Who Cares? An Exploration, using Q Methodology, of Young Carers’ and Professionals’ Viewpoints

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ABSTRACT

This research used Q methodology to explore the shared viewpoints of N=20 children and young people identified as young carers, within the context of looking after a family member with a disability, and of N=20 professionals working with children and young people. A literature search revealed a layer of complex, multi-faceted discourse and social constructions around the subject of young carers in terms of their definition, identification, and circumstances, and the way in which professionals intervene in their lives. A gap in research identified that Q methodology had not before been used to elicit young carers' views, nor were there any published papers within the field of educational psychology relating to young carers' or professionals' viewpoints on the topic. The aim of the study was twofold: to explore young carers' shared viewpoints about their roles, responsibilities and experiences, including intervention and support processes from professionals, and explore the shared viewpoints of professionals about young carers and the intervention and support mechanisms available to them. A Q sort, using 50 statements, was used to elicit participant views, which were analysed using by-person factor analysis.

Results revealed four distinct factors (shared viewpoints) within young carer participants: (Factor 1: "We're proud and positive. We feel included and well supported but don't like being singled out"; Factor 2: "Caring's just what we do. We feel mature, but are unsupported and misunderstood"; Factor 3: "'Parentified' and wanting to care, but we need people to recognise that we're struggling and worried"; Factor 4: "Being mature doesn't stop us from worrying, although we're supported, especially in school"), and two distinct factors within professionals: (Factor 1: "Young carers worry and struggle. They are unsupported and neglected by professionals"; Factor 2: "Young carers are mature and resilient, and want to be treated like every other young person. Professionals could do more, but are getting there").

These factors were interpreted and discussed, and the implications for professional practice explored.

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1.0 INTRODUCTION

The impetus for this research was twofold: my experiences as a child growing up in a household with a mother suffering from significant health difficulties, and a chance meeting with a colleague, whilst undertaking a piece of casework in my role as a trainee educational psychologist.

Firstly from a personal perspective my childhood involved growing up in a busy, happy environment, with a supportive, loving family. Added to this dynamic was my mother's illness (heart disease), which meant that she became significantly less mobile and independent during my teenage years. As a result, my 'caring' responsibilities gradually increased, resulting in me looking after her full time by my early twenties. Secondly, from the perspective of my professional role, as a trainee educational psychologist, a piece of casework involved a Lithuanian boy with leukaemia who had recently arrived in the United Kingdom (UK). Part of my role involved trying to determine the most appropriate educational setting for him, based upon his wishes, his family's wishes, and his medical and educational needs, as well as discussing his needs with colleagues from different agencies. Within the Local Authority the 'Complimentary Education Service' existed to provide education to children who could not access school for whatever reason (including medical difficulties) and also offered bi-lingual support. I contacted this service to ask for advice and met its head, Mr J to discuss any support he could offer. Through this discussion I learned that the service offered support to a variety of children, including young carers. My interest in children and young people looking after sick or disabled parents, due to my personal experiences, and the services offered to them by professionals, were thus brought together and began crystallising into a potential research topic.

After further discussions with Mr J I learned more about the young carer support group he had set up, and the 'virtual learning environment' where young carers were given laptops and access to teaching materials online. Interestingly, Mr J. commented that the young carers had never been asked their views on the service, nor consulted about any aspects of the project in the setting up process. My initial thoughts turned to whether a piece of research could evaluate the young carer project, and although this would have been useful, after further reading around the topic I felt that a much wider focus of investigation would be more appropriate, due to the many conflicting, multi-faceted discourses and social constructions evident surrounding the subject area. Discussions with EP colleagues then followed, which highlighted that many of them were unaware of any young carers within their school ‘patches’, nor were they aware of any research in the area in relation to educational psychology. I decided, therefore, that this study would explore the viewpoints of young carers and professionals in terms of young carers’ roles and responsibilities, as well as their views on support and intervention processes.

Sadly, the cuts imposed by the Local Authority meant that the young carer project referred to above was closed prior to the start of this research process, which meant that the young carers in question could not be easily contacted to become participants and express their views. This is a source of frustration and regret for me, as their stories provided the impetus for this work, yet their voices are not represented within it.

This study firstly explores the research literature and other sources surrounding young carers, followed by a detailed chapter outlining both the methodology used as the research tool (Q methodology) and my position as a social constructionist and critical realist. The procedures chapter then details the process of gathering participants and data, followed by the results chapter, which describes the research findings, setting the scene for the final chapter, a discussion of the research findings in the light of previous research, and the possible implications in relation to professional practice.

2.0 CRITICAL LITERATURE REVIEW

This chapter will explore the literature and discourse surrounding young carers, predominantly within the United Kingdom (UK), in terms of the definition of young carers and the social constructions associated with the label, the role of young carers and the way in which professionals intervene in their lives, and the way in which caring responsibilities can potentially impact at an educational, social and emotional level. The commentary surrounding the needs of the individuals being cared for will also be explored, in order to place the young carer's role within context, and how this may impact upon the intervention and support services available to them as a family. There then follows a 'statement of the problem' which will summarise the main issues raised. The aim and purpose of the study will then be outlined, together with the operational definitions used within this study, and, finally, the research questions to be addressed will be presented.

2.1 Young Carers: Definitions and Labels

Children and young people in a caring role, termed 'young carers' have been the subject of increased debate and discourse between researchers, government policy makers, the voluntary sector and in the media alike, particularly in the last two decades. Within this discourse issues have arisen with regard to the recognition, identification and definition of young carers among professionals, as well as the number that exists within the UK.

2.1.1 Definitions of Young Carers

Despite a recent increase in interest about young carer issues from government bodies and researchers, there remains a lack of consistency in the way in which the term 'young carer' is defined. The official government definition, coming from the Department of Health (DoH, 1996) describes young carers as:

> "Children and young people (under 18) who provide, or intend to provide, substantial amount of care on a regular basis" (DoH, Carers (Recognition and Services) Act 1995, p.2).

This definition raises ambiguities, however, as it does not serve to clarify the meaning or nature of 'care', which could be viewed as culturally specific (Banks, 2003) and also employs terms such as 'substantial' and 'regular' which are difficult to determine, as they can be interpreted subjectively depending upon one's own experiences and perceptions of 'norms'. It has been noted that the generality of this definition, in fact, contributes to the difficulties faced by professionals when identifying and referring young carers, as the process could be considered to be reliant upon subjective judgements (Becker, 2005, Becker et al., 1998).

A further ambiguity when describing young carers is that some definitions focus upon the amount of *duties* performed by the children and young people, as in the example above, whereas others adopt a definition which highlights the *impact* and potential *restrictions* of those duties (Newman, 2002). A young carers' project, for example, advises the use of the following description as guidance for the Local Authority's referral process:

> "Young Carers are children and young people under the age of 18 years, who provide care to another family member who has a physical illness/disability; mental ill health; sensory disability or has a problematic use of drugs and alcohol. (…)The level of care they provide would usually be undertaken by an adult and as a result of this has a significant impact on their normal childhood" (PSS Local Authority Young Carers' Project, 2003, p.4).

Although this definition paints a richer and more inclusive picture of young carers than the first example, as well as providing greater clarity as to the types of circumstances where caring might take place, it employs, nonetheless, terms such as 'significant' and 'normal' which invite challenges as to how such constructions can be measured.

Other government sources describe young carers within a broader category of 'children in need', as a benchmark for service provision, such as the Children Act (DoH, 1989/2004) and Children Act (Scotland) (DoH, 1995). Within this legislation (as well as within the Every Child Matters Green Paper, DfES, 2003) children are seen to be 'in need' and requiring additional support if they are:

> "children who require services to achieve or maintain a reasonable standard of health or development [and/or who] are adversely affected by the disability of any other person in his/her family" (DoH, Children Act (Scotland) 1995, section 93).

Although there is no overt reference to young carers within this description, young carer support groups have argued that the nature and impact of caring for relatives with a disability or illness emphasizes the extent to which young carers are 'in need' and as such should have access to support networks (Carers, UK, 2006). Other voices object to the implicit assumptions in such descriptions, however, as it could be argued that the boundary between a young carer and any child within a family dynamic where illness or disability is evident becomes increasingly blurred when definitions become too diluted (Prilleltensky, 2004). According to Butler and Astbury (2005) almost three million children and young people in the UK live in households in which there is a family member with a chronic illness or disability. At what point, therefore, does a child or young person become a young carer as opposed to being in a household in which a family member has a disability or chronic illness? This raises further questions with regard to poverty, social exclusion and lack of a family support network. A Young Carer Research Group (YCRG), for example, found that over half (54%) of the young carers they surveyed lived in lone-parent households, and 12% were caring for a disabled or sick parent as well as younger siblings (YCRG, 1997), resulting in the young carers being in an environment with little to no support or respite from their caring duties (Manning et al., 2009)

Some researchers argue that a tightening of the young carer definition would serve to provide greater clarity to the social issues surrounding them, such as the referral process and access to resources and support services (Cree, 2003). An alternative view is presented, however, by those who prefer a wider, more inclusive definition, as it is thought that the role of the young carer is so diverse that any nationally recognised definition could potentially deny a child or young person access to the most appropriate support services (Newman, 2002). It has been noted, also, that the way in which young carers, as a group, are defined by others (and by themselves) can impact upon the way in which they are identified and recognised by professionals, as well as raising questions as to the nature, meaning and notion of 'care', leading to negative stereotypes and preconceptions about the role, and potentially creating stigma and barriers to receiving support (Prilleltensky, 2004).

2.1.2 Numbers of Young Carers

The exact number of young carers in the UK has been, and remains, difficult to determine for a variety of reasons. Firstly, it could be said that in order for a phenomenon, group or event to be quantified, a clear definition is needed so that an accurate measurement can be made (Rose and Cohen, 2010). As there is no universally accepted definition of a young carer, this renders the act of counting their number more difficult and can, in turn, affect the estimates of actual young carer numbers in a given region (Newman, 2002, OfSted, 2009). Some figures, for example, estimate that there are between 19,000 and 51,000 young carers in the UK (Banks et al., 2002) although the 2001 Census estimated the figure to be closer to 175,000 (UK Office of National Statistics, 2001). Charity groups have disputed this figure as a gross underestimation, however, and posit that the actual number is, in fact, much higher (Bibby and Becker, 2000, Carers, UK, 2006). Research led by Professor Becker, for example, quoted recently in both the press and on television (Becker, 2010), draws attention to this issue, by claiming that four times as many children and young people care for relatives with a disability or illness than previously suspected. In his research he carried out a questionnaire with 4029 young people in ten secondary schools asking if they considered whether they carried out caring roles. Of those questioned, Becker suggests that one in twelve identified themselves as a young carer, equating to a national figure of 700,000, which is a much greater figure than the 2001 census would suggest (Becker, quoted in *The Guardian,* 16/11/10).

Why would such a discrepancy in numbers exist? Becker reports that the young carer is part of a 'hidden army' *(The Guardian,* 16/11/10) and that children and young people in a caring role can often appear invisible to professionals such as teachers and health care workers as their needs go unrecognised (Gray et al., 2008). In addition, research has shown that the young carers themselves may not see themselves as carers, but simply as daughters, grandaughters, or siblings who help out at home (Cass et al., 2009) and that they may view themselves as no different from their peers (Smyth et al., 2010).

As well as being ignored by professionals, young carers have been reported to actively hide their family circumstances from agencies and avoid seeking assistance from services (or other adults in perceived areas of authority) for fear of family breakdown or being taken into care (Underdown, 2002). Indeed, it has been mooted that parents will often pressure their young carers to "keep their family outside of social services' gaze" (Aldridge and Becker, 1993a, p.13). Another possible explanation for this apparent secrecy is the possible feelings of embarrassment experienced by family members, and the way in which social stigma is attached to the concepts of disability, illnesses such as HIV/AIDS and mental illness (Gray et al., 2008, McAndrew et al., 2012).

2.1.3 Labels and the Concept of Care

It has been suggested above that some children and young people resist identifying with the label 'young carer' for fear of stigma or family breakdown yet the alternative appears to be that only families known to services are in a position to receive support (OfSted, 2009). Those researchers who argue against the labelling of 'young carers' posit that children and young people have always been involved in providing care for younger siblings, or sick relatives, and historically have been encouraged to participate in tasks of a domestic nature (Smyth et al., 2010). Furthermore it is suggested that the term 'young carer' itself is a form of social category, and that the concept of 'care' can be seen as one which is socially constructed, having different meanings and connotations in different environments and cultures, especially within cultures where extended families live in close proximity (Olsen, 1996, Skovdal, 2009). O'Dell et al. (2010), in addition, note that the label of 'carer' implies a level of dependency on the part of the individual being cared for, and that this challenges society's constructions of childhood, of disability and chronic illness, and the way in which 'care' is given and received within a complex family dynamic (O'Dell et al., 2010). Segal and Simkins (1993) also contest societal assumptions of who gives and receives 'help' by commenting that: "The role of 'helper of others' does not belong only to the able-bodied and the well" (Segal and Simkins, 1993, p.4). This suggests that the process of care giving and receiving can be a reciprocal one, rather than a 'burden' and that it can potentially cement loving and rewarding relationships. On the other hand research has shown that this could be interpreted as an idealised view and that the reality of care giving involves sacrifice and increased anxiety on the part of the caregiver (Aldridge and Becker, 1993b).

The label of 'young carer' does not necessarily convey a negative image to some young carers, however, as it has been suggested that it can serve to be: "useful if [it] helps to validate an experience which might otherwise remain inchoate and unarticulated" (Bibby and Becker, 2000, p.7). Whilst this is a useful observation it is also worth asking whether these views were being expressed by young carers already known to the support system, as opposed to being 'hidden', which could have perhaps coloured their responses. The term 'young carer', therefore, can be thought contentious, not least because it has been seen by some researchers to place a wedge between the carer and the cared for and can contribute to negative stereotypes and assumptions from professionals in relation to their perceptions of family relationships and the nature of care (Keith and Morris, 1995, O'Dell et al., 2010, Olsen, 1996). These ideas are developed further in the section below.

2.2 Young Carers: Rise, Research and Rhetoric

2.2.1 Rise in Profile

Prior to the 1980s little was heard of young carers (or carers in general) as an identified social category in terms of government policy, public awareness or in social research (Becker et al., 1998). The Association of Carers (now Carers UK) was formed in the early 1980s to raise awareness of all carers (both adult and children), with dedicated project and fundraising workers to help target support to families needing services, as well as championing carers' rights. Cook (2007) describes that:

> "An important early principle [of the organisation] was that carers themselves are best placed to decide what help carers need. This is something that is written into Carers UK's constitution to this day" (Cook, 2007, accessed via Carers UK website).

Cook describes, furthermore, how the newly formed organisation was denied charitable status for two years, as it was not considered that the carers themselves were a ‘suitable charitable cause’, only the individuals they cared for (Cook, 2007).

The recognition of young carers in the UK, specifically, however, has been led by the voluntary sector, with the development of young carer projects, the first of which was set up in the North West in 1992 (PSS Local Authority Young Carers' Project, 2003). Two such projects existed in the UK in 1992, which were locally driven and set up with the aim of providing recreation and respite for young carers. The current estimate, however, (despite recent local authority cuts) is over 100, with key providers including the Princess Royal Trust, Barnardo's and the Crossroads project (Richardson et al., 2009), which provide both local projects and national organisations such as the National Young Carers' Forum (2010).

In addition to the impetus of the voluntary sector, important legislative changes in the UK and in the United Nations during the late 1980s and 90s began to focus greater attention upon the rights of the child and the well-being of carers in general, some relating to young carers in particular. The United Nations Convention on the Rights of the Child (1989), for example, sets out the world's obligations to the well-being and health of children and young people, and many of its articles, according to Bibby and Becker (2000) relate directly to issues faced by young carers, such as having the right to "rest and leisure" (Article 31) and the right to develop the child's "personality, talents, mental and physical abilities to their fullest potential" (Articles 28 and 29). Others would argue, however, that being a child or young person in a caring role does not necessarily infringe these rights, and that the rights and needs of the individual with an illness or disability are minimised by the preoccupation of carers' needs (O'Dell et al., 2010, Olsen, 1996).

In terms of legislation within the UK, the 1980's and 90's saw social policy becoming high on the political agenda, and a significant amount of government statutory guidance was produced to help assess and support young carers, such as the Children Act (DoH, 1989/2004); Carers (Recognition and Services) Act, (DoH, 1995); Framework for the Assessment of Children in Need and their Families (DoH, 1999) and Jigsaw for Services (DoH, 2000).

Some young carers' projects have used government legislation and policy as a springboard to produce a 'Young Carers' Charter', which is used as an adapted version of the Articles in the UN Convention on the Rights of the Child (1989) as well as other statutory frameworks (mentioned above) to produce rights and needs specifically targeted to the experiences of young carers. Some examples include:

- the right to be children as well as carers
- the right to fun and friends and time off from caring
- the right to move on and become independent adults
- the right to information about the health problems that family members experience

(taken from PSS Local Authority Carers Project, 2003).

More recently, furthermore, government bodies and policy makers have focused their attention upon issues relating to young carers, resulting in research from OfSted (2009), who surveyed eight local authorities about their intervention and support processes for young carers, and Jones et al. (2012), who responded to the coalition government's Carers' Strategy (2010) in a commissioned evaluation of a pilot training workshop delivered to primary healthcare professionals about young carer issues.

It is apparent that the public profile of young carers has risen significantly in the last 15-20 years, in terms of identification and attention, led by both the voluntary sector and government policy. Despite this rise in apparent recognition, however, a significant body of research has highlighted that the needs of young carers are continuing to be ignored and that many remain unidentified and unknown to professional services.

2.2.2 Research Findings

Academic research of young carers in the UK has increased in the last fifteen years, commensurate with the rise in public profile. Prior to 1993, Becker describes a "literature of omission" where research papers in social research made little or no reference to young carers (Aldridge and Becker, 1993a). The Young Carers' Research Group (YCRG), based in Loughborough University, therefore, has led the way in research which has aimed to record the *experiences* of young carers, through qualitative methods such as focus groups and interviews, as opposed to quantifying the nature of the *tasks* they undertake (YCRG, 1997). The YCRG and other researchers believe that this approach provides children and young people in a caring role with a collective voice, so that their experiences can be heard, and their needs expressed, rather than professionals making decisions on their behalf:

> "It is imperative that we first fully understand the experiences and needs of children who care if we are then to adequately provide for their needs" (Aldridge and Becker, 1993a, p.6).

Some of the earliest research findings of young carers have suggested that the impact of the caring role can be significant in terms of the young carers' well-being, mental health, physical and emotional development and can create problems both in an educational and social arena. Meredith (1992) and Jenkins and Wingate (1994), for example, both highlight that the caring role results in children being "robbed of their youth" (Meredith, 1992, p.18) and that they "lose their childhood" (Jenkins and Wingate, 1994, p.734) as a result of the tasks and responsibilities they undertake. A diverse body of literature has emerged which explores the impact of caring for parents with specific illnesses or disabilities such as multiple sclerosis (Segal and Simpkins, 1993), HIV/AIDS (study in Zimbabwe, Martin, 2006), as well as mental health difficulties (Aldridge and Becker, 2003, Gray et al., 2008, McAndrew et al., 2012), physical impairments (Earley et al., 2007) and drug and alcohol dependency (Thomas et al., 2003). It has been noted, however, that many factors influence the variety and severity of the caring roles being carried out, which include not only the type of illness or disability experienced by the family member, but also the nature of the family structure, such as socio-economic status, ethnicity and the gender of the carer (Dearden and Becker, 2000). Girls within single-parent families who are experiencing poverty, for example, are more likely to take on significant caring roles looking after sick or disabled relatives, compared to boys, or other children and young people living within a larger family unit (Rose and Cohen, 2010).

The following research findings have highlighted the significant negative impacts of caring for a sick or disabled family member. Researchers have found that young carers:

- have difficulties with depression and mental health (1 in 5) (Holmstom, 2002)
- go on to develop psychological disorders as adults (Frank et al., 1999)
- have experienced bullying (71 %) and are concerned about school work (Bibby and Becker, 2000, Dearden and Becker, 2004)

- have difficulty sleeping (60%) and self harm (33%) (Rose and Cohen, 2010)
- lose opportunities to socialise with peers out of school (Earley et al., 2007)
- feel isolated and cut off from the outside world (Aldridge and Becker, 1993b)
- have regularly missed school due to caring duties (Dearden and Becker, 2000)

Cree (2003) reports that there is a correlation between the severity of problems faced by carers (such as those outlined above) and the length of time that caring has taken place. Her study outlines that 75% of her participants had been caring: "for as long as I can remember" (Cree, 2003, p.303). Given that 13,000 young carers care for more than 50 hours per week, and can be as young as five (the average age being 12) (UK Office of National Statistics, 2001), these are significant findings that suggest young carers' emotional, social, physical and educational development is being considerably harmed due to their caring role. Above all, however, young carers have been shown to believe that the emotional support they offer to their sick or disabled family member is the most important, and most difficult part of their role, and one which they feel receives the least amount of support from both outside agencies and schools (Bibby and Becker, 2000, The Education Network, 2006).

Not all researchers agree with research findings that focus exclusively upon the negative effects of caring, however. Critics point out that such studies, highlighted above, only involve a small number of participants and that this cannot represent the views and experiences of all young carers (Gladstone et al., 2006, Olsen, 1996). Similarly, others acknowledge that few of the studies compare the concerns and problems expressed with a control (non young carer) group, therefore it is difficult to extrapolate some of the worries and problems of the young carers from those of a typical child or adolescent (Cree, 2003, O'Dell et al., 2010). Lackey and Gates (2001), in addition, found that in their retrospective study of adults who were former young carers there were fewer negative elements expressed by the participants compared to Frank et al., (1999). The former’s participants, in fact, remembered many positive experiences of caring, such as feeling useful, needed and important; feeling responsible and 'grown up'; helping to become more nurturing as adults and that the caring role brought about a close family bond. Lackey and Gates (2001) acknowledge this difference in their discussion and highlight that their methodology involved posing more positively framed questions than did Frank et al. (1999).

There are, in fact, few strengths based studies of young carers' experiences as the majority have focused predominantly upon the negative impact of the young carer role (Prilleltensky, 2004). More recent research, however, has targeted resilience factors and coping strategies of young carers and highlighted positive as well as negative aspects of caring (Gladstone et al., 2006, Skovdal, 2009). Joseph et al. research (2009), in addition, developed and implemented checklists with young carers to help them identify not only the types of tasks they undertake as part of their caring responsibilities, but how they perceive both the positive and negative aspects of their role. In terms of other research a small number of papers were found evaluating young carer projects (Banks et al., 2001, Richardson et al., 2009), however a literature search found no results for papers relating to young carers within the context of educational psychology nor any which directly explore the psychological impact of being a young carer, nor specifically their experiences of education (Moore, 2005b, O'Dell et al., 2010).

It has been mooted that the emphasis on the negativity surrounding the young carer debate serves to sensationalise the life events of the young carers and thus detracts from the process of hearing their genuine experiences and needs (Keith and Morris, 1995, Olsen, 1996, Prilleltensky, 2004). By endorsing such language it could be argued that the media become entangled in the debate and can be seen to exploit stereotypes, viewing young carers as either a 'little angel' or 'little victim'. The role of the media in this dynamic is briefly outlined below.

2.2.3 Media Image: ‘Little Angel, Little Victim’

In 2007 thirteen year old Deanne Asamoah committed suicide after taking an overdose of her terminally ill mother's painkillers (reported in *The Daily Telegraph,* 8/06/08). She had been her sole carer for four years. After the inquest of her death Kevin Brennan, the then Children's Minister, commented that:

> "Too often, young carers take on roles that are too much for them, which can harm their education and broader outcomes. We need to do more to prevent this" (Brennan, *The Daily Telegraph* 8/06/08).

Deanne's death brought the young carer debate into the public gaze, and became the focus of pleas for fundraising and support via charitable organisations, as well as eliciting strongly worded statements from government ministers and professionals in public health. Paul Wainwright (Chair of the Royal College of Nursing ethics forum) highlighted that government bodies should do more to help young carers:

> "How is it, when it has signed the UN Convention on the Rights of the Child that so many children are in this situation? I do not think it is right to support the child in their role as a carer - they should not be a carer in the first place" (Wainwright, 2008).

This statement appears contradictory, firstly acknowledging the burden young carers face, yet not showing a commitment to their support, however it encapsulates the complexities of the young carer debate. The image of the 'little victim - little angel' typified in headlines such as: "Two angels named Charlie are Britain's most caring children" and "Children aged three forced to care for the disabled" *(London Evening Standard,* 1994 and *The Independent,* 1994 respectively, cited in Bibby and Becker, 2000, p.13) serve to both eulogise and undermine the important tasks that young carers are carrying out. Perhaps more importantly, however, they also appear, according to some researchers, to be to the detriment of those being cared for (Keith and Morris, 1995, Prilleltensky, 2004).

2.3 Young Carers and Disability: "Children's Rights, Adult Wrongs" (Newman, 2002)

> "As disabled mothers we have a vested interest in this debate: our children are not our 'carers', they do not parent us; but the social construction of 'young carers' and the media attention which has followed affects us every time we go out with our children, every time we meet new people, especially health and social services professionals. The research and media presentation of 'children as carers' undermines our role as mothers and defines disabled parents as inadequate" (Keith and Morris, 1995, p.39).

Newman (2002) argues that the young carer debate presents the notion of disability and illness as being hazardous to family life, leading to "pathologised and distorted" images of parents with a disability. In addition, Keith and Morris (1995) and Prilleltensky (2004), all three defining themselves as 'disabled mothers', posit that the notion of 'carer' implies that the individual being cared for is in a dependent and passive role, and the researchers are critical of the young carer debate for "framing young people's lives around assumptions about family life" (Keith and Morris, 1995, p.46). Furthermore, research by Earley et al. (2007) found that the negative focus of young carer roles serves to reinforce the feeling of role reversal between the caregiver and receiver, resulting in the children and young people being regarded as 'parentified' by professionals. A stereotypical view therefore emerges, which positions the disabled parent as dependent upon their children, and the children and young people being ‘forced to care’ for the parent, thus potentially colouring professionals’ perceptions of family dynamics in the process. O'Dell et al. (2010), however, exploring young carers' views of their disabled parents, noted that all the participants voluntarily cared for their parent(s) without a sense of moral obligation, and did not feel forced into doing so. Moreover O'Dell et al. (2010) posit that:

> "all families are complicated and if we only see caring for a disabled family member as a problem we are missing out on a lot of information" (O'Dell et al., 2010, p.645).

The implication, therefore, is that if the experiences of the young carer are being viewed as negative and restricting, this is also more likely to position the individual receiving care in a negative light. Research which focuses exclusively upon the needs of the carer, furthermore, is seen by disability rights campaigners to undermine the power and status of the care receiver (Banks et al., 2001, Olsen, 1996), reinforcing social stereotypes which views disability as: "dysfunctional, incompetent, burdened, or brave" (Banks, 2003, p.368). This, in turn, is seen as being counter-productive when families are requiring a needs assessment and access to intervention and support systems from professionals.

2.4 Statement of the Problem

This chapter has drawn attention to the literature, multiple social constructions and varying channels of discourse surrounding children and young people identified as young carers within the context of looking after a sick or disabled family member. In summary, the issues discussed relate to the following areas of concern and 'problems' illuminated when critiquing and examining such material. It is apparent that the issues raised relate to there being:

- multiple discourses and conflicting social constructs about the individuals who inhabit the 'young carer' role
- multiple discourses and conflicting social constructs about the individuals requiring care, particularly of parents with a disability
- uncertainty among professionals about young carer roles and responsibilities, as well as how young carers are identified and referred
- complex issues relating to young carers being marginalised and possibly 'invisible' within educational and social care systems, and the inherent vulnerability this implies
- young carers being potentially denied a voice and remaining a silent, passive agent within intervention processes and family support mechanisms
- a perceived imbalance of power and tension in the process of recognising and meeting the needs of both the young carer and the needs of the person(s) receiving care
- conflicting social constructs of the notion and nature of 'care', which can be regarded as contextually and culturally specific (Banks, 2003)
- a suggestion that there is a predominance of research highlighting the deficit model of being a young carer (Prilleltensky, 2004)
- significant gaps in the research literature in terms of exploring the psychological aspects of being a young carer, or young carers' experiences of education, with specifically no papers currently published within the discipline of educational psychology
- a need for clarity, given the nature of the complexity surrounding the topic

2.5 The Aims and Purpose of the Study

This research aims to use Q methodology as a tool to explore the views of children and young people identified as young carers, and of professionals, about young carer roles, responsibilities and experiences within the context of looking after a sick or disabled family member. For the purposes of clarity the following operational definitions of the terms ‘young carer’, ‘professional’ and ‘disability’ will be employed within this study:

- *‘Young Carers’:* “are children and young people under the age of 18 years, who provide care to another family member who has a physical illness/disability; mental ill health; sensory disability or has a problematic use of drugs and alcohol. (…) The level of care they provide would usually be undertaken by an adult and as a result of this has a significant impact on their normal childhood” (PSS Local Authority Young Carers’ Project, 2003, p.4)

- *‘Professionals’:* are adults who work within social care; health; education; educational psychology; and the voluntary sector, and who may be likely to encounter young carers in some aspect of their working lives

- *‘Disability’:* a ‘disabled’ person is anybody with actual or perceived physical, sensory, emotional or learning impairment, long-term illness, HIV, drug or alcohol dependence or a person with a mental health issue (Princess Royal Trust for Carers, 2006)

This research aims to consider whether there are any shared viewpoints among young carers (given the diverse range of their individual experiences and circumstances) and shared viewpoints among professionals (given the range of professionals from education, social care and health settings, who may encounter young carers in their work) about young carers, their education and support systems, and the way in which they are engaged by professionals in the processes of referral, intervention and support. The research will offer both sets of participants an opportunity to reflect on their experiences (either personal or professional) and to consider their viewpoints towards young carers and how professionals intervene in their lives.

2.6 Research Questions

Given the aim and purpose of the study, the following research questions were formulated:

R.Q. 1: What are the viewpoints of children and young people identified as young carers in terms of their roles and responsibilities, and their experiences of intervention and support processes in education, social care and health settings?

R.Q. 2: What are the viewpoints of professionals about young carer roles and responsibilities and of the intervention and support processes available to young carers in education, social care and health settings?

3.0 METHODOLOGY

This chapter will begin by outlining a brief narrative which explores my own philosophical position as a person, a professional (trainee educational psychologist), and as a researcher, to assist in highlighting the theoretical, ontological and epistemological assumptions underpinning this research, subsequently providing the context for the use of Q methodology as the chosen research tool. As part of this context the historical backdrop of Q methodology will be briefly described and the stages and structure of Q methodology will also be outlined, which will serve to set the scene for the procedures chapter to follow. I will discuss, furthermore, the rationale for choosing this methodology as the most appropriate vehicle for addressing the research questions and conclude by considering why other methods were evaluated and rejected.

3.1 My Philosophical Position

"We see from where we stand"

Haitian Proverb (Diggs, 2010)

By providing, below, an outline of my position as a person, professional and researcher, I hope to provide a brief context for the decisions made within this research at an ontological, epistemological and methodological level.

3.1.1 As a Person

My mother's illness, which was briefly discussed in the Introduction (Chapter 1.0), had a profound effect upon my upbringing. Looking back I would not have described myself as a young carer, especially as at the time the term was not widely known or acknowledged, but more importantly because my mother was fiercely independent and wanted to carry on with as little support as possible for as long as possible. I considered myself to be, rather, as a daughter helping out with household tasks and supporting my mother emotionally in the same way as my other siblings. It was only in my late teens that I began to worry about leaving home as I instinctively wanted to remain near in case anything should happen to her. In my early twenties my caring role increased as my mother had a stroke and became less mobile, and I looked after her as a full time carer for a year, prior to my father's retirement. As well as providing emotional support I became involved in more practical tasks relating to hygiene, dressing, medication and attending appointments, to name but a few.

The experience of growing up in a family environment with worry, upset, and ultimately grief after my mother's death, but equally love, support, humour and mutual care, has given me a valuable insight into the complexities, difficulties and strengths of caring for a parent. Not surprisingly it has contributed significantly to my character and identity as an adult and as a parent, and has moulded the way in which I view the world.

3.1.2 As a Professional (Trainee Educational Psychologist)

In my role as a trainee educational psychologist I continue to develop my practice within Rogerian principles of unconditional positive regard (Rogers, 1967) towards fellow professionals, parents and guardians, children and young people, and any other 'stakeholders' with whom I may come into contact. I am passionate about consultation as a tool for change, and within this framework I aim to employ strategies to empower the consultee(s) in order to elicit their views towards generating and sharing joint hypotheses and a shared understanding of a given situation or 'problem', especially when discussing children and young people, and their parents, who may be perceived by school staff as being 'hard to reach' (Thompson and Holt, 2007). In addition, I find that solution focused methods of consultation (Wagner, 2000) offer an opportunity to explore strengths-based models and exceptions (for example in a child's behaviour) for the purposes of elegantly challenging stereotypical held beliefs. In so doing I hope that I allow marginalised voices and opinions to be heard within a relationship of trust and mutual respect, thus reducing the potential power dynamic of the educational psychologist as 'the expert'.

The framework of practice described above is idealistic in that I am not always successful in my aims, however it is something to which I continually aspire and hold as a model of best practice, using reflection as a tool to explore what has gone well, and what I could do differently when facing barriers, to help bring about improved outcomes.

A further aspect of my role as a trainee educational psychologist is that I regard myself as a critically reflexive research-practitioner, and I hold the view that the terms 'educational psychologist' and 'researcher' are not mutually exclusive, but bound inextricably within the same paradigm of working. This idea is explored in more detail below.

3.1.3 As a Researcher

I consider myself a 'critically reflexive research-practitioner' as within my professional role I attempt to build a bridge between the disciplines of research and practice with an aim to contribute towards the evidence base within educational psychology and to a growing knowledge base, in order to further improve understanding of what it means 'to be human'. Recent research, in fact, has highlighted the need within educational psychology for more reliance upon evidence-based practice in the specific application of psychology, in order to close the 'science-practitioner gap' (Cautin, 2011, Reynolds, 2011). Furthermore, as a critically reflexive research-practitioner I am mindful of the potential dangers of what Isaacs and Fitzgerald (2011) describe as 'eminence based-practice' in which practitioners give undue credence and prominence to the most commonly known and longstanding clinical knowledge base, often erroneously taking for granted that it is the most efficacious with regard to assessment and intervention. Being critical, therefore, requires that I challenge assumptions, remain mindful of alternative theories (however marginal) and use reflexivity to look at my own assumptions and position both within my daily practice and within my research.

With this final point in mind my aim within this research is to employ a methodology which affords me the opportunity to remain 'objective' and 'detached' from the research participants, with regard to the data gathering and analysis process (see 3.2.1). Why would this be the case? Can a researcher ever be truly objective and detached? I have acknowledged that my family history and upbringing grants me a potentially unique insight into what the young carer participants in my study may be experiencing, and as such there exists a transactional dynamic (consciously or subconsciously) which prevents me from completely removing myself from the research process. Although this could be regarded as advantageous, in terms of assisting reflexivity, there is, equally, a concomitant risk that I allow myself to become victim to the 'affect heuristic' whereby the 'validity' of the research data is judged or interpreted by the emotional reaction it elicits in me (Lilienfield et al., 2011). A researcher can never be entirely immune to this affect, but during the process of reflection I am, nonetheless, mindful of: "avoiding the trap of relying more heavily on [my own] introspections rather than on others" (Pronin et al., 2004**,** p.783). This is not to say that my reflective processes should be diminished, however, but that they should not overshadow or dominate the reflections and views of others. Distance, therefore, is not only a preference but, I believe, a necessity within this context, in order to prevent biases and to provide an ethical barrier between the young carers' experiences and my own, both at the level of 'safeguarding' one another, but also at the level of ensuring that the participants' voices are not overshadowed by my own historical perspective and that a "you don't know me but I know you" (Pronin et al., 2001, p.639) approach to my research is minimised. This approach would, in fact, serve to endorse the power imbalance which has been highlighted as a significant issue within the context of young carers.

3.2 The Journey Towards Q Methodology

Q methodology is an innovative method, developed by William Stephenson, as a vehicle for gathering subjective viewpoints (Stenner, 2008) and employs both quantitative and qualitative techniques in the process of studying 'subjectivity'. The two main features of Q methodological studies are the collection of data using Q sorts and the analysing of those Q sorts using inter-correlation and by-person factor analysis (Watts and Stenner, 2012). A glossary of terms relating to Q methodology can be found in Appendix (i) to offer further explanation in the process of reading the sections to follow.

3.2.1 Rationale: Does Q Methodology Fit?

Given the 'statement of the problem', the aim of the study, the research questions (Chapter 2.0), and the philosophical position described above, my initial thoughts concerning the ingredients needed within the methodology were that the chosen method would be required to:

- appropriately address the research questions and be consistent with the aims of the study, as well as with my ontological and epistemological position as a researcher
- address the ethical issues relating to working with children and young people who are considered to be vulnerable
- address the ethical issues raised by my former life experiences (see 3.1.1)

- bring clarity and structure to complex, multi-faceted discourses and social constructions
- provide a vehicle for recording shared viewpoints, but in so doing ensure that each individual voice is heard and is equally valued in the data gathering and analysis process
- reduce the potential power dynamic between participant and researcher
- provide distance for the researcher, to allow the participants' voices to be dominant, without undue researcher influence in the data gathering and analysis process
- be exploratory in nature, without imposing a priori assumptions or hypotheses
- accommodate numbers of participants from differing sample groups

3.2.2 Theoretical, Ontological and Epistemological Assumptions

The theoretical philosophical position I have adopted within this research is one of a critical realist within a social constructionist paradigm. My interpretations of these terms have informed and influenced the resultant methodological decisions outlined in this chapter.

- *Critical Realism*

Theoretical assumptions at an ontological and epistemological level have been bound up within numerous philosophical debates, leading to what some researchers refer to as the 'paradigm wars', where the process of holding entrenched positions on either side of the ontological realist-relativist 'divide' serves only to undermine the philosophical stance being defended (Cromby and Nightingale, 1999). Engaging in debates pertaining to the nature of reality (ontology), therefore, have been seen to lead to polarised 'it's real, no it's not' encounters, resulting in equally polarized notions concerning the nature of knowledge and the extent to which 'reality' can be known (epistemology). Moore (2005a), for example, describes how the two opposing world views can be characterised thus:

> "In the first the world is an orderly, law-abiding enduring, fixed and objectively knowable and constant place. In the second the world is indeterminate, disorderly and constantly in flux and thereby ultimately 'unknowable' in any objective sense" (Moore, 2005a, p.106).

Notions of ‘reality’ and ‘representation’ can be interpreted, here, as being separate entities, and appear unrelated and artificially divided in terms of how humans experience and interact with the world. Bhaskar (2011) describes how natural and social phenomena such as ‘subject and object’, and ‘mind and matter’ are:

> “dimensions of existence in continuous dynamic causal interaction. Thus not only are many ‘natural’ ills and disasters socially produced, but social production may have absolute natural limits and conditions” (Bhaskar, 2011, p.5).

The way in which I am interpreting and understanding critical realism, therefore, acknowledges that there is a third way between the extremes of naïve realism and universal relativism in that reality and representation, and nature and society are not in opposition, but part of a continuous dynamic interaction and can thus be conceptualised as both sides of the same coin, as opposed to disparate entities to be considered in isolation (Sayer, 2000). Furthermore, critical realism, as an ontological position, affords researchers an opportunity to critically reflect upon the society they are investigating, proffering challenges to ‘political’ and stereotypical assumptions, and can therefore be considered as potentially emancipatory in its approach (Harré, 2009). This is particularly relevant within this research, given that young carers have been typically regarded as being representative of a traditionally hidden or marginalised population (Banks et al., 2001).

- *Social Constructionism*

Social Constructionism is a widely adopted term within social science and has been itself constructed in a number of ways, depending upon the epistemological position of the individual researcher, something which Cromby and Nightingale (1999) highlight as counterproductive:

> “Social constructionism’s strength as a critique is simultaneously its undoing as a framework for its future development. Its position is thoroughly grounded in the circumstances of its own construction” (Cromby and Nightingale ,1999, p.2).

Danzinger (1997) in fact, points to there being broadly two strands of social constructionism: a ‘light version’ which focuses primarily upon the minutiae of discourse and built upon theories of speech act deconstruction and a ‘dark version’ which relates to issues of power and subjectivity. Sims-Schouten et al.

(2007) develop this idea further, within a critical realist position, by suggesting that discourse alone is not sufficient to represent the range of human experience and that non-discursive elements such as materiality and embodiment should not be classed as secondary, but be seen as equally representative of social conditions and human agency. Critics of radical social constructionism, therefore, recognise that social constructionists have hitherto relied too heavily upon the role of language as a paradigmatic vehicle, at the expense of the influence of embodied factors (such as a physical disability), material factors (such as the possible restrictions of material objects, for example, flights of stairs, narrow pavements or uneven surfaces), or the power of institutions and governments (with the resulting potential for inequality) (Cromby and Nightingale, 1999).

This research will adopt the latter ‘dark version’ of social constructionism, and will regard discourse and other social constructs (embodiment and materiality) as being equally important to the development of meaning within any given human agency. Whilst critics of this position could argue that non-discursive elements can only be conceived or experienced in any meaningful way when they are transformed into discursive elements (Cromby and Nightingale, 1999) it is apparent that in adhering to discourse as the “only valid unit of analysis” (Sims-Schouten et al., 2007 p.102) other experiences, which are non-discursive (such as dance, or access to buildings) become marginalised (Burr, 1999). Given that my research focuses upon young carers looking after a sick or disabled family member and the multi-faceted discourses and social constructions surrounding the topic, this epistemological position seems appropriate as well as representative of the view that: “[Our] bodies are the intimate place where nature and culture meet” (Cromby and Nightingale, 1999, p.10) and as such it could be considered obstructive to create an artificial divide between the natural and social worlds.

3.3 Q Methodology in Context

Q methodology is considered to be an ‘alternative’ methodology, developed by Stephenson (a physicist and psychologist), specifically within the context of psychological study in order to critically challenge historically dominant paradigms of psychological enquiry, namely those of behaviourism and cognitivism (Stenner, 2008, Watts and Stenner, 2005a). Stephenson considered that the traditional methods of psychological psychometric testing, within the positivist tradition, were unsatisfactory in that they only revealed commonalities between tests (such as IQ scores or personality traits), by clustering together and correlating test scores (Brown, 1993). This is known as R methodology, or by-*item* factor analysis, where the participants are the ‘subjects’ and the questions (test scores) are the ‘variables’ (Webler et al., 2009). In R methodology patterns are sought across variables (for example seeing if the value of one test score is related to the value of another test score in the same participant). Stephenson, on the other hand, inverted this process to create by-*person* factor analysis, designing Q methodology so that the Q set (the statements around a given topic, see 3.3.1) become the ‘subjects’ and the individual Q sorts (the participants’ viewpoints, see 3.3.1) become the ‘variables’, and consequently it becomes possible to correlate the way in which individual Q sorts cluster together to form similar or shared viewpoints. In contrast, therefore, by-person factor analysis highlights patterns between Q sorts by comparing the value of one variable (a Q sort from participant 1, for example) with the value of another variable (a Q sort from participant 2) for the same Q sort statement (Webler et al., 2009). As such the methodology can be used to identify viewpoints of a subjective nature within participants using a structured quantitative framework. It is in this regard that Q methodology can be seen to be unique in combining elements of both qualitative and quantitative enquiry, resulting in it being thus referred to as a ‘qualiquantological’ method (Stenner and Stainton Rogers, 2004), straddling the divide between qualitative and quantitative paradigms, whilst combining the strengths of both, to elicit: “empirical discoveries of a qualitative kind” (Stephenson, 1935, p.205).

The ultimate goal of Q methodology, therefore, is to explore and examine subjectivity (Brown, 1996) and what Stephenson describes as capturing ‘operant’ behaviours and ‘states-of-feeling’ (Stephenson, 2005, p.102) within a given structure and form. Watts and Stenner (2012) define an ‘operant behaviour’ as one which is:

> “made meaningful by the nature of its relationship with, and impact upon, the immediate environment. The term can also be used as a collective noun to denote a distinct class of behaviours, all of which make impact upon the environment in a similar fashion” (p.33).

Q methodology, as such, can be seen to be a vehicle for gathering shared viewpoints within a social constructionist paradigm, via the exploration of operant behaviours and ‘states of feeling’ at a subjective level.

3.3.1 Stages and Structure of Q Methodology

Q methodology can sit comfortably within the social constructionist paradigm (although not exclusively so, see Stainton Rogers and Stainton Rogers, 1990), as it is exploratory in nature, and rejects the logic of hypothetico-deductive conjectures, and is consequently not subject to a priori assumptions by the researcher (Curt, 1994, Watts and Stenner, 2005a). As such it can be considered an abductive process (Watts, 2009). Abduction, according to Peirce (1931/1958), involves the exploration of observed phenomena (which are to be regarded as clues rather than ‘truths’ to be proven or falsified) and the attempt to provide possible explanations as to: “why the observed phenomenon is manifesting itself in [a] particular way” (Watts and Stenner, 2012, p.46).

The structure and stages of Q methodology assist in the process of abduction in that :

> “Q methodology does not impose meaning a priori, but asks participants to decide what is meaningful and hence what does (and does not) have value and significance from their perspective” (Watts and Stenner, 2005a, p.76).

This, from the perspective of Q methodology, adheres to what Harvey describes as: “one of psychology’s most basic and well established principles” (Harvey, 1997, p.146), which is the human desire to attempt to determine structure and meaning from multifarious events and stimuli.

Brown (1993), Van Exel and de Graaf (2005), Watts and Stenner (2005a), and Webler et al. (2009) are among a number of authors who have produced ‘primers’ or guides on the use of Q methodology for the purposes of providing clarity to a ‘misunderstood and misrepresented’ research tool (Watts and Stenner, 2005a) , and also to promote the use of the methodology in diverse areas of research (such as in environmental studies, Webler et al., 2009).

The skeleton of a Q methodology study, therefore, is described as consisting of:

- the identification of an area of study and of a group (or groups) of people (who become the participants, or P set) whose viewpoints the research aims to elicit
- the development of a 'concourse' and a Q set (also known as a Q sample)
- the completion of the Q sort by the P set
- the analysis of the data

Concourse: this describes the list of 'items' which can be compiled about a topic, and should be as comprehensive as possible in order to capture the broad range of representations or items in relation to a specific area of enquiry (Brown, 1980). The 'list of items' can be in the hundreds and is obtained from "the flow of communicability in the ordinary conversation, commentary and discourse of everyday life" (Brown, 1993, p.93), including published literature, research, newspaper articles, television programmes, websites and focus groups. The concourse need not be restricted to discourse alone, however, and can include pictures, photographs and other non-discursive elements, such as music and dance. As Brown (1993) highlights, a concourse should incorporate: "virtually all manifestations of human life, as expressed in the lingua franca of shared culture" Brown, 1993, p.94).

Q set (also known as a Q sample): the Q set is developed through a filtering and sampling of the concourse, and usually consists of a series of numbered statements written on cards (or other stimuli if non-discursive), the goal of which is to provide a miniature version of the concourse (approximately 40-80 statements is typical), without losing any of the comprehensiveness in terms of content or representativeness (Van Exel and de Graaf, 2005). In this respect the formation of a Q set can be considered something of an 'art form' and a 'craft' (Curt, 1994). It is acknowledged that the Q set: "can never really be complete (as there is always 'something else' that might be potentially said)" (Watts and Stenner, 2005a), however it can be considered robust providing that it: "contains a representative condensation of information" (Watts and Stenner, 2005a, p.75). This is justified in that:

> "the main concern in a Q methodological context is not the Q set itself (which is, in any event, not considered to possess any specific meaning prior to the sorting process), but the relative likes and dislikes, meanings,

> interpretations and overall understandings which inform the participants' *engagement* with the Q set" (Watts and Stenner, 2005a, p. 76).

Q sort: this procedure is described as: "the technical means whereby data are obtained for factoring" (Brown, 1980, p.17) and involves individual participants ranking their statements by placing them on a grid (usually of quasi-normal distribution, but not exclusively so, Brown, 1993) depending upon the level of agreement with the statement, and as such a completed Q sort registers a participant's subjective viewpoint. The statements are not considered to be absolute 'facts' and, prior to the sorting process, are deemed to be equal in value, hence they are ascribed meaning by the participants and given value and significance, depending upon their subjective experience, understanding and interpretation of the statements (Watts and Stenner, 2005b). Stephenson (1983) concluded that there is an infinite amount of variation in terms of the possible statement distribution from participants, but equally that there are always fewer viewpoints than persons:

> "It would be remarkable if any two sorts, from different persons, were exactly alike; and unlikely that all will be totally different. It is the purpose of factor theory to determine which distributions, if any, are approximately alike, on the theory that they have the same 'eigenwerken', the same 'characteristic value, the same feeling" (Stephenson, 1983, p.78).

This suggests, therefore, that the same statement can represent different meanings (or constructions) for different participants, thus reinforcing the focus upon individual subjectivity within the method (Brown, 1993), whilst recognising that similar viewpoints can be shared between participants.

Data analysis: a computer program is used to analyse completed Q sorts mathematically, via a by-person factor analysis (see 3.3 above), to determine the extent to which individual Q sorts correlate highly with one another and therefore can be considered to have a 'family resemblance' (Brown, 1993), known as a 'factor'. The purpose of factor analysis is to determine the underlying factors from the data, which can summarize the pattern of correlations (Kitzinger, 1999). The amount of factors extracted from the data and the way in which these are interpreted and described is a matter of judgement and dependent upon the individual researcher, however, which will be influenced by: "where one is coming from" (Stainton Rogers, 1995, p.191) as well as statistical and theoretical processes. This procedure is described in more detail in Chapter 4.0.

Q methodology, therefore, has been chosen as the research tool for this research as it is the ‘best fit’ in terms of meeting the criteria described above (see 3.2.1), not only because it is exploratory and abductive, and is sympathetic to my ontological and epistemological position, but that the structure within the methodology is advantageous in terms of researching marginalised voices within a subject area which is highly complex, potentially contentious and in which there are perceived imbalances in power. The use of the concourse, and resulting Q set, for example, affords the researcher an opportunity to be thorough and comprehensive in searching for the broadest range of social constructions around a given subject, including using focus groups to elicit the voices of the population(s) who are the subjects of the research (see Chapter 4.0). The condensed statements, furthermore, serve to represent a diverse range of information and are thus capable of presenting potentially complex and multi-faceted discourses and social constructions in a more accessible and ‘user friendly’ way, compared to presenting the equivalent body of information within questionnaires or in an interview schedule. The structured process, consequently, renders Q methodology an appropriate vehicle for employing:

> “multi-participant format (…) deployed in order to explore (and to make sense of) highly complex and socially contested concepts and subject matters, from the point of view of the group of participants involved (…) In so doing it [Q methodology] has more than demonstrated its ‘sense-making’ capacity and ability to find qualitative ‘order’ even in domains where variability and disparity seem initially to have prevailed” (Watts and Stenner, 2005a, p. 73).

Q methodology, therefore, has been seen to bring clarity, coherence and structure to complex and socially contested arenas (Stainton Rogers, 1995), including research in subject areas which could be considered controversial or sensitive, such as studies around adolescents in foster care (Ellingsen et al., 2011), or subjective experiences of partnership love (Watts and Stenner, 2005b).

The nature of the Q sort activity itself renders Q methodology a suitable and appropriate method for this research, in that it provides a degree of ‘objectivity’ and distance between the researcher and participant during the data gathering process. As highlighted above (see 3.1.3) this was thought to be desirable in order to minimise potential researcher bias and influence, as well as to safeguard against emotional harm. As participants ascribe their own meaning to each statement in accordance with their subjective viewpoint (see 3.3.1) this lessens the risk that the researcher will impose their own meaning a priori, thus unduly influencing the participants' responses. A recent post on the Q methodology online forum highlights that this is:

> "why we, when collecting Q data, refuse to give our interpretation of any of the statements while the sorting is taking place. If asked we must say 'whatever it means to you' or we run the risk of imposing our subjectivity on the sorter" (Danielson, April 2011).

As a result of the researcher's objectivity, therefore, the subjective nature of the Q sort can emerge unhindered. The process of sorting the numbered statements (or other stimuli), moreover, can be considered an active, dynamic activity (Watts and Stenner, 2005a) and as such the reading, handling and placing of the cards has been seen to be an innovative, engaging and enjoyable experience (McKenzie et al., 2011). Furthermore, the participants have an opportunity to reflect upon and review their completed sorts, each visible in its entirety, at the end of the process, thereby giving them a further degree of control to determine how they would like their final configuration to be presented and recorded. Through this process the power dynamic between the participant and researcher is potentially reduced, as the participants decide what the statements mean to them, where to place them in accordance with their viewpoints, and when the sorting process is over, by confirming their agreement with their finished grid. This is particularly relevant within the context of eliciting voices of marginalised populations (such as young carers) who have been seen, hitherto, to be passive and silenced within 'powerful' institutions or other social systems and processes (see Chapter 2.0).

The data analysis process within Q methodology is one which also affords the researcher a degree of objectivity. It is suggested that the researcher is presented with information:

> "which, although based on subjective responses, is objective in that the identification of different points of view is determined mathematically, and not through the possibly biased lens of the researcher's own perspectives" (McKenzie et al., 2011, p.1).

Kitzinger (1999), furthermore, points out that:

> “The participants in the study [are] in control of the classification process. A factor cannot emerge unless participants sort items in ways that enable it to do so” (Kitzinger, 1999, p.267).

The researcher, therefore, retains the integrity of the participant’s Q sort, which is entered faithfully into the computer programme, the configuration of which is maintained as constructed by each individual participant. Furthermore, the analysis process can be viewed as a gestalt, holistic procedure, as the data are not broken up into constituent parts, but interpreted as a whole, in order to assist in establishing the links between the individual Q sorts and the extent to which they represent the emerging factors (Watts and Stenner, 2005a). This means that all participant Q sorts are analysed equally, and the corresponding viewpoints considered equal, rather than minority voices being dominated by majority views. As mentioned above, however, the exact number of factors to be extracted and their interpretation is dependent upon the researcher, which will inevitably be influenced by their own position, understandings and beliefs about the subject. The researcher’s decision making process in this layer of analysis needs to be transparent, therefore, assisted by the criteria for factor extraction, and other procedures, which are discussed in further detail below (see Chapter 5.0).

Q methodology could be considered a unique methodology in that it is able to support data which are representative of both individual and shared viewpoints, which Watts describes as accommodating both the ‘constructivist’ (individual self-reference) and ‘constructionist’ (social bodies-of-knowledge) approaches (Watts, 2009). He considers that both are required in order to see the ‘whole picture’ of human experience, criticising the ‘dualism’ which creates an artificial divide between the personal and the social, in that it is almost impossible to disentangle one from the other (Watts, 2009).

3.4 Summarising Strengths and Limitations of Q Methodology

Q methodology’s strengths as a research method lie in the way in which it examines subjectivity within an objective framework, offering a clear structure and process, which can help bring clarity to potentially complex and socially contested subject areas. It is also a novel, active and engaging activity, during which participants can have the opportunity to ‘take charge’ in the data gathering process whilst reflecting upon their beliefs, thoughts, perceptions and 'states-of-feeling' to ultimately construct their individual grid to represent their viewpoint. During data analysis, too, the data are not deconstructed but faithfully represent the participants' responses, in that factors can only emerge if the participants data are sorted in that way. The data also allow all voices and viewpoints to be heard, in that minority voices are not overshadowed and are considered equal in the analysis process, and as such it offers an appropriate vehicle for eliciting marginalised and hitherto silenced viewpoints. Q methodology, in addition, focuses upon the shared viewpoints of participants, whilst allowing their individual viewpoints to be heard and as such integrates the personal and the social in a coherent manner (Watts, 2009).

In terms of limitations the innovative and 'alternative' nature of Q methodology increases the potential for the method to be misunderstood and misinterpreted both as a researcher carrying out the process, and also as a member of the research community in terms of interpreting research findings (Dziopa and Ahern, 2011, Watts and Stenner, 2005a). In addition, Q methodology has been criticised for lacking validity, reliability and generalisability within research (see Van Exel and de Graaf, 2005). As Stenner and Stainton Rogers (2004) point out, however, Q methodology should not be judged in the same way as experimental, quantitative research in that it:

> "lays no claims to be measuring anything, and hence adopts a completely different relationship to questions of validity and reliability" (p.102).

Guba and Lincoln (1986), furthermore, refer to the alternative constructions of 'credibility', and 'dependability' when evaluating the nature of qualitative research, specifically the concepts of 'ontological authenticity' (increased understanding) and 'educative authenticity' (increased awareness of others' positions), two principles to which Q methodology could claim to adhere.

Q methodology does not claim to provide research findings which can be extrapolated or generalised across a population, given that:

> "the results are the distinct subjectivities about a topic that are operant, not the percentage of the sample (or the general population) that adheres to any of them" (Van Exel and de Graaf, 2005, p.3).

Results from Q methodology studies, however, have been seen to be reliable and stable over time (see Brown, 1980, Stephenson, 1953, and Watts and Stenner, 2005b) but, crucially, in the shared viewpoints expressed only, rather than in the individual Q sort arrays. As Stenner argues: “It is a safe bet to assume a given set of items has never before been configured in that way” (Stenner, 2008, p.61) which would imply that the same set of items would never be configured in the same way again. This is acknowledged by Watts and Stenner (2005a) who summarise thus:

> “Q methodology makes no claim to have identified viewpoints that are consistent *within individuals* across time [as this would] impose a priori counterintuitive assumption that a given participant is capable of expressing only one coherent viewpoint on an issue. (...) Whilst this leaves individual exemplars free to ‘change their minds’, we might nonetheless expect the emergent *manifold of shared viewpoints* to show a degree of consistency over time” (p.86).

Given, therefore, that in Q methodology there are always seen to be fewer viewpoints than persons, the individual participant’s viewpoint shifts from becoming unique to becoming part of a cluster or shared view (Stainton Rogers and Stainton Rogers, 1990), which is: “consistent across time, place and repeated interrogation” (Watts and Stenner, 2005a, p. 41).

3.5 Why Alternative Methodologies were Rejected?

> *“It is obvious that one can no more set out to experimentally identify the causes of the French revolution than one can contemplate interviewing a gene” (Bhaskar, 1979*, *p.30).*

When reflecting upon the research questions and the aim and purpose of the study, a number of methodologies were considered prior to choosing Q methodology as the ‘best fit’.

As an exploratory method was preferred, without employing a priori assumptions, research methods utilising an experimental design were immediately dismissed.

Questionnaires and interviews were then considered, being more in keeping with qualitative methods, however the limitations of using these tools meant that they were not considered suitable**.** Questionnaires, for example, are designed to reveal communality between individual questions (or items), rather than communality between participants and as such do not offer shared viewpoints, which have been highlighted as a requirement of this study (see section 2.5). Furthermore, questionnaires do not provide analysis of data in a holistic sense, as analysis focuses upon individual questionnaire items rather than the entire configuration or pattern of the placement of items (or statements) as in Q methodology. Although interviews offer a more holistic interpretation of data than do questionnaires the process of transcription and analysis (whether thematic analysis, narrative methods or interpretive phenomenological analysis) is intensive in practical terms, thus limiting the amount of research participants to only a small number (Kvale and Flick, 2008). In addition the complex and multi-faceted nature of the subject area meant that the size of a questionnaire or structured interview needed to ensure a broad coverage of the issues would be prohibitive and impractical at a procedural level.

As my interest in this research lay in the discourse and social constructions around young carers and disability I was subsequently drawn towards discourse analysis, and the notion of positioning. Discourse analysis focuses upon the micro processes of language, and the minutiae of detail emerging from within individual participant responses, thereby restricting the number of participants due to the intensive nature of the data analysis process (Potter and Wetherell, 1987). My research aimed to explore ‘macro’ processes and shared viewpoints, however, and as such discourse analysis was rejected as a method. Discourse analysis, in addition, requires the researcher to be an integral part of the data gathering and analysis process, something which was not appropriate for this research, given the need for an ethical distance and researcher objectivity. As highlighted earlier (see p. 26), however, the degree to which ‘objectivity’ can be achieved is subject to debate, given that researchers can never remove themselves completely from the research process. In addition, ‘ethical distance’, within this context, refers to the way in which I wanted to place an ethical ‘transparent screen’ between myself and the research participants; a screen which would still allow me to see and respond to the emotional well-being of the research participants (see 4.1), but which would also shield against my own introspections, personal reflections and biases potentially overshadowing, contaminating or dominating the participants’ reflections and viewpoints. Narrative methods and Interpretative Phenomenological Analysis were also data gathering and analyses processes (Smith et al., 2009).

Having considered a range of methodological approaches, Q methodology was regarded as the most appropriate tool for gathering and analysing data within this research, given the criteria set out in section 3.2.1 and the content of the research questions.

3.6 Summary

This chapter has outlined my philosophical ontological and epistemological position within this research which has hopefully assisted in explaining the methodological decisions made herein. Q methodology was chosen as the most fitting and appropriate research tool, and a rationale and explanation of the method has been offered in order to set the scene for the Procedures chapter to follow, which will detail the exact processes employed in the gathering and analysis of the data.

4.0 PROCEDURES

The previous chapter outlined the structure of a typical Q methodology study, namely:

- identifying participants (known as the P set) whose viewpoints the research aims to elicit
- development of a ‘concourse’ and a Q set
- completion of the Q sort by the P set
- analysis of the data

This chapter will give a detailed account of how each step of the process was carried out, why methodological decisions were made (including learning points from the pilot study) as well as draw attention to the ethical considerations within the research.

4.1 Ethical Considerations

This study was carried out in accordance with the British Psychological Society’s *Code of Research Ethics* (BPS, 2010), and subject to a procedure of ethical review in compliance with The University of Sheffield’s ethical principles and policies (see Appendix (ii) for confirmation of ethical approval). These ethical principles were considered a minimum requirement when designing the study and liaising with participants, and were an integral part of the decision making processes throughout, rather than just at the outset. Flewitt (2005) describes how, within exploratory research, the concept of ‘informed consent’ can be problematic as research can often be subject to unpredictable and unexpected changes in direction. As such, within this research, ‘consent’ was deemed to be informed but also ongoing and ‘provisional’, dependent upon the research: “being conducted within a negotiated, broadly outlined framework and continuing to develop within the participants’ expectations” (Flewitt, 2005, p. 556). As a result, throughout the research process, participants were reminded of their right to withdraw and their reactions and emotional responses were continually monitored and ‘checked out’, with appropriate support mechanisms in place should they be required (see 4.4 below).

4.2 Participants

4.2.1 Whose Views Were Important?

It has been described thus far that the subject area of young carers is one which gives rise to complexity and discordant views at a variety of levels. Choosing this as a research area was difficult, therefore, in terms of what was considered important to find out and whose voices it was necessary to hear. I had initially thought of exploring the views of young carers and their family members (parents or siblings) requiring care. I reflected, however, that there may be ethical considerations when asking young carers to express viewpoints about family members and vice-versa, in case areas of sensitivity or discord emerged, something, in fact, which could have further contributed to the complexities and discord highlighted in existing discourse and literature. Potential sensitivities could have been minimised by finding young carers and parents (or siblings) from different (i.e. not related) families; however the timescale required to execute this would have been prohibitive. I then discovered studies by Aldridge and Becker (2003) and Becker (2005) highlighting a dearth of research exploring professionals' viewpoints:

> "In the context of young carers and their families, research needs to gather the views and experiences of children [….] as well as the perspectives of professionals who provide services, to check out the extent to which views and experiences are unique or common, to make sense of them and to identify clearly messages and implications for policy and practice" (Becker, 2005, p. 3).

As well as identifying a gap in the research literature (as the vast majority of studies in this area focus exclusively on young carers), this provided a springboard for employing different populations (young carers *and* professionals) within the same study. Giving young carers a voice, through the process of registering their viewpoints, and 'checking out' the extent to which their views and experiences were shared or commonly held, was a vital part of this research and one which I felt could not be ignored or neglected, given that previous research has shown young carer voices to be hidden and marginalised. On the other hand the prospect of focusing exclusively upon young carers and ignoring the viewpoints of professionals felt equally uncomfortable and I felt that to sideline their viewpoints would severely limit the comprehensiveness of the holistic picture being presented when attempting to make sense of the complexities surrounding the topic. As a trainee educational psychologist I was also aware that there were no published papers relating to young carers and educational psychology, which led me to question the level of awareness of young carers within this and other related professions. This study offers a unique opportunity to assemble the complexities of the discourse and social constructions around young carers and disability and present both young carer and professional participants with a chance to register their viewpoints. I found it uncomfortable to privilege the views of one population over another given that *both* sets of views would be equally important in learning more about how to successfully support young carers. It was decided, therefore, to use both young carers and professionals to construct the ‘P set’.

4.2.2 The P Set

For the purposes of this study it was important to define the terms ‘young carer’, ‘professional’, and ‘disability’ (see Chapter 2.0), and these were communicated to participants in the process of obtaining informed consent.

The participants were considered to be a ‘purposive’, homogenous sample (Stenner and Stainton Rogers, 2004) in that they were regarded as having personal investment in the subject (as a young carer), or identified as a professional working within education (school staff, or educational psychologist), social care or healthcare settings with the potential to become involved with young carers in a professional capacity. Initially 22 young carers and 22 professionals agreed to take part in the study. Sadly, two young carers subsequently withdrew due to the death of their respective parents, which was a stark reminder, if one were needed, of the sensitive context within which this study was being carried out. Two professionals, also, withdrew because of time commitments, leaving, finally, 20 young carers and 20 professionals to participate in the Q sort activity.

In Q methodology studies the number of participants is considered less important than the possible range of viewpoints those participants may hold, as the focus is upon participants’ subjective viewpoints and the degree to which those viewpoints are shared (Brown, 1991). The number of participants, therefore, must be sufficient to support the extraction of differing factors from the data (Brown, 1980) and as such, when sampling participants, it is important to select participants whose opinions are regarded as relevant or important (i.e. opinions that matter) on the subject (strategic sampling) but likewise whose opinions may potentially differ, and consequently attempt to obtain diversity in terms of participant age range, gender, and ranges of perceived experiences (Watts and Stenner, 2005a).

Young Carers

It was decided that the young carers to be contacted would be those already known to the Local Authority (referred and registered by their family or professionals), as to attempt to find ‘hidden’, unrecognised carers, aside from being prohibitive within the given timescale, could have had potentially ethical implications relating to family dynamics and unwanted involvement from professionals (issues relating to ‘hidden’ carers were discussed in Chapter 2.0). In addition, young carers with a recognised learning difficulty (subject to a statement of special educational need) were not contacted as it was thought that the potential cognitive and reading demands of the Q sort activity would be potentially too great.

Furthermore the phrase ‘identified as young carers’ has been used in order to allow the participants themselves the opportunity to choose whether or not to engage with this particular label, or whether they see it as something imposed by professionals.

An attempt to contact young carers was initially made by consulting the local authority database, which listed the names of schools with a total of 100 registered young carers on roll. Due to data protection, however, I was not allowed access to the individual names or contact details of those young carers. Headteachers and SENCos of the relevant schools were thus contacted via email and asked to forward a participant information and introductory letter to their registered young carers (see Appendix iiia). None of the schools contacted were known to me in my work as a trainee educational psychologist, as this may have created an ethical difficulty had I potentially encountered the same children or young people in both my professional and researcher role. The participant information yielded only one participant, as all but one school replied that staff were unaware of who the young carers were. This was illuminating and frustrating: illuminating in the way in which young carers appeared to be hidden within the educational establishments despite being formally registered within the Local Authority, and frustrating in that the staffs' lack of awareness appeared to be constituting a barrier to the young carers being contacted and given the opportunity, if they so wished, of having their voices heard.

Attention then shifted to young carer projects in the North West and I contacted the leaders (voluntary workers) of eight regional projects, asking if I could visit them and attend some of their evening sessions. Five young carer group leaders responded and I made visits to their projects over a five week period (February–March 2011), speaking to voluntary staff and interacting informally with the young people as a volunteer (making drinks and serving food). During this period I asked for an opportunity to speak at each of the group meetings, where I described the study and asked that the children and young people take home the participant information if they were interested in taking part, in order to obtain parental consent. I also allowed time after the meetings where together the group leader and I were available to field any questions about me or the study from the young carers.

The age range of the young carers contacted was 9-18. This age range was targeted to address the reading and cognitive demands of the Q sort activity and also to take into account feedback from the pilot study (see 4.3.2 and 4.4 below) as well as being representative of the age range of young carers reported within the literature (see Chapter 2.0).

Four out of the five young carer projects generated a total of 19 participants, and together with the single participant from a high school within the Local Authority resulted in a total of 20 young carers:

- ranging from age 10 to 18 (average age 14 years 6months).
- from four different young carer projects (N=6 project a, N=7 project b, N=2 project c, and N=4 project d) and one high school (N=1) in the North West of England
- 8 boys and 12 girls
- caring for their mother (N=6); father (N=3); mother and father (N=3); a sibling (N=4); mother and siblings (N=3); father and siblings(N=1)

Professionals

A total of 60 professionals were contacted either in person, by email or telephone to enquire whether they would be willing to receive the participant information and introductory letter (see Appendix iiib). These professionals were chosen because of their potential involvement with young carers in their working lives either at school (headteachers, SENCos, teachers, teaching assistants, learning mentors), in Local Authority Children's Services or social care (educational psychologists, clinical psychologists, social workers, education welfare officers, voluntary care workers) or in health care settings (doctors, nurses, speech therapists, occupational therapists). By approaching a range of professionals with diverse, yet related and relevant occupations my intention was not only to find participants who may have differing perspectives, differing levels of experience or 'exposure' to young carers, and thus differing viewpoints, but also to broadly represent the range of occupations found within the key areas identified within the concourse (see 4.3.1).

After discussions with colleagues and tutors I decided to become a participant in this study, given my experiences as a young carer and a professional. This decision was taken in order to provide me with an additional layer of reflexivity and transparency when interpreting the emerging factors (see Chapter 5.0) and give me an opportunity to register my own subjective viewpoint. Crucially however, my own Q sort response would not influence or impact upon the other participants' responses within their individual Q sorts, nor their engagement with and understanding of the statements contained within it, and as such I felt confident that I could remain detached as a researcher within the process of gathering participants' data (see 3.3.1).

In total 20 professionals took part in the study as follows:

- 8 male and 12 females
- average age 41 years 3 months
- six participants within education (N=2 Headteachers, 1 primary, 1 high school; N=1 SENCo/teacher; N=3 learning mentors)
- eight participants within educational psychology (N=7 educational psychologists, N=1 trainee educational psychologist)

- six participants within Local Authority Children's Services or health (N=1 voluntary youth worker; N=1 occupational therapist; N=1 speech and language therapist; N=1 clinical psychologist; N=1 education welfare officer; N=1 disabled childcare team worker)

I had hoped to have more representation from social care and from healthcare settings, however two social workers withdrew from the study due to other commitments, and no replies were received from nurses or doctors.

4.3 Generating the Q Set

4.3.1 Concourse

The process of developing the concourse for this study (see 3.3.1) began by carrying out a thorough literature search of articles and books relating to young carers across the disciplines of education, psychology, social care and health, and noting down comments and ideas raised about young carer roles, responsibilities and experiences. Comments relating to young carers' parents or siblings, and disability were also noted. Other printed sources included young carer project websites; newspaper and magazine articles; government policies; guideline and information packs from young carer charitable organisations and information leaflets from the Local Authority. The concourse was further developed by gathering discourse around the topic, by scanning television and radio broadcasts (including charity events such as Comic Relief), informal discussion with educational psychology colleagues and other professionals (for example school staff, social workers) and through informal discussion with volunteer staff and young carers at the projects I visited (see 4.2.2).

In addition, as part of the pilot study, five young carers (aged 14-18) agreed to take part in a focus group and two parents (one with multiple sclerosis and one with visual impairment) took part in an unstructured interview, to further elicit views and comments. The work with the pilot study participants consisted of discussing young carer roles, responsibilities and experiences, with the participants responding to a series of sentence openers such as: "being a young carer means…." or "at school young carers…" .

Between October 2010 and May 2011 the collection of comments within the concourse grew to 200 (written as statements), and a pattern began to emerge which categorised these into three broad areas, namely statements relating to i) education, ii) intervention and support processes and iii) the social and emotional aspects of caring. These categories were not developed a priori but became apparent in the range of comments and ideas presented during the gathering of the concourse. Stephenson describes that to categorize statements is not the same as ascribing meaning to them, as the meaning begins to emerge as the participant engages with the statements in the Q sorting task (Stephenson, 1953). To remain as transparent and objective as possible I asked three volunteer young carer project staff (within the pilot phase) to view the range of 200 statements and to comment upon the categories and consider whether anything had been missed or if the categories were too narrow. Their responses indicated that the three categories adequately covered the breadth of statements but that a number of statements duplicated ideas or were poorly worded. These comments were taken into consideration in the next phase, which is described below.

4.3.2 Q Set

In Q methodology the exact number of statements is not pre-determined, and is usually dependent upon the subject matter and the participant group (Watts and Stenner, 2012). Using a range of 40-80 statements has been cited as standard (Stainton Rogers, 1995) as too few in number may restrict the coverage and reduce the comprehensiveness of their content, yet too many may introduce impracticality within the data collection process due to increased reading and time demands (Watts and Stenner, 2012).

The process of reducing the 200 statements from the concourse to a more practical and manageable number involved the following process:

- filtering the statements to take account of any duplication without losing any of the comprehensiveness in terms of content (McKeown and Thomas, 1988, Van Exel and de Graaf, 2005)
- amending statements which were poorly worded (for example with double negatives) or too long and complex
- using the exact words of young carers and the parents from the pilot phase, where possible, to acknowledge and honour their opinions and voices

- ensuring that statements contained only one key proposition (for example avoiding two ideas in one statement, such as “young carers enjoy school and spend enough time with friends”) for clarity when interpreting responses
- including a number of positively worded statements to balance the possible negative stereotypes evident within the discourse
- composing statements in the third person (not ‘I’) to accommodate both professional and young carer participants. Statements in the first person could have resulted in the professionals sorting the statements through an imagined lens as a young carer, rather than based on their own, personal experience
- composing statements which would complete a sentence opener (see 4.3.1)
- including statements which gave a broad representation of the three areas emerging within the concourse (social and emotional aspects, intervention and support, education). In Q methodology the final Q set can be considered robust providing that statements: “contain a representative condensation of information” (Watts and Stenner , 2005a, p.75) and that, when taken together, represent the subject matter comprehensively “as a whole” (Watts and Stenner, 2012, p.80)

This process reduced the number to 80 statements, which I considered too many, given the young carer participants’ ages and the reading demands, as well as the possible time required to process and sort this amount of information. Further filtering therefore took place to reduce the number of statements through:

- liaising with other Q methodology researchers at a Q methodology training event in Nottingham (July, 2011), where the statements were discussed and feedback noted
- piloting the statements with two young carers (a brother and sister aged 11 and 18 respectively) and any comments noted, such as changing the complexity of wording in some statements (e.g. “extra-curricular activities” replaced by “activities after school”)

After this process the final Q set consisted of 50 statements (see Appendix iv), which I considered offered sufficient breadth and balance of content, as well as being appropriate in terms of the practicalities of sorting. The final Q set, was used in the Q sort activity as described below.

4.4 Gathering Data – Q Sort

The Q set was identical for each participant (young carer or professional) and consisted of 50 different statements written on rectangular cards of the same size. Each statement was numbered 1-50 for the purposes of identification.

Each of the Q sorts was completed face to face with me and followed the same procedure and condition of instruction. All but one young carer carried out their Q sort in their young carer project, chosen for convenience but also as it was a familiar and comfortable setting for the participant, the remaining participant in her school and each professional in their place of work. Prior to commencing the data gathering process I had made arrangements with an appropriate adult in each of the settings to ensure that support mechanisms were in place (discussion and de-briefing if a young carer and supervision if a professional) should any participant feel emotionally affected by the process. In the event, however, none of the young carers made use of this provision.

The Q sort activity involved the following preliminary procedure:

- a reminder of who I was and why I was there (drawing attention to the introductory letter, consent forms and definitions)
- a reminder that consent could be withdrawn at any time during the process and that confidentiality would be maintained
- completing a brief questionnaire with the participant (see Appendix v) to give additional demographic information and assigning a code name (data tag, see Appendix vi) for the purposes of identifying individual Q sorts without revealing names or identities
- reading aloud the relevant research question from a prompt card (RQ1 if a young carer, RQ2 if a professional) which was then placed on the table as a reminder

The participants were then given a verbal condition of instruction which was repeated or slightly amended to take account of the age and requirements of the participant in question, whilst taking care that the main procedural points within the condition of instruction were identical for each participant.

Participants were shown the statements and informed that each was different; was numbered 1-50; was something which might be said about young carers and completed the following sentence opener:

“In my experience children and young people with a caring responsibility for a sick/disabled family member (called by some ‘young carers’)……..”

The sentence opener (which was read aloud and placed on the table next to the research question) was used to aid the sorting procedure, and provide a frame of reference and structure, and to remind the participants that it was their viewpoint, based on their subjective experience, rather than ‘right or wrong’ answers, that was important. The label ‘young carers’ was used indirectly here in order to allow the young carer participants the opportunity to identify with or reject this term, which has been seen to be contentious and multi-faceted in its interpretation and social construction (see Chapter 2.0).

Participants were asked to read each statement and place it initially in one of three piles, depending on their level of agreement with it. Prompt cards with ‘most agree’ and ‘least agree’ were placed to the right and left respectively as visual reminders during the process. ‘Most agree’ cards were placed in a pile to the right, ‘least agree’ cards to the left, and the remainder piled in the middle. Within this study participants were asked to sort from ‘most’ to ‘least’ agree as feedback during the pilot phase suggested that it was possible to agree with *all* of the statements, but some to a greater extent than others. As a result it was thought that to base the condition of instruction on an assumption of ‘agreement/*dis*agreement’ was inappropriate and that the participants should be given as much fluidity as possible in their responses and given the choice to agree (or indeed disagree) with statements as they saw fit. It was thought, furthermore, that the participant questionnaire, (see below and Appendix v) would be used to help illuminate why statements had been sorted in the way that they had.

Assistance was given for reading statements during the sorting process if it was required (two young carers asked for support with this) although no explanation of statements was given, for reasons already explained (see 3.3.1). A horizontal strip was laid across the table indicating each numbered column (1-9 from left to right) indicating the number of statements to place within each column, (for example “column 9 place 2 statements here”, see Appendix vii) as an aid to constructing the grid. The grid used was fixed and of a quasi-normal distribution (see Appendix viii). In Q methodology the position of each statement is ascribed a positive or negative numerical value (for example +4 or -4) during data analysis, depending upon the column to which it is assigned in the grid (see 4.5 and Chapter 5.0), however these values are not required during the data collection process. I chose, instead, to number the columns 1-9 rather than ascribe a negative or positive value, firstly for simplification (the young carers may have confused the positive and negative symbols) but also that participants may have found the notion of ranking a statement with which they agreed under a column ascribed a negative value, potentially restricting or confusing.

A forced distribution (or fixed grid), as opposed to a free distribution, was chosen in this study to ease the practical process of encouraging participants to rank statements in relation to one another, using a relatively flat distribution with fewer items placed at either end (in the ‘most agree’ and ‘least agree’ columns, see Appendix viii for an example). This has been shown to allow participants who are knowledgeable in the subject area, and who may have strongly held views, greater discrimination between statements (Van Exel and de Graaf, 2005). The shape or ‘kurtosis’ of the distribution of statements within a grid is arbitrary, however, in that it does not affect statistical analysis (Brown, 1993) nor the reliability of the data gathered, given that the finalised grid represents statements ranked relative to one another, regardless of the distribution shape (McKeown and Thomas, 1988).

Participants were then instructed to choose two cards from their ‘most agree’ pile with which they felt most strongly, and place them to the extreme right in the grid. They were then asked to choose two cards from their ‘least agree’ pile and place them to the extreme left, then four from the ‘most agree’, four from the ‘least agree’, and so on, gradually filling in the grid from the outside in until the grid was completed by using up the cards from their centre pile. This process was used (alternating between piles) in order to help the participants to assess the significance of one statement in relation to another. Once completed participants were asked to review their choices and to change any cards they felt were not placed according to their viewpoint, given that the final grid should represent their viewpoint from ‘most agree’ to ‘least agree’ from right to left. A participant’s final Q sort was then recorded on a blank grid. To end the process a brief questionnaire (see Appendix v) asked participants to give reasons for choosing the two statements at the extreme ends of their grid (most and least agree), as well as their thoughts on the process (see Appendix ix) and whether they considered any statements to be missing (I asked participants to construct these statements in their own words, see Appendix x). Furthermore field notes recorded any comments about any individual statements as the Q sort was taking place. These measures were carried out in order to provide an additional layer of qualitative information to aid factor interpretation (see Chapter 5.0).

4.5 Data Analysis

The finer details of data analysis, including factor analysis, factor extraction and interpretation are discussed in Chapter 5.0, however an overview of the process carried out is described below.

A dedicated computer package, PQMethod, (version 2.11, Schmolck, 2002) was used to analyse the Q sorts, which were entered into the program into two separate files (young carers N =20 and professionals N=20) and analysed separately through the process of being inter-correlated and subjected to a by-person factor analysis. The emerging factors (young carers N=4 and professionals N=2) were then extracted and the factor arrays (a computer generated Q sort which exemplifies the factor as an ‘ideal’) used to develop a systematic ‘crib sheet’ (Watts and Stenner, in press) for each factor to aid interpretation, the purpose of which is to help understand and further explain the participants’ viewpoints at a qualitative level. Following the process of data extraction and interpretation the participants who loaded heavily (whose Q sorts exemplified the viewpoints expressed within each factor) were then contacted and asked to comment on the interpretation of the factor onto which they loaded, to check out the extent to which their viewpoint matched that which was presented.

Chapter 5.0 will develop and explain this summary further, including the rationale for analysing the participants’ data in two separate groups, as opposed to one.

5.0 RESULTS

This chapter will begin by outlining the process of by-person factor analysis within Q methodology in general, followed by a more specific description of the processes of factor extraction and factor interpretation employed within this study. In addition, as part of this description, a rationale will be proffered relating to the decision to analyse the participants' data in two separate sets (young carer and professionals) as opposed to jointly. Finally, the details of each factor array will be displayed graphically (as a factor array figure) and described qualitatively, drawing upon and including reference to additional qualitative data gathered via field notes, participants' comments and demographic information within the participants' questionnaires.

5.1 Factor Analysis in Context

Watts and Stenner (2012) describe that a Q methodological study involves three methodological transitions within the process of data analysis. The first of these is the transition from Q sorts to factors. Each Q sort is entered individually and faithfully into a dedicated computer program (PQMethod, version 2.11, Schmolck, (2002) is used in this study), which ascribes a numerical value (for example -4 to +4) to each statement depending upon its position within the grid. Each completed Q sort is then inter-correlated, through the process of by-person (or by Q sort) factor analysis, to determine the level of agreement or disagreement between them (Q sort 1 with 2, 1 with 3, 1 with 4 etc.), producing a correlation matrix. As the variables within by-person factor analysis consist of the individual Q sorts it is possible, through inter-correlation at a statistical level, to correlate the way in which individual Q sorts cluster together and thus can be seen to belong to a similar family, or 'factor' (i.e. a similar viewpoint). The second transition within data analysis is from factors to factor arrays. This process involves the production of a 'factor array' in which the program provides a weighted average of all the Q sorts which correlate (or load) highly with that factor. A 'factor array', therefore, portrays a Q sort which exemplifies, as a 'best fit', the positions of the statements within that factor. The final transition is from factor arrays to factor interpretation. This final process involves the researcher examining the factor array and interpreting the pattern or configuration of statements within the grid at a qualitative level. As summarised by Watts and Stenner (2012):

> “The individual items and their inter-relationships within a particular array then serve as the Q methodologist’s signs or clues. These must be traced back to a clear understanding of the overall viewpoint which explains or makes sense of the configuration. (…) We simply need to grasp the ‘nature of the beast’ that has just passed by, something which can be achieved through close attention to the impression they have left, and by means of interpretation” (p.88).

It is in this regard that Q methodology can be seen to utilise both quantitative and qualitative methods to analyse data. Brown (1991) describes that the statistical and mathematical aspect of Q methodology: “serves primarily to prepare the data to reveal their structure” (Brown, 1991, p.13) in readiness for qualitative factor interpretation. It is through the combination of both statistical and interpretive analysis, therefore, that a holistic picture of the data can begin to emerge as the researcher interprets the factor arrays with the aim of providing a plausible explanation for the appearance of the factor, by describing and highlighting aspects of the viewpoint being presented.

5.2 Why Separate Analyses?

This study involved gathering data in two sets, young carers and professionals, although, as outlined in Chapter 4.0, the same materials and condition of instruction were used for all participants. In terms of data analysis there were three possible options available:

- 1) analyse all 40 Q sorts together in one data set
- 2) analyse two separate data sets (young carers and professionals)
- 3) analyse two data sets (as above) then carry out a second-order factor analysis based on the extracted factors obtained by option two

After careful consideration options three and one were rejected for the following reasons. Option one would have given shared viewpoints, but these would have been shared in terms of how professionals’ and young carers’ viewpoints inter-correlated. Although this would have been interesting on some level it would have been confusing and would serve little to bring clarity to the investigative arena, something which has been highlighted as an aim within this study. In the same way as when one mixes red and blue to become purple, by mixing the data it would have been harder to extrapolate and unpick the views of young carers from those of professionals. As young carers have many differing experiences and circumstances, and professionals many differing roles within the fields of education, social care and health, I wanted to investigate whether there were any shared views from within each separate group. The research questions were particularly worded with this in mind. Furthermore I wanted young carer voices to be heard and empowered without associating their data *directly* with professionals' data, to give them a sense of ownership and clarity when later discussing results (taking the data back to them for 'checking out': see 5.17 below) and to allow their voices to speak independently.

Option three would have involved re-entering the factor arrays produced by the separate young carer and professionals' data (six in total), treated as new data, to produce 'second-order factors', (thus capturing any shared viewpoints or differences across the range of existing shared viewpoints within the two original groups of participants). This process would have highlighted the level of correlation between the young carer shared viewpoints and professionals' shared viewpoints, as a type of 'second-order analysis' (Kline, 1994). This indeed would have been interesting, as an additional layer of analysis, however the process would have given rise to a larger study, and the scope and size of the resulting data would have been prohibitive within the confines of this research.

Option two was then preferred, as each data set would serve to produce shared viewpoints within each participant group, but would also allow comparison of the resulting young carer and professionals' factors at a qualitative level within the discussion chapter and thus was considered the most appropriate and manageable option.

5.3 Factor Extraction and Rotation

Each data set was subjected to the same statistical procedure in terms of factor extraction and rotation. Each set (N=20 Q sorts) was entered into PQMethod version 2.11 (Schmolck, 2002) and analysed using centroid factor analysis (CFA). CFA was chosen, as opposed to the alternative Principal Components Analysis (PCA), as this method is considered the favoured choice of Q methodologists (Stainton Rogers, 1995). Through this process a number of factors were extracted.

The term 'factor extraction' refers to the way in which factors emerge from the correlation matrix (the patterns of similarity or difference between each Q sort with every other Q sort). In statistical terms the complete matrix represents all viewpoints within the data, therefore 100% of the meaning and variability within the data. In Q methodology this is termed the study variance (McKeown and Thomas, 1988). Theoretically this data can be grouped into ‘segments of subjectivity’ (Stephenson, 1953) in an infinite number of ways, rather like slicing a cake into multiple pieces (Watts and Stenner, 2012). The choice of how many segments (or factors) to extract and interpret is usually dependent upon certain statistical and theoretical guidelines, however, as follows:

- factors should only be retained with an eigenvalue greater than 1.00 (Brown, 1980) (an ‘eigenvalue’ is a figure obtained by summing the squares of the factor loadings)
- factors should have at least two Q sorts which load upon it alone (Watts and Stenner, 2005a)
- a Q sort should be considered significant in terms of loading upon a factor based on the statistical calculation $p<0.01 = 2.58\ (1/\sqrt{\text{number of statements}})$ (Brown, 1980, Watts and Stenner, 2012). Within the context of this study the level of significance was initially calculated, therefore, as 0.36 ($2.58\ (1/\sqrt{50}) = 0.36$).
- after further examination of the data, however, in order to be as inclusive as possible and to allow the maximum number of Q sorts to load onto a factor, the level of significance was raised to 0.43. Manipulating the level of significance in this way is considered an appropriate measure in Q methodology to minimise the amount of non-significant or confounding Q sorts within the data and maximise the amount of Q sorts loading upon a single factor (McKeown and Thomas, 1988, Watts and Stenner, 2005a)
- factors should capture as much of the study variance (range and variability of viewpoints) as possible, with a combined variance of over 40% across factors considered to be a sound solution (Watts and Stenner, 2005a).

Within the context of this study Varimax rotation was used to assist in viewing the data to determine the best possible factor solution, based on the above criteria. Varimax is an automated rotation process within PQMethod 2.11 (Schmolck, 2002), which allows the data to be examined from different angles, and can be conceptually compared to the way in which a theatre performance can be viewed differently depending upon the position of one's seat, whether at the front, in the gallery, backstage, on the ceiling etc. Varimax rotation is considered a: "purely technical objective procedure" (Van Exel and de Graaf, 2005, p.11) as opposed to the alternative judgemental (or hand) rotation, which is primarily driven by pre-conceived theoretical concerns and can be influenced by a priori ideas and assumptions. As such Varimax rotation was considered the preferred course of action in this study, as it is consistent with exploratory rather than confirmatory factor analysis (Brown, 1993) and:

> "does not affect the consistency in sentiment throughout individual Q sorts of the relationships between Q sorts, it only shifts the perspective from which they are observed" (Van Exel and de Graaf, 2005 p.13) .

The process of Varimax rotation generated a 3, 4 or 5 factor solution for young carers' data and a 2 or 3 factor solution for professionals. Based upon the criteria highlighted earlier the best fit was considered to be a 4 factor solution for young carers' data and a two factor solution for professionals' data. These factors are described in more detail below.

5.3.1Young Carers' Data

Four factors were retained and interpreted within the Young Carers' Data, which together explained 43% of the study variance. Eighteen of the 20 participants loaded significantly onto one of four factors, with one participant's Q sort being non-significant (not correlating with any of the emerging factors, see participant 9 in Table 1) and one confounding (correlating significantly with more than one factor, see participant 6 in Table 1).

Table 1 indicates the participants and their factor loadings (statistical significance = 0.43). All figures are rounded to 2 decimal places.

participant	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**
1.fyc11mbr	0.62x	0.29	-0.31	0.24
2.fyc11br	0.1	0.12	0.1	0.46x
3.myc10mu	0.64x	-0.03	-0.04	0.35
4.myc16mu	-0.02	0.14	0.53x	0.13

5. fyc11br1	0.51x	0.24	-0.18	0.35
6. fyc11br2	0.44	0.18	-0.35	0.52
7. myc18mbr	-0.04	-0.02	0.62x	0.01
8. myc17mu	-0.07	0.85x	0.1	0.01
9. myc14mda	-0.07	0.34	0.27	-0.00
10.fyc16mda	0.19	0.07	0.1	0.5x
11. fyc11dbr	0.52x	-0.03	0.27	-0.12
12. fyc18mu	0.02	0.01	0.22	0.61x
13. fyc17br	0.17	0.55x	-0.12	0.3
14. fyc15mbs	0.25	0.18	0.02	0.61x
15. fyc16mu	-0.00	0.36	-0.01	0.53x
16. myc16mda	0.55x	-0.00	-0.08	0.09
17. fyc17da	0.26	0.43x	-0.17	0.41
18. fyc16da	-0.1	0.16	0.44x	0.22
19. myc14mu	0.22	0.62x	0.26	0.17
20. myc15da	0.05	0.53x	0.15	0.36
variance	11%	12%	7%	13%
eigenvalue	2.2	2.4	1.4	2.6
Total variance			=	**43%**

Table 1: Young Carers' Data: Four Factor Solution

Green and a x = a Q sort with a significant loading onto the factor

Blue = a Q sort which is non-significant (does not load onto any factor)

Red = a Q sort which is confounding (loads significantly onto more than one factor)

5.3.2 Professionals' Data

Two factors were retained and interpreted within the professionals' data, which together explained 46% of the study variance. Sixteen of the 20 participants loaded significantly onto one of two factors, with one participant's Q sort being non-significant (not correlating with any of the emerging factors, however marginally so, at 0.41. see participant 10 in Table 2) and three confounding (correlating significantly with more than one factor, see participants 2, 15 and 18 in Table 2).

Table 2 indicates the participants and their factor loadings (statistical significance = 0.43). All figures are rounded to 2 decimal places.

participant	**Factor 1**	**Factor 2**
1. mpr41hts	0.51x	0.28
2. mpr35cvc	0.49	0.51
3. fpr22slt	0.76x	-0.05
4. mpr29dct	0.55x	0.34
5. fpr58sen	0.74x	0.33
6. fpr32ewo	0.57x	0.14
7. fpr34lmp	-0.31	0.54x
8. fpr48lms	0.58x	0.35
9. fpr51lmp	0.77x	0.31
10. fpr55htp	0.2	0.41
11. mpr32clp	0.68x	0.06
12. fpr41ep1	0.03	0.61x
13. mpr39ep2	0.58x	0.32
14. fpr55ep3	0.32	0.63x
15. fpr29ep4	0.54	0.44
16. mpr54ep5	0.44x	0.26
17. mpr44ep6	0.81x	0.09
18. mpr30ep7	0.65	0.49
19. fpr45tep	0.28	0.66x
20. fpr46ot	0.6x	0.03
variance	31%	15%
eigenvalue	6.2	3
Total variance	=	**46%**

Table 2: Professionals' Data: Two Factor Solution

Green and a x = a Q sort with a significant loading onto the factor

Blue = a Q sort which is non-significant (does not load onto any factor)

Red = a Q sort which is confounding (loads significantly onto more than one factor)

5.4 Factor Interpretation

Factor interpretation, as the final step in the process of data analysis within Q methodology, involves the researcher examining the statistical data provided by factor extraction and rotation, as well as any qualitative data gathered through field notes and the participant questionnaire (see 5.4.1), to interpret the configuration or pattern of Q sorts and begin to construct the viewpoint being expressed. A qualitative description of the viewpoint then emerges, the meaning of which is encapsulated by an overall theme or 'title' for that factor.

The process described above brings the researcher's subjective experiences, social constructions, prior knowledge, thought processes, pre-conceived notions and potential biases more acutely into focus, as both the statistical and qualitative data serve as clues that are open to interpretation. Within this study, although my aim was to remain as 'objective' as possible during the data gathering and analysis process, I could not be immune from potentially influencing the outcome of the factor interpretation based upon my own position as a psychologist, researcher and former young carer. In order to minimise these possible biases and assumptions, however, a number of measures were put in place. Firstly, I completed the Q sort activity myself, as a participant, and reflected upon it (see 5.16) in order to be transparent in terms of where my own viewpoint and position lay in relation to the other participants'. This would assist in placing the factor interpretations in context. Secondly, I carried out a systemic analysis of each factor array with the use of a 'crib sheet' (Watts, 2010). The 'crib sheet' is a tool designed (by Simon Watts of Nottingham Trent University) to assist in examining the factor array in detail, through a systematic and consistent process, thus ensuring that each factor array is subjected to the same rigorous procedure. Statements which are distinguishing for each factor (distinctive in terms of their statistical significance) or offering a degree of consensus between factors (consensus statements, see 5.15) are also considered within this process. In addition, moreover, the crib sheet allows the researcher to explore the data in a more in-depth manner, by considering the importance of each statement and its position, rather than just the characterising statements (those placed at the extreme ends of the distribution). As such a holistic picture can emerge of the viewpoint being expressed, as the entire configuration is examined in a systematic way. A detailed crib sheet for each factor can be found in Appendices xi to xvi and a table containing the complete factor arrays for each factor in Appendices xvii and xviii. Finally, once factor interpretation had been completed, and by way of verification, the young carers were contacted and asked to comment upon the way in which their respective viewpoints had been represented. This process is described in 5.17 below.

5.4.1 Participant Questionnaire

A brief participant questionnaire was used both pre and post the Q sort activity (see Appendix v), the purpose of which was to provide an additional layer of demographic and qualitative data to assist in factor interpretation. Prior to the Q sort the questionnaire was used to give additional demographic information (name, age, and occupation and level of experience with young carers if a professional), including asking young carers if they wanted to share with me who they cared for within their family, and the nature of their disability or illness. All the young carer participants agreed to answer this question. Once the Q sort had been completed the questionnaire was then used to obtain additional qualitative data about the way in which the participant had sorted the statements. Participants were asked to give their reasons for sorting the two ‘most agree’ and two ‘least agree’ statements at the extremes of the grid, as well as comment on the experience overall and whether or not they considered any statements missing (see Appendix ix and Appendix x respectively). As highlighted in Chapter 3.0 the Q set can never be considered ‘perfect’ in that it is impossible to capture every piece of information, knowledge, idea or discourse around a given topic. By asking participants for their views on the Q set in terms of its comprehensiveness, I aimed to highlight any gaps or possible missing statements which they felt should have been included in the Q set. The participants were then asked to put the ‘missing statement’ in their own words and state where they would have sorted it. This information, together with the field notes about any comments participants made about individual statements during the Q sorting process, was also used in the process of factor interpretation.

5.5 Young Carers' Data: Factor 1

"We're proud and positive. We feel included and well supported, but don't like being singled out"

Factor 1 has an eigenvalue of 2.2 and explains 11 % of the study variance. Five participants (participants 1, 3, 5, 11 and 16) are significantly associated with this factor: three girls and two boys, whose average age is 11 years 9 months. These young carers care for their mother and brother; mother; brother; father and brother; and mother and father.

Least Agree **Most Agree**

-4	-3	-2	-1	0	+1	+2	+3	+4
9	2	6	1	3	7	4	5	14
43	29	8	11	16	10	22	17	50
	32	18	12	21	13	27	31	
	47	19	15	23	20	36	45	
		34	24	33	25	38		
		41	26	35	30	49		
			28	37	39			
			44	42	40			
				46				
				48				

Figure 1: Factor Array: Factor 1 (Young Carers)

(The crib sheet for this factor can be found in Appendix xi)

In the description below (and for the subsequent factor descriptions) the statements discussed are followed by numbers in brackets. The first of these refers to the number of the statement being highlighted, and the second to the position within the factor array, for example: feel proud of their caring responsibilities (50: +4), meaning statement number 50, placed in position +4.

The young carers who represent this viewpoint agree with other factors in that they are proud of their caring responsibilities (50: +4), feel that their caring responsibilities come first before school (10: +1), and do not feel worried about their own health (34: -2). These young carers are positive in their approach to caring for their family member(s) and don’t appear to mind being referred to as a ‘young carer’ (41: -2). They also do not feel they suffer from depression (43: -4), although they constantly worry about the person(s) they care for (36: +2). They also consider they have a close family who all look after each other (45: +3), without feeling like a parent to the person they care for (46: 0), nor losing their childhood (32: -3), and are also happy about the amount of time they can spend with friends (31: +3). Furthermore, they do not feel that the media portray young carers in the role of ‘little victim’ (47: -3).

Within this viewpoint the role of professionals is largely seen as a positive one, as the young carers feel supported and included. They are kept informed by doctors and nurses about the medical condition of the person they care for (17: +3), receive enough support from their family doctor (27: +2), who does not talk down to them like a little kid (19: -2), and feel included in their local community (49: +2). Although they feel listened to by professionals (22: +2), they do not find that professionals ask their opinion (15: -1). This is reinforced by a comment from one of the young carers, whose father has depression and whose brother is deaf, remarking that the Q sort activity:

> “helped. It said, like, opinions. It made me feel good about myself. It’s important people ask us what we think. People usually don’t do that” (fyc11dbr).

In terms of support these young carers find social workers helpful (25: +1), and do not mind if social care become involved with their family (20: +1) as they are not afraid that their family will be split up (29: -3). Although they find that services do not only offer help to the person needing care in their family (18: -2) they do not seem to know what sorts of services are available to them (24: -1). In addition they feel that professionals do not make assumptions about the way in which their parents look after them at home (26: -1) and that professionals are understanding about parents with a drug or alcohol problem (30: +1).

In terms of the young carers’ experiences at school they find that they want to be treated the same in school as every other pupil (5: +3) and prefer that other people in school do not know about their caring responsibilities (4: +2). Although they find that teachers are sympathetic towards them (2: -3) this can sometimes result in them being singled out as being different to other pupils (7: +1), and they do not feel the need to be given special allowances by teachers for handing in homework (6: -2). Teachers, furthermore, are not seen to ask too many personal questions about their family (1: -1). These young carers do not have to miss school regularly due to their caring responsibilities (8: -2), nor do they feel bullied (12: -1) and they feel able to take part in activities or clubs after school (13: +1). Although they struggle to find time to study at home (14: +4) they do not worry that their education is suffering (9: -4) with one carer commenting: "I'm in second top set at school" (fyc11mbr).

5.6 Young Carers' Data: Factor 2

"Caring's just what we do. We feel mature, but are unsupported and misunderstood"

Factor 2 has an eigenvalue of 2.4 and explains 12 % of the study variance. Five participants (participants 8, 13, 17, 19 and 20) are significantly associated with this factor: two girls and three boys, whose average age is 16 years 0 months. Two participants care for their mother, two for their father, and one for their brother.

Least Agree **Most Agree**

-4	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**	**+4**
30	1	13	4	3	5	2	18	39
32	12	15	7	9	6	10	19	40
	22	17	8	20	16	11	38	
	33	24	28	21	26	14	50	
		25	34	23	27	37		
		46	42	31	29	41		
			44	36	35			
			47	43	45			
				48				
				49				

Figure 2: Factor Array: Factor 2 (Young Carers)

(The crib sheet for this factor can be found in Appendix xii)

The young carers expressing this viewpoint are proud of their caring responsibilities (50: +3) but do not identify with the label 'young carer', as they are just a son or daughter helping out (41: +2) and do not feel as if they have lost their childhood (32: -4). One young carer, who cares for her brother with cerebral palsy, commented about the experience of doing the Q sort and elaborated on this point:

> "If all the young carers had this it would be good. It's good to tell people what you need. It's not a sob story, it's just how it is. I don't like using it as an excuse, like 'how disgraceful is that, she's milking it, coz she's got problems. Look at you, you're allowed to be late!'" (fyc17br).

Another carer, whose mother has been diagnosed as 'bipolar', remarked that:

> "they [professionals] officially say she's 'mental', which my mum admits she is. But it doesn't make any difference to me caring for her if she's in bed with the flu. It's the same thing" (myc17mu).

These young carers feel they have a mature outlook on life (38: +3), with better life skills to prepare them for adulthood, compared to other young people (39: +4), as well as a better understanding of difference and disability (40: +4).

This viewpoint paints a negative picture of the way in which professionals intervene in young carer's lives. These young carers feel unsupported in that they find services only offer help to the person needing care in the family (18: +3) and that professionals lack awareness about their needs (16: +1) as well as lack understanding about parents with a drug or alcohol problem (30: -4). Not only do professionals not listen to young carers (22: -3) but they do not ask their opinion (15: -2) and young carers do not find social workers helpful (25: -2), fearing that their family will be split up (29: +1). Although there is a degree of support from their family doctor (27: +1) young carers feel they are talked down to like little kids by doctors and nurses (19: +3), and are not kept informed about the medical condition of the person they care for (17: -2). They also do not know what sorts of services are available to help them (24: -2).

At an emotional level these young carers share, with the other factors, some agreement that no-one understands what they have to go through (37: +2). They also feel they need someone they can talk to in school about their caring responsibilities (10: +2) although they do not feel bullied (12: -3). As they feel they have a close family who all look after each other (45: +1), they do not feel like a parent to the person they care for (46: -2), but worry what will happen to them if their sick or disabled parent dies (35: +1). They also struggle to find time to study at home (14: +2), but do not feel strongly that their education is suffering (9: 0). They find that teachers are not sympathetic towards them (2: +2), although they do not feel singled out (7: -1) and are not asked too many personal questions about their family (1: -3). These young carers want to be treated the same in school as every other pupil (5: +1), however they feel that sometimes they need to be given special allowances by teachers for handing in homework (6: +1).

5.7 Young Carers' Data: Factor 3

"Parentified and wanting to care, but we need people to recognise that we're struggling and worried"

Factor 3 has an eigenvalue of 1.4 and explains 7% of the study variance. Three participants (participants 4, 7 and 18) are significantly associated with this factor: one girl and two boys, whose average age is 16 years 8 months. They care for their mother and brother; brother; and father.

Least Agree **Most Agree**

-4	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**	**+4**
20	5	3	13	2	4	1	35	14
42	31	11	15	6	7	8	36	32
	41	17	21	18	9	12	40	
	45	44	22	23	10	19	46	
		48	24	27	16	38		
		49	26	30	25	50		
			28	33	37			
			29	34	39			
				43				
				47				

Figure 3: Factor Array: Factor 3 (Young Carers)

(The crib sheet for this factor can be found in Appendix xiii)

The young carers holding this viewpoint are struggling emotionally with the responsibility of caring for their family members. They constantly worry about the person(s) they care for (36: +3) and worry what will happen to them if their sick or disabled parent dies (35: +3). In addition they do not feel that they have a close family who all look after each other (45: -3), and feel like a parent to the person(s) they care for (46: +3). One young carer, who describes her mother as having depression and whose 11 year old brother has autism and epilepsy, remarked that:

> “Considering K was born when I was seven, that’s when mum split with his dad. I took on the role of parent. My brother called me dad for six months” (myc18mbr).

As a result of their caring responsibilities these young carers feel they have lost their childhood (32: +4) , and that they don’t have enough time off from caring, cannot take part in clubs or activities after school (13: -1) nor feel happy about the amount of time they can spend with friends (48: -2, 31: -3). This, however, has made them grow up quickly and have a more mature outlook on life (38: +2) and have a better understanding of difference and disability compared to other young people (40: +3). A female young carer looking after her father with clinical depression and psychosis felt she was: “mature, as you know more about lots of things like looking after the house” (fyc16da).

These young carers are happy to take on the caring responsibility and do not want other services to provide enough care so they don’t have to do it (42: -4), nor do they want social care to intervene (20: -4) as they have: “not had a good experience with social care [and] don’t trust other people to sort stuff out” (myc18mbr). Professionals moreover are seen to talk down to them like little kids (19: +2), and they are not kept informed about the medical condition of the person(s) they care for (17: -2). In addition they are happy to be referred to as ‘young carers’ (41: -3), but don’t like getting special attention as a ‘little angel’ (44: -2). This does not mean that they don’t want their needs to be recognised, however. They find that they do not feel included in their local community (49: -2), nor are they listened to, or asked their opinions by professional (22: -1, 15: -1).

It is in the school environment where these young carers appear to be struggling the most, however, in comparison to other viewpoints. They find that they have to miss school regularly (8: +2), are bullied in school (12: +2) and that teachers ask too many personal questions about their family (1: +2). Despite this, however, the young carers do not feel that they need someone they can talk to in school (11: -2), and do not feel best supported when they are linked with one key worker (3: -2). They feel, furthermore, that they should not be treated the same in school as every other pupil (5: -3) as they: “need extra support in school” (myc16mu). They also struggle to find time to study at home (14: +4) and do not feel they can make plans towards their future job or further education (21: -1) as well as worry that their education is suffering (9: +1).

5.8 Young Carers’ Data: Factor 4

“Being mature doesn’t stop us from worrying, although we’re supported, especially in school”

Factor 4 has an eigenvalue of 2.6 and explains 13 % of the study variance. Five participants (participants 2, 10, 12, 14 and 15) are significantly associated with this factor: all girls, whose average age is 15 years 3 months. They care for their brother; mother and father; mother; mother and brothers; and mother.

Least Agree ⟺ **Most Agree**

-4	-3	-2	-1	0	+1	+2	+3	+4
7	1	12	2	4	3	9	5	38
41	6	17	16	13	11	10	35	50
	8	24	20	14	21	30	36	
	19	34	26	15	22	39	45	
		42	27	18	29	40		
		46	28	23	31	48		
			43	25	32			
			47	33	37			
				44				
				49				

Figure 4: Factor Array: Factor 4 (Young Carers)

(The crib sheet for this factor can be found in Appendix xiv)

Like factor 1 the young carers with this viewpoint are proud of their caring responsibilities (50: +4) and do not object to being labelled as a ‘young carer’ (41: -4).

Other positive features of this viewpoint are that the young carers feel they have a close family who all look after each other (45: +3), without them feeling like a parent to the person they care for (46: -2), and that they also get enough time off from their caring responsibilities (48: +2) to spend time with their friends (31: +1). They also share the view, along with factors 2 and 3, that their caring responsibilities give them a more mature outlook on life, (38: +4), a better understanding of difference and disability (40: +2) and better life skills to prepare them for adulthood (39: +2) compared to other young people. A young carer who cares for her mother with schizophrenia, and her two siblings aged four and one, remarked that: “I’ll be sorted as an adult, me, when I have kids, because I’ve done it for six years already” (fyc15mbs).

Despite these positives these young carers worry about their circumstances. They constantly worry about the person they care for (36: +3) and worry what will happen to them if their sick or disabled parent dies (35: +3). Like factor 3 they also consider that they have lost their childhood (32: +1). One young carer, whose mother has Huntingdon’s disease, commented that: “you never know what’s going to happen, that’s the worrying bit” (fyc18mu). Another young carer, whose mother has multiple sclerosis, explained that her fear lay in not being able to respond in an emergency if something went wrong: “We sorted out a fire escape route in the house but it scared me in case I couldn’t move her” (fyc16mu). Further concerns involve being worried that their family will be split up (29: +1) and that their education is suffering (9: +2), although this viewpoint is the most positive in comparison to other factors in terms of young carers finding time to study at home (14: 0) and about their ability to make plans for their future job or further education (21: +1).

Although these young carers’ responsibilities cause them to worry it seems as if the school environment is supportive and offers a greater degree of stability when compared to other factors. Young carers with this viewpoint feel that teachers are sympathetic towards them (2: -1), or single them out as being different to other pupils (7: -4), which is encouraging, as they want to be treated the same in school as every other pupil (5: +3) and do not see the need to be given special allowances by teachers for handing in homework (6: -3). Furthermore they find that teachers do not ask too many personal questions (1: -3) and feel best supported in school when they are linked with one key worker (3: +1), as well as needing someone in school they can talk to about their caring responsibilities (10: +2). These young carers feel that are asked their opinions by professionals (15: 0) and are listened to (22: +1), without being talked down to like little kids (19: -3), although they are not kept informed by doctors and nurses about the medical condition of the person they care for (17: -2) and do not know what sorts of services are available to help them (24: -2). Finally, these young carers find they do not have to miss school regularly (8: -3) and are not bullied (12: -2).

5.9 Young Carers' Data: Non-significant Q Sort

This young carer's Q sort is non-significant in that it does not load upon any individual factor at a statistical level (0.43). His personal viewpoint, therefore, does not agree with any of the other four viewpoints expressed by the other 18 young carer participants.

participant	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**
9. myc14mda	-0.07	0.34	0.27	-0.00

Table 3: Extract from Young Carer Data: Four Factor Solution

The young carer is male, aged 14 years 11 months, and cares for his mother, who has epilepsy, and his father, who has clinical depression. This young carer has epilepsy himself, and related the story of saving his mother's life when he was five years old, as she had a fit and banged her head on the bathroom floor. The young carer covered her up to keep her warm and called the ambulance, which saved her life, as she was bleeding heavily.

Statistically this young carer's viewpoint is closest to factor 2. The two comments he agreed with most (+4) were:

- 35. worry what will happen if their sick or disabled parent dies
- 19. are talked down to like little kids by doctors and nurses

The two statements placed as 'least agree' (-4) were:

- 30. find that parents are understanding about parents with a drug or alcohol problem
- 1. find that teachers ask too many personal questions about their family

This young carer also commented that he thought there was something missing in terms of the statements. He worded it as: "Do you think there should be a rota with your brother about how much time you spend caring?" but did not know where he would sort this in the grid.

5.10 Young Carers' Data: Confounding Q Sort

This young carer's Q sort is confounding in that it loads significantly upon two different factors (statistical significance at 0.43). Her viewpoint, therefore, can be seen to agree with both factors 1 and 4.

participant	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**
6. fyc11br2	0.44	0.18	-0.35	0.52

Table 4: Extract from Young Carer Data: Four Factor Solution

The young carer is female, aged 11 years 9 months, and cares for her 15 year old brother, who has cerebral palsy. The two comments placed at 'most agree' (+4) were:

- 50. feel proud of their caring responsibilities
- 5. want to be treated the same in school as every other pupil

and the two statements placed at 'least agree' (-4) were:

- 12. are bullied in school
- 32. find they have lost their childhood

This young carer did not feel that there were any statements missing from the Q set, and commented on the experience overall that: "It was ok".

5.11 Professionals' Data: Factor 1

"Young carers worry and struggle. They are unsupported and neglected by professionals".

Factor 1 has an eigenvalue of 6.2 and explains 31% of the study variance. Twelve participants (participants 1, 3, 4, 5, 6, 8, 9, 11, 13, 16, 17, and 20) are significantly associated with this factor: six males and six females, whose average age is 41 years 4 months. Represented in this group are two Learning Mentors, three EPs, a Headteacher, a Speech and Language Therapist, a Disability Childcare Worker, a Special Educational Need Co-ordinator (SENCo), a Clinical Psychologist, an Educational Welfare Officer and an Occupational Therapist. Four of these professionals consider they have 'lots of experience' with young carers, whereas the others have 'no' or 'limited' experience.

Least Agree **Most Agree**

-4	-3	-2	-1	0	+1	+2	+3	+4
13	15	20	7	2	1	3	8	29
48	17	22	21	9	4	5	10	36
	24	25	23	12	6	14	11	
	31	30	27	16	19	18	35	
		44	33	32	28	26		
		49	34	37	39	46		
			45	38	42			
			50	40	43			
				41				
				47				

Figure 5: Factor Array: Factor 1 (Professionals)

(The crib sheet for this factor can be found in Appendix xv)

The professionals who share this viewpoint consider that young carers struggle and worry because of their caring responsibilities. These professionals find that young carers worry that their family will be split up (29: +4) and worry constantly about the person they care for as well as what will happen to them if their sick or disabled parent dies (36: +4, 35: +3). Furthermore this viewpoint highlights that young carers do not have a close family who all look after each other (45: -1) and that they feel like a parent to the person(s) they care for (46: +2). Young carers are not considered to get enough time off from their caring responsibilities (48: -4), to be able to take part in clubs or activities after school (13: -4), nor feel happy about the amount of time they can spend with friends (31: -3). There is also a view that young carers are not proud of their caring responsibilities (50: -1) and that they suffer from depression (43: +1). One professional (Clinical Psychologist) commented that:

> “It’s interesting I’ve picked two ‘worry ones’ as most agree. But the young carers I’ve come across *do* worry, and *are* depressed” (mpr32clp).

Another professional (Occupational Therapist) remarked that:

> “Young carers don’t see things ending. They live in the present and daren’t hope. They’re tired emotionally and physically. The future seems grim and they’re frightened of looking ahead” (fpr46ot).

Like the professionals in factor 2, this viewpoint agrees that young carers need someone they can talk to in school (11: +3) and that they are best supported in schools when they are linked with one key worker (3: +2). Further agreement between the professionals’ factors highlights that young carers struggle to find time to study at home (14: +2), prefer that others in school don’t know about their caring responsibilities (4: +1) and that they need to be given special allowances by teachers for handing in homework (6: +1). Unlike factor 2, however, these professionals feel that young carers regularly have to miss school (8: +3) and that their caring responsibilities come first before school (10: +3).

In terms of intervention and support processes this viewpoint finds that services only offer help to the person needing care in the family (18: +2) and that young carers wish services would provide enough care, so they didn’t have to do it (42: +1).

A participant (SENCo) spoke about the Common Assessment Framework (CAF) underway at her school, saying:

> "Professionals are not active enough in being helpful. The CAF I've had in place focuses on the needs of the mum, not the young carer" (fpr58sen).

Furthermore, young carers are not considered to be either listened to by professionals (22:-2) nor asked their opinion (15: -3). A comment by another participant (Education Welfare Officer) reinforces this point, in that:

> "A young carer was referred to me as a bad attender [sic]. She'd had three years of virtually non-attending and no-one asked her why, and there was no relationship between school and parents" (fpr32ewo).

Young carers are seen to be talked down to like little kids by doctors and nurses (19: +1) and are not kept informed about the medical condition of the person they care for (17: -3). The Occupational Therapist spoke about it: "being hard enough to explain things to the patient, or make it accessible, let alone the young carer" (fpr46ot).

This viewpoint also considers that professionals make negative assumptions about the way in which young carers are looked after at home (26: +2), and that professionals lack understanding about parents with a drug or alcohol problem (30: -2). One EP participant remarked, however, that:

> "It's not as simple as that. Our bias is towards the child, naturally. Around drug and alcohol issues it's a more challenging situation from a child protection point of view as there's inevitably a judgement of parental capability" (mpr44ep6).

Finally, this viewpoint does not think that young carers know what sorts of support services are available to them (24: -3).

5.12 Professionals' Data: Factor 2

"Young carers are mature and resilient, and want to be treated like every other young person. Professionals could do more, but are getting there"

Factor 2 has an eigenvalue of 3 and explains 15 % of the study variance. Four participants (participants 7, 12, 14, and including myself, 19) are significantly associated with this factor: all female, whose average age is 43 years 9 months. Represented in this group are three EPs (one trainee) and a Learning Mentor. Apart from myself the other three participants consider that they have 'some' or 'limited' experience with young carers.

Least Agree **Most Agree**

-4	-3	-2	-1	0	+1	+2	+3	+4
43	18	7	1	2	4	11	3	5
44	23	13	8	10	6	14	35	38
	28	33	12	15	9	22	36	
	46	34	19	17	16	40	39	
		42	20	25	21	41		
		49	24	29	26	50		
			27	31	45			
			30	32	47			
				37				
				48				

Figure 6: Factor Array: Factor 2 (Professionals)

(The crib sheet for this factor can be found in Appendix xvi)

Professionals holding this viewpoint regard young carers as having a mature outlook on life compared to other young people (38: +4). They also consider that young carers have better life skills to prepare them for adulthood, and have a better understanding of disability and difference compared to their peers (39:

+3, 40: +2). Furthermore, young carers are seen to be proud of their caring responsibilities (50: +2) and hate being called a young carer, as they are just a son or daughter helping out (41: +2). This is reinforced by the fact that young carers are seen to be ‘little victims’ on television and in the media (47: +1) and want to be treated the same in school as every other pupil (5: +4), as well as disliking getting special attention as a ‘little angel’ (44: -4). It is not thought that young carers come from families with a low income (33: -2), or suffer from depression (43: -4), nor do they worry about their own health (34: -2), however this viewpoint is similar to factor 1 in recognising that young carers, nonetheless, worry about the person(s) they care for and worry what will happen to them if their sick or disabled parent dies (36: +3, 35: +3). In terms of social class one participant (Learning Mentor) said that: “anyone can be a young carer. Disability can affect anyone. It doesn’t have any class” (fpr34lmp).

These professionals did not regard young carers as speaking on behalf of the person needing care (23: -3), nor feeling like a parent to the person they care for (46: -3). One participant (EP) remarked that: “You can still be a parent while you’re disabled. Disabled doesn’t mean incapable” (fpr41ep1). The same participant constructed her own statement: “young carers of sick or disabled parents don’t want to be reliant”, which she thought was missing from the Q set, and which she would have placed at position +3 within the grid.

Unlike factor 1 these professionals think that young carers are listened to by professionals (22: +2) and do not consider that services only offer help to the person needing care in the family (18: -3). One participant (an EP) commented that she thought the Q set lacked a statement about trust and advocacy and worded her own statement as follows: “Young carers and support workers have a positive relationship as they are their advocates” (fpr55ep3). When asked, this participant said she would have sorted this statement as ‘most agree’ (+4). Young carers, also, are thought unlikely to wish that services would provide enough care, so they didn’t have to do it (42: -2) and are not thought to need training in safe lifting techniques (28: -3). As one participant (EP) put it: “children should not be lifting” (fpr41ep1).

This viewpoint was more positive than factor 1 about professionals’ ability to ask young carers their opinion (15: 0), about young carers finding social workers helpful (25: 0) and about doctors and nurses keeping young carers informed about the medical condition of the person they care for (17: 0), without talking down to them like little kids (19: -1). Despite this, however, these professionals agree with factor 1 in that professionals are considered to lack awareness about young carers' needs and that assumptions are made by professionals about how young carers are looked after at home (16: +1, 26: +1). Furthermore young carers are not thought to feel included in their community (49: -2), nor receive enough support from their family doctor (27: -1).

Professionals holding this viewpoint think that young carers do not have to miss school regularly (8: -1), and although they are thought to worry that their education is suffering (9: +1) and struggle to find time to study at home (14: +2), they can make plans for their future job or further education (21: +1). Compared to factor 1 this viewpoint does not consider that young carers' caring responsibilities come first before school (10: 0) and are more positive that young carers feel happy about the amount of time they can spend with friends (31: 0).

5. 13 Professionals' Data : Non-significant Q Sort

This professional's Q sort is non-significant in that it does not load upon any individual factor at a statistical level (0.43). Her personal viewpoint, however, at 0.41 is only marginally insignificant, and consequently correlates more closely to factor 2 than factor 1 (level of significance at 0.43).

participant	Factor 1	Factor 2
10. fpr55htp	0.2	0.41

Table 5: Extract from Professionals' Data: Two Factor Solution

This participant is a female, aged 55 and a Headteacher of a Primary School.

The two statements placed at 'most agree' (+4) were:

- 35. worry what will happen to them if their sick or disabled parent dies
- 10. think their caring responsibilities come first before school

The two statements placed at 'least agree' (-4) were:

- 40. have a better understanding of difference and disability compared to other young people
- 17. are kept informed by doctors and nurses about the medical condition of the person they care for.

In relation to statement 40 this participant commented:

> "they [young carers] aren't old enough to be objective or to understand. They tend to be focused on their own parent and can't deal with other issues because they're preoccupied with their own situation. They're not old enough to see the bigger picture".

5.14 Professionals' Data: Confounding Q Sorts

Three professionals' Q sorts are confounding in that they load significantly upon both factors (statistical significance at 0.43) and, therefore, can be seen to correlate with both factors 1 and 2.

participant	Factor 1	Factor 2
2. mpr35cvc	0.49	0.51
15. fpr29ep4	0.54	0.44
18. mpr30ep7	0.65	0.49

Table 6: Extract from Professionals' Data: Two Factor Solution

Participant 2 works in the voluntary sector, in a youth project, and has worked 'somewhat' with young carers, and the other two participants in this category are EPs, both of whom declared that they have ‘no known experience’ with young carers.

Participant mpr30ep7 remarked that:

> “Any sort of adversity makes you mature more quickly. Challenges make you grow up. Someone shouldn’t highlight your caring every five minutes. It’s not who you are. It’s like kids with behaviour problems. It shouldn’t define you”.

In addition participant fpr29ep4 (a newly qualified EP) commented that:

> “The nature and focus of our studies means that EPs naturally try to think what a young carer would think. We will perceive young carers as being vulnerable. Young carers wouldn’t want to be perceived like that”.

Finally, participant mpr35cvc placed statements 41 and 50 as ‘most agree’, elaborating that:

> “Based on the work I’ve done with two young carers they don’t see themselves as a young carer. They don’t see it as a title, as caring’s just part of their life. When they *do* talk about it it’s with a quiet dignity about their role”.

5.15 Consensus Statements

The term ‘consensus statements’ refers to statements which do not distinguish between any pair of factors, and thus have been sorted similarly across all factors within the data in question.

5.15.1 Young Carers’ Data

No.	Statement	F1	F2	F3	F4
10	think their caring responsibilities come first, before school	+1	+2	+1	+2
23	speak on behalf of the person needing care	0	0	0	0
24	know what sorts of services are available to help them	-1	-2	-1	-2
28	need training in safe lifting techniques	-1	-1	-1	-1
34	feel worried about their own health	-2	-1	0	-2
37	find that no-one understands what they have to go through	0	+2	+1	+1
50	feel proud of their caring responsibilities	+4	+3	+2	+4

Table 7: Consensus Statements: Young Carers

5.15.2 Professionals’ Data

No.	Statement	F1	F2
2	find that teachers aren't sympathetic towards them	0	0

3	are best supported in school when they are linked with one key worker	+2	+3
4	prefer that other people in school don't know about their caring responsibilities	+1	+1
6	need to be given special allowances by teachers for handing in homework	+1	+1
7	find that teachers single them out as being different to other pupils	-1	-2
9	are worried that their education is suffering	0	+1
11	need someone they can talk to in school about their caring responsibilities	+3	+2
14	struggle to find time to study at home	+2	+2
16	find that professionals lack awareness about their needs	0	+1
27	have enough support from their family doctor	-1	-1
30	find that professionals are understanding about parents with a drug or alcohol problem	-2	-1
32	find they have lost their childhood	0	0
33	come from families with a low income	-1	-2
34	feel worried about their own health	-1	-2
35	worry what will happen to them if their sick/disabled parent dies	+3	+3
36	constantly worry about the person they care for	+4	+3
37	find that no-one understands what they have to go through	0	0
49	feel included in their local community	-2	-2

Table 8: Consensus Statements: Professionals

5.16 Reflecting on My Own Q Sort

My position as a person, trainee educational psychologist and researcher has been previously outlined (see Chapter 3.0) and my aim within this research has been to allow the participants' data to 'speak' whilst attempting to minimise the potential influences my prior life experiences and inevitable biases may have. Part of this process, therefore, was to complete the Q sort activity as a participant, in order that it would place my factor interpretations in context, by making my own position and viewpoint transparent. This measure, in conjunction with the process described below (see 5.17), and the use of the systematic crib sheets was put in place to make the factor interpretations as 'objective' as possible, and to help verify the way in which the interpretations were carried out.

I found the Q sort activity a difficult process in that I could not make a distinction between myself as a former 'young carer' and myself as a professional, added to which I also inhabited the role as the designer of the research. As I began to make decisions about the placement of the statements I realised, however, that I didn't need to complete the activity wearing any particular ‘hat’, but go with my gut feeling, thus allowing the statements to speak to me at an instinctual level. Inevitably, therefore, the finished grid represents a hybrid of my perceptions and feelings, based on past and present experiences, and of ‘who I am’ in all of my defined and undefined ‘roles’.

As the table below indicates, my Q sort loaded significantly onto factor 2:

participant	Factor 1	Factor 2
19. fpr45tep	0.28	0.66x

Table 9: Extract from Professionals’ Data: Two Factor Solution

An in-depth description of each statement position will not be provided, however the characterising statements are reported as follows. I placed the following statements as ‘most agree’ (+4):

- 38. have a more mature outlook on life, compared to other young people
- 36. constantly worry about the person they care for

and as ‘least agree’ (-4):

- 32: find they have lost their childhood
- 46: feel like a parent to the person they care for

The completed grid, for further information, can be found in Appendix xix.

5.17 Post-Hoc Interpretation: ‘Taking the Data Back’

As highlighted earlier in the chapter, the process of factor interpretation can be one which brings the researcher’s position, assumptions and pre-conceived notions into question. In order to minimise potential biases, therefore, and to assist in verifying the way in which I had interpreted the young carers’ factor arrays, I revisited the young carer projects, post-hoc, in order to ‘take the data back’ to the participants. In this way I hoped to involve them in the analysis process by asking them to comment on the factor descriptions and invited them to ‘guess’ the factor description (and title) which most closely matched their personal viewpoint. Of the 18 participants who loaded onto one of four factors I was able to meet with 17 to take part in this final process (one participant could not be contacted as she had carried out her Q sort in her school rather than at a young carer project). I also spoke to the participant whose Q sort was non-significant, but was unable to contact the participant whose Q sort was confounding.

From the 17 young carer participants contacted 16 correctly ‘guessed’ and matched with the factor description onto which they significantly loaded. One participant, however, chose factor 4, whereas they had loaded significantly onto factor 1.

In terms of the professionals’ data I was unable to verify my factor interpretations with the participants involved as I no longer had contact with the local authority, and the participants were spread over a wide geographical area, which made gathering them together prohibitively difficult. Furthermore as only two factors were interpreted from within the professionals’ data it rendered the ‘factor matching’ procedure less powerful as a verification process, since the participants had a 50/50 chance of choosing which factor they most identified with. Given these two issues it was decided not to present the professional participants with the factor interpretations.

5.18 Summary

This chapter has outlined the process of data analysis in Q methodology in detail and given a systematic description of the way in which the data within this study has been analysed. Young carers’ and professionals’ data were then reported and described, including a brief reflection upon my own Q sort and the way in which the data interpretations were verified by involving the young carer participants. The following chapter will bring these results into focus, by examining and discussing the implications of what has been reported.

6. 0 DISCUSSION

This chapter will begin by briefly revisiting the aims and purpose of the study, followed by a reminder of the research questions. A critical discussion of the results found within the young carers' and professionals' data will then follow, in respect of the research and wider literature covered in Chapter 2.0. The discussion will also include a comparison of the young carers' viewpoints, of the professionals' viewpoints, and a comparison of the two data sets. Further analysis will reflect upon the suitability of Q methodology in the light of the study's results and, in addition, upon the research findings in terms of the implications for professional practice, including relating to the practice of EPs. Finally, conclusions will be drawn, which will include highlighting the limitations of the study, as well as suggesting areas for further research.

6.1 Aims and Research Questions Revisited

In Chapter 2.0 the aims and purpose of this study were outlined and can be summarised as:

- using Q methodology as a tool to explore the views of children and young people identified as young carers, and of professionals, about young carer roles, responsibilities and experiences within the context of looking after a family member with a disability
- considering whether there are any shared viewpoints among young carers (given the diverse range of their individual experiences and circumstances) and shared viewpoints among professionals (given the range of professionals from education, social care and health settings, who may encounter young carers in their work) about young carers, their education and support systems, and the way in which they are engaged by professionals in the processes of referral and intervention and support

Based upon these aims the following research questions (R.Q) were devised:

R.Q. 1: What are the viewpoints of children and young people identified as young carers in terms of their roles and responsibilities, and their experiences of intervention and support processes in education, social care and health settings?

R.Q. 2: What are the viewpoints of professionals about young carer roles and responsibilities and of the intervention and support processes available to young carers in education, social care and health settings?

6.2 Analysis of Young Carers' Viewpoints

The young carer data elicited four distinct viewpoints, which were interpreted and reported with the aid of the following factor descriptors:

- Factor 1: "We're proud and positive. We feel included and well supported but don't like being singled out"
- Factor 2: "Caring's just what we do. We feel mature, but are unsupported and misunderstood"
- Factor 3: " 'Parentified' and wanting to care, but we need people to recognise that we're struggling and worried"
- Factor 4: "Being mature doesn't stop us from worrying, although we're supported, especially in school"

There were also a number of similarities within the young carers' data and these will be analysed and discussed in further detail in the section to follow.

For the purposes of critical analysis during this discussion, the young carers' viewpoints have been compared and contrasted within three broad areas, namely the social and emotional aspects of caring, the process of intervention and support from professionals, and young carers' experiences in relation to education. These categories were chosen as they are consistent with the broad categories upon which the Q set statements were constructed (see p.49), as well as providing a clear framework for discussion.

6.2.1 Social and Emotional Aspects of Caring

The viewpoints expressed by the young carers show consensus across all four factors in relation to the following statements, concerning the social and emotional aspects of their caring responsibilities (see Table 7), namely:

- they all agree that they are proud of their caring responsibilities with three out of four factors placing this statement at +3 or +4
- none of them express a strong concern about their own health, the highest placement being 0 for this statement
- none of them feel strongly that they speak on behalf of the person needing care

- they all agree that no-one understands what they have to go through

In terms of the first of these statements the pride felt among the young carers was apparent in many of the comments made about this particular statement such as: “It [caring] makes me feel special. It makes me who I am” (fyc11br), “I like having more responsibility, it feels good” (fyc11br2). It is interesting, however, that although there seems to be a shared level of pride there does not appear to be a commensurate level of identification with the ‘young carer’ label, as the young carers in factor 2 indicate a strong dislike of the term in comparison to the other factors. Factor 2, however, also expresses the most negative viewpoint of the way in which professionals are seen to offer intervention and support, and it is possible that the two notions are linked. Could these young carers be rejecting the term as they have found that to be called a ‘young carer’, yet receive little support, is frustrating and pointless? This is not to say that the lack of objection to the ‘young carer’ label from the other young carers means that they actively identify with it in an *emotional* sense, however, but that the amount of support they receive either from professionals generally (factor 1) or particularly in school (factor 4) may serve to cement their care-giving role in context and perhaps give it some recognition in the wider social arena. This is consistent with Bibby and Becker (2000) who assert that the term can be useful to “validate an experience” (p.7) as well as serve as a key to access additional support, in that the alternative may be to remain hidden and unidentified (Dearden and Becker, 2004). The viewpoint expressed by the young carers in factor 2 does not seem to concur with this assertion, however, as it appears that their identification as young carers has done little to access the support they feel they need. To posit notions of ‘label’ or ‘no label’ serves only to simplify what has been seen to be a complex and contentious issue, with much polemical debate as to the purpose, function and accompanying social constructions of the term (Cass et al., 2009, Smyth et al., 2010). Notwithstanding this level of complexity the label ‘young carer’ should not be regarded as defining the young person who ‘inhabits’ the role, so that a holistic view of young carers’ needs within the context of their environment should be prioritised over any definition which may exist. This is explored further in the sections to follow, however.

As well as young carers sharing a consensus that they are not worried about their own health, many other positive aspects of their caring responsibilities were elicited, although not universally shared among all viewpoints. In general, for example, the maturity felt by young carers was highlighted (most strongly in factors 2 and 4), and young carers consider that they have both better life skills to prepare them for adulthood and a better understanding of difference and disability, compared to other young people. This finding is consistent with research indicating that the sense of care-giving increases young carers' feelings of maturity, responsibility, and range of life skills (Becker, 2005, Lackey and Gates, 2001). Other research goes further to suggest that the care-giving role increases the young carer's resilience and that the coping strategies learned can be seen as beneficial agents in negotiating future life events (Gladstone et al., 2006, Skovdal, 2009). Whilst this research concerning young carers and increased resilience is consistent with the more general literature on the concept of 'stress-related growth' (Joseph et al., 2007, Linley and Joseph, 2004) it is worth noting that the concept of resilience is one which incorporates the overcoming of adversity, and "bouncing back" (Dent and Cameron, 2003, p.6). By implication, therefore, it is possible that young carers may first experience a degree of struggle and stress in order to build levels of resilience (Gladstone et al., 2006). The young carers within factors 2 and 4, in fact, report feeling worried about the potential for family break up, and all factors except for factor 2 also highlight a constant worry about the person(s) they care for. This is consistent with previous research outlining the levels of emotional strain young carers may feel (Butler and Astbury, 2005, Gray et al., 2008, McAndrew et al., 2012).

Part of developing resilience is seen to be the support of a close family bond, and a sense of feeling included in the community (Skovdal, 2009). The young carers in factor 1 are the most positive of all the viewpoints about feeling part of the local community, and share with factors 2 and 4 the sense that they belong to a close family, with reciprocal levels of care. Some of the young carers' viewpoints within this study, therefore, appear to support findings by a number of researchers (Earley et al., 2007, O'Dell et al., 2010, Segal and Simkins 1993) who have posited that the notion of 'carer' and 'cared for' is transactional and dynamic, and that 'caring' is not only reserved for the "able-bodied and well" (Segal and Simkins, 1993, p.4), thus challenging assumptions about perceived levels of dependency of the care receiver, as well as perceived notions of parental competence. The viewpoint elicited from the young carers in factor 3, however, is contradictory in this regard as they do not feel like they have a close family. It is interesting to note, furthermore, that there appears to be a link between the way in which the young carers perceive the closeness of their family and two other key areas; whether or not they feel like a parent to the person they care for and whether or not they find they have lost their childhood. Those young carers who viewed their family relationships negatively, for example, also felt more like a parent to the person they cared for as well as feeling like their childhood was lost (factor 3).

As a whole the young carers' viewpoints elicited a range of both positive and negative features concerning the social and emotional aspects of caring, which is the area most commonly focused upon by researchers. Aldridge and Becker (1993a), Earley et al. (2007) and Holmstom (2002), are among many who have found that young carers are more likely to feel isolated from the outside world, lose opportunities to socialize with friends and thus to suffer from depression. These findings appear to be supported by the young carers who exemplify factor 3, as their viewpoint indicates that they appear to be struggling at an emotional level. Whilst all four factors highlight a consensus relating to young carers finding that 'no-one understands what they have to go through', it is possible that the young carers in factor 3 feel more negative and prone to depression, in comparison to the others, as they may feel unsupported by their family members, given that their family relationships are not deemed to be 'close'. This, combined with their apparent lack of 'time off' from their caring responsibilities and little time to socialize with friends, may account for their feelings of negativity and isolation. Conversely, those young carers with a close family appear more positive, which may indicate a higher level of familial support (including perhaps an extended family to help out) and could suggest that the young carers are better equipped with coping strategies and thus a higher level of resilience (Bogosian et al., 2011).

6.2.2 Intervention and Support

All four factors share a consensus that young carers do not consider they need to be trained in safe lifting techniques, although within the context of this study, where 17 of the 20 young carer participants reported that they do not care for a relative who requires lifting, this finding could be considered unsurprising. This statement was particularly important to one participant, however, who cares for her younger brother with cerebral palsy (fyc17br, factor 2), as she had been trained to lift him safely by her mother, who is an occupational therapist. This is interesting in the light of the discussion above, relating to family support mechanisms, in that the support required in this instance (although somewhat specialist) was provided from within the home. What is also illuminating within the young carers' viewpoints is the consensus that none of the young carers feel they know what sorts of services are available to them, a feeling which is shared across all four factors, despite there being a considerable range of viewpoints presented in relation to how young carers experience the intervention and support processes offered by professionals.

The young carers in factors 1 and 4, compared to factors 2 and 3, for example, express almost opposite viewpoints in terms of the amount of support they feel they receive from professionals. Factor 1's viewpoint is largely positive, with the young carers feeling included and listened to by professionals, and especially supported by health professionals. They are also the most positive, in comparison with other factors, about finding social workers helpful and wanting their involvement. Young carers in factor 4, in addition, feel supported by professionals in school (see 6.2.3), although less so by those in health. Conversely, the young carers in factor 2 find that services only offer help to the person needing care and feel strongly, compared to other viewpoints, that they are not listened to by professionals, who are thought to make assumptions about the competence of their parents and who are not understanding about parents with a drug or alcohol problem. The additional qualitative comments made by these young carers suggest, furthermore, that they feel they have been let down by professionals, who: "don't listen to young carers in any capacity" (myc17mu) and equally who: "try and blame everything on health. I don't trust her [the social worker]. Her boss is nasty, not helpful, no empathy" (fyc17br). This view is reinforced by the young carers in factor 3, who feel the strongest, in comparison to other viewpoints, that they do not want social care to become involved with their family, although paradoxically they also find social workers helpful.

Previous research has reported that young carers prefer to keep their circumstances outside social services' gaze for fear of family breakdown (Aldridge and Becker, 1993a, Cameron 2010, Underdown, 2002) yet this does not seem to be a strong concern for the young carers in factor 3, compared to other factors. It is possible that their reluctance to have social care involved could relate more to the general feeling they expressed that they do not want involvement from *any* services, as they prefer to care for their sick or disabled family members themselves. This is particularly interesting given the apparent lack of family bond felt by the young carers in factor 3. These findings appear consistent with O'Dell et al. (2010) findings, who report that young carers, despite experiencing emotional and family difficulties (as do also the young carers in factor 3) feel an "emotional pull" (p.651) and *want* to take on caring responsibilities. This has important implications for the way in which professionals may make judgements and assumptions about family dynamics and the nature of the care taking place.

When directly comparing the viewpoints of factors 1 and 2, (with reference to intervention and support from outside agencies), the participants' ages may be relevant as the average ages are 11years 9 months and 16 years respectively. Is it possible that the younger children feel more supported as, perhaps, they may receive more attention and input from professionals who may consider them more vulnerable than the older teenagers? On the other hand the young carers in factor 4 (whose average age is 15 years 3 months) feel supported by professionals in school, therefore could it be related more to the way in which health and social care professionals intervene, in comparison to professionals in education, as opposed to the young carers' ages? These questions are explored in more detail in the section to follow (6.5. Implications for Professional Practice), however it appears that for the young carers in factor 2 it is not a question of whether or not intervention and support services are in place, but the nature and quality of the support received, and whether the services are being monitored to check that the individuals receiving support are having their needs met. In order for young carers and their families to have their needs met, however, professionals are first required to know what those needs are. It appears as if the findings from factor 2 support previous research which has posited that an exclusive focus on the negative aspects of caring serves both to exploit stereotypes and detract from the process of hearing young carers' genuine experiences and needs (Prilleltensky, 2004) and also serves to reinforce professionals' views of children as 'parentified' (Earley et al., 2007). This, in fact, has also been shown to contribute to assumptions of parental competence and reinforce barriers and stigma to those being cared for (O'Dell et al., 2010, Prilleltensky, 2004). The implication here is that, inadvertently or otherwise, professionals may be allowing assumptions and preconceptions of a negative nature relating to the family circumstances of the young carer to colour the way in which intervention and support processes are put in place. It is possible, therefore, that services may not be targeted appropriately nor sufficiently, and that young carers may be marginalised in any decision making process. In this regard it is interesting to note that although the young carers in factors 1 and 4 report feeling listened to by professionals, none of the viewpoints highlight that professionals ask young carers their opinions. A question is then raised as to how young carers' voices are being heard if they are not asked their opinions in the first instance?

6.2.3 Education/School-based Experiences

In relation to statements about education the young carers' viewpoints highlight only one item about which there is consensus across all four factors, namely that the young carers think that their caring responsibilities come first before school. This perhaps seems unsurprising, given the context of the discussions above relating to the level of pride they feel about their caring responsibilities, and their willingness to provide care, despite experiencing difficult family and emotional circumstances (factor 3). As a whole the factors portray a mixture of positive and negative viewpoints in terms of the way in which young carers experience education and the support they receive within it from professionals.

Among all factors it is the young carers within factor 4 who appear to experience the most support from professionals in school, yet paradoxically they feel the strongest that their education is suffering. Is it possible that these young carers are experiencing a significant amount of pastoral support from staff which, although valuable, may be at the expense of both the academic expectations of the young carers and the curriculum support they may also require from staff? They find teachers sympathetic, and unobtrusive, and are not singled out by teaching staff as being different. They also hold the most positive viewpoint about feeling best supported by one key worker in school, as well as feeling able to make plans for their future education. Other positive aspects of young carers' experiences of education are elicited by factors 1, 2 and 4, which highlight that young carers do not need to miss school regularly and do not feel bullied, and want to be treated the same as every other pupil in school. The young carers in factor 1 feel the least worried that their education is suffering, and agree the most, compared to other viewpoints, that they prefer that no-one in school should know about their caring responsibilities. Three of the five young carers in this factor are new to year 7, however, and it is possible that the transition to their new high school environment, with its many changes of staff and the additional support most schools provide for all new pupils during transition, may have contributed to this finding.

Not all young carers share these positive views, however. The young carers in factor 3 find that teachers ask too many personal questions, and feel bullied, as well as finding that they regularly need to miss school. In addition, these young carers are the only ones who feel that they want to be treated differently in school, yet at the same time prefer that others do not know about their caring responsibilities. In the light of the discussion relating to the social and emotional aspects of caring it is possible that the emotional difficulties faced by these young carers in a general sense, coupled with their perceived lack of family support and feelings of isolation, may be contributing to the way in which they both experience and engage with school. Furthermore, their feelings of wanting to be treated differently to other young people in school appear to be linked less with wanting to be singled out and more to do with struggling to find time to study at home, and thus they may require additional time or special allowances when completing coursework. Whilst the young carers in factor 1 share their concern about struggling to find time to study at home, the fact that the young carers in factor 3 are approaching GCSE and A level exams, perhaps puts their concerns into greater focus.

It is difficult to place these findings in context with previous research as so few studies have focused upon young carers' views relating to their experiences of education (Moore, 2005b). Of those studies, however, the majority report that young carers experience difficulties in school, such as being concerned about school work (Dearden and Becker, 2000), having poor attendance (Butler and Astbury, 2005) and experiencing bullying (Bibby and Becker, 2000). The young carers' viewpoint in factor 3 appears to support these findings, and whilst their voices should not be marginalised it is worth noting that three out of four factors highlight positive aspects of school life, which the young carers consider to be supportive. In other areas of research, such as studies investigating the resilience of Looked After Children, education and the school environment have been found to be a protective factor (Honey et al., 2011), and it is possible that the young carers who are experiencing positive outcomes at school, particularly those young carers in factor 4, may be benefitting in a similar way.

The young carers' viewpoints discussed above are wide ranging in terms of the negative and positive aspects of their education. Becker (2005) acknowledges that:

> "We cannot be certain at this stage why some young carers do or do not experience significant difficulties at school or elsewhere in their lives, nor can we be certain that for those that do, that it is their care-giving responsibilities that account solely for any problems" (Becker, 2005, p.12).

The difficulty for professionals in education (and in other fields) is how to extrapolate the worries or concerns relating to caring from those considered to be typical of all children and adolescents (O'Dell et al., 2010). The viewpoints and perceptions professionals hold about young carers are important therefore, and these are discussed in the sections to follow.

6.3 Analysis of Professionals' Viewpoints

The professionals' data elicited two distinct viewpoints, which were interpreted and reported with the aid of the following factor descriptors:

- Factor 1: "Young carers worry and struggle. They are unsupported and neglected by professionals"
- Factor 2: "Young carers are mature and resilient, and want to be treated like every other young person. Professionals could do more, but are getting there"

There were also a larger number of similarities within the professionals' data, compared to that of the young carers, and these will be analysed and discussed in further detail in the section to follow.

For the purposes of consistency the professionals' viewpoints, like those of the young carers, will be compared and contrasted using the same three broad areas as a framework for discussion.

6.3.1 Social and Emotional Aspects of Caring

The statements relating to the social and emotional aspects of the young carer's role were those about which the most qualitative comments were made by professionals. An interesting aspect of the process of gathering the professionals' data, especially that of the EPs, was that some of them felt they needed to remind themselves that they were carrying out the Q sort activity based on *their perceptions* of young carers, rather than on putting themselves in young carers' shoes to imagine what a young carer might think. Some of the professionals found this difficult, as they reported that they are so used to acting as a child or young person's advocate, and by implication trying to understand what the latter may be thinking and feeling in order to represent their needs, that they felt uncomfortable being asked to make choices purely based upon their own views alone. In relation to young carers being thought of as 'little angels' for example, one participant remarked: "they [young carers] would hate it, but they *are* angels I think" (fpr48lms, factor 1). Similarly another participant commented (about young carers being considered as a parent to those they care for):

> "I would say to another professional that they [young carers] are the parent, but a young carer probably wouldn't think that" (mpr29dct, factor 1).

One's professional role, and the perceptions one holds of others within it, is inextricably linked to a multitude of personal and emotional stimuli, ranging from previous life events to personal and professional biases. As such the processes of placing oneself in the shoes of others and the making of choices (or judgements) based upon one's subjective viewpoint are not necessarily mutually exclusive. Notwithstanding this point some of the professionals remarked that: "these are my views and a young carer may not necessarily agree" (fpr29ep4, confounding sort) but equally that the process was a useful vehicle for: "reflecting upon and challenging my own assumptions" (fpr41ep1, factor 2) (see Appendix ix for further examples).

The consensus statements about the social and emotional aspects of caring indicate that young carers are thought to worry about what will happen to them if their sick or disabled parent dies and that they constantly worry about the person they care for, with professionals placing this last statement in the +4 and +3 column. In addition, all professionals feel that young carers do not come from families with a low income, nor that young carers feel worried about their own health. Furthermore, professionals do not think that young carers have lost their childhood, nor do they consider that no-one understands what they have to go through.

The professionals' viewpoints differ, however, in that those in factor 1 appear to have a negative view of young carers' roles. By contrast the professionals in factor 2 consider that young carers are proud of their caring responsibilities and have better life skills and greater maturity, together with a better understanding of disability and difference, in comparison to other young people. Factor 1, furthermore, compared to factor 2 highlights many negative aspects of the young carer's role such as having limited time off from caring to socialise, suffering from depression, feeling like a parent to the person being cared for and feeling worried about family break-up.

The difference between the professionals' viewpoints appear to be mainly in relation to aspects of young carers' maturity and pride (which are barely recognised by those in factor 1 in comparison) and their perceived levels of depression and resilience, in that factor 1 considers that young carers are struggling emotionally. The professionals in factor 1 reported a range of levels of experience working with young carers, one admitting: “I've never knowingly met a carer? What does that mean?” (mpr39ep2), whilst another had worked as a learning mentor for young carers in high school for 11 years (fpr48lms). As such it cannot be said that factor 1's negative viewpoint is purely based upon what is deemed to be the stereotypical discourse so heavily criticised by researchers and commentators such as Earley et al., (2007), Keith and Morris (1995), or Prilleltensky (2004) as it is built upon professionals' genuine experiences. This is not to say that the professionals within both factors may not be influenced by media or other discourse, however, as one participant commented: “I've always been inspired by [young carers'] stories, but it's clever of the media to make me feel that” (mpr41hts, factor 1).

When attempting to compare these results with previous literature a search revealed only three studies which asked health care professionals their views about young carers, but none was found relating to professionals in education, psychology or social care. Factor 1's viewpoint appears to support findings by Simon and Slatcher (2011) who surveyed General Practitioners (GPs) to find their level of awareness of young carers and their perceptions of them. These GPs highlighted mainly negative aspects of young carers' roles, including their restricted social activities and poor peer networks. Gray et al. (2008) findings were similar in that the perceived isolation, social stigma and invisibility of young carers were commented upon by a range of 65 professionals when interviewed about their understanding of young carers' needs. Finally, Jones et al. (2012), in a piece of work commissioned by the National Carers' Strategy (2010), carried out a pre and post training workshop questionnaire relating to GP and primary care professionals' knowledge and attitudes towards carers in general (with young carers being identified as a sub category). This research is referred to in further detail below.

6.3.2 Intervention and Support

An interesting aspect of asking professionals' viewpoints on the intervention and support services available to young carers is that indirectly they were being asked to make judgements about the working practices of their fellow professionals and of those in other areas of children's services. This was not deliberate or intentional in terms of the design of the Q set and whilst no professionals objected, and issues of an ethical nature were not raised, the process could have had ethical implications and I should have been more vigilant in this regard. Notwithstanding this issue it is worth noting that the professionals' participant group was under-represented in terms of professionals from health and social care, and this has been raised as a limitation of this study (see 6.7), therefore the results from the professional participants need to be digested with this in mind. In addition it is also interesting to note that the statements relating to intervention and support, in comparison to the other two categories (see 6.3.1 and 6.3.3), were those about which the least amount of consensus was reached between professionals' viewpoints.

The consensus statements within this category highlight that professionals perceive that young carers do not have enough support from their family doctor. Professionals were also thought to lack awareness about young carers' needs and lack understanding about parents with a drug and alcohol problem. These findings are consistent with Jones et al., (2012), who found, when questioning 153 health care professionals, that only 51% (pre-training measure) felt confident that they could identify carers in their practices and that they lacked knowledge about issues facing carers in general, and young carers in particular.

As raised by the young carers in factor 2 above, however, it is not only a question of whether services are in place in the first instance, but the quality and nature of the intervention and support being provided. The professionals' viewpoints differ on a number of key statements in this regard. Professionals in factor 1 hold a largely negative view of the intervention and support processes young carers receive from professionals, in comparison to factor 2. They do not consider that professionals either ask young carers' opinions, or listen to them, and consider that services are seen to only provide help to the care-receiver, not the young carer. In addition, professionals in factor 1 do not consider social workers helpful and, compared to factor 2, think that young carers prefer that services should provide care for their family member to relieve them from the caring role. Whilst the professionals in factor 2 are more positive about the process of intervention and support it should be noted that this is relative to the viewpoint expressed in factor 1, and that factor 2's viewpoint could perhaps best be described as 'cautiously positive', with some negative features. It is impossible to qualify the degree to which professional biases may have coloured these findings, given that the efficacy of multi-agency collaboration, information sharing and co-operation may not always be ideal in a professional capacity (Hughes, 2006), leading, potentially to prejudices and barriers to practice. Nonetheless it is interesting that within factor 1 there are a range of professionals represented who share the same viewpoint, although the range is more limited in factor 2.

The findings and discussion above raise questions as to the identification and referral of young carers and whether or not their needs can be met if they are deemed 'invisible' or 'hidden', as well as whether or not intervention and support services are being provided by professionals with an adequate amount of knowledge and awareness of young carers' needs (Ofsted, 2009). Jones et al. (2012) data indicates that primary health care professionals felt much more confident, post-workshop training, in how to recognise and identify a young carer (using provided checklists, see Jones et al., 2012), as well as feeling greater confidence in their level of awareness and knowledge of young carers' needs, and this has significant implications for professional practice (see 6.5).

6.3.3 Education/School-based Experiences

The statements relating to young carers' experiences of education are those which provide the greatest amount of consensus and broad agreement between the professionals' viewpoints, compared to the other categories. Given the large representation of professionals working within education (and educational psychology) among the participant group, however, this may not be surprising, although this is not to assume that professionals from similar occupations are necessarily likeminded in their perceptions and approaches to their working practices.

The professionals within both factors feel similarly that young carers in school are best supported with one key worker, and it is also considered that young carers need someone they can talk to in school. Two of the participants expressing this viewpoint carry out this role within their school environments (fpr48lms and fpr51lmp) and consider that the support they offer to the young carers is invaluable. This finding is consistent with reports from The Education Network (2006) which highlights that the emotional support young carers offer their sick or disabled family member(s) can be the most important and difficult part of their role and one which they feel receives the least amount of support from schools and outside agencies. Providing a key worker as a learning mentor to provide pastoral support may be, thus, a means of maintaining links with the young carer without them feeling potentially overwhelmed by obtrusive and repetitive questioning from multiple members of staff, particularly in high school. Indeed, members of staff asking too many personal questions about young carers' family lives has been highlighted as a concern for young carer participants within this study.

In terms of the main differences between the professionals' viewpoints the two key statements appear to be that, in comparison to factor 2, those in factor 1 agree strongly that young carers regularly have to miss school, and also that young carers are thought to prioritise their caring responsibilities over school. Factor 2, furthermore placed as ‘most agree’ the statement concerning young carers wanting to be treated the same in school as every other pupil. One participant commented, however, that:

> “This has a lot to do with the inclusion paradox. You can’t treat them the same, but still acknowledge they’re a carer” (mpr29dct, factor 1).

This comment raises an important point in that professionals within both factors appear to feel that more should and could be done to support young carers, but the question remains as to how professionals can provide the most appropriate level of support without reinforcing negative stereotypes or singling out young carers as passive recipients of well-meaning but ill-judged interventions (O’Dell et al., 2010), particularly in the light of the discussion above highlighting that young carers are not considered to be listened to, nor asked their opinions by professionals (factor 1).

It is difficult to compare the findings discussed above with previous research, given that no published papers were found in relation to exploring educational psychologists’ or educational staff’s viewpoints about their attitudes and perceptions of young carers. Studies of other children and young people perceived as vulnerable, such as Looked After Children, however, have indicated that teaching staff’s low expectations and adherence to negative stereotypes can be seen to reinforce stigmatization and place barriers to positive outcomes for those young people who want to be seen as ‘normalised’ without being singled out by staff as being ‘different’ (Honey et al., 2011). Whilst to label young carers as ‘vulnerable’ would in itself serve to reinforce stereotypes, it is nonetheless useful to examine research, in the absence of studies specifically related to professionals in education and young carers, in order to examine if any possible parallels may exist. The implications for professional practice in the light of this discussion are reported in section 6.5 below.

6.4 Comparison of Young Carers’ and Professionals’ Viewpoints

The young carers' and professionals' data elicited four and two distinct factors, respectively, within which a range of positive and negative viewpoints were reported and discussed in relation to the social and emotional aspects of caring, the intervention and support processes available to young carers from professionals, and young carers' experiences of education. A qualitative comparison of the shared viewpoints of young carers and the shared viewpoints of professionals involves examining the data in order to explore and extract, in a holistic fashion, any similarities or differences presented therein. Whilst this examination is based upon the data provided in its entirety (statistical and qualitative, including the individual factor arrays, factor descriptions and the comparisons between the factors within each data set), it will also be based, inevitably, upon my subjective responses to that data. Within the context of comparing the two data sets the statistical and qualitative data serve as clues that are open to interpretation. It is possible, therefore, that my own biases and subjectivity may have been influenced by certain categories, statements, questions, ideas or indeed individual comments made by participants. To this end the discussion below is open to scrutiny as it is possible that different interpretations or emphases may exist.

In terms of the social and emotional aspects of caring a particularly strong feature of the young carers' viewpoints is the pride they feel about their caring responsibilities. Equally strong, especially in factors 2 and 4, appears to be their feeling of maturity and of being better skilled in preparation for adult life, with a better understanding of disability and difference, compared to other young people. These aspects, which are clearly important to the young carers, are features of their caring responsibilities which do not appear to be recognised by the professionals in factor 1, in comparison, however. On the other hand factor 1 (professionals) appears to be consistent with the viewpoint of factor 3 (young carers), in that within both there seems to be a greater emphasis upon the negative aspects of the young carer's role, when compared with other viewpoints, such as young carers feeling 'parentified', depressed and isolated. Conversely the viewpoint within factor 2 (professionals) appears to share more in common with the young carers' viewpoints in factors 1, 2 and 4 in reporting more positive features. What is also shared in common is the viewpoint in factor two (young carers), and in factor 2 (professionals), that young carers hate being labelled and prefer, instead, to regard their caring roles as ‘just something they do’.

The two statements relating to young carers having a close family and young carers ‘losing their childhood’ are interesting to examine as in both examples the responses from the young carer participants are more extreme in terms of the range of opinions elicited, in comparison to professionals’. Young carers’ responses, for example, range from +3 to -3 and +4 to -4 respectively, for these statements, whereas within the professionals’ data the responses range from +1 to -1 and 0, respectively. It could be argued, therefore, that these statements elicited a stronger reaction in the young carer participants which may, in turn, imply that they hold greater significance and meaning for them, in comparison to the professionals. For the statement relating to young carers ‘speaking on behalf of the person needing care’, however, it appears that the opposite is the case. In this example the range of responses from the professionals’ viewpoints is -1 to -3, whereas within the young carers it is 0 across all factors.

In relation to intervention and support processes it was reported that the young carer participants appear to hold conflicting viewpoints in respect of their experiences with professionals, given that those within factors 1 and 4 appear to feel more supported in comparison to those in factors 2 and 3. When comparing these viewpoints as a whole to those of the professionals’ it appears that the viewpoints of factor 2 (young carers) and factor 1 (professionals) are broadly similar, in that both express a more negative picture of intervention and support services, in comparison to other factors. Factor 2 (professionals), however, seems to share a similar view to all of the young carers, who do not feel that services should provide the care for their sick or disabled family member(s) in order to relieve them of their caring responsibilities.

It is interesting that most participants (both young carers and professionals) share a broadly similar view on certain statements, such as feeling that professionals lack awareness of young carers’ needs (except for factor 4, young carers) and that young carers do not know what sorts of services are available to them. This suggests that both professionals and young carers are lacking in knowledge and awareness of each other, and implies that a lack of communication between services could be preventing young carers and their families accessing the most appropriate type and level of support.

When comparing the young carers' and professionals' viewpoints in relation to statements about education it appears as if factor 4 (young carers) and factor 2 (professionals) share a similar outlook, in that they portray a largely positive view of the intervention and support processes available to young carers in school. On the whole, however, the variation in responses within both data sets renders the comparison between them difficult in a holistic sense. Some similarities can be highlighted when examining certain statements, however. Factor 3 (young carers) and factor 1 (professionals), for example, share a similar view that young carers have to miss school regularly, and all professionals agree that young carers struggle to find time to study at home, which is consistent with the viewpoints from the young carers in factors 1, 2 and 3. The young carers in factor 3, however, seem unique among all the participants in that they do not want to be treated the same in school as every other pupil, with factors 1, 2 and 4 (young carers) and factors 1 and 2 (professionals) agreeing the opposite case.

6.5 Conclusions: Recommendations and Implications for Professional Practice

The viewpoints expressed by the young carers and professionals in this research are both wide-ranging and at times, contradictory. Whilst this may seem complex in terms of summarising findings and implications for practice it is evident that a 'one size fits all' approach to policy and practice is neither appropriate nor ethical. The challenge for professionals and services, therefore, is how best to develop a shared understanding of young carers and their families' needs so that individual and tailored levels of support can best be put in place. Based upon the results and discussion above it is apparent that the barriers blocking the way to 'best practice' may principally lie in:

- professionals' awareness, knowledge and expectations of young carers
- levels of communication between young carers, their families and services
- effective multi-agency practice

6.5.1 Knowledge and Awareness

At the outset of this research the first obstacle, the finding of participants within schools, highlighted the lack of awareness of school staff as to young carers' existence. Likewise some of the EPs contacted felt that they had not knowingly come across a young carer in the course of their practice. The children and young people 'raised' by school staff with EPs are those who are usually experiencing difficulties in the school environment or in accessing the curriculum, either with perceived learning, social and emotional, or behavioural needs. Young carers, therefore, may not be known to EPs as they could be, as one EP put it: "under the radar" in that staff are not recognising their needs. On the other hand it is also possible that young carers, such as those in factor 4, regard school as part of a supportive and protective system, thus reducing the potential for any difficulties (if apparent) to escalate.

Raising awareness and knowledge with professionals about young carer issues is an important step in developing a shared understanding of what young carers' needs may be and how best to meet them. Recent research has shown the effectiveness of training in raising awareness about young carers among primary care practitioners (Jones et al., 2012, Simon and Slatcher, 2011) with recommendations for practice including allocating a member of staff in health practices to link with young carers and services, posting fliers in waiting areas, and the training of school nurses. Similar training and awareness raising practices would be beneficial for staff within schools, for trainee teachers, as well as educational psychologists, and indeed school governors (OfSted, 2009). Increased awareness and knowledge among professionals would perhaps be improved, also, by the implementation of Joseph et al. (2009) Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) in order to improve understanding of the individual circumstances of each young carer and their family and help target support where it is best needed.

Research by Gray et al. (2008), McAndrew et al. (2012) and OfSted (2009) highlight the possible benefits of awareness raising activities in schools such as implementing a young carer policy; appointing a designated key worker to young carers; developing a 'checklist' for teachers; including young carer issues in assemblies and in the Personal, Social, Health, Citizenship Education

(PSHCE) curriculum, and providing schools with support materials and information training packs. It is not only a question of recognition, however, especially in the light of the discussion above indicating that most young carers do not want to be singled out or treated any differently to other pupils in school. This, in fact, could be seen to be counterproductive and potentially increase feelings of isolation and stigmatisation. Any such awareness raising activities, therefore, must be done sensitively, consulting with young carers and respecting their wishes, particularly with regard to the amount and type of information shared about their personal circumstances. It must be remembered, also, that policies and 'checklists' should not be definitive and rigid, but take account of the individual circumstances, strengths and needs of each young carer. It is thought, that through such awareness programmes and the encouragement of "healthy, open and caring school environments" (OfSted, 2009, p.11), young carers will be encouraged to identify themselves to staff so that the most appropriate support can be put in place.

6.5.2 Communication

> "The dilemma facing policy makers and practitioners is whose evidence, and what kinds of evidence, should be valued the most when it comes to formulating policy or deciding on interventions" (Becker, 2005, p.3).

The results and discussion above indicate that the communication between young carers and professionals is inconsistent, with professionals lacking awareness of young carers' needs and young carers not knowing what sorts of services are available to them. It was noted, however, that where young carers feel listened to, they also feel more supported by professionals (factors 1 and 4).

In terms of intervention and support systems professionals are in a position of power, in that the decision making processes are largely dependent upon their levels of awareness, knowledge and experience, as well as their personal and professional biases. In excluding young carers' voices from this process, by not asking their opinions and by not listening to them within the context of their family dynamic, professionals can make, potentially, decisions based upon partial information thus privileging certain viewpoints over others. As such, professionals may be open to influence from negative perceptions and stereotypes and may make assumptions about parental competence, without taking into account the positive aspects of caring, such as the close family bond, and the maturity, pride and willingness to care that some of the young carers within this study have outlined. This study and previous research (Dearden and Becker, 2000) has also highlighted that the closeness of a family and the support within it is a protective factor and can lead to better outcomes for young carers in terms of their emotional well-being. Young carers should be made aware of their right to an assessment (DoH, Carer (Recognition and Services) Act, 1995) but this should not be carried out in isolation, and, furthermore, should be holistic in nature so that the needs of the family unit are discussed and recognised as a whole, in order to provide ‘wrap around’ support. This is particularly pertinent for young carers in families where there are issues relating to drug and alcohol misuse, and where parents have been identified with mental health difficulties, as these young carers have been seen to be the hardest to identify, and their families the hardest to engage with services (Gray et al., 2008, McAndrew et al., 2012, OfSted, 2009).

6.5.3 Multi-agency Practice

OfSted’s report on young carers (2009) highlighted that a significant barrier to meeting the needs of young carers and their families was that within councils the adults’ services and children’s services were considered as separate agencies, and consequently the needs of the disabled parents (in their study), and those of the young carers, were considered distinct and unrelated. In seven of the eight councils they surveyed, in fact, the joint working practices between multi-agency professionals was considered to be “work in progress” (OfSted, 2009, p.12). The example given by the young carer in section 6.2.2, concerning a social worker ‘blaming everything on health’ shows that services can sometimes be seen to work in isolation, with a lack of information sharing or regard for the practices, policies and protocols of other professionals. Information sharing and closer ‘joined-up practice’, with greater collaboration between adults’ and children’s services, therefore, would serve to improve the way in which assessment and intervention processes are implemented with young carers and their families. This is the ideal, however, but as OfSted (2009) also discovered, a further barrier to ‘best practice’ was considered to be a lack of resources. Since the publication of this report further local authority cuts have taken hold (including the closing of the young carer project mentioned in

Chapter 1.0) and with reduced staffing and a greater workload this poses an even greater challenge to professionals in relation to their practice.

Once a young carer is recognised by professionals, school staff are in an ideal position to help services ‘join up’, especially within systems such as the Common Assessment Framework, and the role of the EP could be useful in co-ordinating these multi-agency meetings as a lead professional. An EP within this context could assist in facilitating a shared understanding of the young carers’ needs in a holistic sense, including the nature of the family dynamic and taking account of the family’s wishes. Consultation and solution focused methods could also be used to reframe any negative perceptions and highlight strengths as well as needs. Given that some EPs may not have knowingly worked with a young carer, however, their role could be useful in training staff (including school nurses) about the psychological aspects of caring, and in eliciting pupils’ voices so that referrals, assessments and interventions are carried out ethically and sensitively with the young carer as an active agent, rather than as a passive recipient.

6.6 Q Methodology as a Research Tool

In section 3.2.1 the criteria and requirements of the methodology needed within this study as a ‘best fit’ were summarised in terms of how best to appropriately address the research questions and be consistent with the aims of the study, as well as with my ontological and epistemological position as a researcher. Part of the decision making process also involved considering the ethical issues relating to working with children and young people who are considered by some to be vulnerable, the potential power dynamic between the participants and myself as a researcher, as well as the issues raised by my former life experiences. The literature has also highlighted the multi-faceted discourses and social constructions surrounding the topic, and the required methodology that would need to be used as a vehicle to bring clarity and structure to a complex social arena.

The use of Q methodology within this study, in my view, has fulfilled these aims and requirements. As an abductive methodology it has allowed me to be exploratory in terms of data collection and analysis, without imposing a priori assumptions, and has given structure and form to a complex and sensitive subject area. The Q sort activity has given participants the opportunity to be active participants in the data gathering and analysis process, as participants have noted that the process of sorting the statements has been a reflective thought provoking, innovative and interactive exercise, and young carer participants were asked to help verify the interpretations of the factors. Most significantly, however, is that Q methodology has given a voice to participants who have been considered to be marginalised and ignored by professionals. As Brown (2006) points out:

> “The methodological task consists of devising procedures that serve to amplify and clarify preferences that have been unintentionally marginalised, as well as reveal those marginalised individuals who hold them, so that the effects of marginalisation can be examined and intentionally added to the social discussion “ (Brown, 2006, p.362).

Furthermore the professional participants in this study have been given the opportunity to register their viewpoints about this subject area for the first time.

Q methodology has allowed the voices of the participants to speak, without being overshadowed by my own, with the minimum amount of researcher influence or bias, and has thus been effective in reducing the power dynamic between researcher and participant.

The data analysis process within Q methodology, also, has meant that a holistic picture of the data is presented, as the entire configuration and pattern of each Q sort is analysed and interpreted, allowing meaningful comparisons to be made within and between viewpoints. At the same time the extracting, analysing and interpreting of factors means that majority viewpoints do not dominate and that minority voices are equally heard, such as factor 3 (young carers) and factor 2 (professionals), as these viewpoints are just as important and relevant to the results and discussion as all the other factors, despite having fewer participants within them.

6.7 Limitations of this Research

After discussing the research findings and the possible implications to professional practice it is apparent that there are a number of limitations relating to this study.

When considering the participant groups, for example, a criticism could be that the young carer participants were those already recognised, referred and identified by either a family member or a professional working in education, social care, or health. As such these young carers could have had potentially skewed viewpoints in terms of their relationships with professionals, the level and nature of professional intervention, or indeed their identification with the term ‘young carer’, particularly as the majority (19 out of 20) were contacted via young carer groups. It could be argued, therefore, that a young person’s willingness to attend such a group (which is a voluntary process) could infer that they both identify, and are comfortable, with the ‘young carer’ label and have experienced a degree of intervention from professionals. This does not indicate the appropriateness or quality of that intervention, however. ‘Hidden’ young carers, on the other hand, may have held completely different viewpoints to those in this study, although, as previously mentioned, the process of finding and liaising with them would have raised significant ethical difficulties, both during and after the research process. Would further support be needed, or indeed wanted by the ‘hidden’ young carers or their families, post-research, for example, and who would assume the power to make that decision? If deemed necessary, what would the nature of that support be? Furthermore, as a researcher, would I be imposing my own assumptions upon the young person by asking them to become a participant in research about ‘young carers’ when, to them, they may simply see themselves as caring for their sick or disabled parent? This has significant implications in terms of a power imbalance. It is interesting, nonetheless, that some of the young carer participants in this study thought that they were ‘hidden’ in school, in that no-one there knew of their caring responsibilities, despite them attending a young carer project.

A further limitation in relation to the young carer participants relates to the exclusionary criteria, insomuch as those participants with a recognised learning difficulty (subject to a statement of special educational need) were not included in the study. I considered that the cognitive and reading demands of the Q sort activity would be potentially too great. In the event no such young carers identified themselves as having additional learning needs. I reflected, however, that I may have been guilty of potentially marginalising any young carers with additional learning needs, who may have wanted to become participants, by excluding them from expressing their viewpoint. This was something I should have been more careful to avoid, especially given the fact that young carers have been seen to have been marginalised in research before (see Chapter

2.0). I should have taken more care to design the Q sort task in order to make it more accessible to all young carers, bearing in mind that the Q set need not be limited to worded statements, especially as this approach has been used successfully in other Q methodology studies (Massey, 2010). This is something I will reflect upon more closely and about which I will be more mindful in the design of future research.

In terms of the professionals in this study a potential limitation is that the participant group was unbalanced, with no representation from social care, nor from doctors or nurses. Despite two social workers initially agreeing to take part in the study, they withdrew due to time commitments and it is unfortunate that they were unable to express their viewpoints. No response was received from doctors or nurses, with the only representation from health professionals being a clinical psychologist, a speech and language therapist and an occupational therapist. As such the professionals' group is made up predominantly of professionals within education and psychology, and it is possible that a more balanced representation across social care and health may have produced different results.

A criticism which can be leveled at Q methodology is that the participants' responses are limited to the range and quality of statements provided at the outset, which in turn could be seen to limit the range of viewpoints expressed. Whilst this could be a valid criticism in general terms, within this study every effort was made to make the concourse as broad as possible, and by asking participants to comment upon what they considered to be missing in terms of the statements (although these were not included in terms of factor analysis) it was hoped that the final Q set would be considered to be as comprehensive and robust as possible. Thorough consultation and advice about the Q set was also sought during the pilot phase. Furthermore, in this study, it has been acknowledged that a Q set can never be 'perfect' in its construction. I consider, for example, that two of the statements were badly worded, in that they contain a negative (2. find that teachers aren't sympathetic towards them and 4. prefer that people in school don't know about their caring responsibilities), although they were worded in this way to maintain the integrity of the comments made by the young carers in the pilot phase. A simpler wording such as "find that teachers are sympathetic", for example, may have made it easier to sort.

6.8 Recommendations for Further Research

In the light of the discussion and analysis of research findings, and of the limitations of this study, further research could perhaps focus exclusively upon the sick or disabled family members being cared for in order to obtain their viewpoints about the roles and responsibilities of those caring for them. This would have to be done sensitively, however, in order to take account of ethical considerations.

Furthermore, research could consider including young carers with additional learning needs. Having reflected upon the limitation of this study in this area, highlighted above, it is possible that professionals may wrongly assume that young carers who are seen to be falling behind, or struggling in school, may be doing so because of their caring responsibilities, thus overlooking any underlying learning difficulties the young people may have. As one professional participant commented: “young carers have their own learning needs” fpr34lmp (worded as a ‘missing statement’, see Appendix x) and in the same way that a young person’s behaviour difficulties in school can be built upon pre-conceived assumptions, it should not be assumed that a young carer’s difficulties in school are exclusively linked to the caring role they undertake.

Finally, it has been identified that there is a dearth of research which examines young carers’ viewpoints retrospectively (see Chapter 2.0). Given that this study has highlighted many strengths of the young carer’s role, in terms of the young carers feeling mature and more equipped for adult life, due to the additional skills they feel they have gained, it may be useful to carry out the Q sort within this study (with the inclusion of the ‘missing statements’ in Appendix x) with young adult former child carers. This would help explore the extent to which their viewpoints are similar to those found in this research.

6.9 Final Reflections

The impetus for this research sprang both from my personal experience and also a need, as a professional, to explore a research area involving participants whose viewpoints appeared to be marginalised and silenced. When I reflect upon the journey this research has taken, using Q methodology as the methodological tool, I have asked myself the extent to which I have succeeded in my aim to empower the young carer participants and the degree to which their voices have been heard? I believe that the use of Q methodology in this study has helped to bring structure and clarity to a complex and multi-faceted arena and has given young carers (and professionals) an opportunity to use an innovative and interactive process (Q sorting) to register their viewpoints in a holistic and comprehensive manner. Is it possible, however, that the focus upon shared viewpoints between the participants may have potentially minimised and diluted the impact of their respective individual voices and experiences? On the other hand, it could be argued that a 'collective voice' should not be regarded as any less 'powerful' than an individual's and may, in fact, have *greater* impact in terms of the potential implications for policy and practice, albeit with less focus upon the narrative details each participant may provide. Although the answers to these questions are open to discussion, I believe that the way in which this study was designed and carried out has helped to reduce the power dynamic between myself as a researcher and the participants, and in so doing has hopefully given the young carers and professionals a feeling that their viewpoints were sought, valued and important.

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8. 0 APPENDICES

Appendix (i):

Glossary of Q Methodology Terms

Q Methodology Term	**Definition**
Concourse	A collection of items about a topic, gathered from a variety of sources
Condition of instruction	The instructions given to each participant (for consistency) prior to starting the Q sort
Correlation (inter-correlation)	**The statistical comparison of one person's Q sort with another person's Q sort to determine the level of similarity or difference**
Crib sheet	A set of questions used to help the process of the interpretation of factors (designed by Simon Watts)
Distribution grid	The grid produces a shape of quasi-normal distribution (bell shaped curve) into which the participants sort the statements
Factor	A viewpoint that can be considered to be part of the same 'family resemblance', represented by participants whose Q sorts are similar
Factor array	The viewpoint of the participants loading onto a factor in relation to the position of all items placed on the grid
Fixed grid/fixed distribution	Where the participants have a forced choice in terms of the position of the statements within the grid
Kurtosis	The shape of the distribution grid in terms of how flat or steep the curve
Operant	Behaviours which can be seen to interact, and have a relationship with the environment
P set	The participants in the study
Q set	The list of statements in the Q sort activity

Q sort	Data which is gathered when participants sort the statements into the distribution grid
Variance	The degree to which a Q sort, factor or study can be said to hold something in common

Appendix (ii):

Confirmation of Ethical Approval

The University Of Sheffield.

Carol Plummer

Dear Carol

Ethical Review Application: Who Cares? Young carers, Professionals and Disability Discourse.

Thank you for your application for ethical review for the above project .The reviewers have now considered this and have agreed that you can go ahead with your research project. Any conditions will be shown on the Reviewers Comments attached.

Yours sincerely

[redacted]

Felicity Gilligan

DEdCPsy Secretary

Appendix (iiia):

Young Carer Participant Information/Consent and Introductory Letter


Dear Young Carer,

Hello, my name is Carol Plummer and I am training to be an educational psychologist, at The University of Sheffield. My training involves learning all about how children and young people think, feel, behave and learn.

What is my research about?

Part of my three year university course is to carry out a research project. I have chosen to research the views of young carers and of the professionals who sometimes work with young carers. My research will aim to hear young carers' views about the things that are important to them, which may be their experiences at school, the people who support them, their family, and the way that professionals deal with them. I will also be asking professionals what their views are about young carers. By asking young carers and professionals what their views are I hope that my research will mean there is a better understanding of young carers and their families, and that professionals will be able to offer support in a way which is useful and helpful.

Why have you been chosen to take part in the research?

You have been chosen to take part in this research because you have been identified by your school or a young carer project as being a young carer. Your views as a young person are very important, and just as important as the adults around you. That is why I would like to hear what you have to say.

You do not have to take part in the research if you don't want to. Before you decide you should read through this letter carefully with your parent and discuss it with them. Your parent has to give their permission for you to take part, and so will the Headteacher of your school, because I'll need to visit you there. If you, your parent, or teacher, have any questions you can ring me or email me, My contact details are at the end of the letter. If you decide you don't want to take part that's ok, and no-one will mind.

What if you want to change your mind?

If you do decide to take part in the research and then change your mind part way through, that's ok too. Your participation is voluntary, which means you can withdraw from the research at any time, without having to give a reason, and no-one will mind or ask you why.

What will you have to do?

You will be asked to complete an activity called a Q sort, which involves reading some statements on cards and placing them on a grid, depending on how much you agree with the statement. The statements will be about young carers and their experiences, for example:

"Being a young carer means I feel more grown up than most of my friends".

If you agreed strongly with this statement you would put it in on one side of the grid, and if you agreed less with this statement you would put it on the other side of the grid. The activity would involve reading about 40 statements a bit like this one.

After that I will ask you a few short questions about the activity and write down some information about you, such as your age and gender. The activity won't have anything to do with school work, and there will be no right or wrong answers. The activity will be all about what *you* think.

How much time will it take?

Altogether the Q sort and follow up questions will take about an hour. I'll come into school to do the activity with you, and your teacher will give you permission to· miss part of your lesson. I will try to come in to school at a time when you're not missing any important learning, such as during assembly.

Will you get anything for taking part?

You won't get any money or any other benefits (such as school merits or rewards) for taking part. I will pay reasonable travel expenses if you need to do your Q sort in a different place other than school, although this is unlikely to happen.

What happens to the information you've given?

All your answers will be confidential. All your responses will be stored safely so that they will not be available for other people to see. You can make up your own codename if you want, so that your name will not be able to be identified by your Q sort or responses to my questions.

The information you give me will be written up in a thesis, stored in the University library and online and may be published, however when I write up the project I will make sure that no participants, their school, or their family will be able to be identified or recognised, as all the information will be anonymised.

Will you be recorded?

No, I won't be making any voice recordings of the Q-sort or follow up activity.

What if you have a complaint?

If you are unhappy about any part of the research and would like to complain about it, you should contact my research tutor. His contact details and my details are listed below.

My research tutor is: Martin Hughes (course tutor, DEdCPsy) Department of Education, University of Sheffield , 388 Glossop Road , Sheffield,510 2JA email: M.J.Hughes@sheffield.ac.uk

My contact details are: home address XXXX

Thanks for taking the time to read this. If you would like to take part in the research, please fill in the consent form and return it to me at my home address above.

Best Wishes,

Carol Plummer (Trainee Educational Psychologist)

Participant Consent Form:

Young Carers and Professionals

Title of Research Project:

Who Cares? Young Carers and Professionals: An exploration, using Q methodology, of young carers’ and professionals' views about young carer roles, responsibilities and experiences.

Name of Researcher:

Mrs Carol Plummer: Trainee Educational Psychologist (Doctor of Educational and Child Psychology, 2009-2012 cohort)

University of Sheffield
388 Glossop Road
Sheffield, 810 2JA
email: M.J.Hughes@sheffield.ac.uk

Participant's Name:

....

Parent/Guardian's Name (if participant is under 18 years of age):

Participant Identification Number/pseudonym for this research project:

……………………………………………………………….

- I confirm that I have read and understood the participant information sheet explaining the above research project and I have had the opportunity to ask questions about the project

I understand that my *participationlmy child's participation* is voluntary and that I am free to withdraw consent at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline

I understand that **my responses/my child's responses* will be kept strictly confidential. I understand that **my/their* name will not be linked with the research materials and will not be identified or identifiable in any writing up or presentations resulting from the research

I agree **to take part/for my child to take part* in the above research project
(~please delete as *appropriate)*

Name of Participant

(or parent/guardian if participant is under 18 years of age)

Signature:…………………………………………………………………………………

Date …………………..

Name of person taking consent

Signature:…………………………………………………………………………………

Date……………………

Appendix (iiib):

Professional Participant Information

Research Project Title: Who Cares? Young Carers and Professionals: An exploration, using Q methodology, of young carers’ and professionals' views about young carer roles, responsibilities and experiences.

Name of Researcher: Mrs Carol Plummer: Trainee Educational Psychologist (Doctor of Educational and Child Psychology, 2009-2012), University of Sheffield.

What is the research about?

Part of my three year doctorate at the University of Sheffield is to carry out a research project. I have chosen to research the views of young carers and of the professionals who sometimes encounter young carers in their work. These professionals may include teachers, education welfare officers, social workers, managers of voluntary groups, educational psychologists, or people who work in health care, such as nurses, occupational therapists or doctors.

My research will aim to hear young carers' views about the things that are important to them, which may be their experiences at school, the people who support them, their family, and the way they engage with professionals during the process of referral and intervention. I will also be asking professionals what their views are of young carers. By asking young carers and professionals their viewpoints I hope that my research will provide a better understanding of young carers and their families, and may help professionals in offering the most appropriate and beneficial levels of support and intervention strategies.

This research has had ethical approval from the Department of Education at The University of Sheffield (see the contact details at the end of the information Sheet).

Why have I been asked to take part?

You have been chosen to take part in this research because you are a professional working within health, social care, the voluntary sector, or education, including educational psychology, and as such you may be likely to encounter young carers in your every day practice. I am interested in your views about young carers, even if you feel you haven't worked directly with a young carer in the past.

Participation in this research is voluntary and before you decide if you would like to take part, please read this information sheet carefully. If you have any questions feel free to contact me (details below). Should you decide to take part you are free to decline to answer any questions, and also you can withdraw from the research without giving a reason, prior notice and without detriment to yourself.

What does the research involve?

You will be asked to complete an activity called a Q sort, which involves reading some statements on cards and placing them on a grid, depending on how much you agree with the statement. The statements will be about young carers and their experiences, for example:

"Being a young carer means I feel more grown up than most of my friends"

If you agreed strongly with this statement you would put it in on one side of the grid, and if you agreed less with this statement you would put it on the other side of the grid. The activity would involve reading about 40 statements similar to the example above. In addition I will ask you a few short follow up questions about the activity and record some information about you, for example your job title and gender.

The Q sort activity and follow up process should take approximately one hour in total. I will visit your place of work, or other venue if you prefer, at a date and time convenient to you.

Will I get anything for taking part?

You will not receive any financial or other benefits for taking part in this research. I will offer, however, reasonable travel expenses should any be incurred in the process of your participation in this research.

What happens to the information I've given?

All data from participants will be confidential, and stored safely so that it will not be accessible to others. To ensure anonymity you will have the opportunity to make up your own pseudonym/codeword so that your name will not be identifiable through your Q-sort or your responses to questions. The information you give me will be written up in a thesis, stored in the University library and online and may be published, however when writing up I will ensure that no participants or their place of work/organisation will be able to be identified or recognised, as all participant information and data will be anonymised.

Will I be recorded?

No recording equipment will be used during the q-sort or follow up process.

What if I have a complaint?

If you are unhappy about any part of the research and would like to complain about it, you should contact my research tutor. His contact details and my details are listed below

Martin Hughes (course tutor, DEdCPsy) Department of Education University of Sheffield 388 Glossop Road Sheffield, S10 2JA telephone:XXXXXXXX	Carol Plummer (researcher) Department of Education University of Sheffield 38 Glossop Road Sheffield, S10 2JA

Appendix (iv):

Q set : List of 50 Statements Used, With Category

key:

- **E = statements relating to education or school-based experience**
- **I & S = statements relating to intervention and support processes**
- **S & E = statements relating to the social and emotional aspects of caring**

St. No	**Statement**	**Category**
1	find that teachers ask too many personal questions about their family	E
2	find that teachers aren't sympathetic towards them	E
3	are best supported in schools when they are linked with one key worker	E
4	prefer that other people in school don't know about their caring responsibilities	E
5	want to be treated the same in school as every other pupil	E
6	need to be given special allowances by teachers for handing in homework	E
7	find that teachers single them out as being different to other pupils	E
8	regularly have to miss school	E
9	are worried that their education is suffering	E
10	think that their caring responsibilities come first, before school	E
11	need someone they can talk to in school about their caring responsibilities	E
12	are bullied in school	E
13	can take part in activities or clubs after school	E
14	struggle to find time to study at home	E
15	are asked their opinions by professionals	I &S
16	find that professionals lack awareness about their needs	I &S
17	are kept informed by doctors and nurses about the medical condition of the person they care for	I&S

18	find that services only offer help to the person needing care in the family	I&S
19	are talked down to like little kids, by doctors and nurses	I&S
20	want social care to get involved with their family	I&S
21	feel they can make plans for their future job or further education	E
22	are listened to by professionals	I&S
23	speak on behalf of the person needing care	S&E
24	know what sorts of services are available to help them	I&S
25	find social workers helpful	I&S
26	find that professionals assume they're not being looked after properly at home	I&S
27	have enough support from their family doctor	I&S
28	need training in safe lifting techniques	I&S
29	are worried that their family will be split up	I&S
30	find that professionals are understanding about parents with a drug or alcohol problem	I&S
31	feel happy about the amount of time they can spend with friends	S&E
32	find they have lost their childhood	S&E
33	come from families with a low income	S&E
34	feel worried about their own health	S&E
35	worry what will happen to them if their sick/disabled parent dies	S&E
36	constantly worry about the person they care for	S&E
37	find that no-one understands what they have to go through	S&E
38	have a more mature outlook on life, compared to other young people	S&E
39	have better life skills to prepare them for adulthood compared to other young people	S&E
40	have a better understanding of difference and disability compared to other young people	S&E
41	hate being called a 'young carer' as they are just a son or daughter helping out	S&E
42	wish that services would provide enough care, so they didn't have to do it	I&S
43	suffer from depression	S&E

44	enjoy getting special attention as a ‘little angel’	S&E
45	have a close family who all look after each other	S&E
46	feel like a parent to the person they care for	S&E
47	are seen as ‘little victims’ on TV and in media	S&E
48	get enough ‘time off’ from their caring responsibilities	S&E
49	feel included in their local community	S&E
50	feel proud of their caring responsibilities	S&E

Appendix (v):

Participant Questionnaire

Name:

Age:

D.O.B:

Young Carer

Who do you care for?

Why do they need care?

Professional

Job title:

What is your level of experience with young carers: lots/some or limited/none

Top Two Statements ……………….. and …………………

Why did you place these as ‘most agree’

Bottom Two Statements ……………….. and …………………

Why did you place these as ‘least agree’

Any Statements Missing?

Thoughts on the experiences of the Q sort Activity Overall?

Appendix (vi):

Data Tags Participant Key

Code	**Meaning**	**Number**
mpr	Male professional (followed by age in numerals)	8
fpr	Female professional (followed by age in numerals)	12
myc	Male young carer (followed by age in numerals)	8
fyc	Female young carer (followed by age in numerals)	12
ewo	Educational Welfare Officer	1
lmp	Learning Mentor (primary school)	2
lms	Learning Mentor (secondary school)	1
slt	Speech and Language Therapist	1
htp	Headteacher (primary school)	1
hts	Headteacher (secondary school)	1
sen	Special Educational Needs Co-ordinator	1
ep1	Educational Psychologist (followed by a numeral to identify different EPs)	7
tep	Trainee Educational Psychologist	1
cvc	Voluntary Youth Worker	1
dct	Disabled Childcare Team	1
clp	Clinical Psychologist	1
ot	Occupational Therapist	1
mbr	Young carer, caring for mum and brother	2
mbs	Young carer, caring for mum and brothers	1
br	Young carer, caring for brother	4
mu	Young carer, caring for mum	6
mda	Young carer, caring for mum and dad	3
dbr	Young carer, caring for dad and brother	1
da	Young carer, caring for dad	3

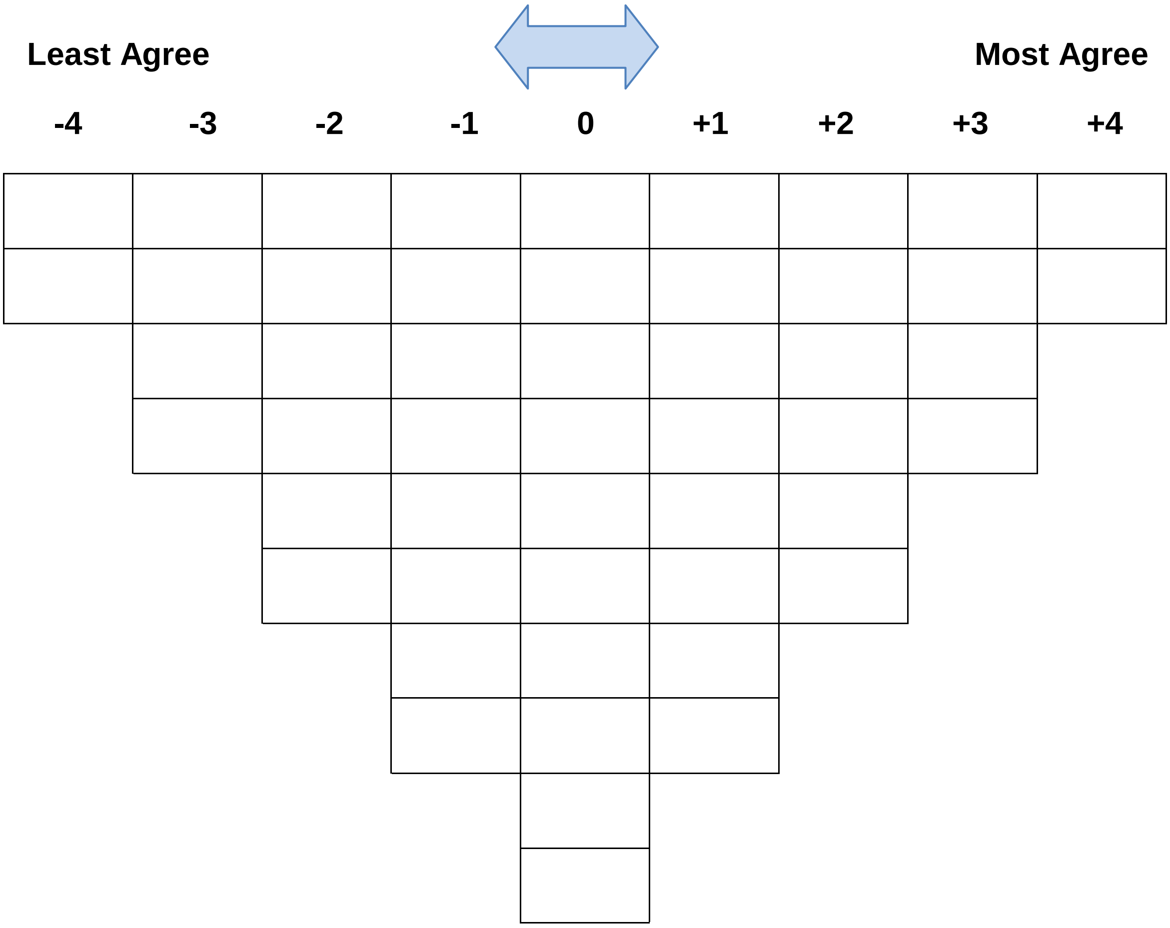
Appendix (vii):

Horizontal Strip Used in the Q Sort Activity

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Place 2 cards here	Place 4 cards here	Place 6 cards here	Place 8 cards here	Place 10 cards here	Place 8 cards here	Place 6 cards here	Place 4 cards here	Place 2 cards here

Appendix (viii):

Quasi-Normal Distribution Q sort Grid



Appendix (ix):

Participants' Experiences Overall on the Q Sort Activity

Participant	**Comment**
mpr41hts	It was hard and thought provoking. A reflective activity. It would work well with my teaching staff. There's so many links across the patterns.
mpr35cvc	I liked it. Really interesting. It was hard to put it into three piles, but then easier to spread out. It focused the mind.
fpr22slt	It was simple enough to do. Quite tricky to think.
mpr29dct	Made me challenge my own perceptions. It's horrible having to narrow it down to just two most agree. Uncomfortable but perversely enjoyable. Quite good to make you think. You can spot the stereotypes. The extremes would stay the same if I did it again.
fpr58sen	Makes you think. It totally depends on the experience of the young person. We're reliant on parents to tell us as other agencies don't refer.
fpr32ewo	Quite good. Makes you realise what they have to contend with. Lots of different categories.
fpr34lmp	Very different and interesting to do. In our local authority it makes me realise our kids have been let down.
fpr48lms	Spot on. Every statement well thought out and useful for the future.
fpr51lmp	Really interesting. Gets you to think. makes me wonder there's stuff going on at home we have no idea about.
fpr55htp	It depends on the child or young person. They don't have the understanding to know what's going on. They all have individual needs. Multi-agency not enough information sharing.
mpr32clp	Different to have a forced choice. I sort of agree with them all. It's what I think, not what I think young carers will think. Enjoyed it. Fun. It doesn't mean you don't have an opinion if you put it in the middle. It's interesting I've chosen the 'worry' ones as most agree. What does that tell me?
fpr41ep1	I wanted to say "it depends" on every statement because each young carer is different and might think different things. It helped me reflect upon and challenge my own assumptions.
mpr39ep2	Thought provoking. I've never knowingly met a young carer. What does that mean? Are they identified? Am I not meeting them because they are well supported, or under the radar. It's made me think.
fpr55ep3	Hard to decide as we question everything as EPs. The visual aids were good. Distribution good, as I don't like yes/no tasks.
fpr29ep4	It's hard. I don't like making decisions. The nature and focus of EPs means we are constantly try to think what a young carer would think. Professionals perceive young carers as vulnerable. Young carers wouldn't want to be perceived like that. These are my views and a young carer may not necessarily agree.
mpr54ep5	It appeared random initially, but now I'm checking it looks better than I thought [the finished Q sort]. Being forced to put it in a grid and a decision helps because when you look at the overall

	shape it articulated it better than you could say.
mpr44ep6	Interesting and a helpful way of looking at things. Our bias as an EP is towards children and young people, naturally. School's threshold to involve social care is much lower than social care's.
mpr30ep7	I tried to put myself in the shoes of a young carer, but then I remembered it was *my* perception. Interesting. I didn't realise how strongly I felt around when people patronise. It makes you think.
fpr46ot	Excellent. Made me think about the young people I've worked with and that it doesn't stop for them. I kept coming back to the sentence opener each time. That helped.
fyc11mbr	Some I weren't sure about. I was thinking lots, especially the ones I don't agree with.
fyc11br	It was really good. Sometimes I'm not like a young carer. I don't worry about it. It's good to let your feelings out.
myc10mu	Nothing. Not too hard. It's alright. I don't know.
myc16mu	Pretty challenging. Hard to decide. It gives me a chance to say what I think.
fyc11br1	It's good. I liked it. Just because some young carers want to be fussed around….I don't.
fyc11br2	It was ok.
myc18mbr	I wanted to have a free grid and not a forced. But that might have been harder to decide in a way.
myc17mu	The extreme ones are easy. Then it got harder to decide what you think.
myc14mda	Some of the words a bit long. Made me think a bit. I were thinking which ones in the middle then it was good being able to move them and change at the end if I wanted.
fyc16mda	It was good. I could tell you what I thought and stuff. There's a big support in the young carer group.
fyc11dbr	It helped. It said, like, opinions. It made me feel good about myself. It's important people ask us what we think. People usually don't do that.
fyc18mu	Made you think. I enjoyed doing it.
fyc17br	If all the young carers had this it would be good. It's good to tell people what you need. It's not a sob story, it's just how it is. I don't like using it as an excuse, like "how disgraceful is that, she's milking it, coz she's got problems. Look at you, you're allowed to be late!".
fyc15mbs	Lots of reading, but ok.
fyc16mu	It were hard to make choices. Lots were important to me.
myc16mda	It was ok.
fyc17da	Don't know. A little hard to decide. Some I believe strongly in. It made me think about what I'm doing and why I'm doing it. I liked that.
fyc16da	It was ok.
myc14mu	I didn't mind doing it. I don't mind talking about me and mum, but most people don't ask.
myc15da	I don't mind. It was good. Everything you've said in the statements make sense.

Appendix (x):

“Anything Missing from the Q Set? Can You Put it Into a Statement in Your Own Words? Where Would You Sort it?”

Participant	**Missing Statement/Comment**	**Sorted In**
mpr41hts	1) Something about guilt and emotional intelligence. **“Young carers feel guilty if they have free time”** 2) **“Young carers are magnets to other students who are experiencing problems of their own”**	+4 +3
mpr35cvc	I’m glad “being listened to” is there. No everything is there I would expect.	n/a
fpr22slt	Nothing I can think of.	n/a
mpr29dct	Nothing missing. These are phrases and statements you see a lot out there	n/a
fpr58sen	Nothing missing. Very comprehensive.	n/a
fpr32ewo	No, nothing.	n/a
fpr34lmp	**“Young carers have their own learning needs”**	+2/+3
fpr48lms	Guilty, always feeling guilty. “Young carers feel guilty if they’re not doing the caring”	+3
fpr51lmp	Nothing. Can’t think of anything that needs to be there.	n/a
mpr32clp	Financial concerns and possible implications if parents aren’t earning. **“Young carers have less money if their parents aren’t working”**	+2
fpr41ep1	**“Young carers’ sick/disabled parents don’t want to be reliant”**	+3
mpr39ep2	Cultural aspects. Nuclear family and comparisons internationally. Different notions of care. **“There’s been a change in the notion of care in the family over time in the UK”.**	+1
fpr55ep3	Advocacy and trust between young carers and support workers. **“Young carers and support workers have a positive relationship as they are their advocates”**	+4
fpr29ep4	**“Young carers are misunderstood”**	+2
mpr54ep5	Something about impact on learning or social/emotional environment in school. **“Young carers have their own mental health or learning needs in school”.**	+2
mpr44ep6	Most things I would have thought of are covered.	n/a
mpr30ep7	What happens if young carers have additional needs themselves, including not having good English? Can’t think how to word that.	n/a
fpr46ot	Something about child protection. **“Young carers have team around the child meetings”**	-4
fyc11mbr	No, nothing really.	n/a
fyc11br	Not sure, don’t think so.	n/a
myc10mu	Nothing.	n/a
myc16mu	**“It’s hard for me to stay on task in lessons because of thinking about what’s going on at home”**	+2
fyc11br1	No, there’s nothing.	n/a

fyc11br2	Nothing.	n/a
myc17mu	Nothing, you’ve covered everything.	n/a
myc14mda	**“Do you think there should be a rota with your brother about how much time you spend caring”**	Don’t know
fyc16mda	No not really.	n/a
fyc11dbr	No.	n/a
fyc18mu	Nothing.	n/a
fyc17br	**“If you’re in a supporting role it’s not about you it’s about them. Supporting my mum and dad is working so hard”**	+2
fyc15mbs	Nothing.	n/a
fyc16mu	Nothing.	n/a
myc16mda	No.	n/a
fyc17da	Don’t know. Don’t think so.	n/a
fyc16da	Nothing.	n/a
myc14mu	No.	n/a
myc15da	Just like being a bit stuck in the house. **“I feel a bit lonely”**	+3

Appendix (xi)

Interpretation Crib Sheet - Young Carers' Data: Factor 1

Top Two Statements (most agree)

50. feel proud of their caring responsibilities +4
14. struggle to find time to study at home +4

Statements sorted higher than other factors

4. prefer that other people in school don't know about their caring responsibilities +2
5. want to be treated the same in school as every other pupil +3
7. find that teachers single them out as being different to other pupils +1
13. can take part in activities or clubs after school +1
17. are kept informed by doctors/nurses about the medical condition of the person they care for +3
20. want social care to get involved with their family +1
22. are listened to by professionals +2
25. find social workers helpful +1
27. have enough support from their family doctor +2
31. feel happy about the amount of time they can spend with friends +3
33. come from families with a low income 0
45. have a close family who all look after each other +3
49. feel included in their local community +2

Statements sorted lower than other factors

2. find that teachers aren't sympathetic towards them -3
18. find that services only offer help to the person needing care in the family -2
26. find that professionals assume they're not being looked after properly at home -1
29. are worried that their family will be split up -3
34. feel worried about their own health -2
37. find that no-one understands what they have to go through 0
38. have a more mature outlook on life, compared to other young people +2
39. have better life skills to prepare them for adulthood compared to other young people +1
40. have a better understanding of difference and disability compared to other young people +1
47. are seen as 'little victims' on TV and in the media -3

Bottom two statements (least agree)

9. are worried that their education is suffering -4
43. suffer from depression -4

Other possible statements of importance

1. find that teachers ask too many personal questions about their family -1
6. need to be given special allowances by teachers for handing in homework -2

8. regularly have to miss school -2
10. think their caring responsibilities come first, before school +1
11. need someone they can talk to in school about their caring responsibilities -1
12. are bullied in school -1
15. are asked their opinions by professionals -1
19. are talked down to like little kids, by doctors and nurses -2
24. know what sort of services are available to help them -1
30. find that professionals are understanding about parents with a drug or alcohol problem +1
32. find they have lost their childhood -3
36. constantly worry about the person they care for +2
41. hate being called a 'young carer' because they're just a son or daughter helping out -2
42. wish that services would provide enough care, so they didn't have to do it 0
46. feel like a parent to the person they care for 0
48. get enough time off from their caring responsibilities 0

Appendix (xii):

Interpretation Crib Sheet - Young Carers' Data: Factor 2

Top Two Statements (most agree)

39. have better life skills to prepare them for adulthood compared to other young people +4
40. have a better understanding of difference and disability compared to other young people +4

Statements sorted higher than other factors

2. find that teachers aren't sympathetic towards them +2
6. need to be given special allowances by teachers for handing in homework +1
10. think their caring responsibilities come first, before school +2
11. need someone they can talk to in school about their caring responsibilities +2
16. find that professionals lack awareness about their needs +1
18. find that services only offer help to the person needing care in the family +3
19. are talked down to like little kids, by doctors and nurses +3
26. find that professionals assume they're not being looked after properly at home +1
29. are worried that their family will be split up +1
37. find that no-one understands what they have to go through +2
41. hate being called a 'young carer' because they're just a son or daughter helping out +2

Statements sorted lower than other factors

1. find that teachers ask too many personal questions about their family -3
4. prefer that other people in school don't know about their caring responsibilities -1
12. are bullied in school -3
13. can take part in activities or clubs after school -2
15. are asked their opinions by professionals -2
17. are kept informed by doctors/nurses about the medical condition of the person they care for -2
22. are listened to by professionals -3
24. know what sort of services are available to help them -2
25. find social workers helpful -2
33. come from families with a low income -3
36. constantly worry about the person they care for 0
46. feel like a parent to the person they care for -2

Bottom two statements (least agree)

30. find that professionals are understanding about parents with a drug or alcohol problem -4
32. find they have lost their childhood -4

Other possible statements of importance

5. want to be treated the same in school as every other pupil +1
7. find that teachers single them out as being different to other pupils -1
8. regularly have to miss school -1
27. have enough support from their family doctor +1
38. have a more mature outlook on life, compared to other young people +3
43. suffer from depression 0
45. have a close family who all look after each other +1
50. feel proud of their caring responsibilities +3

Appendix (xiii)

Interpretation Crib Sheet - Young Carers' Data: Factor 3

Top Two Statements (most agree)

32. find they have lost their childhood +4
14. struggle to find time to study at home +4

Statements sorted higher than other factors

1. find that teachers ask too many personal questions about their family +2
7. find that teachers single them out as being different to other pupils +1
8. regularly have to miss school +2
12. are bullied in school +2
16. find that professionals lack awareness about their needs +1
18. find that services only offer help to the person needing care in the family 0
25. find social workers helpful+1
33. come from families with a low income 0
34. feel worried about their own health 0
35. worry what will happen to them if their sick/disabled parent dies +3
36. constantly worry about the person they care for +3
43. suffer from depression 0
46. feel like a parent to the person they care for +3
47. are seen as 'little victims' on TV and in the media 0

Statements sorted lower than other factors

3. are best supported in school when they are linked with one key worker -2
5. want to be treated the same in school as every other pupil -3
11. need someone they can talk to in school about their caring responsibilities -2
17. are kept informed by doctors/nurses about the medical condition of the person they care for -2
21. feel they can make plans for their future job or further education -1
26. find that professionals assume they're not being looked after properly at home -1
31. feel happy about the amount of time they can spend with friends -3
38. have a more mature outlook on life, compared to other young people +2
39. have better life skills to prepare them for adulthood compared to other young people +1
44. enjoy getting special attention as a 'little angel' -2
45. have a close family who all look after each other -3
48. get enough time off from their caring responsibilities -2
49. feel included in their local community -2
50. feel proud of their caring responsibilities +2

Bottom two statements (least agree)

20. want social care to get involved with their family -4
42. wish that services would provide enough care, so they didn't have to do it -4

Other possible statements of importance

4. prefer that other people in school don't know about their caring responsibilities +1
6. need to be given special allowances by teachers for handing in homework 0
9. are worried that their education is suffering +1
10. think their caring responsibilities come first, before school +1
13. can take part in activities or clubs after school -1
15. are asked their opinions by professionals -1
19. are talked down to like little kids, by doctors and nurses +2
22. are listened to by professionals -1
29. are worried that their family will be split up -1
40. have a better understanding of difference and disability compared to other young people +3
41. hate being called a 'young carer' because they're just a son or daughter helping out -3

Appendix (xiv)

Interpretation Crib Sheet - Young Carers' Data: Factor 4

Top Two Statements (most agree)

38. have a more mature outlook on life, compared to other young people +4
50. feel proud of their caring responsibilities +4

Statements sorted higher than other factors

3. are best supported in school when they are linked with one key worker +1
5. want to be treated the same in school as every other pupil +3
9. are worried that their education is suffering +2
10. think their caring responsibilities come first, before school +2
15. are asked their opinions by professionals 0
21. feel they can make plans for their future job or further education +1
29. are worried that their family will be split up +1
30. find that professionals are understanding about parents with a drug or alcohol problem +2
33. come from families with a low income 0
35. worry what will happen to them if their sick/disabled parent dies +3
36. constantly worry about the person they care for +3
44. enjoy getting special attention as a 'little angel' 0
45. have a close family who all look after each other +3
48. get enough time off from their caring responsibilities +2

Statements sorted lower than other factors

1. find that teachers ask too many personal questions about their family -3
6. need to be given special allowances by teachers for handing in homework -3
8. regularly have to miss school -3
14. struggle to find time to study at home 0
16. find that professionals lack awareness about their needs -1
17. are kept informed by doctors/nurses about the medical condition of the person they care for -2
19. are talked down to like little kids, by doctors and nurses -3
24. know what sort of services are available to help them -2
26. find that professionals assume they're not being looked after properly at home -1
27. have enough support from their family doctor -1
34. feel worried about their own health -2
46. feel like a parent to the person they care for -2

Bottom two statements (least agree)

7. find that teachers single them out as being different to other pupils -4
41. hate being called a 'young carer' because they're just a son or daughter helping out -4

Other possible statements of importance

11. need someone they can talk to in school about their caring responsibilities +1
12. are bullied in school -2
13. can take part in activities or clubs after school 0
22. are listened to by professionals +1
31. feel happy about the amount of time they can spend with friends +1
32. find they have lost their childhood +1
39. have better life skills to prepare them for adulthood compared to other young people +2
40. have a better understanding of difference and disability compared to other young people +2
42. wish that services would provide enough care, so they didn't have to do it -2
43. suffer from depression -1

Appendix (xv):

Interpretation Crib Sheet - Professionals' Data: Factor 1

Top Two Statements (most agree)

29. are worried that their family will be split up +4
36. constantly worry about the person they care for +4

Statements sorted higher than other factors

1. find that teachers ask too many personal questions about their family +1
7. find that teachers single them out as being different to other pupils -1
8. regularly have to miss school +3
10. think their caring responsibilities come first, before school +3
11. need someone they can talk to in school about their caring responsibilities +3
12. are bullied in school 0
18. find that services only offer help to the person needing care in the family +2
19. are talked down to like little kids, by doctors and nurses +1
23. speak on behalf of the person needing care -1
26. find that professionals assume they're not being looked after properly at home +2
28. need training in safe lifting techniques +1
33. come from families with a low income -1
34. feel worried about their own health -1
42. wish that services would provide enough care, so they didn't have to do it +1
43. suffer from depression +1
46. feel like a parent to the person they care for +2

Statements sorted lower than other factors

3. are best supported in school when they are linked with one key worker +2
9. are worried that their education is suffering 0
15. are asked their opinions by professionals -3
16. find that professionals lack awareness about their needs 0
17. are kept informed by doctors/nurses about the medical condition of the person they care for -3
20. want social care to get involved with their family -2
21. feel they can make plans for their future job or further education -1
22. are listened to by professionals -2
24. know what sort of services are available to help them -3
25. find social workers helpful -2
30. find that professionals are understanding about parents with a drug or alcohol problem -2
31. feel happy about the amount of time they can spend with friends -3
38. have a more mature outlook on life, compared to other young people 0
39. have better life skills to prepare them for adulthood compared to other young people +1
40. have a better understanding of difference and disability compared to other young people 0

41. hate being called a 'young carer' because they're just a son or daughter helping out 0
45. have a close family who all look after each other -1
47. are seen as 'little victims' on TV and in the media 0
50. feel proud of their caring responsibilities -1

Bottom two statements (least agree)

13. can take part in activities or clubs after school -4
48. get enough time off from their caring responsibilities -4

Other possible statements of importance

5. want to be treated the same in school as every other pupil +2
6. need to be given special allowances by teachers for handing in homework +1
14. struggle to find time to study at home +2
27. have enough support from their family doctor -1
32. find they have lost their childhood 0
35. worry what will happen to them if their sick/disabled parent dies +3
37. find that no-one understands what they have to go through 0
44. enjoy getting special attention as a 'little angel' -2
49. feel included in their local community -2

Appendix (xvi):

Interpretation Crib Sheet - Professionals' Data: Factor 2

Top Two Statements (most agree)

5. want to be treated the same in school as every other pupil +4
38. have a more mature outlook on life, compared to other young people +4

Statements sorted higher than other factors

3. are best supported in school when they are linked with one key worker +3
9. are worried that their education is suffering +1
15. are asked their opinions by professionals 0
16. find that professionals lack awareness about their needs +1
17. are kept informed by doctors/nurses about the medical condition of the person they care for 0
20. want social care to get involved with their family -1
21. feel they can make plans for their future job or further education +1
22. are listened to by professionals+2
24. know what sort of services are available to help them-1
25. find social workers helpful 0
30. find that professionals are understanding about parents with a drug or alcohol problem -1
31. feel happy about the amount of time they can spend with friends 0
39. have better life skills to prepare them for adulthood compared to other young people +3
40. have a better understanding of difference and disability compared to other young people +2
41. hate being called a 'young carer' because they're just a son or daughter helping out +2
45. have a close family who all look after each other +1
47. are seen as 'little victims' on TV and in the media +1
48. get enough time off from their caring responsibilities 0
50. feel proud of their caring responsibilities +2

Statements sorted lower than other factors

1. find that teachers ask too many personal questions about their family -1
7. find that teachers single them out as being different to other pupils -2
8. regularly have to miss school -1
10. think their caring responsibilities come first, before school 0
11. need someone they can talk to in school about their caring responsibilities +2
12. are bullied in school -1
18. find that services only offer help to the person needing care in the family -3
19. are talked down to like little kids, by doctors and nurses -1
23. speak on behalf of the person needing care -3
26. find that professionals assume they're not being looked after properly at home +1
28. need training in safe lifting techniques -3
29. are worried that their family will be split up 0

33. come from families with a low income -2
34. feel worried about their own health -2
42. wish that services would provide enough care, so they didn't have to do it -2
46. feel like a parent to the person they care for -3

Bottom Two Statements (least agree)

43. suffer from depression -4
44. enjoy getting special attention as a 'little angel' -4

Other possible statements of importance

6. need to be given special allowances by teachers for handing in homework +1
13. can take part in activities or clubs after school -2
14. struggle to find time to study at home +2
27. have enough support from their family doctor -1
35. worry what will happen to them if their sick/disabled parent dies +3
36. constantly worry about the person they care for +3
49. feel included in their local community -2

Appendix (xvii)

Factor Arrays: Factor Q sort values for each statement.

Young Carers' data Factors (F) 1,2,3 and 4.

No.	Statement	F1	F2	F3	F4
1	find that teachers ask too many personal questions about their family	-1	-3	+2	-3
2	find that teachers aren't sympathetic towards them	-3	+2	0	-1
3	are best supported in school when they are linked with one key worker	0	0	-2	+1
4	prefer that other people in school don't know about their caring responsibilities	+2	-1	+1	0
5	want to be treated the same in school as every other pupil	+3	+1	-3	+3
6	need to be given special allowances by teachers for handing in homework	-2	+1	0	-3
7	find that teachers single them out as being different to other pupils	+1	-1	+1	-4
8	regularly have to miss school	-2	-1	+2	-3
9	are worried that their education is suffering	-4	0	+1	+2
10	think their caring responsibilities come first, before school	+1	+2	+1	+2
11	need someone they can talk to in school about their caring responsibilities	-1	+2	-2	+1
12	are bullied in school	-1	-3	+2	-2
13	can take part in activities or clubs after school	+1	-2	-1	0
14	struggle to find time to study at home	+4	+2	+4	0
15	are asked their opinions by professionals	-1	-2	-1	0
16	find that professionals lack awareness about their needs	0	+1	+1	-1
17	are kept informed by doctors/nurses about the medical condition of the person they care for	+3	-2	-2	-2
18	find that services only offer help to the person needing care in the family	-2	+3	0	0
19	are talked down to like little kids, by doctors and nurses	-2	+3	+2	-3
20	want social care to get involved with their family	+1	0	-4	-1
21	feel they can make plans for their future job or further education	0	0	-1	+1
22	are listened to by professionals	+2	-3	-1	+1
23	speak on behalf of the person needing care	0	0	0	0
24	know what sort of services are available to help them	-1	-2	-1	-2
25	find social workers helpful	+1	-2	+1	0
26	find that professionals assume they're not being looked after properly at home	-1	+1	-1	-1
27	have enough support from their family doctor	+2	+1	0	-1
28	need training in safe lifting techniques	-1	-1	-1	-1
29	are worried that their family will be split up	-3	+1	-1	+1
30	find that professionals are understanding about parents with a drug or alcohol problem	+1	-4	0	+2

31	feel happy about the amount of time they can spend with friends	+3	0	-3	+1
32	find they have lost their childhood	-3	-4	+4	+1
33	come from families with a low income	0	-3	0	0
34	feel worried about their own health	-2	-1	0	-2
35	worry what will happen to them if their sick/disabled parent dies	0	+1	+3	+3
36	constantly worry about the person they care for	+2	0	+3	+3
37	find that no-one understands what they have to go through	0	+2	+1	+1
38	have a more mature outlook on life, compared to other young people	+2	+3	+2	+4
39	have better life skills to prepare them for adulthood compared to other young people	+1	+4	+1	+2
40	have a better understanding of difference and disability compared to other young people	+1	+4	+3	+2
41	hate being called a 'young carer' because they're just a son or daughter helping out	-2	+2	-3	-4
42	wish that services would provide enough care, so they didn't have to do it	0	-1	-4	-2
43	suffer from depression	-4	0	0	-1
44	enjoy getting special attention as a 'little angel'	-1	-1	-2	0
45	have a close family who all look after each other	+3	+1	-3	+3
46	feel like a parent to the person they care for	0	-2	+3	-2
47	are seen as 'little victims' on TV and in the media	-3	-1	0	-1
48	get enough time off from their caring responsibilities	0	0	-2	+2
49	feel included in their local community	+2	0	-2	0
50	feel proud of their caring responsibilities	+4	+3	+2	+4

Key
Highest statements in that factor
Lowest statements in that factor

Appendix (xviii):

Factor Arrays: Factor Q sort values for each statement.

Professionals' data Factors (F) 1,2.

No.	Statement	F1	F2
1	find that teachers ask too many personal questions about their family	+1	-1
2	find that teachers aren't sympathetic towards them	0	0
3	are best supported in school when they are linked with one key worker	+2	+3
4	prefer that other people in school don't know about their caring responsibilities	+1	+1
5	want to be treated the same in school as every other pupil	+2	+4
6	need to be given special allowances by teachers for handing in homework	+1	+1
7	find that teachers single them out as being different to other pupils	-1	-2
8	regularly have to miss school	+3	-1
9	are worried that their education is suffering	0	+1
10	think their caring responsibilities come first, before school	+3	0
11	need someone they can talk to in school about their caring responsibilities	+3	+2
12	are bullied in school	0	-1
13	can take part in activities or clubs after school	-4	-2
14	struggle to find time to study at home	+2	+2
15	are asked their opinions by professionals	-3	0
16	find that professionals lack awareness about their needs	0	+1
17	are kept informed by doctors/nurses about the medical condition of the person they care for	-3	0
18	find that services only offer help to the person needing care in the family	+2	-3
19	are talked down to like little kids, by doctors and nurses	+1	-1
20	want social care to get involved with their family	-2	-1
21	feel they can make plans for their future job or further education	-1	+1
22	are listened to by professionals	-2	+2
23	speak on behalf of the person needing care	-1	-3
24	know what sort of services are available to help them	-3	-1
25	find social workers helpful	-2	0
26	find that professionals assume they're not being looked after properly at home	+2	+1
27	have enough support from their family doctor	-1	-1
28	need training in safe lifting techniques	+1	-3
29	are worried that their family will be split up	+4	0
30	find that professionals are understanding about parents with a drug or alcohol problem	-2	-1
31	feel happy about the amount of time they can spend with friends	-3	0
32	find they have lost their childhood	0	0
33	come from families with a low income	-1	-2
34	feel worried about their own health	-1	-2

35	worry what will happen to them if their sick/disabled parent dies	+3	+3
36	constantly worry about the person they care for	+4	+3
37	find that no-one understands what they have to go through	0	0
38	have a more mature outlook on life, compared to other young people	0	+4
39	have better life skills to prepare them for adulthood compared to other young people	+1	+3
40	have a better understanding of difference and disability compared to other young people	0	+2
41	hate being called a 'young carer' because they're just a son or daughter helping out	0	+2
42	wish that services would provide enough care, so they didn't have to do it	+1	-2
43	suffer from depression	+1	-4
44	enjoy getting special attention as a 'little angel'	-2	-4
45	have a close family who all look after each other	-1	+1
46	feel like a parent to the person they care for	+2	-3
47	are seen as 'little victims' on TV and in the media	0	+1
48	get enough time off from their caring responsibilities	-4	0
49	feel included in their local community	-2	-2
50	feel proud of their caring responsibilities	-1	+2

Key
Highest statements in that factor
Lowest statements in that factor

Appendix (xix):

Q Sort Grid: C. Plummer

Least Agree **Most Agree**

-4	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**	**+4**
32	23	15	7	2	1	10	3	36
46	34	17	9	8	4	16	5	38
	42	24	25	12	6	26	21	
	44	30	28	13	11	39	35	
		33	29	18	14	41		
		49	37	19	31	50		
			43	20	40			
			48	22	47			
				27				
				45				