

Fear of death and putting 'life on hold' when one's spouse is hospitalised in a non-local tertiary centre

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Note

In this study pseudonyms are used.

KEYWORDS

health professionals, hermeneutic phenomenology,
semi-structured interviews, non-local tertiary care,
acute care

ABSTRACT

Background

There are unique issues for families when patients are hospitalised in non-local tertiary settings. These challenges include facing the possibility of a loved one's death, especially in an environment devoid of familiarity and social support. This paper presents findings that emerged from a hermeneutic study that explored the experiences of supporting spouses whose partner was transferred to a non-local tertiary hospital. During this time research participants faced the fear of death, and put their 'life on hold' amid social isolation from family and friends.

Objective

The objective of the PhD study was to explore the experiences of those whose partner was hospitalised in a non-local tertiary setting.

Design

Unstructured interviews were conducted with individuals. Hermeneutic phenomenological frameworks were used to analyse the transcribed interviews. Interpretations that emerged from these experiences enlighten understanding of similar situations. Initially, the prime researcher (CM) interviewed the research participants twice. However after interviewing the first four participants it became apparent that the participants told their entire story during the first interview and had no further information to offer. Subsequently, participants were interviewed once with an invitation to contact the prime researcher should there be other memories they wished to share.

Participants

Spouses (n=14) of people who had been admitted to a non-local tertiary hospital took part in this research. Overall 10 women and four men took part in this research. Participants were recruited by word of mouth (snow-balling).

Results

During times of non-local hospitalisation supporting spouses faced the fear of their partner's death, therefore putting their own 'life on hold'. Uncertainty was compounded if the supporting spouse was surrounded by other patients who were dying and the supporting spouses began to anticipate and prepare for their own partner's death. These fears were exacerbated during times when the supporting spouse had to make life and death decisions devoid of the direct physical support that would be available from family and friends had the partner been hospitalised in a local setting.

Conclusions

Spouses of patients affected by hospitalisation in a non-local setting often feared that their sick spouse may die during the time of non-local hospitalisation. This fear resulted in them putting their 'life on hold'. Health professionals can use strategies to minimise the effect of this fear on couples. These can include focussing on the patient as an individual, listening to couples and understanding and addressing their concerns.

INTRODUCTION

The discovery of disease that requires hospitalisation is a potential cause of stress for both the patient and their family. This can be accentuated if the patient is transferred to a non-local tertiary hospital where increased technology and specialisation of services are available. There are five tertiary hospitals in New Zealand, which means that people living in regional centres need to travel for specialist services. When patients are transferred from local to non-local tertiary centres to receive specialist treatment, they can become dislocated from social support. When the disease is life-threatening, such dislocation from social support affects not only the patient, but also the patient's partner, who faces an uncertain future. Fearing the patient's death, especially when the patient is hospitalised in another geographical centre, can have a significant impact on the couple.

In 2006, Mercer conducted a PhD study that explored the impact of non-local hospitalisation on supporting spouses. Trevor needed to be stabilised at the local centre prior to urgent transfer to the non-local tertiary centre. He was accompanied by his wife, Zoë. Warren had several trips to non-local tertiary centres for treatment. Each time Alice juggled her time and commitments to support Warren and the children at home. Victoria and Don needed to change arrangements when Don was suddenly hospitalised in the non-local tertiary centre. Therese and Ernie had long ago adjusted to the illness that resulted in Ernie requiring non-local hospitalisations. Despite having long periods of time to adjust, Ernie's condition suddenly deteriorated. The purpose of this paper is to present research about supporting spouses' fears of the death of a loved one while bereft of social support, which resulted in them putting their 'lives on hold'.

RELEVANT LITERATURE

Acute critical hospitalisation causes distress and a sense of uncertainty for relatives, (Appleyard et al 2000; Giuliano et al 2000; Medland and Estwing Ferrans 1998; Mendonca and Warren 1998). In addition, spouses of acutely ill patients may face

the possible loss of their partner, or prolonged or poor recovery (Miller and Wikoff 1989; Thompson and Cordle 1988). When a loved one is hospitalised with sudden illness, family members provide support by being at the bedside and maintaining watch (Plowfield 1999; Coulter 1989). Carr and Clarke (1997 pp.713-731) defined this as vigilance and proposed that vigilance demands the family pay constant attention to the needs of the ill family member. Maintaining vigilance also provides family members with a sense of control over the potential illness outcomes and the ability to protect the patient from harm (Agazio et al 2003; Carr and Clarke 1997; Darbyshire 1994) thus allaying the fear that something will happen while they are away from the hospital (Leske 1991 p.225). The need to maintain vigilance is driven by the fear of death, but the opportunity to maintain vigilance is a challenge if family are separated by distance (Mercer 2006 p.115).

The desire to have the best treatment available also needs to be balanced with concerns about distance from the treatment area (Weeks et al 2002; Magilvy and Congdon 2000). Davis et al (1998 p.527) suggest that due to the increased burden of being away from home for six weeks, rural women are significantly more likely to undergo mastectomy than have breast-conserving therapy. These women express concern about the potential effect of their absences on their children and have doubts about their partner's ability to cope during those absences (McGrath et al 1999 p.38). These women may have increased psychological needs, but be reluctant to seek help (Girgis et al 2000; Sullivan et al 1993). Furthermore, the reluctance of rural women to seek assistance leads to increased social isolation and emotional turmoil (McGrath et al 1999 p.40).

Financial situations also influence treatment choices (Davis et al 1998; Strickland and Strickland 1995). For example, poor American minority groups prefer to treat themselves at home, rather than face journeys of up to 300 km to health services (Strickland and Strickland 1995 p.47). Estimated out of pocket expenses are among the determinants that rural

American retirees used in deciding whether to use regional hospital centres or closer private providers (Weeks et al 2002 p.558). Additional costs for Australian rural women seeking treatment for cancer include paying for someone to take their place in managing the farm and household (McGrath et al 1999 p.39).

Fear of a loved one's death, while the supporting spouse was bereft of social support, emerged from a PhD study (Mercer 2006) that focused on the experiences of those who had their spouse hospitalised in a non-local tertiary centre. There is a need for nurses to recognise the impact of non-local tertiary hospitalisation and the possibilities of death that supporting spouses face in social isolation.

METHODOLOGY

The aim of the study was to engage in a hermeneutic phenomenological approach to explore the experiences of having a spouse hospitalised in non-local tertiary centres. Phenomenology offers opportunities to explore experiences that capture individual world-views. Hermeneutic phenomenology is the analysis of expressions, both spoken and unspoken, that describe these experiences. Meanings that emerge from descriptions cannot be presented as arbitrary interpretations (Gadamer 1975 p.238). Rather, understanding occurs when the researcher extrapolates the connections between the descriptions of the experience and previous understandings.

Participants

Fourteen participants were recruited for the study through a snowballing method. In other words, people who volunteered to take part in the study also contacted other potential research participants. Participants were informed of the research by means of friends and associates of the prime researcher (CM) and then made further contact with others who had been in similar situations. This is a very effective process of accessing potential participants (Dempsey and Dempsey 2000; Nieswiadomy 1998). Recruitment for the research was conducted over a six month period and interviews conducted shortly

after initial contact. Selection criteria for the study were people in a long term partnership (ie one in which the couple were living together in a committed relationship) with someone who was transferred to a non-local tertiary centre with a life-threatening condition. Research participants did not need to have accompanied the patient to the non-local centre. Overall 10 women and four men took part in this research. When it became apparent to the prime researcher that the same stories were being told, a decision was made not to seek further recruitment.

Ethics

Although the research participants had not themselves been patients in a hospital setting, permission for the study was sought and received from relevant ethics committees. Participation in the research was voluntary. Each research participant was identified by pseudonym to protect their identity.

Data Collection

Unstructured interviews (ie beginning with an opening question and letting the participants tell their individual stories) were used to gather the data. This approach encouraged reflection rather than directed the participants to focus on specific answers to specific questions. Participants were asked to recall the events leading up to their spouse's illness in general, and then focus on finding out that their spouse was to be hospitalised in the non-local tertiary centre. From these reflections, the research participants were then able to describe their experiences. Each interview was audio-taped and transcribed by the researcher to facilitate in-depth familiarity of the data.

Data Analysis

Data analysis began by reading each transcript several times. Unlike quantitative methods that begin analysis processes once all data are collected, when using hermeneutic phenomenology, analysis begins before data collection is completed. This is because analysis requires the researcher to engage in critical dialogue with the text, drawing on key aspects, impressions and interpretations (Benner

1994; Dahlberg et al 2001; Leonard 1994). During the initial analysis, the prime researcher noted words that were used in each transcript, taking special note of the descriptions that captured accounts of the experiences; thus letting the data speak. Letting the data speak involves reading the text, and determining interpretations of the story by seeking partnership with the story-tellers. As the researcher reads the stories some aspect of the experience comes to the fore and generates understanding. This approach requires readers to read individual texts to determine what new interpretations emerge (Benner 1994; Dahlberg et al 2001), enabling an understanding of life to emerge from the experience (Dahlberg et al 2001; Leonard 1994). Hermeneutic phenomenology is not founded on using stories to provide examples of what you want to say; rather it allows the phenomenon to emerge. While the researcher focuses on one part of the description, other components may momentarily recede. These components are addressed in turn. Heidegger suggests that if the causality between two events is interpreted, the phenomenon is interpreted as being alongside another's world (Heidegger 1962 p.88). The extent to which there is convergence between the individual and others' stories validates findings (Burke Draucker 1999).

FINDINGS AND DISCUSSION

Findings that emerged from the study that focussed on the experiences of supporting spouses affected by a partner's transfer to a non-local tertiary setting included fear of the possibility that their partner might die during this time. Four particular characteristics of these experiences that were worth exploring were: putting 'life on hold' because of the uncertainties; awaiting; watchfulness and state of alertness; and anticipation and preparedness for their own spouse's death. Overarching all of these characteristics is the lack of social support particularly when having to make life and death decisions while physically separated from the friends and family that would have been available had the patient been hospitalised in a local centre. Findings from this research are that the fear is especially acute when the couple are

separated by non-local hospitalisation, particularly difficult during the time of transfer.

When I got in the plane [the commercial flight to the tertiary centre], it was the first time I had been away from [Trevor, after treatment at the local hospital]. He was getting on that air ambulance and I was wondering all the way up [during my flight] whether I would get there and find that he had died. And I was going to have to turn around and come back and I was going to have to come back on my own. That's what I was worried about. And I think the biggest joy was to see him coming down that corridor in that wheelchair. Yeah, I do vividly remember that now. I was on the plane and I got to [the city] and if he'd died, I would have to come back...It is not like coming home and being recalled and turning around and coming back ten minutes later. I mean, you're an hour or so, or you are up in the air and you've got no communication whatsoever (Zoë).

The hospitalisation resulted in Trevor and Zoë being approximately 400 km from home; an hour by plane or 5-6 hours road travel. Had Trevor died, Zoë faced the challenge of the distance between home and the city of transfer. Zoë's fears during the flight reflected the supporting spouses' state of alertness that was with them the entire hospitalisation stay.

This was compounded if the supporting spouse was staying in the nurses' home that was now converted to relative accommodation. Although adequate, the accommodation consists of a single bed in a room, with shared shower and toilet facilities. Meals can be accessed at the hospital cafeteria. There was little respite from the constant reminder of the seriousness of the partner's illness. Each time they went to the ward, they were not sure what they would find, adding to the sense of waiting for the unknown. For example, Victoria, whose father had died recently, recalled going to the ward and finding Don's bed empty. Because Don was 'missing', Victoria assumed his condition had deteriorated, or worse, that he had died.

...I got there and Don wasn't in his bed, and of course you freak out when you see that he wasn't in his bed.

And I went to the nurse and I said “where’s Don?...I don’t know if I was paranoid, maybe I was...I think it is because you have in your mind that you almost lost them.

Waiting in the face of uncertainty led to ‘awaiting’; a time of waiting for. The constant state of watchfulness and being alert was compounded if the supporting spouse was aware that other patients had died, especially if that patient had also been transferred to the non-local centre:

There was another chap who ended up in the same ward...I ended up realising that his wife was in the nurses’ home. And, we ended up becoming friends, and having tea, having breakfast and that together. But, unfortunately, he did die...That was really, really sad...I sort of felt a bit guilty, because here was Trevor beside me, and her husband had died (Zoë).

The other man...he died. That was really hard. [We] immediately bonded with him, because they were both in the same room, both getting prepared for [a transplant]...It was the saddest part (Carol).

While it is acknowledged in the literature that parents separated by non-local transfer have to make crisis decisions alone (Agazio et al 2003; Tan and Simmonds 1998), there is no literature that acknowledges the stresses of couples facing decisions during times of acute health crises. From the interviews with the study participants it became apparent that the couples were forced to make important decisions, including those that involved life and death, without the support of familiar surroundings or social support. For example, one couple had to face the possibility that the medical condition could result in death during surgery. Having been warned that this was a possibility, they then had to decide whether the surgery should be undertaken.

...we had been told [earlier] that they were going to operate and [the operation] was going to [be successful]...And then that night we were told otherwise; that it looks like [the operation might not be successful]... They don’t really know until they go in...So we had to make a decision whether

they [should proceed] and there was a fifty per cent chance or even more that he would probably die on the operating table (Alice).

This choice was particularly difficult because Alice and Warren had no other family with them to discuss this life-threatening condition. Another research participant’s story accentuated the enormity of the situation.

He was so confused, and I had to make decisions, and things like that for him... That had sort of quite an effect (Therese).

When anticipating the death of a spouse, Carr and Clarke (1997) and Duke (1998) recommend that families plan some change to life activities so that the transition to bereavement occurs over time. Couples facing death are also told they should reminisce in order to have memories once the spouse has died (Waskowic and Chartier 2003; Duke 1998). However although the participants were facing the possibility of their spouse’s death, their spouse was not dying. It was the fear of death that these participants experienced. Those who accompanied their spouse were reluctant to predict the possibility of becoming widowed without the immediate access to social support. Those who stayed at home to manage the household were reluctant to predict becoming widowed without the chance of being with their spouse at that time. In encountering death so closely, the research participants experienced what Heidegger (1962) calls a projection of ‘being-toward’ death. In everyday living, human beings avoid contemplation of the possibility of their own death, reflecting upon the notion that death happens to ‘others’ (Heidegger 1962 p.296). Findings of this research however, were that it was not un-named others who might die; death was nearby. In contrast the family and friends who could cushion the awaiting were not nearby. The awaiting and dreading death added to the state of putting ‘life on hold’.

IMPLICATIONS FOR PRACTICE

Treatment in non-local tertiary centres is likely to increase as services and technology become more sophisticated. Such medical specialisation has

nursing implications when families are affected by the requirements to travel to specialist centres. Recommendations from this research are that although health professionals are not always able to prevent their patients from dying there are strategies that they can use to minimise patients' supporting spouses putting life on hold in the face of death.

Nurses need to acknowledge that what is common and worldly for the nurses in that tertiary setting is frightening for those who have been transferred from their home town. A simple strategy is for nurses and other health professionals to focus on the patient as an individual and listen to the couples to understand their concerns. This is especially important if the couple need to make life and death decisions without social support. Health professionals also need to acknowledge the fears of this client group if surrounding patients do die and those from local settings feel overwhelmed by the non-local tertiary environs in the face of life-threatening illness.

LIMITATIONS

Hermeneutic phenomenology presents individual interpretations of those who experience a phenomenon, in this instance, non-local tertiary hospitalisations. The findings of hermeneutic phenomenology are unique to those who took part in the study. However the individual stories carry lessons and sharing the individual stories with others who have been in similar situations strengthens the findings.

No other study was identified which has explored the experience of non-local hospitalisation from the partner's experience. There is therefore, a lack of international literature, a concern which is noted by Agazio et al (2003) and Mercer (2002). While this lack of international and national research has resulted in limited literature with which the current thesis can be compared, the findings of the current study form a foundation for further research and scholarly debate. Further research that examines the impact of non-local hospitalisation on families based on differing theoretical perspectives would enable comparison between the current and future findings.

CONCLUSION

Having a condition that causes an episode of non-local tertiary hospitalisation can result in the supporting spouse fearing the death of a partner and, in the resultant uncertainty, putting 'life on hold'. Findings of this study were that research participants felt surrounded by and walked alongside other spouses who faced death on a daily basis. The lack of social support, because family and friends were unable to be physically present, resulted in the supporting spouses being constantly alert and watchful. Through effective communication and listening, nurses can facilitate resolution of the uncertainty and minimise fear of the unknown.

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