

"This is the peer reviewed version of the following article: Jordan, Joanne, Price, Jayne and Prior, Lindsay (2015) Disorder and disconnection : parent experiences of liminality when caring for their dying child. *Sociology of Health & Illness*, 37(6), pp. 839-855., which has been published in final form at <http://dx.doi.org/10.1111/1467-9566.12235>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving."

Disorder and disconnection: Parent experiences of liminality when caring for their dying child.

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Abstract: Parents caring for a child with a life threatening or life limiting illness experience a protracted and largely unknown journey, as they and their child oscillate somewhere between life and death. Using an interpretive qualitative approach, interviews were conducted with parents (n=25) of children who had died. Findings reveal parents' experiences to be characterized by personal disorder and transformation as well as social marginalization and disconnection. As such they confirm the validity of understanding these experiences as, fundamentally, one of liminality, in terms of both individual and collective response. In dissecting two inter-related dimensions of liminality, an underlying tension between how transition is subjectively experienced and how it is socially regulated is exposed. In particular, a structural failure to recognize the chronic nature of felt liminality can impede parents' effective transition.

Keywords: children, parents, life threatening / life limiting illness, transition, liminality

Introduction

Parents caring for children with a life threatening or life limiting illness experience a protracted and largely unknown journey. Practically, this journey is dictated by the ongoing nature of their child's condition, his or her consequent caring needs and the accommodation of such caring within the wider circumstances of their own and their family's everyday lives. Emotionally, it is characterized by uncertainty and anxiety concerning not only their child's prognosis, but also how to manage their new caring responsibilities alongside those persisting from before. Throughout this time, just as their child exists 'in-between' life and death, so parents are suspended in a world that is neither one thing (their lives prior to their child's illness), nor the other (their lives after their child's illness has concluded). Tragically, for some parents, including those who are the focus of this paper, that conclusion is reached with the death of their child.

A brief outline of transition theory

The social nature and consequences of such an intermediate state were first highlighted by the French anthropologist van Gennep (1909, 1960). Based on his analysis of traditional societies, van Gennep identified a pattern common to the movement of individuals between culturally significant

positions (such as child, adult, parent) and events (such as birth, marriage and death). His *rites of passage* framework outlines a tripartite structure to this movement (or passage), comprising separation (involving detachment from a previous status or identity), threshold or limen (in which an individual no longer exists in their old state but is not yet fully incorporated into their new one), and incorporation (in which an individual rejoins society having fully assumed a new social status or identity). In developing his conceptual framework, a primary concern is to demonstrate how rites of passage function at the collective level to ensure that transitions are regulated and the stability of society maintained (Draper 2003).

The British anthropologist Turner (1967, 1969, 1974) built on van Gennep's rites of passage theory in several important ways. Two are of particular relevance to the analysis developed in this paper. Firstly, he extends the notion of rites of passage to include transitions between 'any type of stable or recurrent condition that is culturally recognised' (1969: 94) occurring in the context of everyday life. Accordingly, a more inclusive range of social phenomena are opened up for analysis. Second, Turner shows how ritual actively produces and transforms society rather than merely confirming it. For him, the key site for such transformation is the liminal phase. Here, individuals occupy an ambiguous, 'betwixt and between' status; as such, they may be considered threatening to social stability. Marginalised from others, they temporarily occupy the same social, and sometimes, physical space. His concept of 'communitas' captures the process through which equivalence between members, including group companionship and solidarity, develops, irrespective of differences in their social status either before or after. Given his focus on the social dynamics of transition, Turner's approach allows for a much more open and variable process, including the possibility of change at both the individual and collective level (Hockey 2002).

Following van Gennep, the initial anthropological application of the rites of passage framework was essentially structural-functional. Analyses thus sought to demonstrate how rites functioned at the level of society to protect social stability over time. Clearly, such an application largely precluded consideration of the individual experience of transition. After Turner, accompanying an application of the framework to Western society, studies have increasingly focused on such individual experience, often in the context of health and illness (see, for example: Davis-Floyd (1992), Frogatt (1997), Harrison and Kahn (2004)). Many of these more recent analyses have, like Turner, prioritized the second or liminal stage of van Gennep's framework as a means of demonstrating the, often protracted, upheaval and adjustment required by individuals undergoing transition. Thus, Murphy *et al.* (1988) showed how adversity characterized the experience of liminality for those adjusting to

physical disability, Draper (2003) demonstrated how men's passage to fatherhood involved marginalisation and vulnerability, Navon and Morag (2004) discussed problematic self-identity amongst men receiving treatment for prostate cancer and Mendelson (2009) highlighted a lack of social and self-validation for women waiting for a diagnosis of lupus.

The analysis presented in this paper continues this focus on individual experience of transition, but does so in a way that demonstrates the relevance of the concept of liminality to understanding parents' experiences of caring for a dying child as these are socially informed. Furthermore, it highlights its implications for understanding parents' understandings and responses during their child's illness as well as after death. Our awareness of the relevance of the concept of liminality to parents' experiences of caring for their dying child developed out of our initial analysis of the data collected to meet the original objectives of the study. The study explored, using a qualitative research design, the experiences of parents caring for children with both malignant and non-malignant conditions throughout the entire trajectory of their child's illness and subsequent death. It was prompted by an observed lack of research within children's palliative care generally, and in relation to parents caring for children with life-limiting conditions specifically.

Methods

Data collection

The study adopted an interpretive qualitative approach. Face-to-face interviews were conducted with twenty five parents (16 mothers and 9 fathers) of children who had died (10 of a life limiting condition where death was inevitable and 6 of a life threatening condition where treatment was available and a cure was possible)(see Table 1).

Table 1: Characteristics of children (n=16)

Description	Category	Total
Sex	Boys Girls	8 8
<i>Age of child at death</i>	Under 1 year old 1- 10 10-18 18	5 1 9 1

<i>Diagnosis</i>	Life threatening Life limiting (1 haematological accessing cancer services)	6 10
<i>Location of death</i>	Hospital Hospice Home	3 3 10
<i>Time from death (at interview)</i>	6 -12 months 13 -18 months 19 - 24 months	1 7 8

Interviews took place between November 2007 and September 2008. A limited number of questions asked about issues of specific research interest; otherwise parents were encouraged to tell their own personal stories. All interviews were recorded (with consent) and transcribed verbatim.

Given the study's focus on the care of dying children it constituted sensitive research, with the potential to cause significant emotional distress to participating parents. There was also the potential for those involved in the conduct of the research, especially the interviewer but also the person employed to transcribe the interviews, to experience distress (Dickson-Swift et al. 2008). Consequently, a range of measures was put in place to both help prevent and thereafter alleviate any distress experienced amongst participants and researchers alike.

In relation to participants, the work of Dyregov (2004) was particularly useful. Based on personal research undertaken with bereaved parents, Dyregov (2004) developed a series of recommendations to guide similar types of studies. These recommendations informed the conduct of the research in important ways. All (potential) participants had lost a child no longer than 23 months before a first approach regarding the study was made (that is, no longer than 24 months between the death of the child and the date of the interview). This time frame had previously been found to be reliable in terms of recall, as well as being sensitive to the emotional requirements of parents (Hinds et al. 2007). In order to allow parents time to overcome their immediate grief, none were approached until at least 6 months after the death of their child (Hynson et al. 2006).

Parents were identified through two organisations operating in Northern Ireland: a regional children's hospital that provides care for children with blood disorders and malignancies; and, a

regional children's hospice, providing care for children with a wide range of life-limiting conditions. Parents were not approached in December and January to avoid burdening them at a potentially poignant and upsetting time of the year. Other dates were also avoided, for example, the anniversary of a child's death or child's birthday (Hynson *et al.* 2006). In addition, no parents were approached during Easter or in July and August for two reasons. Firstly, parents are often on holiday during this time; and, second, when arranging some of the early interviews it became apparent that parents preferred to meet when their other children were absent, for example, at school.

Recruitment took place in a staggered manner, helping to shorten the wait for parents between 'opting in' to the study and being contacted by the researcher. Initial contact was made by a designated nurse from each recruiting organisation, already known to parents. At this stage, all parents had an opportunity to decline any further communication about the study. An information leaflet sent to parents who agreed to follow-up contact was designed by the research team in collaboration with a bereaved parent, known socially to the researcher, who provided valuable advice on wording and details of presentation. These parents then chose to either complete an 'opt-in' form (indicating agreement to subsequent contact from the researcher), or an 'opt-out' form (indicating their wish not to be contacted again). This approach to recruitment was adopted on the basis of evidence from previous research which had demonstrated that a straightforward opt-out option proved empowering to parents (Hynson *et al.* 2006). Parents who 'opted-in' were contacted by phone by the researcher and a visit from her was arranged. The main aim of the visit was to explain the study in more detail and, most importantly, to give parents an opportunity to ask questions before, if appropriate, signing an informed consent form. If parents required more time to think about participation a second visit could have been arranged. However, all parents decided to participate during this first visit, requesting the interview to be carried out at that time.

Given the focus of the study, it was to be expected that the interview would provoke painful emotions for parents. Consideration was thus given to how best to support parents both during and post-interview. As a previous paediatric oncology nurse, the researcher had significant experience of providing support to distressed parents. Consequently, she was well placed to be able to monitor parents' emotional wellbeing throughout the interview and to respond appropriately. In addition, all interviews concluded with a discussion of potential follow-up support. Parents were given the contact details of the researcher and advised that they should not hesitate to contact her if they wished to discuss any aspect of the study, including their participation in it. In addition, expressly 'professional' support was, in the first instance, provided by the nurse who initially identified the

parent as suitable for inclusion in the study. As an alternative, and to provide increased choice, parents were given a list of relevant organisations (e.g. counselling), which were made aware of the study and gave a commitment to provide support if required. Additionally, a follow up phone call (2 weeks after the interview, with permission) was made by the researcher to all parents. Not only did this phone call provide an opportunity to underline to parents the value of their contribution, but also acted as a further means of ascertaining their emotional wellbeing beyond the immediate impact of the interview (Dickinson-Swift *et al.* 2008). Finally, at the time of interview and, again, during the follow-up telephone call, parents were asked if they wished to be sent a summary of the research findings. Those who expressed such a wish were forwarded a summary at study conclusion.

The potential for a detrimental impact on the emotional wellbeing of those most immediately involved in the conduct of the research was also taken into consideration. Notwithstanding the researcher's extensive professional experience working with distressed and bereaved parents, a researcher support strategy, which included professional counselling, debriefing in supervision sessions and the use of complementary therapies was devised (Dickson-Swift *et al.* 2008). Finally, given the content of the data, ongoing support from the researcher (including regular emails and phone calls), was provided to the professional typist employed to transcribe the interviews (Dickson-Swift *et al.* 2008).

Data analysis

Thematic content analysis (Green and Thorogood 2009) was employed. Initial re-reading of interview transcripts enabled detailed familiarization with their content. Subsequently, successive rounds of comparison, within and across interviews, led to the assigning of labels or codes, reflecting obvious meaning. These codes were subsequently reviewed, during which process they could be lost, amended or new ones created as we compared their content and meaning in relation to one another and to the dataset in its entirety. This tentative coding framework was refined through further conceptually-led thinking, which clustered codes together under umbrella themes, by identifying what was inherently common to or about them, that is, how they connected. This extended, inductive approach ensured that the final themes and their constituent properties were wholly derived from the content of parents' accounts and encompassed the entire dataset.

Rigour was achieved through: comprehensive treatment of all data, identification of deviant cases and memo writing (Silverman 2006; Glaser and Straus 1961). Additionally, a selection of interview transcripts was shared across all members of the research team in order to promote the full

possibilities for analytical insight (Barbour 2001; Graneheim and Lundman 2004). A data management package, NVIVO, facilitated the more practical and procedural aspects of developing the eventual analytical framework. The main body of findings derived from this analysis has been reported elsewhere (XXXX). Those presented in this paper focus, specifically, on parents' experiences of liminality.

Findings

In what follows, quotes from participants are coded according to interview number, parent (mum ('M') / dad ('D'), and nature of illness (life-limited ('LL') / life-threatening ('LT')).

Subjective uncertainty, disorder and transformation

All parents' accounts included an awareness of the genesis of change, traced from their initial pre-liminal lives as parents of a healthy child or expectant parents of a healthy baby. Depending on the circumstances of (learning about) their child's condition, transition could be understood as beginning very abruptly, as reflected in the following description.

Because she was the first as well and a perfect pregnancy...I just expected to go in give birth come home 2 days later with this wee bundle and from the minute she was born everything just went the other way. (12M-LL)

More frequently, parents talked about a gradual process, as they initially began to suspect, and subsequently had confirmed, that their child was ill.

I noticed whenever he got home from school he would be lying down in his room there tired in the evening just totally exhausted and I thought because he was... doing too much... and then...he took... the sore leg which he thought he'd got a knock. ... And we thought it was just a knock too. (11D-LT)

Yeah she...was doing her 11+ and would have vomited in the mornings I took her to the doctor and you know we thought it was probably to do with nerves. (10M-LT)

The confirmation, by way of a specific diagnosis or clinical recognition of a life-limiting condition, signaled the definitive entering of an 'unknown' world. As Jutel (2011) has argued, diagnosis is 'transformative', and the diagnosis or clinical confirmation acted as a clear demarcation between

their old life and that on which they were embarking. To a limited degree, once confirmation had been received, some of the experienced liminality (the sense of bewilderment and uncertainty), was alleviated. A diagnosis, in particular, provided definitive knowledge concerning what was wrong with their child, knowledge that could be used to plan for their child's, their own and wider family's future over the short to medium term. This was particularly the case for parents of children with a life threatening condition, in the early stages of which at least, hope of a cure was present.

I couldn't wait to get him into the [[hospital]] you know eh...this was the beginning of the the fixing...I nearly twisted [[Consultant]]'s arm to get him in as quickly as ((laughing)) he could.
(9M-LT)

Significantly, the parents of life-limited children who never received a diagnosis commented on how this had intensified their felt confusion and sense of powerlessness.

From this point, parents experienced an increasingly pronounced dislocation between two worlds; the new world which revolved around the (caring) requirements of their child and their old world that did not. Although they possessed only limited insight into the day-to-day direction their lives would assume, one feature was certain, namely, the significant threat of death hanging over their throughout the transition period. For those caring for a child with a life threatening illness, fluctuation was premised on the trajectory of their child's illness as she/he progressed through (successive rounds of) treatment-remission-treatment-imminent death. A concomitant sense of movement or progression is reflected in the following two quotes, as parents' sense of the threat of death becomes increasingly acute.

But if she had have got a headache I would have panicked...I was like oh God oh God...And she kept going "It's not one of them headaches" you know. (15M-LT)

And that was the worst moment of the whole 4 years...Because before...it was a real shock at the start but we...didn't know what we were dealing with then...But we knew at that point that since it had come back we just knew in our hearts. (10D-LT)

For parents caring for a life-limited child, although death was certain, the potency of its threat also waxed and waned as their child experienced more or less acute episodes. Consequently, these parents could never be sure if and when death would occur, even when it appeared imminent.

And we weren't overly... worried because we you know we just thought it was going to be another bad chest infection. (13M & D-LL)

Yes on the Monday night we thought this was it...the nurse actually that was on duty that night was sitting on her knees beside me crying and saying I think this is it I think we have to let her go but she picked up herself. (1M & D-LL)

...to me he was still going to get better you know to me it was just another chest infection...by that last year before he had died he had had up to 14 antibiotics for chest infections and he always got better and to me he was just going to get better you know... (5M-LL)

The waiting for death to occur (as outlined above) was a fundamental aspect of parents' experiences of 'living in limbo'. Although the length and precise nature of waiting differed depending on their child's condition, nonetheless, uncertainty concerning whether and/or when their child would die sat at the top of a hierarchy of uncertainties concerning almost every aspect of parents' experiences of caring.

A sense of fragile or tentative 'holding it all together' pervaded parents' accounts of ongoing circumstances after their child's illness had been confirmed. Fragility coalesced around the unpredictability of the illness (trajectory); circumstances changed, sometimes very quickly. Consequently, the ability to plan ahead and to relax into the comfort and 'security' of a day-to-day routine was, at best, limited. Depending on (changes in) their child's illness, previous arrangements would have to be abandoned and new ways of operating as a family put in place. It was the practical and emotional need for order in the midst of ongoing upheaval and uncertainty that fuelled parents' efforts, as these were bound up with their ill child's requirements. Disorder was practically demanding and, increasingly, emotionally so. In that the organization of family life was never a settled affair, against a backdrop of relentless worry about their child, the demands of trying to bring some degree of stability created additional stressors.

Oh family life was gone...the children were just farmed out here and there...we took it in turns coming home really to try and give some normality to our other children but ... family life with sick children isn't what normal people associate with family life you know. (4D-LL)

What was normal life for everybody else and what was normal for us as a family was what we done and yes the children couldn't go places we didn't go on holiday we couldn't go out as a family. (2M-LL)

...and that was the big thing why we wanted to get him home so ... that I could get back to some sort of normality and help get [[sibling]] back to some sort of normality... (6D-LL)

The disarray and uncertainty that characterized parents' lives encouraged felt vulnerability. Despite the fact that they continued to manage in the most difficult of circumstances, parents saw themselves as lacking control. Two quite different areas of their lives demonstrate this process. Firstly, the parenting of other children; not only did parents experience guilt over the relative lack of care and attention given to these children but they were dependent, at least to some extent, on others to provide this care, sometimes for weeks on end. Knowing that they had to rely on others for something so intimately 'parental', and sensing the potential emotional damage their children were experiencing, parents felt both remorseful and culpable.

...I mean [[sibling]] was thrown in in front of the TV and thrown biscuit after biscuit to keep him quiet. (4M-LL)

...and I can remember sorting feeling bad at times thinking you know that they were being neglected. (5M-LL)

She has taken second seat all her life and that's very hard that's...I feel quite guilty about that at times... (16M-LL)

Second, although parents made strenuous efforts to learn about their child's illness and many became extremely competent in the technicalities of care, they remained dependent, to a greater or lesser degree, on health professionals for ongoing knowledge and advice. Once again, they found themselves reliant on others. The following two quotes convey parents' awareness of being cast adrift from their normal sphere of competence, with an attendant need for direction provided by others.

[[Hospice nurse]] was very good at telling me what to tell [[sibling]] you know because that was a mine field you didn't know what to say to [[sibling]] I didn't have time to think so I just did exactly what [[hospice nurse]] said. (1M-LL)

...I have to say all of the consultants were very good and you know some parents may have found it very upsetting the way they maybe said things but we had said to them from the start be straight with us don't sugar coat it you know.(12M-LL)

Given the disarray pervading their lives in general, the need for such direction, in the form of timely and coherent information and advice from the professionals caring for their child, was compelling. Consequently, when withheld, their sense of injustice was acute, as the following quote demonstrates.

I was never told a lie out of the [[hospital]] but I have been told lies out of other services...it is one thing I would have to say just don't tell people lies about their children tell the truth. (3M-LT)

Collectively, the quotes given above confirm that adequate communication on the part of carers was not simply a matter of professional responsibility or even social etiquette. It was much more profound, being integral to parents' sense of themselves as effective in a world in which they may have retained some of their previous competencies but had lost vital others. Living in this state of limbo, in which their felt sense of ineffectuality rendered them exposed and vulnerable, left them profoundly dependent on how and what professionals communicated.

This process had a spatial dimension in that the location of their child's care impacted directly on parents' sense of themselves as properly involved and effective. In this regard, clear preferences emerged for some locations of care over others. Typically, parents felt least competent in a hospital environment. Not only were they totally unfamiliar with their surroundings, but the vast bulk of decision-making concerning, as well as hands-on, care of their child was the responsibility of others.

I called it civilised hell...the hospital...because you're trying to be polite and keep nice to everybody yet you're fighting this child's corner. ... then you see horrors in [[ward]]... there'd be the odd nurse on and I would not have went to bed so you had all that trauma you know... (4M-LL)

It was her first day on ... she came in and said "Amelia I hope you are a good girl today because I hadn't a clue how to change your trache" and ... my immediate thought was ... how am I going to go to the toilet how am I going to get a cup of coffee I cannot leave this room...she just completely knocked any confidence I had... (1M-LL)

As the quotes above demonstrate, parents' descriptions of hospital care frequently convey felt threat and relative powerlessness, with considerable effort expended to counter this through, for example, constant vigilance. This process was unfolding at precisely the same time as other core aspects of their lives were assuming a similarly threatening quality. In contrast, parents' descriptions of care of their child at home or in a hospice were much more likely to express a sense of sanctuary in their surroundings, confidence in their child's care and overall awareness of being in control. In large part the latter was premised on a realization of the opportunities afforded to maintain order in their lives more generally.

Everything just the care (pause) everything at the hospice was just...you had your own peace and quiet but you were able to go for maybe if you wanted to go into another room for a wee bit of a break and they were excellent they really were... (5M-LL)

...they were doing just everything they could to make everything as easy as possible...so that was just amazing...because we could just...concentrate our time on all three of them... (7M-LL)

Yeah it was great...we have the memories of her here all the time...happy memories...she died in her Daddy's arms and both families were here whereas in hospital you wouldn't have had that...everybody was sitting here...you had all the company here and you know you had great support. (14M-LT)

As can be seen in these descriptions, support to manage the multifaceted aspects of family life, in particular, to care for their other children *as well as* their dying child, was central to the achievement of perceived order and personal effectiveness. Crucially, there was no felt surrendering of authority. Rather, parents saw themselves as being effectively supported to be able to maintain control of ongoing circumstances; they were aware of others being involved but only in ways that they considered to be appropriate.

In the same way that liminality profoundly disrupted parents' sense of self (Beech 2011), as existing identity and roles (for example, as mother/father to other children or effective membership of the social collective) were challenged, so the possibilities for more positive personal development were opened up. In this regard, a number of participants talked about how they had taken up new activities or interests directly associated with the life and death of their child and/or how their experience had led to a fundamental shift in their personal value-system and approach to life.

D: Aye but and I mean he changed our lives round like I was saying...

M: But I do believe that he was a gift to our life and he shaped our lives you know and he made us who we are... (13M+D-LL)

...I think since Ruth died I'm a much more compassionate person I was a pretty compassionate person before...But I'm more compassionate now. (10D-LT)

The fact that the money is going to the hospice and going to a good cause definitely as well you know has...the fact that I can do something for them to give back something for what they have done you know for us and for Harry. (5M & D-LL)

Irrespective of the specific nature of change, all were acknowledged as tangible manifestations of a process through which (their own) life had been affirmed and/or enriched. Accordingly, participants acknowledged themselves as a 'better' person, someone whose ability to appreciate the value of, and to contribute to, life had been enhanced as a consequence of their child's life and subsequent death.

Social marginalization and disconnection

The experiences of transition, as just discussed, foreground the subjective, focusing on parents' responses to their child's illness and caring responsibilities at an individual level. Of course, these experiences were fundamentally social in that their content was closely associated with the response of others, both individually and institutionally. Although manifested in different ways, the core experiential outcome for parents was a sense of being socially disconnected, 'pushed to the margins' of social life. The following section discusses four of the most keenly expressed aspects of this felt marginalisation, namely: support from family and/or friends as gradually diminishing over time; avoidance by those encountered in the course of general social interaction; disruption to sense of self; and, contraction of the physical spaces occupied.

Many of the parents talked about a gradual reduction in contact with, and support provided by, family and friends over time. In essential respects their accounts portray this falling-off as an inevitable feature of the day-to-day circumstances of family life caring for a seriously ill child.

You know your own family would have fallen away...they've been good enough at times of crisis...but when it was the daily grind you know...it would have been the two of us really trying to do it we had a very good friend she would phone me daily to see what I needed done with the kids. (4M-LL)

M: You could rewrite your address book when you have been through something like this

D: Friends that I thought were close friends never once phoned me to ask...

M: Just disappeared. (1M & D-LL)

And [[mum's name]] comes from a big family five sisters...they weren't terrific I have to say they had their own lives... (10D-LT)

As the above quotes demonstrate, it is not that parents were abandoned by family and friends. On the contrary, many received unfailing support throughout the extended period of their child's illness. However, the general trend described was for a majority of people to progressively withdraw, with a minority, sometimes a single individual, being marked out as exemplary in their support. Accordingly, their accounts paint a picture of themselves as an increasingly discrete, relatively isolated entity.

This sense of progressive marginalization was further engendered by the reaction of more socially distant others, with whom parents interacted on a more ad hoc or irregular basis. In this regard, parents' accounts reveal overt avoidance, as when, for example, people evaded any mention of their ill child during conversations or shunned interaction entirely.

...if you met people and they never mentioned it when she was alive ... that freaked me out ... they asked about [[eldest child]] and how [[eldest child]] was ... and never once mentioned Amelia... I stood and kept waiting for them to ask about Amelia... (1M&D-LL)

...everybody avoids you and they don't know what to say and...you know stuff like that. (6M-LL)

As the above descriptions convey, parents were acutely aware of others imposing conditions on the content and/or amount of inter-personal contact. Even when this contact was 'permitted', it frequently excluded the very issue that preoccupied their thoughts and dominated their day-to-day lives, so omission was all the more keenly felt.

Felt exclusion intensified as parents struggled to locate *themselves* within a previously taken-for-granted social order. This order became increasingly unfamiliar, even untenable, as the circumstances of their new lives took hold.

...I've...gone into a shopping centre and looked around and flip me the world's still going on...It's a real strange feeling everybody's going around they've no idea what situation you're in and they're just doing their everyday thing which you used to do... (12D-LL)

...and when I got to the garage...I'd only...brought a pound or something to buy the paper and I thought we need petrol I'll get petrol and then I went oh I've only got a pound you know I was all fingers and thumbs...you know (sighs)...because I didn't...for months I'd just been in the house the whole time. (10M-LT)

The quotes above evidence a subjective incongruity with the previously familiar and routine. This process had a clearly defined spatial dimension in that caring was largely undertaken in either a hospital or hospice environment, and to a lesser degree, at home. As such, parents experienced a progressive contraction of the physical spaces occupied, retreating from previously customary arenas of interaction. The two most common environments now occupied were largely unknown and occupancy of them was not of their asking, so that resentment and/or aversion featured in some accounts, particularly of early encounters.

...I found at the start being on the ward I hated it...I don't want to be here we shouldn't be here and all that craic and then after treatment too you really preferred to be there because everybody else was in the same position as you were. (11M-LT)

I remember initially...when we arrived at the hospice I felt really out of my comfort zone... and then...even by Thursday that was our comfort zone. (7M-LL)

As the first of the quotes above makes clear, a crucial component of the process of being reconciled to new locations of care was the companionship and support provided through interaction with others. A core inter-personal dynamic fuelled the value derived from such interaction, namely, a sense of shared adversity and concomitant bond. Parents recognized other parents as 'the same' as themselves, going through an experience so exceptional that its sharing was sufficient in itself to promote affective connection. Social intimacy was mirrored spatially in that, collectively, parents existed into relatively confined physical spaces.

Everybody in the hospice was in the same boat do you know what I mean? (1M-LL)

There was 3 of us 3 mothers with...3 girls...we were all in together we were like the 3 Amigos just the 3 of us all the time... if one of us was having a bad day...we would have cried you know...they knew what I was crying for because they went through it too you know... (15M-LT)

...even when you met in the little kitchenette and kind of you know... sympathetic or you know cheering each other up or just talking things over and you felt you weren't alone. (9M-LT)

The excerpts above convey the value of parent-to-parent connection, as this helped to combat felt isolation and vulnerability. Brought together in an environment that reinforced their (sense of) uniqueness and separation from others, parents gained significant validation through interaction with those similarly affected. Although the vast majority of parents accepted, even actively sought, such relational support, for one couple it proved too emotionally difficult.

At the time...I felt we were so much in pain that we never thought other people were in the same pain... And that's untrue but that's what we felt...And also I don't think you want to open up that pain... (13M & D-LL)

Although this couple chose to avoid interaction and, as such, appear at odds with other parents, in essential respects their avoidance is understandable for the same reasons previously highlighted. That is, given profound subjective disruption, they felt themselves so completely transformed and 'unique' that they struggled to connect with other people.

Relationships formed with carers, particularly nurses, could assume tremendous importance. Parents' accounts emphasise strong emotional attachment, describing carers as friends, sometimes even as family members. As such, (often long-term) social proximity between formal carers and parents was understood as the basis of a relationship in which 'normal' lay-professional distinctions became irrelevant.

The nurses were brilliant I fell in love with them all I mean I still keep in touch with them.
(12M-LL)

...you do become friends with them because they're in your home and they know...your low points so from that point of view I kind of felt that hard...but then maybe that's what's needed for people to move on... (4M-LL)

The number of consultants and doctors who'd been involved in Cormac's care...who knew us...and the response that we got from them...was pathetic...we feel it's a shame and it's a slur on the medical profession. (4D-LL)

...when we eventually got home it was tears all round because they were just like a family the nurses...they just became like our family... (15M-LT)

As the above quotes testify, the central involvement of formal carers in their child's care meant that they became part of the fabric of parents' day-to-day lives, sometimes for extended periods of time. For this reason, they became integrally bound up in the concentrated intensity of their reduced social world. It was this shared 'intimacy' that facilitates emotional connection. The fact that parents pursued these relationships after the death of their child attests to their felt importance, which is nowhere made clearer than when they were in some way denigrated by carers. Thus, some of the descriptions reveal profound hurt and bewilderment concerning what they saw as rejection of both themselves as well as their (now dead) child. For these parents, a relationship that had begun in the specific context of their child's care endured, despite the fact that this context no longer existed.

Discussion

Caring for a sick and dying child: a subjectively liminal experience

The findings of our study confirm the value of understanding parents' experiences of caring for their sick and dying child as one of liminality, in terms of both individual and collective response. At the

level of the individual, their accounts make explicit a sense of movement away from a state that was known and understood to one of flux, characterized by felt disorder, uncertainty and vulnerability. Suspended is this way, participants knew themselves as altered in terms of their former, and unfinished in terms of their future, selves. As they struggled to understand and control what was happening, they could neither draw on the certainties of the past nor the prospects for the future. A sense of subjective disorientation and diminishment pervades their accounts, what Bury (1982) has talked of as 'biographical disruption'. However, the fundamentally contradictory conditions of liminality meant that such disorientation and diminishment could co-exist with more positive changes to self-hood. Thus, although relatively few parents talked in these terms, it is clear that the very ambiguity that challenged existing ways of 'being and doing' (Simpson *et al.* 2009) could also enable an affirmative re-ordering of personal values, opportunities and interests. Released from the normative pressures of pre-existing identities and roles, participants were permitted the time and space for self-reflection and adjustment. It is thus important to acknowledge that the contradictory potential of liminality can enable both positive and negative changes in subjectivity.

The prevalence of such experiences of liminality at an individual level is demonstrated by the findings of a wide range of studies that have examined transition through largely unknown, often chaotic and frequently adverse periods of change. Of particular note is the fact that, irrespective of the enormous variation in context, this work evidences a significant correspondence in subjective experience. Accordingly, just as the parents in our study spoke of their felt lack of authority and effectiveness, Draper (2003) found a similar sense of redundancy and/or relative ineffectiveness amongst men undergoing the transition to fatherhood, as did Mendelson (2009) amongst women waiting for a diagnosis of lupus, and Barton (2007) amongst nurses undertaking nurse practitioner training. Again, just as parents talked about the ambiguity and uncertainty characterizing their lives, the same experiences were highlighted by Allan (2007) amongst women undergoing treatment for infertility, Navon and Morag (2004) amongst men undergoing treatment for advanced prostate cancer, and Harrow *et al.* (2008) amongst the male partners of women being treated for breast cancer. Finally, although much less prevalent in the literature, there is some evidence confirming the affirmative potential of liminality (see, for example, Simpson *et al.* 2009).

Parents' felt lack of effectiveness was an inevitable consequence of finding themselves in an essentially unknown and uncertain world. The degree to which this ineffectiveness was experienced was closely linked to the nature of interaction with professional carers. Divorced from what they knew and understood, parents stood comparatively unknowing and unprepared. Such relative

helplessness immediately increased their dependence on others for guidance and instruction. From this perspective, it is not simply a case of parents requiring professional support for purely functional or pragmatic caring-related reasons. Rather, its provision is crucial to their overall sense of control and effectiveness, to their felt confidence and ability to work their way through the profound disorder and uncertainty permeating their lives.

It could perhaps be argued that the experience of any transition cannot help but be one of challenge, ambiguity and uncertainty. Individuals regularly face new circumstances that demand personal re-orientation and adaptation. However, the circumstances of the transition experienced by the parents in our study represent a much more fundamental subjective process than that which occurs when adjusting to routine or relatively uncomplicated change. Becoming the parent of a sick and dying child rendered them largely bereft of the taken-for-granted security of before and offered little to compensate for this loss. They were profoundly altered, even reduced, in terms of their (former) social roles and identities, confused within an 'in-between' state of what they were before and will be in the future. As Turner (1967) first demonstrated, it is these experiential features and processes that distinguish the transition as liminal (see also, Jackson 2005). Significantly, as our study has highlighted, this phenomenon holds for those experiencing transition as carers of others, in that they actively participate in their loved one's illness experience on a practical and emotional level (Beaver and Witham 2006).

Caring for a sick and dying child: a socially liminal experience

Parents' experiences of liminality can also be seen to have been constituted at the level of the social, discernible within both micro as well as institutional contexts of interaction. Collectively, this social ordering of transition worked to increasingly deprive parents of previously taken-for-granted social spaces and relations, and so to foster (felt) disconnection. In that similar experiences have been identified in other research documenting transition (see, for example: Little *et al.* 1998, Murphy *et al.* 1988, Navon and Morag 2004), the value of Turner's (1969, 1974) early theorizing concerning the social character of liminality is made clear. Accordingly, the marginalization experienced by parents in our study can be seen as premised on their child's transgression of the boundaries delineating 'alive' and 'dead', and the implications of this transgression for their own identities as they exist as neither one thing (parent of a healthy child) nor another (bereaved parent). This socially ambivalent state was fundamentally threatening for others as it meant that crucial social and cultural prompts to guide interaction were unavailable. The avoidance experienced by parents thus represents an effective means by which these others dealt with social relations that had become confused.

The institutional arrangements for their child's care represent a specific manifestation of the social ordering of transition. As caring took place in specific environments, either in hospital, hospice or home, so parents and their child became progressively restricted to certain social spaces. Such spatial patterning to their child's care thus contributed to parents' marginalization as they were effectively consigned to a sacred world (van Gennep, 1909), where care of (impending) death was managed. As Turner (1967, 1969, 1974) initially posited and subsequent research has confirmed (see, for example: Beech 2011, Jackson 2005, Maruna 2011), movement into institutionally or otherwise specialized locations is a frequent correlate of liminality. Collectively, such activity enables the social regulation of individuals who threaten socio-culturally established ways of being and doing as they are distanced from mainstream arenas of interaction.

Within the institutionalized spaces of care parents interacted with others in whom they recognized an essential similarity. Against a backdrop of shared adversity and (social) isolation, significant benefit was gained from relationships premised on solidarity. The disorder and disconnection otherwise characterizing parent's lives was thus offset by the informal support and personal validation provided by those 'in the same boat' as themselves. The centrality of such 'communitas' (Turner 1967, 1969) to the experience of liminality has been identified in widely varying contexts, from the use of hospitality spaces by lesbian, gay, bisexual and transgender (LGBT) groups (Lugosi 2007), to the use of online support groups by women suffering from lupus (Mendelson 2009). Physicality was highly involved as parents came together as equals in liminal space and time. Crucially, both the hospital and hospice created a liminoid space where communitas could exist (Lugosi 2007).

Strengths and limitations of the study

The study benefitted from the involvement of parents caring for children with life threatening as well as life limiting conditions (Cooley *et al.* 2000) and, unusually, included mothers and fathers (Woodgate and Degner 2003). Irrespective of differences in parental gender and age, or their child's age at or condition of death, all parents' accounts referenced the same core features and processes of transition. As such, the validity of the experiences outlined in this paper, including as they can be understood using the concept of liminality, is upheld. The potential for self-selection bias, based on specific experiences or understandings of caring experiences, needs to be borne in mind (Contro *et al.* 2002). Although only 'White' Caucasian parents participated, based on the last UK Census data, they appear representative of the regional population (NISRA 2011). Furthermore, the sample consisted primarily of parents employed in middle class occupations. As all parents displayed a

similar engagement in a process of transition characterised by liminality, the potential for socio-economic background to mediate these transitional experiences exists (McDonnell *et al.* 2009). Parents had lost their child between 10 and 24 months prior to participation. As they reported retrospectively on their experiences, it is possible that recall bias may have influenced reporting. Notwithstanding, findings from this study as well as other work (for example, Ware and Raval 2007), highlight the clarity with which parents remember events about their child's illness, regardless of timeframe.

Conclusion: a tension between the individual and social dimensions of liminality

A specific aim of this paper has been to confirm the relevance of the concept of liminality for understanding the experiences of parents caring for a dying child at both an individual and collective level. To that end, although the subjective and social dimensions were fundamentally interwoven in terms of practical experience, we used a heuristic division in order to provide conceptual clarity around their operation. From this position, our analysis has delivered empirical confirmation of the veracity of Turner's (1969:93) claims concerning the confirmative *and* constitutive nature of ritual. As the parents in this study underwent their (ritualised) transition from parent of a healthy child towards that of bereaved parent, their experiences confirmed certain aspects of socio-cultural organization and process (namely, normative values and the management of their threat). However, they also demonstrated the potential to *create* these values. One of the most potent examples of this creative function of liminality concerns the self-realization and actualization it enabled. Thus, some of the parents talked about new meaning and purpose in their lives, sometimes practically expressed through involvement in new activities or interests. Again, some parents talked about the new relationships forged and the fulfillment they provided, including those with the professionals involved in their child's care.

Of particular significance is the fact that the latter maintained their felt importance after parents had, from a purely structural understanding of transition, emerged from the period of liminality (having been subject to ritualized activity including, for example, their child's funeral, return to work), and incorporated back into routine social life in their new identity as bereaved parent. How can this apparent anomaly be explained? The content of parents' accounts suggests the value of moving beyond a purely structural understanding to include subjective experience. Accordingly, for parents, moving within a restricted social world, professional carers were part of the resulting *communitas*. As Turner (1979:150) states 'Communitas...does not merge identities: it liberates them from conformity to general norms...' so that distinctions normally used to situate individuals are

suppressed. Unconfined by convention or custom, parents' socialization with carers was based on a perceived uniformity or equality of status as they came to interact with increasing openness and familiarity. In the process, distinctions, in this case between professional/expert carer and parent, became effectively irrelevant.

The issue of parents' felt need for ongoing contact with the professionals involved in their child's care and the typical ending of such contact soon after their child's death highlights a fundamental disjuncture between the subjective experience of liminality and that upheld at a structural level (see Hockey 2002). Whereas other work has identified transition as a 'rites of passage' process through which individuals move in a relatively predictable and uniform manner (see, for example: Barton 2007, Draper 2003, Martin-McDonald and Biernoff 2002), our findings highlight the sustained or chronic nature of parents' liminality. This is why they continued to view health care professionals involved in their child's care as relevant to their lives and to pursue a relationship with them. It is also why they experienced such sorrow and resentment when the relationships were withdrawn. This felt need challenges health care providers to rethink the nature of the support required, and to respond in ways that acknowledge parents ongoing sense of living 'in limbo', not only as they care for their dying child, but in the months and years thereafter.

Acknowledgements

The authors would like to thank the parents who participated. The authors would like to record their sincere thanks to Dr. Jackie Parkes for the immense contribution she made to all aspects of the research reported in this paper.

Conflict of interest: None declared.

Funding: Funded internally by the Queen's University, Belfast Sandra Ryan Fellowship Scheme.

Ethical approval: The study was approved by OREC Northern Ireland (07/NIR02/72).

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References

- Allan, H. (2007) Experiences of infertility: liminality and the role of the fertility clinic, *Nursing Inquiry*, 14, 2, 132-139.
- Barbour, R.S. (2001) Checklists for improving rigor in qualitative research: A case of the tail wagging the dog?, *British Medical Journal*, 322, 1115-1117.
- Barton, T.D. (2007) Student nurse practitioners – A rite of passage? The universality of Van Gennep's model of social transition, *Nurse Education in Practice*, 7, 338-347.
- Beaver, K. And Witham, G. (2006) Information needs of the informal carers of women treated for breast cancer, *European Journal of Oncology Nursing*, 11, 16–25.
- Beech, N. (2011) Liminality and the practices of identity construction, *Human Relations*, 64, 2, 285-302.
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, 2, 167–182.
- Contro, N., Larson, J., Schofield, S., Sourkes, B. and Cohen, H. (2004) Hospital staff and family perspectives regarding quality of pediatric palliative care, *Pediatrics*, 114, 5, 1248-1252.
- Cooley, C., Adeodu, S., Aldred, H., Beesley, S., Leung, A. and Thacker, L. (2000) Paediatric palliative care: a lack of research-based evidence, *International Journal of Palliative Nursing*, 6, 7, 346-351.
- Davis-Floyd, R. (1992) Birth as an American rite of passage. Berkeley, CA: University of California Press.
- Draper, J. (2003) Men's passage to fatherhood: an analysis of the contemporary relevance of transition theory, *Nursing Inquiry*, 10, 1, 66-78.
- Froggatt, K. (1997) Rites of passage and the hospice culture, *Mortality*, 2, 2, 123-137.
- Glaser, B.G. and Strauss, A.L. (1967) *The Discovery of Grounded Theory. Strategies for qualitative research*. New Brunswick: Aldine Transaction.

Graneheim, U.H. and Lundman, B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness, *Nurse Education Today*, 2(4), 105-112.

Green, J. and Thorogood, N. (2009) Qualitative methods for health research. London: Sage.

Harrow, A., Wells, M., Barbour, R. and Cable, S. (2008) Ambiguity and uncertainty: The ongoing concerns of male partners of women treated for breast cancer, *European Journal of Oncology Nursing*, 12, 349-356.

Harrison, T.C. and Kahn, D.L. (2004) Disability Rites: The Cultural Shift Following Impairment, *Family and Community Health*, 27, 1, 86-93.

Hockey, J. (2002) The importance of being intuitive: Arnold Van Gennep's The Rites of Passage, *Mortality*, 7, 2, 210-217.

Jackson, J. (2005) Stigma, liminality and chronic pain, *American Ethnologist*, 32, 3, 332-353.

Jutel ,A.G. (2011) Putting a name to it. Diagnosis in contemporary society. Baltimore: John Hopkins University Press.

Libera, A., Darmochwal-Kolarz, D. and Oleszczuk, J. (2007) Sense of coherence (SOC) and styles of coping with stress in women after premature delivery, *Medical Science Monitoring*, 13, 3, CR125-130.

Little, M., Jordens, C.F.C., Paul, K., Montgomery, K. and Philipson B. (1998) Liminality: a major category of the experience of cancer illness, *Social Science and Medicine*, 47, 10, 1485-1494.

Lugosi, P. (2007) Queer consumption and commercial hospitality: communitas, myths and the production of liminoid space, *International Journal of Sociology and Social Policy*, 27, 3 /4, 163-174.

Martin-McDonald, K. and Biernoff, D. (2002) Initiation into a dialysis dependent life: an examination of rites of passage, *Nephrology Nursing Journal*, 29, 4, 347–352.

Maruna ,S. (2011) Reentry as a rite of passage, *Punishment and Society*, 13, 1, 3-28.

Mendelson, C. (2006) Managing a medically and socially complex life: Women living with lupus, *Qualitative Health Research*, 16, 982-997.

Mendelson, C. (2009) Diagnosis: A Liminal State for Women Living With Lupus, *Health Care for Women International*, 30, 390-407.

McDonnell, O., Lohan, M., Hyde, A. and Porter, S. (2009) Social Theory, Health and Healthcare. Palgrave Macmillan: London.

Murphy, R.F., Scheer, J., Murphy Y. and Mack R. (1988) Physical disability and social liminality: A study in the rituals of adversity, *Social Science and Medicine*, 23, 235-242.

Navon, L. and Morag, A. (2004) Liminality as biographical disruption: Unclassifiability following hormonal therapy for advanced prostate cancer, *Social Science and Medicine*, 58, 2337-2347.

Northern Ireland Statistics and Research Agency (NISRA) (2011) Census 2011, Detailed Characteristics for Northern Ireland on Health, Religion and National Identity.

Available from http://www.nisra.gov.uk/Census/detailedcharacteristics_stats_bulletin_2011.pdf

Silverman, D. (2011) Interpreting Qualitative Data. London: Sage.

Simpson, R., Sturges, J. and Weight, P. (2009) Transient, unsettling and creative space: Experiences of liminality through the accounts of Chinese students on a UK-based MBA, *Management Learning*, 41, 1, 53-70.

Taylor, L. (2008) A Rites of Passage analysis of the families' experience of premature birth, *Journal of Neonatal Nursing*, 14, 56-60.

Turner, V. W. (1967) *The Forest of Symbols*. Ithaca, NY: Cornell University Press.

Turner, V. W. (1969) *The Ritual Process. Structure and Anti-Structure*. New York: Aldine Transaction.

Turner, V. W. (1974) *Dramas, fields and metaphors: Symbolic action in human society*. Ithaca, NY: Cornell University Press.

Turner, V. W. (1982) *From ritual to theatre: The human seriousness of play*. New York: Performing Arts Journal Publications.

van Gennep, A. (1909/1960) *The rites of passage*. London: Routledge & Kegan Paul.

Ware, J. and Raval, H. (2007) A Qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and retrospect, *Clinical child Psychology and Psychiatry*, 12, 4, 349-564.