



DUTY OF CARE FOLLOWING STROKE: FAMILY EXPERIENCES IN THE FIRST SIX MONTHS

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Abstract

Stroke is the third largest cause of death in New Zealand and is a major cause of disability. While a lot is known about the stroke survivor and the primary family caregiver, little is known about how stroke affects the survivor's wider family. Hermeneutic phenomenology, guided by the work of Max van Manen, was used in this study to investigate the experience of becoming and being a family member of someone who has had a stroke, over the first six months from the initial stroke. It is part of a larger longitudinal four year project exploring the stroke family lifeworld. Three participants from the same extended family were interviewed in 2011-2012 at six weeks, three months and six months following the stroke of a family member. Thematic interpretive analysis showed that the stroke survivor is not the only person who needs care. The overarching theme was *duty of care* within and for the whole family. There were three sub-themes: care is *different for different people*, there are care *expectations of self* and *expectations of others*; and care brings *strain*. The family experience revolved around expectations and obligations of their own duty of care and care needs for themselves and that of the stroke survivor, which were also influenced by issues outside the family. In addition there were considerations of fairness regarding the sometimes competing needs of the survivor and the caregiver. Strains on the family changed over time. Competing values of mercy and fairness within this family took up time and risked shifting the focus away from the stroke survivor.

Keywords

Stroke; family; duty; care; experience; New Zealand

Introduction and Background

Stroke is the third largest cause of death in New Zealand and is a major cause of disability. An estimated 45,000 people live with a stroke in New Zealand and around 70% are dependent on others to help with their daily activities (Stroke Foundation of New Zealand, 2014; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). While a lot is known about the impact of stroke on the survivor and the primary caregiver little is known about how stroke affects the wider family. Impacts such as financial difficulties, strain and isolation have been seen as significant

factors on the primary caregivers' experience (Bulley, Shiels, Wilkie, & Salisbury, 2010; Greenwood, Mackenzie, Cloud, & Wilson, 2009; Lutz, Young, Cox, Martz, & Creasy, 2011). The importance of family in stroke recovery was noted by Vincent et al. (2007) and Brunborg and Ytrehus (2014) who described how important family, friends and other social networks were to the stroke survivor's rehabilitation and well-

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being.

In the New Zealand context Dyll, Feigin, and Brown (2008) and Corbett, Francis, and Chapman (2006) focused their studies on Māori stroke survivors and their caregivers. Dyll et al. (2008), using statistics from Feigin et al. (2006), argued there is greater health disparity and financial impact for Māori whānau than non-Māori families, as Māori have strokes at younger ages; 62 years for Māori compared to 75 years for Europeans.

This study is part of a larger longitudinal hermeneutic project (2011-2015) undertaken by researchers from the Department of Nursing, Unitec Institute of Technology and the Waitemata District Health Board, Auckland, New Zealand.

Research Design

Aim

The aim of this study was to investigate the phenomenon of becoming and being a family member of a stroke survivor over the period of six months after the initial stroke.

Methodology

This was an exploratory study using hermeneutic phenomenological research methodology. Hermeneutic phenomenology aims to understand the significance of practical activities and experiences in everyday lives and is well suited to studying human issues and concerns (Plager, 1994) such as family experiences post-stroke. The processes used in the study were guided by those described by van Manen (1997).

Methods

Participants for the study were recruited from the larger longitudinal project (Northern X Regional Ethics Committee: NTX/11/EXP/062/AM02) using purposive

sampling strategies. Inclusion criteria were: (1) family of a person admitted to the Assessment, Treatment and Rehabilitation (ATR) ward following a first-ever stroke where at least two family members agreed to participate; (2) adequate spoken English to complete consent and the interview. Informed consent was obtained in writing at the beginning of the project and on-going verbal consent obtained before each subsequent data collection phase. Consistent with the longitudinal project, 'family' was defined broadly to include people who live in close relationship with the stroke survivor. Five families who met inclusion criteria were recruited by intermediaries for the longitudinal project (total participants = 14), with one of these families consenting to participate in this study. This family were recruited as the stroke event coincided with the first author's availability to complete the study. The family included the spouse of a stroke survivor (Ivy) and two other family members (Deb and Jane). All of the participants were health professionals. To maintain anonymity their specific disciplines are not disclosed and other identifying data excluded. All data were anonymised and stored in password protected digital format only accessible to the research team. Pseudonyms were chosen by the researcher and are used throughout.

Data collection

Face-to-face, semi-structured interviews were undertaken at six weeks, three and six months post-stroke (December 2011 – May 2012). The interviews were between one to two hours in length and were held at a mutually agreed location. Interview questions focused on participants' experiences at the time of the stroke and in the weeks and months that followed. Preliminary interpretive analysis of interviews at each time-point informed questions for subsequent interviews.

Data analysis

All interviews were transcribed verbatim and



anonymised prior to analysis. Data were analysed thematically. Theme consolidation was developed over time through writing, reflecting and rewriting (van Manen, 1997). Mind maps were also used to explore relationships between themes, with analytical processes and decisions recorded in a reflexive journal. The researcher had regular meetings with the research team to discuss analysis and theme development, which opened the interpretation to critique. The overarching theme evolved from words such as care, cope, and expectations, which were derived from key phrases used in the participants' interviews. These phrases became the building blocks to the overall theme of *duty of care*. The participants explained their caring actions differently, including such factors as who provides care and who has particular care obligations, which was reflected in the sub-themes. The overarching theme of *duty of care* was reflective of all participants' experiences, albeit not necessarily mirrored by each at every time point. The analytical processes used

support the credibility of the interpretation and the reflexive account provides the information necessary for evaluation of the plausibility (rigour) of the findings (Koch & Harrington, 1998).

Findings

Duty of Care

The overarching theme was *duty of care*. Societal, personal and perceived pressures from health professionals over issues surrounding *duty of care* were identified as the principal concern of the family's stroke experience. Duty of care was expressed through three sub-themes: *Different for different people*; *Expectations of self and expectations of others*; and *Strain*. These themes interacted and contributed to the primary author's interpretation of the stroke experience (Figure 1).

According to the Oxford dictionary, duty of care is "a

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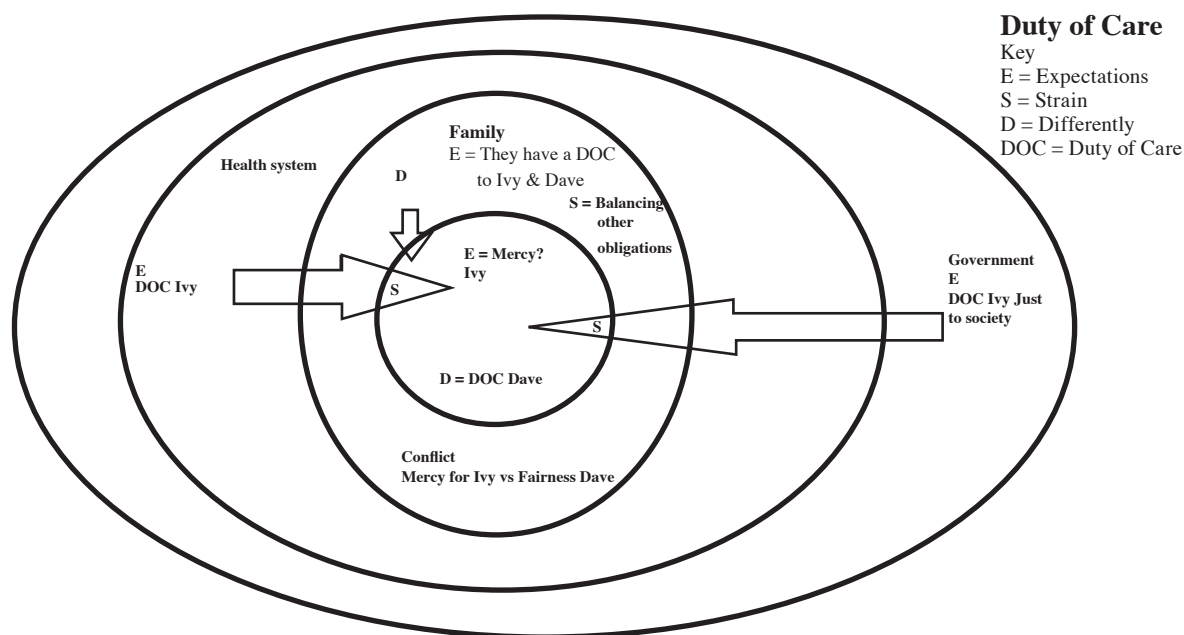


Figure 1: Duty of Care - Interaction of themes



moral and legal obligation to ensure safety or well-being of others" ("Duty of Care," 2014). In considering the moral basis for caring, Noddings (1986) describes how caring for someone is not just about a person's actions. Noddings suggests that caring is about connection, how fully a person considers and has empathy for the care recipient's reality. Caring is also a choice which is sometimes natural and effortless, but at other times and in other situations requires effort and is a response to moral obligation or duty.

Nortvedt (1996) discusses the moral aspects of the ethic of care, contending that moral perception (ability to perceive a recipient's reality) is a crucial skill to fully care for a recipient's needs. Nortvedt argues that, in caring, principles of mercy, fairness and justice are used to help all parties achieve an effective care relationship. He explains that fairness and justice are used to guide care decisions for large populations, but that in face-to-face relationships, the principle of mercy is more appropriate. In this article mercy refers to care actions that are given to an individual beyond standard care in recognition of high needs.

When a health professional is engaged in direct care of a patient the allocation of a needed resource will be influenced by the close face-to-face relationship, as the person-to-person nature of the relationship demands that special consideration should be given. This may go beyond an equal distribution that is ethical in a larger, anonymous group, resulting in extra resources being made available for the individual. Thus fairness characterises caring for a large population, leading to care decisions that are just and fair for all patients, whereas the principle of mercy guides decisions on an individual basis. An example of the ethical challenge is where one patient's care involves a potential use of other patients' resources. Nortvedt (1996) argues that if moral perception is concerned with the patient's condition, and not the patient as a

person, the moral judgement becomes impartial and therefore fits in a justice ethic. Therefore the skill and maturity of the health professional's moral perception, and their ability to balance the wider needs and the individual's needs, have great bearing on a successful outcome. In this study, the family's moral perception and their view of the health system were challenged by questions of fairness, justice and mercy. Over time these perceptions affected how the family care for one another, contributed to family strain and their care capacity.

Different for different people

The research data revealed caring as complex and multi-layered. Different people show their care in different ways and for different reasons. This relates to each participant's expectations of themselves and others within the family as well as society's wider expectations.

The consequences of stroke are *different for different people*. Ivy and Dave were almost expecting the stroke to happen. Before the stroke they were forewarned by their doctor that Dave's lifestyle and co-morbidities would likely lead to a stroke. The event was quite different for Jane, who was shocked and upset when she found out. Deb had expected the stroke and felt much more immediate concern for Ivy than for Dave when she heard the news.

I mean the stroke was kind of like inevitable really because of all his health problems. So it wasn't a surprise ... I wouldn't like to see [Ivy] struggling caring for [Dave] either. I don't think that's really fair 'cause she's like worked hard all her life and I don't think she should have to do that, I don't, and I've already told her that she shouldn't become his caregiver and I really wouldn't want, I wouldn't let that happen to Ivy. (1, Deb)

Deb had personal experience of her own parent's strain



as caregivers and knew what Dave's stroke could mean for Ivy. Deb felt a duty and responsibility for Ivy's care and moved from caring about (*she shouldn't become his caregiver*) to caring for (*I wouldn't let that happen*).

Caring is also dependent on location, knowledge, experience and family relationship. Early on Ivy explained how she met an old neighbour in the hospital after Dave's stroke. The neighbour's husband had recently had a stroke and her way of showing her *duty of care* for him was to stay by his bedside constantly. Ivy on the other hand made sure she took time to look after herself.

I said [to the neighbour], "You've got to take care of number one ... if and when he comes home, you're going to have to have your health like I am". And she [Ivy's old neighbour] said, "Well how many girlie days have you had?" I said, "Well I have about two a week, I know he's in good hands". I just say to [Dave], "that's it, I've got to go to this or do that" and he understands. (1, Ivy)

Perhaps because of her health professional background Ivy could see the need to stay healthy and prepared for the burden of caring. There was already knowledge that caring for the stroke survivor at home would be a burden.

Stroke changes lives. These changes may be different depending on the background of the people affected by stroke. Three months after the stroke Ivy was coming to terms with the changes the stroke had made in her life.

I get the feeling of relief rather than sadness. I mean there's sadness there but not that I can't cope with it and the fact that he is probably in a better position where he is than here. (2, Ivy)

The relief Ivy felt was the relief of a burden lifted and the sadness was for a life changed. She felt ambivalence around her *duty of care* for Dave as, although she would have liked to have him home, she acknowledged that the care in the rest home was better than she could have achieved at home.

The participants showed care for different reasons and in different ways. They also had different expectations around care. They had expectations on who should be doing it, how it should be done and the location. These expectations are explored in the next theme.

Expectations of self and expectations of others

Stroke requires a response from family. The responses of family members in this study depended on expectations around their role in caring within the family. Different expectations were expressed by different family members, and were reflected in experiences reported by the participants in their interactions with employees in government departments and health professionals working in a range of healthcare settings. These expectations of care had to be weighed against the participants' capacity to respond, considering their other duties, obligations and their own health.

Deb and Jane felt they had a role in caring for Ivy and Dave immediately after the stroke. This expectation had to be measured against other duties and their emotional safety. Caring as part of the stroke family was only one duty among many.

I think, there is a danger [that] certain people [could] become too dependent on you and that's not possible because you've got another side to your life. So, I've always found when I have offered assistance that I need to be just a wee bit careful that I don't get eaten alive, but in this case I'm sure it won't be so. (1, Jane)



Jane was concerned that the recipient of her care could become dependent and that she, as a carer, could become overwhelmed. Although both Jane and Deb worried that the care they provided might become all-consuming, there was an implicit expectation that they had a duty of care, especially toward Ivy.

There were also expectations wider than the family. Rest homes have a duty to be fair to all their patients and to use their resources wisely. The government also has a duty to be just, with responsibility to the wider society and the taxpayer. The family perceived that both health service providers and government departments had expectations that the family should take on various aspects of the stroke survivor's care. As a consequence, at three months Ivy felt pressured to take on the additional caregiving activities.

I get the certain feeling that because they know I'm a [health professional] that I'm actually going to be in there doing his exercises and doing 110 things, I'm being very careful to withdraw from that because I'm his wife and his friend but I'm not his nurse... I know that some of the wives do do some of the minor exercises etc. (2, Ivy)

Ivy consciously chose not to take on the caregiving role; she was Dave's wife and friend. Yet she still felt societal pressure and expectations from other wives, rehabilitation staff and employees from government departments to take on the duty of care. The other family members also had the strong impression that Dave and the health professionals involved in his care expected he would go home following a period of rehabilitation. Ivy and Deb reported that the rest home staff asked Ivy to think about selling their family home and purchase one that better suited Dave's needs.

Over time, shifts in needs and capacity to care influenced care responses, both expected and given.

These care responses in turn shaped other family members' perceptions of what care they deserve and ought to receive.

At the six month point, Ivy felt threatened by the possibility of Dave coming home and her expectation that she would be shown understanding and given mercy by health professionals was not met. Care actions were not given in recognition of her needs. Her hope that the duty of care would be maintained by the rest home staff was not being fulfilled. Instead she felt forced to say: *I'm not ready to have him home*. Ivy knew the limits of her ability to care for Dave. She was concerned about what it would mean for her role as Dave's wife if she relinquished her resolve and took on Dave's care.

The stroke burden changed over time for this family. The family appeared to be challenged by expectations and decisions around if, when and how to care for one another. As time progressed, questions of moral judgement around care including the values of mercy, fairness and justice were raised and became tiring and time consuming for the family.

Strain

The burden of fitting in care around life's other ongoing responsibilities and priorities proved draining. By six months the stroke experience became the new norm for the wider family. The prolonged concern and duty of care became tiring.

For Jane the immediate nature and extra energy devoted for caring for Ivy and to a lesser extent Dave caused conflict with other now more immediate duties.

I am concerned [about Ivy's health] and sometimes I feel I almost need time out. That sounds a bit mean but I just backed off just a couple of weeks ago because I had a few problems with a grown up daughter and I just really needed to have just one



thing to concentrate on at the time. My work's lovely and very involved and very busy and I just recognise that there's a limit to what I can cope with. (3, Jane)

While Jane remained concerned for Ivy's health, by six months she felt a need for time out from caring. Other more immediate duties of care, such as to her daughter and to her work took precedence. Sometimes the wider family may feel the need to pull away, to re-prioritise and recognise self-limits in order to fulfil the duty to self of self-care.

Financial strain was a consistent theme throughout the interviews. The perception was that dealing with government departments, instead of providing assistance to reduce the financial burden, increased the strain on the stroke family.

About three or four days after his stroke I learned, to my horror, that WINZ [Work and Income New Zealand] will take away his pension ... Being on the other side [of the health system] is just no joke ... The WINZ experience was probably the worst thing that Dave and I experienced. You're just simply not a human being. (1, Ivy)

The financial strain was immense. Ivy and Dave were faced with potentially losing their home through the inability to pay the mortgage because of the loss of Dave's pension. This caused significant strain. For Ivy it was as if the government was not fulfilling its duty to care for them. The strain was not helped by Ivy's perception of being treated like a case number and not a human being in her interactions with WINZ staff.

The family's moral perception and their view of the health system were challenged by questions of fairness, justice and mercy. These perceptions affected how the family cared for one another and contributed to family strain and their care capacity. Early on, out of a sense of duty Deb took on power of attorney for Ivy

and Dave. While she knew it would only be effective if both Ivy and Dave became incapacitated, Deb still felt a lot of conflicting emotions about whether it was her place within the family to take on such a responsibility. As time changed so did the family duties as they were continually reassessed. Over time strain built and irritation increased.

Like with this whole thing about getting Dave a power wheelchair, Ivy has been trying to use every avenue that she can [including Deb's work] to get him a power wheelchair and Dave is actually able [to use] a manual wheelchair ... I do feel that Ivy has pushed the boundaries. (3, Deb)

By the end of the six months Deb was experiencing a number of conflicts. Deb perceived Ivy as blurring her professional and personal boundaries by using Deb's connections to access an electric wheelchair for Dave. Deb's opinion was that Dave would benefit in the exercise involved in using a manual wheelchair, and her professional view was that other patients had a greater need. There were conflicts between the principles of mercy and fairness.

Deb became concerned with the amount of energy her duty of care towards Ivy and Dave was consuming at the expense of her own immediate family. This caused some resentment around the caring role she had assumed. It seemed Deb was disturbed that Ivy demanded mercy for herself in getting Dave an electric wheelchair to lessen her burden, but at the expense of Dave's rehabilitation. Deb appeared to be conflicted between Ivy's need for mercy and Dave's right to fairness.

Discussion

The overarching theme in this study was *duty of care* within and for the whole family, which was reflected in the sub-themes: *care is different for different people*; there are *care expectations of self and expectations of*



others; and care brings *strain*. While caring is a choice which is sometimes natural and effortless, at other times and in other situations it requires effort and is a response to moral obligation or duty (Noddings, 1986). Both such aspects of care were revealed in the experiences of participants in this study.

The participants were all female family members with no blood relationship but with strong family-like bonds. They were all health professionals which made this sample unusual in that they had professional as well as personal experience of becoming and being a stroke family. Their professional backgrounds meant they had more knowledge and resources available and were more confident in their ability to navigate the health system than other families may have been. Concomitantly, being a health professional gave them increased awareness of the realities of caring for a stroke survivor, including their own limitations of providing that care to an adequate and safe level. This awareness brought greater stress when the health professionals appeared to ignore those limitations and gave the impression that the family, especially Ivy, should take on that duty of care anyway. Also, as a family of health professionals, they focused on caring for the carer. Both Jane and Deb discussed caring for Ivy and themselves, alongside Dave, and expressed their views and obligations of the health system.

The participants' professional backgrounds shaped their perceptions regarding mercy and fairness in the care of stroke survivors and their families, which was reflected in their experiences. As family they initially had a strong sense of mercy for Ivy as Dave's wife rather than as his caregiver. Ivy was a reluctant caregiver, preferring the role of wife and advocate for Dave, which was supported by the other family members. This was tempered as Dave's rehabilitation progressed. Dave's right to fairness around his rehabilitation and his preference to return home conflicted with Ivy's request for mercy. She is a small woman who was

concerned about being the primary caregiver for Dave who is a big man. This value conflict placed strain on the family.

Duty of care encapsulated this family's experience of becoming and being a stroke family. Moral judgements were made around who should provide the care and where Dave should reside. Balancing family expectations and the different care needs increased family strain especially when the family's expectations appeared to differ from those of the health professionals. This is consistent with research by Lutz et al. (2011) which found that the expectations of family members in regard to stroke rehabilitation and discharge planning was not always congruent with those of rehabilitation providers.

Ivy knew her limits and what role she was able to play but did not feel that the health professionals showed her any mercy. Instead she felt a sense of enforced duty that threatened her health and potentially her relationship with Dave. While Ivy was able to recognise her limitations and was able to resist the pressures to bring her husband home, other caregivers may not be able to do so. Similarly, Lutz et al. (2011) described the importance of caregivers recognising personal limits to providing care and having a strong sense of self-advocacy if they are to avoid the "crisis of discharge" where the stroke survivor's level of need outweighs the caregiver's capacity to provide care.

Financial, physical and emotional strains were significant aspects of the post-stroke experience for the family in this study. This is consistent with the findings of Greenwood et al. (2009) and Bulley et al. (2010) who found that financial concerns around entitlements was a common challenge. Bulley et al. (2010) also described how emotional burdens of post-stroke care impacted primary caregivers' self-identity and hope for the future. However these emotional burdens were often prioritised behind physical care by



health professionals. These emotional burdens were reflected in the findings of this study as participants grappled with questions around the moral and practical aspects of their duty of care. The family became preoccupied with what can be considered as moral and ethical judgments regarding who was most in need of care, the stroke survivor or the spouse. Trying to balance their duty of care to the stroke survivor and spouse with other responsibilities brought strain to the extended family. Moral questions around care distracted family members from the possibility of the stroke survivor coming home. Processing these moral judgments appeared to separate the family from the stroke survivor's progress. Considerations of family dynamics may be useful areas of further research.

Strengths and Limitations

The richness of the data gained from the series of in-depth interviews with the three participants over a six month period helped to give strength to this study's findings. Inclusion of family members additional to the primary carer was another strength, given the "concept of the secondary carer is seldom addressed in stroke research" (Greenwood et al., 2009, p. 350). The age range of the participants (40-70 years) allowed experience between generations to be available for analysis. The homogeneity of the study participants

the stroke survivor but also family members.

was a weakness. Participants were all female, Caucasian, and middle class, which limited the study's perspective and may reduce transferability of findings. The data and findings of this study contribute to the larger longitudinal hermeneutic project (2011-2015), which will address the need for longitudinal qualitative studies to identify that articulate experiences of caring for stroke survivors in an environment when over time some challenges diminish and new ones emerge (Greenwood et al., 2009).

Conclusion

Becoming and being a stroke family may call forth a duty of care, which is different between family members depending on what other responsibilities they have. Balancing these responsibilities as they continually change and are reassessed can be a strain on the family. Competing values of mercy and fairness within the family in this study took up time and risked shifting the focus away from the stroke survivor's progress. Assessing expectations of family members from the beginning of the stroke journey and monitoring moral questions of fairness, mercy and priorities between the stroke survivor and the family as the recovery progresses is important. Health professionals should work with families to identify options for ongoing care that balance the needs and expectations of not only

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