

THE LIMINALITY OF PALLIATIVE CARE

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ABSTRACT

This paper discusses the application of the anthropological concept of liminality to narratives of New Zealanders living in the community with life threatening conditions, both malignant and non-malignant. This qualitative research aimed to explore the ways in which people diagnosed with life-threatening conditions managed their life world. Using a narrative approach, 13 participants, eight spousal caregivers, three adult children, three specialists, one general practitioner and one psychotherapist were interviewed. Analysis was thematic and interpretive within a phenomenological framework. Receiving a diagnosis with a poor prognosis heralded significant life changes for patients and their families and precipitated a transition from an identity as a productive member of society and community participant to that of patient living with an uncertain future. Conceptualising end-of-life care in terms of liminality offers a powerful framework for understanding the experiences and challenges faced by people with life threatening conditions and their families.

INTRODUCTION

Hospitals are ultimately liminal spaces, where people are removed from their day to day lives, taken into a betwixt and between space of being diagnosed, treated, operated upon, medicated, cleansed etc. For many people, hospitals are places in which their previous identities as a healthy person, as a mobile person, as an immobile person, are stripped bare. New identities such as a cancer survivor, a more mobile person with a new hip, a rehabilitated person with one less limb are forged ... In hospitals, medical experts determine the rites of passage undertaken (p73) (Long, Hunter, & van der Geest, 2008).

This paper discusses the application of the anthropological concept of liminality to phenomenological narratives of New Zealanders living in the com-

munity with life threatening conditions, both malignant and non-malignant. Receiving a diagnosis with a poor prognosis heralds significant life changes for patients and their families. In our study, it precipitated a transition from an identity as a productive member of society and community participant to that of patient living with an uncertain future. We suggest that conceptualising end-of-life care in terms of liminality offers a powerful framework for understanding the experiences and challenges faced by people with life threatening conditions and their families as they negotiate this particular life change.

Liminality refers to a social space characterised by ritualised degrees of separation from society. The liminal experiences of patients have been the focus of prior research in social science and medicine. For example, Menkes *et al* (2005) identified acute liminality, which begins with the patient's suspicions of the diagnosis and consequent investigations, moving to a sustained liminality, where recovery from active treatment moves them forward to a remission, but often with continuing risk of recurrence. Molzahn *et al* (2008) showed that living with end stage renal disease contained diverse liminal spaces and acknowledging these may help health professionals support patients and their families. Similarly, Kelly (2008) found that rather than being a transitional space, liminality became a way of life for people with AIDS-related dementia. Kelly used the term 'living loss' to describe new ways of loss and grief experienced by these individuals, and the term 'liminality' as a permanent social space rather than simply as an in-between space. Williams and Keady (2008) used the concept of 'bridging' to explain how people living with Parkinson's disease were able to maintain a sense of stability and control. They described three stages of bridging – building on the past, bridging the present and broaching the future which are consistent with the preliminal, liminal and post-liminal stages of the rites of passage outlined by Van Gennep (1960).

Examining Van Gennep's constructs in more detail in reference to rites of passage, Turner (1969) noted that while in the liminal, the subject passed through a realm that combined the experience of the past with hopes for the future. He suggested that these subjects became liminal personae or 'threshold people' who have an ambiguous social status in that they are yet to emerge changed. Their behaviour is normally passive, obeying instructions and accepting what is being done to them. While in this space, they tend to develop comradeship with those sharing the experience.

Turner (1986) later expanded Van Gennep's idea of liminality to being at the threshold of a change in status where the ritual process itself constructs a threshold between secular space and sacred space. Inhabiting the liminal can

be private and/or public where the rituals of performance are either secluded from the public gaze or included in it. Continuing to develop the concept of liminality, Turner (1990) described liminal activities as being neither here nor there and having no status, until transformed by ritual. For individuals and groups, social life involved the experience of 'alternating exposure to structure and communities and to states and transitions' (p149). Turner adhered to the old idea that human life has inherent biological limits, however Squier (2004) noted that Turner failed to represent the complex ways that culture produces nature while nature shores up practices that people have come to think of as cultural. The liminal challenges us to negotiate meaning, and both the form and the trajectory of our lives can be reshaped at will, whether our own or another's.

Kaufman and Morgan (2005) argue that anticipation of death and the condition of the liminal state of not yet dead, as it relates to Foucault's (1993) 'medical gaze', created historic conditions through which life and death could be constituted as biological processes. Knowledge and information about life and death allow transformations in cultural practices which shape not only life and death but also the constitution of a person and opportunities for life and health. Biomedical techniques and economic structures legitimise and make possible extensions of life, prolongation of dying and the creation of new forms of life. Increasing numbers of liminal beings hover between life and death such as the long term comatose, severely demented, or the unconscious (Kaufman & Morgan, 2005).

From the earlier concepts of liminality as being very prescriptive, more recent discourse has developed in relation to the 'othering' of people who inhabit liminal space, seeing them as liminal subjects moving around in an ambiguous way on the margins, temporarily out of place because they are seen to be attacking the natural order of things (Jackson, 2005). Liminality itself can be characterised as a transitional state between different ways of being. People in liminal positions can move between different communities and experience different frameworks so that new ideas and knowledge emerge (Jeyaraj, 2004).

The medical encounter can be conceptualised as a rite of passage with identifiable stages. In the most simplistic view of this, the person becomes a patient during clinical care and exits patient status following treatment. This is reminiscent of the classical definition of liminality as betwixt and between social classifications. However, this view does not account for different forms of clinical care, or the social context of being a patient, particularly in outpatients or primary care healthcare where the person/patient is also continuing

to maintain identities of parent, child, spouse, worker, student etc. When illness threatens, people seek out doctors who will provide an understanding of what is happening to them so that they can maintain a sense of themselves as whole while being 'other' and still belonging to the world of the living (Carson, 2002). Hogue (2006) noted that:

liminal times and spaces function to prepare participants for a new life to be lived under very different conditions or demands, in some cases actually reshaping their identities. But between 'before' and 'after' inevitably there appears a gap of uncertainty and disorder (p5).

Using both Turner's (1969) and Douglas's (1990) notions of liminality, the former being 'betwixt and between' and the latter being 'matter out of place', Jackson (2005) discussed these ideas in relation to people who suffer from chronic pain. She noted the paradoxical nature of pain and the ways in which Parsons' (1952) 'sick role' delineates what is acceptable behaviour and what is not, so that those people suffering some forms of chronic pain inhabit a kind of 'no man's land' between the real and the imaginary. Illness or disabilities disrupt lives by altering the regularity and the routine of habitual behaviour. These events are not predictable and require ongoing adaptation to new circumstances. A person's sense of embodiment changes and they need either to adopt a new way of living or to adapt to a way of living that is thrust upon them (Frank, 1993).

Patients are expected to pass through a temporary liminal state as they leave the time-limited sick role to reclaim their social roles and obligations. However, some move to what was termed 'persistent liminality' where, rather than taking up a normal healthy productive life, they are forced into a 'betwixt and between' state of health and illness (Crowley-Matoka, 2005).

Beginning the medical construction of the patient's story, health professionals focus on measurable abnormalities and symptoms/signs that identify a particular disease or injury. This clinical story is recorded and may be reconstructed and represented at a later time. There are two parallel narratives relating to this construct. The patient is speaking of an intimate experience drawing on their sense of self, whereas the physician is often engaged in solving a problem (by translating symptoms and signs into a diagnosis). The practice of patient centred medicine may mitigate this and provide a relational context for the patient and their doctor. The person as self becomes person as patient, inhabiting a liminal space of the in-between (Montgomery-Hunter, 1991).

When people are given a life threatening diagnosis, some individuals and fami-

lies are able to negotiate liminal space while others find it difficult to comprehend the situation in which they find themselves. 'Pre-liminal variation' is a way of understanding this (Burton, 2006). While Burton's work referred to students in the learning context, this construct could also be applied to people who have been given bad news.

Little and Jordens (1998) suggested that the state into which a survivor of serious illness enters is one of liminality which persists for the rest of the patient's life. Being described as 'in remission', never cured, reinforces this. Liminality in this context has a significant contribution to make because it offers a means of explaining the ever changing process and experiences patients face in adapting to the illness. It preserves the link between medical discourse and individual suffering by facilitating the translation of the body into clinical knowledge and practice and it provides a way in which health workers can communicate and understand patients and why they behave as they do at particular times in their illness trajectory.

Once the liminal state is entered, as in the case of people with terminal disease, there can be no return to the preliminal state. Transposing Meyer and Land's (2005) application of threshold concepts to the medical encounter, similar negotiations seemed to occur in participants with life limiting disease. For example, the extent to which they use health professionals to help them acquire knowledge about their illness and transition to a new identity in the community. Health professionals are the experts who determine the 'rites of passage' (i.e. what these will be, and when they will take place) undertaken by patients and their families (Long, *et al.*, 2008) in the liminal space that is the hospital, home or general practitioner's office.

Clinical institutions and settings represent liminal spaces where individuals are sequestered from society during treatment. Most importantly, institutional settings represent a liminal space in the Parsonian (Parsons, 1952) sense where people are removed from their social responsibilities, becoming either well or not (Charmaz, 1983). In discussing the relationship between time and space within the limina, Hofmeister (2002) noted the significance of liminal times and spaces to transitions which link together what is separated. Because transitions are not predetermined, they can become liminal spaces of communication, connection, encounter and renewal on different levels, for example, economic, sociocultural, and ecological.

More recent literature discussed the liminality of public spaces, especially in regard to the ways people discovered and engaged with the potential for trans-

formation in such spaces. The general liminality of the city has physical and social dimensions where strangers converge on thresholds to manipulate and enjoy liminal spaces that other people are moving through and may become participants or observers of. The social content is always shifting and unpredictable. Public spaces offer opportunity because of the conditions of liminality (Stevens, 2007). Applying this concept to waiting rooms and hospital foyers, there are many similarities to public urban spaces in that people discover and engage with the potential for change offered by these spaces in relation to individual health. People move through this space and converge in a shifting unpredictable environment with order imposed by the institution and its policies and procedures.

METHOD

Thirteen participants living with a life threatening illness were interviewed by the lead author (RMcK) for this present research, along with eight spousal caregivers, three adult children, three specialists, one general practitioner and one psychotherapist. Four participants had been diagnosed with cancer, three with respiratory disease, two with renal disease, three with neurological disorders and one with cardiac disease. A qualitative method was considered to be the most appropriate for this research with its aim to use narrative as a way of explaining the ways in which people diagnosed with life-threatening conditions managed the liminalities of their situation. Analysis was thematic and interpretive within a phenomenological framework. In identifying themes and reconstructing the participants' life stories, the ways in which they managed their life world within the construct of the 'rites of passage' process was elucidated along with an understanding of how the concept of liminality influenced this.

The interviews were conducted as face-to-face interviews in an informal semi-structured fashion. Prior to interviews, patients and caregivers were provided with a 'Life World' chart (Figure 1). This was designed to serve as a visual prompt for participants to think about how these different areas of their lives had been affected by their diagnosis and prognosis and indeed, all the participants reported it helpful while reflecting on their experience and telling their story. It was sent out with the letter of introduction and information sheet prior to the interview taking place.

The interviews were audio-taped and transcribed with the consent of all participants who were offered a copy of their interview transcript and had the opportunity to change, delete or add any information. The transcripts were

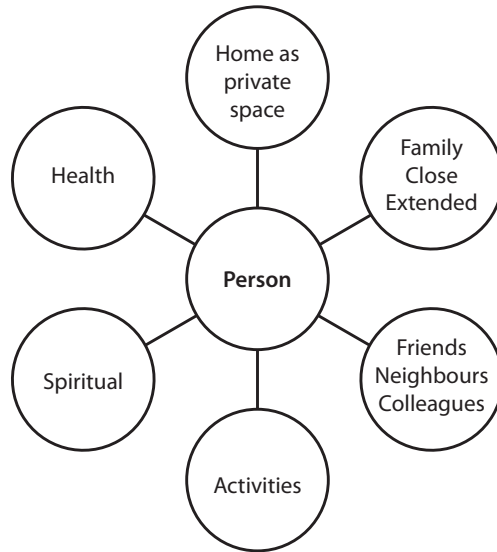


Figure 1. Life world chart

analysed using computer assisted qualitative data analysis software that enabled themes to be identified and participants' life stories reconstructed.

PARTICIPANTS

Biographical details of some of the participants are offered in this section to contextualise and honour the participants in this project, most of whom have since died. Pseudonyms are used to protect anonymity and some identifying details have been altered for the same reason.

Hilary, aged 47, worked as a mental health nurse in an emerging field and enjoyed her work. She was also an artist who graduated with her Doctor of Philosophy after her diagnosis and treatment and had hoped to go on to do further research in the mental health field. She described herself as a very independent person who could do anything she liked and found the limitations of both her disease (cholangiocarcinoma) and treatment irksome.

Ray, aged 79, diagnosed with Cryptogenic Fibrosing Alveolitis, had also been very active in his life with a keen interest in sports, particularly water sports, fishing and motorbikes. He had worked in the same occupation until his retirement. Along with his wife of many years, he played an active part in the com-

munity life of the rural town where he lived. Having been able to do anything around the home, he too found it very difficult living with the liminality of his situation:

I get rather frustrated when I get up in the morning, oh I will go and do that and as soon as I look at it, I just flop. I used to keep all my own garden, mow all my own lawns, handy around the house, I could screw in a bracket, any damn thing, now I just can't do it.

Michael had Duchene's Muscular Dystrophy and lived at home with his parents. He was a young man who had just graduated from University with a double degree. Although he flatted during his university years, he still went home at night to sleep as he had to be turned every two hours and his parents did not feel they could rely on a flatmate to do that. Because he lived in a rural area, he did not have much social interaction with his peers, tending to have friendships with family members who were much younger. The liminality of his situation involved not thinking about the future:

It is better not to think too far ahead in the future and just take each day as it comes.

His mother also described the liminality of her situation as a parent:

Nobody sees us, no phone calls, nothing, just left to manage on our own and I know if we really needed anything we can go and ask but we think we are okay.

Audrey, aged 65, had miliary tuberculosis¹ as a child in Asia. After a lengthy stay in hospital for this illness she kept house for her brothers while they were at university. She later completed her New Zealand Certificate of Science while working as a nurse aide at the same time. She met her non-Asian husband when she was 16 and they married the following year. Against medical advice she had two sons. She was being nursed at home by her husband who had malignant mesothelioma and in fact died a few months after Audrey. He described their combined liminality:

The distressing thing too for me is I thought I would outlast my wife and I would look after her. The thing is I started to fall down and it appeared that she might outlast me and she gets worried now that she can't look after me and I can't look after her so now we are in the hands of the health professionals and everybody else.

Eric, aged 79 years, was suffering from Renal Failure following an elective cardiac procedure. He was a retired carpenter and described himself as being a very fit, active and independent man who hated being taken care of. His liminality was experienced as a loss of independence:

I like to be on my own and it has upset me getting this. I thought even if I am ill, I am asking to be at home but I can't, it's awful isn't it. I never thought it would be that way, even if I could crawl around the bloody floor I would never leave home but there you go. I couldn't stay at home now if you paid me to, it changes.

Sheila had been diagnosed with Motor Neurone Disease at age 61, having previously been an extremely fit healthy woman. Along with her husband who was due to retire, they had made plans to travel overseas which had to be curtailed due to deterioration in her condition. She experienced liminality as coming in to and going out of hospital departments while a diagnosis was being made. She was finally diagnosed with a particularly aggressive form of Motor Neurone Disease, going from walking to almost complete immobility over a twelve month period. Her daughter, who moved from the North Island to help take care of her, described the family's liminality as experiencing the loss of their mother:

I am horrified that I am down here blowing my mother's nose and I am cooking her dinner and feeding her her meals and I am feeding her drinks through a straw and I am doing everything for her but that is not how you picture your mother daughter role... Christmas was extremely hard because mum has always done things – like she makes certain things, bakes certain things and that didn't happen this year. For the first time ever we didn't have the truffles and mum's shortbread, or anything from mum and we have just – we are nearly at the end of mum's bottled fruit and things like that have had a huge impact.

RESULTS

Inhabiting the Liminal

Table 1 depicts a multi-layered and complex experience of liminality that represents participants' attempts to make sense of what was happening to them and to delineate the rules of engagement while in such a space.

Table 1. *Liminality as experienced by the participants in this study.*

Pre Liminal	Liminal	Post Liminal
Level One		
Entering into the medical encounter	Waiting	Emerging Changed
Level Two		
Hospitals as liminal spaces	Experiencing Treatment Doing/Being	Cure vs. Death Living with chronic illness
Level Three		
Developing relationships with Health care professionals	Crossing Using Health care professionals as guides	Ongoing needs met or not
Level Four		
Home becomes liminal ceases to be private	Time – contracting Expanding	The Future

The process of impending patient-hood (or the preliminal period) for participants began with a growing awareness that something was awry in their bodies. They experienced deterioration in their health and increasing disability as their disease presented itself. ‘It was at the stage where I was really finding it hard to put one foot in front of the other and I really got quite tired and I couldn’t work out why’. Their schedules and routines became disturbed as they (and their families) altered their lives in preparation for what they expected was to follow; entering the liminal zone of diagnosis and treatment. This threshold marks the ‘before and after’ described by Bulow and Hyden (2003) when the anticipated diagnosis propels not only soon to be patients into a liminal state, but also those around them, ‘What happened was it made everybody stop and think about themselves I suppose ..., everybody has thought about their own circumstances’. Respondents sought explanations for what was happening to them and willingly stood at the threshold of the medical encounter where they became the subject of ‘the medical gaze’ (Foucault, 1993).

The main theme for the participants in the present study was ‘waiting’. This experience of ‘waiting’ indicated that this group of participants inhabited a liminal space to a greater or lesser extent and moved between home and hospital. Once the diagnosis was made, they emerged changed, having been labelled with a particular disease and a treatment plan instituted. Those with cancer sought cure or remission and attempted to maintain well-being whereas for

those with non-malignant disease, the primary goal was to halt deterioration. All participants attempted to maintain normality similar to the descriptions noted by Hockey and James (2003) when unintended life events such as a life limiting diagnosis can be 'turning points' in a person's life course where identities are changed and meaning is sought from the experience.

People with both malignant and non-malignant illness described moving from pre-diagnostic liminalities into the post diagnostic and post treatment liminal zone of living with increased dependence as they deteriorated physically. One participant with renal failure didn't feel particularly ill and was struggling to accept the prognosis:

He [GP] said the way you are now with your kidneys and heart and bits and pieces, anything might happen at any time. He said you mightn't feel ill but you are sicker than what you think you are and that's why I am having a bit of a struggle to get to grips with it.

Life itself became a sense of 'betwixt and between':

I felt that I was in a place that was between the living world and the dying world and it was like a grey space and everything was grey and I wasn't frightened of it but I was aware that I was in a space that other people aren't in'.

Going on to discuss the experience of being in a liminal space, the participant quoted above, who understood the concept, went on to describe an instance when she was in a café:

Everybody was there talking to friends and there were babies and people having coffees and people rushing through their lunch reading reports or talking on the phone and I was just sitting there and I felt like I was completely and utterly invisible as a person. It was just a horrible sensation of being a non person. I felt like I wasn't there even though I was there physically...nobody could see me or would acknowledge that I was there.

A counsellor described inhabiting liminal space from a more spiritually orientated viewpoint saying:

There is very much that thing about owning who you are and where you are with the earth before your spirit goes down and so for me,

it is really important because whatever the next step is for people, if they don't know themselves, then you know, for me, I have the sense of does that mean that those souls are still around and are troubled because they don't know themselves or they won't ever keep moving forward.

Some respondents with cancer demonstrated an attitude of taking control. 'I am going to do what I want to do and not worry about the little things really' and 'In the end I suppose you just have to make up your mind to what you want to have happen and try and make it happen'. This raised the question about the 'rules of engagement' about inhabiting this liminal zone, not only for the individual but also for others around them. Doing things that can be controlled compared to the uncontrollable event of having a life threatening disease seemed to provoke a conflict between the personal need not to give up, and being an active part of a team who are working together. Despite understanding the diagnosis, hope was often part of the strategy to get a person through the liminal state, 'If I get a lot better, the possibility is there for me to be able to work, or looking to the future:

It is like you know is it [*death*] going to be this year, next year, the year after, in ten years, I don't know. And what this guy at the clinic [*alternative therapist*] said to me was well you know what would make the difference in terms of you living or having more time is to have a plan of what I am doing in five or ten years do you know what I mean? So it is constantly all the time about should I be arranging for my death or should I be arranging for my life – do you know what I mean, it is really bizarre.

Making Meaning from the Diagnosis

All participants talked poignantly and honestly about the impact of the diagnosis. RMcK asked how they thought they and their families were affected by the diagnosis and what they did to adapt. Ann's husband echoed the thoughts of all the participants when asked about how the diagnosis had affected them 'It is more about emotional coping, it is very tiring'.

Participants often described having to adapt to physical limitations as their bodies were affected by the disease. However emotional coping was described as requiring much more effort; whether to share private thoughts and experiences with family and friends meant having to then cope with their emotional responses. Social coping too was a feature in how people adapted to the

changes in their lives, either living with the ‘stigma’ of having such a disease:

when people hear the word cancer they already write you off, they have already got you dead and buried. It is sort of like they can’t get rid of you quick enough

or having to change one’s plans to accommodate living with the disease:

We have had to let our long term planning go, we didn’t want to let it go, we had been saving money for our retirement, but won’t get to spend it.

One person felt he was being punished ‘I must have been an awful little boy and now I am being punished for it’. He started crying at this point in the interview and could not elaborate further because his wife countered this statement by saying that he was joking, seeming to be somewhat embarrassed that he had shown such vulnerability in front of a stranger. He seemed to be seeking reassurance from the researcher in trying to find meaning for his suffering.

Sheila said that she had seen people with cancer in a great deal of pain and was very grateful that she did not have that. She had never ‘gone down the “why me” track’ and said that while it was a shock, she just took it as a matter of fact, saying ‘why not me?’. This may reflect her deep religious conviction. She talked about the disease not affecting her brain and she could still think and take part in family life going on around her and that she was comfortable and enjoying life as much as she could. This was backed up by her counsellor who said:

she is not fighting it, she is living with it and I think that enables her to surf the changes and she does, she surfs them...psychologically she has become stronger.

When questioned about giving bad news, a general practitioner said ‘I don’t think that the patients have the same perception of how sick they are and I would be failing them by not making that clear’. When I discussed this with the specialists, one stated that he finds it really difficult ‘partly because you feel pretty helpless about it too...It [*muscular dystrophy*] is an awful form of bad news to have to pass on’.

None of the health professionals interviewed were prepared to prognosticate overtly with their patients, defining prognosis as something that was very nebulous which, in most cases, could be entirely wrong, so preferred to err

on the side of caution:

I [GP] tend to be very reluctant to give people prognoses in terms of time. I give them prognoses in terms of outlook and in broad terms what is going to happen, but in terms of time frames I am very wary.

Still it was clear that participants were questioning the liminality of their existence, and explained why they got the retrospectroscope out and looked back through their memories for explanations. This lack of clarity around prognosis was reflected by Ray's wife, who said 'I don't know when he comes home this time what the story will be'. This indicated the liminality of their situation, not only for him, but for her which illustrated the point that meanings continually change thus making this form of liminality very nebulous and indeterminate.

All the participants in this research project dealt with their diagnoses in different ways. Of the two with renal disease, one was quite pragmatic about it saying 'You have got to accept it whether you want to or not, you have got no option' while the other, who had gone from doing everything for himself, to total dependence upon others was ready to die:

I don't want to sleep and I don't want to wake up. I want to feel like I am now just comfortable. I can understand people who want the magic bullet and things, I have had enough, do you know what I mean? I would like to just go to sleep.

Those with cancer ranged from positive attitudes and denial of negative outcomes:

you are saying to yourself the chemo is working, the chemo is working...it is a big thing the positive thoughts. It is so important the positive thinking and being relaxed about it and not stressed that it is not going to work

to a feeling of despondency and anger at feeling they had already been 'written off' by colleagues, that they were socially dead:

The whole situation is well if you have got cancer, get on with it, for god's sake, get sick, die and have a funeral and then we can get on with our lives.

For some participants their social networks were changed, leaving them in a

liminal state, particularly where they lived beyond the predicted time of death. People who were diagnosed with a life limiting illness often gravitated towards others with a similar condition ‘when I meet people that have also got cancer you feel a sort of camaraderie’. This was noted particularly with the participants in this present research who had cancer, reflecting the earlier study on how the nature of relationships changed (McKechnie, MacLeod, & Keeling, 2007). It was not so evident in participants with non-malignant conditions, although those with neuromuscular disease turned to organisations such as the Multiple Sclerosis and Motor Neurone Disease Associations for support.

In reflecting on the hospital as a liminal zone, it appeared both private and public. There were public areas set aside for waiting and private areas where the clinical encounter took place. The social relationships of the people involved were reflective of Turner’s (1969) ‘liminoid’ phenomena, where subjects became ‘threshold people’ who, prior to their diagnosis, had an ambiguous status. ‘Somebody was going to come back and tell us what was going to happen. [*Wife*] Yes but nobody did’.

Respondents described becoming passive, obeying instructions and accepting what the ‘experts’ said needed to be done to make them well again. ‘They were more concerned with the liver, that they had to do something about that and consulted with the oncologist and decided that a course of chemotherapy would be the best treatment initially’. The experts in this instance were the doctors, nurses and other health professionals who also inhabited this public/private space. It is no more or less liminal than any other area set aside for a particular purpose, in this case, a work space. It is a space that is familiar and mundane to the expert, but somewhat confusing for those on the outside looking in.

As respondents got on with living with an illness that would cause their death sooner or later they described distortions in the passage of time, for example test results and the period between clinic appointments seemed to take a long time. People with both malignant and non-malignant illness then emerged into the post liminal zone of living with increased dependence as they deteriorated.

One of the premises of this research was that medical professionals, especially doctors and nurses, assisted people with crossing the liminal space in which they found themselves. As the ‘experts’ they were the people who worked in that space every day and were familiar with it and the rituals of the medical encounters that took place there. Level Three represents the developing

relationships with health professionals and the ways in which the patient and family used them as guides to cross the liminal divide into a post liminal state where needs were met or not.

The concept of health professional as expert is something that is discussed with the idea of patient-centred care. This discourse revolves around the recognition that some people who are ill wish to take full responsibility for their care and make fully informed decisions. Others have no wish for that and will accept and do whatever the expert tells them is best in the circumstances.

In this way, health professionals can be seen as offering assistance in the crossing of the liminal zone by the patient, who has, by now, been labelled and identified from a biomedical perspective. Some health professionals recognised that the prognosis with non-malignant disease can be worse than with cancer – the question was whether being in that liminal state ever ends or ends when the adjustment is made:

No, I don't think it does because the prognosis is so bad and so fixed isn't it. You just can't change it and I think it is worse, much worse than cancer in a way because with cancer usually within a year or two, you have either recovered reasonably well or you have died and there is some closure one way or the other but this [*muscular dystrophy*] goes on [*Specialist*].

Additionally, there were the changes that occurred in the home as a result of the diagnosis. It ceased to be a private and safe space. Home became a public and liminal space with the coming and going of carers (both formal and informal), friends, family and equipment but without the institutional boundaries of a hospital department:

often with no warning and you have health professionals like district nurses and doctors and so on coming in so it ceases to be your haven.

Finally there is the post liminal phase of looking to the future:

I sort of want to know what it is going to be like for me at the end. I don't know when the end is and I don't know what it is going to be like so there is this massive kind of gap I suppose in terms of knowledge about what could happen to me.

Respondents described emerging changes in this post liminal phase as someone labelled with a diagnosis and beginning to live with the life limiting nature of their illness. Given the nature of the diagnoses of the participants for this research, with death being the most likely outcome, the way in which they lived depended on whether their needs were met or not and what their perceptions about the future were likely to be.

DISCUSSION

Table 1 depicts a series of liminalities in a much tidier schema than is often experienced by those living with a life threatening condition. As well as moving in a linear fashion across the phases of preliminal, liminal, and post liminal, participants also moved in a vertical fashion from one level to another. They also looped between or within some levels while seeking a diagnosis or repeating treatment. For example, in the preliminal stage, respondents described moving from the initial medical encounter with the general practitioner to the hospital experience where they developed relationships with the health professionals whom they encountered in that environment, going on to the health professionals who looked after them in their homes as their homes ceased to be private.

Once in the liminal, participants waited for test results and the diagnosis followed by decisions about treatment along with the experiences of being treated. They used health care professionals to guide them through this unfamiliar territory as time contracted and expanded as life as they knew it before, changed.

The liminal place of waiting for a diagnosis of a family member's symptoms has been likened to the theory of stress; 'a stressful event leads to appraisal of one's goals and values, one's beliefs about oneself and the world. We then attempt to cope with the event' (p313) (Breitbart, 2006). This could well be a classic example of Van Gennep's (1960) Rites of Passage where, through the ritual encounter with the medical system, the family's experience alters their outlook and they emerge from what Breitbart described as 'a period of intense and painful waiting' (p314) with a changed view of the world.

At the outset, it was hypothesised that individuals diagnosed with life-limiting illness inhabit a liminal zone while enduring the rites of passage of the medical encounter as they transition from person to patient. In reality, the liminal experiences of participants and their families was far more complex than anticipated. In a manner reminiscent of Jackson's (2005) shifty liminality, participants moved between categories and could inhabit several liminal

zones simultaneously. Participants described their life world in ways that were consonant with the 'rites of passage' of liminality. For example, they described liminal zones associated with hospitals and clinics. They also described the ways in which health professionals guided them through living (and dying) with a terminal diagnosis. It was also apparent that caregivers also entered liminal spaces while caring for their family member.

Narrative in medicine has been used to study not only biomedicine but also the illness experience in a thematic, theoretical and methodological way in social science. One purpose of narrative is to impose an order on time in the construction of people's lives (Watson, 2008). Tamboukou (2008) implied a liminal aspect to narrative where the self is always suspended between the past and the future. Stories can be told in a variety of genres and analysis needs to focus on the unfolding of the story as meaning rather than as a sequential structure with the self on the threshold.

The individual illness narratives in this present study revealed the mutable process of adapting to the illness experience. Participants described three phases of liminality through their illness narratives: their lives prior to diagnosis where they were normal citizens going about their business, the period of being diagnosed where their status was ambiguous as someone seeking a medical diagnosis, and the period following diagnosis where they had become a patient with a terminal diagnosis.

CONCLUSION

Liminality, in the classical sense, not only protects the community from the liminal but at the same time sequesters and protects the liminal from the community. The participants in the present study became marginalised as liminal characters inhabiting complex liminal zones outside of society, and for those who were not retired, outside usual economic activity. Their bodies and homes became contested space between the disease, the treatments and the intentions of the health professionals they came in contact with. Van Genep and Turner described liminality as a passage where individuals moved from one state to another, however in the context of living with terminal diagnoses, we suggest that individuals moved between a variety of liminal spaces and places but they never exit liminality. We suggest that an understanding of the liminalities of living with a life threatening condition can help health care professionals develop a more appropriate end of life model of care than the rehabilitative model predominantly used. Specifically, developing palliative care pathways that accommodate and facilitate the navigation of the liminalities commonly

encountered by patients, caregivers and families might improve the quality of life not only for the individual, but for all of those involved in caring for a person who is living with a life-threatening condition.

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NOTES

- 1 Miliary tuberculosis is a potentially lethal form of tuberculosis resulting from widespread lymphohaematogeneous dissemination of *Mycobacterium tuberculosis* bacilli. Clinical manifestations are non-specific and atypical presentation often delays the diagnosis. It is associated with a high mortality despite effective treatment (Sharma, Mohan, Sharma, & Mitra, 2005).

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