the persons they care for and yet feel pressure to 'get through the work'. Staff insights were particularly important in developing a greater understanding of the process of undertaking LSW in practice and these are reflected in section 10.4 and provide a unique contribution from the perspectives of care staff.

A comprehensive understanding of staff experience of LSW is well reported in the literature. Any future research that seeks to explore staff experience of LSW would most usefully seek to gain more in-depth understanding of a particular aspect of using LSW, for example interactions with family carers or overcoming specific challenges reflected in previous research.

10.6.4 The experience of the organisation and care community

Current research does not investigate the experience of the organisation (including managers) and the care community. This present study did not seek to specifically understand the experience of the wider organisation or managers to LSW. The findings from this study do, however, offer some insights.

The LSW findings presented in this thesis draw attention to the significance of the 'context of care' in helping or hindering the use of LSW. The significance of context is reflected in the most recent conceptualisations of person-centred care, and most comprehensively in the Person-centred Nursing Framework (McCormack and McCance 2010). The data from the LSW research was found to share some of the aspects to the workforce and care environment elements of the PCNF.

This thesis reports the range of ways that managers were involved in the research process from the conception of the project and yet this did not, in all cases, translate into their active promotion and support for LSW. This experience is

comparable with the work by Gibson and Carson (2010) who noted that although the commitment of managers was sought, challenges persisted in LSW being utilised and sustained. No studies have yet addressed the organisational and senior management perspectives on the introduction of LSW. This seems essential if the ongoing challenges in implementing and sustaining LSW are influenced by organisational factors.

In summary the findings presented in this thesis demonstrate the range of experiences of participating in LSW from the perspectives of these four main 'stakeholder' groups (i.e. people with dementia, family carer, care staff and the organisation). To ensure that these 'multiple voices' can be heard and incorporated into LSW then a collaborative approach is required.

In seeking a range of views, clarity on who the story is for, is an issue that has emerged from the LSW research. Negotiation and communication is required in order to meet the needs of the range of people who may be involved in LSW. The LSW findings reveal that whose voice to privilege has the potential to be contentious. Privileging only the voice of the person with dementia contributes to respecting the person and supporting their agency and independence but can result in family carers feeling distanced and not being able to contribute to the story and the final product. As the LSW research has shown that can potentially detract from the quality of the end result. Distancing the family also denies them the therapeutic benefits of LSW. However, to privilege the voice of the family carer can have negative consequences for the person with dementia and give care staff the impression that LSW has no relevance for people with more advanced dementia. The LSW research does not offer a simple solution but rather like the research itself LSW practice needs to find ways of incorporating 'multiple voices' into the story whilst maintaining the centrality and prominence of the person with dementia.

10.7 Reflecting on the relevance of person-centred care conceptual frameworks

In Chapter Two I presented a critical analysis of three person-centred care

conceptual frameworks (PCN Framework, VIPS Framework and the Senses Framework within the context of relationship centred care) and have referred to these throughout the findings sections.

In this concluding chapter I would like to offer a further and final critical analysis of each framework in light of the LSW research findings. Aspects of all three frameworks resonated with the findings from the LSW research and I will reflect on each in turn.

The PCN Framework (McCormack and McCance 2010) and the LSW research findings concur on the significance of care staff attributes in influencing the implementation of LSW (person-centred care). Elements of the culture and the context of care were evident in both the PCN Framework and LSW data. The PCN Framework offers practitioners a means of assessing and attending to these challenges by recommending the use of a practice development approach as integral to the implementation of the framework. This approach is in keeping with my own preferred way of implementing new care practices. I too make the recommendations that LSW should be implemented within a planned and systematic approach if challenges in getting LSW into practice are to be overcome.

Although both the PCN Framework and the LSW research findings identify person-centred care processes the data from my research was difficult to map precisely with the descriptions offered by McCormack and McCance (2010). A challenge for this framework is the simplification of terms used to describe person-centred processes so that they are understandable and recognisable to practitioners with a range of knowledge and understanding. Currently they speak an academic rather than a practitioner language. The absence of specific commentary on the application of the PCN Framework to people with dementia makes it difficult to apply the LSW research data on embodied personhood for example.

The person-centred outcomes reported in the PCN Framework had significance for the LSW research findings, particularly for the person with dementia experiencing well-being and involvement in care. The existence of a therapeutic culture as an outcome is more comprehensively articulated in the PCN Framework compared to

the LSW findings, although the detail and language used has a tendency to become quite complex.

The VIPS Framework resonated with the more specific challenges of maintaining the personhood of people with dementia. The VIPS framework could be understood in terms of: organisational, practical, care process and philosophy of person-centred care specifically for people with dementia. Understanding the subjective experience of the person with dementia was a familiar theme in both the LSW research and the VIPS Framework. To date the VIPS Framework has not yet incorporated the embodied aspects of hearing the voice of the person with dementia and perhaps further empirical testing will lead to this. The clinical benchmarking approach to implementation of the framework presented by Brooker (2007) offers a suggested way of implementing the framework in a systematic and comprehensive way, so addressing the organisational and cultural challenges of implementing LSW (and person-centred care).

The VIPS framework appears to offer the most comprehensive framework that can be applied to the care of older people with dementia to date and that resonates most closely with the LSW research data. The previously report questions about its empirical testing in practice (see Chapter Two) must, however be considered.

The Senses Framework shared many similarities with the LSW research data on person-centred care processes. Each of the Senses could be located within the LSW data supporting the claim of Nolan *et al.* (2006) that the Senses 'speaks' to practitioners (and researchers). A 'Sense of Significance' (Nolan *et al.* 2006) seemed relevant to data that reflected pride and well-being in the participants in the LSW research. Perhaps a 'Sense of Significance' is, for people with dementia, a person-centred outcome of successfully achieving the other Senses. What was more difficult to locate in the Senses Framework as it is currently presented is the complexity of the cultural and contextual factors that impacted on the implementation of LSW. Additionally it was difficult to assess the precise way that the Senses Framework is to be implemented in order to impact on the challenges of implementation. Ryan *et al.* (2008) have published data supporting the application of the Senses to dementia care and indeed the LSW research supports

the observations of its general applicability. What is absent to date is an exploration of what might be missing from the current framework when applied to people with more advanced dementia. There is less of a focus on the upholding of personhood as central to the Senses, compared to the LSW research. Additionally it is difficult to locate the LSW data on the need for care staff appreciate the subjective experience of the person with dementia through a variety of ways within the Senses Framework.

The LSW research data on recognising and responding to a range of manifestations of personhood could not easily be applied to any of the existing person-centred care conceptual frameworks. This indicates the need to adjust existing frameworks to enhance their application to older people with more advanced dementia. Person-centred care appears to deserve specific consideration for use with people with dementia, especially when considering the threats to personhood for people with dementia that have been reported in this thesis. Through their ongoing empirical testing and publication of this work there is a perception that the Senses and the PCN Framework would be welcome to adaptation and application to groups such as people with more advanced dementia. McCormack *et al.* (2010) call for more collaborative and less 'uni-field' working to further inform person-centred concepts. I would argue this should not be at the expense of identifying the specific needs of particular groups of people, such as those with dementia. Each Framework refers to 'biography' or 'life history' in one way or another as a discrete element. There is a focus on the outcomes of such work such as improved understanding of the person. Through the analysis of the person-centred frameworks and the LSW data I have highlighted the potential of LSW as a process and a product to enable person-centred care. This is an opportunity not identified by current person-centred frameworks.

10.8 Strengths of the research

There are a number of key strengths of the research presented in this thesis over existing research. These are detailed below.

The LSW research adopted a longitudinal design; this was previously identified as a need for future research (Batson 2002). Previous LSW research has taken a cross-sectional design to the investigation, so providing a 'snap shot' of the use and experience of those involved. By taking a longitudinal approach I was able to follow participants in transitions to other care environments making it possible to investigate the use of LSW in a range of care settings. This approach revealed previously reported findings such as the use of LSW in transitions of care and the attitudes to LSW across a range of staff groups and care settings.

This thesis further extends the debate on how to involve people with more advanced dementia in research (and practice) and has overcome the perceived difficulty of gaining ethical approval for undertaking research with people with dementia. In addition the research has applied a framework of process consent to the realities of research practice (McKeown *et al.* 2010a).

The LSW research has successfully demonstrated that the dual concerns of generating new knowledge and developing practice can be achieved through the use of a constructivist methodology. The close association between the research and the practice allowed person-centred care to be investigated within the realities of clinical practice. A strength of this approach is current person-centred care conceptual frameworks can be appraised and informed by care practices for older people with dementia. This thesis has applied the LSW research data to three of person-centred care conceptual frameworks and demonstrated ways in which the data could both support and extend current understandings.

A strength of this research has been the utility of the research methodologies in enabling multiple perspectives to be uncovered. This was a key aim of the research. A critical analysis of the methodological choices will be presented in the next section.

10.9 A critical analysis of the methodologies employed

Maintaining the multiple participant voices central to the research report is a key indicator of rigour in constructivist research. Rodwell (1998:110) equates this with the 'dependability', stating this can be demonstrated:

'if all perspectives were allowed to have voice and of the data analysis and report represent the multiplicity of perspectives, regardless of assigned or inferred power'

This research extends the knowledge base concerning the use of LSW with people with dementia and offers unique insights into previously un-reported features of the concept from a range of stakeholder perspectives. This research has engaged with people with more advanced dementia and allowed their voice to be heard. By seeking out multiple perspectives the findings have illuminated important differences between, care staff and family perspectives on involvement in LSW and between the attempts of the participants with dementia to communicate personhood and the challenges for some staff in recognising these communications. Not only was this aim of presenting multiple voices important to the rigor of the study, it was also essential to ensure that my own valued way of working with people was upheld. Chapter One detailed my own ontological and epistemological position and I was able to aspire to this through using a constructivist approach although there were challenges.

A challenge in this thesis was finding the opportunities to meet up with the daughter carers, who both had busy lives that impacted on their participation in the research. Meeting up with care staff was also a challenge. In order to access all participants it was necessary to be creative and adapt usual methods of collecting data. Rigour was maintained by carefully recording all decisions in a research diary. Involving people with dementia in conventional ways during the development of the research protocol proved difficult, particularly being able to access people who may have wished to collaborate. Attempts to involve the Alzheimer's Society were unsuccessful as there was not, at that time, a good working relationship between the Trust and the Society. Finding other forums where I could take my proposal or invite collaboration was an issue. The peer review panel who assessed the protocol noted a lack of consultation with persons with dementia. I have reflected the 'authenticity' of involving people with dementia as a demonstration of rigour on the LSW research with its focus on people receiving, predominantly, health and social in-patient care. Had I been able to acquire the contribution of persons in the early stages of dementia would this

have been 'authentic'? It may have satisfied the peer review panel, but I question whether people with a recent diagnosis of dementia are able to reflect the views of people with more advanced dementia receiving long term care. The knowledge and skills gained from undertaking the LSW research and the insights from the participants with dementia will enable me to consider more creative approaches to involving persons with dementia in the planning of any future research. In the future I would be far more confident having conversations with established groups of people who have dementia to seek their views. I would feel more able to justify informal means of seeking the opinions of people with dementia through chance conversations and communication as a part of other activities. I would feel able to argue, as Killick (2001) has, that the advantages of this approach outweigh the possible criticisms over a lack of rigour. I have found that talking to people with dementia about their lives often allows them to share their feelings on other subjects without feeling put on the spot or outpaced. Finally I would be interested in exploring more about the non-verbal and embodied means that people with dementia may communicate their views, desires and wishes. The sample of older persons with dementia was white British and reflected the population currently receiving care within the organisation where the research was undertaken. Similarly all but two of the care staff participants were white British and only two staff participants were men. The findings, therefore, do not reflect the experiences of people from black and minority ethnic groups or culturally diverse communities and this identifies a need for future research. This finding has contributed to me beginning to explore the views of older people from different cultures and ethnic groups as part of my work role.

Guba and Lincoln (1989) developed authenticity criteria for judging the quality of constructivist research, the key principles being: fairness; ontological authenticity; educative authenticity; catalytic authenticity and tactical authenticity. Their attempts to impose such rigid terms appear inconsistent with constructivism. Nolan *et al.* (2003) propose a more 'user friendly' adapted version of the language used by Guba and Lincoln, arguing it is not meaningful to the range of stakeholders constructivism aims to engage. Although such criteria have their place, adherence to such formats may inhibit the demonstration of the range of approaches taken to

ensure rigour. There remains no one agreed single set of criteria to assess quality or rigour in qualitative research. Rolfe (2006) argues that each methodology (and possibly each study) should be assessed on its own merits considering the range of ontological and epistemological characteristics of different qualitative methodologies and the next section details how I approached the issue of rigour in the LSW research.

The active involvement of key stakeholders has been central to this study from before the study commenced and after its completion and has been a key feature in demonstrating the rigour applied to the study. Opportunities were taken throughout the research process to share emerging themes and findings with a range of stakeholders, these include:

- Sharing the development of the research and the emerging findings with the research reference group
- Having three articles from the research published in peer reviewed nursing journals
- Sending a copy of one published article to staff and family carer participants and requesting feedback on my interpretation of the findings
- Feeding back findings face-to-face with care staff participants
- Using emerging findings as the basis for a presentation on LSW to people with dementia and family carers at a memory clinic dementia café and also to a carers group at a residential unit for people with dementia.
- Discussing my work with a group of people with learning disabilities and care staff at a Day Centre
- Sharing the emerging findings through a full day workshop on LSW I facilitated for Care Trust staff (see Appendix 26 for a brief summary and evaluation of the workshop)
- Presenting the early findings at Sheffield Hallam University student nurse conference
- Presenting progress and findings at the Care Trust Dementia Directorate management meetings on two occasions

- Successful Knowledge Transfer bid from University of Sheffield to support the dissemination of the research (see Appendix 27 for KT submission)
- Written report to the Care Trust Executive Board

A rigorous approach was taken to data analysis through the use of the Framework Approach (see Chapter Three). Considerable time was invested in charting and iterating between the thematic framework and the data. The process of how the findings have emerged from the raw data has been detailed and this was possible and indeed a requirement for a PhD study. The realities of applied, funded and time limited research may dictate a more rapid process from data to themes to findings, making its full and correct use more of a challenge when not as part of a programme of study. Having used Framework in its original and intended form, however, should help when I have to face the realities. I valued the structure that Framework provided, but also found that its use inhibited a more creative approach to interpreting the data.

As previously described, the LSW findings were validated with key stakeholders in a range of ways. These activities demonstrate the aspiration to open up the findings to scrutiny and to actively seek feedback from relevant stakeholders. The challenge and indeed the duty for me, is to make sure that the experiences of all participants are reported not only to the research community but also to practitioners undertaking LSW with older people with dementia. The plans for dissemination are reported in section 10.10.

It is not possible to say that LSW alone was responsible for the person-centred outcomes reported, they may have occurred anyway or through the implementation of another activity. What is clear is that for some care staff LSW allowed them the opportunity to spend one-to-one time communicating and interacting with a person with dementia in a way that previously had been difficult. This provided the opportunity for person-centred interactions to be enabled. What is also evident is that LSW is acceptable and enjoyable to care staff and is possible to implement into practice with the necessary support.

A question in any qualitative research is its relevance to other care settings and environments. Constructivist research should not claim 'transferability' (Rodwell 1998), but rather provide enough detail that readers can decide for themselves the relevance to their own circumstances. Chapters Four and Five of this thesis provide rich detail about the organisation, the individual case studies contexts, individual participants and my role in the research and practice. The case study approach enabled the context of each case study setting to be explored and for the differences between case studies, particularly in the implementation of LSW to be analysed. The case studies were also helpful in maintaining boundaries in a complex area of study.

A constructivist approach and multiple case study design have been demonstrated as relevant for this PhD study and consistent with the aims of the research and with my skills and experience. My own experience of working with people with dementia, their families and care staff has contributed to my own belief that multiple realities exist and a constructivist approach allowed me to work within my own value and belief system. It also supported my preferred way of collaborating with and involving a range of people over time to engage them with the topic under consideration. The constructivist methodology complemented the process approach to consent that was used in the LSW research. Researchers undertaking time focussed and outcome orientated health and social research may be reluctant to adopt a methodology that demands such an explicit consideration of respect and engagement with participants unless they can be confident in remaining consistent with its core epistemology.

10.10 Dissemination of findings

A number of approaches are being taken to disseminate the findings reported in this thesis:

- To date three papers have been published in peer reviewed nursing journals. Further papers are planned.
- To explore the feasibility of writing a book based on this thesis.
- Presentation of the findings at local, regional, national and international conferences over the next twelve months.

- Invitations to share the findings on existing web-sites; for example, the Foundation of Nursing Studies: an organisation who support practice development and who have links both nationally and internationally; and 'Storying Sheffield': a Sheffield University project to improve the social inclusion of people with mental health problems through story telling.
- Co-facilitation and evaluation of six workshops on the use of LSW to care staff, persons with dementia and their family carers and one specifically aimed at older people from BME communities. This is supported with funding from a successful Knowledge Transfer bid.
- The design and printing of an information product based on the findings from this research for dissemination to health care workers.
- Maintain links with the University of Sheffield and initiate links other organisations to consider ways of disseminating the findings through educational and practice development programmes.
- Continue LSW dissemination within current work role.

10.11 Recommendations

10.11.1 Research

- Future research could meaningfully explore the therapeutic value of LSW for family members and whether one-to-one or family workshops have an advantage over the other from a family carer perspective.
- Further research may investigate what a planned and systematic approach to implementing LSW consists of.
- There is a need to evaluate how a systematic approach may not only facilitate the implementation and sustainment of LSW, but also exploit the 'added value' of LSW.

10.11.2 Practice

- In light of the multiplicity of factors reported in this thesis as impacting on LSW, its use in practice should be implemented through a planned and

systematic approach that considers the need for adequate preparation, education, supervision, facilitation and evaluation.

- Practitioners need to explore ways in which LSW can become incorporated in existing care planning procedures.

10.11.3 Education

- The educational requirements for undertaking LSW need to be articulated implemented and evaluated to assess their impact on implementation and outcomes for LSW.
- Educational programmes concerned with person-centred care should consider how to facilitate learning in the work place to enable care staff to be able to recognise and respond to manifestations of personhood with older people with more advanced dementia.

10.11.4 Policy

- Current policy needs to articulate more clearly the nature of LSW and the potential complexities and requirements for LSW to be undertaken effectively and safely.
- Policies advocating person-centred care should make explicit links to LSW as a means of enabling person-centred care in practice.

10.12 Conclusion

The interest in the use of LSW in health and social care policy and practice has grown considerably during the time I have been undertaking this research. The findings from this study are current and relevant to researchers, practitioners, educators and policy makers wanting to investigate and improve the care delivered to older people with dementia.

The need to maintain quality care for people with dementia and their family carers is even more essential with the current economic challenges that face health and social care services at this time. LSW is one evidence-based and effective way of achieving this.

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