Young carers of stroke survivors

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ABSTRACT

The UK has been at the forefront of young carer research internationally, creating a sound evidence base, influencing policy and developing support for young carers. Studies have consistently found young carers can gain positive attributes and skills from their caring role but that is not always the case. Where there are unmet needs, young carers can experience detriment to their health, well-being and future life chances. Some of the detrimental causes are condition-specific.

Young carers of stroke survivors are not included in national stroke guidance. No UK studies were found of young carers of stroke survivors. There is therefore a significant knowledge gap about existing unmet needs of young carers of stroke survivors and consequent potential to develop support services to mitigate any detrimental effects of caring.

This thesis reports on a series of three studies taking a sequential exploratory mixed design which aimed to begin to address the identified knowledge gap.

The first study comprised a cross-sectional survey of stroke survivors newly discharged home from hospital. 100% of (n=75) respondents identified a need for support with Activities of Daily Living and 75% did not have any paid carers, suggesting a reliance on family and friends for support. Twelve stroke survivors had young carers (n=24), four were primary young carers and three were providing over 20hrs a week of emotional and over 20hrs of practical care. Eight families expressed an interest in participating in the second study.

The second study explored the lived experience of young carers of stroke survivors through semi-structured interviews. Seven stroke survivors and their 11 young

carers were interviewed. Thematic analysis revealed five themes with 14 sub-themes: Impact of stroke, Insulating the family, Children and young carers of stroke survivors, Knowledge information and learning about stroke and Statutory and voluntary sector services for young carers. Findings showed that young carers were providing a range of support including personal care and rehabilitation. The majority did not recognise themselves as young carers and none had been assessed or were in receipt of support. All young carers were happy providing care and most reported enhancing attributes and gaining positive skills from their caring role. Families were working together to protect and support each other but did not know how to talk to each other about their fears and worries, potentially increasing anxiety. Knowledge and understanding of stroke, and access to information for young carers was poor. This was compounded by a lack of engagement with young carers by health and social care professionals and their apparent lack of awareness of young carers' need for information and support. The greatest unmet need for all young carers was for information about stroke and how they could care more effectively.

Experts (commissioners and providers of young carer services) (n=12) were also interviewed to explore the context and challenges for the provision of young carer services. No stroke-specific support services were identified for young carers of stroke survivors. The study found a large variation in the young carer's assessment tools in use and the way they were being implemented to triage young carers for support. This was contributing to inequity in access to services for some young carers. Experts identified challenges in identifying young carers compounded by many factors including the young carers and families not engaging with statutory services either because they were afraid of unwanted interference or were unaware of their rights to assessments and support; complex and variable pathways to assessment and support and a lack of awareness of the existence of young carers by front line health and social care professionals. This was particularly so for stroke.

The final study reviewed and analysed printed and online information for children and young carers of stroke survivors which was compared and synthesized with information for brain injury, Multiple Sclerosis and Parkinson's disease as comparable neurological conditions. An Appreciative Inquiry approach was taken to identify and build upon best practice in information provision for young carers identified from condition specific information for Multiple Sclerosis and Parkinson's disease. A gold standard core information set was generated from the information synthesis.

Conclusion

This PhD provides the first insight into the lives of young carers of stroke survivors. It has started to address the existing knowledge gap by identifying the unmet needs of young carers of stroke survivors. A gold standard core information set has been identified as a potential support mechanism.

Health and social care professionals could play a key role in supporting young carers of stroke survivors, but require support to maximise opportunities to adopt a more robust whole family approach by disseminating information, teaching families about stroke and encouraging openness. This could enhance outcomes for young carers by mitigating potential damaging effects of caring and optimise beneficial aspects of caring.

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Contents

Index of tables

Index of figures

Index of appendices

ABBREVIATIONS

ABI	Acquired Brain Injury
ADASS	Association of Directors of Adult Social Services
ADCS	Association of Directors of Children's Services
ADL	Activities of Daily Living
BI	Brain Injury
CAQDAS	Computer Assisted Qualitative Data Analysis Software
CCG	Clinical Commissioning Groups
CHSS	Chest, Heart and Stroke Scotland
CLAHRC	Collaboration for Leadership and Applied Health Research and Care
DALYs	Disability Adjusted Life Years
ESD	Early Supported Discharge
EHA	Early Help Assessments
EMAHSN	East Midlands Academic Health Science Network
FAE	Finished Admission Episodes
FKGL	FLESCH-Kincaid Grade Level
FRES	FLESCH Reading Ease Score
GP	General Practitioner
HES	Hospital Episode Statistics
MACA	Multi-dimensional Assessment of Caring
MeSH	Medical Subject Headings
MS	Multiple Sclerosis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NICHS	Northern Ireland Chest Heart and Stroke
NSPRG	Nottingham Stroke Research Partnership Group
NUS	National Union of Students

PANOC	Positive and Negative Outcomes of Caring
PD	Parkinson's disease
PEG	Percutaneous Endoscopic Gastrostomy
PhD	Doctor of Philosophy
SCIE	Social Care Institute for Excellence
SMILE	Stroke Making It Less Exhausting
TAF	Team Around the Family
TAC	Team Around the Child
QUAL	Qualitative
QUAN	Quantitative
UK	United Kingdom
UNCRG	United Nations Convention on the Rights of the Child
WHO	World Health Organisation
YCiS	Young Carers in Schools
YPAG	Young People's Advisory Group
YCRG	Young Carer's Research Group
>	Greater than
<	Less than
≤	Less than or equal to
≥	Greater than or equal to

CHAPTER ONE – INTRODUCTION

1.1 Background

Awareness of the role some children and young people play caring for a relative with an illness, long term condition or disability, has been increasing since the mid-1980s (Becker et al, 2000). Despite this, exact numbers of young carers in the United Kingdom (UK) are still unknown. Estimates commonly quoted are between 177,000 (Office for National Statistics, 2011) and 700,000 young carers according to a survey undertaken for the British Broadcasting Company (Howard, 2010).

Caring can provide positive and rewarding experiences for some young people (Dearden & Becker, 2000b). However, that is not always the case and young people with caring responsibilities have also been reported to experience detriment to their health, well-being and development (ADASS et al, 2012; Becker et al, 2000; Cheesbrough et al, 2017a). Whether the experience affects them positively or negatively, it has been identified that the impact of the caring role on their lives is significant and can be life-long (Aldridge & Becker, 1993b; 2003; Becker & Becker, 2008a; Dearden & Becker, 2000b; Evans & Becker, 2009). Much of the literature pertains to generic young carers but some condition specific research has taken place such as for Multiple Sclerosis, Parkinson's disease and Huntingdon's Chorea.

Little is currently known about the specific needs of children and young people who care for family members who are stroke survivors. No UK studies and a minimal amount of literature pertaining to children of stroke survivors has been found internationally. The existing international studies were all based on children of parents in a large study from the Netherlands and were quantitatively focussed. This PhD aimed to start to address that knowledge gap by exploring the

experiences and identifying the needs of young carers of stroke survivors living at home in the East Midlands.

The East Midlands region covers 12 per cent of the total area of England and 6 per cent of the UK. It has a population of 4.4 million. It comprises five counties; Derbyshire, Leicestershire, Lincolnshire, Northamptonshire and Nottinghamshire, and four unitary authorities: Derby, Leicester, Rutland and Nottingham. There are 36 districts contained within the counties in the region (Beaumont, 2009). There were 2238 schools in the region in 2017 (Schoolsnet, 2017). Data on the stroke incidence and prevalence in the East Midlands can be seen in section 1.2.5.2. The East Midlands was chosen for its diverse economy, population and landscape with large rural areas, conurbations and industrialised areas (Beaumont, 2009). It was also a pragmatic decision for a lone researcher with limited resources to restrict the area to a manageable distance for travel and for networking purposes. In addition, there is a model of care in place for survivors of mild to moderate stroke across the East Midlands of Early Supported Discharge (ESD) provided by 14 stroke specific domiciliary care teams employed in eight provider organisations. This model provided a systematic method of engaging stroke survivors and their families at an early stage in their reintegration to the community after stroke.

Most generic young carer studies have recruited participants who were already identified and labelled as young carers, in receipt of support, and potentially had preconceived ideas of what their role comprised and what support they could expect to receive. This PhD aimed to systematically identify via the stroke survivors, young people under 25years who were supporting them in an unpaid capacity as a family member or friend. This was prior to any recognition of their caring role or intervention by statutory services, and consequently before any expectations of the young carers were raised or altered. The purpose was to gain their uncontaminated view of the role they played in supporting the stroke survivor,

the needs the role generated, and what support they felt would benefit them. The perspective of the young people, stroke survivors and experts in the field were garnered to answer the study questions.

The background, context to the thesis, and key definitions from the field of study are introduced in this chapter. The chapter then covers a review of the literature before presenting a summary of the remaining chapters, the research questions, aims and the paradigm within which the study is set.

1.2 Literature

In order to explore the background and context of young carer research, a Literature Review, was undertaken as classified in Grant and Booth's (2009) typology of reviews. The aim was to; examine existing knowledge from research, policy and grey literature, identify potential gaps, and inform the study direction.

1.2.1 Literature Review

Grant & Booth (2009) assert a Literature Review examines published material exploring current and recent literature. Additionally, there will be a process for: identification; selection for inclusion; synthesizing and analysing materials to assess their contribution or value to the field. They suggest criticisms of the method include a lack of clearly articulated intention at the outset to optimise the scope of the review or to analyse the data collected. The consequence of this lack of specificity could lead to bias from omissions of inclusion of relevant texts and/or from lack of critique of the data collected. However, the strength of the method is to allow identification of what has already been accomplished within the field, to consolidate and extend previous work, avoid duplication and identify gaps in the evidence base. For this particular study, little work had been done in the field previously and the exploratory nature of the research required a broad sweep of

the literature to understand the wider context and potential variables that needed to be considered during the PhD. Some of the inherent weaknesses in the method were mitigated by the systematic way in which this particular Literature Review was designed and executed.

1.2.2 Databases searched

The electronic databases; Web of Science, Medline, PsycInfo, SCOPUS, ASSIA, CINAHL, Cochrane database and Campbell Collaboration Library of Systematic Reviews, were searched. Restrictions were; years 1900-2018; language - English. The initial search was limited to peer review journals and subsequently extended to include relevant policy documents and support group websites.

1.2.3 Methods used

Article titles were scanned and abstracts of pertinent titles were read and assessed for relevance. Relevant articles were then obtained as full text. The Ex-Libris facility was used to track source related articles, and reference lists from relevant articles were also scanned for articles which had not been picked up by the literature search. Applicable policy documents were identified from the literature review and additional policy documents identified from the bibliographies. In the same way, support group websites were identified and links followed to source other related documents, websites and text books. Articles were filed in theme folders, using the bibliographic software EndNote v8.

1.2.4 Search terms

Medical Subject Headings (MeSH) terms were automatically exploded and Boolean Operators 'AND' and 'OR' were used to combine search terms such as; young AND carers AND stroke; young AND care*. Search terms were kept deliberately wide to ensure as many articles as possible were captured in the initial search.

The findings from the literature review are presented below starting with a general introduction to stroke, a brief review of the literature pertaining to families and adult carers before focussing on young carers and finally a summary of the very minimal literature pertaining to children of stroke survivors.

1.2.5 Literature findings

1.2.5.1 Stroke

Stroke has been defined as: "*a clinical syndrome, of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 hours or leading to death*" (World Health Organisation, 1978). A stroke occurs when there is sudden interruption in the blood supply to the brain. There are two main types of stroke; ischaemic strokes resulting from a blocked blood vessel cutting off blood supply to the brain, and haemorrhagic stroke caused when a blood vessel bursts within or on the surface of the brain (Stroke Association, 2017 p.6).

1.2.5.2 Stroke incidence and prevalence

More than 80,000 people are admitted to hospital each year in the UK following a stroke (Royal College of Physicians & Sentinel Stroke National Audit Programme, 2016 p.10). Stroke is the third largest contributor to Disability Adjusted Life Years (DALYs) in the UK according to 2013 figures (Global Burden of Disease Study, 2015). Some studies suggest almost two thirds of all stroke survivors leave hospital with some disability as a direct result of the stroke and stroke is responsible for a greater range of disabilities than any other condition (Stroke Association, 2017 p.18).

Reported stroke incidence rates internationally vary due to differences in the methods and criteria used in data collection (King's College London, 2017). In the UK, stroke incidence was reported to have fallen overall in the period 1990-2010 by 19% (Feigin et al, 2014) and also in Europe (King's College London, 2017). Despite this fall, incidence rates are predicted to rise by 34% between 2015 and 2035 due to the increasing ageing population outweighing the fall in age-standardised incidence rates (King's College London, 2017). This is because stroke occurs more commonly over the age of 65 years with 75% of strokes occurring in this age group (Intercollegiate stroke working party, 2016). There is an increased incidence of 25% in the 20-64 year age group reported globally been between 2005 -2014 which may indicate an increasing trend in the younger age group (Feigin et al, 2014; Giroud et al, 2014). There are no data on the number of parents affected by stroke with children and young people under the age of 25 years.

Stroke prevalence is also expected to rise as improved treatment results in decreased mortality rates combined with increased incidence of stroke. Consequently there are currently estimated to be around 1.2 million stroke survivors in the United Kingdom (Stroke Association, 2018) . Of these, over one third will be dependent on others as a result of their disability, and one in five will be looked after by informal carers such as family and friends (Stroke Association, 2015). Other studies suggest this figure is higher and that between 50% (Greenwood et al, 2009b) and 74% (McPherson et al, 2010) of stroke survivors will be dependent on others for support with independent living tasks. One likely reason for this variation in figures is because there is no agreed or standardised definition of what comprises support in this context.

Published figures for stroke incidence and prevalence in the East Midlands also vary due to the differences in data collection, definitions, reporting periods and geographical footprints. Hospital Episode Statistics (HES) data are widely used for

performance data, service modelling and for statutory reporting. HES figures for 2013-14 showed that there were 5895 Finished Admission Episodes (FAE)[1] for stroke in the East Midlands (Health and Social Care Information Centre, 2014). A report reviewing rehabilitation care pathways in the East Midlands produced similar figures for incidence and prevalence (East Midlands Academic Health Science Network, 2015(EMAHSN)) giving confidence around the numbers of stroke episodes in the East Midlands. There are no data for the number of stroke survivors living at home, in the East Midlands (Hollinshead, 2015). Correspondingly, there are no data available on carers in the East Midlands.

1.2.5.3 Informal adult carers

A distinction can be made between caring, which has been described as the emotional component to the welfare of another person, and the behavioural component, which is the care giving: "*Informal caregiving simply refers to activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves*" (Pearlin et al, 1990 p.583).

Informal carers are often described as unpaid and untrained by statutory services, providing physical, social and psychological support to someone who is unable to manage independently. They are usually close family members, such as a spouse, child, or a close friend (Low et al, 1999). Some researchers use the term family carer(s) to describe the same role:

[1] This is episodes of care and not individual patients. One patient may have more than one admission in the month with a primary diagnosis of stroke and counted more than once.

Adults (18 years and over) who-

- *Are relatives, partners, or people who are as close as kin, to the person they care for (including spouses, partners, adult children, siblings, extended family members, or close personal friends); and*
- *Provide or organise the majority of the care to an adult with chronic physical or mental illness(es), who lives at home (with or without their caring relative) and not in a formal care setting* (Burnell et al, 2012 p.4).

For the remainder of this thesis informal carers will be referred to as carers who are unpaid and untrained adult friends or family members and who are ≥ 25 years of age. Carers who are employed either in a voluntary role or paid capacity as formal carers will be referred to as paid carers.

In line with current best practice (National Institute for Health and Clinical Excellence, 2013 (NICE)), stroke survivors in the UK are being discharged home as early as possible in the recovery pathway for rehabilitation and care. An evidence-based model of care has been developed and implemented in the community for people following mild to moderate stroke, to facilitate the earlier discharge and deliver the same dose and intensity of rehabilitation at home as would be received in the acute setting. The model of care is often referred to as Early Supported Discharge (ESD) (Cobley et al, 2013; Langhorne & Baylan, 2017; NICE, 2010). One consequence of the earlier discharge in the absence of social care provision is that more family and friends of all ages are providing the care and support to enable this change to occur.

Evidence suggests the health and well-being of stroke survivors and their adult carers are interrelated. Carers are affected by their caring role both positively and

negatively (Brocklehurst et al, 1981; Forsberg-Warleby et al, 2004; Greenwood et al, 2010; Haley et al, 2009; Han & Haley, 1999; Legg Lynn et al, 2011; Low et al, 1999; Schulz et al, 1988; Wade et al, 1986), as is the care recipient affected by the health and well-being of the carer (Evans et al, 1987b; Evans et al, 1992). The interconnectedness of the stroke survivor and carer relationship make carers an important area of study and adult carers have been the subject of a significant amount of research in long term conditions generally as well as within the field of stroke.

Adverse outcomes commonly reported by carers, in addition to increased rates of anxiety and depression (Stroke Association, 2013), also include a reduction in social activities with associated isolation (Anderson et al, 1995; Stroke Association, 2013). Deterioration in physical health of the carer over time has also been reported (Brocklehurst et al, 1981). This could reflect the age group of adult carers of stroke survivors and a natural decline in health related to previously underlying pre-existing chronic age related conditions such as arthritis (Anderson et al, 1995). Such adverse outcomes are more commonly reported when the stroke survivor has one or more of the following deficits; dementia, behavioural problems, emotional, cognitive impairment or communication difficulties resulting from their stroke (Cameron et al, 2011; Cameron et al, 2014; Forsberg-Warleby et al, 2004; Gillespie & Campbell, 2011). Some studies have demonstrated a link between the degree of physical deficit, particularly in the immediate post-stroke period, and other specific patient characteristics, with their care givers health and well-being (Forsberg-Warleby et al, 2004; Wade et al, 1986). Others have not shown any correlation (Anderson et al, 1995; Hodgson et al, 1996). Inconsistency in findings are possibly due to the complexity of stroke, the vast range of disabilities experienced as a result of stroke and the variability of instruments used to measure different outcome constructs.

Some studies aim to explore positive experiences and benefits of caring for adult carers. However, Bacon (2009) cautions that some of these studies identify positive outcomes as an incidental finding, rather than having approached the study from a positive stance. Additionally, she claims that some studies claiming to be exploring carer well-being, are merely reporting the absence of negative findings rather than truly exploring the lived experience of being a carer from their perspective.

Despite the warning by Bacon et al (2009) mentioned above, some aspects of caregiving have been identified as being associated with positive outcomes for adult caregivers (Bacon et al, 2009; Pearlin et al, 1990). Positive outcomes reported include a sense of fulfilment (Greenwood et al, 2009b), improved interpersonal relations (Greenwood et al, 2009b; Haley et al, 2009), a perception of 'togetherness' (Greenwood et al, 2009b), valuing and feeling good about themselves (Greenwood et al, 2009b; Haley et al, 2009) and taking better care of their own health (Greenwood et al, 2009b). Haley et al (2009) in a study of 75 dyads (pairs) of stroke survivors and their adult carer, found some negative effects of caring, but less so than previously reported studies. They reported many positive benefits of caring including that 90% felt their experience as a carer had increased their appreciation of life, 81% felt caring helped them feel good about themselves and felt strong and confident, and 67% reported that their experience had encouraged them to learn new skills.

The contribution unpaid carers of all ages make in terms of national economic savings is difficult to quantify. One estimate is that unpaid stroke carers contribute £15.8 billion to the UK economy per annum (Patel et al, 2017). There has also been an acknowledgement that the cost to society of replacing unpaid care with funded formal care would be unaffordable within the current economic environment (Beesley, 2006) and therefore it is important to protect and support this valuable resource.

1.2.5.4 The impact of stroke and informal care giving on families

Families are propelled in to the role of caring when one of the family members has a stroke. Caring, which is usually a reciprocal arrangement and part of many relationships, can begin to change into something less balanced and equal when one partner in the relationship becomes ill. This can occur following a stroke, as the stroke survivor may be unable to fulfil their usual roles and obligations. The change from voluntarily caring within a relationship, to one in which the carer takes on the additional caring roles mandated by the deficits imposed by the illness or condition, is not always negotiated. There is almost an expectation that this role transition will occur.

Social support has been strongly associated with lower mortality rates and improved recovery from serious illness, including stroke (Evans et al, 1987b; Glass et al, 2000). Individuals who sustained regular contact with friends and neighbours have been reported as having some protection from depression (Carnwarth & Johnson, 1987). More specifically, it has been postulated that it is particularly important for both the stroke survivor and the carer to sustain family support as other social networks have a tendency to diminish over time (Simon et al, 2009). This can leave carers and stroke survivors feeling increasingly isolated.

Family functioning has been suggested as an important influence on psychological and functional outcomes for stroke survivors (Gillespie & Campbell, 2011) and has been significantly correlated with adherence to rehabilitation regimes and thus contingent outcomes for stroke survivors (Clark & Smith, 1999; Evans et al, 1987b). There is also evidence to suggest that family problems, stress and depression negatively impact on the stroke survivor's psychological state with adverse consequences for their physical recovery (Carnwarth & Johnson, 1987; Evans et al, 1992; Glass et al, 2000).

In addition to the nature of the relationships between stroke survivor and carer having a variable impact on outcomes, the type of deficit in functioning of the stroke survivor following a stroke has also been examined. Physical deficits such as aphasia[2] have been linked to marital problems (Williams & Freer, 1986), family members' health and social functioning (Brocklehurst et al, 1981).

The sudden nature of stroke means that families experience shock and anxiety, widely connected to uncertainty about the future (Gillespie & Campbell, 2011). Apart from the psychological distress which can be experienced by family members, disruption to other aspects of life are reported including but not limited to, social and leisure activities (Anderson et al, 1995; Gillespie & Campbell, 2011), loss of freedom (Greenwood et al, 2010), financial hardship (Anderson et al, 1995; Dorsey & Vaca, 1998; Wade et al, 1986), and sleep deprivation (Wade et al, 1986).

Many studies that purport to be about families actually relate to the spouse or partner rather than the entire family. Studies that do encompass the complete family have produced inconsistent findings with some finding family functioning remains fairly stable following stroke (Evans et al, 1987a), and others identifying changes in family dynamics (Evans et al, 1988). Clark and Smith (1999) found that changes in family functioning occurred in the immediate post stroke period, and remained relatively stable following discharge from rehabilitation. Other studies suggest that stroke affects the quality of life and the well-being of the entire family over long periods of time (Anderson et al, 1995; Bishop & Evans, 1995; Evans et al, 1992). This variation could be explained by the fact that the impact of the stroke on each family member will be dependent on the nature of the relationship between

[2] A partial or total inability to produce and understand speech, caused by brain damage resulting from either injury or disease

them and the recipient of care. For example, a spouse may have a response to changes in intimacy and sexual relationships in addition to the caring role to assimilate, whilst an adult child may have stressors and demands to balance between caring for their own children and maintaining employment. Indeed, Clark and Smith (1999) support this concept as they posit that changes in family functioning are perceived differently by different family members over time. It could also be that the timing of research studies in respect of the stroke survivor's recovery may be critical depending on the research question being asked in any particular study.

A survey undertaken by the Stroke Association (2013) looking at the emotional impact of stroke on survivors, their adult carer's and families, received over 2700 responses. Only one in five respondents had been specifically asked to take on a caring role and assumptions had been made by the health care professionals that the remainder would take on the role of primary carer. This assumption has been conceptualised by Pearlin et al (1990 p.10) as: "*role captivity*". The caregiver experiences a state in which they feel compelled to do things which they do not want to engage in. Role captivity was explored as one variable in a study of 555 informal carers of people with Alzheimer's Disease and was strongly associated with an increased likelihood of the patient being placed into institutional care; adult children felt more captive than spouses; and there was also variation in ethnic groups with white carers experiencing more role captivity than other ethnic groups.

1.2.5.5 Young carers

The concept and recognition of the existence of young carers appears to be growing and becoming more widely accepted (Becker et al, 2000). This has been evidenced by changes to policy and legislation in the UK to protect them and strengthen their rights to assessment of needs and support (Aldridge, 2004; Aldridge et al, 2016a).

Despite this there is still no single agreed definition of a young carer. The resultant ambiguity has been reported to create confusion for professionals, young carers and their families and to contribute to the hiddenness of young carers (Aldridge & Becker, 1993b). It also contributes to inequity of access to support services as providers apply different definitions to their access criteria.

For brevity the term young carer will be used throughout this PhD to describe the children and young people aged under 25 years who participated in the study. Where age is an important or critical factor in the narrative, the term young carer will be used for those aged 0-17years, and young adult carer will be applied to those aged 18-24 years.

1.2.5.5.1 Paradigmatic influence on young carer research

Young carer literature has been reported within three different paradigms (Figure 1) each recognising the role of young carer but focussing on different aspects and having a separate influence on social policy (Becker et al, 1998).

The first paradigm, identified as the medical paradigm originated in the 1950s and focussed on the impact of illness and disability on families, child development and outcomes (Becker et al, 1998). Becker et al (1998) identified four categories of impact of parental illness on children in the medical literature:

- Acquisitional - concerned with the transmission of illness to the child as in hereditary illness such as Huntingdon's Chorea and for parents with mental illness, the transmission of psychopathology.
- Social - refers to social stigma associated with illness and impact on the children and the impact that pitying remarks from well-meaning professionals and members of the public can have.

- Emotional – suggests children experience increased stress and anxiety which is further impacted by the stage of their development.
- Behavioural – in which children adopt a number of different roles as a coping mechanism including caregiver and recluse involving a state of silence self-imposed by children affected by parental illness.

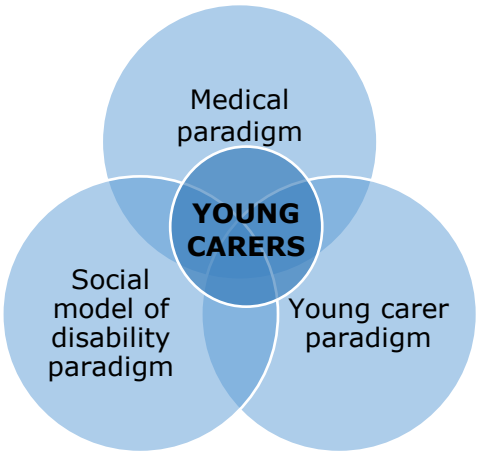
The medical paradigm also recognises children in a care-giving role but focusses on the morbidity of the child taking on the role (Becker et al, 1998). Outcomes such as: "*false maturity*" (Arnaud, 1959 p.18), "*precocious competence*" (O'Neill, 1985 p.260) and "*parentification*" (Byng-Hall, 2008 p.147; Schier et al, 2015) have been described; each one warning of the long-term impact on the mental health and well-being of young carers if the underlying causes are not addressed.

This increasing interest in young carers led in some part to the emergence of the young carer's paradigm in the mid-late 1980s from a growing awareness of the role some of these young people take on as carers and the impact the caring role has on them (Aldridge & Becker, 1999; Becker, 2007; Becker et al, 2000). A response to welfare concerns for children and young people who were caring unsupported was then initiated by key researchers and organisations such as the Carers National Association (Bibby & Becker, 2000) and the Young Carers Research Group (YGRG) at Loughborough University which was established in 1992. These groups plus other key researchers in the field put young carer's research, driven by a children's rights approach, firmly in the academic arena. They also contributed to legislative and policy changes to protect and strengthen young carers' rights.

The third paradigm is labelled the social model of disability and is said to have emerged in the late 1970s (Aldridge, 2008; Becker et al, 1998). This paradigm emphasises the rights and needs of the disabled parent to be supported and

enabled to parent and manage their own independence (Aldridge, 2008). There have been tensions between the young carer's paradigm which advocates recognition of the agency of children and ensuring they have a voice, and that of the disability rights approach favouring the rights of the disabled person. Some researchers espoused that by supporting the disabled parent effectively, the need for children to care would be removed (Keith & Morris, 1995). Further, that by supporting young carers, vital funding was being (mis)directed to young carer services and was actually perpetuating the disablement of parents with a disability (Newman, 2002).

Figure 1 Young carers' paradigms



This dichotomous debate has developed over time with a recognition that both children and their disabled parents are disempowered when children are constructed as young carers and a preference for a family centred approach began to emerge (Olsen, 2000). The contribution that lack of support makes to adverse outcomes for both young carers and parents has also been recognised (Dearden & Becker, 1998b).

1.2.5.5.2 Defining young carers

A review of definitions of young carers from research published since the mid-1980s has revealed a huge diversity in age ranges and dimensions incorporated within the definitions, which have changed over time.

There are several important distinctions to be made in relation to age groups of young carers. Those aged under 18 years are legally children, have legal rights and are protected under specific legislation in the United Kingdom (UK). Those aged 18-25, referred to as young adult carers, also have legal rights in the UK to assessments at transition between adult and child services and access to benefits.

The review of the literature, has revealed the following dimensions are commonly incorporated within definitions of young carers:

Table 1 Dimensions incorporated within definitions for young carers

	Factors
I.	Age ranges specifying the legal definition of children as being under 18 years
II.	Who the cared for person is
III.	Confirmation of lack of financial reward for the care provided
IV.	Roles or tasks undertaken
V.	Place of care
VI.	Reasons for caring; physical or mental illness, alcohol or substance abuse, disability, specific illness or condition
VII.	Frequency of caring
VIII.	Duration of caring
IX.	Extent of caring
X.	Unmet needs of children and families creating the need for the child to care
XI.	Potential for adverse impact of caring on children with respect to their health (which can be physical, mental or emotional health, well-being and transitions into adulthood)

(Adapted and expanded from Cheesbrough et al, 2017a p.14)

In early young carer literature, the terms 'significant' and 'substantial' were often included within the definitions referring to the unpaid support young carers provide (Social Care Institute For Excellence, 2005 (SCIE)). These terms have largely fallen out of favour as they could not be quantified and were applied subjectively within studies.

A further common inclusion is regarding the taking on of roles normally performed by an adult:

> *..Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision* (Becker, 2000 p.378).

In addition, 'excessive' and 'inappropriate' care have been used but again the terms are not clearly delineated and are seldom used in the most recent papers:

> *.. children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances… a young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances* (Hounsell, 2013 p.6).

One definition currently in use by statutory agencies in the UK which incorporates the range of conditions young carers can be providing care for is:

> *A person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work). …this relates to care for any family member who is physically or mentally ill, frail elderly, disabled or misuses alcohol or substances. This …also applies to young adult carers aged up to 25 and the transition from children's services to adult care and support* (ADCS et al, 2015 p.4).

The most recent definition used in a national study commissioned by the Department for Education incorporates the place of care, the range of conditions, and the duration of caring. The definition also implicitly suggests for the first time that caring can be a positive experience by suggesting that adverse impacts of caring are resultant from the family and young carer having unmet needs:

> *A child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol. The care provided by children may be long or short term and, when they (and their families) have unmet needs, caring may have an adverse impact on children's health, well-being and transitions into adulthood* (Cheesbrough et al, 2017a p.14).

Many studies report the lower age range of young carers as being five years old (Cheesbrough et al, 2017a). However, other researchers have reported children aged just three years old (Aldridge & Becker, 1993b; Frank, 1995; Lackey & Gates, 2001). There is minimal literature on young carers at the lower end of the age range.

The heterogeneity within definitions minimises opportunities to make comparisons across different studies. It may also contribute to the variation in the reporting of prevalence data as discussed below, as different studies refer to different groups of young carers.

1.2.5.5.3 Defining young adult carers

The second group of young carers who are of interest in the PhD are referred to as young adult carers:

> *.. people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision* (Becker & Becker, 2008a p.14).

Distinctions have been drawn between children under 18years, and young adult carers aged 18-24 which are separate to the legal and policy implications for children. Young adult carers have been identified as having experiences and needs which are different to the younger age groups (Becker & Dearden, 2004; Hamilton & Adamson, 2013). Needs are related to life stage and transitions to adulthood and independence.

1.2.5.5.4 Needs of young adult carers

This important group of young carers have received little attention in the academic world and the research base remains sparse (Day, 2015; Levine et al, 2005).

Arnett (2000) refers to the period between the ages of 18-25 as emerging adulthood. He conjectures that this period is an important and volatile period in the

life course which is distinct from adolescence and young adulthood. It is characterised by a move away from the dependence of childhood and adolescence, but with a future that has not yet been set in stone. It is a period in which educational and vocational skills are being acquired to equip the emerging adult with the tools and skills they will need in their future lives, and a variety of life directions and views are being explored. He suggests that the scope of exploration at this stage is greater than at any other stage in the person's life course. As such this is a critical phase which if interrupted by caring responsibilities could have life-long ramifications for the emerging adult.

Dearden & Becker (2000b) looked at transitions to adulthood for 60 young adult carers. They concluded that although family structure and the nature of the parental illness or disability played an important part, it was the absence of timely and sufficient family focussed support in conjunction with inadequate finances that were responsible for negative outcomes for young adult carers.

Becker & Becker (2008a) undertook a research study reviewing experiences, needs and service provision for young carers in the UK aged 16-24. The study revealed that many young adult carers had been caring from a very young age. Despite this, many were unaware of help that may be available for their relative, or how to access it. Young adult carers reportedly had increasing demands on their time beyond their caring responsibilities which were generated by education, jobs and personal relationships as they made the transitions to independence and adult life. For those who managed to complete school with adequate or good educational attainment, engaging with higher education was particularly challenging with a lack of support apparent for them at university. Some young adult carers had opted to remain living at home and attend a local university to continue their caring role, others returned home at weekends and holidays to care. Many young adults found moving to independent living very challenging. Some could not envisage leaving

the cared for person to cope, or didn't want younger siblings to have to take on the caring role. Others did manage to leave home but experienced significant feelings of guilt for having done so. Young adult carers also reported many positive outcomes of caring such as gaining maturity, empathy, life skills and experience for future career choices.

The needs of young adult carers are therefore arguably even more complex than for young carers as they deal with the turbulence of adolescence and transitions to adulthood and independence, whilst dealing with the extra roles and responsibilities involved in care provision. Care provision becomes increasingly more socially acceptable and expected once a young person reaches adulthood at the age of 18 (Becker & Becker, 2008a). This group of young people whilst potentially having the greatest need have the least research evidence base to inform the development of support mechanisms.

1.2.5.5.5 Numbers of young carers

Despite the UK being acknowledged as the founding nation of the young carer movement (Stamatopoulos, 2015b), exact numbers of young carers are unknown and there is an ongoing controversy over estimated numbers (Aldridge & Becker, 1993b). Estimating numbers of young carers is hampered by many factors such as a lack of an agreed definition, an absence of a systematic method of identifying young carers and the lack of recognition of many young carers by themselves, their parents and professionals.

The latest census data from 2011 suggests there were 177,918 young carers aged 5–17 years of age in England and Wales, and 54% of these were girls. There were 14,327 young carers aged 5-17 in the East Midlands showing a 13.7 % increase since 2001. There were 15,728 (8.8%) young carers in England and Wales

providing over 50 hours of care a week (Office for National Statistics, 2013). Other studies have suggested that the number of young carers in the UK is nearer 700,000 (Howard, 2010; James, 2017), however, Cheesbrough et al (2017b) reported that the source of that figure is a BBC report, and no peer reviewed published paper could be found to establish how that figure was reached.

The population of interest for this PhD covers a broader age range (5-24 years) than reported above and is focussed on the East Midlands. The 2011 census (Office for National Statistics, 2011) showed that in the East Midlands there were 35,098 young carers aged 5-24 years and of these: 3,758 (10.7%) were providing more than 50 hours a week of care; 83% reported very good or good health; 13% fair; and 4% bad or very bad health. However, some researchers believe that currently published figures based on the 2011 census are an underestimate of true numbers (Barry, 2011; Rose & Cohen, 2010). This is due to variations in definitions used (Bibby & Becker, 2000) and differing study inclusion criteria. Differences include the amount of care being provided and a lack of self-recognition of being a young carer. In addition, the census is completed by parents who may not recognise the caring role or may choose to keep it private. Lack of recognition is attributed to an unwillingness to reveal caring status either by the young person or the person being cared for (Bolas et al, 2007), fear of stigmatisation or discrimination, and fear of being taken in to care (Rose & Cohen, 2010). Particularly for boys, some studies report a fear that the caring role could threaten their emerging masculine identity (Bolas et al, 2007; Rose & Cohen, 2010). Current figures therefore rely on secondary analysis of census data. Prevalence figures, scale and scope of care provided and outcomes for young carers of stroke survivors are unknown as there is currently no method for systematically identifying who and where these young people are, or for identifying their needs.

1.2.5.5.6 Profile of young carers

Young carer profiles have demonstrated a notable degree of consistency over the past 30 years. Young carers are typically reported as having a mean age of 12 years (Alexander, 2014; Dearden & Becker, 1998a; 2004; James, 2017; Nagl-Cupal et al, 2014; Pakenham & Cox, 2015; Social Care Institute For Excellence, 2005). A recent study of young carers for the charity Barnardo's (James, 2017), found that 12% (of 79) young adult carers surveyed had started caring before the age of five years. Census data from 2011 suggest an almost equal gender split for young carers (James, 2017). The majority of studies, with the exception of Pakenham and Cox (2014), report that slightly more young carers are female (Lackey & Gates, 2001; Nagl-Cupal et al, 2014; Stamatopoulos, 2015a). These differences increase with age as females take on more caring responsibilities as they get older (Stamatopoulos, 2015a). Young carers are also associated with lone parent families and low income (Barry, 2011; Becker & Becker, 2008a; Becker, 2008; Dearden & Becker, 2004; James, 2017; Lackey & Gates, 2001). James (2017) suggests the financial deficit is around £5k per year per family. The majority of young carers are caring for single mothers (Aldridge et al, 2016a; Becker, 2008; Dearden & Becker, 1995; Dearden & Becker, 1998b; 2004). Around 50% are caring for someone with a physical disability and 55% for a mental health problem (James, 2017). One in ten young carers are caring for more than one person (Becker, 2008). Young carers have also been found to be more likely than non-carers to have a disability of their own, a long term illness or special educational needs (James, 2017). Aldridge & Becker (1999) caution that not all children living in a household with a disabled or ill parent will become a carer.

1.2.5.5.7 Tasks and time spent caring

Young carers have been reported to undertake a broad range of tasks on a continuum from routine household tasks to nursing, emotional, personal and

intimate care (Chikhradze et al, 2017). Other tasks include translation where English is not a first language, dealing with professionals, financial management and care of siblings (Aldridge et al, 2016a; Becker et al, 1998; Cheesbrough et al, 2017b). In part, caring is a reciprocal part of family life and is to be encouraged to enhance normal development and cultivate good citizenship behaviours (Aldridge & Becker, 1999; Becker et al, 1998). However, the type and degree of caring must be commensurate with age and physical and emotional maturity to optimise beneficial outcomes of caring and limit detrimental effects of caring (Becker et al, 1998; Warren, 2007). The range and magnitude of caring is affected by: the type and severity of illness; the make-up and co-residency of the family; the financial situation; age; gender; and availability of external support (Chikhradze et al, 2017; Warren, 2007).

The amount of time spent caring can be difficult for young carers to assess, as it so embedded in young carers' everyday lives (Cheesbrough et al, 2017a). This is important because some definitions incorporate 'significant' and 'substantial' tasks as a key part. If young carers are unable to identify and quantify the amount of time they spend caring, it renders this already vague and unquantifiable definition of even less utility. James (2017), reported that 27% of young carers did not know how much time they spent caring. Cheesbrough et al (2017a), in a survey of parents and young carers, triangulated results from both sets of interviews to increase the validity of the findings and reported that 14% of children were providing at least 4 hours a day of care which increased to 26% weekends and in school holidays. Therefore, for some young people a large amount of their non-school/work time is committed to caring, leaving little time for friends and leisure activities.

It can also be challenging to assess how much of the time spent on individual tasks directly results from the caring role, and how much would be performed as part of

usual family participation. Becker et al (1998) suggest the domestic tasks and responsibilities taken on by young carers differ from children without caring responsibilities, and further tasks and roles are distinguished by the lack of choice young carers have in taking on the roles. Normal maturation and development processes for children will affect the types and amounts of tasks undertaken by them and expected of them at various stages in their lives. The vast majority of studies do not compare young carers with non-young carers and therefore assumptions about impact of caring based on the amount and type of tasks performed could be flawed, as the impact could be created by the magnitude of the tasks themselves regardless of caring.

Warren (2007) surveyed 378 young people about the nature and amount of tasks undertaken, the level of responsibility the young person assumed for the tasks and their ability to participate in social and leisure activities. Twelve of the participants were known young carers. The purpose of the study was to compare the experiences of carers with non-carers specifically around tasks and leisure time. Whilst there were a number of methodological weaknesses apparent, the study provided some valuable insights into the differences between the two groups. Weaknesses included the recruitment of young people from the vicinity of leisure and school facilities, which would have excluded anyone with significant caring or domestic responsibilities who were unable to participate in leisure activities.
The study reported that young carers took on complete responsibility for a more extensive range of domestic and general tasks than those with no caring responsibilities. They were also less likely to spend time cleaning and maintaining their personal space, giving priority to cleaning and maintenance of the communal areas. The provision of personal and intimate care, and the careful observation of the cared for person's emotional state and identification and provision of appropriate support also distinguished young carers from non-young carers. Young carers were more likely to be prevented from participation in clubs and groups such

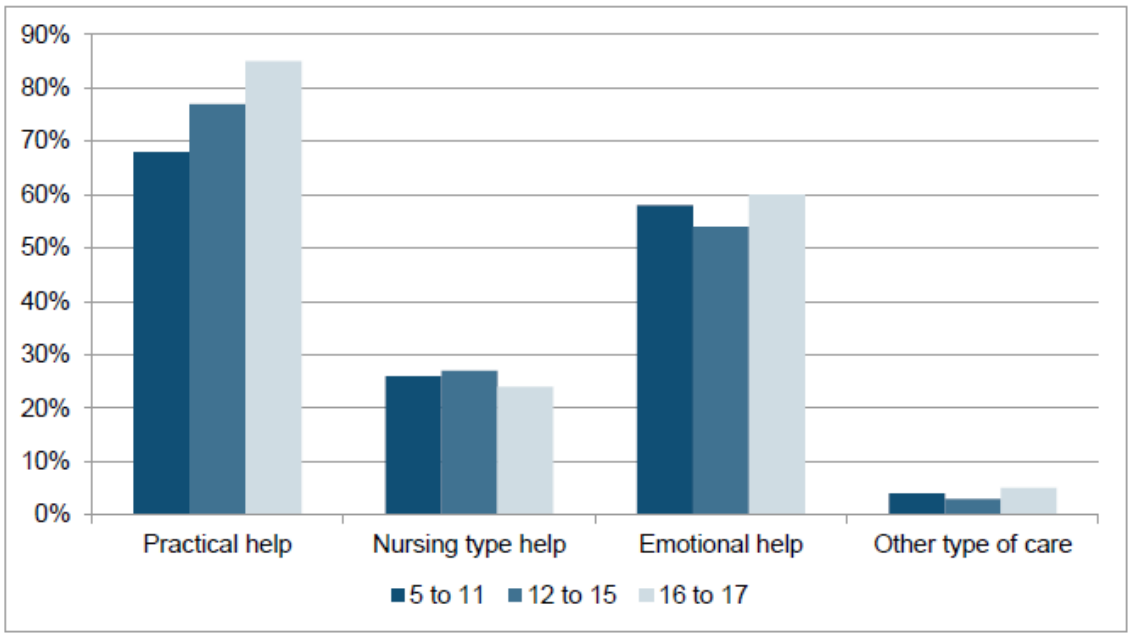
as scouts and guides by their caring responsibilities and were more likely to experience bullying and isolation.

A large scale survey commissioned by the Department for Education also attempted to breach the knowledge gap about differences between young carers and non-carers by employing a sample of parents of young people who did not have caring responsibilities as a comparator group (Cheesbrough et al, 2017a p.28). The young people were also interviewed. On all measures young carers were performing significantly more tasks than a comparator group with no caring responsibilities. The difference was particularly marked for children under 12 years. Practical tasks such as cooking and cleaning were being performed by 78% of young carers, 26% were providing nursing care and 57% were providing emotional support.

Emotional caring is commonly reported (Cheesbrough et al, 2017a; James, 2017) and Becker (2008) drawing from the young carer literature noted that 82% of young carers were providing emotional support and supervision. The composition of emotional support reported in young carer studies is broad and variable, ranging from minor to major interventions. Cheesbrough et al (2017a), include keeping the cared for person company, and trying to cheer them up in the emotional caring category (Figure 2). Whilst at the other end of the scale Aldridge (2006), incorporates critical crisis support for parental episodes of acute mental illness, monitoring and assessing mental health and administering prescribed drugs. Moore et al (2011), suggests that emotional caring alone is sufficient to identify a young person as a young carer, even in the absence of any other caring responsibilities, as it is not something usually expected of a young person. Banks et al (2002b) incorporates children who worry about their parent's illness or addiction as: "*undertaking emotional labour, even if they are not taking on additional caring tasks*" (p.15). Thus when studies report on emotional caring, assumptions cannot

be made about what that comprises and in fact as a very broad category it could be incorporating a number of different constructs under the same heading.

Figure 2 Type of help provided in the home



(Cheesbrough et al, 2017a p.26)

Emotional caring is often reported as being a significant proportion of caring.

The literature would suggest that young carers perform a greater range of tasks and for more of the time than young people without a caring responsibility. They also more likely to assume total responsibility for the tasks they take on. Further, the responsibilities hinder their participation in socialisation in community groups and render them more likely to experience bullying.

1.2.5.5.8 Positive and negative outcomes of caring

Studies of young carers have reported both positive and negative impacts of caring. Positive effects include:

- developing maturity and responsibility
- closer family relationships
- feeling respected by the person they care for

- valued
- feeling appreciated and needed for the caring role
- feeling closer to the person they care for
- learning life skills such as cooking and paying bills
- gaining independence at an earlier than expected age
- increased self-esteem

(Armistead et al, 1995; Bolas et al, 2007; Lackey & Gates, 2001; Rose & Cohen, 2010).

In a study of young carers aged 16-29 years, Heyman and Heyman (2013), found that young carers felt their experiences as a carer had equipped them with skills for potential future roles in caring professions as a career option. They also reported unexpected benefits from attendance at young carer support groups and projects, with opportunities to be involved in political lobbying, fund raising and adventure activities that they would not otherwise have been exposed to (Heyman & Heyman, 2013).

van de Port et al (2007) reported that children of stroke survivors identified many positive outcomes of caring including: feeling more needed (56%); having more responsibilities (72%); feeling more mature (81%); having more time with their parents (24%); and increased positivity from their parents (43%) (p.705). This was a longitudinal study over three years and it was unclear whether the positive outcomes were due to maturation processes or the impact of stroke. The study did not ask about negative outcomes.

In a systematic review of the young carer literature, Chikhradze et al (2017) also found young carers report an increased sense of self-esteem, early maturity, a closer relationship with their parents, and feel well prepared for life. In contrast

they also found negative impacts in relation to physical, psychosocial and educational development (p.2).

Negative impacts have frequently been reported in young carer studies such as:

- increased levels of stress and anxiety
- social isolation
- school absence
- poor educational attainment
- bullying
- being less likely to be in education, employment or training at the age of 19 than young people without caring responsibility (Hounsell, 2013).

1.2.5.5.9 Hiddeness, invisibility and silence of young carers

Silence, hiddenness, and invisibility of young carers have been key concepts reported consistently in many studies situated in the young carers / children's rights paradigm over the past 30 years. The terms are used interchangeably to describe the same findings. For example (Aldridge & Becker, 1993b; Banks et al, 2002a) refer in their studies to a self-imposed silence resulting from young carers not wanting anyone outside of the family to know about their caring role, were afraid of the consequences of telling anyone or just found it difficult to talk about. Frank (1995) and Tatum & Tucker (1998) refer to similar findings but categorise them as hiddenness. It could be argued then that the three are interconnected and could be part of the same construct. Silence contributes to hiddenness and invisibility can either contribute to hiddenness or be a manifestation of it.

Hiddenness appears to result from active or passive behaviours, by young carers, parents and professionals, and can also be a response to societal norms. The concept is so powerful it has generated many titles including, Aldridge and Becker' s

(1993c) study, 'Punishing children for caring: The hidden cost of young carers', through the Children's Society study, 'Hidden from view: The experiences of young carers in England', (Hounsell, 2013), and more recently, 'Still hidden, still ignored. Who cares for young carers' (James, 2017). Silence as a concept also features in titles: 'Silent, invisible and unacknowledged: experiences of young caregivers of single parents diagnosed with multiple sclerosis' (Bjorgvinsdottir & Halldorsdottir, 2014). Silence relates to the reluctance of young carers to reveal and talk about the young carer role and contributes in some cases to their hiddenness. It is usually reported as a conscious decision and action.

Silence has been reported as sometimes being imposed by the parent not allowing the child to discuss their role outside of the family (Aldridge et al, 2016a). However, many studies have also reported that the child / young carer has decided not to reveal their caring role as discussed below (Aldridge & Becker, 1993b). It is possible that hiddenness and silence are constructions created by mutual decision and interactions between parent and child, and that children have more power and are more capable of making their own informed decisions than they are sometimes credited with. Kuczynski et al (1999) suggest that children are far from being passive recipients of one-way discipline and control and consequently becoming products and victims of parental actions which he terms: *"a unilateral model of parent child interactions"* (p.25). Instead, they suggest that parent and child interact together to develop and make changes rather than reacting to each other. They call this: *"a bilateral model of parent child relations"* (p.27). The model proposes that children and parents have equal agency and that children are capable of: *"transforming, selecting from, resisting or judging the appropriateness of parental messages"* (p.27). They also propose that children can select, shape and induce their parent's behaviour such as has been observed in parent infant interactions where babies cry and smile to bring their parent under their control (Bell, 1974). Further, that effectiveness of the child's agency is dependent on their

developmental stage, the responsiveness of parents and external support (Kuczynski, 2003).

Sturges (1977) recognised the difficulties some parents face in communicating their illness with their children and how children in turn maintain a state of silence to protect their parent. She cautioned that the child's fantasies about someone's illness can be worse than the reality. The most recent studies of young carers have identified young carers maintaining a state of silence, and have highlighted the importance of encouraging openness and communication in families to enhance outcomes for children and young people affected by parental illness (Mauseth & Hjalmhult, 2016).

Research has found that young carers conceal their caring role by maintaining a silence for many reasons largely based around fear and mistrust of social workers (Aldridge & Becker, 1993b; 1994; Becker et al, 1998). Frank (1995) found some young carers were embarrassed about their parent's illness and some of the caring tasks. This created a reluctance to bring friends home which hindered the development of friendships, increasing isolation and loneliness, a finding replicated in other studies including Banks et al (2002a). Other reasons for maintaining a silence and remaining hidden included loyalty to the family and feeling responsible for keeping everyone together especially when parents had mental ill health, drug or alcohol addictions (Frank, 1995). Young carers fear intervention by statutory services and separation of the family, because either the young carer or the cared for person could be taken into local authority care (Aldridge & Becker, 1993a). Young carers also fear that peers will have a lack of understanding and empathy for their situation that they will be seen as different leaving them vulnerable and at risk of bullying (Aldridge & Becker, 1993b; Becker & Becker, 2008b). In addition, parents colluded with the concealment or actively encouraged it due to a mistrust

of social workers and fear of separation of the family if they admitted they were struggling (Aldridge et al, 2016a).

Some young carers are hidden because they do not identify with the term young carer. This can either be because they are unaware of the concept of young caring or because they do not relate what they are doing to a caring role. They are simply doing what families do. Young carers who have been identified and labelled by statutory agencies are more likely to relate to the role (James, 2017). Many have been caring for so long they are socialised into the role and do not realise there is a different way of being (Aldridge & Becker, 1993a). In addition, parents do not always recognise their child as a young carer as they do not consider their role to be outside of expected family obligations (Smyth et al, 2011).

Hiddenness is also compounded by the actions and behaviours of some professionals who have reportedly ignored or not recognised children's caring roles (Aldridge & Becker, 2003; Warren, 2007). This applies to health professionals, teachers and social care staff (Thomas et al, 2003). Health care professionals have been reported to focus on the cared for person and ignore the young carer (Thomas et al, 2003). GPs in particular are thought to have more contact with families and awareness of family circumstances, including young carers, than any other health care professional. Despite this, referrals to assessment and support services from this source are extremely rare (James, 2017). Social workers have been reported to focus on children where there are safeguarding issues and otherwise overlook young carers (Banks et al, 2002b). This has been attributed to a lack of knowledge and understanding of the parental condition on young people in the family, a lack of training to enable them to assess and refer young carers on to support services, and increasingly a lack of resources for them to refer them on to (James, 2017). Similarly, some schools were found to be lacking in awareness of young carers and a lack of ability and confidence to identify and refer them (James, 2017).

Hiddenness can also be exacerbated by the nature of the condition of the cared for person. Caring for someone with a physical illness or disability is more visible than a mental health problem or alcohol or drug addiction and is arguably more socially acceptable.

1.2.5.5.10 Pre-determining factors for young caring

The reasons children and young adults take up the mantle of young carer have been variously described and categorised in different ways such as causes that are situational (Becker & Becker, 2008b) and mechanisms that act (Kain, 2009).

Becker et al (1998) propose key causal factors include the nature of the illness or condition; family configuration; gender and co-residence of the young carer and cared for person; status and power; and the type and availability of external support for the young carer and the person they care for (p.22).

Becker & Becker (2008b) expand on these proposals by identifying a range of factors drawn from the historical young carer literature which they propose as situational triggers for young carers to take on unpaid caring roles for family and friends:

- The need for care - is established by the onset of illness or disability and the nature of the illness will define the type of care they provide
- Co-residency - means that the young person is readily available, creating sufficient flexibility to provide care and support in response to changing needs of the cared for person
- Attachment and love - for the person requiring help and support is a reciprocal arrangement and parents retain their parental roles and authority

- Lack of availability of another adult to act as primary carer - as in lone parent families, due to work commitments or a lack of willingness to take on the role
- Religious and cultural norms and expectations – can be powerful influencers
- Increasing age – as young people reach 18 years they are considered adults and caring becomes much more acceptable
- Gender – girls are more likely to take on caring roles but boys will assume the role if there are no female relatives to do so
- Money – low income restricts families' ability to purchase care leading to a greater reliance on children and young adults in the family to provide the support.

Taking a different approach, Kain (2009 p.32) describes three mechanisms by which young carers take on their role: *"Embracing the Challenge"*, in which they observe and are intrigued by adults caring and wish to take on the skills themselves: *"Sharing the Load"*, in which the concern about the negative impact of caring on adult members of the family drives an incentive to remove some of the burden, and: *"Being Assigned"*. The reason some young carers are assigned can be because they become socialised in to the role from a very early age as the gradual incremental increase in roles and responsibilities is so insidious they are unable to remember a time they were not caring (Aldridge & Becker, 1993b). They may also be allocated the role by another family member who is unable or refuses to take on the caring role (Aldridge & Becker, 1994; Becker et al, 1998).

Many of the Becker & Becker (2008b) propositions are supported in many studies including a systematic review of young carer of chronic illness literature (Chikhradze et al, 2017). However, there are also findings in other studies which propose other causal factors such as young carers taking on their roles to preserve the family unit (Metzing-Blau & Schnepp, 2008). Further, that children want to put

the family first and try to hold the family together whilst attempting to maintain everyday life (Chikhradze et al, 2017 p.6). Adolescents have been found to subjugate their own needs to prioritise those of the person they care for as the family's needs assumed a greater priority than their own and this extended to a limitation of their own future plans for further education and leaving home (Mauseth & Hjalmhult, 2016). Other researchers suggest that lack of availability of statutory support for the cared for person also contributes to the young carer taking on the role. It is likely that the reasons young carers take on the role are complex and most likely multifactorial.

Kain's model (Kain, 2009) suggests an element of choice for some young carers whereas the Becker model (Becker et al, 1998) indicates a lack of agency on behalf of the young carers and proposes that they are victims categorised by the circumstances within which they live. This lack of agency is likely to be aggravated by the lack of information young carers are reported to have about their rights to assessment and support and the rights of the person they care for to support. The provision of such information and education could potentially empower young carers to seek out their entitlements to relieve any enforced responsibility and leave them free to decide how much and what type of care they would like to provide (James, 2017).

1.2.5.5.11 Young carer's rights and legislation

The history of children's rights and relevant legislation to support young carers is complex and beyond the remit of this thesis. However, some key Acts are important and will be covered in brief here. Young carer's rights have emerged as a subset of children's rights and in part as a response to a recognition that early adult carer's legislation could not be applied to children (Becker et al, 1998). Young carers are children first but also have additional needs.

The United Nations Convention on the Rights of the Child (UNCRC) (UN General Assembly, 1989) comprises 54 Articles recognising children's rights to participation, prevention, protection and provision. The UK ratified the Convention and were therefore obligated to implement the standards. Becker et al (1998) suggest that at least 13 of these Articles are at risk of being denied to young carers by nature of their caring role. These include:

- The right to access information especially that will promote their well-being, physical and mental health (Article 17)
- For the wishes of the child to be taken in to account, depending on age and maturity (Article 12)
- To enjoy opportunities for leisure and to relax and play (Article 31)
- To education (Article 28 and 29)

There is an obligation for the standards to be implemented but no legal redress if they are not. The Convention applies to all children, unlike The Children Act (1989) which provides a framework for protecting young carers, but only if they are identified as 'children in need' by social services. The status of being a 'child in need' has significant implications for children, their families and social services where ultimately the child can be removed from the family and placed in care. This risk is known and feared by many families and contributes to the unwillingness of many young carers and their families to reveal their caring role (Becker et al, 1998). The Carers Act (1995) provided the right for all young carers to have an assessment of their needs. However, the assessment had to be requested, presupposing the child or family have an awareness of their rights and the way to access them. There was no duty under the Act to provide support.

The most recent legislation Children and Families Act 2014, and the Care Act 2014 (HM Government, 2014b) have strengthened and increased young carer's rights to assessment and support. All young carers under the age of 18 now have a right to

a needs assessment. Local authorities have a duty to take reasonable steps to identify young carers in their area who have support needs. The assessment should consider the young carer's view of the situation and identify whether it is appropriate for a young person to have such responsibilities. The assessment must then decide to what extent the young carer provides or intends to provide 'inappropriate' or 'excessive' care, defined in the Care Act 2014 statutory guidance as, anything which is likely to have an impact on the child's health, wellbeing or education, or which is unsuitable for that particular child. Based on the results of the assessment, the local authority should decide whether to provide services to the child and the family (Children's Commissioner for England, 2016).

1.2.5.6 Impact of parental illness

There is some research to suggest that parental illness without any caring responsibility can impact upon the health, well-being and outcomes for their children. Visser-Meily et al. (2005a) maintains that there is evidence to suggest that parental illness alone is not sufficient to cause psychological problems within the clinical range. However, others have disputed this claiming that there are clear links between serious physical illness in parents and psychological problems in their off spring (Barkmann et al, 2007). Where it does occur, adolescents are most at risk and girls in particular are most at risk of experiencing emotional problems when a parent becomes ill (Korneluk & Lee, 1998; van de Port et al, 2007; Visser-Meily et al, 2005a), particularly the mother (Armistead et al, 1995; Compas et al, 1994). Not all studies have reproduced this finding (Barkmann et al, 2007). Barkmann et al (2007) also claim that risks reduce for boys as they reach puberty. In addition, some studies have shown that there are poorer health, educational outcomes and increased behavioural problems for children and young people where parents have mental health problems and physical health problems than for young

people with healthy parents (Abraham & Aldridge, 2010; Aldridge & Becker, 2003; Aldridge & Sharpe, 2007; Armistead et al, 1995; Barkmann et al, 2007).

A grounded theory study of young carers and their families in Germany, (Metzing-Blau & Schnepp, 2008) revealed two central phenomena which embody the way in which families cope with chronic illness: the first is "*keeping the family together*", which describes how tasks are redistributed to manage everyday life and "*to live a normal course of life*" embodies hope and wishes and expectations of outside help. The two phenomena comprise the "*model of experience and construction of familial care*", in which children take over an active role reconstructing and maintaining family life in the face of increasing impact and dominance of chronic illness (p.4). Children worry about their parents and in fearing separation, the family closes rank and children play an active role in trying to keep the family together. Young carers are constantly on the alert to tasks that are not being fulfilled due to the illness, either on an ad-hoc basis or as a primary carer. The study also found young carers maintain a state of silence to prevent unwanted intervention from statutory agencies and to maintain a sense of normality with their peers. The findings revealed the importance of timely and adequate support for the family and describe how the absence of such support leads to a downward spiral. The family closes ranks further, the children try harder by subordinating their needs in an attempt to maintain and protect the family, leading to negative impacts on the child's development (Metzing-Blau & Schnepp, 2008).

For people who experience stroke, physical and mental health problems in addition to changes in behaviour are all possible outcomes and therefore their young carers have the chance of being exposed to all these risk factors.

1.2.5.7 Instruments and measures

An important component in identifying and supporting young carers are suitable instruments and measures to assess caring and outcomes. Initial research into the lives of young carers has been criticised for being small scale and lacking objective measures of the degree of caring or the psychological or emotional impact on the young carer and their development (Early et al, 2006).

Instruments have been developed to measure specific constructs such as psychological and unmet needs of young people of a parent with cancer; Offspring Cancer Needs Instrument (OCNI) (Patterson et al, 2011) and for siblings; Sibling Cancer Needs Instrument(SCNI)(Patterson et al, 2014). Other studies have used generic instruments such as the Child Behaviour Check List (van de Port et al, 2007; Visser-Meily et al, 2005a; Visser-Meily et al, 2005b) and the Youth Self-Report (van de Port et al, 2007), Child Depression Inventory and Functional Status II (Visser-Meily et al, 2005a). Several studies have attempted to isolate and measure different constructs as outcome measures for young caring, such as perceived stress, benefit finding, personal value of the caring role (Early et al, 2006), perceived social support (Procidano & Heller, 1983), coping style (Frydenberg & Lewis, 1993), psychological distress (Banks, 1983) and observed burden of care (Aldridge & Becker, 1993b). There are no specific measures for assessing outcomes for young carers of stroke survivors.

Ireland & Pakenham (2010) following a review of the extant literature found a number of limitations in measures used to assess young caregiving including lack of information on the development of the measures, a lack of rigour in developing scales, limited age ranges, lack of validity data and only one having internal reliability measures. Further, they criticise the wide array of measures specifically

developed for individual studies inhibiting comparisons across studies and declare a need for the development of a standardised and psychometrically sound measure.

The need to measure more accurately impact of caring and young carer workload, and identify their needs has become increasingly imperative as legislation has been enacted and strengthened to enforce statutory bodies' responsibility to identify, assess and support young carers. Financial constraints on budgets for young carer support services further increase the need to be able to target resources at those in greatest need.

Many tools exist to assess the needs of young carers in relation to their caring responsibilities, some are described in Table 2. However, not all are validated or provide a score from which assessment of level of need for support can be made. Thus, a need for an objective measure of levels and impacts of caring by young carers was identified (Joseph et al, 2009). In response to the gap, the MACA-YC-18 and 42 (Multidimensional Assessment of Caring Activities) and PANOC-YC-20 (Positive and Negative Outcomes of Caring), validated scales for measuring the amount and type of caring and outcomes for young carers aged 8-21years were developed. Both scales are self-report scales; important as parents can underestimate their child's involvement in the home (Early et al, 2006) and children have been shown to perceive their family circumstances differently to their parents (Utting, 2007).

Scores are useful as objective measures of progress towards goals and to provide evidence of positive outcomes for young carer projects to show value for money. Joseph et al (2012) propose the MACA and PANOC as suitable validated measures for the purpose, and caution against generic instruments as not being validated for use with young carers.

Table 2 Screening tools, Instruments and Measures for young carers

MACA-YC-18 and MACA-YC-42 Multidimensional Assessment of Caring Activities	18/42 item self-report measure completed by young carers on a scale of never/some of the time/ a lot of the time. Provides an overall summary of the amount of caring. Six subscales: Domestic tasks; Household management; Personal; Emotional; Sibling; Financial/practical care (Joseph et al, 2012)
PANOC YC-20: Positive and Negative Outcomes of Caring	20-item self-report measure, positive and negative impacts, to provide an index of the subjective cognitive and emotional impacts of caring. Young carers indicate if they do a task: never, some of the time, a lot of the time. (Joseph et al, 2012)
2YC-QST-20: Young carers: Questionnaire and Screening Tool (Identifying and Recognising young carers	A research and screening tool for young carers. Intended to assess their understanding of the condition, the type and amount of caring responsibility and their needs as carers (Young Carers Research Group, 2013).
My Life Now Pizza	Individual assessment and planning tool. There are either 8-18 spokes/pieces of pizza each relating to an aspect of the young carer's life including: Health and body, Money matters, House and home, Safety at home, My parents and family etc. Each item is scored. Scores are plotted on a spider diagram giving a visual representation of need as a basis for discussion and action planning. (Carers Trust, 2013)
Carers star, family star, child star	Various forms of the Outcomes Star exist to measure and support change in key areas such as health, caring role, relationships, feelings, behaviours, education and learning. Different versions include the Carers Star, My Star and the Family Star.(Outcomes Star, 2018)
Signs of safety	A risk assessment tool designed for use in child protection and children in need. Used collaboratively with children / families to focus on strengths, networks and resources families and young carers have available to them and identifying needs and risks (NSPCC, 2013)
Helping hand	Identifies support networks for young carers (Pinterest, 2018)
The blob tree	A range of visual tools to be completed by young carers as an aid to discussing feelings, worries, wishes, hopes. The completed drawings act as a catalyst for discussion identify needs and plan support (Wilson, 2004)
Common assessment framework	A holistic assessment of a child's needs, in the context of the wider family and community (Carers Trust, 2015)
Three houses	The child draws or writes in the house of worries, good things and dreams. The drawings / notes are used to discuss needs, plan support (Stiborova, n.d)
Early help assessment	Based on the common assessment form, assesses the child and family behaviors and needs as an aid to planning and onward referral.
Young carers perceived stress scale (YCPSS)	A five factor, 31 item scale to assess the demands of care giving in young carers taking account of the social and educational context of their caring role (Cassidy & Giles, 2013; Early et al, 2006)
Youth Activities of Care Giving (YACs)	Multi-item scale of care giving tasks for 10-24 yr. olds. Four factors are measured; instrumental, social-emotional, personal-intimate and domestic - household (Pakenham & Cox, 2012)

The final category of instruments are those used by social services such as the Carers Star and Signs of Safety as described in Table 2. These do not provide scores but rather provide a mechanism to open dialogue and plan services.

1.2.5.8 Children of stroke survivors

Four published studies related to children of stroke survivors were found. All four studies were based on cohorts of children taken from the same large-scale multi-centre study of stroke survivors in the Netherlands called the Functional Prognosis after Stroke (FuPro-Stroke) Study.

Visser-Meily et al (2005a), assessed 77 children aged under 18years of parents in the Fu-Pro-Stroke study at the start of the parent's rehabilitation and again two months after the parent's discharge. Instruments to measure behavioural problems, depression and health status were applied. The study also reviewed which children received support from the rehabilitation team during the inpatient stay. Support was a self-report by the children and comprised:

- one or more consultations with the rehabilitation specialist
- and/or the social worker
- and/or attending one or more (of the parent's) full-day therapies, thus spending more time with the parent.

Half of the children received at least one type of support. Support was related to the severity of the parent's stroke and not to the child's health or behavioural status. No difference in outcomes were noted for children receiving support. However, none of the support seemed to be tailored to the child and appeared to be ad hoc. The different types of support were not analysed and therefore little can be concluded about the support as each type measured seemed to be a completely different construct. Unsurprisingly, no relationship was found to the patient's

characteristic or to any support that half the children received from the rehabilitation team. Children's adjustment was related to stress of the well parent.

Visser-Meily et al (2005b) undertook a longitudinal study over the first year of 82 children aged four -18 years, with parents who were also participating in the FuPro-Stroke study. The same tests were used at the same time frames as the Visser-Meily et al (2005a) study with the addition of a follow up at one year. The identical figures of 54% of children with clinical or subclinical depression at the first assessment were reported and therefore it is likely that these two studies are reporting on the same cohort of children. Depression reduced to 29% at the end of the first year suggesting that mental health improved over the first year. The child's mental health was significantly positively correlated to the mental health of the non-affected parent.

van de Port et al (2007) assessed 44 children aged 10-21 years from 29 families at four time points: "*as soon as possible after informed consent had been given*" (p. 704), two months post discharge from rehabilitation centre, one and three years after stroke. Children were assessed for behavioural problems and stress, were asked if they assisted the stroke survivor with activities of daily living (ADL) and asked if they experienced positive changes in their relationship with their parent due to their stroke. Tasks and changes in relationship were presented as forced choice yes or no answers with only positive outcomes offered. The methods for identifying the tasks and relationship changes that were included were not described. The study was unusual being longitudinal as very few young carer studies have followed children up over time. There were no qualitative data included in the study.

The authors concluded that stress scores were significantly higher in girls, which has been reported in other studies but were not related to care giving tasks. Stress

was related to depressive symptoms, poorer functional status and lower life satisfaction scores in the stroke affected parent. All children performed some household tasks and 66% assisted parents with ADL. Positive outcomes reported at 3 years were (p. 705):

- Feeling more needed 56%
- More responsibility 72%
- More mature 81%
- Parents spending more time with them 24%
- Parents more positive 43%

Sieh et al (2010) also assessed 44 children from 29 families at the same time points as the van de Port et al (2007) study. The study reported that patient's depressive symptoms at each time point were positively correlated with stress in the child. Decreased quality of the marital relationship was also related to child stress as was the spouse's depressive symptoms in the first year. Girls experienced more stress than boys.

All four longitudinal studies were taken from the same cohort of patients from the FuPro-Stroke study. The two Visser-Meily studies (2005a and 2005b) reported child adjustment was related to the well-being of the unaffected parent in the first year. The van de Port et al (2007) study and the Sieh et al (2010) study measured stress as an outcome for children at three years. The Sieh study showed stress was related to the well-being of both parents but the van de Port study showed stress was not related to the unaffected parent.
The difference was explained by the small sample size, and different outcome measures used.

1.2.6 Conclusions from the literature

There is a large volume of generic and condition specific literature exploring the lives of young carers from long term conditions and disabilities which suggests that young carers experience many benefits and positive outcomes from their caring role. However, detrimental effects can also be experienced if young carers or their families have unmet needs. Young carers of stroke survivors are an under-researched subset of young carers.

Only four studies were identified internationally looking at children of stroke survivors. All four studies drew from the same cohort of patients in the large scale FuPro-Stroke multicentre study in the Netherlands. One of the studies looked at tasks completed by children of the stroke survivors but responses were forced choice yes or no answers and there were no qualitative or exploratory aspects to any of the studies. The heterogeneous and small scale nature of the studies, lack of consistency in definitions, concepts and constructs being measured do not allow for any comparisons or conclusions to be drawn from the literature.

Despite the UK being recognised as the world leader in young carer research, which has contributed to changes in policy and practice to improve the identification and support for young carers, some challenging problems remain. These include the continued hiddenness, invisibility and silence of many young carers.

Contributory factors to the hiddenness include deliberate actions on behalf of some young carers and their families driven by fear and embarrassment, or a lack of awareness of their own status as a young carer and the associated rights to assessment and support. The lack of agreed definitions for young carers also causes confusion for young carers, families and services providers and contributes to some young carers being overlooked. Professionals from health, social care and

education often ignore young carers and the opportunities they have to educate and support families holistically. This is driven by many factors including lack of awareness, training and knowledge of young carers and support services to refer them on to.

The situation for young adult carers is even more challenging as age specific support services are rare and provision tends to be with adult services and a much older average age group of peers.

No existing research looking at the needs of young carers of stroke survivors in the UK was identified. There are no systems in place to capture accurate data on prevalence, or to systematically identify young carers, and assess their needs. This PhD therefore aimed to start to fill the knowledge gap identified in the literature.

1.3 Study methodology

It is important that the philosophical assumptions underlying the study are clarified at the study outset in order to decide how to formulate the research questions and seek information to answer them.

A sequential mixed design (Teddlie & Tashakkori, 2009 p.26), was selected for the overall PhD to investigate this new and minimally exposed area of study of young carers of stroke survivors. Teddlie & Tashakkori (2009) define sequential mixed design as:

> *a family of MM [mixed methods] designs in which mixing occurs across chronological phases (QUAL [qualitative], QUAN [quantitative]) and of the study; questions or procedures of one strand emerge from or are dependent on the previous strand; research questions are built upon one another and may evolve as the study unfolds* (p.344 abbreviations in original)

This was deemed appropriate as little was known about the field, and the best way to identify and engage young carers in the research was not apparent at the PhD outset. It was also unclear what might emerge from the study in terms of priority for deeper exploration and contingent research questions.

1.3.1 Philosophical assumptions

In order to frame the overall study a paradigm must be chosen (Creswell & Poth, 2017 p.19). The paradigm, also referred to as the world view, comprises: the nature of reality or ontology; how we gain knowledge of what we know (epistemology); the role researcher values play in the research (axiology); the methodology which is the process of the research; and the language or rhetoric (Creswell & Plano Clark, 2011). In determining the paradigm within which this study would sit, a bottom up approach was taken such that development of the research question held primacy. The methods, methodology and theoretical perspective were then explored to identify the best fit for answering the study question. This process suggested a mixed method approach would be apposite to enhance understanding of the scale, scope and lived experiences of young carers, from the perspective of both carer and cared for. In addition, the values of the researcher required that the voice of children and young people who are supporting stroke survivors was heard and that the study would produce findings which could be utilised in the real world to support young carers in the future. The paradigm chosen as best suited to answer this question, fit the values of the researcher and to the mixed-method methodology was pragmatism (Burke Johnson et al, 2007; Creswell & Plano Clark, 2011; Creswell & Poth, 2017; Tashakkori & Teddlie, 2003; Teddlie & Tashakkori, 2009). The traditional dichotomy between Positivism and Constructivism is abandoned in favour of this alternative paradigm. Within this paradigm the focus is on the primary importance of the question asked rather than the methods, and multiple methods are used to collect data to answer the research

questions. It is therefore pluralistic, concerned with what works, real world practice and values both objective and subjective knowledge (Creswell & Plano Clark, 2011).

A mixed methods approach has been described as the "*third methodological movement*" (Teddlie & Tashakkori, 2011 p.285). Melding both qualitative and quantitative methods and data in a research study is deemed to neutralise the inherent bias and weakness present in different data collection methods (Creswell, 2014). Teddlie & Tashakkori (2011) succinctly capture the essence of mixed methods research in their definition:

> *Our definition of methodological eclecticism goes beyond combining qualitative (QUAL) and quantitative (QUAN) methods to cancel out respective weakness.* ***Eclectic,*** *the root of work of eclecticism, means choosing what appears to be best from diverse sources, systems or styles. For us* ***methodological eclecticism*** *involves* ***selecting and then synergistically integrating the most appropriate techniques from a myriad of QUAL, QUAN and mixed methods*** *in order to more thoroughly investigate a phenomenon of interest. A researcher employing methodological eclecticism is a* ***connoisseur of methods*** *who knowledgeably (and often intuitively) selects the best techniques available to answer research questions that frequently evolve during the course of the investigation* (p. 286. Bold italics highlighted in the original).

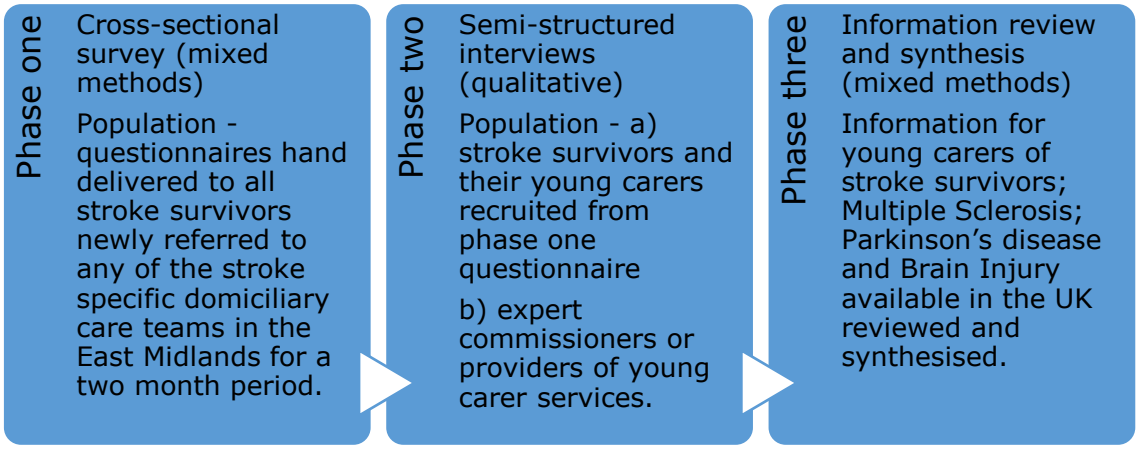
The philosophical assumptions and methodology for each phase will be discussed in more detail in the relevant chapters as each phase required a different approach to answer the specific study questions posed. Creswell & Plano Clark (2011) describe how multiple paradigms can be used in a mixed method study to relate to the procedures chosen for each phase. Some methods are wedded to particular paradigms such as a structured survey being aligned within the positivist paradigm beginning with specific variables that are empirically measured and observed. Other

methods such as semi-structured interviews seek to construct meaning from the perspective of the participant and as such would sit with in an interpretivist constructionist world view. Thus in order to explore the topic of young carers of stroke survivors different paradigms are required for each new phase seeking to explore the lives of young carers from differing perspectives.

1.3.2 PhD structure

The overall PhD comprised three study phases of the sequential design (Figure 3)

Figure 3 Diagram of the three phases of the PhD



1.4 Personal reflections

During the course of this study I developed insights into my own past which in the interest of openness, transparency and good practice for this type of research I declare here. I was a carer for my two younger siblings and was not aware this was the case until I began to immerse myself in the literature. Like so many young carers, including those interviewed in the course of this study, I believed what I was doing was a normal part of family life and indeed the juxtaposition of young caring and normal fraternal responsibilities are hard to separate. The issue must therefore be whether the caring role causes harm or inhibits the future

opportunities for the young person concerned and whether those aspects of the caring role can be mitigated and the full benefits of caring can be exploited.

I can see with the benefit of hindsight that my life path and choices follow a typical path often described as being carved out for young carers in the career choices made and returning to the caring role again and again throughout the life course. The conundrum potentially is aligned to the nature versus nurture debates and whether personality type predisposes one to be open to taking up the caring role or whether the caring role steers one towards a life of caring and associated career choices; in my case as a nurse. This enigma is beyond the scope of this study however, identifying the potential benefits of caring for future exploitation and isolating potential detrimental effects which could be potentially mitigated against were a strong intention at the study outset.

1.5 Study Aims and Questions

The purpose of this PhD was to start to address the knowledge gap of young carers of stroke survivors by building solid foundations in our understanding of the needs of young carers of stroke survivors.

The aim was to investigate the experiences of young carers (aged under 25 years) of stroke survivors who are providing care in an unpaid capacity to relatives or friends who are living at home in the East Midlands after having a stroke.

The main questions to be answered in the thesis were:

1. Are there young carers of stroke survivors living in the East Midlands?
2. What are the barriers and facilitators to the identification of young carers of stroke survivors?

3. What support needs do young carers of stroke survivors have specifically related to their caring role?
4. What support services exist for young carers of stroke survivors and what are the challenges and gaps in service provision?

The specific questions and objectives for each phase of the study will be described within the relevant chapters.

1.6 Overview of subsequent chapters

To facilitate orientation to the thesis the structure and content are briefly summarised here.

Chapter two reports on the first of three sequential studies comprising a cross-sectional survey of stroke survivors living at home in the East Midlands. The pertinent literature is revisited before the methodology and results are presented and explored.

Chapters three and four describe the second study exploring the experiences of young carers of stroke survivors through semi-structured interview with stroke survivors, young carers and experts.

Chapter three presents the findings of the semi-structured interviews with stroke survivors and young carers.

Chapter four explores in depth the context within which young carer support services are delivered, the challenges and good practice are elucidated by giving voice to the expert commissioners and providers of young carer services.

Chapter five presents the third and final study comprising an exploration and synthesis of information for young carers of stroke survivors, Parkinson's disease, Multiple Sclerosis and Brain Injury. The methods used to analyse and synthesise

the data are described in detail before the findings of a thematic and content analysis of the digital and printed material are presented. A gold standard core information set is proposed for future information as part of the conclusions and recommendations

Chapter six summarises and discusses overall findings for the PhD and implications for practice, theory, future policy and research are presented.

CHAPTER TWO – CROSS-SECTIONAL SURVEY OF STROKE SURVIVORS

2 Introduction

This chapter reports on a cross-sectional survey of stroke survivors living at home in the East Midlands who were newly discharged home from hospital after a confirmed diagnosis of stroke. The purpose of this first study was to explore the stroke survivor's support needs from their own perspective, investigate who was supporting and living with them and specifically to identify any young carers. The intention was to build robust foundations upon which the remainder of the thesis could be constructed utilising a sequential mixed design in which the subsequent study questions and design emerge from the previous study findings (Creswell, 2014).

There are currently estimated to be 1.2 million stroke survivors in the UK and up to 74% (McPherson et al, 2010) are believed to be dependent on family and friends for support with ADL after discharge from hospital. There are no data on how many of these carers are under the age of 25 years. Additionally, although there is a wealth of literature concerning adult carers of stroke survivors and their needs, there is minimal literature pertaining to younger carers who are known to have specific needs related to their age, life and developmental stage.

Stroke is responsible for a wider range of disabilities than any other condition (Stroke Association, 2017) potentially causing multiple and complex needs (Nelson et al, 2008). Physical impairments can often affect one side of the body. At three months after stroke over 75% of stroke survivors experience weakness in the arms leaving the individual unable to complete essential tasks of independent daily living

such as maintaining personal hygiene, dressing, toileting or maintaining nutrition (Lawrence et al, 2001). More than 70% have lower limb weakness impairing mobility. This can extend to the person being unable to walk unaided or at all, leaving them wheelchair dependent (Lawrence et al, 2001). Sensory problems can also be manifest including visual loss or disturbance, hearing loss, and loss of taste or smell. Around half of all stroke survivors experience urinary incontinence (Lawrence et al, 2001). In addition, one third of stroke survivors are reported to have a communication impairment which can be of overwhelming concern to stroke survivors and their carers due to the impact this deficit has on their ability to: function independently; maintain personal relationships; sustain employment; and socialise (Institute for Research and Innovation in Social Services, 2010(IRIS)). Half of all stroke survivors experience cognitive deficits after stroke (Royal College of Physicians, 2015) and the risk of developing dementia doubles (Leys et al, 2005). Emotional problems are not uncommon such as uncontrollable laughing or crying and up to 50% of survivors will experience depression which not infrequently lasts in excess of 5 years (IRIS, 2010). Currently, 75% of strokes are accounted for by the over 65 age group and the incidence is predicted to increase from the current 100,000 first stokes in 2015, to 187,000 predicted in 2035 (King's College London, 2017). In addition, the incidence in younger age groups (> 45 years) is increasing (Béjot et al, 2016; Kissela et al, 2012; Wang et al, 2013) and is expected to increase by 59% by 2035 (Patel et al, 2017). Consequently, there may be a corresponding rise in the numbers of stroke survivors living at home with co-resident children and young people under the age of 25 years who could be at increased risk of being affected by the familial changes brought by stroke.

2.1 Background

Needs of stroke survivors have been described as complex and wide ranging encompassing physical, social and psychological well-being (Murray et al, 2009).

Needs are often framed in terms of met and unmet needs and focus on information needs, the needs of their carer's, or needs that can be translated in to service developments to meet the needs (Low et al, 2003). In order to address the heterogeneity of needs as a precursor to identifying service developments or developing interventional studies a combination of tools have been utilised. Tools measure different aspects of need but the approaches explored have been found to be time consuming, expensive and cumbersome (Murray et al, 2009). Other studies have sought to deliver shorter, more comprehensive and psychometrically validated tools. In a survey of needs of young disabled people, Badley & Tennant (1991) found that self-reported needs did not match the level of assessed disability or difficulties with activities of daily living (ADL). Other studies have found that expressed needs of people with disabilities do not match those identified by healthcare professionals such as General Practitioners (Kersten et al, 2000). This may in part be due to needs assessments being based on the availability of resources rather than actual need (Kersten et al, 2000). Support with family life has been identified as a need, particularly for younger stroke survivors under 65 years (Kersten et al, 2002; Teasell et al, 2000). Information needs are reported as a top priority for stroke survivors in many studies (Low et al, 2003; McKevitt et al, 2004).

Few studies review self-identified needs of stroke survivors that are met by themselves or by family and friends. Pierce et al (2004) explored the self-care needs identified by stroke survivors living at home which revealed that:

> *preventing falls/hazards; maintaining adequate nutrition / food; staying active / normalcy; managing stress / normalcy and solitude and social interaction; dealing with emotional and mood changes / normalcy and solitude and social interaction were the top five needs identified* (p.16).

Health care professionals' opinions generated a completely different set of priorities and this has been reiterated in other studies (McKevitt et al, 2004). Emotional support needs are significant for stroke survivors and their carers. In a survey with 2,700 responses from people affected by stroke, two-thirds said their emotional needs were not as adequately addressed as their physical needs and 67% had experienced anxiety. Only two in ten respondents had received any information about coping with emotional needs following stroke and half reported relationships with family and friends being under strain (Stroke Association, 2013 p.5).

Stroke affects the whole family and not just the stroke survivor (Gillespie & Campbell, 2011; Visser-Meily et al, 2006; Wade et al, 1986). However, few studies look at the family as a whole and much of the research purporting to be about impact on families, actually relates to the primary carer, often the spouse, rather than the entire family (Clark & Smith, 1999). Greenwood et al (2009a) in a systematic review of qualitative studies of carers of stroke survivors found that the majority of carers were spouses, but also identified examples of adult children, daughter-in-laws and friends providing care.

van de Port et al (2007) in the only long-term study of children of stroke survivors, found that at one year post stroke all children in the study conducted household activities such as cooking, cleaning their own room and shopping. Two thirds provided care such as helping the stroke survivor with nutrition, dressing and pushing the wheelchair (p.39). All of the children in the van de Port et al (2007) study lived with both parents and the question of whether the child was a primary or secondary carer was not addressed.

Frank (1995) classified young carers as, sole carers: *"a young person or child who has sole responsibility in the home for care tasks needed by the care receiver because there is no other able adult in the home"* (p.17); supportive carers:

"children or young people who give assistance to an able adult who is the main carer in the home" (p.17); and sibling carers. The study revealed that supportive carers were hidden by the able adult who was presumed to be taking on all of the caring tasks and statutory agencies did not look for young carers in dual parent households. In eight of the two parent families, the child was the main carer for their mothers and the partners were either working full time or did not see caring as their role. Some of their roles were as demanding as a sole carer. The children also revealed their concern for the able parent and their workload. Thus, assumptions cannot be made about who is providing the majority of care and secondary caring. Vicarious caring by supporting the well parent can be as demanding as being a sole carer. Of the utmost importance is the impact that caring for a stroke surviving adult has on the individual child or young person.

The current ethos of stroke management supposes that early discharge home after mild to moderate stroke enhances recovery (Indredavik et al, 2000b). Thus UK guidelines suggests that stroke survivors following mild to moderate stroke should have their care transferred from a hospital to community setting as soon as they are medically fit for discharge (NICE, 2013). Care should be delivered at home with the same expertise and level of intensity of rehabilitation therapy as in an acute hospital setting.

The teams delivering this type of care are often referred to as Early Supported Discharge teams (ESD)(NICE, 2010). ESD teams comprise a multi-disciplinary team of nurses, doctors and therapists allowing stroke survivors who fulfil the criteria, to be discharged home from hospital earlier than would otherwise be possible (Cobley et al, 2013; Langhorne & Baylan, 2017). ESD services have been implemented in some but not all areas of the UK. However, they do exist across the East Midlands and many areas also have a follow on community stroke rehabilitation service (EMAHSN, 2015). This model requires health care professionals to visit the home on

a daily basis for a minimum six weeks to administer required therapies. A systematic review of the literature (Langhorne & Baylan, 2017) suggested that evidence for cost effectiveness of the model were mixed. Disability was slightly reduced for patients receiving ESD services and there was no difference for subjective mood or satisfaction for stroke survivors or carers between ESD and conventional care groups. The review concluded that a co-ordinated team was an important variable in terms of improved outcomes compared to a non-coordinated team. Therefore, the quantitative evidence base for this wide spread model is conflicting. This is perhaps for multiple reasons including; the complex nature of the intervention, the heterogeneity of the service models being assessed, combinations of deficits that can be experienced by individuals following stroke, and the variability of family and carer support available.

Despite the challenges of showing consistent benefit of the ESD model, the concept of community reintegration following stroke is considered to be an essential part of rehabilitation with a reduction in length of stay being associated with increased independence, a reduction in social isolation and increased mobility (Indredavik et al, 2000a). Some medical interventions are so complex, that a combination of quantitative and qualitative research techniques are imperative to more effectively explore the phenomena under study. Therefore, in an attempt to explore whether the patient and carer experience is enhanced by the ESD model, Cobley et al (2013) undertook a qualitative study of patient and carer perceptions of ESD services. The study found that ESD services in Nottinghamshire were positively received by patients and carers. Limitations of services were experienced in terms of information and education provision and delivery, and in support for carers. This suggests that the principles of early discharge with the correct support is probably beneficial in terms of recovery and social reintegration but gaps in preparation and support of carers for whom the major responsibilities and burden of care lie need to be addressed to enhance patient and carer experience. The model of care firmly

embeds the responsibility for rehabilitation and maintenance of therapy once home with the patient and carer and yet there is seemingly no recognition or training to optimise the outcomes. There was no mention of young carers in the study.

2.2 Study aims and objectives

The overall aim for this first phase of the PhD was to explore the support needs of stroke survivors living at home after discharge from hospital following a stroke, to establish who was providing the support and generate participants for phase two of the PhD. In particular young carers of stroke survivors were the focus of interest. The literature has shown how challenging it can be to engage young carers, because they may not identify with the term young carer, or may choose not to reveal their caring role for fear of unwanted statutory intervention, or simply do not want to appear different to peers. Families can collude with or encourage young carers to hide the extent of their caring role for the same reasons. Therefore, a pragmatic decision was taken to ask more broadly about carers in an effort to make the questionnaire more acceptable and elicit the required information in a less direct manner which was potentially less threatening. It also provided context for the remainder of the PhD by giving voice to the stroke survivors and providing some understanding of their perception of the role of young carers in their families. The objectives were to:

- Identify the amount and type of support required by stroke survivors living at home in the East Midlands
- Establish who is providing the support
- Determine whether any young people aged under 25 years were supporting stroke survivors in the East Midlands
- Estimate the amount and type of support young people under the age of 25 years are providing
- Identify participants for phase two of the study

2.3 Methodology

2.3.1 Philosophical orientation

In accordance with the overall PhD design this phase of the study was embedded in pragmatism as the paradigm or world view. The method chosen to answer the questions for this study was a semi-structured questionnaire. This incorporated both quantitative and qualitative data collection and as such required a world view that could encompass both. It was important to explore the needs of stroke survivors, and the provision of the support both from their own perspective as well as collecting data to make comparisons with other stroke survivors in similar situations using fixed response items. As Teddlie & Tashakkori (2009) explicate: "*Pragmatism views knowledge as both constructed and based on the reality of the world one experiences and lives in*" (p.74).

2.3.2 Ethical approval

The study was conducted in accordance with the University of Nottingham Code of Research Conduct and Research Ethics v6 2016, the ethical principles that have their origin in the Declaration of Helsinki, 1996, the principles of Good Clinical Practice and the Department of Health Research Governance Framework for Health and Social care, 2005.

Ethical approval for phase one and two of the study was obtained from The Proportionate Review Sub-Committee of the London Fulham Research Ethics Committee, REC reference number 16/LO/0548, 21st March 2016 (Appendix 1). Site specific assessments were completed for all 14 sites / eight providers through their NHS Trust Research and Innovation Departments and approvals were granted.

2.3.3 Patient and public involvement

Patient and Public Involvement (PPI) in research has been defined as: *"research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*" (Hayes et al, 2012 p.6). The 'public' refers to current, past and potential future patients, and their carers', family and friends.

PPI is central to UK health research policy and the importance of involving people who are affected by research in what and how publicaly funded research is undertaken is becoming a requirement of funders and recognised as a democratic right (Hayes et al, 2012). Guidance and standards exist for involving the pubic in research for both adults (Public Involvement Standards Development Partnership, 2018) and children (INVOLVE, 2016). PPI has been described as:

> *..an intrinsic part of citizenship, public accountability and transparency. In addition public involvement in research can lead to empowering people who use health and social care services, providing a route to influencing change and improvement in issues which concern people most* (Hayes et al, 2012 p.8).

There are multiple benefits derived from involving people with experience of the condition of interest, which will inevitably differ from that of researchers and experts, no matter how knowledgeable. Public involvement is said to improve research relevance and quality by: making language and content of participant information and questionnaires more appropriate and relevant; ensuring methods are acceptable and sensitive to the circumstances of potential participants; ensuring outcomes used are important to the public; increasing participation by making the research more relevant and accessible to the target population including seldom heard groups (Hayes et al, 2012 p.8).

Brett et al (2014) in a systematic review of research studies reporting the impact of PPI on health and/or social care research, replicated the positive findings. However, some challenging impacts were also identified such as: conflict between what researchers consider as robust research methods and the lay members of the research group deem acceptable (e.g. none intervention control groups); tokenism by some researchers resulting in a poor experience for the lay member; and challenges in recruiting from a diverse range of users such as seldom heard groups. They also found that the PPI section of published papers was often sacrificed to save on word counts demonstrating a lack of value by some researchers of PPI. Challenges have also been identified with some lay members taking over meetings to relate their personal experience stories, and some dominant parties over emphasising problems that are of a particular personal concern to them skewing the research purpose and questions. There are also tensions between the level of training recommended for lay members of research committees and groups to ensure they are able to contribute confidently and effectively, and concerns that this professionalises the lay person and damages their objectivity (Brett et al, 2014). All of these challenges can be managed by effective planning, guidance and chairing of meetings, and should not be a barrier to effective PPI.

The intrinsic values of the researcher leading this study fully embraces the principles of public involvement in the process of research. Therefore, the outline study proposal was presented to the University of Nottingham Stroke Research Partnership Group (NSRPG) at a very early stage of the PhD in May 2015. The NSRPG was convened in 2004 and comprises stroke survivors, carers and researchers from the University of Nottingham who together inform research strategy, review research proposals, sit on steering groups and participate in relevant trials. It is jointly chaired by two patient representatives and two senior academics from the Division of Rehabilitation and Ageing, a melding of academic and lay chairing (University of Nottingham, 2017). The presentation comprised a

brief overview of the background to the proposed study and an outline of broad aims which included:

- A systematic way of identifying young carers
- Identifying tools to measure outcomes for young carers
- Identify needs of young carers of stroke survivors

The purpose being to

- Start to build research and knowledge base
- Provide information for service development
- To improve outcomes

A series of questions were then posed to the group:

- Do you think people will be willing to answer the questions for the survey?
- Is there a better way or an extra way we can collect this information?
- What problems do you think we will have in finding young carers to take part in semi-structured interviews and any ideas for getting around that?
- Is there anything else you think is important for this study?

A briefing sheet was also prepared as an additional format for group participants to be able to access the information.

Suggestions from the group included: seeking input from the Young People's Advisory Group (YPAG) (see below for details of the YPAG); be cognisant that many carers do not consider themselves as carers and to be careful of language used in the survey; to ensure that respondents remain anonymous; to contact the voluntary sector organisation Carers Federation to identify any young carers of stroke survivors who may help with the study design; one group member with a child who had supported them after their stroke agreed to help with any further input required to the study design. Support for the study was granted by the group on 11th May 2015 (Appendix 2).

Consequent to the advice from the NSRPG, contact was made with the YPAG. The YPAG consists of five regionally situated groups of which one is based in the East Midlands. Each group comprises 15 members aged between eight and 19 years old. The groups meet every six weeks locally and nationally on an annual basis. The YPAG:

- Helps researchers with their projects
- Works with external organisations such as the Medicines and Healthcare products Regulatory Agency, NIHR Central Commissioning Facility, National Research Ethics Service and INVOLVE
- Raises research awareness amongst young people (through summaries)
- Design and deliver national conferences to highlight the importance of children's research and the key role they can play in its development
- Carry out their own research projects (National Institute for Health Research, no date)

The YPAG routinely charges researchers to engage the group and receive advice however, an exception was made for this study after considerable negotiation as no funding was allocated in the PhD studentship for Public Involvement work. The group were interested to engage with and learn from a qualitative study design as the majority of their work comprises Randomised Controlled Trials and complex interventional studies. The meeting was convened as a workshop which took place at relatively short notice when a vacancy on a regular meeting was identified by the group conveners. The half day workshop took place in June 2015 (Nottingham University Hospitals NHS Trust, 2017). There were 10 young people present:
Three x 11year olds,
One x 13year old,
One x 15year old,
Four x 16year olds,
One x 17year old.

The workshop comprised a brief presentation by the researcher introducing the background to the study and key literature. The overall aims of the study were presented as:

- Young carers are the experts about young carers
    - Is the support they get helpful?
    - Can we make things better?
- We want to find ways of measuring what they do and how it affects them – we need numbers and facts
- We want to know the good things as well as the bad things
- We want more people to know what it is like to be a young carer

A series of seven questions were posed on individual flip charts stationed around the room. YPAG members were asked to form pairs. Each pair were allocated an initial flip chart and asked to discuss the question in their pair, add any comments on to the flip chart before moving on to the next flip chart adding to the comments posted by the previous group. YPAG facilitators and the researcher circulated round the groups to ensure everyone was given the opportunity to contribute. Questions asked were:

- Study title ideas?
- What is the best way of finding young carers for my study?
- What do you think about the definition of young carer?
- What should I call people in my study – young people? Children? both?
- How should I keep in touch with the people in my study?
- What important things do I need to ask?
- Anything else you want to say about the study?

The group designed a study logo (Appendix 3) and the title of the study which was SMILE – **S**troke, **M**aking **I**llness **L**ess **E**xhausting. One member of the group

revealed that she was a young carer of a stroke survivor and said: "*it needs to be positive, illness is not appropriate word. Stroke isn't an illness it's a way of being*". The acronym was therefore amended with the consent of the group to **S**troke, **M**aking **I**t **L**ess **E**xhausting. A number of ideas were incorporated in to the study design including: building the facility for young carers to divide the interview over more than one session; dividing the age groups for interview questions into ≤ 18 years and over 19 years; to refer to young carers as young people rather than children to prevent them feeling patronised; and some of the questions were incorporated in the semi-structured interview questions for the second phase of the PhD.

Contact was also made by email or via websites with all of the young carer projects in the East Midlands to inform them of the study and ask for support by commenting on the study questionnaire and semi-structured interview schedules. Only two out of five providers responded in the first instance and agreed to comment on the study design, questionnaire for phase one and interview schedule for phase two. Meetings were held with the two consenting young carer project leads to discuss the research. Topics included:

- The services they were providing
- Challenges for their services
- Numbers of young carers of stroke survivors in their service
- Issues they predicted with accessing young carers for the study
- Advice on questions to be incorporated in the questionnaire and semi-structured interview schedules
- Any general advice they could offer.

One project provided contacts with two young carers of a stroke survivor. Their contribution to the study is reported in chapter three. Both project leads agreed to review the questionnaire and interview schedules but did not make any changes to

the final drafts sent to them. One suggested a signposting information sheet for young carers participating in the study. This was actioned and is described in chapter three.

Two lay assessors were also asked to comment on the questionnaire design, participant information sheet and introductory letter. Lay assessors are members of the public, often with experience of using health care services, who are trained to appraise and advise on research design and implementation and they also sit on research steering groups (Jonathan et al, 2015). They have been defined as: "*members of the public who contribute their own experience and independent review by reading and commenting on proposed research projects*" (Horobin, 2013 p.1).

2.4 Methods

A cross-sectional survey utilising a semi-structured questionnaire (Appendix 4) comprising both closed and open free text response questions was administered to a convenience sample of stroke survivors newly discharged home from hospital following a stroke. The purpose was to collect baseline information about the population of stroke survivors newly discharged home from hospital in the East Midlands, and to identify potential participants for the next phase of the PhD.

2.4.1 Cross-sectional survey

Cross-sectional surveys are commonly used to collect a large amount of data about a population at a given point in time. It can be used in planning health care by determining prevalence of different needs of the population under study (The British Medical Journal, no date). Denscombe (2014) suggests the following criteria should be taken in to account when a survey is being considered:

- The objective of the research

- Resources available
- Geographical area to be covered
- Methods of data collection to be used
- Speed of responses required
- Contact with potential participants
- The need for face to face contact
- The need for indirect contact
- Ability / disability of respondent
- Validity of the answers – need to avoid social desirability (p.9)

This chosen method facilitated contact with a large number of participants, in a short time frame, at relatively low cost and with limited resources in terms of a lone researcher. As the population of interest was dispersed geographically across the East Midlands, a postal survey was selected as the method of choice. An internet survey was suggested by the NSRPG and considered, however, it was not a viable option. This was because no database existed from which stroke patients in the East Midlands could be identified and contacted either by post or email, and a systematic way of contacting stroke survivors early in their community pathway was required for the study.

2.4.2 Population

The population of interest included: all stroke survivors aged over 18 years; newly referred in to the caseloads of a stroke specific domiciliary care team in the East Midlands at the time of the study; and who were living at home and not in residential or nursing home care. The inclusion and exclusion criteria can be seen in Table 3.

Table 3 Inclusion and exclusion criteria for the cross-sectional survey

Inclusion criteria	Exclusion criteria
Patients with a confirmed diagnosis of stroke newly referred in to the caseloads of a stroke specific domiciliary care team in the East Midlands at the time of the study	Not on the caseload of a stroke specific domiciliary care team in the East Midlands
Aged between 18-125 years	Aged under 18 years or over 125 years
Living at home in the East Midlands	Living in a residential care

A time frame of two months was chosen for data collection based on estimated numbers patients who would be discharged in the period to all 14 stroke specific domiciliary care teams. Lead clinicians from the stroke domiciliary care teams estimated 600 new patients during the two month study period based on previous average numbers of referrals. Denscombe (2017) suggests sourcing a survey similar to that proposed and on which to base expected response rates and thus calculate sample sizes. The response rate for the NHS Mental Health Survey was reported at 29% (Care Quality Commission, 2016 p.6) and similarly to the SMILE survey explored potentially sensitive issues. Therefore, a response rate of 29% of a potential sample size of 600 would yield a response rate of 174 which was deemed an acceptable number of responses for this exploratory survey.

2.4.3 Questionnaire development

The purpose of this phase of the PhD was to garner information on the type and amount of support stroke survivors needed at home and about who was providing the support, with a specific focus on young carers under 25 years old. A review of the literature failed to reveal a pre-existing questionnaire deemed suitable to answer the research questions. This was because the survey was to focus on tasks known to be performed by young carers as established in the literature (Joseph et al, 2009) in order to answer the research question regarding the amount and type of support young carers were providing for stroke survivors. Existing questionnaires

focussed on tasks carried out by adult carers and did not match the tasks identified by (Joseph et al, 2012; Joseph et al, 2009) as central to young carer roles. Recent large scale surveys of young carers have also utilised the same categories of tasks to assess caring responsibility (Aldridge et al, 2016a; Cheesbrough et al, 2017a). A bespoke questionnaire (SMILE questionnaire) was therefore developed (Appendix 4) using these tasks. The amount of time spent caring was presented as fixed choice responses of ≤19 hrs a week or ≥20hrs a week. These time scales were taken from the Barnardo's survey of young carers (James, 2017) and 2011 census (Office for National Statistics, 2011) question 14. In retrospect these categories are very broad, making analysis difficult. However, it has been recognised that young carers find it very difficult to identify how much time they spend caring (Cheesbrough et al, 2017a) and therefore an approximation is probably the most accurate possible representation of actual time spent. Existing questionnaires for stroke survivors and their adult carers were reviewed for formatting of questions related to demographic details and general layout of the questionnaire (Carers UK, 2016; Picker Institute Europe, 2004; Stroke Association, 2015).

Drafts of the questionnaire were discussed with study supervisors, young carer project leads, Lay Assessors and two clinicians working in community stroke teams. Minor changes were made as a result of the feedback. Changes included:

- moving the demographic data to the back of the questionnaire
- changing some of the wording in the instructions to simplify and clarify what was required
- amalgamation of some of the subscales from the MACA –YC42 in to two instead of an original five sections in the SMILE questionnaire to shorten the questionnaire.

The SMILE questionnaire was tested by one clinician assisting a stroke survivor to complete the questionnaire. No further amendments were suggested and no further piloting was done due to time constraints.

The final questionnaire comprised 19 items on eight sides of A4 paper utilising a size 13 sans serif font. Guidelines suggest a minimum of size 12 font to enhance accessibility (Hoffmann et al, 2006). Size 13 was slightly above the minimum but still allowed the questionnaire to fit on to eight pages. Demographic data was requested at the end of the questionnaire to encourage completion before personal data were collected, and to ensure that the questions requiring the most cognitive input were placed first (Dillman et al, 2009). Harvesting of demographic data was kept to the minimum and fixed item responses were employed where possible to simplify and reduce the burden of completion for participants, e.g. Age ranges were:

- under18
- 18-55
- 56-65
- 66-75
- 76-85
- over 85 years.

The convention in the literature is to measure and classify young carer support in terms of the tasks to be completed. The Multidimensional Assessment of Caring Activities (MACA-YC42) (Joseph et al, 2012) assesses the extent and nature of caring activities in children and young people (Joseph et al, 2012) and was therefore selected as the basis for the SMILE questionnaire. This also incorporated activities of living which have been identified as being significant for young carers generally (Dearden & Becker, 2004; Joseph et al, 2009). The MACA-YC42 is a 42 item questionnaire designed and validated for ages 7-22 years. The items

incorporated in the MACA-YC42 have been subject to psychometric testing and are representative of particular domains. There are six subscales within the instrument (Joseph et al, 2012 p.8):

- Domestic tasks
- Household management
- Personal care
- Emotional care
- Sibling care
- Financial/practical care

For the SMILE questionnaire these were compressed in to two sections (see *Table 4*) to keep the questionnaire as short as possible with the intention of minimising the time required for completion which was hoped would result in an increase in response rates. The first section was Practical Care and the second was Emotional / Social Care. Each section comprised three items: the first asking about the frequency each task required input from a carer; the second was an open response question harvesting additional practical tasks not included in question one; and the third asking who assisted with the tasks, their age and the amount of time spent helping.

Table 4 Mapping of MACA- YC42 subscales to new categories

Original MACA-YC42 subscales	New categories
Domestic tasks Household management Personal care Sibling care Financial / practical care	1. Practical care
Emotional care	2. Emotional / Social care

The SMILE questionnaire employed a scale of never, some of the time, a lot of the time or not applicable which was adopted from the MACA-YC42. An example of how to complete each question was presented at the beginning of each question. An example can be seen in Table 5.

Table 5 Example of completing a question in the SMILE study questionnaire

Task	Never	Some of the time	A lot of the time	Not applicable
E.g. Tidying /dusting		✓		

Not all of the MACA YC42 tasks were appropriate to be included in the SMILE questionnaire and some of the wording was changed to be relevant to the stroke survivor rather than a young carer. Changes for the Practical Section can be seen in Table 6.

Question one comprised:

> *In the past two weeks since you came from hospital have you needed any **PRACTICAL** help from family or friends because of your stroke with any of the following? **Please tick one box to show how often you need help for each task i.e. never, some of the time, a lot of the time, or not applicable**.*

The amalgamation of the subscales provided 39 items in the practical section. After adaptions and deletions to target the questions for stroke survivors, 32 items remained.

Table 6 Mapping of MACA-YC42 to the SMILE study Practical section

MACA-YC42 tasks	SMILE study questionnaire task	Reason for change
Tidy / dust your own bedroom Tidy / dust other rooms	Tidying / dusting	Tidying / dusting questions combined
Hoover your own bedroom Hoover other rooms	Hoovering	Hoovering questions combined
Lay the table	Laying the table	
Make main meals	Making main meals	
Make snacks	Making snacks	
Wash up dishes or put them in the dishwasher	Wash dishes or put them in the dishwasher	
Wash your own clothes Wash clothes for people you live with	Washing clothes	Washing clothes questions combined
Iron your own clothes Iron clothes for people you live with	Ironing clothes	Ironing questions combined
Mow the grass	Mowing the grass	
Weed or look after the garden	Weeding or looking after the garden	
Do repairs to the home	Repairs to the house	
Decorate rooms	Decorating rooms	
Take responsibility for shopping for food	Shopping for food	
Help with lifting or carrying heavy things	Lifting and carrying heavy things	
Help with paperwork e.g. writing letters for someone, filling in forms	Paperwork e.g. writing letters or filling in forms	
Help with financial matters such as dealing with bills, banking money, collecting benefits	Financial matters like collecting benefits, dealing with bills, banking money	
Work part time to bring money in	Omitted	Could not be turned into a task someone else could help with
Interpret for someone you live with because English is not their first language Signing for someone you live with because they are hearing impaired	Communication because of your stroke	The questionnaire was targeting tasks specifically related to stroke therefore pre-existing conditions were not relevant
Give medicines to someone you live with e.g. making sure s/he takes their pills, giving you injections or changing dressings	Taking medicines, giving you injections or changing your dressings	

Prepare a special food or diet because of medical needs of the person you care for	Preparing a special diet because of your stroke	
Take someone you live with to the doctors or hospital	Going to the doctors or hospital appointment	
Help someone you live with to walk, get up the stairs, get into and out of bed	Walking, getting up the stairs or into and out of bed	
Help someone you live with to dress or undress	Getting dressed or undressed	
Help someone you live with to have a wash	Having a wash	
Help someone you live with to have a bath or shower	Having a bath or shower	
Help someone you live with to have a shave	Having a shave	
Help someone you live with to cut their nails	Cutting your nails	
Help someone you live with to use the toilet	Using the toilet	
Help someone you live with to eat and drink	Help with eating and drinking	
Taking brothers or sisters to school	Taking your children to school	
Look after brothers or sisters whilst another adult is nearby	Looking after your children	Child care questions combined
Look after brothers of or sisters on your own		
Talking with officials (e.g. doctor or benefits office) about the person you care for	Talking with officials (doctor or benefits person)	
Miss out on sleep e.g. have to get up in the nights or stay up late in order to look after someone	Helping in the night	

The Emotional / Social care section was framed by the following question:

> *In the past two weeks since you came home from hospital have you needed **EMOTIONAL or SOCIAL** help from family or friends because of your stroke with any of the following things? **Please tick one box to show how often you need help for each task i.e. never, some of the time, a lot of the time, or not applicable***

Mapping the MACA to the SMILE questionnaire for the emotional/ social section can be seen in Table 7.

Table 7 Mapping of MACA-YC42 to the SMILE study Emotional / Social section

MACA-YC42 tasks	SMILE study questionnaire task	Reason for change
Keep the person you care for company e.g. sitting with them, reading to them, talking to them.	Keeping you company, reading to you, talking to you	
Keeping an eye on the person you care for to make sure they are alright	Keeping an eye on you to make sure you are alright	
Take to person you care for out e.g. for a walk or to see friends or relatives	Taking you out for a walk	Single MACA-YC42 question divided into the two component parts forming two questions in the SMILE questionnaire.
	Taking you to see friends and relatives	

The remainder of the SMILE questionnaire comprised:

- A front sheet requesting contact details for the stroke survivor and details of anyone assisting with completion of the questionnaire.
- Items 7-10 related to paid carers and the age and identity of the main carer.
- Items 11-15 collected demographic data
- Items 16-17 questioned composition of households and co-residency
- Items 18-19 explored willingness to participate in the next phase of the study and whether the participant wished to receive study updates.

2.4.4 Choosing the questionnaire distribution method

The study purpose: to explore the support needs of stroke survivors living at home, required a systematic method of distributing the questionnaire to stroke survivors who were living at home in the East Midlands. The most pragmatic method of distribution identified was via the stroke specific domiciliary care teams in the East Midlands.

As the stroke domiciliary care team leaders had been engaged in a recent study with the University, they were introduced to the researcher by the previous

research team via email. Meetings were then arranged with all of the team leaders to discuss the study protocol, and how the questionnaire could be distributed to their patients. It was apparent that it would not be feasible in the time frames and with the resources available for the researcher to gain access to patient data to distribute the questionnaire. Each team was structured and worked in a different way and after much exploration and discussion with team leaders it was agreed that questionnaires would be distributed by clinicians at the first home visit. This was a systematic way of capturing all patients at a given point in their pathway but meant that they did not know accurately how many questionnaires were distributed and was not able to send reminders to non-responders. All 14 teams across the region which covered all the counties agreed to assist with the study and each organisation's ethical and governance requirements were met before the questionnaires could be distributed. All team leaders and teams were visited a second time by the researcher just prior to the start of the study to provide background information for the study and inform team members what was required of them. Clinicians were asked to deliver the questionnaire to all new patients aged over 18 years who were referred in to their teams for a two month period between May and September 2016. Details of the expected number of patients in each team, based on actual admissions in the previous year can be seen in Table 8.

Table 8 Numbers of expected admissions during the study period

Team ID code	County within the East Midlands region.	Number of admissions expected in a two month period based on previous monthly averages
1	Nottinghamshire	50
2	Nottinghamshire	80
3	Nottinghamshire	44
4	Nottinghamshire	26
5	Leicestershire	80
6	Derbyshire	14
7	Derbyshire	30
8	Derbyshire	22
9	Lincolnshire	40
10	Lincolnshire	40
11	Lincolnshire	40
12	Lincolnshire	40
13	Northamptonshire	60
14	Nottinghamshire	35
Totals		**601**

2.4.5 Distribution of questionnaires

Packs containing: questionnaires, coded on the back to identify the team from which it was generated; cover letter introducing the researcher and study; participant information sheet; and self-addressed pre-paid envelopes were prepared and hand delivered to each team in a box clearly marked with the study logo and researcher contact details a few days before the start of the study. The start date for each team varied due to significant delays and variation in requirements in the R&D processes for some of the Trusts. Contact was made with each team leader two weeks after the start of the study and plans made for a follow up visit to be made by the researcher at mid-point for the study to discuss any issues and establish how many questionnaires had been distributed. Further contact was made six weeks in to the study and in the final week.

Questionnaires were returned by participants in the pre-paid envelopes to the researcher at the University of Nottingham. In an effort to optimise response rates, as many of the strategies identified in a systematic review by Edwards et al (2002) as possible were employed including the pre-paid envelope, printing in colour, sending from the University of Nottingham, an introductory letter with a photograph of the researcher to personalise the study, and targeting a group for whom the subject was of interest. An option was also given to return questionnaires anonymously.

2.4.6 Data management

In accordance with the University of Nottingham policy, all data were stored on the secure university server. Data were entered in to a password protected Microsoft Excel spreadsheet. Participant identifiers were formed from the initials of the participant and a number generated by the order in which the questionnaire was returned; the stroke team distributing the questionnaire; and date of return of the questionnaire. Original hard copies of the questionnaire were stored in a locked cabinet at the University.

2.5 Analysis and results

2.5.1 Response rates

Seventy-five questionnaires were returned. Accurate response rates could not be calculated as numbers of questionnaires distributed could not be established. Teams did not maintain records of the numbers of questionnaires distributed and some team members admitted after the study closed that they had not distributed questionnaires to all new patients and had stores of blank questionnaires in their cars which they had not returned. Potentially up to 601 questionnaires could have been hand delivered during the study period based on

estimated numbers of new patients, and 105 unused packs were returned at the end of the study suggesting a maximum of 496 had been distributed. Table 9 shows the numbers of packs returned by each team. This was most likely an over estimate of distributed questionnaires as not all unused questionnaires had been returned but if correct would have equated to a response rate of 15%.

Table 9 Packs returned at the end of the study period

Team ID code	Number of admissions expected in a two month period based on monthly averages	Packs returned	Packs potentially distributed
1	50	0	50
2	80	0	80
3	44	7	37
4	26	22	4
5	80	22	58
6	14	2	12
7	30	11	19
8	22	13	9
9	40	0	40
10	40	0	40
11	40	0	40
12	40	0	40
13	60	0	60
14	35	28	7
Estimated Totals	601	105	496

2.5.1.1 Remedial action taken to address poor response rates

Response rates in the first few weeks were negligible with only three questionnaires being returned in the first month. Team leaders were emailed to ask if there were any unforeseen problems and if the researcher could offer any further support. Not all team leaders responded but some admitted they had not started distributing the questionnaires despite having set an agreed start date. Reasons for this included: forgetting; waiting for a team meeting to agree a

start date with the team; planning to start on a future date; and being confused with other research studies they were participating in.

Two teams invited the researcher to a further team meeting as a result of the reported poor response rates to remind them about the study and these were attended as requested. One team leader suggested a newsletter to update the team on the study and remind them of the need to deliver the questionnaires. A single page newsletter was devised and tested with two team leaders. No amendments were required. The researcher then visited all 14 teams again taking biscuits as a good will gesture and hand delivering individual hard copies of the newsletter for every team member providing an update on study progress and their responsibilities. The researcher spent up to an hour with each team being available to answer questions, building relationships with administrators and clinicians and reminding them of what they were asked to do. During this follow up visit, processes for ensuring the questionnaires were distributed were discussed with administrative staff, clinicians and team leaders and remaining copies of the questionnaire packs were counted. The visits confirmed that very few questionnaires had actually been distributed and one team could not find the box of questionnaires initially and denied all knowledge of the study. The team leader was contacted and a new start date agreed, however this date passed and the questionnaires were still not being distributed. A further call resulted in a new start date being agreed for that team in July 2016.

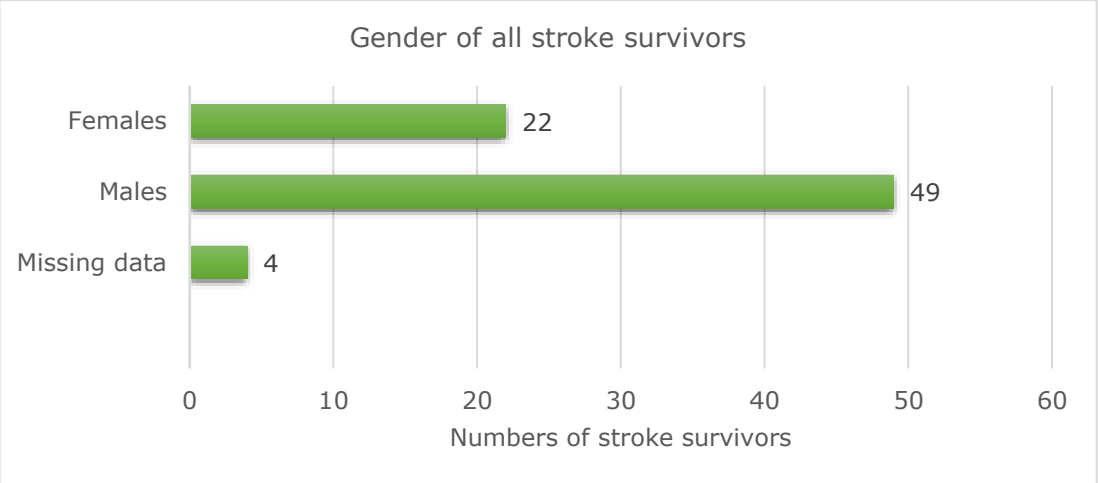
2.5.2 Analysis of data

Analysis of the data were completed using Microsoft Office Excel software. Descriptive statistics were used to define the population and sample characteristics. All data were rounded to one decimal place and both absolute numbers and percentages shown due to the small sample size.

2.5.2.1 Stroke survivor age and gender

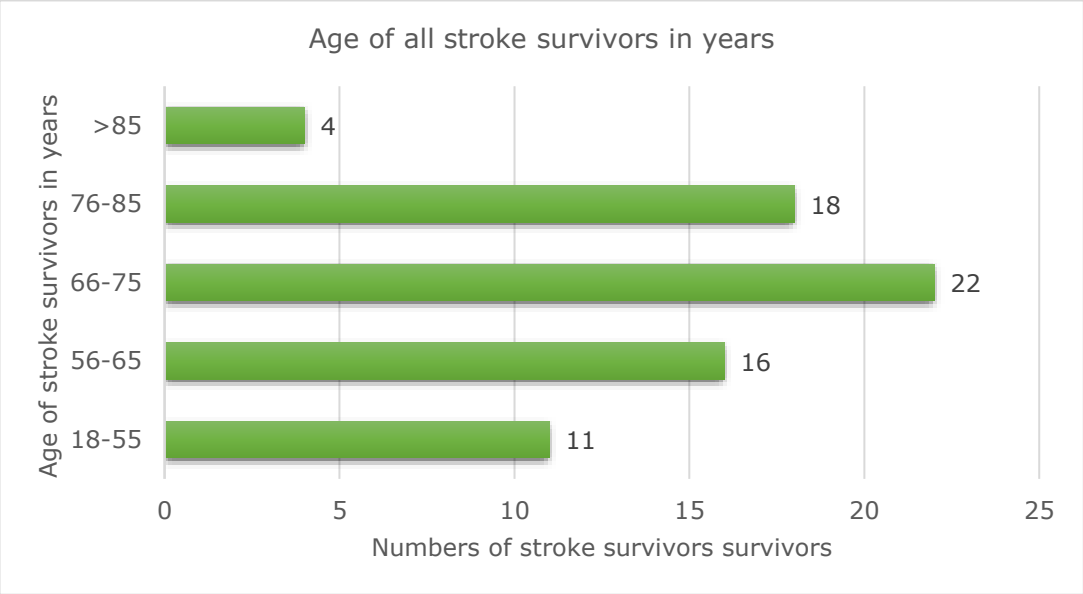
There was a higher proportion of male stroke survivors (n=49, 65%) than females (n=22, 29%) (Figure 4). There were four missing data. There were also more male stroke survivors (n=8, 67%) with young carers than females with young carers (n=4, 33%).

Figure 4 Gender of stroke survivors



A small majority (n=44, 57%) of stroke survivors were over 65 years old. The majority of the sample of stroke survivors with young carers were under 55 years (n=7, 58.3%). Ages can be seen in Figure 5.

Figure 5 Age of stroke survivors



2.5.3 Demographics and co-residency

Sixty-three stroke survivors lived without young carers. Of these 34 lived solely with their spouse or partner, 15 lived alone, seven did not complete the question, and seven lived with people in addition to, or instead of a partner or spouse as shown in Table 10. The maximum number of people living with a stroke survivor was six (Figure 6). None of the stroke survivors living alone received support from a young carer. Twelve stroke survivors lived with 21 young carers and four children who were not recorded as providing care. Children not providing care but resident were aged 6, 16 and two 19 year olds (Table 11). Two of the stroke survivors lived solely with young carers (each with two young carers) and these were all reported as the primary carers. In all other cases there was another adult living in the same household. Two stroke survivors received support from one or more grandchildren. Grandchildren were resident with one stroke survivor (n=1 young carer), but not the other stroke survivor (n=3 young carers). The remainder of young carers were supporting parents. The vast majority of children and young people residing in a household were providing some care with the exception of one 6 year old in one household and in a further household two sons aged 19 and 16 and one of the son's girlfriend aged 19 were reported as resident but not recorded as providing care (Table 11). Two stroke survivors reported that their sons and daughters were providing care but did not declare their age (Table 10). These could also potentially be young carers.

Figure 6 Numbers of people living in the household - all respondents

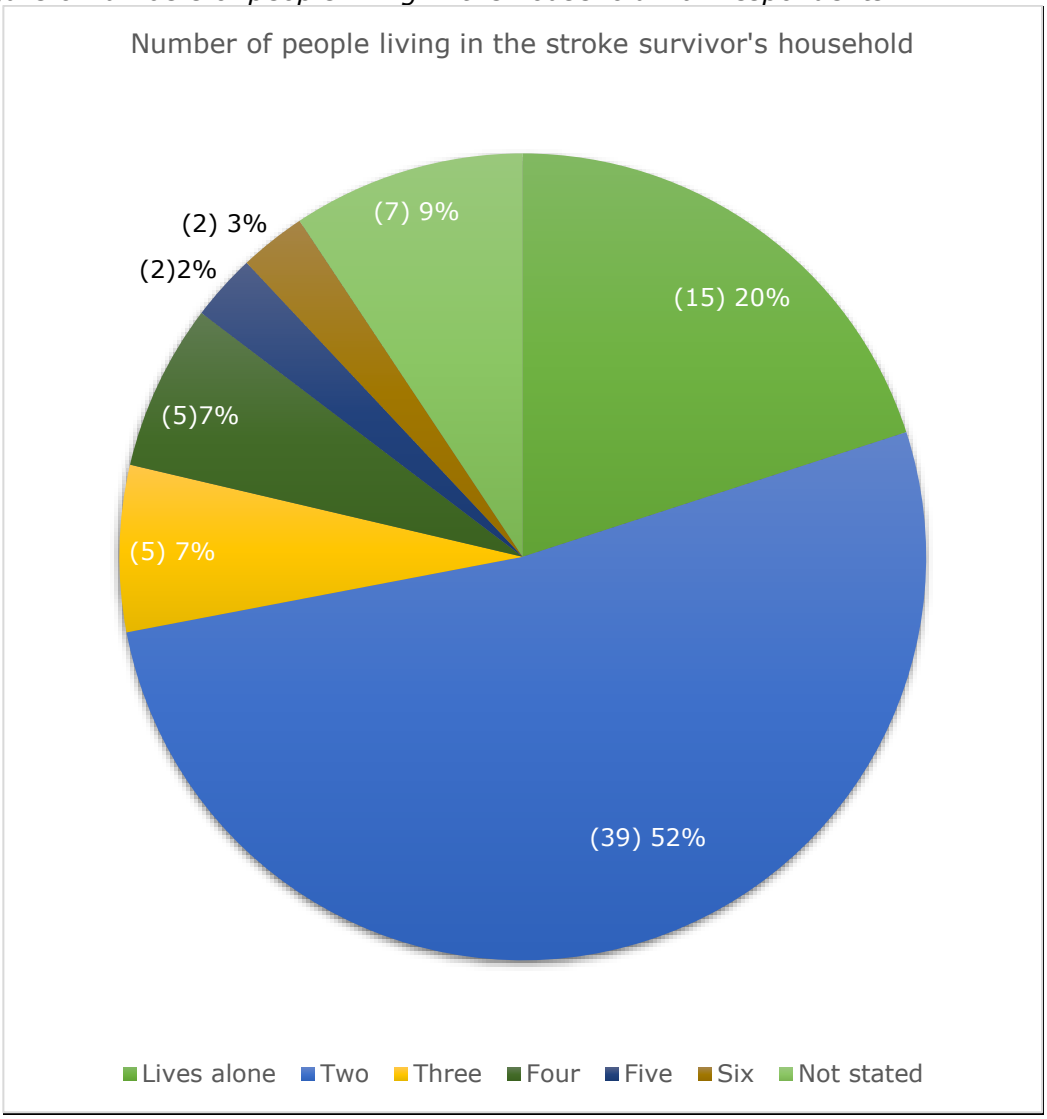


Table 10 Stroke survivors without young carers – co-residents

Gender of stroke survivor	Total residents in the house	Age range of stroke survivor	Number of stroke survivors	Named main (primary) carer	Relationship to stroke survivor of co-residents	Comments
Male	2	56-65	5	Wife /partner	Wife /partner	
Male	2	66-75	7	Wife	Wife	
	2	76-85	10	Wife	Wife	
Male	2	>85	2	Wife	Wife	
Female	2	19-55	1	Husband	Husband	
Female	2	56-65	4	Husband /partner	Husband /partner	
Female	2	66-75	5	Husband	Husband	
Male	2	19-55	1	Housemate	Housemate	
Male	2	56-65	1	Daughter	Daughter	
Female	2	76-85	1	Daughter	Daughter	
Male	3	19-55	1	Brother	Brother Brother in law	Age of carer not stated
Male	3	19-55	1	Wife	Wife Daughter	
Female	3	56-65	1	Husband	Husband Son	Age of carer not stated
Female	4	>85	1	No main carer named	Daughter Son Partner	Paid carer less than 5 hours a week. Son and daughter reported as carers but not the partner. Age of carer not stated

N.B Age of carers all over 25 years unless, 'not stated' is recorded in the comments column

Table 11 Stroke survivors with young carers - co-residents

Age range and gender of stroke survivor	Total residents in the house	Named main (primary) carer	Young carers' relationship to stroke survivor	Age of young carer in years	Comments
19-55 years					
M	4	Wife	Son Daughter	11 9	All residents contributing to care
M	5	Partner	Step daughter Stepdaughter Stepdaughter	20 15 15	All residents contributing to care
M	6	Partner	Son Daughter Daughter	14 17 13	Son 6 years old not recorded as contributing to care
M	3	Wife	Daughter	22	All residents contributing to care
F	6	Wife	Son Daughter	15 24	Mother in law and Father in law resident but not providing care
F	5	Husband	Son	22	Son 19, Son 16 and Son's girlfriend 19 resident but not recorded as providing care
F	4	Both sons	Son Son	16 12	Partner resident but not recorded as providing any care. Bothe sons recorded as main (primary) carer
56-65 years					
M	2	Both daughters	Daughter Daughter	21 18	No partner and both daughters reported as joint main (primary) carer
M	4	Wife	Son Son's girlfriend	20 19	All residents contributing to care
M	3	Husband	Daughter Son	14 20	All residents contributing to care
M	3	Wife	Granddaughter	17	All residents contributing to care
66-75 years					
F	2	Husband	Granddaughter Granddaughter Granddaughter	17 14 12	Granddaughters not resident but providing care

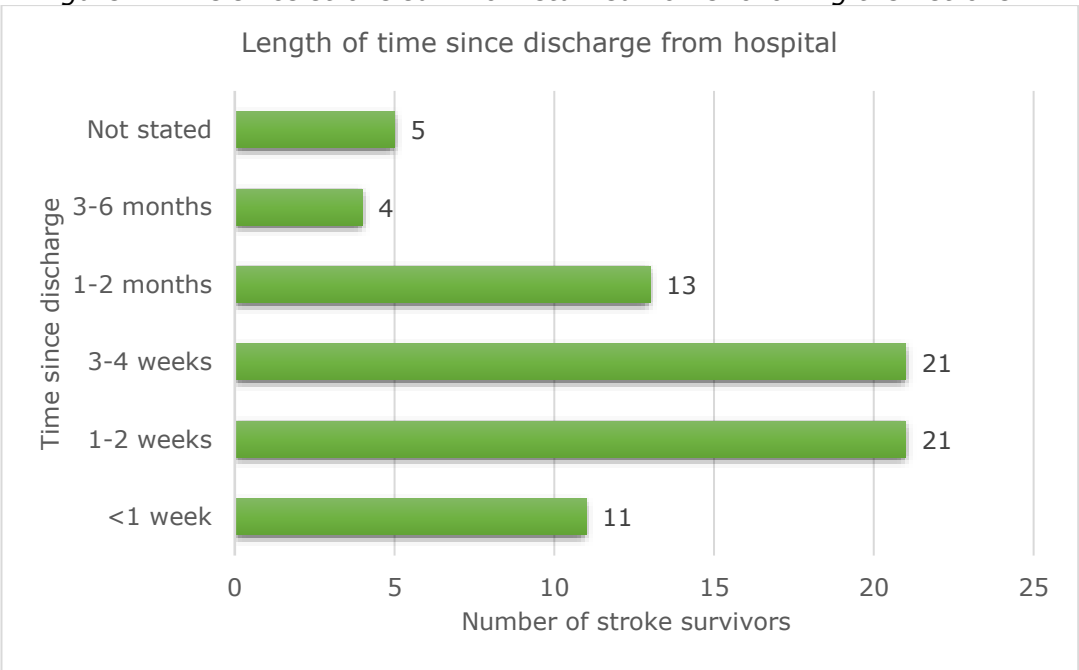
2.5.3.1 Time since stroke and return home

Days were calculated from the 1st of the month in which the stroke occurred (only the month of stroke were collected) to the date of receipt of the questionnaire at the University.

The time from the stroke occurring to return of the questionnaire was mean 76.2 days; minimum 9 days; maximum 369 days.

The length of time stroke survivors had been at home following their stroke was between 1 week and 6 months with the majority (n=66, 88%) being under two months (Figure 7).

Figure 7 Time since stroke survivor returned home following their stroke



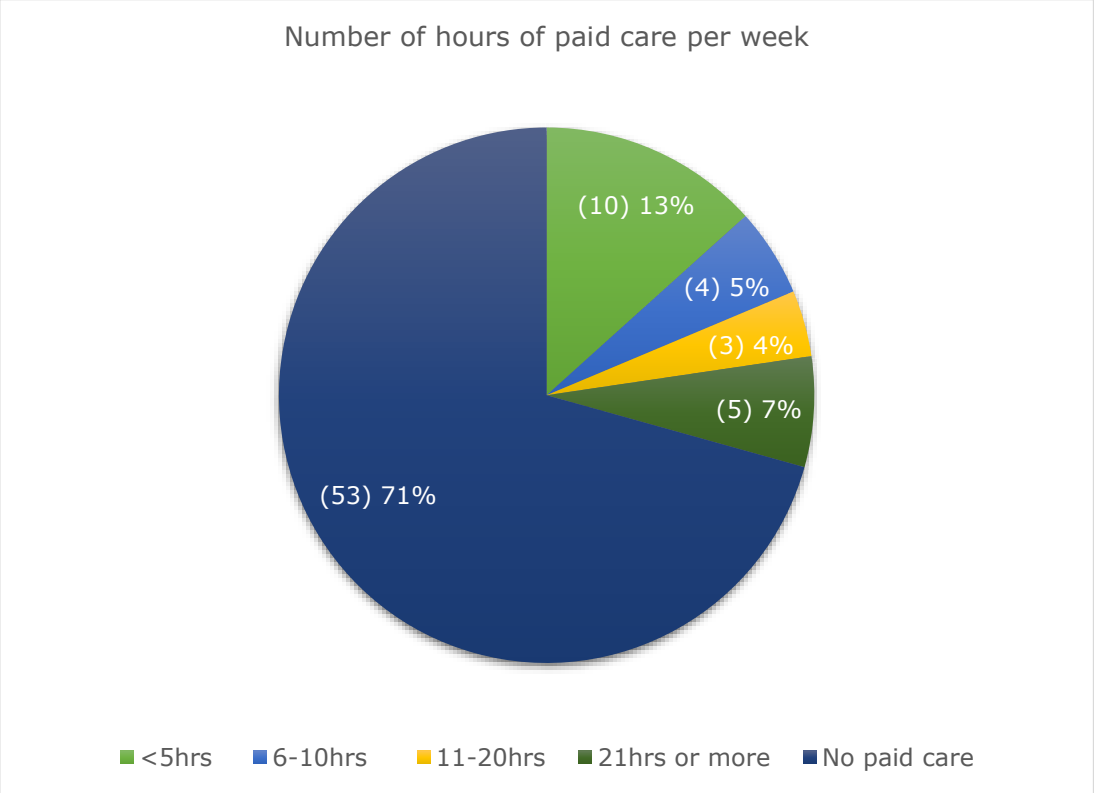
2.5.4 Support needs of stroke survivors

There were 74 responses for this section.

2.5.4.1 Support from paid carers

Numbers of stroke survivors with paid carers were small (Figure 8). There were 21 (28%) stroke survivors with employed paid carers. Only four (33%) of the stroke survivors with young carers employed paid carers; two with over 21 hours of paid care per week, one 6-10 hours and one under than five hours a week.

Figure 8 Numbers of hours stroke survivors received paid care per week



2.5.4.2 Unpaid support from family and friends

Frequency categories were; some of the time, all of the time, never, not applicable or not completed.

- 'never', 'not applicable' and 'not completed' categories were combined and shown as 'never'.

The 36 individual tasks were merged into five categories shown in Table 12 below.

Table 12 Categories of support needs

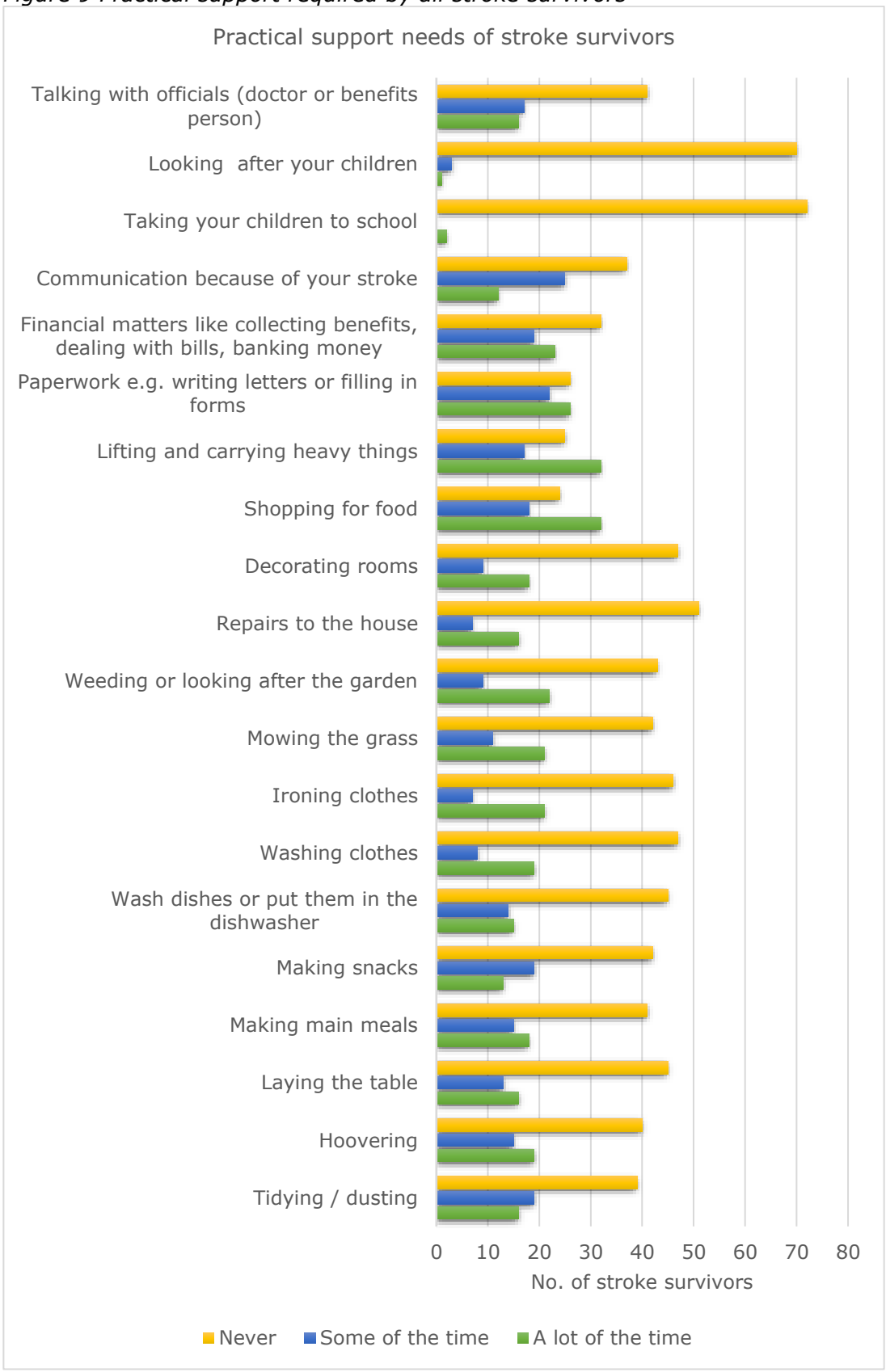
Category name	Number of tasks in the category
Practical support needs	20
Physical support needs	2
Nursing support needs	2
Personal support needs	8
Emotional support needs	4

2.5.4.3 Frequency of support needs by individual tasks

2.5.4.3.1 Practical support needs

For practical support, taking your children to school (n2, 2.7%) and looking after your children (n4, 5.4%) were least often required. The most common practical support needs were shopping for food (n=50, 67.6%), lifting and carrying heavy things (n=49, 66.2%) and help with paperwork e.g. writing letters or filling in forms (n= 48, 64.9%). See Figure 9 for details.

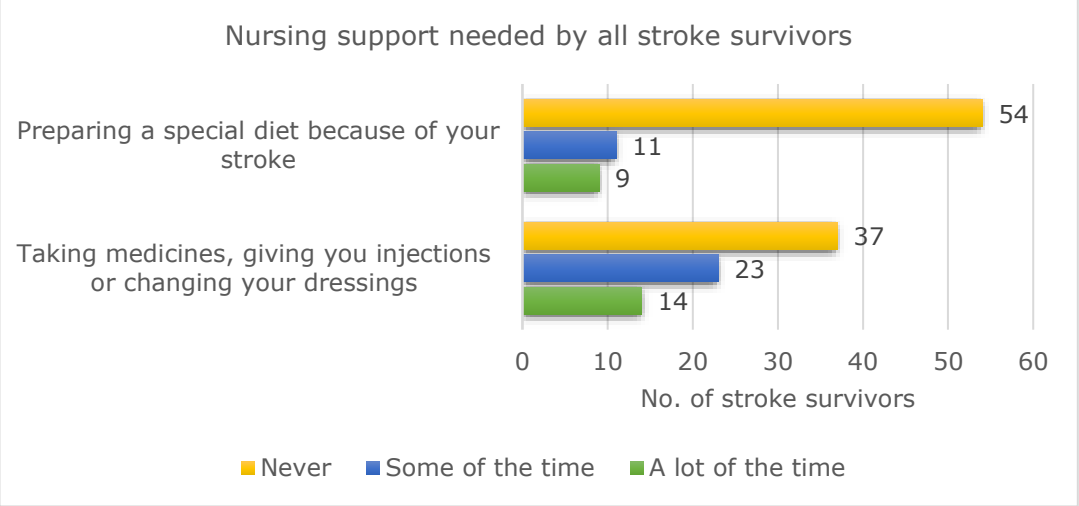
Figure 9 Practical support required by all stroke survivors



2.5.4.3.2 Nursing support needs

For nursing needs, (n=37, 50%) half of the stroke survivors required help with taking medicines, administering injections or changing dressings, and n=20, 7% needed help preparing a special diet because of their stroke (see Figure 10).

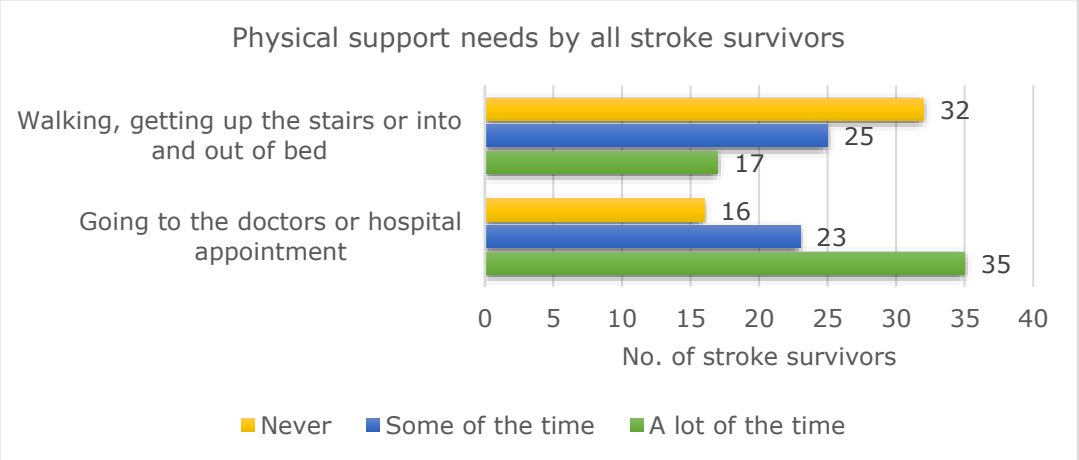
Figure 10 Nursing support required by all stroke survivors



2.5.4.3.3 Physical support needs

Help with going to the doctors or hospital appointments was the highest physical need (n=58, 78.4%) and n= 42, 56.8% needed help walking, getting up the stairs or into and out of bed (see Figure 11).

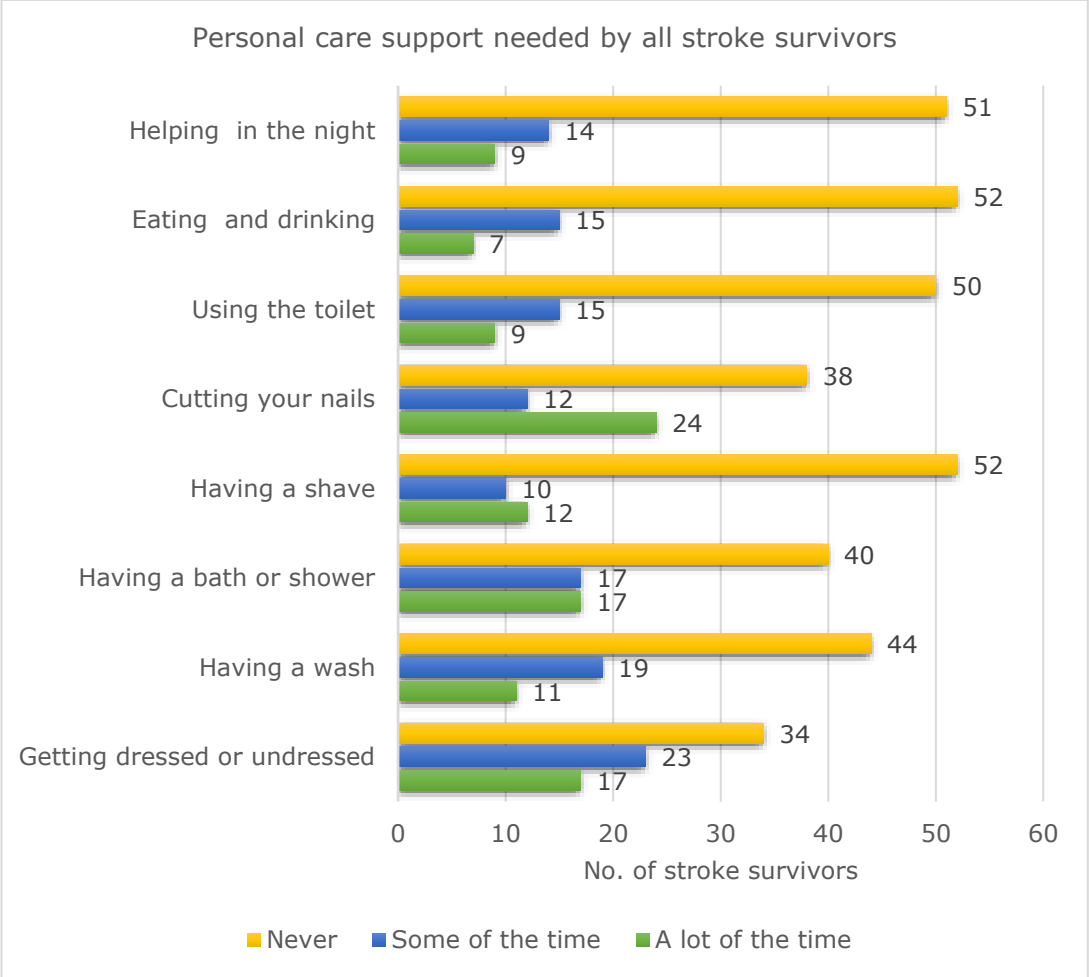
Figure 11 Physical support required by all stroke survivors



2.5.4.3.4 Personal care support needs

The greatest personal care needs were help with getting dressed or undressed (n=40, 54.1%), cutting nails (n=36, 48.6%) and help with bathing or showering (n=34, 45.9%). Having a shave (n=22, 29.7%) and eating and drinking (n=22, 29.7%) were the least frequent personal care support needs (see Figure 12).

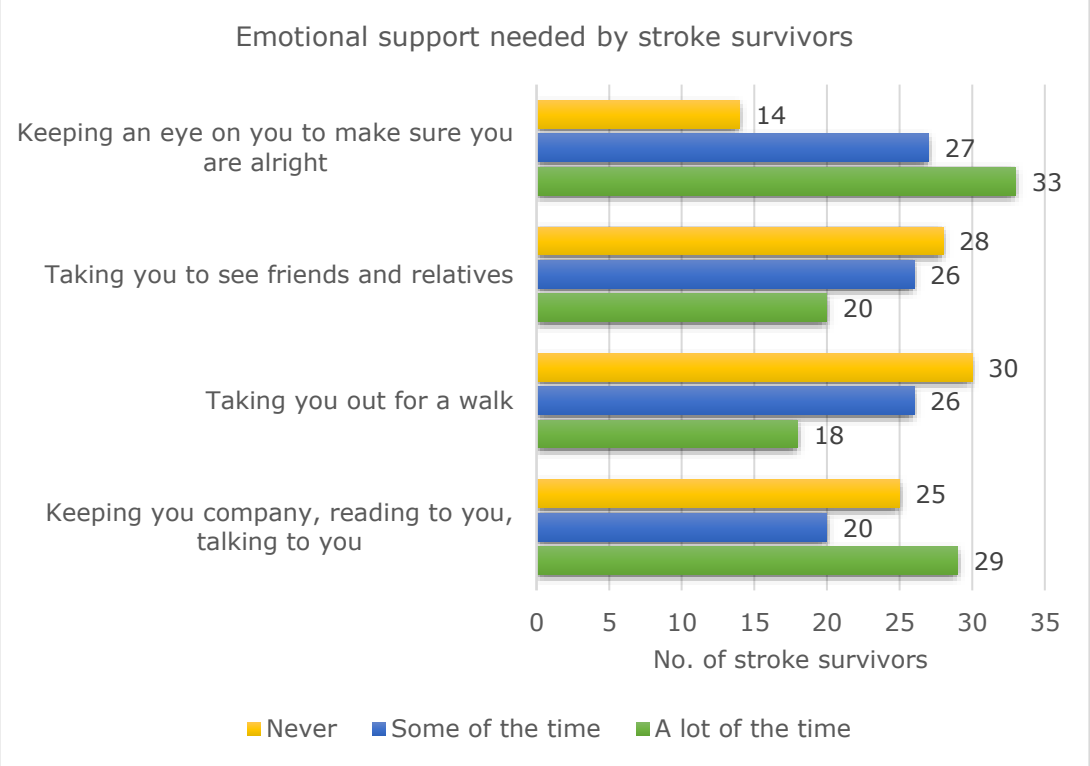
Figure 12 Personal support needed by all stroke survivors



2.5.4.3.5 Emotional support needs

The least frequently reported emotional support need was being taken out for a walk (n=44, 59.5%) and the most common need was having someone to keep an eye on the stroke survivor to make sure they were alright (n=60, 81.1%). See Figure 13.

Figure 13 Emotional support needed by stroke survivors

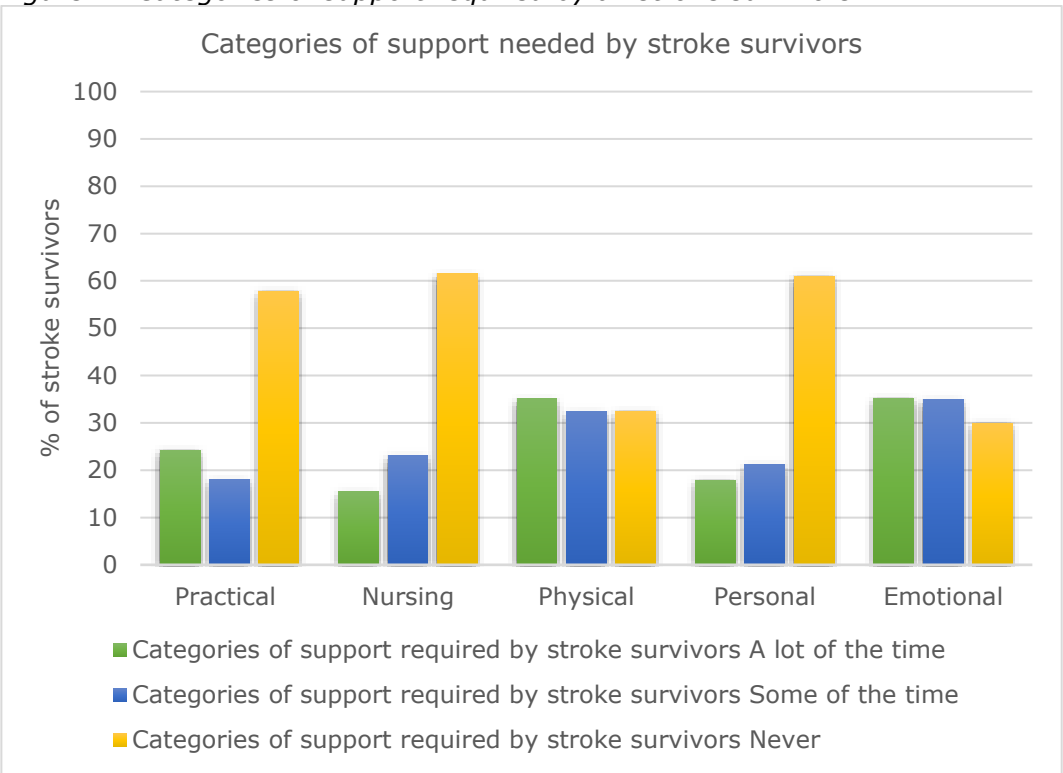


2.5.4.4 Support needs by category

Overall, emotional support needs were the most commonly reported (70.1%) followed by physical support needs (67.5%), practical (42.2%), personal (39%), and nursing support needs (38.5%) being the least frequently reported need.

100% of this study population require some support from family and friends for their ADL and the majority (n=63, 84%) required some emotional or psychological support. All (n=12,100) of the sample of stroke survivors with young carers reported emotional support needs (Figure 14).

Figure 14 Categories of support required by all stroke survivors



2.5.4.5 Additional tasks identified in free text

The questionnaire also asked for free text answers on any additional support needs that were not included in the questionnaire. Additional tasks not included in the questionnaire were read and re-read repeatedly until four overarching themes and fourteen sub-themes were revealed (Table 13).

Table 13 Themes and sub-themes of additional tasks identified by participants

Themes	Sub-themes
Mobility	Driving and transport Pushing a wheelchair Social
Physical	Helping with exercises Personal care Visual problems Physical aids
Practical	Walking the dog and looking after pets Practical tasks Environment
Well-being	Emotionality and emotional support Psychological support Cognitive support Fatigue

The largest overall theme was well-being encompassing emotionality and emotional support (n=14 stroke survivors), psychological support (n=2), cognitive support (n=7) and fatigue (n=1). Support was needed while coming to terms with changes in cognitive ability such as memory and communication, or physical disabilities such as visual loss. Fear of having another stroke or it happening to another loved one and fear of falling were mentioned. Disempowerment and feelings of helplessness were mentioned by three. Seven people had cognitive problems requiring support such as memory and communication.

The next largest theme was mobility. Ten people stated that they were unable to drive and needed help with transport. Four required pushing in a wheelchair and one person was bedridden. Three people had visual problems requiring practical help. Items identified by stroke survivors that were not included in the questionnaire can be seen in Table 14.

Table 14 Additional support needs identified by stroke survivors

Themes	Sub-themes	No of stroke survivors	Quotes
Mobility	Driving and transport	10	Not able to drive (x9 people) "*Getting me to doctor or hospital appointments*" x3
	Pushing a wheelchair	4	"*Going out in a wheelchair needs someone to assist*"
	Social	3	"*Taking me out to maintain sanity"* *"Using the internet and phone to keep in touch with my family" (overseas)* *"Going into town and shopping*"
Physical	Helping with exercises	1	*"Helping with exercises given by Occupational Therapy"* *"Motivation –sharing progress on exercises"*
	Personal care	3	*"Washing my hair"*

			"I have no use of my left leg, arm and only partial use of my left leg and cannot walk. I am currently confined to a wheelchair and totally reliant on carers for my day to day living". *"Needs full-time care. Bedridden and unable to complete any tasks".*
	Visual problems	3	*"Help dialling telephone numbers - unable to see numbers clearly"* *"Guiding around due to sight loss"* *"Reading instructions TV Times / guide"*
	Physical aids	2	*"Adjustments to chair by a neighbour so it doesn't move when I sit / stand"* *"Buying unusual objects e.g. shoe horn / sponge ball"*
Practical	Walking the dog and looking after pets	2	Looking after the pets and walking the dog
	Practical tasks	7	*"Setting the ironing board up"* *"Receiving visitors"* *"Sorting out medication"* *"Day to day running of my business"* *"Carer arrangements. Setting up domiciliary care, liaison with health professionals e.g. community stroke team, district nurse, occupational therapist etc."* *"Watching up and down stairs"* *"Only filling glasses half way to avoid spilling"* *"Laundering"* *"General housework"*
	Environment	1	*"My current property has heavy duty fire doors and I struggle with them because I am still in recovery period, the doors are really heavy. At the property our stairs are incredibly steep and I find that a real challenge. I feel incredibly nervous because I am scared of a fall. I'm still very shaky and unsteady on my legs and my current property is a hazard considering my situation"* *"The inside and outside stairs cause me a lot of bother"*

Well-being	Emotionality and emotional support	14	*"Feeling that I cannot do anything. Frustration"*
			"Felt de-powered at first"
			"Not able to drive or cope with practicalities"
			"No disability from stroke but needs general care and companionship"
			"Friends and relatives visit me"
			"Emotional well-being and support to become self-managing"
			"Listening to me and understanding moods and tearful times"
			"Distressed as couldn't remember the names of family members"
			"Sometimes when family, friends come to see me feel emotional because I am happy to see them"
			"When it was my wife's birthday"
			"Family buying cards and flowers for me"
			"Staying overnight when husband is out"
			"Learning to deal with visual loss"
			"Coping with PIP assessment"
			"Dealing with worry over finances. Currently getting £88pw and struggling"
			"Taking me out to be involved in buying a bed"
			"Since the stroke the stroke has mentally changed me, my outlook on life has changed, I am very aware that I could suffer a stroke but also anyone else".
			"I feel incredibly nervous because I am scared of a fall".
	Psychological support	2	*"Onward support Community Mental Health Team"*
			"Occupational therapist and psychologist"
	Cognitive support	7	*"Remembering things"*
			"Difficulty in using ATM and card reader. Couldn't locate where to put card in"
			"Reminding me as to medicines"
			"Communication"
			"Reading"
			"Writing"
			"(Name) has aphasia which means that he has difficulty talking, reading and writing"
			"Understanding of the situation"

		"Communicating with people as I suffer from aphasia"
Fatigue	1	*"Eliminated the bulk of physical activity. Very slow recovery included mental"*

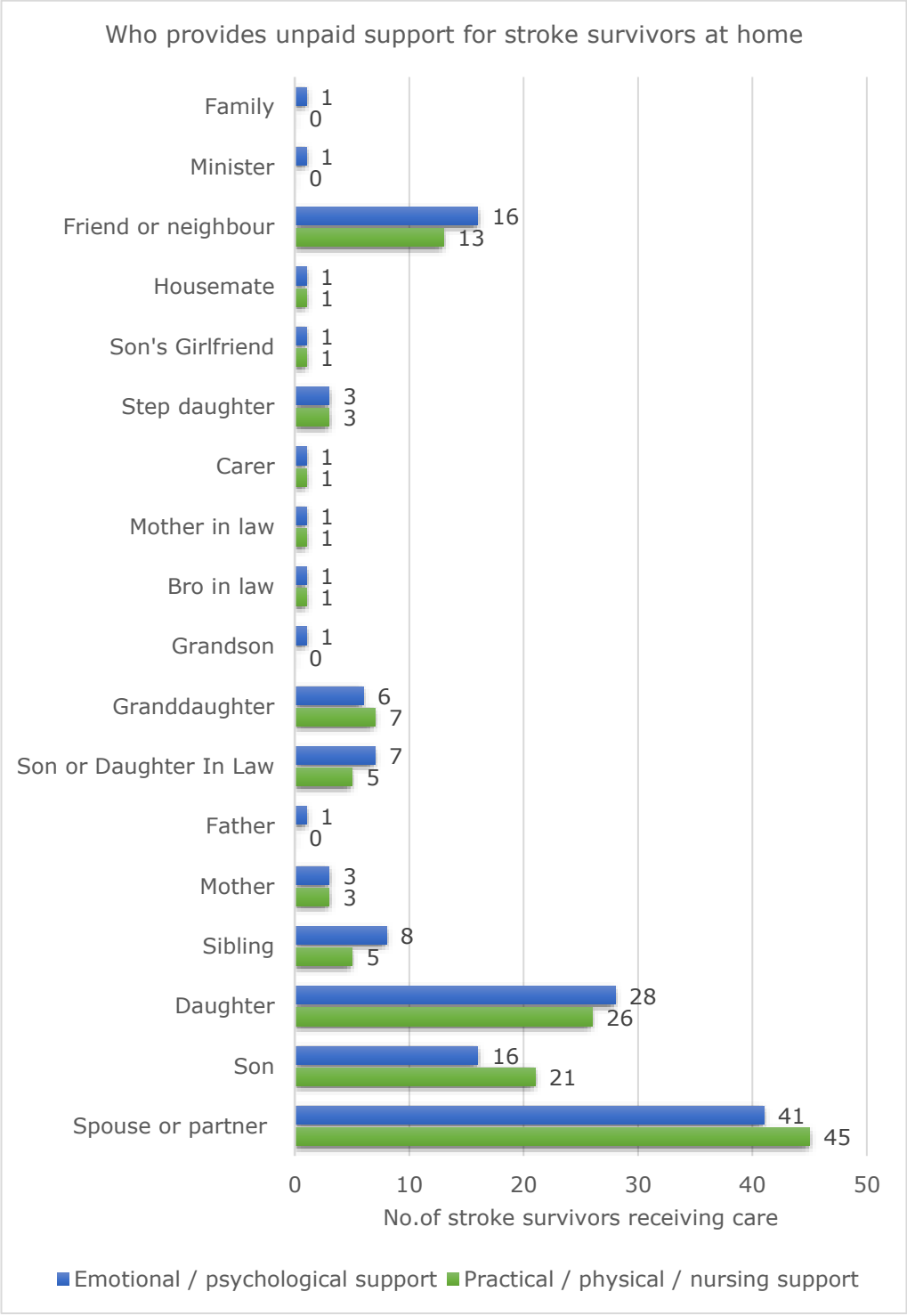
New items identified that were not included in the questionnaire were:

- Driving
- Pushing someone in a wheelchair
- Using the internet or phone
- Guiding and helping someone due to sight loss
- Adapting the house
- Walking the dog and pet care
- Receiving visitors
- Motivation and helping with exercises
- Prompting memory

2.5.4.6 Relationship of supporters

Spouse and partners were the most common supporters for both practical (n=45) and emotional (n=41) support. Daughters were the next most frequent supporter providing slightly more emotional (n=28) than practical support (n=26), and sons provided slightly more practical support (n=21) than emotional support (n=16). See Figure 15.

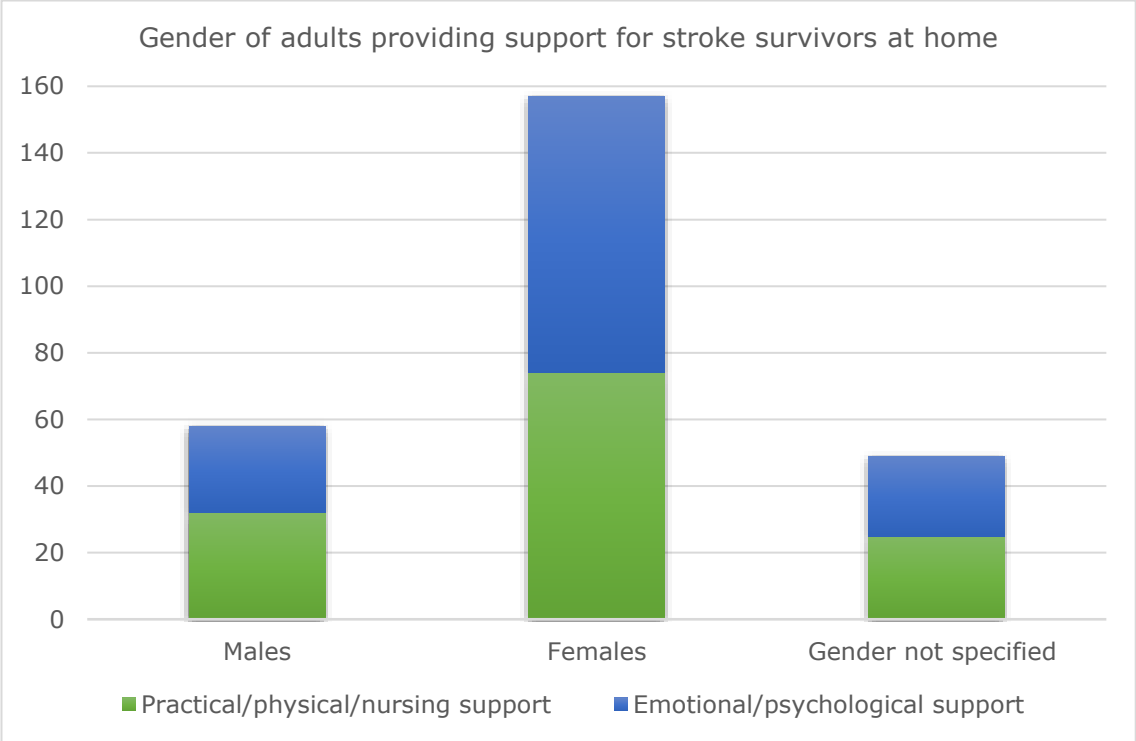
Figure 15 Friends and family providing support at home for stroke survivors



Overall, there were more female carers and they were providing less practical (n=74) and more emotional support (n=83) than male carers who were

providing more practical support (n=32) than emotional support (n=26) (Figure 16).

Figure 16 Gender of people providing unpaid support to stroke survivors



2.5.5 Young carers

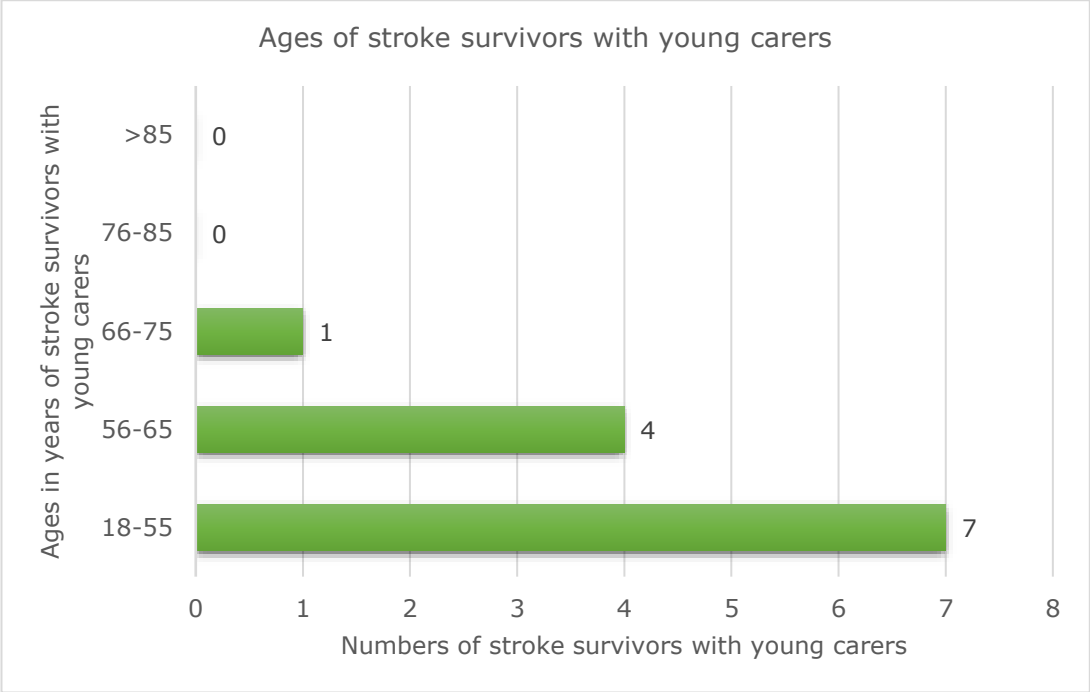
There were 24 young carers identified. Young carers were defined as any children or young people aged under 25 years of age who were identified by the person completing the questionnaire as providing any care or support for the stroke survivor. Question nine in the survey asked who the main carer was. These main carers are referred to in this study as primary carers. All other people providing care, and not named in question nine as the main carer, are referred to as secondary carers. The gender of stroke survivors being cared for by gender of young carer can be seen in Table 15.

Table 15 Numbers of primary and secondary young carers

Young carer	Number	Primary carer	Secondary carer	Providing care for males	Providing care for females
Male	8	2	6	4	4
Female	16	2	14	12	4
Total	24	4	20	16	8

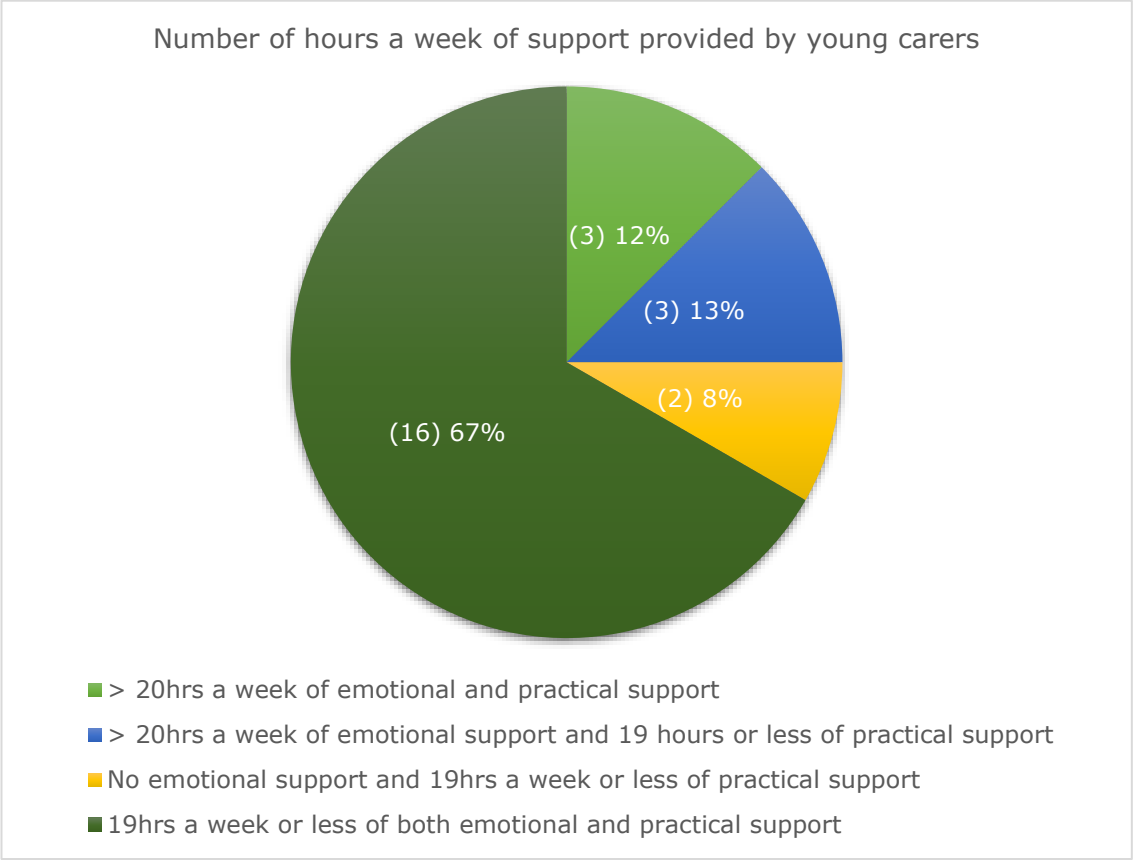
The age range of young carers was 9-24 (mean 16.5 years). There were twice as many females (n=16) as males (n=8). The ages of the stroke survivors with young carers can be seen in Figure 17.

Figure 17 Age of stroke survivors with young carers



Four young primary carers were identified caring for two stroke survivors in lone parent households. The remaining 20 young carers were secondary carers with another adult, usually a spouse or partner being identified as the main carer. Three (12%) young carers were providing 20 hours or more a week of both practical and emotional care. These were all primary carers. The fourth primary carer was providing 15 hours a week of practical care and 20 hours a week or more of emotional care. Two young carers were providing only emotional support. The majority (n=16, 67%) were providing 19 hours or less a week of both practical and emotional support. Details can be seen in Figure 18.

Figure 18 Number of hours of support provided per week by young carers

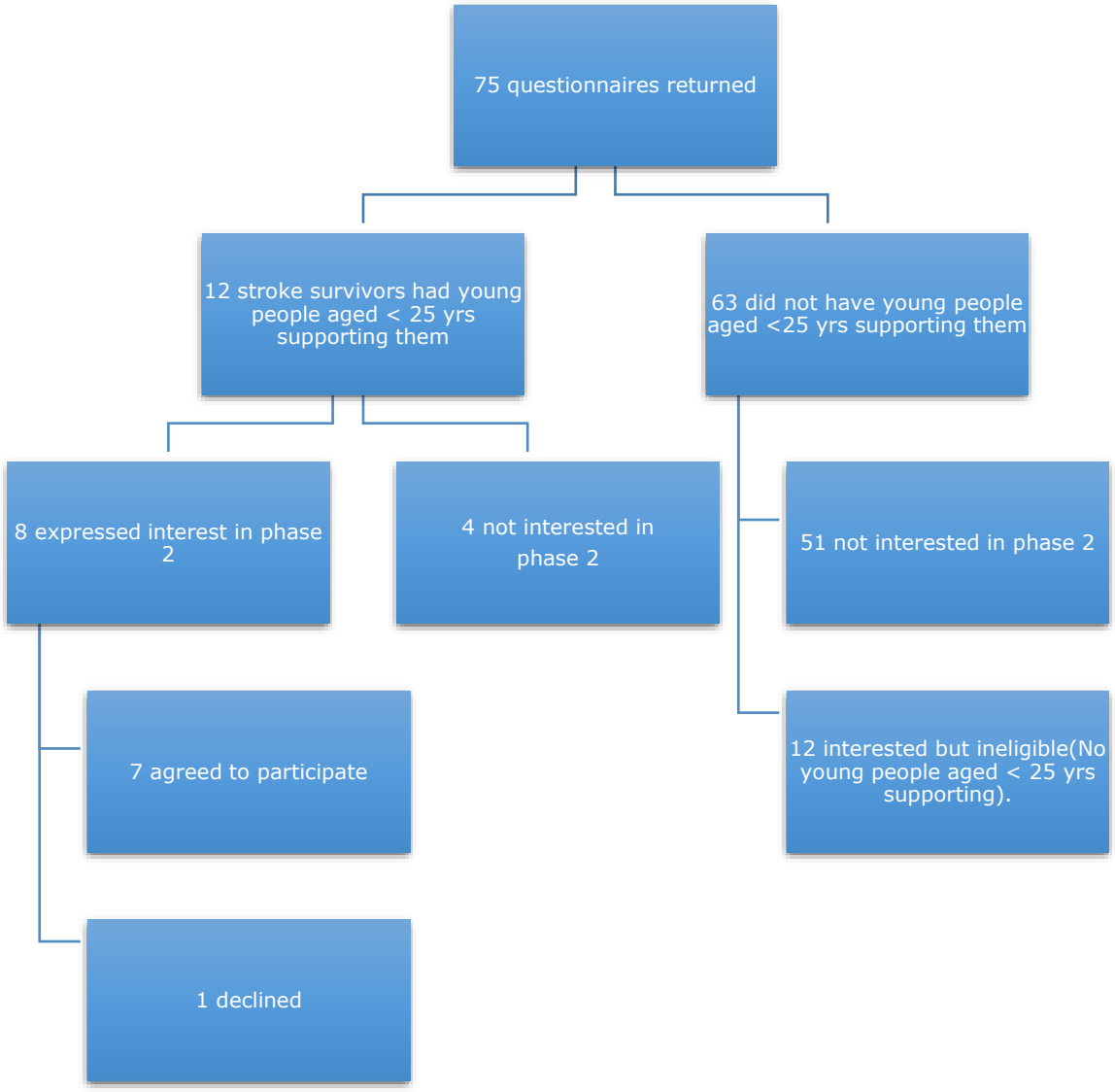


(N.B Practical in this chart incorporates practical, nursing and physical support, Emotional includes emotional and psychological support)

2.5.6 Participants for Phase Two

A final aim of this first phase of the study was to identify potential participants for the second phase of semi-structured interviews with stroke survivors and their young carers. Participants were asked if they were interested in hearing more about the study either by post, email or telephone; 24 people indicated an interest in the next phase of the study. Of these 16 were not eligible as they did not have any young people aged under 25 years supporting them. One of the remaining eight declined further involvement and seven agreed to take part (see Figure 19).

Figure 19 Diagram to show stroke survivor interest in phase two of the study



2.6 Discussion

As very little is known about young carers of stroke survivors this first phase of the sequential study design for the PhD provided the foundation knowledge upon which subsequent phases of the study were built. The key purpose of this study was to try to capture the essence from families of what comprises caring and support before children are identified as young carers and without any preconceived ideas being imposed by statutory agencies. The results provide some insight into the support needs of stroke survivors living at home after discharge from hospital following a stroke, and who is providing the support. The

data showed that there are young people aged under 25 years are providing care and support for stroke survivors living at home in the East Midlands and provided some information on the contribution they were making to support the study participants. The recruitment via this route into phase two of the PhD was very limited.

2.6.1 Population characteristics

The majority of stroke survivors in this study were over 65 years and male, which is as is commonly reported in the literature (Royal College of Physicians, 2017; Stroke Association, 2017). A systematic review of sex differences in stroke epidemiology also found that male stroke incidence was 33% higher and prevalence was 41% higher than females (Appelros et al, 2009 p.1082). In this study young carers were supporting eight males and four females. This was unusual as most studies report young carers support mothers more commonly than fathers (Aldridge & Becker, 1993b; Becker et al, 2000; Bilsborrow, 1992; Dearden & Becker, 2004; Ecorys, 2016) and a recent large scale study commissioned by the Department for Education in the UK that aimed to provide a baseline of the lives of young carers in England also found that 55% of young carers were caring for their mother (Cheesbrough et al, 2017a). It is likely that the difference was due to the demographics of stroke with a higher incidence and prevalence in males or alternatively could have been caused by chance due to small numbers.

2.6.2 Residents in the household

Two of the stroke survivors in this study were lone parents each with two of their children as primary carers. The remaining 20 young carers lived in households with at least one parent or step-parent in addition to the stroke survivor. This is unusually high as most studies report children caring in lone

parent households (Becker et al, 2000). Aldridge & Becker (1993b) in their study comprising in-depth interviews with 15 young carers found that some of the young carers also had fathers living with them or close by, who refused to help with the care. There were no cases of mothers refusing to help (p.45). This would suggest that the presence of another adult in the household does not necessarily mitigate the need for some children and young people to take on the caring role, neither should there be an assumption that a co-resident adult will be shouldering all the responsibility for caring (Dearden & Becker, 2000b).

2.6.3 Time since stroke and return home

The time since discharge was positively skewed. This was partially due to two outliers at 288 and 117 days. Timings will also have been affected by the distribution methods used for the questionnaire. Teams distributing the questionnaire were ESD teams. ESD teams have a time limited period within which they work with stroke survivors at home, often a maximum of six weeks from discharge from hospital. Therefore, as expected and intended, the majority of respondents were in the early phase of the stroke rehabilitation pathway in the community.

The early stage of the pathway may have influenced some of the responses as caring roles, particularly for younger members of the family may not yet have been established or recognised. Families may have been still living from day to day as has been reported as a coping mechanism for carers in the early days after stroke (Hunt & Smith, 2004) which could have influenced their responses to the questionnaire.

2.6.4 Support needs

2.6.4.1 Paid and unpaid support

The results showed 100% of this study population required support with some aspects of their ADL and the majority required some emotional or psychological support (n=63, 84%). As 71% of the entire population and a similar proportion 67% of the sample with young carers did not have paid support it could be assumed that they were relying on friends and relatives to provide the majority of needed support. We did not explore whether paid care was available and not wanted by the family, or whether it was not available and therefore enforced the role of carer(s) on the family.

Some adult carers have been reported in the literature as feeling coerced into taking on the caring role in the belief it is expected by health care professionals (Stroke Association, 2013; 2016). This can have an adverse impact on their mental health and well-being (Greenwood et al, 2008; Greenwood et al, 2009a), a finding replicated in young carers studies (Bolas et al, 2007; Rose & Cohen, 2010). Studies have also shown that professional support for stroke survivors after discharge from hospital is variable and limited in some areas (Care Quality Commission, 2011; East Midlands Academic Health Science Network, 2015) and stroke survivors and their carers often feel abandoned once they are home and do not feel as well supported as they did in hospital which can also be detrimental to their mental health (Stroke Association, 2013; 2016). The number of stroke survivors dependent on friends and relatives to provide support for ADL varies in the literature. Stroke Association (2015) figures state that over one third of stroke survivors will be dependent on others and one in five on friends and family. Other studies have reported higher rates, such as Dewey et al (2002) who found in their Australian study of informal support for stroke survivors, that 74% of participants required support from family and

friends for ADL which is more in line with the findings from this study. This variation in the amount of support needs reported in the literature could in part reflect the lack of a standard definition and agreement of what comprises care and support, and possibly the heterogeneity of disease and disability types studied. It could also be participants' understanding and beliefs regarding where the boundaries lie between delivering practical, physical, emotional and nursing care and the emotional component of caring present within many friendships and family relationships (Pearlin et al, 1990) such as described in section 1.3 of this thesis.

In this study, families appeared to be providing much of the required support and this is consistent with findings from previous studies as discussed above.

Emotional support needs were high for the study population and for the stroke survivors with young carers. These higher levels of emotional support needs in this younger age group were not unexpected. A survey with 2,700 responses was undertaken by the Stroke Association (2013) to look at emotional impact of stroke on stroke survivors and their adult carers in the United Kingdom. They reported that the emotional impact of stroke was particularly apparent in the 30-59 age group with anxiety (76%), depression (69%) and fear (55%) featuring highly (p.10). A further survey of 1,424 stroke survivors in the UK (Stroke Association, 2016) also reported that 70% of stroke survivors experienced depression or low mood (p.7). In this study we did not explore whether these needs were being fully met, rather just identified that there were needs and who was providing some of that support.

2.6.4.2 Additional tasks identified in free text

The questionnaire included a free text option to explore tasks requiring additional support that were not captured in the questionnaire design. Some of

the free text responses included practical tasks that were present on the questionnaire, however some items were new.

- Driving
- Being pushed in a wheelchair
- Using the internet or phone
- Guiding and helping someone due to sight loss
- Adapting the house
- Walking the dog and pet care
- Receiving visitors
- Motivation and helping with exercises
- Prompting memory

These items are unlikely to be unique to stroke however, they are particularly relevant for the condition. Mobility was an issue in terms of being able to drive as the current guidance is that people must not drive for one month after stroke (DVLA, 2017). This is due to the complexity and uncertainty of the type and degree of both physical and cognitive deficits ensuing from stroke (Stroke Association, 2012b). The timing of the administration of questionnaire in the patient pathway would mean that many respondents who normally drive would be in the one month post stroke prohibition period, hence the probable reason for the high rate of reporting it as an issue. It is not possible to assess how many would not be given permission to drive after the month and so for whom the restrictions could create a permanent constraint on their lives.

Visual problems including needing help to be guided around, and help coming to terms with sight loss were not unexpected as up to two thirds of people have been reported to experience visual problems after stroke (Stroke Association, 2012d). A multicentre study of visual impairment following stroke found that of 323 stroke survivors, only 8% had normal vision after stroke. The remainder

were found to have problems with eye alignment/movement impairment, visual field impairment, low vision and perceptual difficulties. This was a higher proportion than expected and may have been due to the recruitment criteria which was patients post stroke with suspected visual problems (Rowe et al, 2009). A Cochrane review of interventions for visual field defects in patients with stroke reported that 20-57% of patients experience visual field defects after stroke. The deficit impacted functional abilities such as mobility, driving, and reading, quality of life and ability to engage in rehabilitation, and increased depression, anxiety and social isolation (Pollock et al, 2011). This is therefore an important need with a significant impact on many areas of stroke survivors' lives if the need generated by the visual impairment is unmet.

Problems with cognition were specifically mentioned by seven people. Cognition is the mental process of knowing, including aspects such as awareness, perception, reasoning and judgement. Those mentioned by respondents included memory, communication and specifically aphasia; reading and writing and help to understand the situation. Problems with cognition are common after stroke (Patel et al, 2002; Stroke Association, 2012c). In a systematic review and meta-analysis of the literature Flowers et al (2016) found that rates of reported aphasia after stroke varied from 25-50% in community settings and further complete recovery by 18 months occurred in less than one quarter of the sample. Similarly to visual field deficits, the impact is potentially significant in terms of numbers of people and the degree to which each individual is affected. Problems with communication and cognition in particular have been associated with poorer mental health outcomes for adult carers (Anderson et al, 1995; Scholte Op Reimer et al, 1998; Williams, 1993). However, other studies have linked more severe physical disabilities to poorer outcomes. Low et al (1999), in a literature review of the impact of stroke on informal carers cautions that many

of the studies they reviewed had methodological weaknesses, lacked refinement in terms of definitions, and consistency of standardised outcome measures used.

Well-being was a common area of additional need reported by 14 people. This incorporated emotional, psychological well-being and social support. Frustration at not being able to do things they could do before their stroke and not being able to cope in general, or with more specific issues like benefit claims, were mentioned. Fear of falling and having another stroke was described by one person. These same areas were reported in a large-scale survey by the Stroke Association. In their survey of stroke survivors and their carers, the Stroke Association (2013) found that eight out of ten stroke survivors did not feel that they were given appropriate help and advice coping with the emotional aspects of stroke (p. 5). This lack of formal support impacts on the adult carers of whom 79% had experienced anxiety and 56% depression and who also did not receive help or support with their emotional or psychological well-being (p.5). In addition, 63% of stroke survivors reported their greatest fear was of having another stroke (p.10).

2.6.5 Relationship of carers

The most common carers in this study were a spouse or partner. Daughters were the next most frequent carer and they provided slightly more emotional support than practical support, whilst sons provided more practical than emotional support. This pattern was repeated in the overall carers, with more female carers and they were providing more emotional than practical support, whilst male carers were providing more practical than emotional support. This gender bias has been reported in previous studies (Greenwood et al, 2008; Greenwood et al, 2009a; Hirst, 2001; Ingersoll-Dayton et al, 1996). Dahlberg et al (2007) in a secondary analysis of the 2001 census data identified that in the

younger age group, women were more likely to be caring, for a greater proportion of their time. However, by the older age groups (70+) there were a larger proportion of males. In this study, the larger majority of female carers is because there were a higher number of male stroke survivors being cared for by their spouse/partner.

2.6.6 Demographics of young carers

Overall, a small number of young carers were identified from the questionnaire. As the questionnaires were completed by either the stroke survivor or another adult, spouse, partner or health care professional, it is possible that the degree to which the young people identified were supporting was not accurately reported (Aldridge et al, 2016a).

In this study, a larger number of female young carers than male were identified. This has been found in previous studies (Aldridge & Becker, 1993b; Becker et al, 1998) but it is unusual for the difference to be quite as marked as it was in this study. The difference could be because the mean age in this study is higher at 16.5 years than is commonly reported in the literature at 12 years (Becker et al, 2000; Nagl-Cupal et al, 2014), and because caring responsibilities increase with age (Aldridge & Becker, 1993b) and disproportionately more so for female young carers (Becker & Becker, 2008a; Dearden & Becker, 2004). Participants in the Aldridge & Becker (1993b) in depth qualitative study of 15 young carers in Nottinghamshire, in the East Midlands had an average age similar to this study of 15 years (p.10).

2.6.6.1 Primary carers

Four primary young carers were identified in this study and in all cases, there was no other adult living in the household. The remaining carers were identified

as secondary carers. The distinction between primary and secondary carers has been included in previous studies (Aldridge & Becker, 1993b; Meredith, 1991; O'Neill, 1988). Frank (1995) refers *to "primary carers"* as "*sole carers*" and "*secondary carers*" as "*supportive carers*" (p.18) in her study which aimed to establish the numbers of young carers, their needs, and make recommendations for future services in Hampshire; a small number of children interviewed were primary carers. However, the larger number of secondary carers were often masked as the adult carer in the home was assumed to be the main carer performing and coping with all the caring tasks and this was not always the case. Becker et al (1998) suggest that it is the impact of caring rather than the intensity or extent of the caring role that is important. This would suggest that the distinction between primary and secondary carers is or should become redundant as the perception could be that primary carers have greater needs and a greater legitimacy and primacy than secondary carers. In reality this may not be the case and could result in some secondary young carers who are in need of support being overlooked.

What was not identified in this study was the amount of time young people were spending supporting the unaffected parent. The focus was on the support young carers were offering to the stroke survivor. In hindsight, this was an important omission and should be included in future studies as research has identified that all roles change within a family after stroke (Bastawrous et al, 2015; Greenwood et al, 2010; Greenwood et al, 2009a; Greenwood et al, 2009b; Visser-Meily et al, 2006). Young carers may therefore not necessarily be providing care for the stroke survivor directly, but could be taking on significant extra roles to support the main carer in the household, including paid employment to compensate for the loss of earning by the stroke survivor. These types of additional responsibilities would not have been captured in this questionnaire.

2.6.7 Methodological challenges and response rates

Overall, the response rate for this phase of the study was low with only 75 questionnaires returned which could have led to non-response bias. Non-response bias occurs when not everyone responds to a survey and those who do not respond are different in a way that is important to a study to those who do respond (Dillman et al, 2009). Although postal questionnaires response rates are known to be low (Dillman, 1972), this response rate was even lower than expected.

The low response rate was despite employing as many of the techniques as possible described in a systematic review of questionnaire responses by Edwards et al (2002).This included sending a pre-paid stamped rather than franked envelope, using colour, being addressed from the University of Nottingham, a photograph of the researcher to personalise the introductory letter and an option of returning the questionnaire anonymously. The questionnaires were hand delivered by the clinician to stroke survivors at home and were returned by pre-paid envelopes to the University by the stroke survivor. The personalised delivery of the questionnaire can increase response rates but can also increase variability in the amount of encouragement potential respondents receive to complete and return the questionnaire (Dillman et al, 2009). Therefore, clinicians could have encouraged those they expected to have young carers and missed those whose young carers may have been less obvious, increasing response bias. It seems likely that this was the case given that clinicians admitted informally at a networking event after the study closed to not giving out the questionnaires to all new patients as they had been asked. Reasons given were that they forgot, or they didn't think there were any young carers in the house so had not left a pack, or the social circumstances were complex and they didn't think the family would be suitable for the study. This was despite repeated reassurance and requests that questionnaires were to be delivered to

all new stroke survivors at the first home visit. The lack of delivery of packs was apparent from the numbers of packs left over at the end of the study period, some of which weren't disclosed until several months after the end of the study.

The questionnaire length was also restricted to eight pages of large size font to minimise participant burden. Restriction of length is controversial. Rolstad et al (2011), in a meta-analysis of research into response rates and survey length caution that there is little robust evidence to suggest that length of questionnaire can reliably be correlated with response rate, as content and complexity of questions asked are variables which are difficult to separate from survey length. In this survey, the questionnaire was checked by lay assessors and found to be acceptable and the questions easy to understand and answer.

The order of the questions was also carefully considered and those requiring more personal and sensitive information were placed towards the end. Dillman et al (2009) suggest this increases response rates as respondents are already invested in completing the questionnaire as they reach the end and are more likely to respond to personal questions at this stage. Later questions in this survey related to co-residents, the employment of paid carers and demographic data.

The timing of the questionnaire may also have been an inhibiting factor as the questionnaire was to be delivered during the first home visit by the stroke specific domiciliary care teams. It is possible that families were thrown in to crisis by the stroke and already overwhelmed with the new responsibilities of caring (Stroke Association, 2013). They are also given a large volume of paperwork during the first week at home and were therefore less likely to have the capacity to complete this additional questionnaire. However, a pragmatic decision was made to use this opportunity to administer the questionnaire as it

was important that stroke survivors were invited to participate in a systematic way and there were few identifiable and standardised points in the community stroke pathway at which this could be done. It was also identified by clinical teams as the preferred time point for clinicians to be able to deliver the questionnaire with other standardised documentation.

Previously, young carer studies have recruited participants through young carer projects and this was an attempt to identify young people who were supporting stroke survivors that were not necessarily identified or did not identify themselves as young carers and were not yet known to statutory or support services. It was felt important in this exploratory study that the impact of caring and supporting stroke survivors on young people was investigated without any constraints of predicated determinants of what young caring might comprise in this situation. This was in preference to just finding young people that fitted the orthodox embodiment of a young carer. It was also in an effort to truly explore the experiences of young carers of stroke survivors with as little bias as possible being introduced by preconceived ideas of who and what comprises young carers, and which young people may need support.

A further important reason for identifying young people early in the young carer pathway is to improve their outcomes before patterns of caring become established (Becker et al, 2000; Dearden & Becker, 2000c; Heyman & Heyman, 2013). In a study of 60 young people who cared for, or had cared for their parents, Dearden & Becker (2000c) concluded that services need to rapidly respond to needs of the whole family in particular needs of disabled and ill parents to prevent children taking on inappropriate caring roles and to improve their long term outcomes. In this study, there were no resident children or young people in the stroke survivors' households who were not actively engaged in supporting or caring for them. In other words, there were no children or

young people living with a stroke survivor for whom life had not changed as they all had additional responsibilities and roles. However, the impact of those additional responsibilities was not assessed in this questionnaire, neither was the impact of caring on the adult carers or the stroke survivor themselves. This was felt to be an important area to explore in phase two of the study through the semi-structured interviews with both the stroke survivor and all of the young people aged under 25 years who were living in the household.

A further reason for the low response rate could have been a reluctance on behalf of the stroke survivors to admit that children and young people were supporting them. This is a known limitation of young carer research. So although the questionnaire was aimed at the stroke survivor, and the language used very carefully avoided the use of the term young carer, opting instead to establish what the tasks were and using less evocative terms such as supporting and helping, it is possible that people were still reluctant to admit that children were providing some of their care (Aldridge & Becker, 1993b; Banks et al, 2002a; Becker et al, 1998; Frank et al, 1999; Meredith, 1991; Princess Royal Trust for Carers, 1999).

The final objective for this phase of the study was to identify and recruit participants for the second phase of the study. This will be discussed in chapter three in more detail.

2.7 Conclusion

This study aimed to explore the support needs of stroke survivors living at home in the East Midlands after discharge from hospital following a stroke, and to establish who was providing the support. In particular, information was sought about the numbers of young people under 25 years of age who were supporting,

and the kind of tasks they were helping with. Although the response rate was poor, some useful insights were gained into the support needs of stroke survivors living at home in the East Midlands.

Engaging with young carers and their families is known to be a challenge. Young carers are frequently described in the media and literature evocatively as a 'hidden workforce' or 'hidden army' and with good reason in some circumstances. It is believed that there are many young people who do not recognise themselves as a young carer, or do not disclose their caring status for fear of intervention by statutory services, stigmatisation by association, or for reasons of maintaining the privacy of the family and the cared for person. Similarly, parents are often reluctant to disclose their child is a carer or may not recognise them as a carer. This survey attempted to mitigate against some of these difficulties by attempting to find young carers before they even self-identify or are identified as young carers. The purpose of this approach was to capture the essence of what it is to care for a stroke survivor at home, without imposing pre-conceived ideas adopted from other long-term conditions or illnesses. A second reason was to establish a robust and systematic way of identifying caring early in the patient pathway before patterns of caring, which could be detrimental for some, are established. Questionnaires were therefore distributed early in the community pathway at a standardised point i.e. first visit by a stroke specific domiciliary care team in order to capture data as early in the pathway as possible and also in an attempt to introduce some rigour into the questionnaire distribution process. Tasks were also used as a proxy measure of caring, in an attempt to destigmatise the role of caring, particularly in relation to young caring. However, the method chosen of a survey given at such an early stage in the community pathway was not entirely successful and response rates were disappointingly low. In addition, the attempt to reduce the burden on the participants by collecting some data as ordinal data and keeping the

questionnaire as short as possible in an attempt to optimise response rates meant that analysis potential was restricted and some of the richness of possible data was lost. It was also clear with hindsight that more emphasis could have been placed on the changed roles within the family, rather than just focussing on the individual needs of the stroke survivor.

It was therefore decided to invite stroke survivors and all of the children and young people aged under 25 years who were living with them, to participate in the next phase of the PhD which comprised semi–structured interviews. This was in order to gain more insight in to the roles and responsibilities of young carers of stroke survivors.

CHAPTER THREE - EXPLORING THE EXPERIENCES OF YOUNG CARERS OF STROKE SURVIVORS THROUGH SEMI-STRUCTURED INTERVIEW

3 Introduction

This chapter explores the lived experience of young people caring for a stroke survivor through the voice of young carers aged 11-24 years and the stroke survivors they were caring for. Experts (providers, commissioners and support workers in young carer services) were also interviewed as part of the study. Expert interviews are reported in-depth in chapter four.

Internationally, researchers have reported challenges in engaging with young carers and the people they care for (Aldridge & Becker, 1993b; 1994). The constraints on the researcher's ability to identify and engage with young carers have been attributed to either a lack of awareness of their status as a carer by themselves and the person they care for, or unwillingness by both carer and cared for to expose themselves to external scrutiny by researchers and statutory agencies (Aldridge & Becker, 1997). An additional layer of complexity is added when Health Care Professionals are aware that children are involved in caring and overlook or ignore their needs (Aldridge & Becker, 1993b). Further, the children, young people and families are not informed about the condition or illness they are caring for and are unaware of their rights or where to go for help (Aldridge & Becker, 1997; Becker et al, 1998). Consequently, the scale of the presumed issue of young carers who may need but are not yet receiving support is still not known in the UK. This is despite the strengthened statutory duty for local authorities to identify and assess young carers through the legislative

requirements of the Care Act 2014 and Children and Families Act 2014. No studies of young carers of stroke survivors in the UK were found and very little was found internationally. A rising incidence of stroke in younger people in the UK (Tsendsuren et al, 2016) makes it increasingly likely that more families with children and young people under 25 years of age will be affected by stroke. These survivors will probably be cared for at home and the majority of care is likely to be provided by family and friends. Thus stroke affects the whole family, not just the stroke survivors (Epstein-Lubow et al, 2009; Han & Haley, 1999; Schulz et al, 1988), making this is an important issue to understand and address.

3.1 Background

Young carers are children under 18 years of age and have specific legal rights and protection in the UK, and those aged 18-25 years are often referred to as young adult carers. Young adult carers are legally adults with the associated legal rights to assessment and benefits, but have specific needs related to their life stage and transitions to independence and adulthood (Becker & Becker, 2008a). Definitions are described in detail in section 1.2.5.5.2.

The impact of a chronic condition on a family can be all pervading and management of the illness has been found to involve the entire family (Chikhradze et al, 2017; Metzing-Blau & Schnepp, 2008). Young carers experience a strong: "*we feeling*" (p.9), in the family and draw from the family team spirit to cope with the additional demands on family life brought by the chronic illness (Chikhradze et al, 2017). Young carers have also been reported to be very watchful of the ill parent and have a high degree of worry (Chikhradze et al, 2017). The degree to which the young person can share the worries is dependent on the level of openness encouraged within the family. A higher

degree of openness was associated with improved coping (Mauseth & Hjalmhult, 2016).

Both positive and negative outcomes of caring have been reported for young carers as described in chapter one however, the most important contributory factor consistently reported to increase negative outcomes is the impact of unmet needs on both the young carer and family (Cheesbrough et al, 2017a; Dearden & Becker, 2000c).

The experiences, needs and outcomes for the young carer cannot be separated from that of the family as a whole and agencies are cautioned against focussing on the young carer in isolation. Such an approach is destined to enable the caring role to continue without establishing why it has occurred, what can be done to reduce it and what support can mitigate the more harmful effects of caring and optimise the beneficial aspects of caring (James, 2017). A whole family approach is therefore endorsed as the model of choice for supporting young carers. This approach requires that:

> *when practitioners are working with families, staff whose primary focus is the adult(s) will give due regard to the needs of the child(ren), and any impact on them from adult behaviours or difficulties, and the practitioner whose primary focus is the child(ren) will consider the needs of any vulnerable adult in the family*....(Malin et al, 2014 p.66).

Despite this recommendation gaps have been reported in the provision of family focussed support (Ronicle & Kendall, 2011).

The opportunity to optimise outcomes for young carers and their families and to mitigate any potential harm from caring is apparent from the literature. This

study was an important first step in understanding the impact on young people of caring for a stroke survivor and identifying possible avenues to support them.

3.2 Study aims and questions

This second phase of the PhD aimed to explore the lived experience of young people aged 11-24 who were caring for a stroke survivor residing at home in the East Midlands. The study objectives and questions, shown in Table 16 were:

Table 16 Study objectives and questions for phase two of the PhD

Objectives:	Study questions
To establish what young carers know and understand about stroke and how that knowledge is gained	What do young people know and understand about stroke and how was the knowledge gained?
Establish the needs of children and young people age 11-24 years created by helping to support stroke survivors	What support is required by young people aged 11-24 years who are helping to care for stroke survivors living at home in the East Midlands?
Identify whether needs of children and young carers of stroke survivors are being met and if so, how and by whom	What support is available for young carers of stroke survivors and how is the support accessed and delivered?
Explore in depth the lived experience of children and young carers of stroke survivors from their own perspective and that of the stroke survivors they are supporting	• How is caring for a stroke surviving relative experienced by the young people aged 11-24 years? • What support are young carers providing for stroke survivors?
Investigate the impact of stroke on family roles and relationships	What impact does stroke have on family roles, relationships and future plans?

3.3 Methodology and methods

3.3.1 Philosophical orientation

This phase of the PhD was an exploration of the needs of both stroke survivors, and the young people aged 11-24 years who were supporting them using semi-

structured interviews. An interpretivist-constructionist orientation was considered most suited to address the aims of the study.

Benton & Craib (2011) state this type of exploratory research is commonly situated within an interpretivist-constructionist standpoint. Schwandt (1998) agrees: *"Proponents of these persuasions share the goal of understanding the complex world of lived experiences from the view point of those who live it"* (p.221). Thus, the stroke survivors, young carers, and expert participants in this phase of the study were active agents helping to explain and interpret their life experiences and social world through semi-structured interview. Interpretivists believe there can be no objective knowledge as researcher and the object of the research are intertwined such that the central tenet, how we understand ourselves, others and the world in which we live, is how we see ourselves and how we understand the world (Guba & Lincoln, 1994). Therefore: *"multiple realities exist and are dependent on the individual"*, (Guba, 1996 p.102). These realities can produce conflicting accounts based on different experiences, knowledge and perspectives but none merit greater primacy over the other (Rubin & Rubin, 2012 p.19). This is particularly apposite in this study in which the voice of children and young people were equally as important as all of the others. In addition, the first phase of the PhD had given voice to the stroke survivors but not to children and young people. Therefore, an opportunity to hear the young people's voices was needed.

This phase of the PhD took a phenomenological approach to dive more deeply in to the subject. Moustakas (1994 p.13) explicates the aim of phenomenological research is to determine what an experience means for the individual experiencing it. Thus, the approach in this study aimed to give voice to the lived experience of care received, its delivery, and impact on the children and young

people providing the care, from perspectives of stroke survivor, the young carers, and experts in the field.

3.3.2 Selecting the study design

In accordance with the phenomenological approach, semi-structured interviews were considered best suited to allow a high degree of interaction and flexibility between the interviewer and the interviewee. The interviewee is able to shape the interview to express their own understanding and interpretation of the current situation and their experiences in relation to young carer services and interactions without resorting to trying to attribute causal factors; the point of interest being what is happening rather than why. As van Manen (2016) explains:

> *Phenomenology is more a method of questioning than answering, realising that insights come to us in that mode of musing, reflective questioning and being obsessed with sources and meanings of lived meaning* (p.23).

The 'musing and reflective questioning', were integrated within the interview and during the thematic analysis of the transcripts.

3.3.2.1 Semi-structured interviews

Semi-structured interviews allow an extended conversation between the interviewer and interviewee and encourage the interviewee to*: "answer at length and in vivid detail"* (Rubin and Rubin 2012, p.31).

The method provides sufficient structure to address specific topics of interest for the inquiry, whilst allowing participants to contribute new insights and meaning to enhance the depth and breadth of the exploration of the topic. In addition, a

key benefit of the method is to allow attention to the lived experience whilst simultaneously addressing theoretically driven variables of interest. (Galletta, 2013 p.24). The flexibility offered within the method allows it to be carried out over one or more sessions enhancing opportunity to build trust and rapport and allowing reciprocity between the researcher and participant. Reciprocity can create space for the researcher to probe for clarification, understanding and meaning. Galletta (2013) cautions that reflexivity is also a key part in the process to ensure that probing and clarifying enhance the process and do not stifle opportunities for new insights to emerge (p.24).

3.3.3 Researching with children

Christensen & James (2008) emphasise the importance of undertaking research with rather than on children, listening to what children say and paying attention to ways in which they communicate to help with a progression towards research that is truly co-produced with children. Involving children and young people in research engenders opportunities to view the world through a child centred rather than an adult focussed lens. This potentially provides a depth of understanding of the issues and challenges they face and the relative importance, providing a priority of order in which they could be addressed.

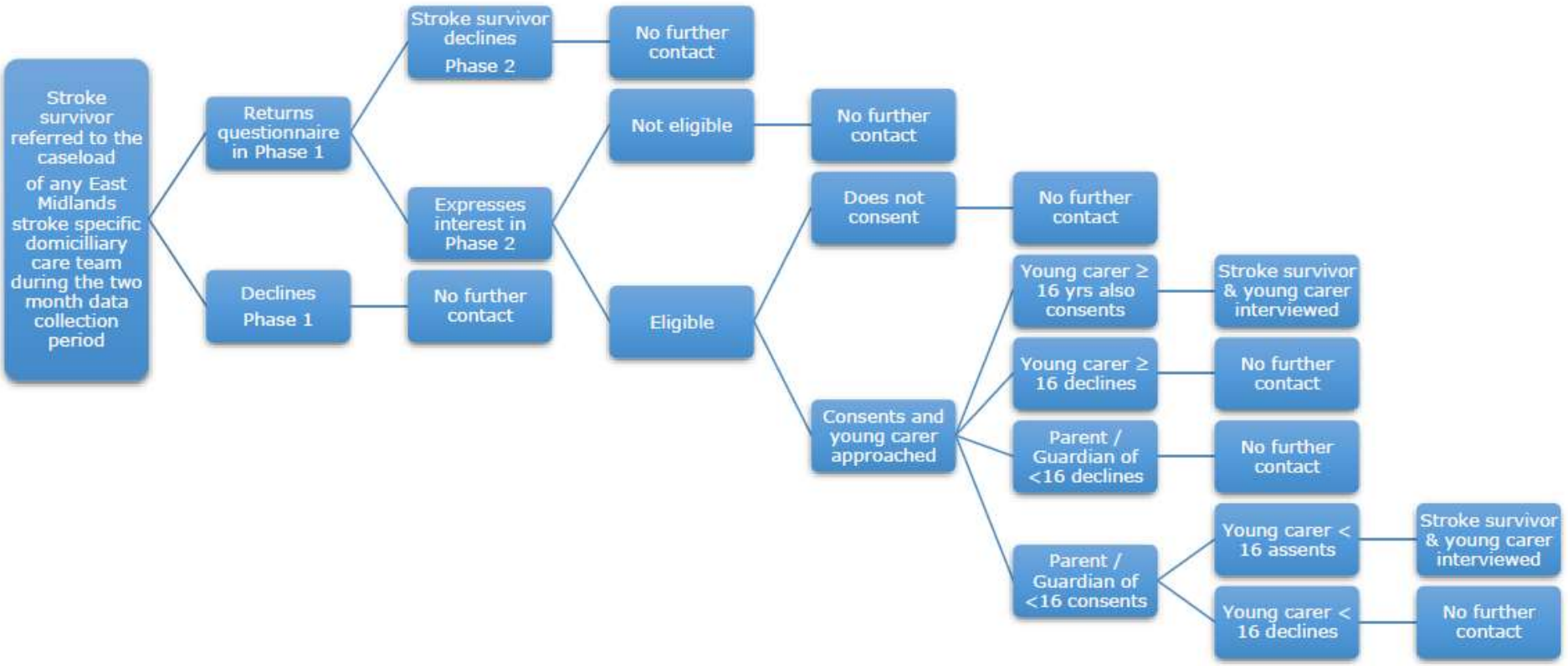
3.3.4 Ethical approval

Ethical approval for the study was obtained from The Proportionate Review Sub-Committee of the London Fulham Research Ethics Committee, REC reference number 16/LO/0548, 21st March 2016 (Appendix 1). See section 2.3.2 for more details.

3.3.4.1 Study amendments

As numbers of potential participants from the planned method of recruitment from questionnaire respondents in phase one was low, an application was made for a substantial amendment to the study protocol. This proposed to extend recruitment across the East Midlands via two voluntary sector support organisations: The Stroke Association and Different Strokes. A favourable ethical opinion was granted on 21st September 2016 by a sub-committee of the London - Fulham Research Ethics Committee ref 16/LO/0548 (Appendix 8).

Figure 20 Phase two protocol flow chart for stroke survivors and young carers



3.4 Methods

3.4.1 Sample size justification

A maximum of 20 dyads of stroke survivors and young carers were initially sought.

There are no specific guidelines and no methods for calculating sample sizes for qualitative research such as there are for quantitative research studies. Marshall et al (2013), in a systematic review of 83 qualitative studies, reviewed the extant literature with regard to justification of sample size, optimal ranges of interviews, and the cultural impact on sample size including journal and country of publication. They reported that there is often little or no justification of sample size in published qualitative research and cultural factors are correlated with the number of interviews conducted. They posit this demonstrates the subjective nature of sample size selection. Based on their synthesis of studies, between 15 and 30 interviews would be considered optimum for this type of study.

Data saturation is one method commonly used in qualitative studies to justify sample size (Bowen, 2008; Charmaz 2003; Mason, 2010; Nelson, 2017; O'Reilly & Parker, 2012). Saturation has been variously described, however Corbin & Strauss (2008 p.263) propose it is:

> *The point in analysis when all categories are well developed in terms of properties, dimensions and variations. Further data gathering and analysis add little new to the conceptualisation though variations can always be discovered.*

The operationalisation of the concept of saturation poses a number of challenges for researchers including lack of agreed process, definition and guidelines for what comprises saturation (Bowen, 2008). In addition, the concept was initiated in grounded theory where saturation is the sum of two parts, namely the iterative

process of data collection, merged with the focus on theoretical concepts in the data (Nelson, 2017). The translation of the concept of saturation in other qualitative approaches which do not comprise these two parts and rely on alternative methods, may result in error created by researchers mistaking repetition of events in the data as evidence of saturation (Charmaz 2014 p.213; Nelson, 2017). O'Reilly & Parker (2012) argue that saturation cannot and should not be used as a quality marker unquestioningly for all types of qualitative research and the cultural shift towards its expected use by academics and journal editors must be challenged. Indeed, Mason (2010) proposes that one occurrence of a piece of data is enough and potentially as useful as many in understanding a process or particular issue within a study. This is because qualitative research is concerned with meaning rather than hypothesis testing, and generating a large sample can be time consuming and impractical due to the labour intensive nature of the analysis. Gaskell (2000) suggests that the number of participants required depends on the nature of the topic and the resources available (p.43). He further claims that more interviews do not necessarily imply better quality or more detailed understanding as there are a limited number of interpretations or versions of reality and the lone interviewer must be able to deal with the corpus of data produced from the interview transcripts. Overload of data can lead to superficial analysis and the loss of intention of the analysis. He thus recommends no more than 15-24 interviews for a lone researcher (p.43). For phenomenological studies, up to 10 interviews has been quoted as the optimum number by Groenewald (2004 p.46).

3.4.2 Participant selection and recruitment

Stroke survivors were recruited from participants who indicated an interest in taking part in the interviews in their survey response in phase one of the PhD. Participants were contacted via their preferred method indicated in their questionnaire response. Options were by email, telephone or post. Participant

information sheets were posted or emailed if stroke survivors and young carers met the inclusion criteria in Table 17. Age appropriate information sheets were also enclosed for the young carers and separate information for parents / legal guardians of young carers aged under 16 years. A minimum of one week was allowed before stroke survivors were contacted again by telephone or email to establish whether both they and the young carer were willing to participate in the study.

Adverts for participants were also placed on the Stroke Association website and leaflets designed to be hand delivered by community project workers to new stroke survivors at first home visits. Team leaders declined permission for the researcher to attend team meetings to engage project workers in the recruitment process. Local Stroke Association support group convenors were also approached to ask permission for the researcher to attend groups to hand out information leaflets. This was also declined and the reason given was that that group convenors did not believe there were any young carers of stroke survivors.

Adverts were placed on the Different Strokes website asking for study participants. The study information was unfortunately incorrectly attached to a different study in another region by the administrator which took several weeks to correct. This could have misled potential participants into thinking the study required more intensive involvement and at more distance to their home than was the reality.

In line with the study protocol, no more than three attempts made to contact each potential participant at any stage. Both the stroke survivor and young carers over 16 years had to consent to participate. Young carers under 16 years of age had to give their assent to participate and consent also had to be gained from the parent / legal guardian. Written informed consent was obtained at the start of the interview

meeting. No remuneration for taking part was offered. The flow chart to recruitment can be seen in Figure 20.

Table 17 Inclusion and exclusion criteria for interview participants

	Inclusion criteria	Exclusion criteria
Stroke survivors	• Aged ≥ 18 years • Living at home in the East Midlands • Returned a questionnaire in phase one and consented to be contacted for phase two or recruited via the Stroke Association website or via Stroke Association community project workers or via the Different Strokes Facebook page • Receiving support from a family member or friend aged 11-24 years • Able to communicate verbally and in English • Give consent to participate • The family member or friend aged 11-24 must also consent to the study. • Young people under 16 years must assent to take part and their parent / legal guardian must also give consent.	• Unable to communicate verbally in English • Living in residential care • Living outside of the East Midlands • Young person supporting them does not consent to take part in the study • The young person aged under 16 years of age, does not give assent to take part in the study and / or the parent or legal guardian do not give consent
Children and young people	• Young people aged 11-24 identified in phase one of the study by a stroke survivor as providing unpaid care or support • The young person and the stroke survivor must both consent /assent to take part in the study	• Stroke survivor does not consent to take part in the study • Unable to meet inclusion criteria

	• Young people under 16 years must assent to participate in the study and the parent \ legal guardian must also consent

3.4.3 Developing the interview schedule

Three semi-structured interview guides including follow on questions and prompts were devised, for age 11-18 years in full time education, 19-24 years in further education or work (Appendix 5), and stroke survivors (Appendix 7). Interview guides were developed following consultation with the Young People's Advisory Group (YPAG as described in chapter two), lay assessors, adult carers of stroke survivors, two young carers, and two young carer project leads.

The interview guides for both groups of young carers consisted largely of the same themes, differing only in the sections related to school or post 18 education / vocational issues for the older group. Themes included:

- Knowledge of stroke and how that was ascertained
- Insights in to the impact of the stroke on the stroke survivor
- Involvement in the care of the stroke survivor
- Awareness of changes to individual and family roles and dynamics
- Perception of benefits and detriments of caring and supporting the stroke survivor
- Friendships and other support, including educational and vocational support and other coping mechanisms
- Future life and career plans
- Ideas for improving services and experiences for future families of stroke survivors.

Themes for the stroke survivors included:

- Impact, effects and affects of their stroke
- Perception of the role and impact of caring on their young carers
- Support needs of young carers
- Suggestions for future improvements is family support

The interview experience was discussed with the first set of interview participants and the order of questions changed as a result to improve the flow of the interview. For the stroke survivors, question seven which was a detailed review of type of support needs, was abandoned after the first interview as it was not felt to add any value. Additionally, the information could be elicited in less direct and obtrusive ways throughout the interview process. As new areas for discussion emerged during subsequent interviews, they were added to the interview schedule and posed to future participants. Rubin & Rubin (2012) classify this approach as responsive interviewing in which the interviewee is treated as a partner in the research; their ideas influencing subsequent questioning and in which interviewing is supportive, non-confrontational and gentle. Further, they purport the study design remains flexible from beginning to end by responding to what is heard through changing questions asked, the participants interviewed and the concepts and themes being investigated. Issues explored evolve as evidence emerges for identified themes (p.38).

3.4.3.1 Interview process

Participants were offered the opportunity to complete the interview over three sessions at a time and place convenient to them. This was recommended by stroke survivors and members of the YPAG during the consultation phase.

Interviews were scheduled for a maximum one hour. Apart from participants' time being recognised and respected as a valuable resource, each group of participants

had specific needs which necessitated time limited interviews. Stroke survivors not uncommonly experience extreme fatigue and the researcher was cognisant of this and the need to limit any additional burden created by the interview process. Rubin & Rubin (2012 p.174) recommend keeping interviews short for children as attention spans can be limited.

Young carers were offered written information on signposting to national and local support services by the researcher at the end of the interview. Information was developed with the help of project workers from young carer support services in the East Midlands.

3.4.4 Data management and transcription

Interviews were audio recorded with the consent of participants and audio recordings were transcribed verbatim by the first researcher. Phenomenological research requires complete transcription but not detailed transcription conventions such as marking lengths of pauses (Thastum et al, 2008). This is because what is said has primacy over the way it is said during analysis.

All electronic audio data were uploaded to the university server on a password protected database immediately after an interview was completed and recording devices were then wiped of all data. All written records were stored securely in a locked cabinet at the university.

3.4.4.1 Data analysis

Data were analysed using a combination of manual techniques and computer assisted software, QSR NVivo (version 11) for Windows. NVivo is a type of Computer Assisted Qualitative Data Analysis Software (CAQDAS). It can assist with storage, organisation, retrieval and sorting of textual or visual qualitative data. Data can be coded for sifting, segmentation and comparison across different codes

to assist with analysis. Visual representations such as word clouds, mind maps, comparison diagrams etc. are available and were therefore generated to stimulate novel thought processes about the data as part of a thematic analysis. NVivo does not analyse qualitative data in the same way as statistical packages analyse numeric data and the researcher must still be actively involved in the identification of themes and detailed analysis of the data. CAQDAS has been criticised by some. Concerns such as: the time commitment in learning how to set up and run the software; interference with analysis by creating distance between data and researcher; limitation on different analytic techniques created by a focus on code and retrieve methods; mechanisation of the analysis aligning it more to a positivist quantitative approach; and a misperception that it can only be used for grounded theory methodology, have been espoused over the past decades since the technology was introduced (Bazeley & Jackson, 2013; Creswell & Poth, 2017; Strauss & Corbin, 1998). In reality, all of these concerns could be equally levelled at paper based systems of qualitative analysis and can be easily overcome with common sense and rigorous application of sound analytical methods (Bazeley & Jackson, 2013). For this study, the combination of paper based and CAQDAS analytical methods were planned to optimise the benefits of both systems.

3.4.4.1.1 Thematic analysis

As the first researcher had completed the interviews and the transcription, they were already very familiar with the corpus of data however, each transcript was read in hard copy at least once at the start of analysis and notes made in the margins of key words and phrases. Transcripts were then uploaded to NVivo. These processes helped to immerse the researcher even further in the data.

As part of the process of sifting and familiarisation of the data, the word frequency query was run in NVivo and word clouds created to stimulate further thoughts

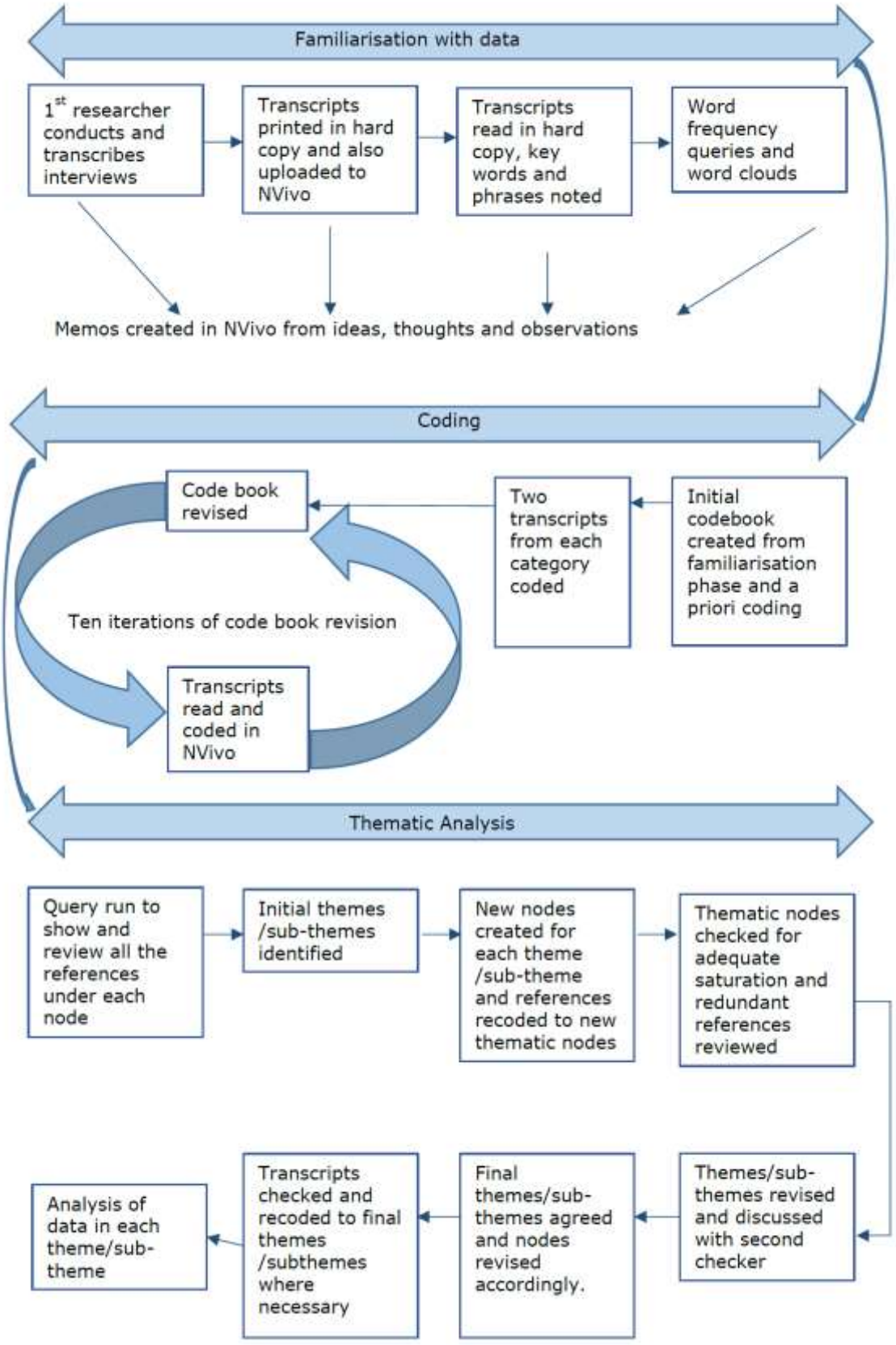
about the data. An initial list of codes was created in NVivo from the memo, word cloud, notes made in hard copy on the transcripts and a priori codes taken from interview schedules. One set of codes was devised for all three categories of participants. Codes were created as nodes and a description of the inclusion criteria for each node was recorded in NVivo. A code book (as an auto function in NVivo) was generated from this and printed in hard copy as an aide memoir to ensure codes were consistently and systematically applied during the remaining coding process. Two transcripts were read in each category and codes applied. Codes were amended and descriptions refined during this process. The code book was then updated. Remaining transcripts were subsequently read in NVivo and the codes applied to the text. As an iterative process, codes were revised and refined as each transcript was read and re-coded. In all, there were ten iterations of codebook revisions. After all the transcripts had been coded with the final code book, a query was run in NVivo to produce a report for each node (code) with all of the coded references listed below the headings. These were read again and notes made of potential themes. Themes were refined through discussion with a senior researcher within the Division and final themes were checked with a second senior researcher in the Division. There were five final themes and 14 sub-themes seen in Table 18.

Table 18 Final themes

Themes	Subthemes
Impact of stroke	Changing relationships
	The lived experience of the biopsychosocial effects of stroke
	Living differently
Insulating the family	Supporting each other
	Protecting each other
	Living in limbo
Children and young carers of stroke survivors	Support needs
	Tasks of caring
	Benefits and detriments of caring
Knowledge, information and learning about stroke	Knowledge
	Information: access, sources, quality and dissemination
Statutory and voluntary sector services for young carers	Identifying young carers and children of stroke survivors who may require support
	Service provision – context, challenges, gaps and good practice
	Educational and vocational issues

After the last iteration of coding with the final themes, a report was run in NVivo to show all the references collated under each theme and sub theme. Explore diagrams (Figure 31 and Figure 32) using the Explore feature in NVivo were also created to review relationships between themes and individual cases. Memos and annotations that had been created during the coding process were again reviewed. A flow diagram of the process of thematic analysis employed can be seen in Figure 21.

Figure 21 Flow chart of thematic analysis



3.5 Findings

This chapter focusses on the stroke survivor and young carer interviews. Expert interviews are reported in chapter four.

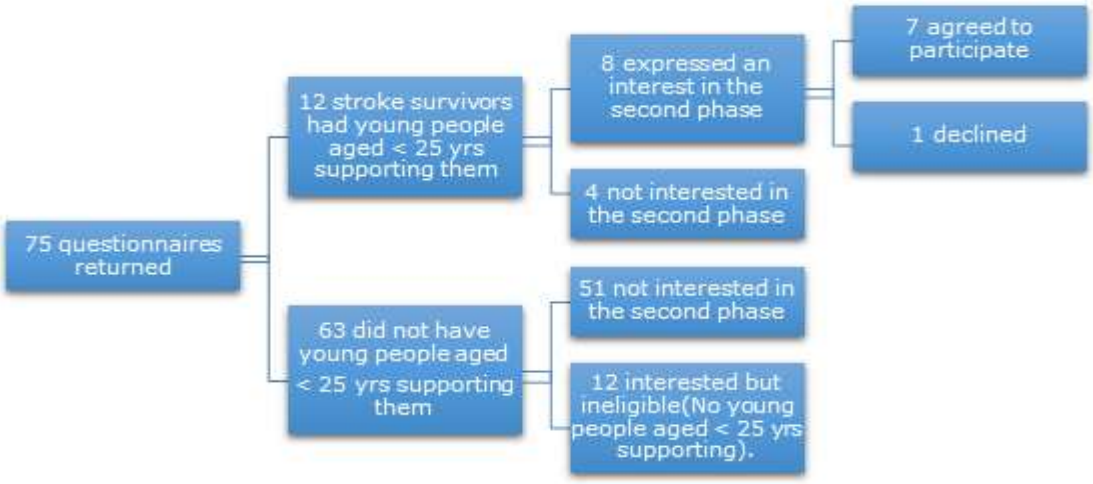
3.5.1 Participants

The survey reported in chapter two revealed twelve stroke survivors were receiving support from 24 young people aged under 25 years, and four of these young people were main carers. Eight of these stroke survivors provided consent to be contacted by the researcher as potential participants for this next phase of the study. One person declined on the grounds that the young people declared as carers on the questionnaire were about to return to school and would not have time to participate. The final recruitment can be seen in Figure 22.

As the first few stroke survivors were contacted, it became clear that it was not feasible to establish which of their young carers should be identified as primary carer to be interviewed as part of the dyad. This combined with low numbers of stroke survivors, created a necessity to interview all young people involved with each stroke survivor, providing the appropriate consent and / or assent could be obtained.

No participants were recruited from the either the Stroke Association or Different Strokes following the study protocol amendments despite frequent postings on social media websites, Facebook and Twitter.

Figure 22 Flow chart to show recruitment for stroke survivors and young carers



Seven stroke survivors and 12 young carers were interviewed which meets the guidance recommended by Gaskell (2000) as described in section 3.4.1.

3.5.2 Interviews

Interviews were all carried out at the stroke survivor's home. One pair of siblings wished to be interviewed together. Although not ideal, some interviews were completed with other family members present where there was only one shared family room.

3.6 Description of participants

3.6.1 Stroke survivors and young carers

A description of stroke survivors can be seen in Table 19 and the young carers can be seen in Table 20.

Table 19 Stroke Survivor Participants

Number of stroke survivors interviewed	Seven
Age	41-60 years (mean 50.6 years)
Gender	Five males and two females
Ethnicity	All White British
Employment before stroke	Social worker, Managing Director, Security guard, Librarian, Kitchen Designer, two were unemployed
Time since stroke	44-366 days (mean 158, median 127 days)
Time since return home	14-127 days (mean 77, median 70 days)
Total Number of young carers	Total 15 young carers (range 1-3, mean 2.1) Four had two, two had three, and one had one young carer
Relationship of young carers interviewed	Daughters – two Sons - six Step daughters - five Granddaughter - one Other one – one
Interviews	18.4 – 103.2 minutes (mean 42.3 minutes)

Table 20 Young carer participants

Number of young carers interviewed	11
Age	11-20 years (mean 16 years)
Gender	Four males and seven females
Ethnicity	All White British
Employment	Five at school, two at college, one apprentice in child care, one at university, two employed
Interviews	15.1-44 minutes (mean 31 minutes)

All stroke survivor and young carer interviews were conducted between July and October 2017. All young carers resided with the stroke survivor and interviews

were conducted on the same day. Stroke survivors were interviewed first, followed by young carers.

3.6.2 Sample description

Seven stroke survivors had a total of 15 young carers and consent was obtained for 11 to be interviewed. The majority (5/7) of stroke survivors were male and there were no single parent households. Stroke survivors were aged 41-60 years (mean 50.6 years). Time since stroke was 44-366 days (median 127 days) and since return home from hospital was 14-127 days (median 70 days) thus, interviews took place at a relatively early stage in the stroke recovery. Most young carers in this sample were female (7/11) and the mean age was 16 years. All stroke survivors and young carers classified themselves as White British. Vignettes describing the families can be seen in Table 21. Names are fictitious to maintain anonymity.

Table 21 Vignettes of participants

Stroke survivor (fictitious names)	Age	Sex	Time since home in days	Time since stroke in days	No of young carers	Relationship of young carers to stroke survivor	Young carers interviewed	Notes
Dennis	58	Male	125	366	2	Son and son's girlfriend	Molly aged 20 (College) Ben aged 20 (Joiner)	Lives with wife (primary carer), son and his partner. Wife resigned from paid employment to care. Profoundly affected by brain stem stroke. No swallow reflex, PEG[3] fed, wheelchair dependent. Conservatory converted by the family to a ground floor bedroom. Paid carers daily. Attends rehab unit x2 weekly for physio and a shower.
Geoff	46	Male	104	228	2	Son and Daughter	Jamie aged 11 (School)	Lives with wife (primary carer) and children aged 11 and 9. No paid carers. Attends hospital for rehab. Home rehab has ended. Profoundly affected by stroke. Wheelchair dependent and communication problems.
Kevin	50	Male	70	78	3	Step daughters and son	Alfie aged 17 (College) Sally aged 13 (School)	Lives with wife (primary carer), 2 stepdaughters, 5year old son and grandchild < 1yr. Wife resigned from paid employment to care. Problems include: visual, cognitive, concentration, communication, impaired balance and mobility, sensory issues with sensitivity to noise and touch and nerve pain.

[3] **PEG** - percutaneous endoscopic gastrostomy. A **feeding tube** is placed through the abdominal wall and into the stomach to allow food, fluids and/or medications to be put directly into the stomach, bypassing the mouth and oesophagus (American Society for Gastrointestinal Endoscopy 2017).

Jim	56	Male	40	44	1	Grand daughter	Laura aged 17 (College)	Lives with wife (primary carer) and granddaughter. Co-morbidities include severe depression and Parkinsonism. Physio and occupational therapy at home. Hemiplegia and balance problems but walks unaided
Les	43	Male	56	140	3	Step daughters	Anna aged 20 (Sales Assistant) Lisa aged 15 (School)	Lives with wife (primary carer), three stepdaughters and one of their boyfriends. Wife resigned from paid employment to care. Wheelchair dependent, communication and cognitive impairment, clinically depressed. The bed and commode were in the lounge which was the only shared space for the family. Paid carers daily.
Sue	41	Female	14	124	2	Sons	Declan aged 12 (School)	Lives with partner (long distance lorry driver away during the week), two sons aged 17 and 12. 12year old provides most care in the week. 17year old in full-time apprenticeship and also a primary carer declined interview. Co-morbidities including rheumatoid arthritis and renal failure, two previous strokes. House is very isolated with no internet connection. Hospital bed and commode in the only downstairs room. Washes at kitchen sink. No paid carers due to remote location.
Jan	60	Female	127	127	2	Daughter and son	Faye aged 14 (School) Jack aged 20 (University)	Lives with husband and two children. Oldest son at University in term time. Husband has severe depression and both children are on autistic spectrum. Fully mobile and self-caring. Some continence problems and depression, very verbose and difficulties concentrating since stroke.

3.7 Reporting of key themes

Of the five overarching themes that were identified, four are reported here; Children and young carers of stroke survivors, Insulating the family, Knowledge, information and learning about stroke, and Impact of stroke. The fifth theme of Statutory and voluntary sector services for young carers is reported in chapter four. Participants are identified by their pseudonym and age in brackets after the quote. The researcher is identified by the initials TC in brackets after the quote.

3.7.1 Children and young carers of stroke survivors

Only two young people in the study identified themselves as young carers. The remaining nine considered themselves as children or grandchildren of the stroke survivor providing family support. Young carers and their families did not therefore appear to identify with the term carer and had a much narrower view of what comprised caring than the very inclusive definitions which are now enshrined in legislation in the UK as described in chapter one. Most young carers defined their contribution to caring as an extension of their routine family life. Their perception of what comprised 'carer' was mainly based on whoever was providing personal and intimate care, whether that was the stroke survivor's partner or a paid carer. They did not perceive emotional and practical support as falling within the remit of carer: *"It is more of the normal family thing for us. My mum is more of the carer. Me and my sister, we are here to help with him but …its normal routine for us"* (Alfie 17).

None of the parents in this study recognised their child as a carer either, even when the amount of care provided was significant including personal care and emptying commodes:

They are just family members. Carers to me come in from a company but family members to me aren't carers they are just family…. You don't see yourself as a title of a young carer do you?"(Sue 41) [Speaking to young carer son aged 12 who shakes his head].

Two of the young people did identify themselves as young carers because they had been given the label of young carer by social services in previous young carer roles:

Who told you were a young carer? (TC)

The school. Then social services referred me [to young carer group]. When you grow up with something like that you don't realise your life is different to everyone else's you just get on with it. It's just how it is. (Molly 20)

Therefore, most were unable to articulate their own support needs and were managing their expressed anxieties and fears in their own way.

3.7.1.1 Support needs of young carers

None of the young carers interviewed in this study were in receipt of support from any statutory or voluntary sector providers and none had received any sort of assessment. Neither were they aware of the existence of any support or services: "*It's just one of those stressful things isn't it. I can't think of any way you could alleviate the stress. It would have been nice like mum said to have had a doctor sit down with you and the family about things that are going on".* (Lisa 17)

Two 17year olds were aware of the availability of support projects for younger carers because of their prior experience as young carers but were not aware of any services for their age group and so were managing by themselves. One 12year old who was the main carer for his mother during the week, was completely unaware of

his rights to assessment and support and was very excited to be given the information by the researcher about support services in the area.
Most young carers were developing their own coping mechanisms which largely involved talking to friends. Several were very selective about which friends they shared information about the stroke, preferring not to talk in detail about their experiences.

The most frequently reported need which applied to all the young carers interviewed was for information about stroke and how to help the person they cared for more effectively.

3.7.1.2 Benefit and detriment of caring

Most young carers and their parents were able to identify beneficial aspects of the caring role and expert opinions of the impact of caring were overwhelmingly positive. Benefits were categorised in terms of attributes enhanced, skills learned, and experiences gained.

Many young carers were able to identify personal attributes that had been enhanced by the experience of supporting and caring for the stroke survivor in that they had learned to be more compassionate, patient, tolerant and considerate of others. Several had learned new skills which had increased their independence such as cooking, shopping, washing laundry and cleaning which they felt would help them as they made the transition in to adulthood. Parents also reported a significant increase in independence as a result of the stroke:

> *Over the past 6 months [since the stroke] it has made them grow up a lot…… They are a lot more independent. .. I used to do everything for them.. make sure their bags were ready for school .., get their school uniforms out,*

but over the last six months I just haven't had the time to do that for them. They have become very independent children. They get themselves ready in the morning, … They will potter around the kitchen and get breakfast whereas I used to so all that for them before. .. I don't think they resent that. I think they are at an age where they are probably ready for a little more independence and I think it's probably forced them into it ... Especially with [son] because he is starting secondary school in September so I think it's sort of been a bit of an eye opener for him and probably what he needed (wife of Geoff).

Some also recognised they were gaining experiences they could put in a CV to enhance future job opportunities as some were considering entering into caring type career pathways.

The two young carers who had accessed young carer projects in earlier caring roles both reflected on the friendships they had gained through the projects and the opportunities and experiences they had accessed which would not have been possible without the young carer projects such as formal nutrition and cookery courses, travelling to Lapland and touring Europe in an orchestra. They both missed the support they had gained in their previous roles as young carers and recognised the positives they had gained as an unintended but welcome positive outcome of caring: *"it [the young carer project] has helped me. I have been to Europe with young carers and played in a music concert with [name of famous person]. That helped me come out of my shell a lot"*

In essence, the reports in this study were overwhelmingly positive with very few negative impacts of caring being reported. Negative experiences were largely

related to a more restricted social life for a few young carers, anxiety about the workload for the well parent and time pressures induced by caring for a younger sibling for one young carer who had assignments to complete for her course.

The impact of the stroke itself was experienced more negatively than the impact of the caring role for both for the stroke survivor and the young carer. Uncertainty over the future recovery and consequent planning, and restrictions on living arrangements were frequently reported. However, it was noteworthy that even though the negative impacts were reported, the families were keen to project a positive image of the way they were dealing with the challenges they were facing. Experts identified young carers report feelings of being trapped in the role of carer and not being able to envisage leaving home, concerns about impacts on future life chances and mental health and wellbeing. The important factor was felt to be timely recognition and support to enhance beneficial effects and mitigate risks and detriment to health, well-being and future prospects.

3.7.1.3 Tasks of caring

Tasks of caring for the stroke survivor were largely described in five different categories: emotional caring; physical tasks; personal care; helping with rehabilitation; and supporting the well parent. It was sometimes difficult to extract which tasks were age appropriate as families varied in expectations of contributions to household tasks and chores before the stroke had occurred.

A further challenge was trying to elicit what constituted age appropriate tasks for young carers as it is a subjective judgement based on personal experience, cultural and individual family norms. Some of the families in the study had not expected children to complete any chores or tasks in the home prior to the stroke and so

even small tasks like preparing their own breakfast at 11 years was a significant change. In other families, this had been expected from a much younger age and for some the changes required after the stroke involved significant demands on their time and involved developing new skills such as helping with PEG feeding. Thus, the change was more of an issue than the task itself. All new tasks and skills were viewed positively by all the young carers.

Emotional support to the stroke survivor was provided by all of the young carers in the study. This included keeping them company and listening to them. Most of the young carers were aware of lability of moods in the majority of the stroke survivors and were trying to be understanding and tolerant even though they did not really understand what was happening. Young carers were also cognisant of the need to motivate the stroke survivor:

> *To help my dad I did his speech and language thing on his IPAD…. but he said it's too babyish ….I helped him with that and I have done a few more chores around the house now because mum has to help him with other things. So I've had to do more or less some of hers (Jamie 11).*

and to remain positive and focus on recovery and particularly on rehabilitation exercises: *"He gets quite upset about what he realises what he can't do. We try to keep him focussed on what he can do to keep him motivated because he can move his right leg a bit and we keep getting him to do that".* (Molly 20)

Some young carers were keen to help with physiotherapy exercises and mobilisation and had watched the professionals and felt they knew what they had to do. This included putting splints on. Others did not feel comfortable to even try because they had not specifically been taught by relevant professionals. Experts

described how exhausting maintaining a positive and motivational attitude was for young carers over time.

The majority of young carers could not identify any tasks that they didn't like doing with the exception of one young carer who said*: "The worst job? Probably taking the commode out because it stinks".* (Declan 12)

All young carers were able to identify that they enjoyed doing almost all of the tasks because of the pleasure they vicariously obtained just from helping and knowing that they were making a positive contribution to the recovery of the stroke survivor. Many expressed enhanced fulfilment from seeing the stroke survivor happy as a result of their help and intervention:

> *What do you like about helping your mum? (TC)*
>
> *Keeping her company so she's alright and helping her (Declan)*
>
> *What's your favourite thing? (TC)*
>
> *I am not sure. Probably everything to help her (Declan 12)*.
>
> *I just like helping him because I know I am doing something good and I know I am helping him very well. And it's helping him to get better so that's what I like with him* (Jamie 11).

Personal care was limited to one young carer. The remainder were protected from having to deliver any personal care by the primary caring adult in the family and the stroke survivor. Most of the participants felt it was neither appropriate nor desirable for young carers to deliver any personal care: *"I like them [young carers] helping me but not when it comes to food or toilet".* (Dennis 58)

3.7.2 Knowledge, information and learning about stroke

Most young carers had a limited knowledge and understanding of stroke which had been gained in an informal, unstructured and ad-hoc way.

Young carers were asked to describe their understanding of stroke. Only two of the young carers had pre-existing knowledge of stroke due to having a previous family member of neighbour who was a stroke survivor. The majority had learnt about stroke by talking to their parents, listening in to conversations by doctors and nurses on ward rounds and handovers and observing the impact of stroke on the stroke survivor they were helping to care for*: "I have [over] heard bits of what the doctor said but I've not really understood it properly. I just know it's something to do with the brain"*. (Laura 17)

Some young carers were still unable to articulate what they thought comprised stroke:

> *It's when you lose all feeling isn't it? (Alfie)*
>
> *There aren't any right or wrong answers. I am just interested in what you understand by it and if anyone has explained it to you. (TC)*
>
> *Not really (Alfie 17)*.

One young carer had been shown a YouTube video by his mother and knew it was a: "*bleed on her brain… Well when people have a stroke they kind of forget some stuff and sometimes they get kind of like … in a mood or something like that, they get stressed out"* (Declan 12).

None of the families could recall any specific sources of information about stroke for children or young carers and no one had been offered any information which in turn led to a lack of awareness of support services that may be available to them. The lack of access to information could have largely been due to a deficiency in signposting by health care professionals, but also in some cases was a lack of opportunity as not everyone had access to the internet at home due to financial constraints or rurality limiting internet connectivity. One young carer said she was sure her grandfather had some written information but as she had severe dyslexia she felt overwhelmed by the volume of information he had and had not been able to access it.

Health care professionals were seen as being task focussed failing to recognise or optimise opportunities to engage with and educate families and young carers in particular. This was both during inpatient stays:

> *Even the nurses, they are very sort of, job and move on. They don't really like, tell you anything. The majority of things I learned from them was from when they were like reading from their handovers to each other at the end of the bed. (Anna* 20)

And in the community: *"they just do their job and then they skidaddle".* (Jamie 11)

The two young people who had previous experience of stroke in grandparents and neighbours did not feel they needed any more information at the time of the interview. They both appeared to be more relaxed and less worried about the future than other young carers. However, this was purely a subjective observation and not measured. The remainder of young carers said they would like some written information. Young carers were asked what they thought would be helpful for families in the future when a family member had a stroke. All of them said

information about stroke would be useful and in retrospect would have helped them. Some felt that information about stroke should be part of the school curriculum and several also felt public awareness was generally still poor despite the FAST[4] adverts on the television which highlights the key signs of stroke. Almost all of the participants had been unaware that stroke could happen in younger people and had been very shocked when it had occurred to their loved one.

Several young carers suggested that information delineating the potential consequences of stroke would be useful. One young carer pointed out that the physical effects were obvious but the mood swings and psychological problems such as depression could not be seen and families needed to be warned to be on the lookout for such things and advised about what they could do to help. Most stated a preference for outside sources or experts to provide them with some guidance on how they could support the stroke survivor more effectively. One young carer suggested that the stroke survivor could be supported by their medical team to produce a list of things they were struggling with and wanted help with from the family and some suggestions for how those needs could be met. This was an interesting point in relation to the difficulties some families reported in talking to each other about the stroke and how it was affecting them all. Some felt the information could be a starting point to open up communication pathways. This is discussed in more detail later.

[4] F.A.S.T is a government campaign with a series of adverts highlighting common presenting signs of stroke. The acronym stands for **F**ace (has it fallen to one side?), **A**rms (can they raise the above their heads?, **S**peech (is it slurred?), **T**ime (if you notice any of these signs it's time to call emergency services)

Several young carers said that now they knew what to look for and what to do if a stroke occurred they felt they could cope more effectively in future. Particularly for families where the stroke survivor had experienced more than one stroke, they felt they knew the subtle signs to look for and knew what to do:

> *Now I feel better because we know the steps to take. Because although on the telly it looks like it like it all happens straight away we know the signs for [Grandfather] like an individual thing so we know what to do now. It's worrying but at least we know what to do* (Laura aged 17).

Young carers felt helpless and out of control without information on what was happening, what to expect or what they could do to help.

Some young carers were providing physical care for the stroke survivors including helping them to transfer between bed and chair, assisting with walking and rehabilitation. None had been shown by health care professionals how to transfer, lift or handle the stroke survivor to prevent injury to themselves or the person they cared for. This included the carers of the three stroke survivors who were wheelchair bound and unable to stand independently. One of these stroke survivors was cared for solely by her 12year old son during the week, a fact which seemed to go unrecognised by the healthcare team who were visiting on a daily basis at the time of the interview. No one in this study reported any physical injuries sustained from their caring role.

3.7.3 Impact of stroke

In this study, we have seen that the effects of stroke had more impact on the young carers interviewed, and on the family unit and the way it functioned than the caring role did. Every aspect of family life was affected for most young carers and

their families. Young carers had to learn to deal with changed behaviours and personalities of the stroke survivor, physical disability, lability of emotions and in one case the loss of the parent to be able to parent as effectively as they had before.

Changes were wide ranging and affected relationships, roles, life styles and routines but also inspired novel adaptions to the home to enable the stroke survivor. Stroke did not happen in isolation and families often had other stresses and life events to deal with at the same time, thus the specific impact of the stroke itself could not always clearly delineated and attributed simply to the stroke occurring. Additionally, families could not always articulate which changes to family life were due to the stroke and those that were due to progression through usual stages of maturation and development of children within the family. In this study the impact of stroke on the young carers and families is considered in terms of the lived experience of the biopsychosocial effects of stroke, changed relationships, and the ways in which families and the young carers were learning to adapt and live in different ways to try to cope with the effects of the stroke.

3.7.3.1 The lived experience of the biopsychosocial effects of stroke

Three stroke survivors were wheelchair bound and unable to move or transfer between bed and chair unaided. One of these also had swallowing difficulties, was PEG fed and needed regular suction to clear his airways. One was unable to walk but able to transfer with some support. Three were mobile with varying degrees of balance and communication problems. One also had significant visual loss resultant from the stroke. Several experienced emotional lability and depression following the stroke. Most required support with at least some aspect of their personal care due to problems with fine as well as gross motor skills. One was experiencing significant

nerve pain which caused him great distress. Two were experiencing sensory overload issues with regard to sound and all were suffering from extreme fatigue.

The physical deficits ensuing from stroke created a number of challenges for stroke survivors and their families. Three participant stroke survivors were unable to get upstairs to their bedroom and one had just learned to manage the stairs with assistance a few days before the interview took place. He was relieved to be sleeping back in his own bed and his wife described how she felt they had reached a milestone in his recovery which was marked by the removal of the hospital bed and the consequent de-medicalisation of their downstairs living space. They also both expressed how much easier it was to attend to his personal hygiene in the family bathroom.

Two other stroke survivors were living in the family living room which was the only shared family space. Both had hospital beds and were being washed and using the commode in the same room. For the third stroke survivor the family had converted a sun lounge at the back of the house to a bedroom and had converted an under stairs cupboard with the help of family friends into a bathroom. None of the stroke survivors with severe disabilities had received statutory help to make adjustments to the home to make the space more usable and enhance independence. This was not a short term issue as some families had been told it would be at least 18 months before an assessment would even be made. This was attributed by the stroke survivors to statutory agencies waiting to see how much recovery would be achieved before they would assess and commit to expenditure on adaptions. This meant the two stroke survivors being cared for in the shared space of the living room had no privacy and no opportunity to have down time or time alone to relax, and when they needed to use the toilet, everyone had to leave the room:

> *.. once he has finished his rehabilitation they will assess what he can and can't do and then they will do it [make adaptions] whereas it makes more sense to have it done now because since he came out of hospital he hasn't had a shower and for someone who used to shower twice a day and is not able to do that now it's not the same.* (Wife of Les 43).

One of the stroke survivors described how the constant presence of others in the room made her short tempered and stressed as she just wanted some time alone:

> *They [social services] said I need my independence because I am trapped in this room and the kitchen. If I want to get away to be on my own I can't because everyone uses this room and the kitchen* (Sue 41).

Where stroke survivors were living in the downstairs shared living room young carers were forced to change morning and evening routines around paid carer visits. They restricted nights out to return home before the stroke survivor went to sleep at night, were unable to have friends round and spent more time isolated in their bedrooms, or in some cases more time out of the house during the day.

Some families claimed the stroke survivor living in the shared space as a positive change as they reported young carers had learned to be more considerate and thoughtful of the needs of others. It was interesting to note that during stroke survivor interviews despite being asked to leave, family members all crept back in to the room and often joined in the interview, but the majority of young carers insisted on having privacy for their own interviews.

Physical deficits caused frustration for several of the stroke survivors who had difficulty accepting that they were at best slower to be able to complete tasks and at worse unable to perform them at all. The children were very aware of the

frustration caused and expressed sadness at the loss they were witnessing*: "He was always doing stuff around the house. He misses that now and struggling to accept other people want to do stuff for him now"*. (Molly 20)

Pain and sensory issues also caused problems for some. Pain lowered tolerance in one stroke survivor who was aware he was quicker to lose his temper than he had been before his stroke. Neither of his young carers mentioned being aware that he was in pain despite being asked what difficulties they thought he was experiencing after his stroke. Two stroke survivors were experiencing problems with auditory sensory overload and could not tolerate loud noises or more than one person speaking at a time. One stroke survivor spoke of how he knew it must be difficult for the children to keep the noise levels lowered but he could not help reacting to the noise.

Emotionality was unexpected, poorly understood and without exception caused consternation on behalf of young carers and embarrassment on behalf of the stroke survivor. Some pretended nothing was happening in order to cope with the confusion and embarrassment:

> *…. Like sometimes she is just alright and sometimes she gets really angry and it's just confusing. Sometimes and me and my brother say just calm down and she calms down. …. sometimes she just starts to cry and when we ask her are you crying she says no. But we know that she is crying. She doesn't want to ...* (Declan 12).

Personality changes in some stroke survivors were noted by their young carers, largely related to confidence: *"I don't think he will ever be as completely the same as he was. I think he is more wary of things now, how he walks and stuff like that…*

we could tell when he had the stroke he was scared. He just changed completely". (Alfie 17)

Changes in cognitive abilities were not always recognised by some younger carers, whereas some older siblings were troubled by the changes they were witnessing. One stroke survivor was able to describe significant problems with his short-term memory, concentration and mood swings since his stroke. He also exhibited difficulty during the interview with finding the right words to express himself and keeping focussed on the interview. His stepdaughter, Alfie, was much more aware of his difficulties than her younger sibling, Sally: *"Just day to day things he used to do but .. I don't know. It's like he's lost something that was there all the time but he can't think what it is. It is there but he just can't get it"* (Alfie 17).
Whilst her younger sister said: *"Well when he had his stroke he was like stressed a lot and now he's alright. He's like just normal".* (Sally 13)

Fatigue was a major issue for many. Young carers were aware of the need to be quiet during rest periods. Particularly for the stroke survivors with beds in the shared living room space young carers were aware of the need to be completely quiet so they could rest undisturbed.

3.7.3.2 Living differently

Stroke necessitated changes in lifestyles, living arrangements, physical alterations and adaptions to the home. However, not all young carers felt that life had changed for them. They were still able to see friends and carry on much as they had before: "*Not a huge deal [has changed as a result of his mother's stroke] really. I don't think it's affected my studying at all. When I am over there [at university] I don't think of home at all. Its two separate lives in a way".* (Jack 20)

For others change was significant but did not seem to be the cause of any ill feeling or resentment. Young carers spoke at length about the importance of ensuring that the needs of the stroke survivor were met as far as possible and reported that the resultant impact on themselves was insignificant. There was often incongruity between young carer's claims of inconsequential changes to their lives and the reality of what they were reporting as complete changes to routines, tasks, life styles and living arrangements.

For two of the families of stroke survivors who were unable to get upstairs, routines changed substantially for the whole family. Young carers were no longer able to have friends come to the house to collect them before school or to play or meet up. Morning and evening routines revolved around paid carers coming to the house necessitating earlier starts in the morning to make sure no one had to go through the lounge while the carers were getting the stroke survivor dressed. For one family with four teenagers and young adults in the house there was an 11pm curfew imposed by consensus as they had to walk through the living room where the stroke survivor was sleeping to get to the upstairs.

Some families had been resourceful in making adaptions to enable the stroke survivor to start participating more in family life. For one family this had led to them making their own physical adaptions such as ramps and building a downstairs bathroom in order to facilitate the stroke survivor leaving residential care. No statutory assistance had been provided despite the stroke survivor being completely dependent on others for personal care, mobility, nutrition, fluids and maintaining a clear airway. The young carers had made the adaptions utilising their own skills and those of their friends. They had also devised an adaption to a fishing rod so that Ben (aged 20) could go fishing with his dad again. This was an activity

they had enjoyed together before the stroke and Ben had missed being able to do. Some of the young carers had enjoyed very active life styles with their parents before the stroke and had given up hobbies they had been involved in for many years as they didn't want to do them alone. When asked what had changed about his father Ben said:

> *Only physically. He's exactly the same as he was. We used to do so much together, that was the biggest change, biggest shock really. We used shoot together on Tuesdays, if I had stuff to do on the car he would help me with the car, you know everything. We used to go fishing at the weekends, go out on the boat, all sorts of different things so yeah physically more than anything. You can talk to him and still have the same conversation with him. …..I have stopped shooting now. We started when I was at school. Probably about six years maybe we were shooting together. But it didn't feel right going without him. I didn't really want to go. So we stopped doing that* (Ben 20).

Another young carer who was running competitively and had ambitions to be an Olympic runner had stopped running because his father could no longer take him to training or competitions: *"When I found out dad had a stroke it kind of didn't make me feel I could do it anymore"* (Jamie 11). He had also stopped going camping and hill walking for the same reasons despite other people being willing to transport him.

Several other young adult carers said that they no longer went out as frequently but ascribed this to getting older and not feeling the need to go out as much as they used to as the reason for the change. However, for some the reasons were attributed to the caring role and one young carer (Laura 17) described how she no

longer went out with her friends as she wanted to be near home in case anything happened and she was needed urgently.

For the one primary young carer in the study Declan (aged 12), life completely revolved around being available for his stroke surviving mother. He described how there was a skate park in the nearby village but he: *"made do"* with using kerbs outside of the house instead of purpose built ramps at the skate park, to make sure he was near if his mother needed him. He explained how he could no longer have friends over to play as his mother's bed was now in the living-room so he would come straight home from school, do any jobs she needed doing and would then go to his friend's house but would always have his mobile phone with him in case she needed him. He was also sleeping downstairs on the settee during the week while his father was away working as he was worried he wouldn't hear her upstairs if she needed anything in the night. He denied that this made him tired. His mother also confirmed during her interview that he insisted on sleeping on the settee but said she did not know why he did that. Other young carers reported positive changes to the family dynamics wrought through a realisation of each other's mortality: *"We all have tea together now. We always used to make our own. just to bring us closer really. There was like devastation in the family and mum was determined to make it better so .."* (Alfie 17).

3.7.3.3 Changing relationships

For stroke survivors, relationships changed with the majority of their friends as without exception friendships had faltered and visits lessened even over the comparatively short time frames for some since their stroke. Some young adult carers were cognisant of the loss of social life and expressed sadness on behalf of

the stroke survivor: *"…not being able to go out with his friends. Not being able to socialise with them as much as he would. It's horrible"* Alfie (aged 17).

Some stroke survivors were very conscious of the changes within the family relationships which were attributed to stroke:

> *Everybody's life changed. And the way they all approached me changed. I thought that before they always treated me nicely but I never realised how nicely they could treat me until I had the strokes and then they were. the boys have been wonderful haven't they? All of them.* (Dennis 58)

Some young carers maintained that their relationship with the stroke survivor was unchanged however the incongruence of this became apparent as interviews progressed and specific examples provided evidence of the incongruity of their assertions.

The young primary carer was very conscious of the change in the relationship between him and his mother:

> *What about looking after you? Can she look after you the same? (TC)*
>
> *No not really. But I look after her. So it's alright. I look after myself and I look after her yeah! (Declan 12).*

His mother confirmed that Declan took over when her partner was away during the week and was also aware that she was not able to parent as effectively as she wanted to and was not able to get to school parent evenings at all: *"They get away with a lot… I think if they are cheeky or answer back [long pause], I think have I changed? because I am getting more,[long pause] I can't put up with it"* (Sue 41).

Other young carers were also aware of the change in their relationship with the stroke survivor and were able to articulate how the stroke had also affected other relationships*: "instead of him being there for you, you have to be there more for him"* (Molly 20). Other young carers were also adamant that relationships hadn't changed and that their stroke surviving parent was the same as before

Molly was the girlfriend of Ben (aged 20). She had moved in with the family to help after Dennis (aged 58) was discharged home from the rehabilitation unit he had been in for almost a year. She did feel her relationship with Ben had been affected by his reaction to his father's severe disabilities resultant from his stroke. He was particularly close to his father and shared many hobbies and much of his leisure time before the stroke. This loss of camaraderie and companionship had led to Ben developing depression for which he had received counselling.

The nature of relationships are multifaceted and as such the love and respect young carers had for their stroke surviving parent seemed to over-ride any losses associated with disability arising from stroke. There was also a sense that the reality of stroke and the increased awareness of their own and each other's mortality had acted to bring families closer together and had made them value the relationships more highly.

3.7.4 Insulating the family

In this study, stroke could be seen to have affected and brought together the whole family and engendered a sense that they all needed to protect and support each other. This paradoxically created unforeseen pressure and tensions for some families. The importance of family was apparent throughout all of the interviews. Family members supported and protected each other despite often living in a state

of limbo and were keen to portray a positive image of their ability to cope with the daily challenges and tasks engendered by the stroke

3.7.4.1 Supporting each other

A hierarchy of support was apparent in most families in the study. The majority of primary carers were the spouse or partner of the stroke survivor. Young carers were often mindful of the additional stresses placed upon the well parent and attempted to mitigate some of the additional load they could see had been generated by caring responsibilities and the tasks stroke survivors were no longer able to perform: *"She [mother] does most things. We help her out when she needs some help. But I think she's got a hard job if I am honest. He's not easy to look after"* (Alfie 17).

Young adult carers were next in line for any additional workload with a gender bias towards the female members of the family. Although support was largely described as coming from within the nuclear family, some parental siblings and grandparents were also offering support with childcare and were providing respite by taking young carers away for holidays and days out.

Young carers were almost without exception positive about their caring role. Only one young adult carer said that sometimes she resented having to look after her four year old brother when her mother was busy caring for their step father, because it interfered with things she wanted to do herself and her ability to complete her course work on time, however she qualified that by saying she would always put him first.

Support was not seen as a time-limited commodity for many of the young carers. Even some of the younger young carers were already planning to live nearby so they could continue to support in the longer term. One young carer was planning to go to University but had decided to apply for places nearer to home than originally planned so she could still help and be nearby if she was needed. Several young carers were worried about how their well parent would cope in the future when they left home. One young carer could not envisage leaving home at all.

3.7.4.2 Protecting each other

Families appeared to invest a great deal of energy in protecting each other from negative feelings and worries by not talking about the subject openly to each other. Most participants expressed some fears and negative feelings about the stroke but had not discussed them with other members of the family. There was thus a sense that young carers were physically being present but were restricted in their ability to interact with the stroke survivor in an authentic way by avoiding the subject of stroke and the impact it was having on them all. Young carers talked about keeping the stroke survivor company and watching films together but not being able to talk about the stroke for fear of upsetting them. One young carer said:

> *We will always come down [stairs] and sit with him and stuff and speak to him. We never really speak about the stroke though because it's a hard subject to touch on, do you know what I mean? It's hard for him, rather than us* (Alfie 17).

When asked what could have been done to help her to talk to her step father about his stroke, she said she didn't know and admitted she was scared to raise the subject. Her desire to protect the stroke survivor may therefore have in part been in an effort to protect herself as much as him. Alfie's stepfather was very open

about his fears and attributed his withdrawal from social life to his fear of having another stroke in public. He spoke at length about his realisation of his own mortality and the risk of having another stroke, how distressed he was about the impact his stroke had wrought on the rest of the family and talked about being a burden on them. Conversely, his young carers did not express any thoughts of him being a burden and in fact stated they were happy to provide as much support as he needed. He was acutely concerned about his sensory issues around noise and was conscious of the restrictions his need for quiet was having particularly for the 13year old young carer. However, both young carers had accepted that was just what he needed and were more than happy to comply. Thus, there was evidence of both young carers and stroke survivor worrying about things that they did not need to worry about but had been unable to discuss.

This conundrum was also reiterated and captured in another interview with a young carer:

> *So is that your fear that he is going to have another stroke?* (TC)
>
> *Yeah definitely. And then I am worried about him worrying about having another one, so it doesn't really stop.* (Laura)
>
> *So you are all worried about each other and worried about upsetting each other so you don't talk about it?* (TC)
>
> *No* (Laura 17).

Some stroke survivors were expending a great deal of energy in hiding their innermost feelings and some of the physical and cognitive challenges they were facing from the young carers. One stroke survivor described how he didn't like his

young carer to see him depressed and so pretended to be upbeat when she was around:

> *She doesn't need to see me … I don't know how to describe it. I am trying to describe it* (Dennis)
>
> *When you are a bit depressed* (Dennis' wife)
>
> *Yes* (Dennis)
>
> *I think you tend to cheer up a bit when the young ones are around don't you?* (Dennis' wife)
>
> *I think I am more, I think I am better* (Dennis)
>
> *Is that an act you have to put on or does it actually life your spirits when they are around?* (TC)
>
> *Generally they lift my spirits but occasionally I have to act.* (Dennis 58)

Dennis' young carers were aware that he experienced some low days despite his best efforts to conceal them:

> *Every now and again [stroke survivor gets depressed]… There's probably been in total about five days when he's been down and that's because he hasn't been able to do things he could do. Other than that he's doing really well. He's still positive every day working towards getting better* (Ben 20).

Another of the stroke survivors spoke at length about her attempts to conceal her stroke diagnosis initially from the children and to manage as much as she could without exposing the cognitive and emotional sequelae of her stroke. This was

exhausting for her but appeared to be quite effective as the young carers had limited awareness of the problems she was facing and were positive that she had made a good recovery.

Protection extended beyond psychological and emotional damage limitation to physical safety of the stroke survivor. Declan (12) described how he had been forced to take over pushing his mother's wheelchair recently because his grandmother had almost tipped her out of the wheelchair, declaring that he knew how to push the wheelchair better than she did. He also recounted stories of two falls she had experienced, one in which she had broken her arm and both of which he had had to deal with and help her to get up. On one occasion she had fallen in the garden and another male adult had walked past without offering to help which consolidated his belief that he had to manage to look after her by himself. He appeared to have little faith in adults to look after her as well as he could. Throughout the interview he reiterated that he was: *"ok"* and did not need any extra help. He frequently checked in on his mother during the day by telephoning from the school reception as he was not allowed to have his mobile phone on at school. This was evident throughout both interviews as he repeatedly checked in on her. He said he would love to be home schooled so that he could keep an eye on her: *"I just want to stay here. To be here. I'd love to be home schooled so I could check on my mum and work at the same time yeah"* (Declan 12).

Most of the young carers were extremely positive about their role even when a specific question was asked about the more challenging aspects of their life. Many recounted stories of the significant impact that stroke had levied on their lives in terms of restrictions and extra duties which appeared on the face of it incongruent with the optimistic attitude they were exhibiting and reporting. This may have in part due to an attempt to protect the family from external influences. One young

carer explained how they managed to provide all the care their step-father required as they knew that he would be upset by a stranger coming in to the home to provide personal care: *"We've just done it together. We would rather do it as a family than him be with someone he is uncomfortable with and he doesn't know"* (Alfie 17).

Another young carer had a similar view to providing care and not accessing external support or discussing caring responsibilities with friends or work colleagues:

> *"Do your friends know you have some caring responsibilities?"* (TC).
>
> *"No not particularly. It's just something you try to keep in the family".* (Molly 20)

3.7.4.3 Living in limbo

Uncertainty engendered by the stroke spilled over to many areas of the young carer's current lives and future planning leaving them almost in a state of limbo.

Despite the negative connotations traditionally associated with this concept, young carers did not seem to mind not having any long-term plans and particularly the older young carers spoke about the need to be flexible with arrangements and to take things a day at a time: *"As mum says, when we get into thing swing of things we will go on holiday. It's just finding the right time and getting to that stage where we are all comfortable to go"* (Anna 20).

Young carers were generally unclear about the implication of the stroke in terms of how much recovery could occur, and over how long it could continue. No one had discussed this with them leaving them to conjecture for themselves. This led to

some magical thinking by some of the younger young carers who were confident that there would be a full recovery and everything would get back to normal. Two young carers stated that their parents were already fully recovered and everything was back to normal despite both parents still having significant cognitive and in one case physical and sensory deficits including sight loss. Older young carers were more realistic and said they didn't think things would ever be the same again but were very positive that things would keep improving. Many of them talked about taking things a day at a time and accepted that holidays and plans had had to be cancelled and weren't sure when they could be reconvened but all were accepting of the inevitability of the current restrictions on the family.

For Declan (12) whose mother had experienced three strokes, the uncertainty of not knowing what would happen was starting to cause him some distress: *"When I go into hospital sometimes to see her I get upset because I don't know what's going to happen. Yeah but I am always fine so yeah."* Despite his obvious distress he was still keen to transmit the idea that he was fine and not needing any support.

Young carers were starting to develop coping mechanisms and friendships played a vital role in handling the uncertainty and change for many young carers. The majority talked about hanging out with their friends and talking to them about what had happened. The young adult carers who were working, found work a respite from thinking about problems and issues at home: *"But yeah my social life is not great. So work is time for me to enjoy, you know what I mean?"* (Alfie 17).

Young carers keenness to portray a positive image of the family's coping and unity has been reflected in many previous studies and is commonly attributed to a fear of unwanted intervention from statutory services such as the young carer, siblings or the person they care for being removed into the care system. Certainly, there was

a dissonance between the disruption young carers in this study were reporting to everyday lives and their assertion that everything was fine and no outside help was required. This could have been an attempt to divert unwanted attention from statutory services however no such fears were openly expressed:

> *I get ready for myself. Get my mum ready. On a Tuesday she used to go up to (village) to pay the bills and stuff but she can't, so I help her and everything* (Declan)
>
> *When you get her up in the morning do you have to get her washed and get her clothes?* (TC)
>
> *She has her clothes on the side that have already been washed and she shouts me up in the morning* (Declan)
>
> *Do you have to empty the commode?* (TC)
>
> *Yeah* (Declan 12)
>
> *Do you do that in the morning before you go to school?* (TC)
>
> *Yeah* (Declan 12).

Laura described how her social life had become more limited:

> *I used to go out every single Saturday with my friends. Now I just go occasionally. … I just feel more comfortable being at home and knowing if anything happened I would be here. And then they'd have to contact me and I'd have to find a way home. I just feel more comfortable knowing I am here just in case. It just makes me feel a lot better* (Laura 17).

This study aimed to identify children and young people who had not already been identified or assessed as a young carer. This was to try to capture how the young carers and stroke survivors themselves characterised caring before any preconceived ideas were imposed by others. The findings show that although few were primary carers, secondary caring is still a significant role and has consequences in terms of time commitments and impacts on other aspects of the young carer's lives. Many young carers, particularly the older ones, were acutely aware of the impact of primary caring on the well parent and strove to minimise their burden and take on as much of their work as they could to allow them time to deliver primary care to the stroke survivor such as the personal and intimate care: *"My mum's job is so hard. She'll look after him [stroke survivor], and she'll look after my brother, she'll have no time for her life, so for us to help out is better off for her ….."* (Alfie 17).

They were also aware that the primary carer often bore the brunt of mood swings and frustration of the stroke survivor and felt the only thing they could do to help was to take on additional household tasks.

The uncertainty about future recovery young carers reported that was creating difficulty in planning anything beyond the immediate future did not appear to be causing any great problems in these early stages of the recovery. Uncertainty in relation to future recovery was reflected in all the young carer's plans to stay nearer to home than they had originally intended so they could continue to offer support to the well parent and younger siblings:

> *We are hoping to have somewhere close to here because I will want to have [sisters] around and whatnot to give mum a break from them and obviously I want to see them as well. So I want somewhere they can walk to …and if*

they want to sleep over for a few nights. Somewhere they can walk to school. (Anna 20)

This was a concrete example of the long-term impact of the stroke on their lives but also an outward display of their need to continue supporting and protecting younger members of the family into the future. Uncertainty in terms of recurrent stroke and recognition of their own mortality was more difficult for them to deal with and several were having difficulty coming to terms with the fear which was restricting their social lives as they were opting to stay near to home in case they were needed: *"One day you are there and the next you could be gone. It gave us the fright of our lives"* (Alfie 17).

This was a further demonstration of the significant impact of the stroke on their lives. No one seemed to recognise the anxiety they were feeling and the self-imposed silence did nothing to ally their fears.

Young carers expressed need to protect the stroke survivor from every day worries and their own fears was taking a toll on their energy as they supressed their anxiety. Stroke survivors equally were protecting the young carers from their own fears and this also was impacting on the well-being of some. Thus, the need to protect each other whilst laudable was itself creating additional tensions and pressures. Several young carers suggested they just did not know how to open a dialogue with the stroke survivor and other members of the family. This could have been compounded as most of the young carers in this study either did not have a close circle of friends in whom to confide or chose not to disclose what was happening at home.

3.8 Discussion

This study aimed to explore the lived experience of young people aged 11-24 who were caring in an unpaid capacity for stroke survivors living at home in the East Midlands. The study found that none of the young carers had been identified or assessed by statutory services and the majority did not associate the support they were offering with the role of young carer.

Young carers were universally positive about their caring role and reported acquisition of beneficial skills and attributes from caring such as independence and learning to be cognisant of, and sensitive to the needs of others.

Five categories of caring tasks were identified; emotional caring; physical tasks; personal care; helping with rehabilitation; and supporting the well parent. Few young carers were expected to provide personal care but all were providing emotional support.

Knowledge and understanding of stroke was poor and most information had been gleaned by young carers observing the impact on the stroke survivor or listening in to health care professional ward rounds and handovers.

The sense of unity and importance of the family entity was very strong in all of the stroke survivor and young carer interviews. Families appeared to have pulled together and were keen to portray a positive image of their closeness and coping almost insulating themselves against outside interference during the early phases of stroke recovery which were encumbered with uncertainty about the future and recovery potential.

Finally, stroke survivors and their young carers were expending a great deal of energy protecting each other against worries and fears, each feeling they were successfully cloaking their own worries. No one knew how to start the conversation to broach fears and worries each feeling the other person would be upset by having an open and honest dialogue but wishing it could happen.

The study population of young carers of stroke survivors was atypical in comparison to previous studies. The sample comprised more females than males which is as expected, but the proportion of females was unusually high. This could have been due to the higher than average age range of females in the study as caring responsibilities increase with age for females. The mean age of young carers was 16 years which is the same as in the van de Port et al (2007) study of children of stroke survivors, this is in contrast to the average age in almost all studies being 12 years (Becker et al, 2000; Dearden & Becker, 1998b; 2004). It is possible that the average age was higher as stroke occurs more frequently in older age groups and consequently children of stroke survivors are likely to be older.
In most studies young carers are caring for a mother in a lone parent family (Becker et al, 2000). In this study, none of the young carers lived in lone parent families and this may be one reason why few primary young carers were found as most primary carers were spouses or partners. The majority of care recipients were male, which would reflect the demography of stroke with incidence being higher in males than females.

The inherent difficulties encountered in identifying and engaging young carers of stroke survivors in this study replicates many prior research studies involving young carers (Aldridge & Becker, 1993b; Bilsborrow, 1992; Dearden & Becker, 1995; Frank, 1995). This difficulty is also experienced by local authorities with a duty to ensure that assessments are offered and support provided. Young carers of

stroke survivors through not being recognised or identified early, if at all, may not have the beneficial aspects of caring optimised and could even be at increased risk of harmful effects of caring.

The hiddenness of young carers has been consistently identified as an issue since services for young carers began to emerge in the 1980s (Aldridge et al, 2016a; Banks et al, 2002a; Bibby & Becker, 2000; Children's Commissioner for England, 2016; James, 2017) and little progress appears to have been made with ameliorating the underlying issues. In the recent large scale survey of young carers, less than 19% of young carers had received an assessment and 64% were not receiving any support (Cheesbrough et al, 2017a p.8). None of the young carers in this study had been identified or assessed as young carers. Young carers themselves did not recognise the support they were proffering as caring, they were simply doing what families do except for the two who had previous experience of caring for a parent. The role of carer for the majority was someone in a paid capacity who visited intermittently to deliver personal and intimate care. Thus there was a dissonance between the experts' understanding of young carer defined by the type and complexity of tasks they take on as well as the time committed, and that of the young carers themselves.

The majority of young carers in this study did not wish to access any external support, as they were developing their own coping mechanisms, largely involving talking to selected friends. It is possible that the early stage of caring at which these interviews took place meant that support needs had not yet emerged. It is also possible that as no objective measures of well-being were taken that young carers were unaware of any potential detriment to their well-being of not being supported. They were also unaware of their rights to assessment and support, or of the existence of such services and therefore had low expectations of external

support. There is some evidence to suggest that children of stroke survivors show improved functioning one year after stroke (Visser-Meily et al, 2005b) and do relatively well at three years after stroke (van de Port et al, 2007) and therefore the possibility of some unique protective factor in stroke cannot be ruled out. Neither the Visser-Meily et al (2005b) or Visser et al (2004) studies stated whether the children had received any support. It is therefore unclear whether the improvements occurred in the absence or presence of formal support.

Young carers in this study already labelled by statutory services in a previous caring role were more comfortable with self-identification and acceptance of support from statutory services. These findings are in keeping with previous studies (Aldridge et al, 2016a; Children's Commissioner for England, 2016; James, 2017; Smyth et al, 2011).

Tasks of caring described in previous studies are often based on the six subscales categories identified in one of the commonly used assessment tools for young carers (Joseph et al, 2012). In this study, young carers were offering a wide range of support but the provision of personal and intimate care reported by young carers was very limited in comparison to some other studies (Aldridge & Becker, 1993b; Bjorgvinsdottir & Halldorsdottir, 2014) as they were largely protected by the primary carer, usually the partner, delivering personal care.

Young carers were moving forward on the continuum of caring from minimal support to primary or sole carer dependent on the availability of another adult to fulfil that role.

The majority of care was practical or offered vicariously, by supporting the well parent with their increased roles and activities created as a result of the stroke; everyone was providing emotional care. The impact of this should not be

underestimated as Frank (1995) reported that: *"supportive"* (p 18) young carers sometimes had roles which were as demanding as sole carers and were often anxious about the well parent, being very aware of their workload and isolation and felt responsible for ensuring the strain of caring was reduced for them.

Helping with rehabilitation was common in stroke and was not found in any other studies. This may have been condition specific as stroke occurs suddenly with recovery continuing for many years and rehabilitation as a key component of management. In addition, the specific model of care in the East Midlands of Early Supported Discharge (ESD) as described in chapter two places a major focus on rehabilitation in the home environment with at least daily visits by therapists for six weeks after discharge home. In addition, the majority of interviews took place during the six-week long summer break and so children were at home to observe the therapists working. Thus, family members were exposed to the concept of rehabilitation and often witnessed the therapy sessions. Some young carers were intrigued and could identify supporting and motivating the stroke survivor with rehabilitation as something they could do to help and for some the drive to do this was to see their parents return to full health.

Although none of the children had been taught what to do by health care professionals, they had observed and copied the therapists to help with speech, occupational and physiotherapy. In the ATTEND study Lindley et al (2017), no benefit was found in training family members to deliver rehabilitation in the community. However, in this study the benefits to the young carers was in helping them to take some control over a situation. This made them feel valued and gave them a sense they were doing 'something good'. Caring for a stroke survivor at home provided young carers with opportunities to learn and develop skills not previously envisaged, but which were nevertheless embraced and viewed positively

by young carers and their parents. Some researchers have reported a sense of resentment at the enforced caring role (Frank, 1995; Rose & Cohen, 2010), yet others have corroborated the positive findings of this study.

In line with this study, many previous researchers have found that young carers have a limited knowledge of the condition of the person they are caring for (Bjorgvinsdottir & Halldorsdottir, 2014; Mauseth & Hjalmhult, 2016; Moberg et al, 2017; Paliokosta et al, 2009; Schrag et al, 2004; Uccelli, 2014). Järkestig Berggren & Hanson (2016) in a scoping review of support interventions for children of parents with a serious physical illness, purport that children who do not receive appropriate information about their parent's condition can invent their own interpretation of events and becoming increasingly isolated in their worries. This study was at too early a stage in the parent's stroke pathway to be able to identify whether this would become an issue however, the evidence would suggest that this would be a potential future risk for these families.

None of the young carers were aware of stroke specific information for children of stroke survivors which is freely available (chapter six discusses information needs of young carers in more depth). Whilst it is clear that there are resources and support for generic young carers which would meet some of the needs of the young carers in this study, there is a gap in the type of information the participants were asking for which was specifically about stroke, the effects on the person they were caring for and how they could help.

In this study, young carers felt ignored and undervalued by healthcare professionals both in the acute and community settings. Similarly Bjorgvinsdottir & Halldorsdottir (2014) reported that young carers of parents with multiple sclerosis did not feel able to approach medical and allied health professional staff and were

not offered any information about their parent's illness. Health care professionals have been accused of seemingly being blind to the plight of young carers, and issues are further compounded when parents obfuscate the issues by pretending all is well (Bjorgvinsdottir & Halldorsdottir, 2014; Dearden et al, 1994).

What is not clear is whether health care professionals turn a 'blind eye' to what is really happening in families with young carers as the challenge to find a solution is too great or resources are too limited, or whether they genuinely do not see the need because they are task and patient focussed rather than family focussed. Leu & Becker (2017) argue that it is a partially a lack of awareness of statutory duties on behalf of responsible healthcare professionals and partly lack of available resources. Whatever the reality, opportunities are apparently missed to assess the needs of the younger members of the family or offer information or advice which could improve outcomes for all concerned.

The impact of the stroke itself was significant and wide ranging for the majority of families interviewed. Effects included altered living arrangements, changed routines and social lives, changed ability to parent in the same way as before the stroke and psychological impacts on family members. In order to cope with the state of limbo within which they found themselves, families developed mechanisms to support each other, insulate the family unit and protect each other from unwanted outside interference.

The changed living arrangements described earlier for some families, involving the stroke survivor living and being cared for in the main living room of the house impacted upon everyone in the family. Young people had to get up earlier to accommodate paid carer's arrival and attendance of the stroke survivor, go to bed earlier to avoid waking the stroke survivor and friends were no longer able to visit

the house. Despite these apparent inconveniences, young carers were keen to convey a positive attitude and communicated that they didn't mind the changes and considered them insignificant. Several young carers were also restricting their social lives to stay nearby and were constantly on call in case they were needed. Previous studies have identified that young carers suppress their own needs in an effort to protect their ill parent and younger members of the family (Bjorgvinsdottir & Halldorsdottir, 2014; Mauseth & Hjalmhult, 2016; Moberg et al, 2017; Uccelli, 2014). For some, this can persist into adulthood and future relationships and lead to chronic inability to assert themselves creating frustration and leading to depression and anxiety (Moberg et al, 2017). This apparent subjugation of their own needs could therefore be a cause for concern in the longer term and should be considered as an issue that needs to be broached with families and young carers to raise awareness.

Families insulated themselves from outside interference or judgement by displaying a united front of positivity and concern for the stroke survivor and were keen to convey how well they were coping. They minimised the inconveniences experienced which was incongruent with the reality of the way in which they were forced to live and manage without formal adaptions to the home. Delays in adaptions to the home were created by the uncertainty over the potential for recovery for stroke survivors and contingent delays in assessments by statutory services. Families were in effect living in a state of limbo. Limbo is defined as*: "an uncertain situation that you cannot control and in which there is no progress or improvement"* (Cambridge English Dictionary 2017), or: *"An uncertain period of awaiting a decision or resolution; an intermediate state or condition"* (Oxford English Dictionary 2017).

Greenwood et al (2009b), in a longitudinal study of adult carers of stroke survivors also found that uncertainty was an important component of early experience of

carers and that they adopted strategies for coping such as adopting new routines and living day by day. Other researchers have similarly found uncertainty can create additional stress and remaining positive and living on a day to day basis formed a large part of the coping mechanisms adopted (Hunt & Smith, 2004; O'connell & Baker, 2004). It is unclear whether the positive attitudes expressed in this study could have been genuine emotion or a short-term coping mechanism.

In the same way as the Metzing-Blau & Schnepp (2008) study, young carers picked up tasks that were not being completed because of the stroke. Some of the tasks were to take the pressure off the well parent and young carers were constantly on the alert and watchful of all family members to make sure they were ok. This contributed to the stroke survivors and their young carers protecting each other from their individual worries and fears by keeping quiet. A state of silence is referred to by several studies and refers to families closing ranks and not revealing their problems outside of the family for fear of unwanted interference from statutory services and enforced separation of the family (Aldridge & Becker, 2003; Aldridge et al, 2016a; Becker et al, 1998; Becker & Becker, 2008b; Metzing-Blau & Schnepp, 2008). This may have applied in this study, but a further state of silence pertained to young carers and stroke survivors protecting each other by not sharing their fears and worries within the family. Mauseth & Hjalmhult (2016) reported that adolescents of parents with multiple sclerosis experienced improved well-being was dependent on the openness about the illness within the family and wider networks. Further, it was influenced by knowledge of the disease and support from healthcare professionals. The authors recommended long term support from health professionals offering information and guidance. Families need to be enabled to start the conversation in order for support needs to be identified and addressed.

3.9 Summary and conclusion

This was an original study exploring the lived experiences of young carers of stroke survivors from multiple perspectives. Unlike many previous studies of young carers, this study engaged young people who had not previously been identified or assessed by statutory services as young carers, and who were not receiving any external support. The challenges encountered and the strengths and limitations identified by the researcher will be expounded here before the final conclusions and recommendations are presented.

3.9.1 Challenges and benefits

The challenges of working with young carers and their families was expected in line with many previous studies and has been discussed earlier in the thesis and so will not be covered here. However, another major challenge experienced which was not anticipated was the lack of engagement from voluntary sector and NHS health care professionals. The difficulties associated with health care professionals not handing out the questionnaires in phase one has been discussed in chapter two, however their failure to accept that young carers of stroke survivors existed contributed to a low response rate and a consequently small pool from which to draw participants for the second phase of the study.

A further challenge was created by parents being present for part or all of the interview for some young carers. This was sometimes due to restricted space available to conduct the interview or because the parent returned to the room during the interview process. Rubin & Rubin (2012 p.174) concede that parents are often present and can create difficulties for the researcher in separating out the suggestions of the parents from the answers of the child, conversely parents can also assist by prompting the child to elaborate on their answers. The researcher

was cognisant of this risk and took care to ask sensitively worded questions which could be answered by the young carer without embarrassment or fear in front of their parents.

One unexpected benefit arising from the study was the identification of one young primary carer and a subsequent referral for assessment for support with his and his mother's permission. This also raised the awareness of his existence with the clinical community team who had been involved with his mother for several months and had been unaware of the extent of his role. The team leader contacted the researcher to say as a direct result of this case they were changing practice to ask more in-depth questions about who was providing care for stroke survivors living at home, whilst not making their own assumptions in future.

3.9.2 Strengths, limitations and gaps

This was the first study in the UK of young carers of stroke survivors, giving a unique insight into their lives, their understanding and experience of stroke, and of caring for a stroke survivor. The majority of previous young carer studies have accessed young carers through young carer projects or statutory services who were already identified and receiving support. This was identified as a gap in the literature by Moore & McArthur (2007). In this study young carers were unknown to services, and consequently had not received due assessments or offers of support. Thus, they were reporting their lived experiences entirely from their own understanding and without any preformed identity or preconceived idea of how society has constructed the concept of young carer.

This was also the first in depth qualitative study of young carers of stroke survivors internationally providing a sound baseline from which future studies can be built.

Leu & Becker (2017) assert that sound nationally specific evidence base is key for the development of policy and interventions to support young carers.

Limitations of the study include sample size and the population being specific to areas with ESD teams and within the first year of stroke. The study population could also have been biased by self-selection as only those who recognised they may have young carers or were prepared to admit they had young carers were included. A further limitation was potentially that interviews were held during the six week long national school summer holidays and so the full impact of the stroke and caring role may not have been experienced as some young carers did not have the additional normal pressure of caring and attending school to reflect upon. With hindsight in order to reflect the drive to provide care within a whole family approach then the well parent should have been interviewed to establish their perspective too.

This study did not look at the younger age range of under 5 years which is also recognised as a gap in the literature (Children's Commissioner for England, 2016) and is important as caring has been identified as often starting in this age group and early intervention is essential to prevent children becoming socialised in to their caring role (James, 2017). Additionally, no services were found for young adult carers aged 18-24 years and vocational issues were not covered in any depth. Both of these issues warrant future investigation.

3.9.3 Final conclusions and recommendations

Children of stroke survivors in this study existed on a continuum of caring from primary carer, providing personal care and intimate care, to those whose daily tasks and responsibilities had changed little as a result of the stroke. Although the

number of young people at the primary caring end of the spectrum identified were small, the numbers could potentially multiply as the incidence of stroke in younger age groups increases over time. It is also possible that the number of primary carers were an underestimate of true numbers due to the small sample size and in line with previous study findings of the challenges of identifying and engaging with young carers due their predilection to remain hidden. Responses to questionnaires in phase one showed some stroke survivors were living alone with a young adult carer and were requiring significant amounts of help from them, including personal care and were not in receipt of any paid care. Therefore, as they did not consent to be contacted for the interview stage of the study, the extent of primary caring by those who opted out of this phase of the study cannot be confirmed.

The impact of caring and of stroke itself can both have beneficial and detrimental effects on the children and young adults in the family. Findings from the study overall showed many positive outcomes and effects for the children and young adults. However, judgements should not be made by professionals about who is likely to be providing different types of care or the impact that the stroke and / or caring responsibilities may have on an individual family member. Young carers moved along the caring continuum on different days and times dependent on the availability of adults who could function as a primary carer. What is clear is the need to ensure all children and young adults co-residing with a near relative stroke survivor are in receipt of signposting and information about stroke, and rights to assessment and support. This will aid mitigation of any potential detrimental aspects of caring and enhance the beneficial facets of caring.

The fact that the study identified information and education was desired by children and young adults to enable them to support the stroke survivor more effectively, showed its importance and could potentially reduce anxiety and improve family

cohesion and was an important finding. This was particularly germane for stroke as there was a lack of understanding by young carers of the aetiology and outcomes for stroke and no one had seen or were aware of relevant information or sources of support that were freely available. This demonstrated both a lack of relevant information and signposting, and poor dissemination of existing information that was available. Information content, formats, accessibility and dissemination need to be reviewed as a matter of some urgency.

The recognition of the unique pathways for stroke into the ESD and other domiciliary care teams in the community for mild to moderate stroke needs to be recognised and incorporated in the information as rehabilitation is an important and main component of care to which families are exposed currently without any training or support. Not all information needs to be produced specifically for stroke as many of the needs of young carers are generic such as rights to assessment and support and therefore use can be made of existing generic young carer resources by more effective and timely signposting. Similarly, generic support services for young carers will also meet many of the needs of young carers of stroke survivors provided the stroke specific information and education is provided.

The need for and potential to provide opportunities for young carers to make contact with other young carers of stroke survivors, through for example online fora could be investigated further. This could be particularly valuable for young adult carers for whom even more limited services currently exist. However, the current financial climate and the small numbers of young carers of stroke survivors make the provision of specialist support groups an unlikely and inefficient option.

Changes to family roles, circumstances and living arrangements were significant for many of the families interviewed and support for home alterations to alleviate some

of the negative impacts were not forthcoming from statutory services in the short and medium term. This is unlikely to change in the foreseeable future due to financial constraints services are operating within. Therefore, interventions which can minimise detrimental impacts and optimise beneficial impacts of stroke and resultant care which can be achieved now become even more critical. One such area with potential to exploit is the overall support to families. Young carers reported a lack of engagement from clinicians in both primary and secondary care, meaning opportunities to educate and signpost young carers to appropriate information sources and support were missed. This potentially reduces their capacity and capability to provide support to stroke survivors in a safe and effective manner for both the stroke survivor and young carer themselves.

Families struggled to communicate with each other about stroke and the impact it was having on them as individuals and the family as a whole. Information could be amended to help facilitate discussions, but clinicians already working with families could play a significant role in helping families to 'start the conversation' with each other. In order to do this, some education and awareness raising of professionals will be required.

Clinicians could enhance the experience of young carers and children of stroke survivors and mitigate against any potential harmful effects of caring whilst optimising all the beneficial effects of caring by adopting a whole family approach to planning and identifying care needs, encouraging an open and honest dialogue amongst family members about the impact of the stroke on everyone and signposting to existing information and support service

CHAPTER FOUR - INVESTIGATING THE STATUTORY, VOLUNTARY, EDUCATION AND SUPPORT SERVICES FOR YOUNG CARERS IN THE EAST MIDLANDS

4 Introduction

Chapter three reported the findings of semi-structured interviews with stroke survivors and their young carers. This chapter reports on the analysis of the expert interviews, considers the context within which young carer services are situated and how children and young carers of stroke survivors who may need support, can be identified. Experts were working as commissioners or providers of young carer services.

The Care Act (2014) and Children and Families Act (2014) have strengthened rights for young carers in the UK to an assessment of their needs and provision of support for them and the person they care for. Support is theoretically available from voluntary sector providers, social care and health services. However, many young carers are not being assessed and are not in receipt of services (Aldridge et al, 2016a; Hounsell, 2013). This is in part due to failure to identify them in the first place. Causality of the failure is attributed to young carers not identifying themselves either through lack of recognition of their role or an unwillingness to disclose it to statutory services (Smyth et al, 2011). Additionally, the challenges of identifying and working with young carers have consistently been exposed by researchers in the field (Aldridge et al, 2016a; Hounsell, 2013).

The findings from the stroke survivor and young carer interviews in this study, reported in chapter three, revealed that none of the participants had been identified or assessed as young carers. This study aimed to explore the current service

provision in the East Midlands for young carers. Assessment tools and instruments in use in the East Midlands to identify young carers and assess their needs are presented and the applicability and utility for the condition of stroke are discussed. Pathways and referral mechanisms are presented from the perspective of the experts working in the field, both for initial referrals and transitions between children's and adult services. Gaps, challenges and good practice are discussed. Finally, educational challenges and good practice are also discussed.

4.1 Background

4.1.1 Legislative responsibilities and duties of statutory organisations

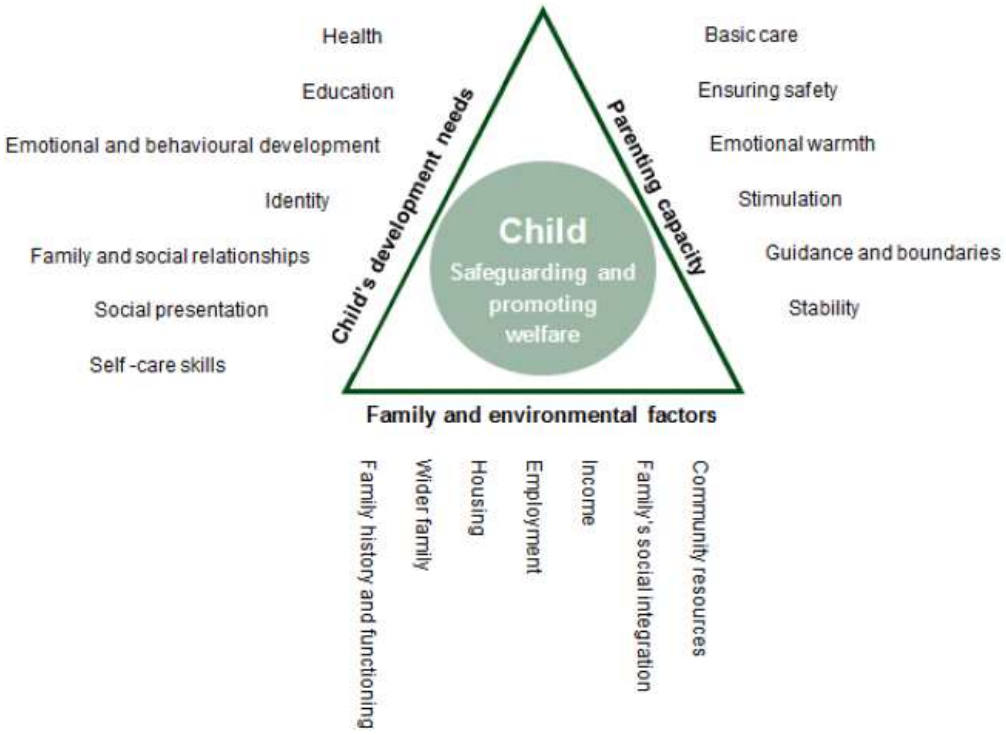
The Children Act, (HM Government, 2004) amended by The Children and Families Act (HM Government, 2014b) gives young carers the legal right to an assessment of support needs regardless of the type of care they provide, and to introduce a whole families approach to assessment and support. During assessments of adults, local authorities have a duty to identify if children are providing or intending to provide care. If so, they must make an assessment of the impact on their development, education and general wellbeing, incorporating all domains depicted in Figure 23. Some young carers may be identified as a: *"child in need"* (Children Act section 17) if the child is:

> *17(a) … unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health and development without the provision for him of services by a local authority; or*
> *(b) His health or development is likely to be significantly impaired or further impaired, without the provision for him of such services…*

Local authorities may avoid duplication by combining assessments to ensure the inherently linked needs of the young carer, cared for and other family members are identified and met. One disadvantage of this may be that an adult social worker

may be assessing the child and may not have the same level of knowledge and expertise as a children's social worker (The Children's Society et al, 2015). The needs of the child and the required assessments are comprehensive and complex as can be seen in Figure 23 below.

Figure 23 The Dimensions of Children's Needs



(The Children's Society et al, 2015 p.13)

Local authorities also have a duty under the Children and Families Act 2014 (Section 96(12*)): "to take reasonable steps to identify the extent to which there are young carers in their area who have needs for support".* Thus, local authorities now have a duty to do what is reasonable to find and identify young carers, assess their needs alongside those of the cared for person and other family members, and provide support to ensure their health and developmental needs can be met. There is also a duty to ensure the person responsible for undertaking any combined

assessments has the appropriate knowledge, skills and training (The Children's Society et al, 2015 p.9).

Young people moving from children's to adult services at 18 years of age also have rights to transitional assessments under the Care Act 2014 (HM Government, 2014a section 63-64). The assessment must consider whether the young person wishes to continue to be a carer after the age of 18 years, and their needs and wishes as a matter of primary importance. Transitional assessments should be started before the age of 18 with the timing jointly agreed with the young person and the family.

The provision of timely assessments continues to be a challenge. Numbers of young carers who have been assessed have remained persistently low (Aldridge et al, 2016a; Children's Commissioner for England, 2016; Dearden & Becker, 2003; Hounsell, 2013). The importance of early recognition of young caring and assessment of needs is essential to prevent young carers becoming socialised into the role (Children's Commissioner for England, 2016) at which point intervention from statutory agencies can be resented and seen as undue interference (Dearden & Becker, 1995). However, families need to be kept under review as some take on services initially and then cancel them. This can be for financial reasons or because services provided are deemed inappropriate by families as the time lag from assessment to service delivery can be so great that the family circumstances have moved on (Dearden & Becker, 2000b; Keith & Morris, 1995). Assessment and early support play an essential role in enhancing the positive effects of caring and negating the harmful effects.

4.1.2 Support services and referral pathways

Support services for young carers first appeared in response to the emergence of a social movement identifying the existence of young carers and their needs which was started by pioneer researchers in the field such as Aldridge & Becker (1993b; 1993c; 1994); Aldridge et al (1995); Becker et al (1998); Becker et al (2000), Bilsborrow (1992); Dearden & Becker (1998b); Dearden & Becker (2000a); Dearden & Becker (2004); Frank (1995); Frank et al (1999).

Much of the early support was focussed on respite for the young carer. The existence of young carer respite projects have grown rapidly from two in 1992 to > 350 by 2008 (Becker & Becker, 2008b). Early studies, whilst acknowledging the needs of the young person, quickly identified the need to address the underlying causes of young people taking on roles for which they were not physically, emotionally or developmentally equipped. Underlying causes identified include the type of illness or disability; single parent families; gender; co-residence; and access to external support for both the cared for person and the young carer (Becker et al, 1998 p.22; Dearden & Becker, 1998b). This suggested a need for a different approach to offering support but created tensions between those who believe the needs of young carers have primacy and those who would prioritise the needs of the parent to enable them to fulfil their parenting role.

A further stance taken is to address the needs of the family as a whole (Carers Policy Team, 2010). However, the reality of adopting a whole family approach in the management and support of young carers whilst lauded and widely espoused appears to be a challenge.

In 2008/9 18 local authority family pathfinder projects were funded to develop and test new models of family focussed working, there were no projects in the East

Midlands. Projects focussed on reducing the impact of inappropriate caring; delivery of support to the whole family; changing workforce delivery; increasing identification of young carers and developing strategic change (Ronicle & Kendall, 2011 p.58). Outcomes showed 31% of families, demonstrated improved outcomes in terms of level of assessed needs, however, 13% showed an increased need in support. Three critical elements were identified that contributed to improved outcomes: a persistent and assertive key worker role; a robust framework of support such as Team Around the Family; and an intensive and flexible whole family focused response (York Consulting, 2011 p.iii). Despite the apparent success, pathfinders reported difficulty in cross agency working. This was attributed to a lack of awareness of support available from other services, and different language and terminology across services and agencies making communication and planning more difficult. Projects struggled to influence change by engaging at a strategic level and some agencies reported an inability to provide sufficient resources to deliver family focussed support (Ronicle & Kendall, 2011). Therefore, the ideal model of family focussed working may still be challenging.

Projects continue as a significant source of support for young carers and are provided either by local authorities or the voluntary sector. Provision varies enormously with some simply providing time with other young carers and others offering mentorship; counselling; advocacy; activities and trips and information and education about relevant issues (Aldridge et al, 2016a; Banks et al, 2002a; Dearden & Becker, 1998b). Some groups are generic, supporting young carers from all backgrounds and covering all conditions whilst others are disease or condition specific usually run by voluntary sector organisations (Banks et al, 2002a).

Gray et al (2008) in a study of 65 professionals involved in supporting young carers of parents with mental health problems recommended as best practice young carer groups and forums and having key workers and outreach workers (p.172).

However, no studies have suggested a gold standard for generic groups and Banks et al (2002a) cautioned that the complexity of offering age appropriate support should not be underestimated.

Many studies report that young carers value projects highly (Aldridge et al, 2016a; Dearden & Becker, 1998b) particularly the ability to spend time with other young people who are in a similar situation. Some report that they feel more mature than other young people of a similar age due to their caring role and therefore community groups such as football clubs or scouts, in which they are grouped by age do not meet their needs. Referral pathways have been studied extensively and have found that referrals to assessments and projects are most commonly via social workers (Dearden & Becker, 1995; Dearden & Becker, 1998b) and less commonly via schools and health services even though these services should be best placed to identify young carers and refer them for support.

Information provision has consistently been found to be lacking and young carers are unaware of their rights or the existence of services and do not have the knowledge of how to access them. This is further compounded by professionals who do not recognise young carers, engage with them or have knowledge of services to refer them on to.

4.1.3 Young Carer in School Awards

The inherent challenges involved working with young carers and the potential for universal services such as schools and primary health care to play a greater role in identifying and supporting young carers have long been recognised (Becker & Becker, 2008a; Carers Trust & The Children's Society, 2015; Dearden & Becker, 1998b).

In April 2015, the Carer's Trust and The Children's Society Young Carers in Focus partners jointly launched Young Carers in Schools (YCiS) an England wide initiative. The purpose was to raise awareness of young carers in schools, how to identify and support them, and to share and spread best practice. The scheme encourages schools to submit evidence of achievement of five standards working incrementally through a bronze, silver and gold award level. Resources to work towards achieving the standards are freely available on the Carers Trust website. (Carers Trust & The Children's Society, 2017). Standards are based on structure and process rather than being outcome focussed. The scheme has to date only received internal review without independent scrutiny.

The Carers Trust surveyed 35 schools who had received a YCiS award. The methods and criteria used for measuring outcomes are not published, however, they claim as a result of the programme 94% of schools had identified more carers, 94% had noticed an improvement in young carers well-being and confidence, 91% had seen a positive impact in the achievement of young carers and 74% had noticed an improved attendance among young carers (Carers Trust & The Children's Society, 2016).

4.1.4 Ethical approval

Ethical approval and amendments were obtained for the study as described in chapter three from The Proportionate Review Sub-Committee of the London Fulham Research Ethics Committee, REC reference number 16/LO/0548, 21st March 2016 (Appendix 1).

4.2 Study aim, objectives and questions

Aim:

To investigate the statutory, voluntary, and educational support services for young carers in the East Midlands. Study objectives can be seen in Table 22.

Table 22 Chapter four study objectives and questions

Objectives	Questions
To understand pathways and referral mechanisms for young carers into support services	What referral pathways and mechanisms for identifying and assessing young carers exist in the East Midlands?
To explore the challenges of identifying young carers of stroke survivors from the perspective of statutory services	What assessment tools are in common use for young carers in the East Midlands and how applicable are they for the condition of stroke?
To investigate challenges for service providers and commissioners	What are the challenges for statutory services of identifying young carers of stroke survivors and providing services for them?
To identify good practice in terms of identification of young carers and provision of support services	What good practice exists for identifying, assessing and referring young carers to support services and how is it disseminated?
To explore current service provision	What young carer support services are available for young carers of stroke survivors in the East Midlands?

4.3 Methodology

The philosophical and epistemological approach to this study are as described in chapter three; interpretivist-constructionist with a phenomenological approach. The essence of this approach allows the researcher to question participants broadly and interact with them through discussion enabling them to construct their own meanings of the situations within which they live and work. The researcher positions themselves within the research being cognisant of the way in which their own knowledge and background shapes the interpretation of the findings (Creswell,

2013). An interpretation of the context within which young carer services are commissioned and provided within the East Midlands was therefore made by the researcher. Knowledge and understanding of the contexts within which each participant works, and positioning that within the data already collected from other experts, stroke survivors and their young carers was utilised by the researcher.

4.3.1 Methods

Semi-structured interviews were selected for the expert interviews in the same way as for the interviews in chapter three 3.3.2.1. The purpose of the interviews was to explore the context within which young carer services are currently situated from multiple perspectives. This was to gain a deeper understanding of the way in which young carer services are commissioned and provided, the challenges and constraints they face within the current financial climate, to identify good practice and innovation and to allow consideration of where children and young carers of stroke survivors can best be supported.

4.3.1.1 Selection and recruitment of expert participants

Purposive sampling was selected as the most appropriate method of identifying the first potential participants. Experts from a range of services involved in the provision and commissioning of young carer services were sought across health, social care, local authorities and health services, as well as the five counties in the region, to explore the subject thoroughly.

In this non-probability sampling method, the researcher selects participants who are able to inform an understanding of the research problem and central phenomenon in the study (Creswell 2013, p.156). Schwandt (1998) confirms that many qualitative studies rely on purposive sampling based on the researcher's belief or prior knowledge that the person chosen will be able to shed light on the

research question. Snowball sampling was then used to expand the sample by asking participants to recommend others for interview with an in-depth understanding of the phenomenon (Groenewald, 2004). Braun and Clarke (2014, p 57) describe the snowball technique as building the sample through the networks of the researcher and other participants.

A maximum of 15 experts were required for the study (Marshall et al, 2013) (for sample size selection see 3.4.4.1). Experts were defined as anyone working to commission, provide or work in young carer support services in a voluntary or statutory organisation. No services were found explicitly for young carers of stroke survivors and therefore experts from generic young carer services were targeted to find suitable participants. Details and outcomes of the snowball exercise can be seen in Table 24 and Figure 24

Initial potential participants were identified from the researcher's professional networks or via an internet search of young carer projects and support services in the East Midlands. Service leaders were approached via email or face to face at networking events and asked if they were interested in participating in the study or if they could recommend any other potential participants. Potential participants were sent the expert participant information sheet by email and a minimum of one week allowed before they were contacted again (a maximum of three times), to establish whether they were interested in participating in the study.
Interviews were carried out at a time and place convenient to the participant. Employers were reassured that interviews would be restricted to a maximum of one hour to minimise impact on work productivity. All interviews were conducted between July 2016 and February 2017. No remuneration was offered. Informed and signed consent was established at the beginning of the interview.

4.3.2 Data management and transcription

Interviews were audio recorded with the participant's consent. Following the interviews audio recordings were immediately downloaded on to a password protected database held on a secure university server and data were then deleted from the portable recording device. Hand written contemporaneous notes were typed up and stored on the same secure university folder with the audio recordings. Recordings were transcribed by the researcher. Interview transcriptions were complete but did not record length of pauses, focussing on what was said rather than the way it was said (Thastum et al, 2008). All identifying information was omitted from the transcripts to maintain anonymity.

4.3.2.1 Analysis of interview transcriptions

Interview transcripts were uploaded to QSR NVivo (Version 11). Analysis is described in chapter three (section 3.4.4.1). NVivo is computer software which can be used to assist with analysis of qualitative data as described in chapter three section 3.4.4.1. Graphs were generated for each transcript to visualise the coding. This demonstrated that the majority of expert interviews were coded to the theme and subthemes within the theme labelled, 'Statutory and voluntary sector services for young carers'. In order to interrogate the contextual data around young carers in more detail, the expert interview data were re-analysed three months later. The same process was followed with regard to generating nodes which were used to code the transcripts. New nodes were virtually identical to the original nodes and were broken down into more detailed themes and subthemes suggesting a degree of intra-rater reliability. Final themes were checked, refined and agreed with a second researcher.

Table 23 Final themes and sub-themes from the expert interviews

Themes	Sub-themes
Identifying young carers and children of stroke survivors who may require support	Numbers of young carers Pathways and referrals Assessments and tools used
Young carer support service provision	How young carer teams and services work Levers and challenges Innovations and good practice Measuring outcomes
The role of schools in supporting young carers	School engagement Young carer awards for schools Good practice in schools

4.3.3 Developing the interview guide

A semi-structured interview guide for experts was developed following discussions with two experienced young carer project workers. The guide was tested with one of the experts and the order of questions altered slightly to enhance the flow of the discussion. Throughout the interviews, questions were amended in a dynamic process designed to capture the additional issues which emerged during the interview period.

Themes for the interviews included:

- A synopsis of the expert's experience and involvement with young carers
- Description of service provided, gaps, challenges and good practice
- Identifying young carers – systems, processes, tools and definitions
- Benefits and risks for young carers
- Suggestions for future improvements

4.4 Findings

4.4.1 Description of participants

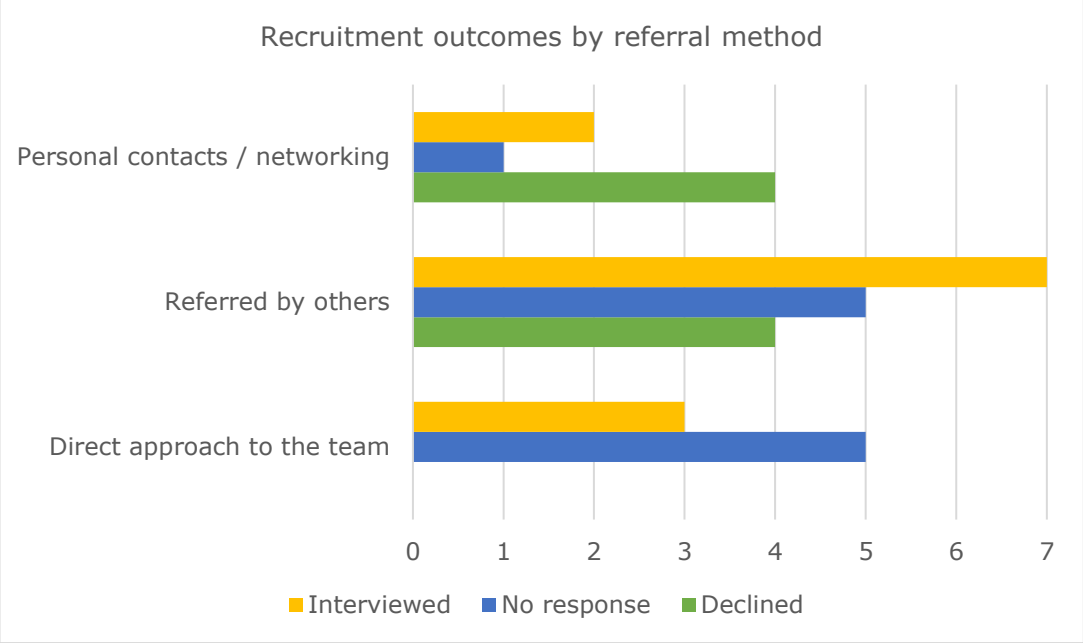
Thirty one potential experts were identified through the snowball technique. Eleven people didn't respond to three invitations extended to them, seven declined, one agreed but did not respond to the interview dates offered, 12 were finally interviewed. The majority of experts were interviewed at their place of work, two at the University of Nottingham and two were interviewed jointly at their request by teleconference. One person initially agreed to audio recording of the interview but withdrew consent for recording at the start of the interview. Detailed notes of that interview were manually recorded contemporaneously. Notes were typed up immediately following the interview and uploaded with the other transcripts to NVivo. The hand-written notes were stored in a secure locked file at the university.

Table 24 Snowball technique record

ID	Role title (some titles are slightly amended to avoid identification)	Referred by	Outcome	Provided contact details
001	Commissioning project lead	Suggested by an R&D lead from a phase one study trust	Interviewed	002 003
002	Provider project lead	001	Didn't respond	
003	Non-exec director – lead for young carers	001	Declined	001
004	County Council commissioner	Researcher approach to contacts in County Council	Interviewed	006
005	County Council commissioner	Researcher approach to contacts in County Council	Declined	004
006	Voluntary sector young carer project lead	004	Didn't respond	
007	County council Young Adult Carer Lead and Young Carers in Schools Programme Lead	Personal contact	Declined	011
008	Voluntary sector young carer project lead	Direct approach to service	Didn't respond	
009	Team manager voluntary sector young carer project	Direct approach to service	Didn't respond	
010	Support worker young carers	Direct approach to service	Interviewed	015 010
011	Early Help Team - young carer lead	007	Interviewed	013 014
012	Council project lead	Direct approach to service	Didn't respond	
013	School young carer lead	011	Didn't respond	
014	Early Help Team – young carer lead	011	Interviewed	
015	Community care worker	010	Interviewed	
016	Healthwatch young carer lead	Networking at a conference	Declined	017
017	Healthwatch young carer lead	016	Declined	018
018	Commissioning manager	017	Didn't respond	

019	Service manager voluntary sector provider	Personal contacts	Interviewed	
020	Local Authority lead for young carers	Direct approach	Didn't respond	
021	County Council young carer schools lead	Direct approach	Interviewed	029
022	Voluntary sector provider – project lead	Direct approach	Didn't respond	
023	NHS Commissioning Manager – young carer lead	019	Declined	023
024	NHS Commissioner	023	Didn't respond	
025	Statutory organisation young carer lead	Personal network	Declined	026 027
026	Statutory organisation young carer lead	025	Interviewed	
027	Statutory organisation young carer lead	025	Interviewed	
028	Project worker voluntary sector young carer project	Direct approach to project	Interviewed	
029	Health service acute trust carer lead	021	Declined	
030	Education lead voluntary sector provider	Personal network	Agreed and then failed to respond to interview invitation	
031	School pastoral support worker	011	Interviewed	

Figure 24 Snowball technique outcomes



4.4.2 Sample description

A description if the expert participants can be seen in Table 25.

Table 25 Expert participants

Number of experts interviewed	12
Gender	11 females and one male
Time in role	Two weeks – eight years (mean 2.6 years)
Length of experience working with young carers	Combined years of experience total 83.3 years (range 4 month – 20 years, mean 8.3 years)
Roles	Three working for a government organisation, one NHS Trust, three council project workers, one local authority commissioner, one education provider, three voluntary sector provider project workers.
Interviews	31.5-79.4 minutes (mean 51.9 minutes)

Participants were almost all female (11:1), had been in their current role between two weeks and eight years (mean 2.6 years), and had a mean 8.3 years of experience of working with young carers. This provided a total contribution of 83.3 years knowledge and experience of working with young carers to the study. The roles and locations have been separated and role

categories rather than titles are presented to maintain anonymity. Details can be seen in Table 26.

Table 26 Participant's organisations and geographical locations

Type of organisation		Location	
Government organisation	3	Nottingham city and Nottinghamshire county	3
NHS	1	Leicester city and Leicestershire county	2
Local Authority provider	3	Northamptonshire	1
Local Authority commissioning	1	Derbyshire and Derby city	1
Education	1	Lincoln and Lincolnshire	3
Voluntary sector	3	National	2

4.4.3 Reporting of key themes

Three final themes and 10 sub-themes were identified from the expert interview analysis. Themes were; Identifying young carers and children of stroke survivors who may require support; Young carer support provision; and the role of schools in supporting young carers.

Participant's quotes will be referred to in the findings section by the following identifiers (Table 27).

Table 27 Participant identifiers

Identifier	Role title
E1	Commissioning project lead/school nurse
E2	County Council commissioner
E3	Support worker young carers
E4	Early Help Team - young carer lead
E5	Early Help Team – young carer lead
E6	Community care worker
E7	Service manager voluntary sector provider
E8	County Council young carer schools lead
E9	Statutory organisation young carer lead
E10	Statutory organisation young carer lead
E11	Project worker voluntary sector young carer project
E12	School pastoral support worker

(NB some titles are slightly amended to maintain anonymity)

4.4.3.1 Identifying young carers and children of stroke survivors

Identifying young carers created a challenge for all experts interviewed. Reasons articulated were multifarious and included issues related to young carers and their families as well as broader organisational matters (referred to below as organisational barriers).

Experts believed that some young carers and families did not recognise their role as a young carer. Where young people had been in receipt of services in the past, they were more likely to feel comfortable with and recognise their role as a young carer. Experts also believed that those young carers who did recognise their role did not always engage willingly with statutory services due to fear of being separated, either because the cared for person could be moved into a formal care setting or the child themselves could be taken in to care:

> *I think a lot of young people and families can be scared about speaking about what is going on at home for fear of social services becoming involved as well, .. there are a lot of young carers that are hidden, so that's a challenge for us.* (E10)

Experts cited a drop in referrals when support services were returned from voluntary sector providers and taken in house to local authority Early Help Teams, and refusal of proffered assessments by many families as evidence of family and young carer reluctance to engage with statutory services*: "Self-referral has lessened by the families because they have to phone in to the TAC (Team Around The Child), parents are obviously reluctant to do that*" (E5).

Organisational barriers to identification of young carers were manifest in several ways. Experts reported a lack of up to date strategy and clear leadership for the young carer agenda in some areas which appeared to be leading to a piecemeal approach to identifying young carers, services provision and monitoring outcomes. In one county, the revision of the young carer's strategy was two years overdue:

> *I think what we lack is a clear understanding of who the strategic lead is for young carers across [the county]. I've got it attached to me in Adult Social Services, but I get comments from children's services saying why is that in adult social care … we need to review our young carer strategy. In practice it works because the workers talk to each other but I think one of the reasons it got lost in development issues is because it has been a bit disjointed.* (E2)

The challenges created by the lack of clear strategy in some cases were compounded by pre-existing and new budgetary challenges. The strengthening of legislation to identify, assess and support young carers in 2014 had not attracted any additional funding and appeared to have received a low priority in some local authorities in terms of strategy, planning and resources.

Challenges of identifying young carers within health services are similar to those identified above for social services but are compounded by an absence in the

consciousness of healthcare professionals working in the stroke field. Voluntary sector organisations involved in supporting stroke survivors are similarly unaware of the existence of young carers in their sphere. This is evidenced by the lack of information for children and young carers and absence of any support groups specifically for stroke. This identified gap creates a major opportunity to raise awareness for families, young carers, voluntary sector organisations and clinicians to ensure young carers and families of stroke survivors have the right information and signposting to navigate to the appropriate resources at the requisite point in time for them.

A further issue raised by experts was a lack of parity between physical ill health and mental ill health which was purported to compound the hiddenness of young carers and their ability to access the right kind of support. Care for a physical disability is visual and fits the stereotypical young carer as portrayed in the media:

> *When comic relief and sport relief come on and they show a young carer making mum in a wheelchair a cup of tea, and if you tell me that's the vast majority of experiences of young carers I will disagree…..if that's a young person's perception and their issues are around parental drug or alcohol abuse… that's nothing like that at all. So that's them not identifying with that term at all.* (E5)

The young carer of someone with a visually obvious physical disability is more easily identified and supported. However, concern was expressed about those caring for someone with a mental health problem or a personality change, both of which can be experienced following a stroke, as they can be less visible, more nebulous and easier to overlook or ignore. The effects of the resultant lack of support can be further compounded if there isn't a well parent or significant adult in the young person's life to support them:

> *I think for young carers or children in general, if the personality changes that would be far more difficult to deal with than if dad was still dad but just happened to be in wheelchair, ……I always say with physical disabilities there is a physical solution sometimes but with a mental health or personality condition or whatever it is, it's not as easy to get around. But at the end of the day if you can still have a chat with dad about your career, the future, your first boyfriend.... you have a more solid base in life than if he wasn't able to do that. So if you had another parent there or another relative who could be that rock in that situation?* (E7)

The difficulties of establishing how successful statutory and voluntary sector organisations are in identifying young carers of stroke survivors is obfuscated by the lack of accurate prevalence information.

4.4.3.1.1 Numbers of young carers

Commissioners had no conception of the true numbers of young carers in their local authority area although all felt the numbers registered were a fraction of the actual population of young carers:

> *The numbers we support are about 300-400. The only way we have of identifying young carer numbers is by extrapolation of national data and the last census wasn't that helpful in terms of identifying young carers. … To be honest I really have no idea.* (E4)

Calculation of numbers of young carers in the East Midlands relied on estimates from the 2011 census and young carers actually registered with social services or young carer's projects. However, this is a spurious figure as not all young

carers are identified or can access services, service provision is patchy and gateways to access services are variously configured.

No databases or systems to collect data on young carers of stroke survivors in the East Midlands was found. Hospitals did not collect any information about children or young carers of stroke survivors. One school nursing service has developed a database to record all young carers identified through the routine national child measurement programme in reception and year six. A tick box to identify young carers has been added to the form completed by parents, asking if any family member has a long-term condition that affects family function. If it is ticked, the school nurses contact the family to establish more information and identify any support needs. This information is uploaded to the database, however, extracting data by specific condition can only be completed with a secondary hand search of the manual records. The innovation had not been shared outside of the local team.

A minority of experts could remember looking after one or two young carers of a stroke survivor during their careers and there was an overall feeling that they did not exist with some saying it was a disease of older age and so they wouldn't expect to see any. In Northamptonshire, there were three young carers of stroke survivors registered under the age of 25 years at the time of the interviews.

4.4.3.1.2 Pathways and referral routes

Pathways and referrals to assessments and services were complex. A distinction should be made between the different types of referrals and assessments. Referrals were made to local authorities as the responsible body for the statutory assessment of need. Some local authorities also provide support either as a bespoke package of care for an individual following assessment, or as an in-

house young carer project. Referrals are also made to universal services such as health and education for their organisationally specific assessments and support packages which may be individual, or in the case of education sometimes provided as a young carer support group. Finally, referrals are made to voluntary sector young carer support services, some of whom are also commissioned to provide the statutory assessments for local authorities. Thus, some young carers may be in receipt of services from multiple sources, whilst others do not receive any support. This is particularly so where there are issues relating to rurality:

> *Are there any other young carer groups around here?* (TC)

> *There is one that was run by (name of the charity). They have a youth club in (name of town 15 miles away), that's the only one and some of my young carers are part of that but not many of them.* (E30)

4.4.3.1.2.1 Local Authorities

Great variation and some inequity were reported in the manner in which young carers were referred to local authorities for assessment and support. This was compounded in some cases by where the responsibility for young carers was positioned within the organisation. One participant reported their local authority support for young carers is situated with the team looking after the cared for person. For instance, if the cared for person were an adult, the young carer would be looked after by the adult team, or generic older people's team. However, if the cared for person was a young disabled person, the young disabled team would be responsible with additional resources available to them such as specialist young carer workers. Thus, young carers of stroke survivors may be less likely to have access to the specialist skills within the young disabled team.

Routes into local authorities for assessment and statutory support included referrals resulting from Early Help Assessments (EHA) and Team Around the Family assessments (TAF), social workers from adult and disabilities teams working with the cared for person, young carer projects, schools and school nurses. The majority of participants could not remember any referrals from GPs, however, one recalled one referral in twelve years and another two referrals in a similar period. One other remembered one referral, however, the contact details had been incorrect causing delays in identifying the young person correctly. This was despite some targeted projects working proactively in GP practices to raise awareness of young carers. One Clinical Commissioning Group (CCG) [5] had invested in a 12 month programme to identify young carers through GP practices, however, this did not identify any young carers.

There was a perception by some experts that referrals from school nurses were declining. This was attributed by one participant to the role becoming more task-oriented focussing on vaccination, and health monitoring programmes. In addition, an increasing workload in terms of the number of schools covered by each individual nurse limits the time available for opportunistic drop-in sessions in each school. Some school nursing services were reported to require a referral for the young person and to have placed a limit on the number of sessions the young person is able to access. As stroke occurs suddenly, young people may need to have rapid access to advice and support from an independent healthcare professional who is able to mediate with school on their behalf. One participant school nurse during a redesign of their school nursing service identified the greatest needs of young people: *"Most of them just wanted someone to talk to*

[5] CCGs Clinically-led statutory NHS bodies responsible for planning and commissioning health care services in their local area

and someone they knew would be on their side in school" (E1). The limited access to ad hoc and spontaneous support could be a further potential barrier to young carers of stroke survivors accessing support when they need it.

No referrals from acute trusts were reported. One expert with significant experience of working as a carer support worker within a stroke unit, suggested this is due to uncertainty over how much care the stroke survivor may need once home, how complete the recovery will be, how long recovery will take and who will provide the care*: "it's different in hospital for stroke because they might be seen just as a visitor and it may not become apparent that they have a caring role until several months down the line"* (E7).

4.4.3.1.2.2 Young carer support projects

Referrals into young carer support services were reported from social services, Early Help Assessments, schools and school nurses, and self-referrals.
One young carer support worker had experienced a number of changes of employer as short-term contracts resulted in frequent changes in project providers. The most recent change was from a 3rd sector provider being brought in house to a local authority provider. This had resulted in a fall in referrals ascribed to a fear of interference from social services as the service had become synonymous with the statutory services due to families having to self-refer via the TAC team. Thus suggesting self-referral routes may be a barrier as well as an enabler to accessing support.

4.4.3.1.3 Assessments and tools used

Assessments for young carers varied in the East Midlands in terms of the instruments and tools used, pathways in, and who was tasked with delivery.

There was no standard tool in use to assess young carer well-being or needs. More than 13 different tools were in use across the region (Table 2). Some were recognised published tools and others were developed in-house. Some tools provide an opportunity to create a dialogue with the young carer as a precursor to planning interventions. Others (MACA and PANOC Table 2) provide a score which is used by some services as a level above and below which services and budgets are either provided or withheld. This is of particular relevance for stroke as some experts were of the opinion that the emotional and vicarious caring common in young carers of stroke survivors are not captured by the tool and may therefore be disadvantageous for young carers of stroke survivors. Additionally, some tasks commonly found in caring by young people were not incorporated in the tool. This led some teams to develop their own tools creating duplication and preventing comparisons of outcomes for young carers across teams.

The complexity of assessments for young carer projects varied from using multiple tools and developing time bound action plans, to asking simple questions about the illness of the person they care for and what tasks they perform. Tools for statutory services also varied but were more formalised. Some statutory services had delegated their assessments to commissioned young carer projects and others had retained the assessments in-house. In the latter case some young carers were assessed twice, once by statutory services and once by the young carer service. Best practice involved both organisations sharing information to avoid duplication, but this was not common-place. The most commonly used tools were the MACA-YC-18 and the PANOC-YC-20. Use varied from being integral to a larger battery of measures used to assess needs, to being used as a gateway to access support services contingent on scores:

> *It's dependent on what they score on the MACA and PANOC. Depending on where the cut off is we can go up to £1000 but we tend to want a*

strong justification for what that is going to be used for. We can exceed that if there is a particularly dire situation. (E6)

Some teams used the scores as a guide to explore issues of concern and others used them as a definitive benchmark for accessing support. Most experts were satisfied with the MACA, however, some expressed concerns. One participant was concerned that the tool was not sensitive enough to identify age appropriate tasks and could raise expectations of some young people for support:

I would say the MACA 42 is still very good but you get a young person who will tick the box and say, 'oh well I clean my room and I do the washing up once or twice a week and I take the bins out', and I think ok well you should be doing those thing at twelve or thirteen and the confusion then for that young person is they say 'I am a young carer then because I have ticked the box' and I say well ….. I don't want it to be rigid but I think there needs to be a way of identifying them from a certain number of questions, positive questions that they answer. (E5)

Several people raised the issue of missing items such as ordering and collecting prescriptions, making hospital appointment and pet care including dog walking:

For a long period of time we used them [MACA and PANOC] properly and then we got frustrated because we knew different and we knew what they were saying wasn't right. (E5)

I think ... as a team we struggle with the MACA, there are some questions for the 42,.. asking about decorating and repairs, and other questions like that.. 'We've got loads of animals', so that seems to be a big add on, and 'I am having to walk the dogs and pick up dog poo all the time'. That for me is potentially more of an issue. (E4)

The perception that there is a lack of recognition of emotional caring, or vicarious caring for the stroke survivor by taking over tasks and supporting the well parent within the MACA and PANOC was considered a significant gap in assessment of young carers of stroke survivors:

> *The issue is that the eligibility falls with the physical need the child is meeting rather than the emotional need, and more often than not there is higher emotional need rather than a physical one. Because as the child is developing they don't mind cooking, cleaning and they don't mind helping mum dress, it's not a massive issue for them, but what they do have an issue with is mum is always sad, or they can't go out and that's actually a bigger need for that child's emotional development…the MACA and PANOC looks at physical demands and I think the emotional demands should be a higher priority.* (E6)

There were also concerns expressed about the use of PANOC for younger children:

> *So for children under I would say under ten years old, there is a question about suicidal thoughts which I think is inappropriate to ask children who don't present as in a depressed state. So I don't think it's appropriate to go down the pathway that could trigger thoughts later after you have gone.* (E6)

> *As a team we don't used the PANOC for anyone under nine or ten because the questions are just not appropriate.* (E5)

> *I have really mixed feelings about them [PANOC and MACA]. The PANOC for secondary school age can be fantastic. If you ask me to ask a six year old, 'I feel so sad I can hardly stand it', or 'life's not worth living', I can't*

do it. I can't do it. I would really struggle with primary age, unless it was a particularly mature year six maybe. (E4)

So, you wouldn't use it out of preference? (TC)

I wouldn't use it. I would be looking at wishes and feelings through different tools really. Maybe through three houses, that kind of thing. (E4)

4.4.3.2 Young carer support service provision

Young carer support service provision varied enormously including online, one to one and group support. Some young carers had access to school support groups and twice weekly community support groups, whereas others did not have any local services.

Some groups provided regular respite in the form of day trips, holidays and weekly meetings with one to one support. Others had much more limited activities largely based in a group type setting. In some areas but not all, individual support comprised between six and 12 one to one, face to face visits. Some services were able to access funding for individuals with specific identified needs such as for ice skating lessons as respite, or purchasing a laptop. Examples also included supporting young adult carers to access direct payments to pay for driving lessons, gym memberships and short breaks. Some budgets were capped at £200 and others at £1000 depending on the local authority area. Some providers used MACA scores as a cut off for the level of individual funding to be provided. Others sought to match statutory funding from charitable sources to double the amount available.

Services providing one to one support completed an action plan in conjunction with the young person to ensure sessions were focussed, included an exit strategy and were limited to a specific number of sessions. Support needed after this time period would trigger a new referral and assessment.

Group sessions varied from being very structured with sessions on life skills including budgeting, nutrition and emergency planning, to others that were completely unstructured and simply provided an environment to meet other young carers. Some groups meet every fortnight and others meet twice a week. Some included trips and activities and others did not. Inconsistency across local authority areas was therefore very evident in terms of the types of support and support services available.

4.4.3.2.1 Support for young adult carers

Young adult carers were described by some experts as being between 14-25 years, but the majority focussed on the 18-25year age group. All recognised the legal transition from childhood to adulthood at 18 years and the commensurate changes associated with the progression. Transitional assessments were started at 16 years for most services planning to hand over from children's to adult services. Service provision post children's services was almost entirely from generic adult services. Some good practice existed in terms of transitional care:

> *We are offering transitions assessments from around 16. They can then be supported as young adult carers up to 25. We try to make that as joined up as possible .... I did her [young carer] transition assessment, she is just over 16 heading off to college. That's when they tend to [say], 'no we're adults now we don't want to mix with the younger ones', which is absolutely fine. So, I have liaised with [name of adult carer support provider] and at the moment we're both doing a little bit to support her*

and we will gradually.... take on more of that role because we want that seamless. (E4).

All experts recognised the specific needs of the age group as well as the statutory rights to assessments and benefits but did not have any specialist services to refer them on to*: "I don't think we do enough for young adult carers. I think they get overlooked"* (E2). Many of the experts interviewed were not aware of any specialist services and neither were the young people interviewed. For the majority of young adult carers in this study the lack of support was not yet an issue for them. They were finding sufficient support from spending time with and talking to friends and work colleagues.

Gaps were also identified in services for children at the lower end of the age range as some local authorities did not assess or provide support for those under 5-6 years.

4.4.3.2.2 How teams and services work

Existence of support services were patchy across the region with some areas running several short-term young carer pilots being managed by relatively inexperienced teams and others with established long-term projects in place. Pilots were seen as a quick solution to provide care and avoided the need for formal tendering processes:

That's where the pilot projects have come about for two reasons, one because I think it's a good idea and other EU procurement regulations make it very hard to set up something very quickly and so it kind of meets a gap. (E2)

The constant change resulted in uncertainty for staff and young carers and frequent changes of providers meant that some young people fell through the support net:

> *Those kids you have worked with,.. you know 1000 young people that we've had, …haven't heard from us for months and years, because we just don't offer that any more. You might get a young person that you only see on 3 activities a year and they really look forward to them, ... We don't offer that now. So, if we are currently not working with them, the chances are they won't get invited to anything.* (E5)

One young carer interviewed had previously received long term support due to her grandfather's pre-existing co-morbidities. She had been lost to follow up during provider transitions and did not have emotional energy to re-refer herself, be reassessed and have to build a relationship with a new support worker. Her support needs were significant, she had stopped socialising and had turned down opportunities for an apprenticeship in order for her to be close at hand if her grandfather had a further stroke.

Others had expectations raised by the level of support by one provider that could not be matched by new providers. This had led to disappointment and a loss of respect for providers from some young carers. Changes from voluntary sector to in-house providers also brought unexpected problems. These were aside from the fear engendered for some families of assessments being completed by statutory services as already mentioned. As a charitable organisation, the staff had been allowed to fundraise to provide additional resources and trips out for young carers, but this was no longer permitted under the management of statutory services:

> *Whereas before [the change of provider] …we've had young carers since they were five or six or seven, and they might be 15 or 16 now. And they*

> *are coming and saying, we haven't been there, we used to do that, you're rubbish, children's services are rubbish. We haven't done a residential for two years now I think. They miss those get togethers.* (E5)

Additionally, because groups were funded by local authorities they could no longer be restricted to young carers and the entry gate had been widened to include children in need, those on a child protection plan and families in crisis. This had led to bullying and some young carers opting not to attend future groups and outings as a result of the loss of their protected space.

Some projects had waiting lists of up to eight weeks for a first assessment and others had immediate access. Some had strict criteria for access to time limited support and other projects were actively looking for young carers and had a much lower threshold for providing respite. This was despite a restriction on their budget and resources already over committed:

> *Even if we had another 30 that were referred to us and then engaged then you are closing the door to somebody aren't you? And saying well you can't come to that because it's fully booked. And because one of the challenges is funding and we are already pushing the funding out to have all these outings and groups, we couldn't probably do any extra than we are doing.* (E3)

The need to create demand was heightened by the short-term funding and repeated tendering for services and had led to some services actively searching for young people who may not have been considered young carers in other services in order to show demand. On the continuum of caring spanning from children affected by but not caring for someone with a condition or illness, to a primary carer for the person with the condition, some projects work at one extreme end and others work at the other end.

In one school project a self-identified young carer who put the bins out once a week for a neighbour was included in the weekly support group sessions and trips out alongside a primary young carer of a mother with a terminal illness. Some pilot projects were actively seeking out young carers:

> *One man rang up to refer himself to our adult [carer] service …I heard some children in the background and I said would you say they are affected by their mum's condition and do they do extra at home? And he said yeah, and I said they could actually be on carers, why don't you bring them along to one of the support groups? We have another young carer who is only 7 and his mum said, 'I wouldn't describe him as a carer but his brother has a life limiting condition'. So, I said because of his life limiting condition does this mean he can't go to a party that he would like to go to because his brother needs extra attention? Or at home you might say can you get this for your brother, or because his behaviour is quite unpredictable they are less likely to do things like the cinema? And she said 'well yes, absolutely. He does have to take a step back at times and lose out I suppose'. So that's another way you can identify him as a young carer. Because of his brother's condition he's having to sometimes miss out* (E3).

4.4.3.2.3 Levers and challenges

The changes in legislation enshrined in the Children and Families Act 2014 had enabled levers for improving services for young carers as well as introducing new challenges. Opinion was divided on whether the legislation had made a positive difference to young carers or not. For some, the statutory duty to identify, assess and support young carers had created challenges. Demand was unknown and attempts to respond to this information gap by assessing young carers and placing them on local authority registers had caused consternation

and fear in some parents resulting in them being unwilling to have their child assessed.

Some young carers and their families were reported to be reluctant to reveal the true level of their contribution to caring for fear of triggering unwanted statutory intervention, especially when assessments sat within the statutory services. This created concern by professional staff that it would limit some young carer's ability to access the level of support they really need: *"I've had it several times where the child is anxious because I am from social services and all they see on television is social services taking children away and there is always that massive anxiety*" (E6).

Finance was a challenge for many organisations with no additional funding attached to implementing the legislation. This resulted in services which already considered their services to be over stretched being stretched further: *"We would love to have double the workforce to be able to do double the work but at the moment the work doubles and the budgets don't"* (E7).

In response to the legislation, some local authorities appeared to have had an unplanned immediate reaction and had commissioned various pilots for young carer projects as a rapid response to provide assessments and services. This was creating uncertainty about the future and a lack of ability to plan more than a few months ahead for affected projects. Overall commissioning for young carers appeared to have a low priority. Some strategies were out-of-date or non-existent and responsibility comprised a small component of someone's portfolio leading to an ad hoc system of providing services. Many parts of the region had multiple providers delivering services to a specific age group creating challenges for other professionals involved in the support of young carers to keep up to date with current services*: "I don't know how many [projects] are*

left. I know some are closing …… I don't actually know now anymore. There were cuts at the end of last year. I'll find out on Friday what's left" (E1).

For one service, the legislation had triggered a cancellation of voluntary sector provider contracts to bring assessments and services back in-house. The statutory duties and the change to contracts were seen as an overwhelmingly positive change by one expert:

> *It [old provider] had gone very much 'well you don't provide medical care or practical care so you are not a carer'. The previous provider had turned away lots of referrals saying no they are not providing enough care. And I personally had a huge issue with that. It is about the impact of a disabled sibling, I think there was a responsibility to assess, now there is a responsibility to assess as a right, so I am feeling really really chuffed about that.* (E4)

4.4.3.2.3.1 Multiagency working

All experts were clear about the need to work with colleagues across sector and organisational boundaries to share information and support young carers to fully meet their needs, especially in the current climate of financial and budgetary constraints:

> *I think it's everybody's responsibility. Any professional that is working with a young person. I don't think it's one person or one authority or for one group of people to oversee it because obviously children are accessing all sorts of services at different times. It might be the scout leader has noticed something, or it might be the nurse at the surgery where mum is going for her treatment and not asking the right questions. So there isn't one person that's responsible, I think everybody is*

responsible to know what is out there and that's the hard bit. Because it changes. (E5)

However, despite this belief there were gaps in knowledge about other services and young carer projects in the area and no examples of sharing good practice or innovation were found. Many teams were 'reinventing the wheel' by designing their own assessment tools, programmes and evaluations methods: *"There's a project running … in the city. So, I don't know much about what they are doing. I have been on the website but I think they are more like doing the education side. I don't know"* (E3).

Barriers to multiagency working effectively included complexity:

[When] it comes to getting physical help in.., for young carers it's difficult because it's that mixture of education and social care and health. And that's a difficult balancing act to get them all acting on the same page really. In an ideal world that would be one system, but it isn't so it's quite complex. (E7)

and lack of knowledge and training:

It's the role of the person who has identified the young carer until the worker is identified. More often than not because they don't specialise in young carers, or never worked with children, they work with adults, it is very very different. The responsibility becomes quite difficult because they are like a general practitioner, they can't be experts in everything and they can tell you where to put a grab rail but they can't tell you where to put a child with complex anxiety or with complex behavioural issues so until they have made that referral, they are managed unsupervised. There may be conversations internally, but until that referral gets through it's left with the worker that's identified it. (E6)

Sharing of information plays a vital role in multi-agency working but doesn't always happen across agencies due to issues of confidentiality. For one expert it was the top priority for improving services for young carers:

> *I remember being at safeguarding training with adult mental health nurses and talking about information sharing they have patients with extreme mental health problems. .. they are not telling the school nurses, because that's their patient's information. They could have that conversation with their patients about – look this may be really hard on the children. But that wasn't happening …. The biggest challenge is sharing of information. We just don't know how many young carers there are in our school we just don't know. That's been our barrier all the time.* (E1)

Other relationships could be more challenging and frustrating when young carer projects had identified needs for support for young carers and their families and other agencies were unable to respond to their responsibilities in a timely fashion:

> *I have made a referral for a mum who suffers from epilepsy and she has four children under the age of 11 and when she has suffered a major seizure she is in bed for 2-3 days and she struggles obviously to maintain her personal care. She's had an initial assessment and that was back in September, and that assessment did identify that she has care needs and they now need to refer to the long-term team and her case is still waiting for allocation. So, it's like waiting list and workers capacity and that for me is quite frustrating and a challenge because the adult needs the support, you have done the appropriate referrals and it's just a matter of waiting now so that can be quite challenging.* (E10)

4.4.3.2.4 Innovations and good practice

The cuts to budgets and the need to do more with less money in response to the new responsibilities enshrined in the 2014 legislation had led to some innovation and creativity to meet perceived gaps in service provision. Transport budgets had without exception been cut which was a significant issue for rural locations and those within large conurbations where young carers were required to travel around 20 miles to access group activities. Innovations included working with other charities to provide volunteer drivers, project workers collecting young carers on the way to and from work, and older young carers being taught and encouraged to use public transport as part of developing their independence and life skills:

> *We did used to provide taxis for the older group but that budget has been cut now. ... It's about empowering them as well and just building up on their confidence and their independence skills. It's not such a bad thing, it's just working creatively with the young people and the youth service to get there.* (E10)

There was also a recognition that for some young carers, their needs could more adequately be met by accessing existing community groups and project workers were sourcing local groups to meet the needs of young people they were supporting. Other links were also being made with generic youth workers to ensure young carers had access to support on days that young carer projects were not running and also to build resilience and sustainability into the support services:

> *Although they [young carer project] are at a generic youth centre it's a closed group so only our young carers will attend that session. And I think it's a really good outlet for young people because it builds up a relationship with the youth workers and also the groups tend to be based*

in certain areas of the city, so which ever group is closest to that young person, they would go to that group. So, we've also built that link for them to continue going to the youth centre when the group isn't on so they can still have that support from the youth workers and they can attend other activities that are there as well. (E10)

Others recognised the need to work more efficiently by innovating and focussing on core responsibilities:

We try to be novel and use technology where we can to be more efficient on the areas where people just want a quick bit of advice and information. So, we can free up the manpower to do what I think is the most important thing as an organisation we do, whether it's a young carer or an adult carer whatever the condition is, sit down and listen. (E7)

4.4.3.2.5 Measuring outcomes

Evaluation of services was largely reliant on quantitative methods involving numbers of young carers seen, number and type of sessions provided and numbers of one to one support cases closed within agreed time frames. This focus on provision for young carers already in the system obscures the true demand for services. Some projects had devised their own evaluation tools and methods which were subjective and designed to tell them what they wanted to hear:

We do evaluations after every group …. We do a 3-4 monthly outcome scale. So, the evaluations are questions like, what did you like about the group today? What do you think could be done differently at the group today? Did you feel supported? What did you enjoy about the activity? And any other comments. We let them be anonymous and so far all we

> *have had is good feedback really. … We've got quite a lot of picture evidence as well. But it's like I said to my team leader it would be hard to get negative because the poor young carers haven't been supported up to yet. So, for them this is probably like gold dust.* (E3)

Others used audit of individual cases as an evaluation tool:

> *There is obviously a Team Around the Child plan, and its following that process through I guess, that's where your outcomes are. So, every six weeks if you are meeting, it's what do you need to happen? This, this and this, how is that going to happen? Right we are going to do this, this and this. And then that next meeting is almost used as a bit of an audit.* (E4)

There was no independent evaluation of services or peer review. Few appeared to be held to account for the quality of the service.

Benefits attributed to the services included those for individual young carers and also their families. One couple reported that they were able to go out together as the children were being cared for at the project which they felt had improved their relationship. Young carer benefits included building personal networks and friendships with other young carers, accessing assessments to provide individual funding for things such as ice-skating lessons, attending day trips, experiences such as archery, and voluntary work experience as an older member of the group supporting younger carers.

Benefits gained also depended on the type of service being provided. Some of the more comprehensive services provided counselling and advocacy services to help young carers access the support they needed from school or adult social services to enhance care packages for the cared for person:

Some who come to the young carer groups, you see them come in as quiet self-conscious teens and you see them flourish and grow. ..Those that feel actually I am never going to be able to leave home, I am never going to be able to be away from this situation, and they have gone off to university. That's raising expectations and aspirations I think. (E4)

4.4.4 The role of schools in supporting young carers

Schools were recognised by all as having a vital role to play in identifying and supporting young carers as the only organisation and place the majority of children attend. Despite this, a significant gap has been uncovered with many schools lacking in knowledge and awareness of young carers and the legislation designed to support them. Additionally, there was great variation in different schools readiness to recognise and address the needs of young carers:

I've had schools come back and say, 'oh we don't have any young carers', and I think hey, I am not going to start by saying actually I think you are wrong …I just emailed this school back and said I absolutely appreciate you might not have any young carers, but just tomorrow someone could come in ….who's parent has cancer……. I think they get a bit fixed that they haven't got a parent in a wheelchair at that school maybe. (E4)

4.4.4.1 School engagement

In an effort to mobilise additional resources in the form of universal services, some local authorities and CCGs had invested in roles to liaise and work with schools to raise awareness of young carers. One such project worker had visited every educational establishment within the local authority area and she estimated less than 1% were aware of the Children and Families Act 2014. Work to raise awareness included the appointment of a young carer champion in every

school and the development of a toolkit which included templates to help develop young carer policies and strategy. Training and on-going support was also offered. Formal networks of champions had been developed with representation on multi-disciplinary groups to inform local authority strategy for young carers. 'Feeder meetings' had been established between primary and secondary education to assist in the handover of young carers at key educational transition points. Numbers of young carers on each school register were also recorded and tracked each term to ensure no one was slipping through the net as they moved schools.

In some areas, there was a sense that a great deal of progress had been made in raising awareness and engaging with schools. However, in others young carers were still reporting a lack of awareness and support in their school. Project workers had responded by liaising with schools to raise awareness of needs of young carers. This had been done with a small number of schools resulting in some invitations to present at school assemblies and to run drop in sessions for young carers. Some experts felt the way to encourage greater consistency in overall school engagement and awareness was to encourage all schools to apply for the young carer school awards.

4.4.4.2 Young Carers in Schools Awards

Investment in the young carer school awards programme varied across the Region. One local authority was supporting the design of a local initiative to raise awareness of young carers in schools. Another envisaged all schools in their area should be working through the different levels of the YCiS award scheme. They had invested in one fixed term full-time post to ensure plans were in place for young carers in every education provision in the county. Despite this investment

and intention, no schools in that authority had received an award[6]. The lack of progress may in part be due to the end of the fixed term contract and no succession plan to drive the changes forward.

Although the application for the award was seen by one school as an additional time pressure, it had also been a useful tool to identify and address gaps in support and services and they were able to articulate a number of improvements they had implemented as a result of preparing for the bronze and silver awards. Improvements included updating the school website to incorporate young carers, advertising the support group, trips and achievements, and preparing a pack for supply teachers with photos and details of young carers in their groups for the day. None of the improvements had been evaluated for outcomes.

Overall seven schools in the East Midlands had received a bronze award Young Carers in Schools awards (30th January 2018) and six of these were in Lincolnshire (Carers Trust, 2018). This represents 0.3% of the 2238 schools in the East Midlands (Schoolsnet, 2017).

4.4.4.3 Good practice in schools

One school was very proactive in identifying and working with young carers. Significant resources had been invested in staff and young carer services. In a school of 300 pupils, 40 were identified as young carers. New starter forms included a field for parents to identify if anyone in the family had a long-term health condition or the child had any caring responsibilities. Young carers lead lessons about young carers and there is no stigma attached to the label. There

[6] As of March 2018

are weekly support groups held within the formal timetable for the school for which there is a mix of external speakers, formal teaching with a focus on a specific long-term conditions or practical sessions such as first aid. There are annual respite breaks to the seaside and regular trips to the theatre funded by local charities. There is also a Christmas party each year for the young carers and the cared for person. None of this good practice had been shared proactively outside of the school.

4.5 Discussion

This study aimed to investigate the statutory, voluntary, and educational support services for young carers in the East Midlands by exploring the challenges of identifying young carers of stroke survivors from the perspective of statutory services; exploring pathways and referral mechanisms for young carers into support services; investigating challenges for service providers and commissioners; exploring current service provision and finally to identify good practice.

The study found that identifying young carers was a major challenge and concern for all experts interviewed and numbers of young carers of stroke survivors was unknown. Referral and assessment pathways were complex and could exacerbate existing barriers to young carers and their families accessing services. Legislation designed to strengthen identification, assessment and support for young carers had unintended consequences, which detracted from existing service provision in some cases. Professionals' knowledge, beliefs and understanding of the existence, needs and rights of young carers of stroke survivors augmented challenges in identifying, assessing and supporting young carers of stroke survivors.

The challenges of identifying young carers revealed in this study has been consistently recognised in previous research (Aldridge & Becker, 1993b; Aldridge et al, 2016a; Bilsborrow, 1992; Dearden & Becker, 1995; Frank, 1995). Factors contributing to the hiddenness of young carers were the same as those in previous studies. Factors were attributed to three main causes: young carers and families; organisational strategy and policy; lack of awareness, knowledge and education by all sector professionals in young carer issues.

The reasons young carers and their families choose not to reveal their caring role or the extent of the caring often driven by fear or shame has been described elsewhere in this thesis and has been reported since the earliest studies of young carers (Aldridge & Becker, 1994; Becker et al, 1998; Dearden et al, 1994). More than two decades later and the same issues are still being reported (Children's Commissioner for England, 2016; James, 2017). Such barriers to young carers and their families accessing the services they need and to which they are entitled may remain inexorable as long as tensions exist between local authorities' duty to their statutory safeguarding responsibilities that preclude false promise of non-intervention, and their role in identifying, assessing and supporting of young carers and their families.

The experts' belief that lack of recognition of the role by young carers and their families also acts as a barrier to identification has been widely recognised (Aldridge et al, 2016a). This is exacerbated by a lack of awareness of rights to assessment and support (Becker et al, 1998). This is likely to be heightened for stroke as the lack of awareness of the existence of young carers of stroke survivors was apparent making the chances of identification and referral even more remote for this group.

A further reason for hiddenness may be deliberate choice on behalf of the young carer. Some may be aware of their rights to assessment and support but may choose to exercise their own agency. They may gain a great deal from their caring role and may not need to access any help over and above that which they have already sourced for themselves.

The strengthened statutory duty to identify and assess young carers has driven some local authorities to take more control over assessment and support, bringing services back in house from voluntary sector providers. This has further compounded the tensions between service provision and safeguarding duties increasing the likelihood that some young carers and their families could remain hidden. Some young carer teams are attempting to breach these barriers by visiting schools to deliver assemblies and provide advice and drop in sessions for young carers. However, this initiative may not sustainable in the long term as resources are stretched by the strengthened responsibilities and finances become more restricted. Alternative strategies to break down these barriers may need to be explored.

Despite the increased imperative to identify and assess young carers introduced by legislative changes enshrined in the Children and Families Act 2014 and Children Act 2014, it seems little has changed in some areas.

The legislation strengthening support for young carers has resulted in some unintended consequences already described above and has placed extra costs on local authorities affecting service provision. In addition, the lack of strategy, service and financial planning, and high-level leadership around young carer service provision hitherto largely unnoticed has become more apparent.

James (2017) in a review of young carers on behalf of the charity Barnardo's, similarly found funding nationally had not kept pace with the demand created by the strengthened duties to identify, assess and support young carers. Recent reports by the Children's Commissioner supported this as they found only a small proportion of young carers were being identified and local authorities appeared to be focussed on statutory duties to assess rather than providing necessary support. They also revealed a huge variation in the types of services available. Many voluntary sector projects were having to re-allocate funding provided by local authorities from service provision to assessments, and were having to find alternative money to provide their support services (Children's Commissioner for England, 2016).

Similarly to this study, James (2017) also found that many young carers were being failed by statutory bodies due to ambiguity as to where responsibility for identification and referrals rested within local authorities (p.17). Children's Commissioner for England (2016) in a lightening review found that 13% of local authorities that responded to their survey, did not or could not confirm whether they had any mechanisms in place to identify young carers despite the statutory duty to identify and assess them. They suggested that for people with physical and mental illness or disability, mechanisms and pathways should be put in place to identify and refer young carers by whichever agency is most involved. However, multi-agency working has been found to create new problems for the identification of young carers: "by making it 'everybody's business' it has almost become nobody's business" (James, 2017 p.27). This study's findings that the same issues were apparent in the East Midlands, suggests referral pathways would benefit from being much more transparent and easier to navigate with clearly defined responsibilities at each stage.

In spite of the recognition of the need for universal services such as education and health to become more involved in identifying and supporting young carers (Carers Trust, 2016; Department of Health, 1999; James, 2017), referrals from GPs and school nurses in-to support services were low in this study. This replicates the findings of many studies (Barnardo's, 2006; Butler & Astbury, 2005; Carers Trust, 2016; Dearden & Becker, 1998b; James, 2017). This failure has previously been attributed to a lack of awareness of young carers by teachers, GPs, other health and social care practitioners; a lack of confidence in approaching children of adults they are supporting; and a lack of awareness of who and where to refer on to. GPs in this study did not exploit the opportunities they have to engage and identify young carers. Experts felt GPs are best placed to know which families are affected by long term conditions and should ask the questions about who is providing support on a daily basis. This is especially where there are co-resident children and young people. Other researchers have reached the same conclusions (James, 2017).

GP recognition and engagement with young carers could be particularly apposite for stroke in the East Midlands as stroke survivors are moved rapidly from acute to community care with the ESD pathways. Current initiatives to raise awareness of the young carer agenda with GPs were reported by expert participants as unsuccessful. They are potentially even less likely to be successful for stroke as it has traditionally been associated as a disease of older age and therefore doesn’t enter their consideration.

Much more work is required to raise awareness and encourage GPs and other healthcare professionals engaged in the provision of home care to ask the questions about who is providing care and signpost individuals and families to appropriate support and information in case it is needed in the future. Particularly in stroke, healthcare professionals can play a key role in educating

families about stroke and helping them to talk to each other about the changes that have been wrought on individuals and family by the stroke.

The majority of needs for young carers of stroke survivors might be met by generic young carer services. However, the provision of stroke specific knowledge and information are an essential part of that support package. It is important that young carers are identified early to prevent them becoming socialised in to the role to ensure benefits of caring are realised and any potential harm is mitigated against. Healthcare professionals working in the home in the early stage of stroke rehabilitation are ideally placed to do so.

Further barriers to identifying young carers are perpetuated by the media and community as a whole. The media view of young carers often sustains the image that young carers are caring for a stereotypically physically disabled mother in a wheelchair. The young carer is often cast in the role of hero or angel which can itself create tensions and additional stress by raising expectations for young carers (Moore & McArthur, 2007; Rose & Cohen, 2010). In reality caring is much more varied, and not all cared for people have outward or visible manifestations of their disability or need. This dissonance between how the media often portray young carers and the reality of what young caring really is will perpetuate the problems researchers and statutory authorities currently report in identifying young carers in general. This will continue to challenge statutory services to search for significant numbers of young carers who modelling suggests exists, but who will not be discoverable.

In respect of stroke, all the issues mentioned above are particularly pertinent as clinicians involved in the stroke pathways did not engage with the study on the grounds that they didn't believe young carers of stroke survivors exist, one reason given being that it is a condition associated with older age (Stroke

Association, 2017). However, as stroke incidence in younger age groups is increasing (Tsendsuren et al, 2016), there is likely to be an associated increase in people at the life stage of having children as co-residents. Co-residency is a major indicator of young caring (Dearden & Becker, 1998b). Therefore, the incidence of young carers of stroke survivors could be expected to increase. Without the evidence to support increasing numbers, clinicians may continue to ignore the problem and more young people could be left without support. Education of healthcare professionals, teachers and voluntary sector adult service staff will be key in raising awareness of the existence of young carers, their needs and rights to assessment and support.

The patchy and inconsistent nature of young carer support services identified in this study has been reported with seemingly little or no improvement over the past two decades (Aldridge et al, 2016a; Banks et al, 2002a; Bibby & Becker, 2000; Children's Commissioner for England, 2016; James, 2017). This is despite benefits of young carer projects being recognised as a vital part of support packages for young carers and their families to enhance benefits of caring and mitigate negative consequences(Becker et al, 2001). Calls for local authority commissioners to improve the sustainability and stability of young carer services have been made by key organisations as they have a vested interest in strengthening services (Carers Trust, 2016 p.11).

Concerns expressed by some experts about some of the tools commonly in use to identify and assess young carers, may benefit from further investigation to establish whether concerns are generated by a lack of knowledge and understanding or are justified. Concerns included the perception that emotional caring and vicarious caring by supporting the well parent were not reflected sufficiently, and a lack of incorporation of some key tasks. Concerns about the outcome tool PANOC in common use for younger children could benefit from

further debate. This was leading to some teams duplicating work by developing their own tools. A review of tools with the aim of standardising the approach across the East Midlands could bring many benefits in respect of familiarity with the tools for all first point of contact staff and equity of accessibility of services. Additionally, with current restrictions on budgets and resources, provision needs to be targeted at those in greatest need and therefore standardisation and confidence in tools are key.

This study like previous studies, reports services being under increasing pressure from budgetary cuts further compounded by the unintended consequence of the 2014 legislation increasing workload created by the required assessments. The consequent dilution of time and resources available to actually deliver support is endangering the very essence of what is most appreciated and required by young carers, which is protected time in a safe environment with other young people with shared experiences (Bibby & Becker, 2000; Dearden & Becker, 1998b). Difficulties for young carers in accessing bespoke services are further challenged by their lack of awareness and information about what is available, the lack of awareness, and knowledge about services by frontline staff who need to signpost and refer young carers, and the constantly changing picture of providers caused by short term contracts and pilots. There were no specific services for young carers of stroke survivors found and it seems unlikely with the current constraints within which charities and other providers are operating that the provision of such specific services is likely to materialise. Therefore, use will need to be made of generic young carer services and the more specialised needs of young carers of stroke survivors, such as understanding and working with the complexity of stroke impairments, will have to be met in different ways.

4.5.1 Study strengths and limitations

This was the first study in the UK to look at the provision of support services for young carers, specifically in the East Midlands utilising a stroke lens. The study looked at services across a range of voluntary and statutory sector views and built upon the findings presented in chapter three of the views of young carers and stroke survivors themselves.

The study was limited by the sample size and the findings may not be relevant beyond the East Midlands. Sample size was restricted by the lack of engagement of some voluntary sector providers who appeared to be suspicious of the motives behind the study. There was a misperception expressed by some experts approached that young carers of stroke survivors did not exist and therefore they could not contribute anything to the study. Health services were also challenging to engage, partly as young carers did not seem to fit in any individual's particular portfolio, making identification of potential participants very difficult.

The snowball technique whilst being partially successful also introduced some bias as networks did not extend into young adult carer networks. Whether this was because they did not exist or were separated from the young carer networks was not apparent.

4.6 Conclusions

This chapter explored the support services available for young carers of stroke survivors in the East Midlands from the perspective of experts in the field who either provide or commission young carer support services. Referral pathways, assessment tools and challenges for support services were also explored in addition to examples of good practice being identified.

The study found experts identified challenges in identifying and engaging with young carers. This was compounded by their lack of certainty about how many young carers they should expect to be working with. Accurate numbers are still unknown and estimates are based on historical census data and individuals currently being supported in young carer projects. Such figures are unreliable as many young carers are not identified or are not able to access any support for multifarious reasons. This hinders planning and poses a threat to future provision of support services. Estimating figures for young carers of stroke survivors is even more challenging as existing databases do not distinguish between stroke and other physical disabilities. Thus, there are no data to be able to quantitatively challenge the notion that young carers of stroke survivors do not exist.

A lack of clear leadership, up to date strategy and resources to implement legislative requirements for young carers exacerbate the issues.

Referral pathways to assessment and support services were complex and variable and created difficulties for first point of contact staff to know what services were available to refer young carers to. The constant changes to service providers created by short term contracts resulting from a pilot culture in some areas, and lack of clear strategy and leadership in others, further compounded the issues. The study also found some good practice existed but was rarely shared beyond the immediate team. Some organisations such as schools with identified young carer champions are to be lauded and encouraged to spread their best practice.

This first study exploring the lives of young carers of stroke survivors in the UK from the perspective of experts working in the field exposed the challenges currently experienced by young carer service providers and commissioners.

These challenges are compounded for stroke as the concept of young carers of stroke survivors has not yet entered the consciousness of many health and social care professionals who are likely to be the first point of contact for young carers. These young carers are not being identified, nor referred through the complex pathways to support services. This study is the first stage in starting to raise awareness of health, adult social care and education workers of the existence and needs of young carers of stroke survivors. Future studies could potentially address educational needs of frontline professionals, and the development of robust referral pathways and support packages for young carers.

CHAPTER FIVE – INFORMATION ANALYSIS AND SYNTHESIS

5 Introduction

In accordance with other studies of young carers (Aldridge & Becker, 1993b; Aldridge et al, 2016b) the findings from the second phase of this PhD, revealed that children and young carers of stroke survivors do not have the relevant and condition-specific information they need to support the person they care for as effectively as they would wish. None of the young people interviewed had any awareness of stroke-specific information for their age group or knew how to access it. Previous research has shown that gaining information about a parent's chronic condition can decrease emotional distress and increase overall life satisfaction (Horner, 2013; Pakenham & Bursnall, 2006).

As a result of the findings from the previous phases of this PhD and congruent with the sequential nature of the overall PhD design a new and important area which required exploration emerged. The question pertained to the availability and quality of information available for young carers of stroke survivors. In order to address this the final phase of the PhD explores and synthesises information available for young carers of stroke survivors with other comparative conditions specifically Brain Injury (BI), Multiple Sclerosis (MS), and Parkinson's disease (PD), applying the essence of an Appreciative Inquiry (AI) approach to identify and spread best practice. Content and quality of information were analysed in addition to the models for delivery of the information in a synthesis aimed to identify best practice, gaps in current stroke information and make recommendations for improvements.

5.1 Justification of condition choice

The three long term conditions of BI, MS and PD were selected as comparators to stroke because they produce some deficits similar to stroke, and are neurological conditions affecting people from a wide age range including those who may have children in the age group 11-24 years who are included in the study.

5.1.1 Brain injury

BI is often described as either a traumatic brain injury (TBI) or an acquired brain injury (ABI). TBI is defined by Menon et al (2010) as: *"an alteration in brain function, or other evidence of brain pathology caused by an external force*". (p.1637)

However as Teasell et al (2007) explicates,

> *ABI is an umbrella term, encompassing a wide spectrum of brain injuries that generally includes traumatic and non-traumatic etiologies [sic] such as cerebral concussion, brain contusions, subarachnoid hemorrhages [sic] or other 'acquired' problems. (p.108)*

A further definition is proposed by the Toronto Acquired Brain Injury Network,

> *ABI is defined as 'damage to the brain that occurs after birth and which is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain. (In Teasell et al 2007, p.108)*

Thus, stroke is a form of ABI and information for children or young carers for someone with any type of BI was included.

5.1.2 Multiple sclerosis

MS is an autoimmune disease of neurological origin affecting the brain and the spinal cord. The myelin sheath covering the nerves becomes damaged by an inflammatory process leading to scaring with a resultant reduction or complete lack of neural transmission through the affected nerves. It has an uncertain path and outcomes (Mutch, 2005) in the same way as stroke, and can affect muscle control, vision, balance and fatigue, sensation, and cognitive function. In a 20 year prevalence study of MS by Mackenzie et al (2014) around 127,000 people in the UK were estimated to be living with MS in 2010 and a further 6,000 were diagnosed each year. Peak incidence occurred between 40 and 50 years and more frequently in women. MS is rare in children but can occur at any age.

5.1.3 Parkinson's disease

PD is a neurodegenerative disorder, prevalent with increasing age and in men (Hirsch et al, 2016). The majority of diagnoses are made over the age of 60 years, but also occurs in the younger age groups. There are around 127,000 people affected in the UK (Reeve et al, 2014). The brain cells which produce the chemical neuro-transmitter dopamine start to fail with a consequent impact on efficiency of the transmission of neural impulses. This leads to a wide range of symptoms including rigidity, slowness of movement, freezing when trying to move, problems with balance, speech, continence, fatigue and anxiety and depression. Symptoms can vary each day and progression is unpredictable (Brain and Spine Foundation, 2016).

PD and MS were also chosen as conditions which recognise young carers and have well developed information and support services in place (Morley & Jenkinson, 2013). By adopting the principles of an Appreciative Inquiry

approach, models of best practice found in existing services are intended to act as a conduit for improvement in stroke information provision.

5.2 Appreciative Inquiry

An AI approach was adopted for this phase of the study to identify best practice from stroke and other comparator long term conditions and to build upon it to enhance information for children and young carers of stroke survivors. AI seeks to ask what works rather than to focus on problems:

> *AI concentrates on exploring ideas that people have about what is valuable in what they do and then tries to work out ways in which this can be built on—the emphasis is firmly on appreciating the activities and responses of people, rather than concentrating on their problems (Reed 2007 p.7).*

5.3 Study aim, and questions

Aim: To explore and synthesise the information available for children and young carers of stroke survivors and other comparative conditions, specifically BI, MS and PD, applying the essence of an AI approach to identify and spread best practice. To identify:

- What freely available information for 11-24year old children and young carers of stroke survivors, BI, MS and PD exists in the United Kingdom?
- How is the information accessed?
- What best practice can be identified in terms of information provision for children and young carers of stroke survivors, BI, MS and PD?
- What recommendations for making improvements in stroke information for children and young carers of stroke survivors can be made?

5.4 Literature

5.4.1 Information

Information in its simplest form is defined in The Oxford English Dictionary (2018) as: "*Facts provided or learned about something or someone*". In terms of the literature pertaining to young carers, there are two types of information reported but not distinguished between. This difference refers firstly to information that is produced in a material form by health, social or voluntary care sectors for young carers and secondly that which is known about and shared between family members and which is impalpable. The Knowledge Cafe (2017) describes to the first type as either: **"***Explicit information or knowledge that is set out in tangible form or implicit information or knowledge that is not set out in tangible form but could be made explicit."* The second type would be**:** "*Tacit information or knowledge that one would have extreme difficulty operationally setting out in tangible form*."

For the purposes of this review of the literature the main focus will be the explicit form of information, except for one exception, exploring the concept of openness discussed below, in which both types of information play a key part.

The availability and accessibility of the right information for young carers is crucial and should be child-centred (Aldridge & Becker, 1993b). Rose & Cohen (2010) suggest enhanced information about caring, rights and the condition of the person they care for could empower young carers to make their own decisions about their care giving role, rather than being subjugated by the constitutional definitions and the consequent enforcement of roles imposed on them by statutory services.

The exponential rise in the use of the internet by people searching for health and associated information has led to increasing concern about the accuracy and quality of the information being accessed (Eysenbach, 2000; Eysenbach et al, 2002). Assessing quality is an on-going challenge with inconsistencies in criteria used to assess it. This has necessitated the identification of the gold standard core indicators; accuracy, currency of information and completeness, which have become the basis of some of the most frequently used and cited quality assessment tools such as HONcode, DISCERN and JAMA benchmarks (Fahy et al, 2014). HONcode certification has been associated with increased reliability and higher quality of information (Mousiolis et al, 2012; Nason et al, 2012; Soobrah & Clark, 2012). Proxy indicators for assessing website quality are also used such as authorship, attribution (references and sources), and disclosure (Bernstam et al, 2005; Silberg et al, 1997). However, none of these tools assess the accuracy of the information published. Much of the literature related to information quality is very condition-specific for that reason as it requires an expert in the field to assess it (Fahy et al, 2014).

The United Nations Convention of the Rights of the Child Articles 13, 17 and 24 (UN General Assembly, 1989), recognises the rights of children to get and share information that is important to their health and well-being, in forms they can understand. Despite this directive, many studies have found that children or young carers of someone affected by a long-term condition have limited knowledge and understanding of the illness and are often excluded from receiving information by health care professionals (Aldridge & Becker, 1993b; 1997; Barnes et al, 2000; Becker et al, 1998; Gladstone et al, 2011). The impact of this negatively effects many aspects of their lives (Horner, 2013).

Limited understanding of parental chronic illness has been associated with poorer outcomes for children and young people in terms of mental health

(Bjorgvinsdottir & Halldorsdottir, 2014; Carers Trust, 2016; Gladstone et al, 2011). Some studies have recommended the provision of tailored information for children, about their parent's condition and coping mechanisms as a buffer to mediate against some of the potentially harmful effects of having an ill parent and caring responsibilities (Visser-Meily et al, 2005a). Aldridge & Becker (1993b; 1997) go further and suggest timely and appropriate information for young carers and their families could be incorporated in a strategy to limit unwanted caring responsibilities or even prevent it occurring.

In a study of adolescents' experiences of coping with a parent with MS, Mauseth & Hjalmhult (2016) reported that they would have coped better had they received more information about their parent's condition, although coping better was undefined, unquantified and unmeasured. In addition, they found that few of the 15 young people interviewed had received information from health care professionals, but those who had, evaluated it highly. None had accessed the internet as a source of information. In contrast, Ettel et al (2012) in a study of high school students found half of the student had accessed health information on the internet. However, this was an American study and possibly rates of access to the internet vary in the UK. Gray et al (2005) found that adolescents perceived clinicians as trusted advisors but also sought to verify information given through internet searches. The convenience and anonymity of being able to do so through the internet was of prime importance to them. In a further study of adolescent internet searching behaviour, Hansen et al (2003) studied 12 students searching for health-related information on 68 observed searches. The majority of sites accessed (77%) were directly from search engines results and only 7% from links from another site. Further, 83% of searches were from the first nine search engine results. Similarly, Eysenbach & Köhler (2002) found participants only searched on the first 10 links from the search engine.

Nicholls et al (2017) studied 16-24year olds of a parent with a chronic condition, aiming to develop a measure of unmet needs. They found being fully informed about the condition facilitated emotional coping. They also identified that some of their participants reported some barriers to accessing the information they required including those erected by parents sheltering and protecting them. This has also been reported in other studies including Gladstone et al (2011) who reported that some parents and young carers cited embarrassment, shame and guilt as barriers to seeking information about mental health issues. Further, some parents believed more information would be burdensome and upsetting and there was nothing more for them to learn. Yet others believed the children did not want to know what was wrong or the parents themselves were in denial that there were any problems. Conversely, those who did seek more information for their children did so in the belief that it would correct any misconceptions children had developed about their own behaviour impacting on or even causing the parent's ill health. Children from age five reported knowing there was something wrong even when parents were withholding that information and suppressing signs of their illness. Young people expressed frustration at being expected to be mature enough to provide care but not afforded the respect and trust of being fully informed that they felt was consistent with the role they were fulfilling (Bjorgvinsdottir & Halldorsdottir, 2014; Nicholls et al, 2017).

In parallel with information provision and difficult to extrapolate cause and effect of negative outcomes for young carers, is that of the absence or presence of openness within families, including the willingness to share feelings, worries, fears and exchange information and views on the condition or illness and changes within the family. The two concepts of information provision and openness appear intertwined as both children and parents protect each other by not sharing this tacit information. Openness has been associated with improved

short and long-term outcomes for young carers and conversely a lack of openness has been reported as having negative effects.

Moberg et al (2017) in a study of 14 young adults aged 18-25 years explored their experiences of growing up with an adult with MS and the long-term outcomes of those experiences. They suggest these young carers conceal information about true feelings, questions, worries and wishes to avoid distressing their parents and that these behaviours become so ingrained they carry over into other relationships including with future partners. This restraint is credited with being the causation of episodes of anxiety and depression and creating future relationship problems. The study also found the lack of openness resulted in a lack of knowledge about MS which further compounded anxiety and depression. Participants reported that absence of opportunity to ask questions in part as a result of them not wanting to worry their parents, and in part a reluctance by parents to share information for fear of upsetting the child, resulted in children creating their own negative fantasies to fill the information and knowledge void, thus reinforcing negative feelings and increasing anxiety further. This finding has also been reported previously (Aldridge & Becker, 1993b). Moberg et al (2017) recommended health care professionals should encourage openness and increasing knowledge about the condition to support family coping and improve outcomes. Mauseth & Hjalmhult (2016) also found openness in families was key to improving adolescent coping and that healthcare professionals could play a major part in this by offering support and imparting knowledge. Aldridge & Becker (2004) also found some parents were reluctant to discuss their illness or didn't feel they knew enough to discuss it with their children and this led to negative psychological outcomes for the children.

A further issue for information for young carers is the manner in which children and young carers learn about parental illness and access information. In a

literature review comprising 20 studies of children with a parent experiencing mental illness, Gladstone et al (2011) reported that young people learned about mental illness from the well parent, other family members, school counsellors, libraries, printed materials and other media. Some accidentally overheard adult's conversations. Few reported being taught by health and social care professionals even when they had regular contact. However, there was no consensus in the papers examined about the type, amount of information children had or how much or how they wanted to access it (Gladstone et al, 2011).

In response to the growing evidence base pertaining to the information needs of children and young people in relation to their relative's illness or condition (Morley & Jenkinson, 2013; Schrag et al, 2004), and the potential to enhance outcomes by its provision, some societies elected to produce information specifically aimed at children and young carers (Aldridge & Becker, 1997). Parkinson's disease Society and Multiple Sclerosis Society and Multiple Sclerosis Trust are some examples. Despite this no literature was found pertaining to the information needs of children of stroke survivors which perhaps explains the dearth of literature for this group of young people.

5.5 Methodology

The ontological approach for this third and final phase of the PhD programme is pragmatism. Creswell & Plano Clark (2011) explicate researchers utilising a pragmatic approach: "*collect data by what works to address research questions*" and: "*collect both quantitative and qualitative data and mix them*" (p.42).
A mixed method design comprising qualitative (thematic analysis) and quantitative methods (content analysis) to synthesise information found for children and young carers of people with four long term conditions was used. An

epistemological approach of AI allowed best practice to lead the synthesis and allow potential improvements to emerge.

5.5.1 Content analysis

Content analysis was utilised in this study. Stemler (2001) defines content analysis as: "*a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding*" (p.1). He goes on to describe how it can also be used for examining trends and patterns in documents. Stemler et al (2010) utilised this approach in a study of school mission statements aiming to compare and reflect on the core purposes of schools in America.

5.5.2 Information Synthesis

Goldschmidt (1986) defines an information synthesis as: "*a systematic gathering of research findings on a defined topic for use by a specific audience for a given purpose"* (p.217).

5.6 Methods

A systematic search of the internet was conducted in the week commencing 23rd October 2017 to obtain written and on-line information for inclusion in this study.

No attempt was made to systematically approach hospitals to harvest any locally produced health information, however, anecdotal information from informal networks, including stroke community teams suggested no such information existed in the East Midlands. This was in part corroborated by a failure to identify any local sources through intensive internet searches and by the lack of

any information specifically for children or young carers being made available to any of the participants in phase two of the study. Inclusion and exclusion criteria can be seen in Table 28.

Table 28 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
On-line or written information Produced by health, social care or voluntary sector organisations Feely available via the internet either for reading, download or order No subscription required Specifically produced for Stroke, BI, MS and PD Targeted at young carers or children of someone affected by stroke, BI, MS and PD Websites or organisations producing the information were based in the United Kingdom Information produced specifically for the 11-18year age group	Information not meeting the inclusion criteria Information for parents or adult carers Locally produced information that could not be accessed by a young person performing an internet search On-line chat rooms or support Social media

The search terms Stroke AND information AND young carer OR child, Parkinson's disease AND Information AND young carer OR child, Multiple Sclerosis or MS AND information AND Young Carer OR child, TBI or Traumatic brain injury or brain injury AND Information AND young carer OR child were entered in to Google and Yahoo. Bread crumbs were also followed to reach other potential sites. Short listed websites and information were reviewed again and those not meeting the inclusion criteria were discarded.

Hyperlinks to identified webpages were copied and stored in a word document for later assessment. Written information was downloaded and stored for assessment and hard copies were ordered if no online version was available.

A review of the literature was also undertaken to:

1) Identify any existing tools to assess quality of websites and written information

2) Explore the evidence base around information for young carers.

5.6.1 Tools for assessing information quality

A number of tools were identified and reviewed for suitability to assess the quality of the print and online material (Table 29). Some papers reported they were including content analysis but no details were included on how the content to be assessed was generated or how the content analysis was carried out (Joubert & Githinji, 2014).

Table 29 Tools discarded and rationale

Name of tool	Reason for exclusion	Reference
EQIP (Ensuring Quality Information for Patients)	Tool validated and only allowed to be used for patient information based on research evidence.	(Moult et al, 2004)
EQIP 36	Focussed on medical interventions	(Charvet-Berard et al, 2008)
JAMA benchmarks (Journal of the American Medical Association)	The four criteria are included in DISCERN and LIDA tools chosen for the study	(Silberg et al, 1997)
Health Summit Working Group. Information Quality Tool	Link could not be found	(Harland & Bath, 2007)
HI quality guidelines	Link could not be found	(Harland & Bath, 2007)

Raj et al (2016), in a study of health information websites evaluated 25 sites for quality and readability by utilising The LIDA Instrument, an automated validated tool for assessing quality, accessibility, usability and reliability of on-line material. Unfortunately, the link has been disabled and the tool is no longer available. A manual version of the tool is freely available but is highly technical

and unwieldy and was not therefore appropriate for this study. However, the shortened version, also freely available, was adapted for use in this study. The shortened tool scores items on a four-point Likert scale from 0-3, 0 = never 1 = sometimes 2 = mostly 3 = always. When testing the tool, one of the questions: "*Does the site conform to web accessibility standards*?" was deemed too complex to use and was omitted. A proxy indicator of compliance with national quality standards by the existence or absences of quality kite marks was substituted for the omitted question. Kite marks HONcode, Internet crystal mark and the Information Standard were either present or not. No attempt was made to assess adherence to the standards set within each quality mark. Further testing of the shortened LIDA tool revealed some of the remaining questions were difficult to apply as they contained more than one query, for example: "*is the format of the information clear and appropriate for the audience*". In order for the researcher to be able to apply the scoring systematically, meanings were attributed to each score which can be seen in Appendix 10. This was also done for the DISCERN instrument described below.

The DISCERN instrument has been cited in papers assessing written information quality, however, it is validated to assess information about treatment choices. Section two: "*How good is the quality of information on treatment choices*", was not relevant for this study and was therefore omitted. The two remaining sections were retained; section one: "*Is the publication reliable*", comprising eight questions, and section three: "*overall rating of the publication*" requiring a judgement on behalf of the user. Each of the included questions were scored on a five-point Likert scale. Each point from one to five on the scale was allocated a description (Appendix 11) to facilitate a more consistent approach to scoring as described above.

Readability has been utilised in previous studies as an additional proxy indicator of quality of written information in both print and web-based information (Friedman & Hoffman-Goetz, 2006). There are numerous readability scoring systems in existence, however none are recommended as a gold standard (Badarudeen & Sabharwal, 2010).

The FLESCH Reading Ease Score (FRES) and FLESCH-Kincaid Grade Level (FKGL) scores, two commonly used, well validated and established instruments were therefore selected for this study. Flesch-Kincaid readability tests are designed to assess how easy a piece of text written in English is to understand. The FRES and FKGL both use the same measures of average number of syllables per word and average number of words per sentence but are weighted differently.

FLESCH Reading Ease Score =

206.835-0.846 x number of syllables per 100 words-1.015 x average number of words per sentence.

FLESCH-Kincaid Grade =

0.39 x average number of words per sentence + 11.8 x number of syllables per word – 15.59.

The test results should roughly have an inverse correlation (Badarudeen 2010 p.2575). The FRES scale is 0-100 with 0 being unreadable and 100 being very easy to read (Friedman & Hoffman-Goetz, 2006; Patel et al, 2013). The FKGL score ranges from three-12. The number represents the American year grade required to be able to read the document (Patel et al, 2013).

FRES and FKGL scores were therefore generated for both written and website information utilising tools available in Microsoft Office Word. Text was copied into a word document and diagrams, headings, sub-headings, headers and footers removed as these can distort scores (Friedman and Hoffman-Goetz 2006 p.355) before the tests were run.

One criticism of using the FRES and FKGL scores is that they focus on the text and not on other factors that can influence reader motivation and comprehension such as diagrams, illustrations and layout (Badarudeen & Sabharwal, 2010; Friedman & Hoffman-Goetz, 2006). However, for the purposes of this study, they provided a guide with regards to the likelihood of the targeted audience being more or less able to understand the material.

Two Microsoft Excel spreadsheets were created to collate the data, one for the on-line material and one for written information. Each spreadsheet contained four sections: General section covering ease of access to the information and word counts; standard tools containing LIDA or DISCERN tools; quality section assessing kite mark presence, FRES and FKGL scores; and content.

Overall scores for online information were:

> Modified LIDA usability score 0-15, modified reliability score 0-12 = maximum modified LIDA score 0-27; quality kite-marks present or not 0-3; content criteria 0-27. Overall maximum possible score = 57

Scores for printed material were:

> Modified DISCERN score 0-45; quality kite-marks present or not 0-2; content criteria 0-72. Overall maximum possible score = 128

Word counts and FRES and FKGL were calculated utilising standard tools available in Microsoft Word. Processes for generating content criteria scores varied for the two spreadsheets as less content was apparent for on-line information sources. Processes are described below.

For websites, the quality (LIDA tool) criteria were applied to the whole website and the content criteria were applied only to pages specifically aimed at children and young carers of people affected by the relevant condition. Written

information was sub-divided into two categories; those comprising a section contained within a bigger document and whole documents dedicated and aimed at children or young carers of people with the specified condition. Quality criteria (DISCERN tool) was applied to the whole document and content criteria were applied only to pages targeted at children and young carers of people affected by any of the four included conditions.

5.6.1.1 Derivation of content criteria for online information

An inductive approach to generating categories of information to be incorporated in the content criteria section of the online information collection spreadsheet was utilised. All of the online information collected was repeatedly read and emergent themes noted. Emergent themes were reviewed and succinctly named to capture the essence of the category. Nine categories of information were generated for the online information: description of a young carer; physical caring described; emotional caring described; description of support that may be needed; support available; rights; medical information about the condition; signposting; other information. Each category could score 0-3 giving a maximum of 27 points for content for online information. The details of definition of each score for each criteria varied and can be seen in Appendix 10. For example, physical caring described, scored 0 = not at all, 1 = physical or practical care only described, 2 = both described but minimal detail provided, 3= Examples of both physical and practical caring. These criteria and scoring definitions were then incorporated into individual data collection forms (Appendix 10 and Appendix 11). The first two websites were assessed and as no further categories of information emerged the tool was applied to the remaining websites found.

5.6.1.2 Derivation of content criteria for written information

Written information was subjected to a thematic analysis as there were more data available to assess than in the online versions and the information could be imported into NVivo 11 to assist a more structured analysis. Documents were read repeatedly and emergent themes were generated inductively. Themes were named concisely and represented by codes stored as nodes in NVivo. All documents were then read again and coded. Codes were applied to every pertinent statement, thus some sentences contained more than one code. In an iterative process any new themes which emerged were added as nodes and retrospectively applied to documents already coded. Two documents were then coded again two weeks later by the researcher to check intra-rater reliability. Charts were generated to give a visual representation of the coding comparisons. Some anomalies were noted, and the relevant sections were checked to establish where the differences lay. It was apparent that the definitions for some nodes required clarifying and some nodes needed to be merged as there was some overlap. The relevant changes were made and two documents checked again which showed much greater consistency in the coding with only two references coded differently out of 43 references across both documents. All documents were then coded again with the new coding scheme. After all coding had been completed reports were generated in NVivo to show the number of times each node occurred within individual documents and overall to check congruence between overall scores, the number of references and the range of nodes coded for each information source. As expected, the highest scoring information had the greatest number of references and the range of nodes coded and conversely the lowest scoring had the smallest number and range. Reports were also run for individual nodes which showed some overlap which resulted in some nodes being discarded. For example, medical description

of the condition and explanation of the condition shared a number of coded references and were therefore combined as Medical Description of the condition. Twenty-four categories were generated for printed material: explanation description of condition; physical / emotional / psychological / cognitive / behavioural effects of the condition on the person with the condition; management / treatment / investigations / diagnosis /rehabilitation; prognosis; recovery; risk factors / causes of the condition; prevention; health promotion; description / contribution of the MDT; research into the condition; effect of the condition on other family members; impact of the condition on the family; impact and emotional impact of the condition on the young person; emotional caring tasks; physical caring tasks; practical caring tasks; rehabilitation tasks; description of young carer; rights of young carers; assessment of young carers; positive impact of caring; negative impact of caring; support needs; support sources; coping mechanisms for children / young carers.

Each category heading was given a score on 0-3 with 0 being not present and three being comprehensive coverage of the topic. The maximum score for content for printed material was therefore 72. Details of the definitions for each score varied for each criteria and can be seen in Appendix 11.

The content criteria headings were added to the written information data collection and Excel spreadsheets. Each written information document was then read again and scored for each of the four domains; general information, DISCERN, quality criteria and content. For the content scores, NVIVO coding was cross checked against the manual scoring for each content criterion. Findings were transferred into the spreadsheet to enable analysis.

5.7 Results

5.7.1 Online resources

Overall 16 websites were included in the final analysis as containing information, or signposting to information or services for young carers or children of people with stroke (six websites), BI (one website), MS (five websites), and PD (four websites). Searches were completed in the week commencing 23rd October 2017.

5.7.1.1 Stroke websites

The stroke search terms returned 4,020,000 hits on Google and 233,000,000 on Yahoo. The hits contained in the first 10 screens of google were reviewed for relevant content. Six contained information for young carers or children of stroke survivors. No pertinent items were found after the first three screens. The first 30 screens of Yahoo search were checked and no new sources of information were returned. Redundant items included young carer sites, scholarly articles, links to this study or links to websites outside of the UK and so out of scope for the search.

Of the six stroke sites only one (National Union of Students (NUS) website) had information for young carers. The remainder contained information for children of stroke survivors or brief signposting information to other sites and resources such as young carer projects.

stroke4carers.org is a website providing an e-learning resource delivering on-line advice, support and information for informal carers. There is a single webpage entitled, 'Training and support; young carers'. The target audience is unclear but there is a brief description of young carers, why their needs differ to adults and hyperlinks to seven other websites including the Stroke Association

and young carer projects. Two of the links were broken. There were no quality kite marks and no information attached.

stroke.org is the website of the Stroke Association, a charity which aims to reduce the incidence and impact of stroke through research, support, campaigns and publications. There is no specific section for young carers. A search within the website using the term 'child' navigates to an information sheet; 'All about stroke: information for children 9+'. The information is free to download or can be ordered through the website. There are no quality kite marks for the website.

chss.org (Chest, Heart and Stroke Scotland) is a Scottish health charity website which aims to improve life for those affected by chest, heart and stroke conditions, through research, influencing public policy, advice, information and support. There are no pages or information for young carers. A search using the term child within the website yields a children's resource pack which is not accessible on line and can be ordered at no cost. There are no website quality kite marks.

nichs.org.uk is the Northern Ireland chest heart and stroke charity aimed at improving outcomes for people affected by the conditions through support, campaigning, research, health promotion. There are no resources for young carers and child information is focussed on health promotion.

nus.org is the National Student Union website. Their aims are to support students and campaign on their behalf. The stroke page describes stroke, common sequelae, a definition of carer and the kind of support they may need, and some suggestions of the kind of support that may be available with some hyperlinks to other sites. The hyperlink to the Stroke Association leaflet for adults is broken. There is a contact number for the Stroke Association helpline.

There are no website quality markers. The page can only be reached through searching on an external search engine. The internal search using the terms 'stroke' or 'young carer' does not yield any results.

differentstrokes.co.uk is a charity which supports younger stroke survivors with information and peer support. There is no information for young carers, however, a resources pack can be ordered to help parents explain stroke to children. The internal link to the information pack was broken and had to be accessed by searching through the information list.

5.7.1.2 Brain injury

There were 2,190,000 results from Google and 163,000,000 from Yahoo using the BI search terms listed above. Only one website was found containing information for children of someone with a BI.

Headway.org is the website for Headway which aims to provide information, support and services to survivors and their families. There was no specific information for young carers although there was a booklet on supporting children when a parent has a BI and a section on young carers in the 'Caring for someone with a brain injury' booklet. There was also a 'Parenting after brain injury' booklet.

5.7.1.3 Multiple Sclerosis (MS) Websites

The MS search returned 1,020,000 hits on Google and 201,000,000 hits on Yahoo. Five websites were found containing the requisite information.

Mssociety.org is the Multiple Sclerosis Society website. The MS society provides support, education, information and funding for research in to MS. The

young carer information can be found either through a google search or through the website search. There are links to two information booklets which can be downloaded. The young carer information is in the process of being updated and opinions are being sought on the website. The second booklet called: 'Supporting someone with MS', has a section on young carers and was newly uploaded in June 2017. There are a series of blogs and podcasts of young carers and the parents they care for sharing their stories. There is also a video of a conference presentation on young carers in MS. On the main young carer information page there is an in-depth description of young carers, some examples of the roles they may take on, sources of support and signposting to other organisations, and hyperlinks to apply for a financial grant. There is also a telephone number of a dedicated support line.

Mstrust.org is a UK charity which supports people with MS and their families and provides information and foundation training for MS nurse specialists. The brief information for young carers is embedded in the page about research into young carers.

Ms-society.ie is the website for Multiple Sclerosis Ireland. The charity provides information, support and advocacy for people with MS and their families. The page for carers included a section for young carers, describing who young carers are and what the effect of an MS diagnosis may have on the affected person as well as the rest of the family. There was a hyperlink to the young carers support services. There were resources for parents 'How to talk about MS to your children', and 'Don't lose your balance', information for teenagers. Neither could be downloaded. There was also an interactive booklet for younger children which could be downloaded free of charge, which included information about caring responsibilities.

5.7.1.4 Parkinson's disease websites

The PD search yielded 726,000 results on Google and 98,300,000 on Yahoo. Four websites with information for young carers or children of people with PD were found.

Parkinson's.org is the website of Parkinson's UK, a charity providing support, information and funding research into the disease and potential treatments. The young carer page could be found through google search and by searching on the website. There was a comprehensive description of what comprises young caring, needs and support services as well as rights to assessment and support for both the young carer and the cared for person. The information on the page was supplemented by a video diary of a family of young carers. The hyperlinks to external websites worked, except for the one to Babble (a chat forum and on-line support group for young carers. The service closed due to withdrawal of funding in April 2017). There was also a link to a comprehensive booklet which could be downloaded or ordered as a printed booklet.

Plymouth University had a dedicated webpage to a news article (Gould, 2016) about a family's experience of the mother receiving a diagnosis of PD. The family co-produced a short film with the University and other partners entitled: 'Listen to my thoughts', featuring a child's experience of having a mother with PD. The article also contained information about PD and the impact it can have on the affected person and their family. The film was signposted from numerous other sites.

Parkinson's Life was a website for the Parkinson's community sharing events, stories and research across Europe and Internationally. There was a page giving advice for parents on explaining PD to their children. There was also a series of

five books which could be downloaded for younger children and the teenager's information from Parkinson's UK.

NUS.org was the National Union of Students as described above in stroke. The page dedicated to young carers of someone with PD defines young carer, offered suggestions for coping strategies and signposts to Parkinson's UK as a source of support and further information.

5.7.1.5 Analysis of website information

- Of the 16 websites examined, 10 contained some direct information for children or young carers, the remaining six comprised links to external organisations and information sources only.
- Only four websites were addressed to the child or young carer, the remainder were addressed to parents or professionals and one vacillated between the two.
- Six (one stroke) websites contained information or links to information for young carers and 10 were for children of the person with the condition.
- Although websites had dates suggesting they had been updated, many did not appear to have any recently added information and two websites directed to Babble, an on-line support group for young carers which had been decommissioned six months earlier.
- Some of the websites were very hard to navigate.
- None of the websites mentioned or signposted young carers or children from the front page.
- Several websites had links to other sources of information which were incorrect or broken. One of the stroke websites solely contained links to seven external sites. Of these four were incorrectly directed. Details can be seen in Table 30 below.

- The two webpages specifically developed for young carers were engaging with comprehensive information presented in different formats and multiple links to both internal and external support and information.
- Only two websites carried a recognised kite mark for information quality.
- Most websites had satisfactory scores for usability and reliability as assessed by the LIDA instrument, but limited content lowered overall scores. This is discussed in more detail below. The overall scores for the websites can be seen in Table 31.

Table 30 How websites mapped to other websites

Website	Organisation signposted to	Page directed to	Information available	Next steps
Stroke4Carers	Stroke Association	Generic page does not link to young carer information	No information for young carers or children on the site	Search on the website for children directs to a link to download an information sheet for children of stroke survivors (see printed information results for details)
	Different strokes	Generic page does not link to young carer information	No information for young carers or children on the site	Family resource pack can be requested by email or telephone (see printed information results for details).
	Barnardo's	Generic page does not link to young carer information	No signposting for young carers. Search using term young carer yields an error message 'unauthorised access'.	
	CHSS	Directs to a page for young stroke survivors.	Searching using the term young carer directs back out of the website. Using the term children directs to a page to order hard copy resources for children	Children's resource pack can be ordered by email or post (see printed information results for details).
	Carers Trust	Directs to main young carer website. Comprehensive information and links to generic young carer support and services		
	NHS young carers	Directs to main website for young carers with comprehensive information and links to generic young carer support and services		

	Dundee young carers	Directs to main website for young carers with comprehensive information and links to generic young carer support and services

Table 31 Overall scores for websites

Condition	Website URL	Organisation	Page title	LIDA Score							
				Usability /15	Reliability /12	Total /27	Quality criteria score/3	Content criteria scores/27	**Overall score/57**	FLESCH Reading Ease Score (>60)	FLESCH Kincaid Grade Level (<8)
Multiple Sclerosis	https://www.mssociety.org.uk/ms-support/for-carers/young-carers	MS Society	Young carers	15	12	27	1	27	55	63	9
Parkinson's disease	https://www.parkinsons.org.uk/	Parkinson's UK	Young carers	15	11	26	0	27	53	69	8
Multiple Sclerosis	http://www.ms-society.ie/pages/living-with-ms/carers-/being-a-carer/who-is-a-carer	MS Ireland	Who is a carer	15	12	27	0	15	42	56	10
Parkinson's disease	https://www.nus.org.uk/en/advice/caring-and-studying/caring-for-someone-with-parkinsons--/	National Union of Students	Caring for someone with Parkinson's disease	15	6	21	0	16	37	54.4	12.1
Stroke	https://www.nus.org.uk/en/advice/caring-and-studying/caring-for-a-stroke-survivor/	National Union of students	Caring for a stroke survivor	15	6	21	0	14	35	57.5	8.7
Multiple Sclerosis	http://www.healthtalk.org/peoples-experiences/long-term-conditions/multiple-sclerosis-friends-family-experiences/peoples-profiles/child	Healthtalk.org	Multiple Sclerosis: friends & family experiences	9	9	18	1	15	34	60.4	9.7

Multiple Sclerosis	https://www.nus.org.uk/en/advice/caring-and-studying/caring-for-someone-with-ms/	National Union of Students	Caring for someone with MS	15	6	21	0	11	32	34.6	13.3
Parkinson's disease	https://www.plymouth.ac.uk/news/film-supports-young-children-with-parents-with-parkinsons-disease	Plymouth University	Film supports young children of parents with Parkinson's disease	14	12	26	0	6	32	57.7	10.5
Brain Injury	https://www.headway.org.uk/	Headway	Downloads. Supporting children when a parent has had a brain injury	15	12	27	0	0	27	-	-
Stroke	http://www.stroke4carers.org/?p=2788	Stroke4Carers	Training and support young carers	15	12	27	0	0	27	69.5	9.3
Multiple Sclerosis	https://support.mstrust.org.uk/shop?prodid=286	MS Trust	Publications	15	12	27	0	0	27	69.5	9.3
Parkinson's disease	http://parkinsonslife.eu/5-free-books-to-help-explain-parkinsons-to-children-and-teens/	Parkinson's Life	5 free books to explain P to children and teens	15	12	27	0	0	27	65.1	8.7
Stroke	https://www.stroke.org.uk/	Stroke Association	Search results	15	9	24	0	1	25	84.6	5.3
Stroke	https://nichs.org.uk/how-we-can-support-you/publications/	Northern Ireland Chest Heart & Stroke	Publications	15	10	25	0	0	25	60.5	11.7
Stroke	https://www.chss.org.uk/chss-publications-dvds-and-resources/childrens-resources/	Chest Heart and Stroke Scotland	Information pack downloads	15	9	24	0	0	24	55.6	8.6

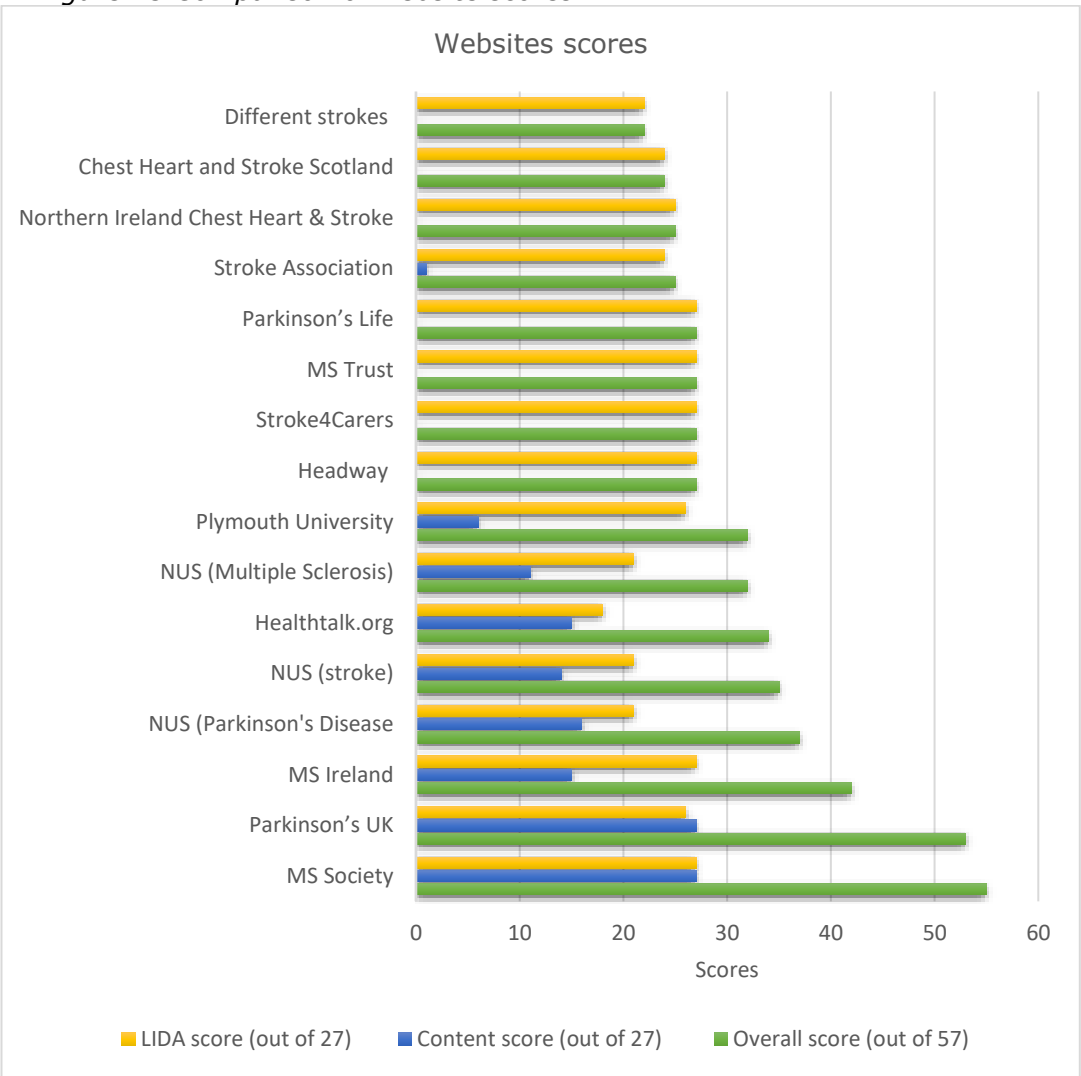
Stroke	http://differentstrokes.co.uk/stroke-information/downloads/	Different strokes	Information pack downloads	14	8	22	0	0	22	64.2	10.1

N.B Ranked by overall scores. Maximum overall score 57.

Overall, the highest scoring website was the MS Society website with a total score of 55, followed by Parkinson's UK with 53 points. The lowest scoring website was Different Strokes with 22. The bottom 50% of scores (n=8) were occupied by five of the six stroke websites and the brain injury website suggesting an overall lack of easily accessible stroke and BI specific information for young carers and children of stroke survivors. In comparison, there is a wealth of information available for PD and MS thus demonstrating that the provision of more in depth information via the internet is a feasible option. Although stroke had the greatest number of websites with information, overall the content provided was less than that for MS and Parkinson' Disease.

All websites scored above 70% for the LIDA (quality) score, the lowest scoring sites were hampered by the lack of specific content for young carers or children of people with the specified condition, relying on signposting to other sites or downloadable or hard copy information to provide the required information. The content component of the total scores can be visualised on Figure 25 below.

Figure 25 Comparison of website scores



There was a clear demarcation between stroke and BI, scoring overall mean 26.3 and 27 respectively, and PD and MS with scores of 37.3 and 38 respectively. This suggests there is less information available for children and young carers of stroke survivors than for those caring for MS and PD and potentially good practice from these information sources could be imported to stroke information to improve the content and availability of information for children and young carers.

Table 32 Overall scores aggregated by condition

	LIDA Scores/27	Quality criteria scores/3	Content criteria scores/27	Overall scores/57
Stroke				
Range	21-27	0	0-14	22-35
mean	23.8	0	2.5	26.3
Brain Injury				
Range	27	0	0	27
mean	27	0	0	27
Multiple Sclerosis				
Range	18-27	1	0-27	27-55
Mean	24	0.4	13.6	38
Parkinson's disease				
Range	21-27	0	0-27	27-53
Mean	25	0	12.3	37.3

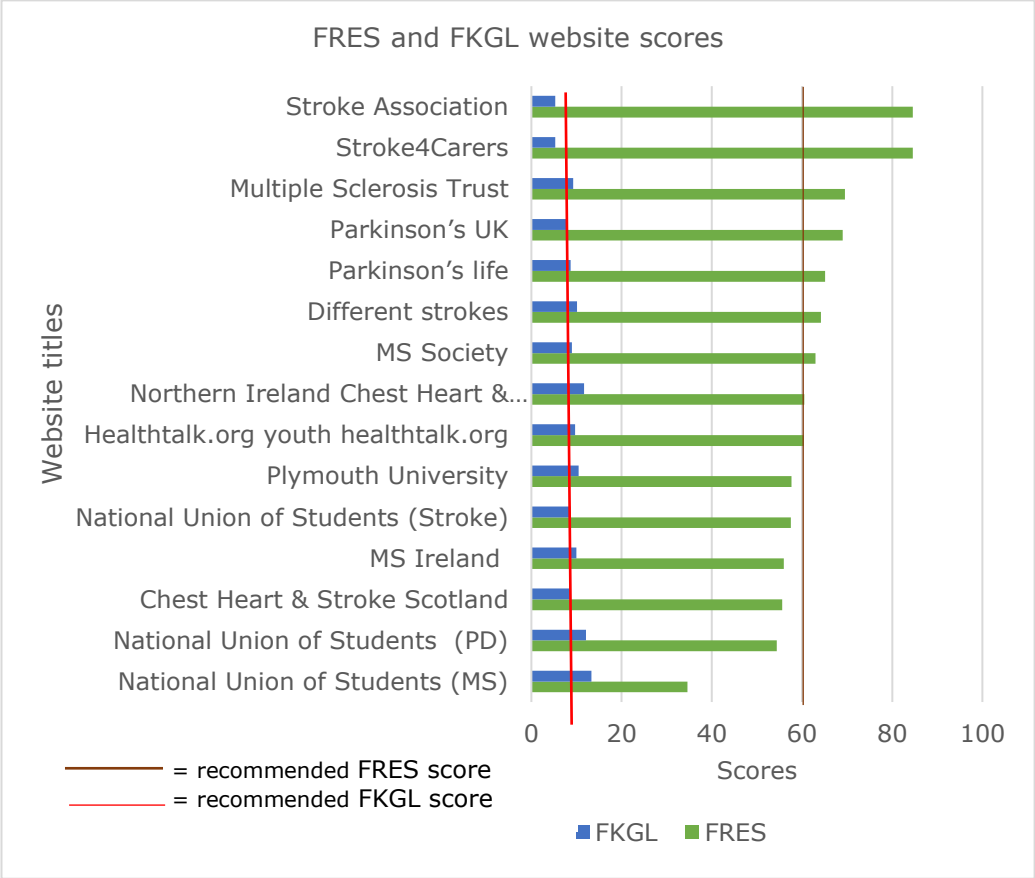
Only one website carried a recognised quality kite mark for the information. The MS Society carries the Information Standard. The Information Standard has been introduced to reassure users that the information carrying the mark is trustworthy. It indicates that an organisation is a reliable source of health and social care information. Organisations applying for it must demonstrate that the systems and methods used to produce the material are robust and provide accurate, accessible, impartial, balanced, evidence based and well-written material. Absence of the mark does not necessarily mean that information is not reliable as the standards are voluntary.

5.7.1.6 FRES and FKGL scores

Scores for Headway could not be calculated as there was no text to score. FRES range for the remaining sites was 34.6-84.6, mean 62.4, median 60.5. For the

age range being studied a score of over 60 (Figure 26) would be recommended which leaves six websites above the desired age range.

Figure 26 Website FRES and FKGL scores



FKGL scores ranged from 5.3-13.3, mean 9.4, median 9.3. Scores for this age range should be below eight leaving the majority of websites above the recommended grade level score (Figure 26).

Overall, websites are above recommended reading levels for the age group under study meaning the information may be hard for some of the young people to access.

5.7.1.7 Formats for information

Websites contained information in differing formats (Table 33). Sources found included written information on the website, video links and podcasts, hyperlinks to download and print information, links to verbal information in the form of

support lines and web chats and links signposting to external organisations offering physical support such as young carer projects. Parkinson's UK and the MS Society had the greatest range comprising all five of these alternative sources for information delivery. Conversely, the Different Strokes website contained only a telephone number and email address to order information with no supporting text.

Table 33 Information formats by website

	Information formats					
Organisations	Written info on website	Video / podcasts	Links to download info	Links to support line / web chat	links to external organisations	Total no. of media types
Parkinson's disease Society	✓	✓	✓	✓	✓	5
MS society	✓	✓	✓	✓	✓	5
National Union of Students (Multiple Sclerosis)	✓		✓	✓	✓	4
National Union of Students (Stroke)	✓		✓		✓	3
University of Oxford	✓	✓	✓			3
European Parkinson's disease Association	✓	✓	✓			3
Stroke Association	✓		✓			2
Stroke4Carers	✓				✓	2
Plymouth University	✓	✓				2
The Multiple Sclerosis Society of Ireland	✓				✓	2
National Union of Students (Parkinson's disease)				✓	✓	2
Chest Heart & Stroke Scotland				✓		1
Northern Ireland Chest Heart & Stroke			✓			1
Multiple Sclerosis Trust			✓			1
Headway			✓			1
Different strokes						0

Overall, very little information was found on the internet specifically for children or young carers of stroke survivors. Information that is available is hard to find and several key links to sources of support were broken. Most information had to be downloaded and there were no dedicated pages specifically for children or young carers of stroke survivors.

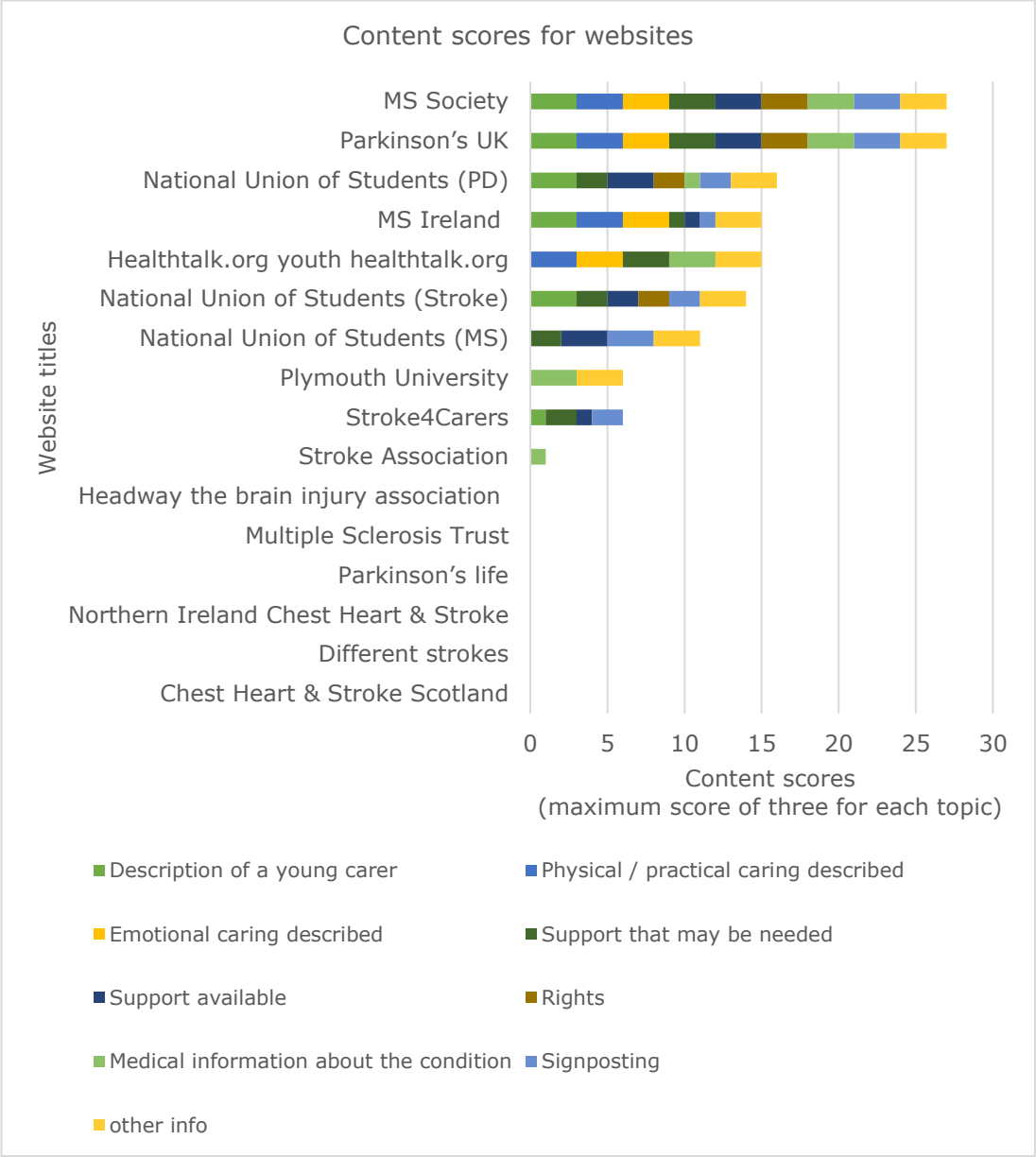
5.7.1.8 Content of websites

Websites were assessed for content in nine categories. Scores ranged from 0 (not present) - 3 (comprehensive coverage of the topic). The maximum score for website content was 27. Comparisons of website content scores can be seen in *Figure 27*.

Two websites scored the maximum 27 for content and five websites scored 0. The websites scoring 0 consisted of links to other sites or resources with no text for young carers. Eight of the websites contained additional information not contained in the tool. These included positives and negatives of caring; impact of the illness on the affected person; suggestions for coping mechanisms; impact of the disease on the family; grants; how school can help; impact of caring on life chances.

The most frequently covered content was for support needs (8 websites), sources of support (7) and signposting for young carers (7), followed by descriptions of young carers (6) and medical information (6). The websites with the highest scores for content also had the most comprehensive links to other resources and websites, in contrast to Stroke4Carers which relied on signposting to external organisations but had the most broken and incorrect links.

Figure 27 Comparisons of website content scores



5.7.2 Printed information

Web searches using the terms described in the methods section above yielded 22 potential written information sources containing material for young carers, parents of children affected by someone who has the condition, or information for children with a family member with the condition. After reading the information in detail, 11 sources were discarded (Table 34). Twelve sources of

written information containing a specific section for young carers or children and / or young carers aged 11-18 with a relative affected by the condition were included in the final analysis. 'When my mum was ill' and 'When my dad was ill' were identical resources and therefore only analysed and counted as one document, leaving 11 sources to be assessed. Sources included seven full information booklets and five documents which contained a section for children or young carers. Only one printed booklet was found specifically for young carers; 'MS in your life – a guide for young carers'. Many sources comprised written information in a standard health information booklet type format. However, some were more interactive and presented as a magazine article, comic type formats and one interactive cartoon quiz booklet.

Table 34 Excluded resources with rationale

Organisation	Year	Title	Rationale for exclusion
Scottish Intercollegiate Guidelines Network (SIGN)	2011	Rehabilitation after a stroke: a booklet for patients and their carers and families	No specific information for young carers. One address included for signposting to Princess Royal Trust for carers
Chest, Heart and Stroke Scotland and Different Strokes	n.d	When my dad was ill When my mum was ill When my gran was ill When my grandad was ill	Age group 3-7 years which is below the age criteria for this study
Multiple Sclerosis Trust	2010	Talking with your kids about MS	Aimed at parents and how to talk to their children.
Multiple Sclerosis Trust	n.d	Kid's guide to MS	Information for children about MS. No mention of young carers
Parkinson's disease	n.d	My mum has Parkinson's My dad has Parkinson's My gran has Parkinson's My grandad has Parkinson's	Information for younger children about Parkinson's disease and no young carers mentioned.

5.7.2.1 Printed information for Stroke

Four sources of printed information for stroke for children and young carers of stroke survivors were analysed. All focussed on the first part of the pathway in the early post-stroke period. Information was produced by the Stroke Association, Northern Ireland Chest Heart and Stroke (NICHS), Different Strokes, and Chest, Heart and Stroke Scotland (CHSS). Information was available for free download and in hardcopy from Stroke Association and NICHS. Information packs from Different Strokes and CHSS are not available to download but can be ordered by telephone or email. Packs are free to patients with children of the appropriate age for the information, but a charge is made for healthcare professionals and researchers.

5.7.2.1.1 Different strokes and Chest, Heart and Stroke Scotland

Information for Different Strokes and CHSS have been jointly produced. Packs were aimed at the start of the stroke pathway and contained;

- Two books: 'When my mum was ill', and: 'When my dad was ill',(CHSS & Different Strokes, no date-b) are ring bound books with fold out pages and activities for younger children aged 3-7 years. Versions about Gran / Grandad were also available from CHSS.
- Two A4 booklets in comic style: 'When my mum was ill' and: 'When my dad was ill', (CHSS & Different Strokes, no date-b)for children age 8-12 years.
- 'Jo's story',(CHSS & Different Strokes, no date-a) A4 magazine article style for teenagers about Jo's mother's stroke and the immediate post stroke period. FRES 93.7 and FKGL 3 indicate the material is very easy to read and accessible by children much younger than the teenage group indicated. No factual information or signposting is incorporated.
- Evaluation sheet asking for feedback on the resources.

5.7.2.1.2 Stroke Association

'All about stroke: information for children (aged 9+)', (Stroke Association, 2012a), comprises five A4 sheets of largely clinical and medically based information for children of stroke survivors. There were no references to young carers. FRES was 74 and FKGL 6.8 which might be challenging for children at the bottom of the age range to access. The information was produced in December 2012 with a review date of June 2014 which had not been updated on either the website or the printed information (access date 23rd October 2017). There were signposts to 11 further sources of reading and information. Six incur costs, three were not available currently, one was available freely online and one was an American information website. The information carries The Information Standard kite mark.

5.7.2.1.3 Northern Ireland Chest Heart and Stroke

'A Carers Guide to Stroke' (Northern Ireland Chest Heart & Stroke, no date), contained a small section (2.7% of the overall document) for young carers. The section focussed on the rights of the young carer for assessment and support. There was also signposting to other services. FRES 57.2 and FKGL 6.6 suggest the entire source should be accessible for those with a reading age of 11+.

5.7.2.2 Printed information for Multiple Sclerosis

Four sources of information were included for MS. Information was produced by the MS Society, The MS Trust and the MS Society of Ireland. Only one information source was found targeted specifically at young carers and two others were aimed at children and young people. The fourth source was targeted at adult carers with an embedded section for young carers.

5.7.2.2.1 The Multiple Sclerosis Society of Ireland

'Myelin's activity quiz book', (Multiple Sclerosis Society of Canada, 2003) is a highly interactive quiz book. It provides information in addition to encouraging young people to reflect on their experiences of living with someone with MS as a conduit for stimulating and opening opportunities for discussion between the young person and other family members including those with MS.

5.7.2.2.2 The MS Society

'MS in your life - a guide for young carers', (MS Society, 2009), was the only resource found which was specifically created for and targeted at young carers. It comprehensively covers medical facts about MS, family life, living with MS, becoming a young carer, school and friends, feelings and emotions, looking after yourself and sources of information and support. It was the second highest scoring printed information source with an overall score of 83/128 (64.8%) and a content score of 43/72 (59.8%). Publication date was February 2008 and no updates were found.

'Supporting someone with MS. A guide for family and carers', (MS Society, 2017), contained a section for young carers. The section focusses on rights to assessment and support, feelings of the young carer and the cared for person, and signposting to support and further information.

5.7.2.2.3 Multiple Sclerosis Trust

'The Young Person's Guide to MS', (Multiple Sclerosis Trust, 2010)**,** was revised in 2010. It incorporates many quotes, sharing experiences of young people as well as young carers with a parent who has MS. It covers medical information, feelings and how to cope with them. There is also a focus on the positive aspects

of caring for someone with MS. The information targets the 10-16 year age group and a FRES 71.1 and FKGL 7 should ensure the material is accessible for this cohort, although some 10 year olds may find the grade level slightly challenging.

5.7.2.3 Printed Information for Parkinson's disease

Only one information source was found for young carers or children of someone with PD. This was produced by Parkinson's UK.

5.7.2.3.1 Parkinson's UK

'Parkinson's in your life: a guide for teenagers', (Parkinson's UK, 2013), produced in 2013 and with a planned revision date of December 2016 which was not recorded as having been done. It was the highest scoring information with an overall score of 84 /128 (65.6%) and a content score of 39/72 (54.2%). The FRES 66.2 and FKGL 7.5 should ensure the material is accessible by the targeted age group. The information covers the medical issues surrounding PD, feelings and how to cope, living with someone with PD and sources of information and support. There are quotes and stories by young people of personal experiences of living and caring for someone with PD, there is also space to record personal thoughts, questions, reflections and feelings. These spaces include prompts to encourage the person completing them to discuss any questions or concerns they have with family members or other sources of support signposted at the back of the book. It was one of the few booklets with photographs of young people providing care for a relative. Most other information contained cartoons or other hand drawn material. Photographs of the targeted population for information have been shown to be more appealing and engaging than generic graphics and pictures.

5.7.2.4 Printed Information for Brain Injury

Two information sources were found for BI, both were produced by the same organisation comprised sections within other information booklets.

5.7.2.4.1 Headway

'Supporting children when a parent has a brain injury', (Ahmad & Johnson, 2016)**,** is, as the title suggests, targeted at parents as a guide to support children after one of the parents has sustained a BI. There is a short section dedicated to young carers which occupies 6.8% of the document. The section focusses on the detrimental effects of caring, rights to assessment and signposting to external support. One of the support organisations, 'Babble' was closed in April 2017 and so is no longer available.

'Caring for someone with a brain injury', (Morris, 2016)**,** also contains a section for young carers contributing 2.2% of the overall content. The content is largely signposting including to the closed website, Babble.

5.7.3 Analysis of printed information

Overall scores for printed information can be seen in Table 35.

- There was more printed information than website information for all conditions
- The majority of the stroke information was targeted at the start of the pathway
- Seven printed sources were whole documents and four were sections in a booklet intended for adults
- Five were directed to young carers and six were directed to adults, either parents or healthcare professionals. Sections contributed between 2.2-6.8% of the document.

5.7.4 FRES and FKGL scores

The FRES and FKGL scores are presented in Figure 28. The FRES score range was 44-100, mean 71.9, median 71.9. The mean and median show the majority of FRES scores (n=8) fell above the recommended score of 60, suggesting the material would be accessible by the targeted age group. The three below the recommended level were for BI (n=2) and stroke (n=1). The FKGL score range was 1.8-12.7, mean 6.8, median 6.8, again showing the majority (n=9) information sources were within an accessible range for the targeted age group. The two above the recommended grade level (8) were for BI.

Figure 28 Printed information FRES and FKGL scores

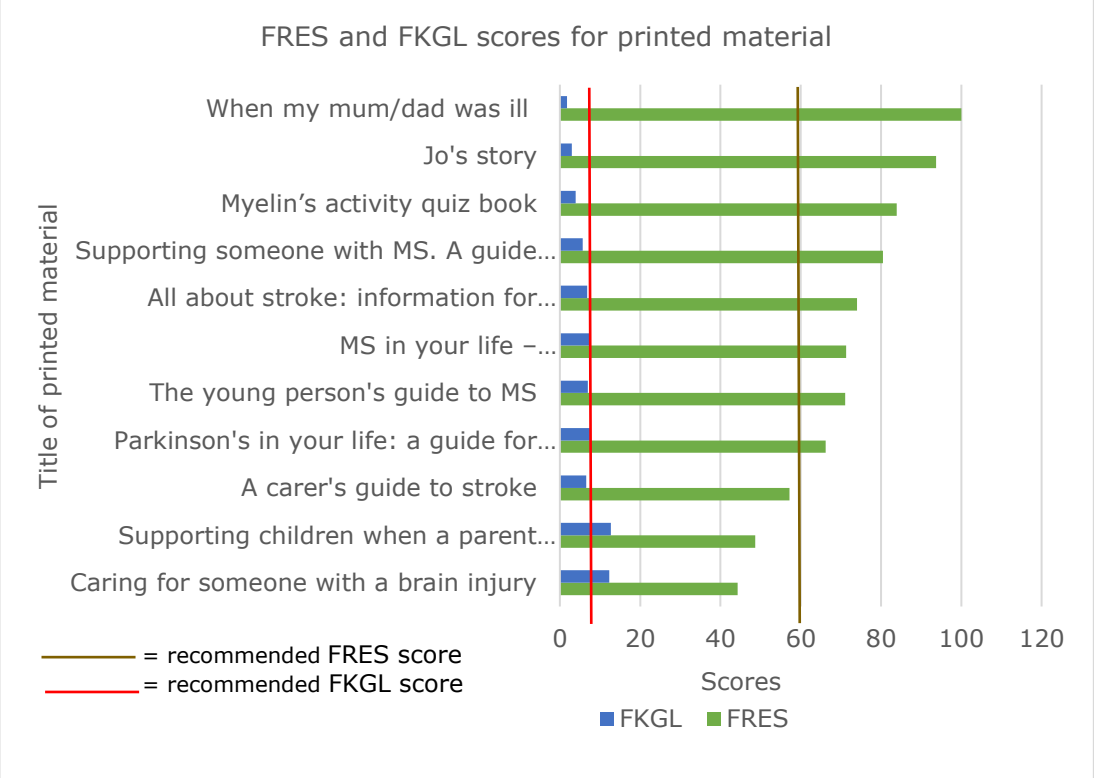


Table 35 Scores for printed information

Condition	Resource title	Target age group	Publishing organisation	Date	% of document dedicated to children / young carers	General section score /9	DISCERN score totals /45	Content criteria score /72	Quality criteria score /2	Overall score /128	FLESCH Reading Ease Score	Flesch-Kincaid Grade Level
Stroke	Jo's story	Teens	Different Strokes and Chest Heart and Stroke Scotland	n.d	100	3	30	28	0	61	93.7	3
Stroke	When my mum was ill and When my dad was ill	8-12yrs	Different Strokes and Chest Heart and Stroke Scotland	n.d	100	0	22	14	0	36	100	1.8
Stroke	All about stroke: information for children (aged 9+)	9-18yrs	Stroke Association	2012	100	0	32	25	1	58	74	6.8
Stroke	A carer's guide to stroke	< 18yrs	Northern Ireland Chest Heart and Stroke	n.d	2.7	0	34	9	0	43	57.2	6.6
Multiple sclerosis	Myelin's activity book Quiz book for children	< 18yrs	The multiple sclerosis society of Ireland	2003	100	3	33	27	0	63	83.9	3.9
Multiple sclerosis	The young person's guide to MS	10-16yrs	Multiple Sclerosis Trust	2010	100	3	38	40	0	81	71.1	7
Multiple sclerosis	Supporting someone with MS. A guide for family and carers	< 18yrs	MS Society	2017	4.6	5	40	17	1	63	80.5	5.7
Multiple sclerosis	MS in your life – a guide for young carers	< 18yrs	MS Society	2009	100	3	37	43	0	83	71.3	7.5
Brain injury	Supporting children when a parent has a brain injury	< 18yrs	Headway the brain injury association	2016	6.8	2	35	16	0	53	48.7	12.7
Brain injury	Caring for someone with a brain injury	< 18yrs	Headway the brain injury association	2016	2.2	2	35	6	0	43	44.3	12.3
Parkinson's disease	Parkinson's in your life: a guide for teenagers	Teens	Parkinson's UK	2013	100	8	37	39	0	84	66.2	7.5

Overall, BI had the lowest score with a range of 43-53 (mean 48). Stroke was second lowest with a range of 36-61 (mean 49.5). MS was second highest with four sources of information and a range 81-113 (mean 93). The highest scoring individual information source was: 'MS in your life - a guide for young carers', scoring an overall 113/143 (79%). PD was highest but with only one source of information in the relevant age group; Parkinson's in your life: a guide for teenagers', with an overall score of 84 (65.6%). Aggregated scores for printed material by condition can be seen in Table 36.

Table 36 Aggregated scores for printed information by condition

	General score /9	**Discern scores /45**	**Content criteria scores / 72**	**Quality criteria scores /2**	**Overall scores /128**
Brain Injury					
Range	2-2	35-35	6-16	0-0	43-53
mean	2.0	35.0	11.0	0.0	48.0
Stroke					
Range	0-3	22-34	9-28	0-1	36-61
mean	0.8	29.5	19.0	0.3	49.5
Multiple Sclerosis					
Range	3-5	33-40	17-43	0-1	63-83
Mean	2.8	28.8	25.0	0.3	56.8
Parkinson's disease					
Range	8	37	39	0	84
Mean	8.0	37.0	39.0	0.0	84.0

In the same way as the on-line information, the DISCERN scores were similar for all printed information and were all above 65%. However, the content criteria for stroke and BI lowered the means for the overall scores.

Scores for whole documents can be seen in Figure 29 and scores for sections within a larger document can be seen in Figure 30.

Figure 29 Scores for printed information (whole documents)

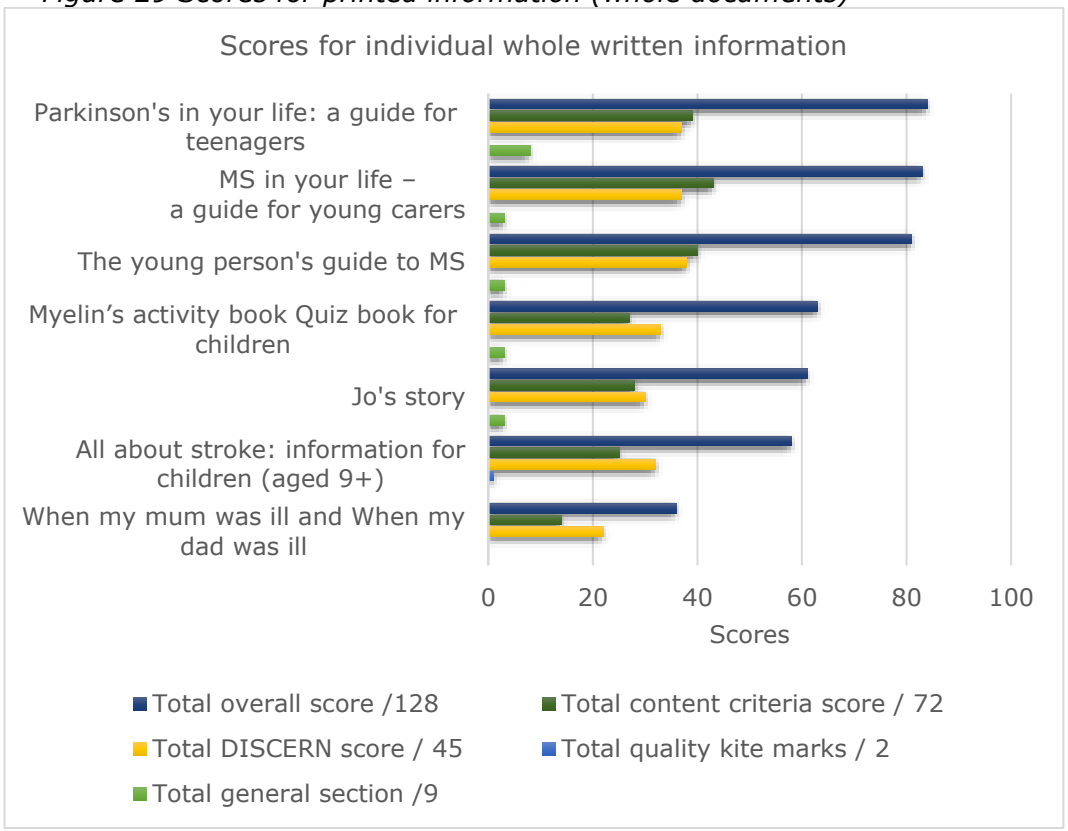
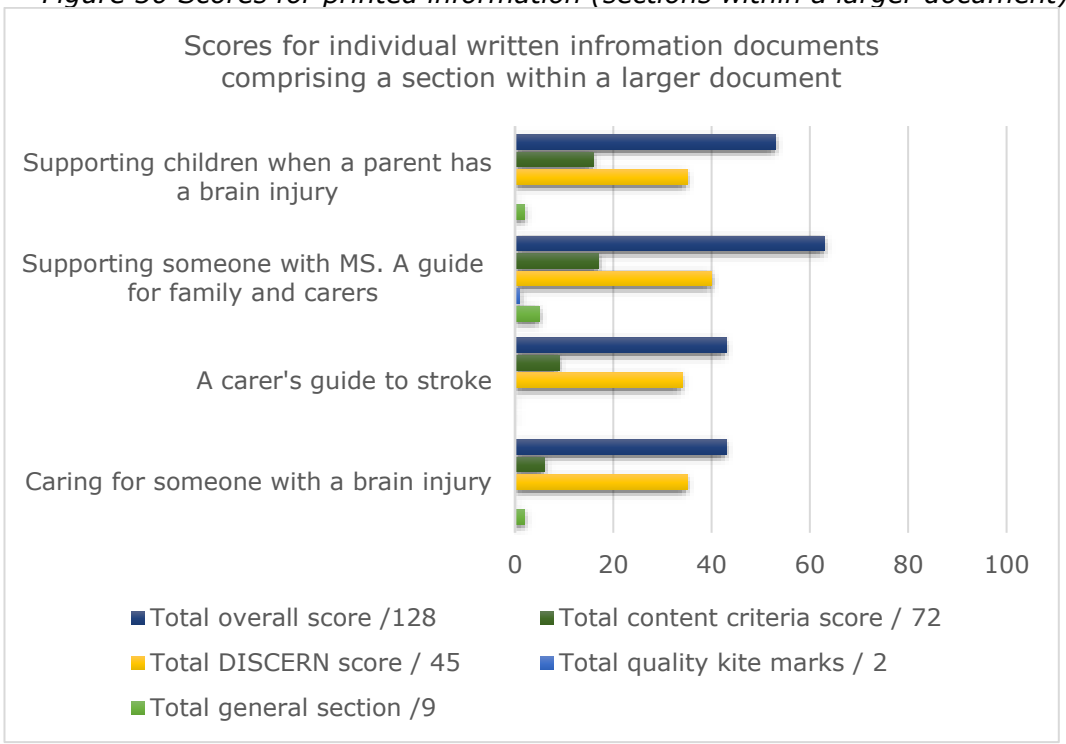


Figure 30 Scores for printed information (sections within a larger document)



5.8 Content analysis of printed information

Reports were run in NVivo to show the number of references coded to each node by condition and analysed to establish any anomalies or patterns in the numbers of references coded at each node. Reports were also run to establish the number of nodes and references for each printed information source (Figure 30). Explore diagrams were created to examine which nodes each document had been coded to as a visual representation. Examples of an explore diagram can be seen in Figure 31 and Figure 32. The purpose of this exercise was to establish the type and scope of information provided in the highest scoring information sources and compare and contrast with information for stroke. The aim was to identify gaps in the stroke information and be able to make recommendations for strengthening information being updated or produced in the future.

The explore diagrams revealed that for stroke, each of the four information sources found had a different focus. 'All about stroke: Information for children 9+' was very medically focussed. There were 11 nodes coded and eight of them were related to medical information such as prognosis, risk factors and recovery. The carers guide to stroke, containing a section for young carers, had five nodes coded and all were focussed specifically on young carers such as their rights and assessments for young carers. Jo's story covered the widest range (15) of nodes using story-telling to convey the key messages but made no specific mention of young carers or their rights. None of the documents comprehensively covered all areas. In contrast the one document for PD, 'Parkinson's in your life: A guide for teenagers', there were 18 nodes covering a comprehensive range of topics. Similarly, the MS Guide for young carers had 21 nodes coded covering a broad range of topics.

Analysis of the nodes coded at each information source revealed that stroke was the only condition in which rehabilitation and the role of young carers in supporting

the cared for person with their rehabilitation tasks was mentioned. Two of the information sources for MS discussed therapy in the management and treatment of people with the condition but no mention was made of the child or young carer's involvement in that.

Recovery was only mentioned in stroke with 14 references found across three of the documents. This may in part reflect the nature of MS and PD as progressive diseases, underlining the importance of condition-specific information. Prevention of disease was also specific to stroke and further highlights the differences in the conditions. Description of the research and evidence base of aetiology, management, and treatment of the conditions was strongest for MS, with one mention in PD and nothing in stroke.

It was also noteworthy that there were almost twice as many references to positive outcomes of caring (28) as there were negative outcomes (14). MS had positives mentioned in all four sources and had the highest number of references at 22 to one negative. Positives included feeling closer to other family members, learning new skills for the future, becoming more understanding and less judgemental of others, developing qualities for future caring roles or careers, and feeling good about themselves. Conversely, stroke was negatively portrayed with eight negatives and three positives. BI was also negatively focussed with four negatives to no positives. Negatives included fear about coping with caring responsibilities, being fed up with caring for younger siblings, and negative impacts on social life and school work. Table 37 summarises the number nodes and the number of times each information source was coded to them.

Table 37 Number of references and nodes coded by information source

Sources	Number of coding references	Number of nodes coded
Whole documents		
Stroke - All about stroke: information for children (aged 9+)	137	12
Stroke - Jo's story	68	15
Stroke - When my mum / dad was ill	25	8
Multiple Sclerosis - Myelin's activity book Quiz book for children	76	12
Multiple Sclerosis - MS in your life – a guide for young carers	181	21
Multiple Sclerosis - The young person's guide to MS	235	19
Parkinson's disease - Parkinson's in your life: a guide for teenagers	152	18
Sections in a larger document		
Stroke - Young Carers Section A carers guide to stroke NICHS	11	5
Multiple Sclerosis - Supporting someone with MS. A guide for family and carers	21	9
Brain Injury - Caring for someone with a brain injury	12	5
Brain Injury - Supporting children when a parent has a brain injury	23	11

Figure 31 Explore Diagram created in NVivo for 'When my mum was ill'.

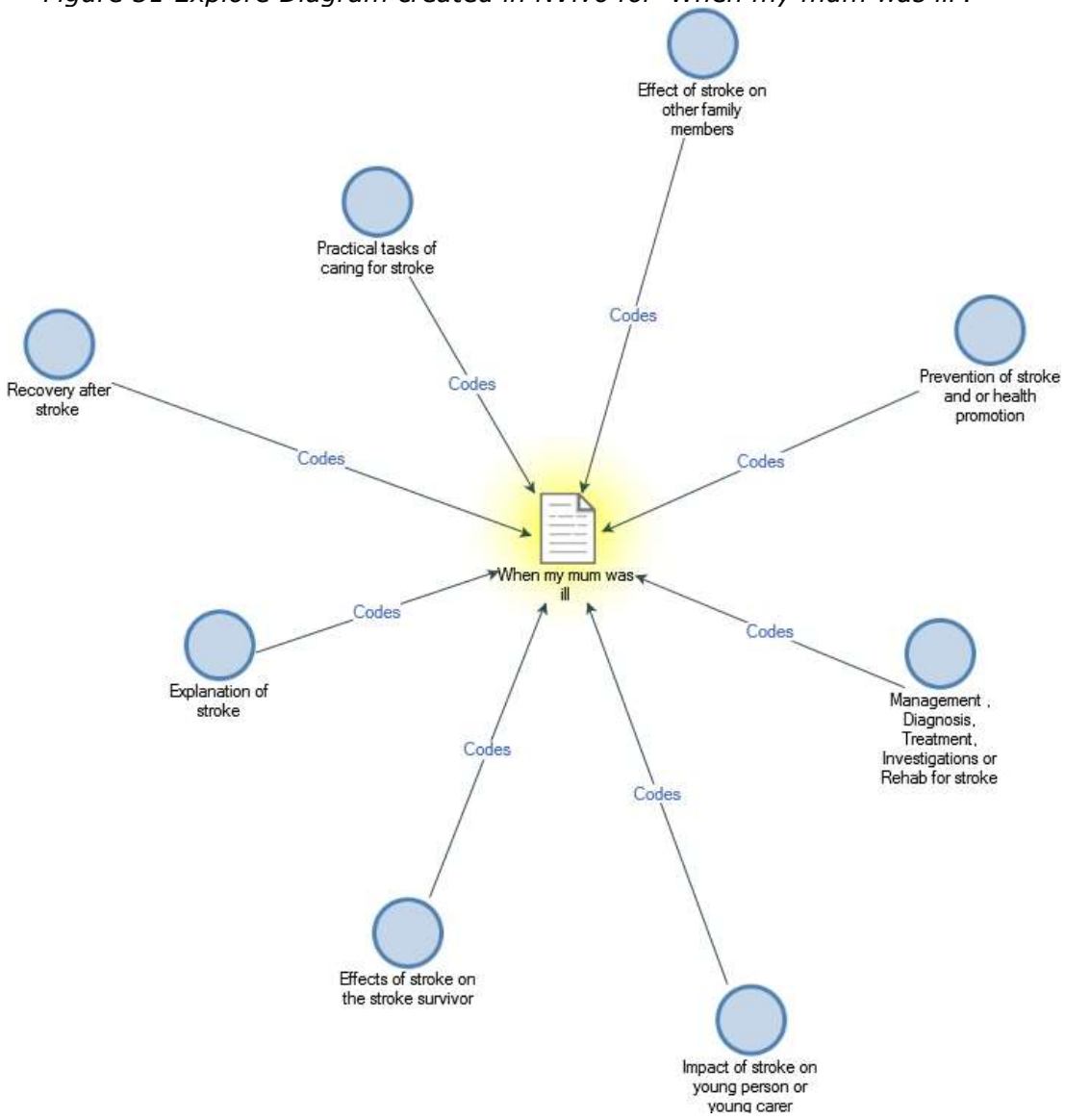


Figure 32 Explore diagram created in NVivo for - 'A Young Person's Guide to MS'

5.9 Discussion

5.9.1 Introduction

This information synthesis aimed to explore the gaps in information provision for children and young carers of stroke survivors exposed by participants in phase two of the PhD programme. Young people did not have the requisite information either to provide the support and care as effectively as they desired, or to explore and access support services both for themselves and the person they cared for. An appreciative inquiry approach was utilised to compare and synthesise the information available for young carers of stroke survivors with other comparative conditions specifically BI, MS and PD. The aim was to identify a core information set for young carers of stroke survivors and exploit best practice in terms of information delivery by the comparator conditions. The core information set was identified through an inductive thematic analysis and content analysis of relevant websites and printed information.

Suitable methods to undertake the study had to be designed as similar previous studies focussed on one specific condition and were largely directed on evidence-based treatment options, rather than synthesising information from a number of different conditions, focussing on support needs and signposting which are not necessarily evidence based. The study produced a core information set and discovered that no single existing website or printed material for children and young carers of stroke survivors provides comprehensive coverage of all necessary information.

Additionally, printed information for stroke and BI were less comprehensive than that for MS and PD. Information developed specifically for young carers of someone with MS and guides for young people affected by a family member with PD and MS were the most comprehensive. Overall quality of websites was generally not an

issue, however, content, accessibility and signposting could benefit from some attention.

5.9.2 Overall scores of website and printed information

The highest scoring websites and printed information rated by the scoring system designed for this study were for young carers and young people affected by someone with MS or PD. Five of the six stroke websites and BI website were in the bottom 50% of scores overall. The reason for the difference was not explored, however, Parkinson's UK involve a minimum of three people from the target audience in the design of information and test widely with the appropriate age group before publication (Baskerville, 2017). Similarly, the MS Society work with people affected by MS in the production of their material. Potentially, their models of co-production of information could have influenced a more comprehensive information set. It is also possible that the changing demographics of stroke with improved survival rates and an increasing incidence in the younger age group means that the imperative of considering children as part of the caring community for stroke survivors has not yet fully entered the consciousness of the stroke community. However, the mechanism for the difference is perhaps not as important as the fact that information for stroke and BI is not as comprehensive or accessible for young carers of stroke survivors as it is for young carers of people with MS and PD.

Quality of websites was largely not an issue, however, the lack of comprehensive content lowered the scores. Eysenbach et al (2002), following a systematic review of 79 studies evaluating 5941 websites and 1329 webpages, suggest that lack of completeness of content was a common but spurious finding as a single webpage is: 'part of a universe of information' (p.2696) and may be linked to another page which contains information comprised of a different focus. They distinguish this

from printed information which may need to be more complete as a stand-alone information source. The review of the relevant websites in this study showed that not all websites exploited fully the potential to link to other appropriate organisations and websites with links being broken, misdirected or we found were out of date. Some sites were confusing and difficult to navigate which has also been reported previously (Cline & Haynes, 2001). In this study, the websites with the highest scores for content and quality also had the best and most consistent links to external sources and were easiest to navigate. Stroke resources had the lowest scores, along with BI, due largely to lack of required content, and the poorest signposting. Many of the supplementary resources signposted in the printed information for stroke had a cost attached. This could be a barrier to accessing further information for some children and young carers as the negative impact of stroke on family finances has been well documented.

5.9.3 FRES and FKGL scores

FRES and FGKL scores designed to assess readability of written information were within recommended ranges for the majority of printed information. For the website information 5/16 websites had a FRES score <60 and 13/16 had a FKGL score of >8. The outliers for both were the BI information. FRES and FKGL have been criticised by some for not taking into account other attributes of written information that either enhance or inhibit comprehension. Doak et al (1996) suggest print size and style; colour contract; self-efficacy factor (does it look hard to read?); density (are multiple concepts and facts incorporated into each paragraph?); unfamiliar context (familiar words are not always understood in unfamiliar contexts) also significantly impact the accessibility of written information (p.48). A further criticism is that readability does not equate to appropriateness of content of information, as acceptable readability scores may mean that breadth and depth of material is sacrificed. An attempt to mitigate these potential shortfalls in

assessment of material was made by the development of the composite scoring system used in this study.

5.9.4 Interaction with healthcare professionals

Several studies highlight the imperative that written material should be supplemental to and should not replace direct information from health care professionals. However, it was clear from the semi-structured interviews in phase two of this PhD that children and young carers are being overlooked by healthcare professionals in terms of being included in discussions and information giving (Bibby & Becker, 2000), neither were they aware of the existence of any internet or printed information. This is despite studies showing that adolescents perceive clinicians as a respected source of information to be supplemented by other media (Eysenbach & Köhler, 2002). The enhancement and distribution of printed information and development of an appropriate website to direct young people to could raise the awareness of the potential existence of young carers of stroke survivors with health care professionals and facilitate the initiation of conversations between them which could identify the presence of any unmet needs.

5.9.5 Gaps in information provision

This review of information showed there is limited material for children and young carers of stroke survivors. Conversely more comprehensive and easily accessible information were available for MS and PD demonstrating the feasibility for stroke information to be improved. No internet or printed information was found specifically targeting young adult carers aged 18-24 years, leaving the assumption that they will access the generic adult information. This is despite the increasing recognition that the 18-24 year age group have very specific needs for support and information in respect of their transitions to adulthood encompassing leaving home, and making decisions about embarking on future studies or entering the workforce

(Dearden & Becker, 2000b; Hamilton & Adamson, 2013). This remains a significant gap in current information provision for stroke, and also for BI, MS and PD. There is also an identified gap for information which is targeted and specific for the individual stroke survivor's needs identified in chapter four and which has also been found in previous studies (Kersten et al, 2002; Low et al, 2003).

5.9.6 Information quality

Quality of health information generally is of increasing concern for researchers and health care professionals. Assessing quality and directing patients to trusted and appropriate sites remains a challenge, particularly in view of the exponential rise in availability and diversity of information sources and providers via the internet.

5.9.6.1 Information quality and assessment tools

There is a plethora of published tools for assessing quality of websites. Kim et al (1999) in a study aiming to review published criteria for evaluating health related information on the internet, and identify areas of consensus, found 29 published rating tools. Gagliardi & Jadad (2002) found 98 instruments for assessing quality of websites but only five provided information on which they could be evaluated. Bernstam et al (2005) examined quality-rating instruments for use by health care consumers to assess websites displaying health information. Of 273 instruments they identified or found reference to, 92% either had too many elements to be usable by consumers, or were no longer available for use. Eysenbach et al (2002) also identified issues with quality assessment tools which included that there was insufficient detail to evaluate them, or they were judged too long or complex, and many were not validated. Historically, tools have been criticised as being inherently subjective and measuring different constructs of quality (Gagliardi & Jadad, 2002). In addition, many tools are designed and validated to assess

evidenced-based information which is not the case for the type of information assessed in the study. Thus, no suitable published tool was found for this study.

5.9.7 Justification of the methods used

In order to facilitate the comparison and synthesis of information across the four chosen conditions, as a precursor to identifying best practice and developing the core information set for young carers and children of stroke survivors, the bespoke tool was designed as described in the methods section. The tool (similarly to many others assessing quality of health information (Eysenbach et al, 2002)) has not been formally validated. However, the systematic way in which the content criteria were developed and the multiple methods used to check, and verify data mitigated some of the potential limitations in the methods. In addition, gold standard quality markers (Fahy et al, 2014; Kim et al, 1999), as represented in commonly used and validated existing tools, were incorporated as part of the composite scoring system developed to enable comparisons to be made between stroke and the three comparator conditions.

Customised content criteria also had to be generated as none existed previously. Methods used in previous studies to generate content criteria for specific conditions have utilised clinical guidelines to generate content (Bryant et al, 2001; Impicciatore et al, 1997; Saiklang & Skirton, 2015) or generated a priori themes from systematic reviews of the literature (Veronin & Ramirez, 2000) and then used a framework analysis to assess printed information sources (Blencowe et al, 2015). Others have generated content from self-reports of information needs via surveys and focus groups (Harland & Bath, 2007). None of these mechanisms existed or were available for this study, hence the need to systematically identify potential criteria as described earlier.

The overall tool was designed purely as a mechanism for systematically comparing information across the four conditions to identify gaps, best practise and a core information set. It was not designed to be transferable to other conditions. In this study, we do not wish to attribute judgements to the completeness or lack of comprehensiveness of content, preferring to focus on developing the core set of information content which should be available as a minimum either directly or through easily navigated links.

This is a first stage in identifying potential content to strengthen information for children and young carers of stroke survivors. Future research will be required to validate the core information set, working with children and young people of the appropriate age groups to verify and refine the content for future information sources for stroke.

5.9.8 Accessing health information on the internet

Members of the public searching for information about a specific condition or services are faced with a bewildering array of potential websites presented to them via whichever search engine they use. As presented in the findings, the search terms used for stroke generated 4,020,000 hits of which only six were found to contain relevant information. For young carers who are already time pressured by their caring role and school or work commitments, the additional time required to search and filter appropriate information, may not be feasible. Research has shown that young people accessing health information only look at the first few screens generated by the internet search engines (Hansen et al, 2003)all of which work on algorithms based on popularity rather than quality. The paucity of information for young carers and children of stroke survivors is an added hindrance to young people finding good quality, comprehensive information. The lack of signposting further compounds the challenges.

5.9.9 Incorporating white space in printed material

Young people in phase two of the study struggled to share worries with both the well parent and the stroke survivor as they did not want to add to the burden of either. Similarly, stroke survivors did not want to worry their young carers with their own fears and needs and were investing precious energy in maintaining a façade of 'being ok'; neither side knew how to, 'start the conversation' with each other. The two booklets (Myelin quiz book and Parkinson's in your Life – a guide for teenagers) containing space to interactively record thoughts and feelings actively encouraging the young person to use the thoughts they generated to talk to the person affected by the condition and other family members are one way of stimulating that discussion and starting the process of sharing their tacit information and knowledge. This could have significant benefits for all parties if it were incorporated in information for stroke.

5.9.10 How information can be used to empower children and young carers

Children and young carers of stroke survivors can be considered as being on a continuum from children who provide no care through to young primary carers, providing full-time care and support for their parent or other relative. Phase two of this PhD showed that assumptions cannot be made about the place of individuals on that continuum as it changes within the complex family environment on a daily or even hourly basis. A child or young person who normally does not provide any physical or personal care may be needed to move into the primary caring role if the primary carer is absent due to unexpected or unavoidable reasons including their own ill health, working at paid employment, or on other essential errands. Additionally, children were often watchful of and supporting the well parent to assist them in their primary care role. These children's lives were as affected as those providing more hands-on care, but was not recognised as caring by some young carers, their parents or services, thus excluding them from accessing

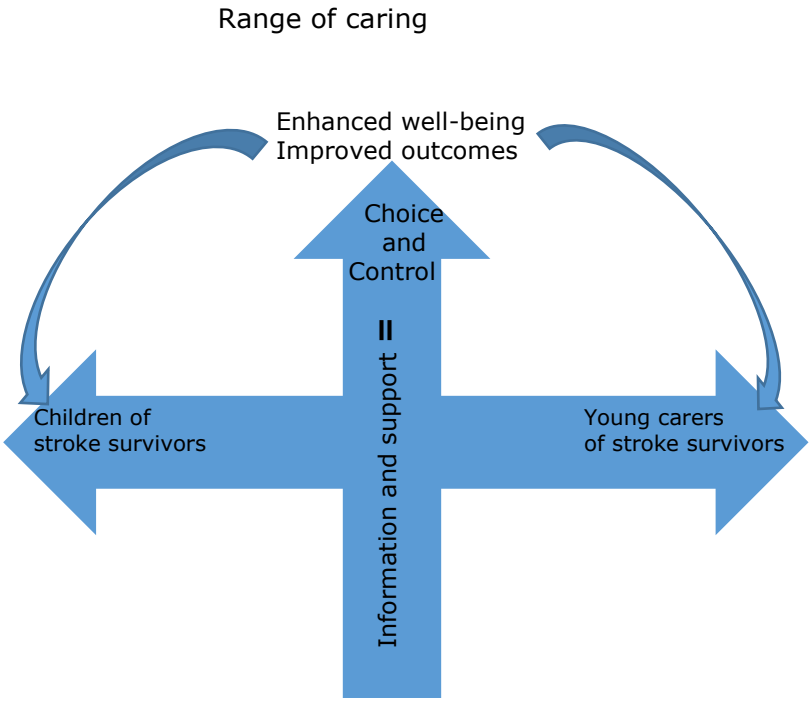
external support. Some young people wanted to provide care and support for their relative but resented the lack of choice over the amount of support they were giving and the impact that was having on them and did not have the information or knowledge of how to access services to help them regain some control.

The rights of children and young people to receive appropriate information about their parent's condition is undisputed (Department of Health, 2003; UN General Assembly, 1989), and the evidence of the benefits to health, well-being and outcomes of providing suitable information for children and young carers is strong (Aldridge & Becker, 1997; Bjorgvinsdottir & Halldorsdottir, 2014; Gladstone et al, 2011; Visser-Meily et al, 2005b). Thus, there is an opportunity and imperative to enhance current provision of information both in terms of content and availability, for children and young carers of stroke survivors. This could help mitigate potential negative effects of caring and increase the agency of young carers through the provision of comprehensive and accurate information. Information will allow them to make choices about the amount of caring they wish to undertake and how to seek support to which they are entitled.

Some services already exist to support young carers living in the East Midlands. However, young carers of stroke survivors in the earlier phase of this PhD were not accessing these services as they had not been identified or assessed and the majority were unaware of the existence of such services. In addition, many of the young carers moved in and out of the caring role, sometimes on an hourly basis, depending on whether the unaffected parent / grandparent was available and able to provide the needed care (Figure 33. For these reasons, age appropriate information must be made available in easily accessible places and formats to ensure those needing access to specialist young carer support are able to benefit from it as and when they need it. This should ensure that all children and young carers have the requisite knowledge and information to make informed choices

about the amount and type of care they feel able and willing to offer to their stroke surviving relative.

Figure 33 Range of caring provided by children of stroke survivors



5.9.11 Core information set

The following core information set as shown in Table 38, was generated for information for children and young carers of stroke survivors in the 11-18 age group. These items are generated by a thematic and content analysis of existing information which has been co-produced with young people working with MS and PD organisations. Some a priori themes were also incorporated from phase two of the study which are specific to stroke such as rehabilitation tasks of caring. Rehabilitation may be even more particular to the East Midlands as there is a specific model of care for stroke survivors after discharge from hospital involving intensive therapy at home. This may raise awareness of young carers of the need for therapy to be part of everyday care and provide them with exposure to

therapists and their own potential in contributing to that part of the recovery process.

Table 38 Core information set

Core Information Set	
Topic area	What may be included
Assessments for young carers	What comprises assessments, how to access them and benefits of being assessed
Coping mechanisms for young people dealing with the condition	Suggestions of ideas for different coping mechanisms
Definitions or descriptions of young carers	What a young carer is and how to identify if you are one
Description and contribution of the Multi-Disciplinary Team	Different health care professionals involved in the stroke care pathway and what they each contribute
Effects of the condition on other family members	How other family members may change, react or be affected by the impact of stroke in the family
Emotional/ physical/ psychological/ cognitive/ behavioural effects of the condition on the person with the condition	Impact and effects of stroke on the stroke survivor
Emotional caring for the person with the condition	Description to enable recognition of what comprises emotional caring
Explanation of the condition	Medical explanation of the anatomy and physiology of stroke and the sequelae
Impact of the condition on the family	Changes to family roles and circumstances which can be experiences by some families after stroke
Impact of the condition on the young person or young carer	Impact of being a young carer or child of a stroke survivor, emotionally, physically, socially, psychologically, developmentally
Management, diagnosis, treatment, investigations or rehabilitation	Medical and clinical management of the stroke survivor and their condition
Negative effects of caring	Potential detrimental outcomes for young carers of unwanted and unsupported caring responsibilities
Physical caring tasks	Description to enable recognition of what comprises physical and personal caring
Positive impacts of caring	Benefits of caring for the young caring including skills gained, future opportunities and enhanced self esteem
Practical tasks of caring	Description to enable recognition of what comprises practical caring
Prevention of stroke or health promotion	Health education, prevention of stroke for the young carer and secondary stroke for the stroke survivor.
Prognosis, and disease progression	Prognosis for stroke
Recovery	Recovery patterns and trajectories

Rehabilitation tasks of caring	Description to enable recognition of what comprises support with rehabilitation and therapy
Research into the condition	Current and future research
Rights for young carers	Rights to assessment, support, information and to control the amount of caring provided
Risk factors, causes, incidence, prevalence, history of the condition and reassurance	Risk factors, causes, incidence, prevalence, history of the condition and reassurance
Support needs for young carers and children of people with the condition	Support which may be needed by the young person to enable recognition of needs
Support sources for young carers and children of people with the condition	How to access different types of support at different times and signposting to organisations and information.

5.9.12 Study limitations

One of the limitations of the study was the single researcher assessing websites and printed information. This is not unusual due to time and resource constraints as evidenced by Eysenbach et al (2002) in a systematic review of 79 studies evaluating 5941 websites and 1329 webpages, in which 50 (63.3%) of the studies relied on a single researcher to assess websites. However, it still needs to be acknowledged as a limitation.

The core information set was generated from a priori criteria identified from phase two of the study and from a thematic analysis of information for 11-18year old children and young carers of people with stroke, BI, MS, PD, and BI. No information was found specifically for 18-24 age group and therefore no thematic analysis was possible to generate a core information set for this group of young people with very specific needs. This is acknowledged as a gap in the study which needs to be addressed in future studies using different methodology to inductively generate potential content criteria for bespoke information for the age group.

5.10 Conclusions and recommendations

This study found that extant information directed at and addressed to children and young carers of stroke survivors and brain injured relatives was limited in content, accessibility and variability of formats when compared to information co-produced by young people caring for and affected by MS and PD. A composite tool was developed to assess and compare both web-based and printed material to enable a synthesis of information for the four comparator conditions. A minimum core information set has been produced as a result of the synthesis which will need to be taken forward, tested and developed in to age appropriate information for children and young carers of stroke survivors. It is hoped this newly modelled information will: provide the knowledge and direction young people require to help them to deliver care in an effective way; empower children and young carers to understand their rights to exercise control over the amount and type of care they provide; provide them with knowledge and confidence to access support when needed; facilitate conversations within and between families to discuss needs, fears and worries; and raise awareness of the existence of young carers with health care professionals thus enabling them to ensure statutory duties towards young carers are enacted in a timely way to limit and mediate any potential negative impacts of caring and maximising positive outcomes of caring for young people.

No information was found specifically targeting young adult carers in the 18-24 age group for any of the four conditions included suggesting there is a significant information gap for this age group addressing the issues relevant to their life stage which may need addressing.

White space in printed material to encourage the expression of thoughts, feelings and questions to be used as a catalyst for opening up honest and frank communication between stroke survivors and their children and young carers should be explored.

Stroke websites should have specific pages for young carers in the same way as the MS and PD websites do which have been developed with the input of young people. It would be useful to establish with a group of young people whether it would be desirable to have webpages for children and young carers signposted from the front page for ease of access. Printed information for children should be separated from that intended for adults to ensure younger children are not exposed to material that may not be appropriate for their age such as advice on sex lives (MS Society, 2017).

In addition to the core information set, attention could be paid to the format, age appropriateness and accessibility of the material to enhance its acceptability for young carers and engender a feeling of ownership (STEP Young Carers, 2017). Information also needs to be extended beyond the first part of the pathway.

Gold standard principles should be adhered to in the production of material for the internet (Fahy et al, 2014; Kim et al, 1999) and printed material (Department of Health, 2003) to ensure delivery of appropriate and comprehensive information is optimised.

The use of printed and web-based materials should not be relied upon as a primary source of information and should be used as supplemental to information provided by health care professionals. Awareness of the existence of young carers of stroke survivors needs to be raised with healthcare professionals to ensure they are supported and directed to appropriate resources. Assumptions should not be made of where children of stroke survivors sit on the continuum of young carers as they can move in and out of the role at any time and therefore information needs to be made available for all.

CHAPTER SIX - DISCUSSION AND CONCLUSIONS

6 Introduction and overview of thesis

This PhD was the first exploration of the experiences of young carers of stroke survivors in the UK and the first qualitative study internationally. The thesis has successfully fulfilled the purpose stated in chapter one which was to start to address the knowledge gap about young carers of stroke survivors by building solid foundations in our understanding of the needs of young carers of stroke survivors.

The aim of this PhD was to investigate the experiences of young carers (aged under 25 years) of stroke survivors who are providing care in an unpaid capacity to relatives or friends who are living at home in the East Midlands after having a stroke. This was achieved through a sequential design comprising three studies.

The foundation for the thesis was laid with a cross-sectional survey of the needs of stroke survivors who were living at home in the East Midlands. This gave voice to the stroke survivors and revealed their perspective on day to day needs requiring help from family and friends; explored the extent and type of support being provided; the age and relationships of those offering it; and identified participants for the second study.

The second study explored in more depth the lived experience of stroke survivors and their young carers aged 11-24 years through semi-structured interviews. The experiences and needs of the young carers generated through their caring role and the impact of stroke on the family were specifically explored. The context and challenges for the assessment and provision of statutory support for young carers

in the UK was investigated through semi-structured interviews with expert providers and commissioners of stroke survivors.

The final study explored a major unmet need exposed during the semi-structured interviews, which was for information about stroke and its impact to enhance the agency of young carers of stroke survivors.

Each chapter contains its own discussion section and therefore this chapter summarises and discusses the key overall findings from PhD before critiquing the strengths and limitations of the study and presenting the implications for practice and future research opportunities.

6.1 Key overall findings

All of the overall thesis questions were answered during the study and have been reported in the relevant chapters:

1. Are there any young carers of stroke survivors living in the East Midlands? – chapter two
2. What are the barriers and facilitators to the identification of young carers of stroke survivors? – chapters three and four
3. What support needs do young carers of stroke survivors have specifically related to their caring role? – chapters three and four
4. What support services exist for young carers of stroke survivors and what are the challenges and gaps in service provision? – chapter four

A fifth major question emerged during the semi-structured interviews. The emergence of a new question was congruent with the overall PhD of an exploratory sequential design. The final question to be answered was:

5. What information exists for young carers of stroke survivors and what recommendations can be made for improving information content and delivery? – chapter five

The challenges of accurately identifying numbers of young carers both in the UK and internationally has been consistently reported over the past three decades of young carer literature (Dearden & Becker, 1995; Dearden & Becker, 1998b; 2004). The lack of accurate data was declared by experts interviewed as a hindrance to strategic planning and efficient procurement of young carer services. Figures presented for numbers of young carers vary enormously including the 166,000 based on the 2011 census to 700,000 suggested by the BBC study (Howard, 2010). Exact figures are challenging to establish due to the lack of an agreed definition, no central database and no systematic way of identifying young carers. The hidden nature of young carers also hinders the collection of accurate data. One of the aims of this PhD was to determine whether there were any young carers of stroke survivors in the East Midlands. Some young carers were identified but accurate numbers could not be established. This was because similarly to the generic young carer literature, there was no systematic way of identifying young carers in the East Midlands, and even more specifically, no data collected on young carers of stroke survivors. The issues for stroke were compounded by the scepticism about the existence of young carers of stroke survivors by health care professionals and voluntary sector providers. This impacted all the way through the PhD as partners were very hard to engage and to persuade to assist with handing out questionnaires and study information. This resulted in a smaller number of families to recruit in to the interview phase of the PhD than had been hoped for. It is possible that as stroke has traditionally been considered a condition of older age that young carers have not previously been considered, in comparison with other long term conditions such as MS in which young carers have been part of the culture for many years. The expected rise in stroke incidence in younger people

over the next 35 years could potentially mean an increase in the number of young carers of stroke survivors (King's College London, 2017). The need to increase awareness of the needs of children and young carers of stroke survivors with front line professionals working in the field is imperative.

The findings from the semi-structured interviews with stroke survivors and their young carers had many parallels with, and supported those of previous generic and condition-specific studies of young carers. These included hiddenness, silence and beneficial effects of caring. Hiddenness and silence are potentially even more exaggerated for young carers of stroke survivors. This is because frontline professionals including acute and secondary care health clinicians, despite coming into regular contact with families, were reported by young carers to ignore or be completely unaware of the children in the families and the role they were playing in support and care delivery. The paucity of both printed and online information for them adds further weight to the apparent lack of awareness of the potential for young carers generally in the field (information will be discussed further below). It is possible that the incidence of stroke historically as a condition of older age has led to this lack of awareness of young carers. The increasing incidence of stroke in younger age groups has not yet filtered through into a culture change in which children and young carers of stroke survivors are routinely considered as part of the care planning for stroke survivors and their families.

The researcher also found a high degree of scepticism of young carers of stroke survivors with both clinicians and adult stroke voluntary sector providers. The lack of engagement from the voluntary sector was particularly unexpected. This was partially due to a lack of belief in the existence of young carers of stroke survivors, and prioritisation of workload but also there appeared to be a mistrust of motives behind the study. Possibly the competitive environment for funding led them to not wish to disclose any shortcomings, or good practice which could be stolen by

another competitor. In future, this could be anticipated and more time invested if possible in building networks relationships and trust with senior figures in the organisations at an earlier stage in the study.

Many past studies of young carers have also reported the risks young carers face to their health, well-being and future prospects if support isn't forthcoming at the appropriate time and results in unmet needs (Aldridge et al, 2016a; Becker et al, 2000). One commonly unmet need is for information and knowledge about the condition being cared for, and for signposting to services and support (Aldridge & Becker, 1993b). Nicholls et al (2017) reported being fully informed about their parents condition facilitated emotional caring for adolescent young carers. This study reported young carers had completely unmet needs in terms of information about stroke, evidenced not only by their own testimony but also by their lack of knowledge and understanding of stroke and of their rights to assessment and support. This also contributes to the exaggerated silence of young carers of stroke survivors alluded to above.

Young adult carers appeared to be even less well supported than young carers aged 18years and over. No age specific services were identified in the East Midlands for these young adult carers. Service provision for this age group was delivered via adult carer services, which was deemed inappropriate by professionals involved. The key benefit attributed to membership of a support group, which is to meet people of a similar age and with comparable experiences, is lost for young people aged 18-24 being placed with much older carers. Local authorities utilising this approach may be hitting the target of providing support but are missing the point of the provision. The Children's Commissioner for England (2016) recognised that for young adult carers (aged 18-25) this reliance on adult services to assess and deliver support can be inappropriate as the majority of adult carers being supported are over 60 (p.20). The lack of identification of suitable services in the East

Midlands may have been either because they didn't exist or because of limitations of the snowball technique to identify potential expert participants did not extend into young adult carer networks

The third study in this thesis, reported in chapter five, showed a dearth of information for children and young carers of stroke survivors, and the information that was available was incomplete, poorly signposted, difficult to access and some carried a financial cost. A suggested gold standard core information set was proposed after a comparison and synthesis of information for children and young carers of stroke with other long term conditions. The overall findings suggest that better quality and access to information could be key to improving outcomes for young carers of stroke survivors particularly in the early phases of the stroke recovery pathway.

The importance of listening to, and hearing young carer's voices, to gain their perspective of their experiences, situation and needs, and to recognise their agency is a key element of much of the young carer research (Aldridge, 2008; Ciara & Samia, 2010).

Kuczynski's (2003) model of bilateral parent-child relations provides a framework to help us to understand why this is so important and how vital correct and timely information can be in contributing to positive outcomes. The model suggests that far from children being passive recipients of their parent's upbringing, they are active participants and the interactions between parent and child constantly contribute to changes within both parties. Thus, enhancing the agency of young carers could potentially improve not only their own outcomes but also those of their parents. Agency is described in the model as being constructed through three interconnected elements: meaning construction, intentional action and self-efficacy as described in the introduction to this thesis. The model suggests that children

actively interpret information they extract from their experiences and interactions with their environment. The consequent interpretations create their own understanding which they utilise to adapt the tasks they have to complete. Their propensity to act on their own interpretation of events, regardless of how erroneous that may be, will outweigh the likelihood of them responding to objective events. Improved information about stroke in respect of quality, accuracy and access is fundamental. Content on how to support the stroke survivor, signposting to rights and how to access assessments and support is also vital. Thus by recognising children's agency and providing timely, accurate and comprehensive information young carers will be empowered to make their own informed decisions about the amount and type of care they can safely deliver.

This approach to young carer research would fit most comfortably within the young carer's paradigm, however, it does not preclude the consideration of the needs of the stroke survivor which could be viewed from both the medical or disability paradigm. Each of the three paradigms of young carer studies contribute a different viewpoint of the experiences of young carers of stroke survivors and each has an important contribution to make to the understanding of their experiences. Moving forwards, a combination of all three in the form of a whole family centred approach, taking into account the equal needs of both young carers and the cared for person and recognising the bilateral parent child interaction model would be most apposite for moving the agenda forward for young carers of stroke survivors and their families.

6.2 Theoretical implications of this PhD

The field of young carer literature has hitherto been dominated by a unilateral model of parenting either implicitly or explicitly. The unilateral view presumes that children are passive recipients of parenting and are affected by their parent's behaviours (Kuczynski et al, 1999). Young carer literature has evolved in three

different paradigms as presented in chapter one. The medical paradigm examines the young carer in terms of the impact of the illness and disability on the young carers' development and outcomes. It also focusses on negative outcomes such as precocious competence (O'Neill, 1985), false maturity (Arnaud, 1959) and parentification (Byng-Hall, 2008) as described in chapter one. These models all assume a unidirectional model of parent-child interactions. The young carer paradigm, whilst not entirely focussed on a unidirectional model has not explicitly explored the potential for adopting a bidirectional view of parent-child relationships, although it is implicit in some studies. The unidirectional view is not entirely negative, and has been used implicitly at times by the media within the young carer paradigm to capture the attention of the public by portraying young carers as victims of circumstances (Rose & Cohen, 2010). This has served an important function in raising awareness of the existence of young carers, acting as a catalyst to change legislation, policy and practice around young carer's rights. The social or disability paradigm, focusses on the needs of the parent, their rights to independence and to be enabled to parent (Keith & Morris, 1995), but does not necessarily explicitly explore a bidirectional model of parent-child relationships. Kuczynski et al (1999), suggests that some fields of child and family studies are constrained by the use of a unidirectional model. This constraint could limit the potential to think innovatively about future interventions for young carers and their families. Innovation in the future will be key to managing the financial and resource constraints currently being experienced and described by the experts in this study.

The findings from this study showed how the young carers and parents were working together in partnership to deal with the changes wrought by the stroke which affected every aspect of their lives. The study approach, which was to seek out young carers before they had been identified as such by statutory agencies, gave their unadulterated view of their lives which was overwhelmingly positive despite the magnitude of change they were experiencing. Families were supporting

and protecting each other and at this early stage in the stroke pathway, this reciprocity seemed to be sufficient to allow them to meet their own and each other's needs. By interpreting these findings with a bidirectional lens it is possible to see that children and parents have the resources between them to deal with many of the challenges they face on a daily basis. This study population expressed a wish to have more information about stroke in order to be able to understand the condition and be more effective in the support they were offering.

Unmet needs of young carers or their families have been shown to have potentially detrimental effect on the young person's health, well-being and future life chances (Aldridge et al, 2016a). The explicit consideration of a bidirectional model of parenting within the young carer paradigm and research field could have the potential to exploit the two way relationship more to further enhance coping within the family relationships. More resources could be focussed on recognition and enablement of internal family resources to limit unmet needs, enhance outcomes and place less demand on over-stretched statutory services. This was the first exploration of the potential to utilise a bidirectional model of parent-child interactions within the field of young carer research and has the potential to change the way young carers are viewed and supported.

6.3 Contributions to the literature, and study limitations

This was an original study contributing to the minimal extant international literature of young carers of stroke survivors and providing the first data about those living in the UK. The study outcomes and implications for research and practice are based on needs identified by the stroke survivors and their young carers. Needs identified were not constrained by preconceived ideas or restricted by resources available to meet any needs, but emerged from the voices of the stroke survivors and young

carers themselves expressing every day needs at an early stage in the stroke pathway.

A core information set was generated as a result of a gap identified by the young carers and the analysis and synthesis of available information including best practice examples from other fields. Current information provision for young carers of stroke survivors is limited in content, poorly disseminated and signposted. The core information set could strengthen and expand current information provision with the potential to improve outcomes for young carers and the stroke survivor they care for.

One fortuitous outcome of the research process was specific to a previously unidentified 12 year old who was the main carer for his mother and was not in receipt of any support. Healthcare professionals involved were unaware of his plight despite visiting the home on a daily basis. He was referred for local authority assessment and support by the researcher with his and his mother's consent. The referral also raised awareness with the stroke domiciliary care team involved in the family and anecdotally changed their practice by prompting them to ask about children's involvement in support and caring as a routine part of their assessment of new patients.

Limitations of the study included the low response rate for the questionnaire leading to a small pool of potential participants and eventual recruits for the semi-structured interview study. However, qualitative exploratory studies of this nature do not require large sample sizes and can even be detrimental in some cases (Gaskell, 2000) by overwhelming the researcher with data leading to superficial analysis of the corpus of data. The restricted pool for recruitment and the known predilection for young carers to remain hidden either because they do not recognise themselves, or are not recognised as carers, or choose not to reveal their status

could potentially have led to the omission of young carers with a higher caring workload from the study. Thus the findings in this PhD could be an underestimate of the caring responsibilities undertaken by young carers of stroke survivors.

The geographical focus of the study in the East Midlands could also be a potential limitation due to the specific nature of the models of care in place in the community for stroke rehabilitation and care must be taken before findings are transferred to other areas.

The almost exclusive White British participants at all stages of the PhD is a further limitation and given the higher incidence of stroke in black and minority ethnic populations is not representative of the general population. Other potential biases created by non-responses are also unknown as follow up reminders could not be sent and reasons for non-response were not collected.

6.4 Future research

One possible area for further research includes testing of the core information data set generated. The core data set requires testing and validating with young carers in the requisite age range of 11-18 years. It would also benefit from being assessed for relevance for the younger age group under 11 years and the older age group 19-24 yrs. Young carers should be involved from the inception of the study at every stage to ensure the data set fully meets their needs and is easily accessible and presented in desirable formats and alternative languages. Future studies could also evaluate the outcomes of the information provision to assess whether it enhances young carer and stroke survivor experience. Longer term information needs also need to be explored as this PhD focussed on the early stages of the stroke pathway and needs for later in the pathway might require additional information and signposting. In addition, children's needs may change over time.

A further area of exploration could be the generation of a list of common sequelae of stroke and ways in which the young carer could help which could be tailored for each individual. The potential to develop this in to an APP which could be updated as the stroke survivor improves or develops late sequelae could also be explored. Some gaps in the literature remain which were outside of the remit of this study and warrant investigation, include exploring the experiences and needs of young carers from non-white British young carers, and young carers under the age of 11 years.

6.5 Implications for practice

The awareness of the existence and needs of young carers of stroke survivors needs to be raised with clinicians, teachers and adult social workers. Front-line professionals need to be equipped with the knowledge, skills and confidence to be able to identify and engage with young carers and refer them to the correct services for assessment and support.

Professionals need to optimise all contacts with families by asking the questions about who is or is likely to be providing care and not making assumptions. They should involve the whole family in discussions about things that affect them all and encourage and facilitate openness between family members about worries and fears.

Relationships and networks also need to be extended and improved between academic, voluntary sector providers and clinicians. In addition referral pathways need to be streamlined, accessible and more easily navigable.

6.6 Conclusions

This PhD provided the first exploration of the lives of young carers of stroke survivors and the people they care for. It revealed that young carers of stroke survivors do exist and continuously move between providing no care or support, through to being a primary carer delivering personal and intimate care contingent on the availability and ability of other adult carers. Some young carers remain at the primary carer end of the continuum for the majority of their time. For others, the movements on the continuum can occur on an hourly basis as the primary carer may leave the house for short periods to run errands or longer periods for paid work, relying on the children and young adults in the family to fulfil any needs the stroke survivor exhibits during their absence. The need to step up in to a carer role in combination with the self-appointed role young carers take on to watch and support the well parent, creates a constant state of vigilance and has a significant impact on the social lives, future plans and emotional and mental well-being of the co-resident children.

Uninformed judgements cannot be made by professionals who may be delivering care within a family. Awareness raising, education and training for front line staff in health, social care and education is essential to ensure they understand and are capable of delivering their role in identifying and supporting young carers. This will ensure whole family assessments are offered and information and signposting to support services provided for all children in the family. The requisite information delivered at the right time, and clear and unequivocal signposting should enhance the agency of children to make their own decisions about their caring role and provide them with the tools to access their rights to support. This should not detract from the rights of the cared for person to also exercise their agency and obtain the support they need to optimise their independence.

Finally, the ability of families to talk to each other about stroke, their fears, worries and the future is key in enhancing health and well-being and potentially future life chances for young carers and the stroke survivors. Front line staff can play a vital role in facilitating these discussions and helping families to start the conversation.

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APPENDICES

Appendix 1 Ethical approval letter

NHS
Health Research Authority

London - Fulham Research Ethics Committee
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

31 March 2016

Professor Marion Walker
Professor in Stroke Rehabilitation, Associate Pro Vice Chancellor for Equality and Diversity
University of Nottingham
University of Nottingham Division of Rehabiliation and Ageing
Medical School, Queen's Medical Centre
Nottingham
NG7 2UH

Dear Professor Walker

Study title:	**Identifying the needs of informal young carers of stroke survivors in the East Midlands**
REC reference:	**16/LO/0548**
Protocol number:	**16032**
IRAS project ID:	**193831**

Thank you for your submission, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Anna Bannister, nrescommittee.london-fulham@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

A Research Ethics Committee established by the Health Research Authority

Appendix 2 Approval letter from the Nottingham Stroke Partnership Group

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Joint Chairs: Professor Marion Walker and Ossie Newell MBE

astroke

Nottingham Stroke Research Partnership Group
School of Medicine
Division of Rehabilitation & Ageing
Room B114 B Floor
Medical School
Queen's Medical Centre
Nottingham NG7 2UH

Tel: +44 (0)115 8230246
Fax: +44 (0)115 8230231

Mrs Trudi Cameron
Division of Rehabilitation & Ageing
School of Medicine
University of Nottingham
Floor B, Medical School
Queens Medical Centre
Nottingham NG7 2UH

15 May 2015

Dear Trudi

Nottingham Stroke Partnership Group Meeting 11th May 2015
Research Presentation: Identifying Needs of Informal Young Carers of Stroke Survivors

Thank you for presenting details of the proposed research study for members to the Nottingham Stroke Research Partnership Group for comment on 11th May 2015.

It was useful for the group to learn more about this project involving an overview of the proposed study focusing on the needs of young carers of stroke survivors.

The group felt that it is an important piece of work to inform the study design, and agreed to support this. It was proposed that you liaise with members of the group who are willing to provide input.

The group asks that you consider all the feedback from the group members and that you report back to the group on progress in due course.

Yours sincerely,

Professor Marion Walker MBE, and Mr Ossie Newell MBE
Joint Chair of the Nottingham Stroke Research Partnership Group

Appendix 3 Study logo

Appendix 4 SMILE questionnaire

YOUNG CARERS OF STROKE SURVIVORS

Questionnaire for stroke survivors

We are interested in the kind of help you need from family and friends because of your stroke, now that you are back at home.

If you have been home from hospital after your stroke for more than two weeks, please tell us about the last two weeks. If you have been home for less than two weeks, please tell us about all of the time since you came home.

Please write your contact details here:

Name:	
Address:	
Email address:	
Telephone number:	

Has anyone helped you to fill in this form **No** ☐ **Yes** ☐
If yes, please tell us the name and relationship of the person who helped you to fill in the form :

1. In the past two weeks since you came from hospital have you needed any **PRACTICAL** help from family or friends because of your stroke with any of the following? ***Please tick one box to show how often you need help for each task i.e. never, some of the time, a lot of the time, or not applicable.***

Task	Never	Some of the time	A lot of the time	Not applicable
E.g. Tidying / dusting		✓		
Tidying / dusting				
Hoovering				
Laying the table				
Making main meals				
Making snacks				
Wash dishes or put them in the dishwasher				
Washing clothes				
Ironing clothes				
Mowing the grass				
Weeding or looking after the garden				
Repairs to the house				
Decorating rooms				
Shopping for food				
Lifting and carrying heavy things				
Paperwork e.g. writing letters or filling in forms				
Financial matters like collecting benefits, dealing with bills, banking money				
Communication because of your stroke				
Taking medicines, giving you injections or changing your dressings				
Preparing a special diet because of your stroke				
Going to the doctors or hospital appointment				
Walking, getting up the stairs or into and out of bed				
Getting dressed or undressed				
Having a wash				
Having a bath or shower				
Having a shave				
Cutting your nails				
Using the toilet				
Eating and drinking				
Taking your children to school				
Looking after your children				
Talking with officials (doctor or benefits person)				
Helping in the night				

2. Please tell us about any other **PRACTICAL** things that you have needed help with because of your stroke that **weren't** included in **Question One** :-

3. Please tell us how much time you think your friends or family members have been helping you with the **PRACTICAL** things you have told us about in **Question One.** An example has been given in the first row of the table below. We want to know the average amount of help, so if you had different amounts of help from one week to the next, then please tell us the higher number of hours. ***Please continue on the back of the sheet if you need more space.***

Relationship	Age if under 25 years	Number of hours on average each week giving help with **PRACTICAL** things in Question One. **Please tick the box that applies**		
		Under 19 hours a week	**20 or more hours a week**	**Other please specify**
Son	**20**		✓	

4. In the past two weeks since you came home from hospital have you needed **EMOTIONAL or SOCIAL** help from family or friends because of your stroke with any of the following things? ***Please tick one box to show how often you need help for each task i.e. never, some of the time, a lot of the time, or not applicable.***

Task	Never	Some of the time	A lot of the time	Not applicable
Keeping you company, reading to you, talk to you				
Taking you out for a walk				
Taking you to see friends and relatives				
Keeping an eye on you to make sure you are alright				

5. Please tell us about any other **EMOTIONAL or SOCIAL** that you have needed help with because of your stroke that **weren't** included in **Question Four**:-

6. Please tell us how much time you think your friends or family members have been helping you with **EMOTIONAL or SOCIAL** things you have told us about in **Question Four**. We want to know the average amount of help, so if you had different amounts of help from one week to the next, then please tell us the higher number of hours. ***Please continue on the back of the sheet if you need more space.***

Relationship	Age <u>if under 25 years</u>	Number of hours on average each week giving **EMOTIONAL or SOCIAL** help with things in Question Four. **Please tick the box that applies**		
		Under 19 hours a week	**20 or more hours a week**	**Other please specify**

7. Do you have care and support at home from people paid to care for you (i.e. not friends or family)

Yes ☐ No ☐ ***If no, please go to question 9.***

8. How many hours a week do you have of care from people who are paid to care for you? ***Please tick one.***

Less than 5 hours a week ☐ 6-10 hours ☐ 11-20 hours ☐ 21 hours or more ☐

9. Who would you say is your main carer? (we are interested in anyone regardless of whether they are paid or unpaid)

Name of main carer: _____ Relationship: _____

10. Is your main carer under 25 years of age?

Yes ☐ No ☐

THIS SECTION IS ABOUT YOU

11. When did you have your stroke?

Month _____ Year _____

12. When did you come home from hospital after your stroke? ***Please tick one.***

Less than one week ago ☐ 1 to 2 weeks ago ☐ 3 to 4 weeks ago ☐

1 to 2 months ago ☐ 3 to 6 months ago ☐ More than 6 months ago ☐

13. Are you? ***Please tick one.***

Male ☐ Female ☐ Prefer not to say ☐ Other ☐ **(please state) :-**

14. Please describe your ethnicity. ***Please tick one.***

White/European ☐ African/Caribbean ☐ Asian Mixed ☐
Hispanic/Latino ☐ Other ☐ **(please state) :-**

15. How old are you? ***Please tick one.***

Under 18 years ☐ 18-55☐ 56-65☐ 66-75☐ 76-85☐ Over 85 years☐

16. Do you live alone?

Yes ☐ No ☐ ***If yes, please go to question 18.***

17. Please tell us about all the people you live with. ***Please continue on the back of the sheet if needed.***

Relationship	Age if under 25 year

18. We would like to talk to stroke survivors living at home and any young people aged 11-24 years who support them. If you would like to find out more about the next part of the study please tick the box below so that I can contact you.

I would like / would not like to hear more about the second part of the study and would like you to. ***Please tick one***.

Ring me ☐ Email me ☐ Post details to me ☐ I do not want to hear about the second part of the study ☐

19. Would you like me to send you information about the study findings? ***Please tick one.***

Yes by post ☐ **Yes by email** ☐ **No** ☐

Thank you for taking the time to complete this questionnaire.

Please return it in the prepaid envelope to:
Trudi Cameron, Postgraduate Researcher,
Room C101, Division of Rehabilitation and Ageing,
School of Medicine, Queen's Medical Centre,
Nottingham, NG7 2UH.

Appendix 5 Interview schedule and prompts for young carers

YOUNG CARERS OF STROKE SURVIVORS

Interview schedule – Young people 11-17 and ≥18

1. What is your name and what would you like me to call you?
2. How old are you?
3. What is your ethnic background? (show prompt card)
4. Please could you tell me a bit about your family and who lives with you?
5. Please can you tell me what a stroke is?
    a. Has anyone explained what it is to you?
    b. Has anyone talked to you about the effect the stroke has had on (name of stroke survivors (SS)) and what might happen to them in the future?
6. Can you tell me about the person who has had a stroke that you help?
    a. What do you call them and how are you related to (name of the SS)?
    b. How long ago did (name of the SS) have their stroke?
    c. Has (name of the SS) changed at all since their stroke?
        i. What has changed?
        ii. How do you feel about that?
        iii. Has it changed your life, if yes how?
    d. What sort of things do you think (name of the SS) finds difficult since their stroke?
    e. Have you talked to (name of SS) about their stroke and has this helped?
    f. How long have you been helping (name of the SS)?
    g. What sort of things do you help (name of the SS) with?
        - Emotional support
        - Nursing type help / personal care
        - Practical help – including financial
        - Sibling care
        - Domestic tasks
        - Household management
    h. How much time do you spend helping (name of SS) each week?
    i. Who would you say is the main carer for (name of the SS)?

j. Who else helps (name of the SS)?
    i. Who would you say is the main carer for (name of SS)?
k. What do you like about helping (name of the SS)?
    i. Which of your helping jobs is your favourite and why?
    ii. Which of your helping jobs do you dislike the most and why?
    iii. Do any of your helping jobs upset you? why?

7. Which school / college / do you go to? Or what is your job?
    a. Tell me about a typical school / college/ work day for you?
    b. What do you like about school / college and why?
    c. Do you dislike anything about school / college and why?
8. Tell me about a typical weekend?
9. Tell me about your friends?

    Prompts might include

    - Who is your best friend?
    - What sort of things do you do with your friends?
    - Do your friends know about your helping responsibilities?
    - Has helping affected the amount of time you have for friends?

10. Do you have any hobbies or interests?
    a. Tell me about them?
11. Do you, or have you had any support with your helping responsibilities?
    a. Can you tell me a bit about the support?
        i. Was/is it useful?
        ii. Could it be improved?
    b. Do you need any other support?
        i. What would be helpful
12. Have you thought about your plans for the future?
    a. Can you tell me a bit about these?

    Prompts may include

    - What do you hope to do when you leave school / college?
    - Where do you think you will live?
    - Does anything worry you about your future?

13. Is there anything else you would like to tell me?

Appendix 6 Interview Schedule and prompts for expert interviews

YOUNG CARERS OF STROKE SURVIVORS

Interview schedule - Experts

1. Could you tell me about your involvement with young carers
    a. How many years have you been involved with young carers?
2. How would you define young carers?
3. How are young carers identified / referred into your service?
    a. Do you use any screening tools?
    b. If so, which ones?
    c. If not, are you aware of any?
    d. Why don't you use them?
4. Which instruments and measures do you use to assess caring and outcomes?
    a. Why do you use these?
    b. Can you tell me about any others you are aware of?
5. What support do young carers currently receive from your service?
        i. What do you think you do well?
        ii. How do you know that?
        iii. What are the challenges for your service?
6. What do you think the implications are of the new legislation (The Care Act 2014 and the Children and Families Act 2014) for your services?
7. What other support are you aware of for young carers to access?
    a. What do you think the challenges are for those support mechanisms?
    b. How easy do you think those support mechanisms are to access for young carers and why do you think that?
8. What are the gaps in services and how could these be addressed?
9. Whose responsibility do you think it is to support young carers?
    a. Whose responsibility should it be?
10. What are the positives for young carers i.e. what do you think they gain from their role?
11. What do you think the main challenges are for young carers currently?
12. What do you think is the single most important thing which needs to be addressed or continued for young carer's well-being in the future?
13. Anything else you think may be important?

Appendix 7 Interview schedule and prompts for Stroke Survivor Interviews

YOUNG CARERS OF STROKE SURVIVORS

Interview schedule – Stroke survivors

1. How would you like me to refer to you during this interview?
2. Who lives with you?
3. How long ago did you have your stroke?
   a. How long have you been home since your stroke?
4. Was it your first stroke?
5. How did your stroke affect you?
   - Physically, emotionally, socially?
6. Who would you say is your main carer?
7. What other things does (name of young carer (YC)) help you with?
8. What is it like having help from (name of YC)?
   a. What's your favourite thing about having (name of YC) help you?
   b. Do you dislike anything about (name of YC) helping you?
      i. What?
      ii. How?
   c. Does anything upset you about (name of YC) helping you?
      i. What?
      ii. Why?
9. Do you think that (name of YC) benefits from helping you?
   a. How?
   b. Why do you think that is?
10. Do you think (name of YC) has any difficulties created for them by helping you?
    a. What and how?
    b. How could that be avoided?
11. Does (name of YC) have any support to help you?
    a. What is it?
    b. How helpful do you think it is?
    c. Would anything else help?
12. Do you think (name of YC) should continue you help you?
    a. If not how can it be changed?
13. Is there anything else you want to tell me?

Appendix 8 Ethical approval for study amendments

NHS
Health Research Authority

London - Fulham Research Ethics Committee

Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Tel: 0207 104 8021

04 October 2016

Professor Marion Walker
Professor in Stroke Rehabilitation, Associate Pro Vice Chancellor for Equality and Diversity
University of Nottingham
Division of Rehabiliation and Ageing
Medical School, Queen's Medical Centre
Nottingham
NG7 2UH

Dear Professor Walker

Study title:	**Identifying the needs of informal young carers of stroke survivors in the East Midlands**
REC reference:	**16/LO/0548**
Protocol number:	**16032**
Amendment number:	**1**
Amendment date:	**31 August 2016**
IRAS project ID:	**193831**

- The amended protocol extends the recruitment of stroke survivors for phase two of the study (interviews) via the Stroke Association and Different Strokes third sector organisations as insufficient families have been recruited through the original plans.

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Flyer]	1	31 August 2016
Copies of advertisement materials for research participants [Internet Flyer]	1	31 August 2016
Notice of Substantial Amendment (non-CTIMP)	1	31 August 2016
Participant information sheet (PIS) [Parent or Guardian]	3	31 August 2016
Participant information sheet (PIS) [Stroke Survivors]	3	31 August 2016
Research protocol or project proposal	2	31 August 2016

Appendix 9 Final codebook for phase two

YC of stroke survivors – Final code book

Nodes

Name	Description
CHILDREN OF STROKE SURVIVORS	How stroke affects the children or YC of stroke survivors
Benefit and detriment	Positives and negatives, gains and losses for YC including social and developmental gains and losses, emotional effects of caring.
Educational and vocational issues	School, college, university , work issues for YC; adjustments and support for education or work; school initiatives to support YC; Added after first read through; bronze, silver, gold young carer awards; bullying; homework.
Identifying YC	Screening tools and instruments; referral mechanisms into social services, local authority, young carer projects; who is referring i.e. referral routes; systems and processes for referrals; recognising YC.
Definitions	Definitions of YC and carers, defining what makes a carer.
Instruments and tools	Instruments to measure caring and impact such as MACA etc.; models and tools used to support YC and teach coping strategies.
Tasks of caring, new responsibilities and changing roles	What has to be done; worst tasks, favourite tasks; what stroke survivors want from YC; time involved in caring.
Emotional caring	Issues specifically related to emotional caring; what comprises emotional caring; impact of emotional caring
Young carer support services	Knowledge and awareness of young carer projects; availability of projects and services; what is provided; accessibility criteria; limitations; good practice.
Caseloads	Size and complexity of social worker's caseloads; youth workers; project teams; frequency YC of stroke survivors are encountered.
Fragile services	Lack of resilience in service provision; lack of resources; short term funding; uncertainty over future service delivery; viability of resource provision for specific conditions

Name	Description
Levers and challenges for young carer services	Implications of legislative changes in 2014;challenges for current and future provision of services; gaps in services; future direction and viability for young carer services
Multi-agency working	Multi-agency and multi-disciplinary working; GPs; School nurses; challenges and benefits of multi-agency working
Outcomes and measurement	Formal evaluation tools and mechanisms for young carer services; showing value of YC services; outcome measures for services and individuals
Pathways and referrals	Pathways and referrals into YC support services ; includes mechanisms, complexity and challenges
Suggested improvements	Suggested improvements for YC services delivery, organisation and structure
YC and young adult carers	Services for young adult carers; specific issues for young adult carers
Shaping the future for YC and young adult carers	Long term impact of stroke on the children of stroke survivors; children and YC of stroke survivors plans for the future.
Young adult carers	Services for young adult carers; specific issues for young adult carers.
Experiences and needs	Support needs; experiences of caring.
FEARS, WORRIES, HOPES & DREAMS	Fears and worries about stroke; of dying; recurrence of stroke; the future; hopes for the future; dreams about future possibilities.
General fears and worries	General fears and non-specific worries.
Hopes and dreams	Hopes and dreams for the future in relation to the recovery of the stroke survivor; things returning to normal; possibilities for the YC own future.
Mortality and morbidity	Fears and recognition of mortality and morbidity for the stroke survivor, YC themselves and other people.

Name	Description
Resilience and determination	Resilience and determination to overcome obstacles either by the YC or stroke survivor, positive mind frames.
Talking to each other about stroke	Talking to each other about stroke or not being able to broach the subject.
IMPACT OF STROKE	Changes to lifestyles for stroke survivor, young carer and wider family; changes to relationships with family, friends and YC ; changes to routines for family and young carer; changes in roles and responsibilities; needs of the stroke survivor; who is helping the stroke survivor and what they do; impact as perceived by the young carer. Added after first read through - effects of stroke on the stroke survivor – physical, psychological, social.
Changing relationships	The change in relationship between parent and child, either actual or no change; what changes and what stays the same; change in friendships.
Effects of illness	The effect of stroke separate to any effects or impact of caring; effects of generic illness on children and young people and family relationships in general.
Finding new ways and future plans	Finding new ways of living with the effects and impacts of stroke; new ways of doing things to adapt for disabilities; adaption of future plans.
Loss	Loss as a result of stroke; changes to relationships seen as loss; loss of friends; loss of ways of being; loss of independence by the stroke survivor.
The lived experience of the bio-psychosocial effects of stroke	Living with the physical, psychological and social effects of stroke.
INSULATING THE FAMILY UNIT	Families closing ranks to protect each other from unwanted intervention from statutory services; unwanted sympathy; wanting to cope alone.
Protecting the stroke survivor	Protecting the stroke survivor from outside interference; providing care from within the family.
Shielding each other	Underplaying sequelae of stroke to protect each other from worry; pretending everything is normal; denial of the restrictions and changes created by stroke.

Name	Description
Supporting each other	Support for stroke survivor from family and vice versa; stroke survivor views on whether children should provide support.
KNOWLEDGE, INFORMATION AND LEARNING ABOUT STROKE	Knowledge related to stroke; understanding of stroke; who provides what type of information; how people learn about stroke.
Information -access, sources, quality and dissemination	Information access, quality, sources, dissemination and gaps; suggestions for future information.
Knowledge and understanding of stroke	Knowledge and understanding of stroke and how that was gained.
Professional's knowledge and experience	Professional's training for young carer project work and expertise of working with YC; supervision for case workers.
Suggestions for improvements in information provision and education	Suggestions for how to improve information for future families.
LIVING IN LIMBO	Living in a state of uncertainty and without proper adaptions and resources and the impact that has on the stroke survivor and the family.
Coping	Coping mechanisms developed by individuals and the family as a whole; includes hobbies and friendships; relaxation and time away from caring.
Statutory services; limitations and gaps	Limitations and gaps in statutory services and the impact; ending of community stroke services, ESSD etc.; insufficient provision of rehab at home and how families plug the perceived gap.
Surviving	How families go into survival mode in the early months following stroke.
Uncertainty	Living with uncertainty and the impact on individuals and the family as a whole. Uncertainty over future recovery potential; returning to work; adaptions to the home.
Miscellaneous	Categories created just to index and hold references in an easily identifiable place.

Name	Description
Cultural issues	Issues related to specific communities or cultures.
Demographics	Age; who they live with; who the main carer is; length of time since stroke; length of time since return home; job / role title; length of experience with YC; length of time in role.
Different paradigm or view points	Young carer paradigm; disability paradigm; medical paradigm; focus on a particular issue
Good practice	Good practice identified during interviews relating to service provision or delivery or identifying YC
Great quotes	Identified quotes which may be useful for the thesis
Issues specifics to stroke	Why stroke is different to other conditions
Negatives	For sentiment analysis - detrimental effects of caring on the young carer; any negative experiences or emotions expressed.
Positives	Young carer gains from caring role; any positive experiences or emotions expressed.
Rehabilitation	Rehab from the SS perspective; rehab services provided; rehab YC help with; include all types of therapy, informal and social rehab.
Story of when stroke happened	Stroke survivor and family accounts of when stroke happened and hospital stays.
Suggested improvements for future services	Participants asked what they would do to improve services if they had a magic wand; YC asked what would have helped them in the early days.

Appendix 10 Modified LIDA data collection tool for online information

Question	Scale	Score	Comments
Website name			
URL			
Organisation			
Page title			
Number of clicks to get to the page			
Can the page be found on the internal search button			
Is the young carer content well signposted			
What information formats are available	Written info on the website		
	Video / podcasts		
	Links to download info		
	Links to support lines / on line support / chat rooms		
	Links to external organisations		
Aimed at young carers? or someone searching on their behalf.			
LIDA Scores			
Usability scores			
Is the site accessible without a log in?	3 = yes 2 = mostly 1 = some parts 0 = no		
Is the site design clear and transparent?	3 = yes 2= moderately clear 1 = poor 0 = no		
Is the site design consistent from one page to another?	3= consistent 2 = most pages consistent 1 = no 0 = N/A i.e. only one page		
Can users find what they need on the site?	3 = easy to find 2 = quite easy to find 1 = very difficult to find 0 = none found		
Is the format of the information clear and appropriate for the audience?	3 = yes 2 = not very clear 1 = inappropriate or unclear 0 = N/A i.e. no information, just hyperlinks		
Total LIDA usability scores /15			
Reliability scores			
RQ Is it clear who has developed the website and what their objectives are?	3 = yes explicitly stated 2 = yes both but not very clear 1= either the who or objectives absent 0= no		

RQ Is the page content checked by an expert?	3 = yes explicitly stated 2 = yes but process unclear 1 = claimed but no evidence 0 = no		
RQ Is the page updated regularly?	3 = date stated and within planned revision date and within previous 12 months 2 = yes but more than 2 years old 1 = date stated but revision date missed 0 = no dates and or website appears out of date		
RQ Does the page cite relevant sources where appropriate	3 = references clearly stated 2 = some references but not easily traceable 1 = references but not traceable 0 = no		
Total LIDA reliability score / 12			
Total LIDA scores/ = 15 +12 =27			
Readability scores			
FLESCH reading score (FRES)			
FLESCH-Kincaid Grade level (FKGL)			
Quality kite marks			
HONcode certification	1 = yes or 0 = no		
Internet crystal mark	1 = yes or 0 = no		
The Information Standard	1 = yes or 0 = no		
Total quality kite mark score / 3			
Content criteria scores			
Description of a young carer	3 = comprehensive description 2 = fairly comprehensive 1 = weak 0 = no		
Physical caring described	3= Examples of physical and practical caring 2 = minimal description of both 1 = only physical or practical care 0 = no		
Emotional caring described	3= Recognition of impact of wider caring responsibilities such as keeping company emotional support 2 = recognition of either keeping company or emotional caring 1 = limited recognition 0 = no		

Description of support that may be needed	3= comprehensive description of support needs 2 = > 3 types of support mentioned 1= 1 or 2 types of support 0 = no		
Support available	0-33 = comprehensive support described and links provide to other sites and sources of support 2 = good description of support and resources on the site 1= limited description but links to other sites 0= no		
Rights	3 = comprehensive description of rights including rights to assessment and not having to take on the caring role 2 = limited rights described including assessment 1 = right to assessment only 0 = no		
Medical information about the condition	3= comprehensive covering condition, problems, effects and affects 2= explanation of medical problems and some complications 1= limited cover 0 = no		
Signposting	3=comprehensive covering external and internal sources of support and different types 2= signposting to different sources but links not working 1 = limited e.g. internal signposting		
other info	3 = wide ranging and comprehensive 2 = moderately ranging and comprehensive 1= some limited additional information 0=no		
Total content criteria scores / 27			
Overall total scores / 27+3+27= 57			

Appendix 11 Modified DISCERN data collection tool for printed material

Question	Scale	Score	Comments
Condition			
Title			
Date			
Organisation			
Section (S) or whole booklet (WB)			
Age group			
Available on line?			
Where can the document be obtained?			
Number of pages			
Word count			
Is the young carer content clearly signposted in the document	3 = yes from the index 2= yes but not on the first page 1 = not clearly signposted 0=no		
Space to write thoughts and feelings	3 = lots of space and guidance for what to write /draw 2 = space to write / draw and some suggestions 1= space but no prompts 0 = no		
Quotes / stories from young people	3 = more than nine quotes / stories from children / young carers and stories in media other than written 2 = several quotes / stories by children / young carers. Written only 1 = occasional short quotes 0 = no		
Total score for general section / 9			
Quality kite marks			
HONcode	1= present 0 = no		
Information standard	1= present 0 = no		
Total quality kite marks score / 2			
Readability scores			
FRES	60-70 would be 13-15 yr olds. Higher score is easier to read so this would be		

	the year below so around 11-12		
FKGL	7-8 Lower grade the easier to read. Equates to American Grade system		
DISCERN scores			
Are the aims clear?	No 1-5 Yes		
Does it achieve its aims	No 1-5 Yes		
Is it relevant?	No 1-5 Yes		
Is it clear what sources of information were used to compile the publication	No 1-5 Yes		
Is it clear when the information used or reported in the publication was produced?	No 1-5 Yes		
Is it balanced and unbiased?	No 1-5 Yes		
Does it provide details of additional sources of support and information?	No 1-5 Yes		
Does it refer to areas of uncertainty?	No 1-5 Yes		
Rate the overall quality of the publication as a source of information for children or young carers of a relative with the specified condition	1=serious or extensive shortcomings 2 3= potentially important but not serious shortcomings 4 5=minimal shortcomings		
Total DISCERN scores / 45			
Content criteria scores			
Explanation description of condition	3= comprehensive covering condition, problems, effects and affects 2= explanation of medical problems and some complications 1= limited cover 0 = no		
Physical / emotional / psychological / cognitive / behavioural effects of the condition on the person with the condition	3 = comprehensive description of symptoms and sequelae of the condition and enablers 2= some symptoms and sequelae and some enablers 1= limited information 0 = no		

Management / treatment / investigations / diagnosis /rehabilitation	0-3		
Prognosis	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Recovery	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Risk factors / causes of the condition	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Prevention / health promotion	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Description / contribution of the MDT	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Research into the condition	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Effect of condition on other family members	3 = comprehensive description of potential effect on other family members 2 = some description of potential effect 1 = mentions effect but no detail given 0 = no		
Impact of the condition on the family	3 = comprehensive description of potential impact on the affected person and other members of the family. May include emotional, financial implications and life style changes 2 = some description of potential impact		

	1 = mentions impact but no detail given 0 = no		
Impact and emotional impact of the condition on the young person	3= comprehensive description 2 = some description 1 = mentioned but no detail 0 = no		
Emotional caring tasks	3= Recognition of impact of wider caring responsibilities such as keeping company emotional support 2 = recognition of either keeping company or emotional caring 1 = limited recognition 0 = no		
Physical caring tasks	3= Multiple examples given 2 = some examples given 1 = only one example 0 = no		
Practical caring tasks	3= Multiple examples given 2 = some examples given 1 = only one example 0 = no		
Rehabilitation tasks	3= Multiple examples given 2 = some examples given 1 = only one example 0 = no		
Description of young carer	3 = comprehensive description 2 = fairly comprehensive 1 = weak 0 = no		
Rights of young carers	3 = comprehensive description of multiple rights 2 = limited rights described 1 = one example given 0 = no		
Assessment of young carers	3 = comprehensive description of rights, how to access and contact details 2 = comprehensive description but weak signposting 1= very limited description and / or no signposting 0= no		
Positive impact of caring	3= Multiple examples given 2 = some examples given 1 = only one example 0 = no		
Negative impact of caring	3= Multiple examples given 2 = some examples given 1 = only one example 0 = no		
Support needs	3= comprehensive description of support needs		

	2 = > 3 types of support mentioned 1= 1 or 2 types of support 0 = no		
Support sources	3 = comprehensive support described and links provide to other sites and sources of support 2 = good description of support and resources on the site 1= limited description but links to other sites 0= no		
Coping mechanisms for children / young carers	3= Multiple examples given 2 = some examples given 1 = only one example 0 = no		
Total content criteria scores / 72			
Overall total scores / = 9+2+45+72= 128			