RESEARCH PAPER

Needs, priorities, and desired rehabilitation outcomes of family members of young adults who have had a stroke: findings from a phenomenological study

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Purpose: This study explored the experience of stroke from the perspective of family members of young adults who have had a stroke. Gaining understanding of the short, medium and long-term needs and desired rehabilitation outcomes of family members assisted identification of appropriate family-centred multidisciplinary rehabilitation interventions. Method: A qualitative approach based on Merleau-Ponty’s existential phenomenology enabled exploration of family members’ experience of stroke. Eleven family members, including parents, spouses, children and siblings, participated in 24 interviews over 2 years. A subsequent iterative process of critical reflection was used to identify family-centred needs, priorities and associated rehabilitation outcomes. Results: Within a thematic framework, family members’ experience was conceptualised as Disruption of Temporal Being. Against this overarching theme or (back)ground, figural themes were identified: Uncertainty, Disrupted and Altered Relationships, and Situatedness. In addition, sixteen short, medium and long-term effects of stroke were identified along with associated family-centred needs and rehabilitation outcomes. Conclusion: An empathetic understanding of the experience of family members of young adults who have had a stroke will enable health professionals to consider how they may improve practice and enhance service provision to ensure delivery of effective, family-centred interventions. The table of family-centred needs and outcomes can be used by members of the multidisciplinary stroke rehabilitation team in conjunction with their own knowledge, experience and resources to inform family-centred practice.

Keywords: Family-centred, family-centred outcomes, phenomenology, Merleau-Ponty, stroke, young adults

Introduction

Stroke is a life changing event, which has a significant impact on individuals and on their families [1]. A considerable body of research has reported the effects of caregiving on informal carers, most notably family members (e.g. [2–6]). Recent reviews have demonstrated that informal carers experience many challenges including difficulty accessing information, training and emotional support, giving up employment to assume a caring role, and having to take on new and increased responsibilities [7,8]. Other challenges associated with caregiving included negative effects on interpersonal relationships, particularly spousal relationships, especially if the caregiver provides personal care for their spouse. Carers also identified challenges associated with post-stroke caregiving. The aim of this study was to explore the experience of stroke from the perspective of family members of young adults who have had a stroke.

Implications for Rehabilitation

- Following stroke in a young adult, families’ needs, priorities and associated rehabilitation outcomes change over time; rehabilitation services should reflect this dynamic process.
- To deliver family-centred care, rehabilitation professionals need to develop a deeper understanding of the experience of families affected by stroke, gained from qualitative research findings and from their own reflective practice.
- Gaining understanding of the experience of family members of young adults who have had a stroke will enable health professionals to consider how they may improve practice and enhance service provision to ensure delivery of effective, family-centred interventions.
- The table of family-centred needs and outcomes can be used by members of the multidisciplinary stroke rehabilitation team in conjunction with their own knowledge, experience and resources to inform family-centred practice.

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impairments such as fatigue, cognitive problems (e.g. poor short-term memory; reluctance to make decisions) and perceived changes in behaviour. Informal carers also reported experiencing decreased social participation and increased social isolation, and having no time for their own concerns [7,8]. A few studies did identify satisfactions associated with caregiving, including development of a greater sense of closeness with the stroke survivor or with the wider family, feeling fulfilled by their caring role and having the opportunity to reappraise carers’ priorities (e.g. [6]).

Stroke is often perceived to be a condition of older age, yet it is prevalent amongst younger adults i.e. adults aged <55 years [9]. Within the general stroke population, young adults are considered to be a group with specific rehabilitation needs relating to aspects of life such as parenting and employment [10–12]. In recognition of this potential difference in desired rehabilitation outcomes, there is a growing body of research, which has explored the experiences, needs and priorities of young adults following stroke (e.g. [13–16]); however, little is known regarding the needs and priorities of family relatives of young adults and how these may differ over time. Findings from the general stroke carers’ literature, described above, indicate that health and social services often fail to meet the identified needs of families and leave both patients and families feeling excluded from the rehabilitation process and dissatisfied with the outcomes. This potentially exclusive nature of routine stroke care may be due to implementation of a paternalistic approach to rehabilitation, which is evident in some Western societies, including the UK [4,8,17].

Medical paternalism is a biomedical model that focuses on the recovery of motor skills and function. In contrast, a biopsychosocial model focuses on the biological, psychological and social influences on the individual’s or family’s functioning. Such an approach, using, for example, a family systems model, facilitates assessment of a family’s needs and priorities and seeks to secure their involvement in the rehabilitation process [4,8,17–19]. Actively involving family members in rehabilitation is thought to improve rehabilitation outcomes [1,18–20]. However, health professionals often fail to engage with family members due to perceived barriers such as lack of time, and fear of opening a “can of worms” that they do not have the skills to deal with [18]. Yet, Foster et al. [20], working in the field of brain injury rehabilitation suggest that “Family can be considered the most important members of the rehabilitation team (in addition to the client themselves)” (p.2).

As noted above, the stressors and burdens associated with family caregiving are well documented (e.g. [7,21]), and yet there is also a body of literature, which demonstrates that family members lack preparation for assuming this demanding role, often at the expense of their own employment, social and leisure activities (e.g. [6,21]). “Equipped” carers i.e. carers who have been taught practical and psychological coping skills are more likely to feel competent in their caring role once they are home and less likely to experience the burdens associated with caring for someone who has had stroke [6,8]. In addition, better rehabilitation outcomes for patients and families imply less demand on rehabilitation and long-term support services, and an associated reduction in cost for health and social care budgets. In societal terms, family members are better able to resume participation in and contribution to society if, for example, they are well enough to work rather than care full-time. And although clinical guidelines recommend an inclusive approach to rehabilitation (e.g. [22–24]), there is limited guidance as to when to intervene to include families and how to determine the interventions which are appropriate at particular stages of the rehabilitation process [8,25].

Stroke rehabilitation researchers have argued that meaningful involvement of family members in the rehabilitation process may be achieved by adopting a family-centred approach that originates with an empathetic understanding of the experience of stroke from the perspective of family members [1,23]. Qualitative research approaches enable exploration of how individuals experience and give meaning to phenomena [26]. Findings from qualitative research are important, as they provide answers to research questions which can inform evidence-based practice. For example, by accessing qualitative research findings, rehabilitation professionals can develop deeper understandings of the experiences of patients and family members [26]. This deeper understanding should lead professionals to reflect on their clinical practice and the ways in which they can enhance service provision and improve patient outcomes [26]. This study aimed to explore, over an extended period of time, the experience of being a family member of a young adult who has had stroke, and to determine specific needs, priorities and outcomes of family members throughout the stroke recovery trajectory with a view to facilitating understanding of the perspective of relatives and providing an evidence-based which health professionals can use to support their decision-making with regards provision of appropriate and relevant interventions.

Method

A longitudinal qualitative interview study was conducted according to the phenomenological approach of Merleau-Ponty [27]. Using this approach, researchers aim to capture the spontaneous speech of participants who have experience of the phenomenon of interest, and analyse interview transcripts with the principal aim of providing a description of that phenomenon [28]. The study reported here was part of a research programme, which sought to describe the key elements that constitute patient-centred rehabilitative care from the perspectives of young adults who have had a stroke and their families [16].

Participants

Purpose sampling had been used to recruit 10 young adults who had had stroke between 3 months and 2 years prior to recruitment [29]. Note, in the speciality of stroke, definitions of “young” vary considerably. We elected to adopt a definition used in previous epidemiological and qualitative studies i.e. adults aged 18–55 [9,13,30,31]. The young adult participants were asked to recruit one or two family members, with “family” being defined as “a self-identified group of two or more individuals who consider themselves to be a family [32].”
Advisory Group
In keeping with the patient-centred approach, a Project Advisory Group was also convened and contributed to the research process, analysis of the qualitative data in particular. The group comprised young adults who had had a stroke, family members of young adults who had had a stroke, and an occupational therapist and former neurological rehabilitation nurse (ML) with expertise relating to stroke in young adults.

Interviews
Participants were invited to take part in one-to-one, face-to-face interviews, in a location of their choosing, usually their own home. Participants were interviewed alone, with the exception of two sisters who chose to be interviewed together. The interviews were unstructured, a method which has congruency with the underpinning phenomenological methodology. Participants were asked to tell the interviewer (ML) about their experience, as a relative of a young adult who has had a stroke. No further questions were posed and a phenomenological stance, designed to elicit the spontaneous, unreflected upon speech of the participants, was adopted [33]. When adopting a phenomenological stance the principle skill required is the art of listening. The interviewer’s non-verbal communication demonstrates understanding of what is being said and undivided attention. The interviewer’s posture is supportive of the participant’s speech but is neutral with regards response and this facilitates the flow of the participant’s verbal contribution.

Analysis
An iterative three-stage process of phenomenological analysis, congruent with the underpinning phenomenological approach was used [33]. In stage 1 (phenomenological description), a phenomenological stance [16,33] was adopted during the interviews, which enabled the researcher to obtain participants’ spontaneous accounts. In stage two, phenomenological reduction, the researcher’s knowledge and experience were brought to bear on the data. The researcher endeavoured to “see” the phenomenon from all perspectives using a process of critical reflection. Critical reflection requires immersion in the data, which was achieved by listening repeatedly to the interview recordings, often while reading the transcripts. The Advisory Group played an important role in this stage of the analysis, as both their spontaneous and considered responses to the anonymised interview excerpts provided yet another perspective on the data. Meaning units were identified and, in a further iterative phase, themes were identified from the convergence of like meaning units identified from across the interviews. To support the process of phenomenological reduction, a conceptual framework was used, which comprised existential concepts (e.g. Time, Body, World, Other) congruent with the underpinning methodology and with emergent understandings of the data [34].

In stage 3, phenomenological interpretation, a theoretical framework was developed as the result of an iterative process of reflection, writing and modeling [35]. During this stage, ML met with colleagues (experienced qualitative researchers) to discuss how the stage 2 themes related to one another [36], identify overarching themes and to develop a thematic framework. The thematic framework enables understanding of how particular existential concepts, phrased as themes, facilitate understanding of the phenomenon under investigation i.e. the framework demonstrates how the predominant, or figural, characteristics of the experience are revealed against a “(back)ground” concept, which may be thought of as an overarching theme [3,36].

Following the meeting, ML further refined the thematic framework using the conceptual modeling feature of NVIVO qualitative analytic software. In the final framework, the ground of family members’ experience was expressed as the Disruption of Temporal Being (Time), against which were figural interrelated concepts of Uncertainty (Body), Disrupted and Altered Relationships (Others), and Situatedness (World). These existential constructs are used below as headings under which to present the findings.

Identification of family-centred needs and outcomes
As described above, an iterative process of phenomenological analysis was used to develop a theoretical framework that enabled a description of the lived experience of stroke from the perspective of family members. Using this theoretical framework and associated findings, a subsequent process of iterative reflective analysis enabled extrapolation of family-centred needs and subsequently, identification of associated family-centred outcomes for presentation in tabular form. Using the qualitative findings as the basis for this process ensured that the family-centred needs and outcomes articulated in the table are firmly based in research-generated evidence [37]. The identified needs and outcomes were validated by comparing the contents of the table with themes generated by discussion with the Advisory Group [16].

Rigour
Transparency and systematicity have been described as key principles of rigorous qualitative research [38] and were the criteria adopted in this study as the means of ensuring its quality and rigour. Phenomenological writing is a controversial act due to the unique perspective of each researcher [39]. This inherent “uniqueness” reinforces the need for transparency of reporting. For example, decisions made throughout the research process should be documented and made available for scrutiny, and any deviations from the stated design should be described and justified, as was done in this study [16]. Systematicity requires, for example, that the researcher should consistently apply congruent methods of data collection and analysis throughout the research, and where the researcher deviates from the study protocol this should be recorded and discussed, as has been done in this paper [38].
Ethical considerations
The study was approved by the university Ethics Committee and the National Health Service Central Office for Research Committees. Principles of Research Governance (e.g. informed consent, anonymity) were observed throughout the study to ensure participants were protected [40]. Principal ethical considerations included the possibility of participants becoming distressed during the course of an interview, or by the serial nature of the interviews. Processes to address these issues included referral to a local Stroke Nurse Specialist or a national stroke helpline [16].

Results
Eleven family members were recruited by 9 of the 10 young adult participants. One young adult (Gordon) had secured his wife’s agreement but when contact was made at the various time points she was unavailable to participate. The family member participants included mothers and fathers, a sibling, spouses/partners and daughters. At time of recruitment, family participants were aged between 17 and 71 years and lived in a range of rural and urban settings (Table I).

Interviews lasted between 15 min and 1 h. With one exception, the interviews were digitally recorded, and all were transcribed by ML; 24 interviews were conducted (Table II). Participants were invited to take part in four interviews conducted at 6 monthly intervals over the course of 2 years; however, only one participant was able to comply with this request. Reasons for not participating in interviews during the 2-year period, or for ending involvement after one or more interviews, included terminal illness in the family and work-related stress.

In this study, we found that family members experienced a sense of their taken-for-granted life course being abruptly and irrevocably disrupted. This experience was conceptualised as the Disruption of Temporal Being i.e. their existence in time. Figural against the ground of temporal disruption were existential themes of Uncertainty, Disrupted and Altered Relationships and Situatedness. These findings are reported below and are followed by a table (Table III) reporting the extrapolated needs and outcomes of family members.

Disruption of Temporal Being
Temporal Disruption denotes disruption of the taken-for-granted life course of family members as the stroke event shocked them out of their familiar way of being, and disrupted and altered their relationships with young adults and with others. It gave them cause to reappraise their understanding of themselves and their place in the world. They struggled to adjust to a new and altered understanding of the world as they sought to regain “normality.”

Table I. Family participants.

<table>
<thead>
<tr>
<th>Young adult (YA)</th>
<th>YA age at Time 1</th>
<th>Family member (FM)</th>
<th>Relationship to YA</th>
<th>Residence</th>
<th>Location</th>
<th>FM age at Time 1</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>48</td>
<td>Mairi</td>
<td>Wife</td>
<td>Living with YA</td>
<td>Village</td>
<td>40</td>
<td>f/t office manager</td>
</tr>
<tr>
<td>Audrey</td>
<td>46</td>
<td>Katie</td>
<td>Daughter</td>
<td>Lives close by</td>
<td>Town</td>
<td>20</td>
<td>Housewife; mother</td>
</tr>
<tr>
<td>Cathy</td>
<td>44</td>
<td>Douglas</td>
<td>Partner</td>
<td>Living with YA</td>
<td>Town</td>
<td>18</td>
<td>f/t student</td>
</tr>
<tr>
<td>David</td>
<td>50</td>
<td>Rebecca</td>
<td>Wife</td>
<td>Living with YA</td>
<td>Large town</td>
<td>Unknown</td>
<td>f/t clerical worker</td>
</tr>
<tr>
<td>Andrew</td>
<td>39</td>
<td>Janet</td>
<td>Mother</td>
<td>Lives close by</td>
<td>Town</td>
<td>71</td>
<td>Retired (teacher)</td>
</tr>
<tr>
<td>Gordon</td>
<td>43</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a City</td>
<td>n/a City</td>
<td>n/a</td>
<td>f/t student</td>
</tr>
<tr>
<td>Jim</td>
<td>45</td>
<td>Mary</td>
<td>Sister</td>
<td>Lives a few miles away</td>
<td>Unknown</td>
<td>f/t student</td>
<td></td>
</tr>
<tr>
<td>Juliet</td>
<td>48</td>
<td>Claire</td>
<td>Daughter</td>
<td>Lives close by</td>
<td>City</td>
<td>70</td>
<td>Informal carer</td>
</tr>
<tr>
<td>Lorraine</td>
<td>37</td>
<td>Doris</td>
<td>Mother</td>
<td>Living with YA</td>
<td>City</td>
<td>17</td>
<td>Gap year</td>
</tr>
<tr>
<td>Robert</td>
<td>n/a</td>
<td>Robert</td>
<td>Husband</td>
<td>Living with YA</td>
<td>Town</td>
<td>60</td>
<td>p/t receptionist</td>
</tr>
<tr>
<td>Norma</td>
<td>54</td>
<td>Lisa</td>
<td>Daughter</td>
<td>Lives a few miles away</td>
<td>Hamlet</td>
<td>32</td>
<td>Housewife/ mother</td>
</tr>
</tbody>
</table>

Table II. Interview timetable.

<table>
<thead>
<tr>
<th>Family member</th>
<th>1st interview (T1)</th>
<th>2nd interview (T2)</th>
<th>3rd interview (T3)</th>
<th>4th interview (T4)</th>
<th>Time span</th>
</tr>
</thead>
<tbody>
<tr>
<td>Claire</td>
<td>08.11.04</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>6 months</td>
</tr>
<tr>
<td>Doris</td>
<td>23.09.04</td>
<td>27.04.05</td>
<td>16.10.05</td>
<td>07.04.06</td>
<td>20 months</td>
</tr>
<tr>
<td>Douglas</td>
<td>31.05.05</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>One off</td>
</tr>
<tr>
<td>Janet</td>
<td>29.11.04</td>
<td>01.06.05</td>
<td>–</td>
<td>16.08.06</td>
<td>22 months</td>
</tr>
<tr>
<td>Julie &amp; Katie</td>
<td>18.02.05</td>
<td>06.09.05</td>
<td>–</td>
<td>–</td>
<td>7 months</td>
</tr>
<tr>
<td>Lisa</td>
<td>09.11.04</td>
<td>–</td>
<td>03.11.05</td>
<td>22.08.06</td>
<td>22 months</td>
</tr>
<tr>
<td>Mairi</td>
<td>16.11.04</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>One off</td>
</tr>
<tr>
<td>Mary</td>
<td>24.01.05</td>
<td>–</td>
<td>13.02.06</td>
<td>–</td>
<td>14 months</td>
</tr>
<tr>
<td>Rebecca</td>
<td>09.02.05</td>
<td>–</td>
<td>22.04.06</td>
<td>–</td>
<td>15 months</td>
</tr>
<tr>
<td>Robert</td>
<td>17.11.04</td>
<td>25.05.05</td>
<td>28.11.05</td>
<td>–</td>
<td>13 months</td>
</tr>
<tr>
<td>Sam</td>
<td>09.06.05</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>One off</td>
</tr>
<tr>
<td>Total interviews</td>
<td>11</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>24</td>
</tr>
</tbody>
</table>
Uncertainty

Initially, family members were shocked by the stroke event, particularly in someone young:

"I was just shocked at [Andrew, her forty-year old son] having a stroke ... it knocked the wind from me" (Janet, T1)

Subsequently they experienced a new awareness of mortality and of physical vulnerability, their relative's and their own. For example, the occurrence of this life-threatening event in her daughter's life caused Doris to reflect on her own mortality as well as on that of other members of her family. She was frightened by the realisation that an individual's tenure in the world is uncertain, and questioned the purpose of human existence:

"You get frightened a bit by life, you know ... and you think, 'Why?' and 'What's in it for us all at the end" (Doris, T1)

Family members also worried about the recurrence of stroke, particularly in the first few months following the stroke event:

"[We] panicked when she came out of hospital first because ... [my mother's stroke] came on so suddenly, and it could happen again, you panic along that line" (Katie, T1)

Most family participants described living with the fear of recurrence on a daily basis. For example, if seventeen year old Claire's mother, Juliet, fell asleep on the settee, Claire would check that Juliet was still breathing. In the mornings, if Claire

<table>
<thead>
<tr>
<th>Table III. Family-centred needs and outcomes.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Short-term effects</strong></td>
</tr>
<tr>
<td><strong>Uncertainty</strong></td>
</tr>
<tr>
<td>Shock</td>
</tr>
<tr>
<td>Mortality</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Recurrence</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Intermediary effects</strong></td>
</tr>
<tr>
<td>Effects of stroke</td>
</tr>
<tr>
<td>Frustration</td>
</tr>
<tr>
<td>Cognitive problems</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Sameness/difference</td>
</tr>
<tr>
<td>Providing care/support</td>
</tr>
<tr>
<td>Care/service provision</td>
</tr>
<tr>
<td>NHS</td>
</tr>
<tr>
<td>Social services</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Long-term effects</strong></td>
</tr>
<tr>
<td>Situatedness</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Regaining normality</td>
</tr>
<tr>
<td>Family activities</td>
</tr>
<tr>
<td>Driving</td>
</tr>
<tr>
<td>Work</td>
</tr>
<tr>
<td></td>
</tr>
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<td></td>
</tr>
</tbody>
</table>

*Education; I, Information; M, Medical needs; PA, Practical assistance; PS, Psychological support; R, Rehabilitation.

*Identified in the Advisory Group analysis.
Family members of YAs: needs, priorities, outcomes

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did not hear her mother moving around, she tiptoed into the bedroom to check that she was alright (Claire, T2). Some family members found that the fear of recurrence persisted. As Lisa described 18 months after her mother’s stroke:

“It’s hard, it’s very hard … there’s never been a day since it happened that I’ve not thought, ‘Is it going to happen today?’” (Lisa, T3)

However, nine months later, Lisa described an ambiguous sense that her fear had receded. With the passage of time fear of recurrence was not present in such a figural way; it blended into the fabric of daily life:

“You’re not … thinking [about it] all the time … but … it doesn’t make it any easier … every time somebody phones you think it’s going to be something bad” (Lisa, T4)

In contrast, as time went on, some family members were able to forget that the stroke had happened, but this was largely due to the “normal” appearance of the young adult concerned (see below) (e.g. Robert, T2; Julie & Katie, T2).

Some family members were aware that certain lifestyle behaviours such as drinking excessively or smoking are risk factors for recurrent stroke. Continued practice of such lifestyle behaviours by the young adults caused concern. For example, Jim’s sister, Mary, and his father, Sam, were concerned about Jim’s heavy drinking and smoking (Mary, T3; Sam, T1). Sam was “worried sick” and described feeling helpless. He was forced to acknowledge that there was a limit to what he could do. He could provide practical support and he could counsel his son, but if Jim was not motivated to make changes to his life, then Sam was powerless to protect him (T1).

Smoking was a source of contention in several families. Claire’s greatest fear, 12 months after Juliet’s stroke, was that her mother had started to smoke again. When Claire and her grandmother tackled Juliet about it, she denied that she still smoked, but they did not believe her. Claire shouted at her mother because she was frightened (T2). Similarly, Douglas was frustrated by his partner’s refusal to listen to advice:

“[Cathy] hasn’t stopped smoking, [she’s] not interested, you know, [she] just doesn’t want be told what to do, [sounds angry and frustrated] so there’s not really a lot [I] can do!” (Douglas, T1)

Disrupted and altered relationships

Family members felt their experience to be “hard” because they perceived that the relationship between them and the young adult had altered; taken-for-granted harmonies had been disturbed. New demands were made on them, and new relationships had to be forged with others, particularly with health and social care professionals. Ambiguously, family members sought to return to their familiar, pre-stroke intersubjective relationships with the young adults while acknowledging that, following stroke, there would always be a difference in the young adult.

Family members spoke about physical, cognitive and social effects of stroke. For example, Mairi and her young son were aware of that Adam was less capable physically than he had been prior to his stroke. However, in the first few months after his stroke Mairi felt that it was important not to draw attention to his physical limitations. She tried to manage by discreetly asking other family members to help (T1). And Mary was concerned that her 45-year-old brother, Jim, would not be able to live independently following his stroke which had compounded pre-existing health problems. Mary was also concerned that Jim’s impaired mobility put him at risk, both in his home (risk of falls) and within his neighbourhood (risk of assault) (T3).

Tiredness was a common consequence of stroke mentioned by family members. It impacted negatively on the lives of the young adults, including their capacity for family activities. For example, 5-year-old Angus found his father’s lack of capacity for “play” difficult to understand:

“Angus felt [frustrated] as well because [he would say], ‘Dad, come and play with me’, ‘Come and do this, come and do that’, and Adam couldn’t!” (Mairi, T1)

Family members also described frustration as a source of tension, with young adults flaring up in anger (e.g. Mary, T3). However, family members themselves also experienced frustration and they would lash out verbally at the young adults. For example, Robert fought with his wife because he felt that, rather than getting on with life she was dwelling on the past and living in fear of what might never happen:

“She’ll still sit and dwell on, ‘Oh, I’ve had a stroke. It might happen again’ … and that annoys me and we fight about it [I say], ‘Why? Look … it’s not going to happen again! … you’re fine, you’ve got over it!’” (Robert, T1)

Cognitive effects of stroke were also a source of frustration to family members, including apparent clumsiness (e.g. Rebecca T3), short-term memory problems (e.g. Robert, T3), and apparent reluctance to shoulder responsibility or make decisions:

“David doesn’t cope under stress … he just tends to walk away, which is a … bit tiring … to be honest … you end up having to make all the decisions, and, Och! It is wearing! I mean I love him, I love him dearly but just occasionally you think, ‘Just decide!’” (Rebecca, T3)

Following stroke, an ambiguous aspect of family members’ experiences centred on a perceived contrast between the young adults’ outward appearance, which often was the same as prior to stroke, and the family member’s perception that the young adult was in some way different. Outward “sameness” often resulted in family members forgetting that the young adults had had a stroke (e.g. Julie T2). Similarly, although some young adults were perceived to have made a good recovery, this was tempered by the family member’s awareness that, often in quite subtle ways, the young adult would never be entirely the person they were before the stroke. This was a cause of sadness for family members, as Doris said 2 years after Lorraine’s stroke, Lorraine was no longer “the type of girl she had been before” (T4), i.e. confident and full of energy.

Family members found that new demands were made on them, physically and emotionally. Practical support ranged from providing assistance with personal hygiene and toileting to

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doing household chores and maintenance. Emotional support included offering advice and counselling about health and lifestyle issues, providing company and entertainment, keeping in daily contact and importantly, listening. For example, Doris saw her daughter, Lorraine, every day and every day she listened to Lorraine recount her fears, an emotional stressor, which exacted a considerable toll (Doris, T1).

In the main, contact with health and social services was limited, as most young adults had made a swift recovery from the physical effects of stroke. However, some family members were not happy with the care the young adults had received in hospital. For example, Lisa was frustrated by health professionals’ apparent inability to answer questions (T3), and 17-year-old Claire was unhappy with the lack of rehabilitation input:

“Basically [my mother] was just left to lie there … she wasn’t getting any … rehab, no treatment or anything … she was on her own all day” (Claire, T1)

Following discharge from hospital, family member’s perceptions were that very little help was offered or made available. Robert’s summation was typical:

“There doesn’t appear to be a lot of help, there’s a bit of initial consultant, ‘Right, what’s caused this?’ ‘Oh, very unusual’ and they did a few tests … and they discharged her after a week” (Robert, T3)

Alone amongst the participants, Lisa and her family were dependent upon social services for Norma’s essential care needs. Their experience was not positive; they had many complaints about the service, from its structure to delivery of hands-on care. Throughout the protracted process of transfer of care from hospital to community the family was frustrated by their lack of involvement; not even Norma was consulted about what she wanted and needed:

“They [Social Work Department] had a meeting a few weeks ago and we didn’t know anything about it … it’s like they’re choosing what’s right for her, but she’s got a mind of her own, you know … the care system is absolutely shocking … I’ve seen my mother being put to bed at 6 o’clock at night” (Lisa, T3)

Situatedness
Following the stroke event, family members experienced “being-in-the-world” differently. Situatedness refers to the family members’ sense of dislocation, or disorientation following stroke. Their attitude to life and understanding of life, and their “place” in the world had changed. They made adjustments and re-oriented themselves, processes which required using coping skills, including the need to reclaim “normality” for themselves, the young adults and the wider family.

Practical coping strategies included resumption of “normal” routines (e.g. Lisa T3). For example, returning to work helped Doris and her husband cope after the initial shock of Lorraine’s stroke:

“We were off work for some time … and I think it was worse actually … but now that we’re back in our daily routine it’s … for [my husband] it’s a lot better, you know, he’s been better and more able to cope with things” (Doris, T1)

Family members also adopted emotional coping strategies such as pragmatism, positive thinking and re-framing. Some family members compared their situation with that of others and in that light considered themselves, and the young adult “lucky” (e.g. Robert, T2; Doris, T1).

With the passage of time family members began to regain a sense of “normality” as the familiar, taken-for-granted course of life was taken up again. When Robert bemoaned his plight as family chauffeur, 9 months after Lorraine’s stroke, he also reflected that essentially it was “business as usual”:

“We’d have had the same [arguments] even if Lorraine could have driven, because it would still have been my job … [laughs] you have to realise, this is a normal marriage! … I do what I’m told!” (Robert, T2)

And a year after Juliet’s stroke, Claire thought that her Mum was just about back to the way she always was. Juliet was tired and they didn’t see much of each other but that was how it usually was for them (Claire, T2). And Katie and Julie, 14 months after their mother’s stroke reflected that stroke was more or less forgotten because:

K: She’s almost back to her …
J: usual self
K: … crabbit [bad-tempered] self, I was going to say! [they laugh] (Katie & Julie, T2)

Family members identified pre-stroke activities that represented recovery milestones, including shared family activities, resumption of driving, and return to employment (e.g. Robert, T2; Doris, T3). Lisa, who had several young children, found it hard to get Norma out and about in her wheelchair, but it was managed on occasion:

“We’ve had her out when it’s been snowing, [laughs] silly things … she thought it was absolutely great, you know … she really enjoyed it, she kept laughing because of the snow, she was getting covered in snow” (Lisa, T3)

The resumption of driving was a significant recovery milestone, as it represented recovery from stroke and regained independence (e.g. Robert, T3; Janet, T2). However, when Lorraine’s driving license was revoked, for Doris, this was a sad reminder that Lorraine’s recovery was not complete and that she remained in some way different after her stroke (Doris, T2 & T4).

Return to work was another significant milestone (Robert, T2 & T3). However cognitive problems often proved prohibitive to a successful return (e.g. Doris, T4), and other family members were concerned about the young adults overdoing things and running the risk of having another stroke (e.g. Claire, T2):

“[David’s] working in [a warehouse] … and he’s not having to think, at all … and he’s sort of enjoying it … [laughs] in a funny sort of way … I wonder whether he should be maybe trying for something else where he’d be using his brain a wee bit more … [pauses] … I wonder whether he’s becoming a wee bit lazy … I don’t know what the answer is to that! [laughs] … What is it that he should be doing? What is it that he can do? But … you don’t want to put him under [any stress], I mean you wouldn’t; he doesn’t cope under stress’ (Rebecca, T3)
Family members also sought to engage young adults in pre-stroke activities. Lisa described her father’s failed attempts:

“He tried all these different things … he even bought her a mini ironing board to put over her chair - that never worked! She never used it! … [laughs] well, I laughed … I said, ‘Well, there’s trying to get her to do things and there’s trying to get her to iron your shirts!’ [laughs] [Mum said] ‘Oh! I wish I could do that,’ and then she’ll look at me and start laughing!” (Lisa, T4)

Family-centred needs and outcomes
Table III is divided into three sections labelled Uncertainty, disrupted and altered relationships and Situatedness. These sections are mapped to the short, medium and long-term post-stroke. This temporal perspective reflects the ways in which the experience of stroke and associated family-centred needs and outcomes are subject to change over time. The table comprises three columns i.e. effects of stroke, family-centred needs/interventions and family-centred outcomes.

Discussion
This paper reports the findings from a qualitative investigation of the experience of stroke from the perspective of family members of young adults who have had a stroke. The design and conduct of the research was congruent with major precepts of Merleau-Ponty’s existential phenomenology [27]. Phenomenological analysis revealed that family members of young adults experience of stroke was grounded in time; figural against that ground were Uncertainty, Disrupted and Altered Relationships and Situatedness. Similar themes were noted by Banks and Pearson [4] in their study of young adults post-stroke and their spousal partners, but have also been noted in studies of general stroke populations which included spousal carers (e.g. [3,5,6]), which suggests that these experiences are “universal” and not specific to family members of young adults.

From the qualitative findings, ML extrapolated families’ needs and associated rehabilitation outcomes in the short, medium and long-term following stroke (Table III). Over recent years many arguments have been made in support of family-centred approaches to rehabilitation (e.g. [1,8,41,42]), but little guidance has been offered regarding appropriate interventions. In this section, we discuss key findings and associated family-centred needs in terms of appropriate interventions, with a view to informing multidisciplinary rehabilitation practice over the course of the stroke recovery trajectory.

Being a family member of a young adult who has had a stroke was found to be “hard” because it was permeated with uncertainty and worry. After the initial shock of the stroke event, a sense of mortality was figural to the lived experience, as family members realised that life could not be taken-for-granted. They were afraid of an uncertain and unknowable future [7,43]. Rehabilitation professionals need to be alert to and acknowledge this aspect of familial caring relationships and address some of the associated issues by listening to family members’ fears and worries [3], and by providing appropriate psychological interventions [44]. It is worth noting that recent clinical guidance on psychological care following stroke, makes little mention of families’ needs [45].

Family members feared recurrence of stroke, and this fear endured over time, particularly if the young adult persisted with lifestyle behaviour that constituted a risk factor for recurrent stroke. For rehabilitation professionals, a practical means of addressing this fear is initiation of secondary prevention interventions i.e. interventions which include prescription of medication (antiplatelet, antihypertensive and statin, as appropriate), together with active provision of information and education regarding lifestyle risk factors and medication adherence [46,47]. Clinical guidelines recommend tailoring of secondary prevention interventions to meet the needs and priorities of individuals and their families (e.g. [47]).

Commonly, family members observed in the young adults a pattern of continuing recovery over time, yet simultaneously remained aware of residual effects of stroke. Family members perceived young adults to be changed in some way, which gave rise to feelings of sadness and loss. New tensions were evident in inter-family relationships, often due to frustrations experienced as a result of effects of stroke, fatigue and cognitive impairment in particular. Similar effects on relationships have been noted in other studies of families affected by neurological disorders (e.g. [3,4,48,49]). Assessment of pre-stroke family function is recommended as a first step towards addressing the issue of adaptation to life post-stroke. It also provides an opportunity for rehabilitation professionals to counsel, teach and negotiate goals, as appropriate [1,3,8]. However, family assessment is not routinely undertaken in stroke rehabilitation, although it has been shown to be effective in the acute phase post-stroke [50] and education and training would be required in order to implement this innovation.

Family members identified resumption of key activities i.e. driving and employment, as recovery milestones for the young adults. Failure to achieve these milestones was a source of disappointment and reinforced the family members’ awareness of difference in the young adult. It is essential that rehabilitation professionals ascertain patients’ and families’ expectations and work together with the family to achieve mutually agreed feasible goals. Research has demonstrated that families often feel that their needs relating to employment, for example, are not met by rehabilitation services (e.g. [44,51]). Based on findings from their studies of young adults’ experiences of returning to employment after stroke, Corr and Wilmer [10] recommend implementation of comprehensive, well sign-posted, vocational programmes, delivered in partnership with employers and other agencies [10].

In the study reported here, many young adults and their families had minimal contact with health services and social work departments, and very few accessed formal or statutory support services. Those that did often found the experience unsatisfactory, time consuming and frustrating. Generic reviews of the stroke literature have highlighted problems faced by stroke family carers accessing formal support [21,52]. Notably, service providers often fail to determine the needs and priorities of families and young adults (e.g. [53]). Increasingly, research evidence highlights the need for rehabilitation professionals to identify the families’ needs and...
priorities and to agree achievable goals, as an integral element of practice [1,8].

The sudden and devastating impact of stroke on family members caused a shift in family members’ understanding of their place in the world, of their taken-for-granted understanding of their familiar, pre-stroke way of being. Such shifts in orientation required implementation of a variety of practical and emotional coping strategies, as family members aimed to regain pre-stroke normality and their habitual way of being. Studies of general stroke populations also report that family carers aim to return to pre-stroke normality (e.g. [3,7]) and that a range of problem-based and emotional coping strategies are used (e.g. [5,7]). Clinical guidelines recommend that rehabilitation professionals implement psychological interventions that promote effective use of coping skills and other mechanisms to support adaption (e.g. [11,24]). However, rehabilitation professionals are not necessarily equipped to provide such emotional support and interventions are likely to target the stroke survivor rather than the family [45,54].

Limitations
A potential limitation of this study is the small sample. However, small numbers are common in phenomenological studies (e.g. [3]); Thomas and Pollio [36] suggest that between 6 and 12 is appropriate. Eleven family members participated in this study, which meets the methodological criterion. Another potential limitation relates to lack of heterogeneity in the sample, specifically with regards gender, ethnicity and stroke severity. Most of the participants were female, however this may be a reflection of the typical “carer” demographic i.e. informal carers are more likely to be female [55]. Participants were recruited from two major cities in the UK, it was expected that the sample would include people from different ethnic groups; however, all potential participants referred to the researcher were Caucasian. In terms of stroke severity, only one family member was related to a young adult who had had a “severe” stroke resulting in severely limited functional ability [56]. The majority of young adult participants had made a good recovery i.e. they had few “visible” effects of stroke [57]. However, one of the differentiating features between younger and older adults who have a stroke is the rapid physical recovery made by younger adults [58]; therefore it is likely that the study participants were representative of the wider young adult stroke population. In terms of gaining understanding of the long-term experience perspective and associated needs and outcomes, participation was sporadic, and at Time 4 only three family members participated in interviews. A longitudinal perspective was gained from six individuals who took part in interviews at Time 3 and/or Time 4; however, a more flexible approach to timetabling interviews will be implemented in any future work to facilitate sustained involvement of participants.

Conclusion
The qualitative findings from this phenomenological study enabled a deeper understanding of the experience of stroke from the perspective of family members of young adults, and contribute to the swell of research evidence that supports a family-centred approach to rehabilitation.

From the starting point of understanding stroke from the perspective of family members, and drawing on available research evidence combined with their professional expertise, rehabilitation professionals may use the table of family-centred needs and outcomes generated by this research to identify short, medium and long-term rehabilitation needs and priorities of family members. They can then select appropriate interventions which align with identified family-centred needs and outcomes throughout the stroke recovery trajectory. From this informed starting point, members of the multidisciplinary team can begin to work with family members to develop meaningful goals, which are of mutual benefit to patients, families and rehabilitation professionals.

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