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Fathers' experiences of their child's limiting condition: An attachment narrative perspective

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and

Abstract

When a child has a life-limiting illness, parental involvement is amplified, having to respond to the increased needs of the child. Both parents are affected by the illness, yet research has largely under-represented fathers' experiences of their child's illness. Seven fathers were interviewed about their experiences with their child's life-limiting illness. In addition, fathers' attachment strategies were assessed using the Adult Attachment Interview. Narrative analysis was implemented to explore the interviews, and indicators of attachment markers employed in the Adult Attachment Interview were also identified. The dominant themes were found to be 'experience of the diagnosis', 'living with the illness', 'struggling with emotions' and 'relationship with staff'. Within each theme, there were differences which related to the father's attachment strategies. This was particularly evident in parts of their narratives recounting critical moments of threat and anxiety in the course of discovering and adjusting to their child's illness. Importantly, the findings also suggested that the experience for the fathers stressed, and in some cases disrupted, their attachment coping strategies. All fathers told stories of trying to get it right for their children and family. Their experiences of, and adjustment to, the illness were related to their attachment strategies. The clinical implications for health professionals are discussed.

Keywords

Attachment, AAI, DMM, fathers, childhood life-limiting illness

Introduction

Life-limiting conditions for children are illnesses which are so severe that there is no likelihood of there being a cure and certainty that the child will eventually die from the condition. In 2010, the prevalence of such conditions was approximately 32 per 10,000 children aged 0–19 years. This figure had risen by 7% in 10 years, with congenital anomalies being the most prevalent diagnostic category in the year 2010 (Fraser et al., 2012). **AQ3** Each condition will progress differently; for some children, care is palliative from birth or diagnosis, while other children might go through invasive treatments and medical procedures aimed at improving the quality of, or prolonging, their life (Widdas, McNamara, & Edwards, 2013). Research has shown that children with a life-limiting illness and their parents are more likely to experience mental health difficulties than community samples (Quittner et al., 2014).

In 37.6% of families of children diagnosed with a life-threatening condition, at least one parent will meet the criteria for post-traumatic stress disorder since the diagnosis (Kazak et al., 2004). Parental involvement in their child's care is amplified during such times since the child will be dependent on the parent for safety and security as the illness threatens their life. Understanding the experience of parents is incredibly important given the gravity of a life-limiting illness and the reliance of the child on their parents. While this importance is acknowledged, in the majority of the research in this area, fathers are under-represented.

It was suggested by May (1996) that fathers were the forgotten parent in relation to childhood illnesses. Ten years later, research supported this claim as fathers remained significantly under-represented within the research literature (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). While this bias has been recognised, research on parental experiences of their child's illness continues to over-represent mothers, and research on fathers is relatively scarce (Goldstein, Akré, Bélanger, & Suris, 2013). Fathers often take up primary caregiver roles or active roles supporting their family with their child's life-limiting condition (Wolff, Pak, Meeske, Worden, & Katz, 2010, 2011), and research has indicated that fathers' adjustment to the illness might influence overall family adjustment (Swallow, Macfadyen, Santacroce, & Lambert, 2012).

This research on fathers' experiences of their child's illness has utilised a mixture of methodological paradigms. To date, two studies have used a narrative approach to understanding fathers' experiences (Wolff et al., 2010, 2011). The narrative approach is premised on the assumption that people tell stories to structure and

communicate their experiences. These stories are created through connecting a series of events over time which serves as a way for us to give meaning to and make sense of our lives (Stephens, 2011). The stories that we tell and hear about ourselves convey information about our experiences, identity, feelings and intentions and are considered internal constructions that shape our world (Smith & Sparkes, 2006). The narrative approach is well suited to exploring fathers' experiences of caring for a child with a life-limiting illness as threats such as illness can disrupt one's sense of self which can force individuals to change their personal narratives to accommodate their circumstances (Stephens, 2011). Therefore, the stories recounted about themselves will provide insight into their experiences and processes that are shaping their world.

A life-limiting illness poses an enormous emotional and physical threat for a parent because of the anticipated early loss of their child. For a parent, this can be the greatest tragedy of their lives and places them in a highly distressing position, combined with a sense of powerlessness in feeling unable to save their child. Alongside this, they also have to face the vicarious distress of witnessing their child being subjected to a variety of painful and upsetting invasive medical procedures as part of their care (Kazak, 2006). This situation can be seen as posing a high level of emotional danger for the parent who fundamentally feels the urge to help and protect their child. **AQ41**

How we cope with threat and danger is the central concern of attachment theory which posits that we have evolved biologically mediated mechanisms for responding to threat and seeking comfort (Bowlby, 1969). Attachment theory presumes infants are born with an instinct to protect themselves and seek comfort from a caregiver when in danger or threatened (Bowlby, 1969). Bowlby proposed that, through an attachment bond between child and caregiver, internal working models are developed about ourselves, others and the world, the quality of which is informed by the type of care that we receive (Ainsworth, Blehar, Waters, & Wall, 1978). Over time, these mental representations organise how dangerous and threatening events are processed and how expectations of comfort and care from others are optimally managed. These representations are expressed as attachment strategies which were initially developed for children but were adapted by George, Kaplan, and Main (1985) for adults. The child strategies focused on children's behaviours, for example, seeking or avoiding contact and comfort from their parents. The adult patterns relate to their narratives and cognitions regarding attachment: Type A (Dismissing): dismissing the importance and relevance of emotions and attachments and showing a preference for cognition; Type C (Pre-occupied): an ongoing pre-occupying concern including both fear and anger regarding attachment and prioritising emotional expression over cognition; Type B (Autonomous): an orientation involving both seeking and offering attachment connections and using a balance of both emotion and cognition in an integrated way. Importantly, these strategies may also be mixed, for example, with different strategies towards different attachment figures. Under severe conditions of distress, which push the preferred strategy to its limits, there can be a switch or 'intrusion' to the opposite strategy. Where this switching is triggered by powerful or traumatic events, the strategies can become extreme as the person tries to maintain their preferred pattern or switch more unpredictably between patterns (Crittenden & Landini, 2008, 2011). Attachment strategies become more complex with maturation, and the way we organise ourselves around danger develops throughout our lives. These strategies can be used at different times depending on the context and the dangers that are present. They are therefore dynamic and can be shaped by our experiences (Crittenden & Landini, 2011).

Attachment strategies acquired in childhood continue to influence our reactions to danger and distress and were seen by George et al. (1985) to represent a continuity from childhood to adulthood. Over time, our internal working models are held not just as embodied representations which feature in early childhood but as narratives about ourselves and others. George et al. (1985) developed the Adult Attachment Interview (AAI): a semi-structured interview specifically designed to explore the nature of our attachment narratives. In this interview, participants respond to questions about their childhood experiences of distress, comfort, loss, abandonment and also their reflections of how these experiences have shaped them into the adults they have become. The central concept of this interview is that what is important is 'how' people talk about these experiences rather than the specific content of what happened – in particular, what defensive processes are revealed as people describe their childhoods, for example, whether they show angry pre-occupation and resentment about their parents, an over-positive idealising account or a balance of positive and negative emotions. It is argued that these defensive processes revealed as they talk about the past also embody their current attachment strategies and shape their reactions to danger and relationships with significant others in their lives.

It follows that our attachment strategies in adulthood will influence how we process and react to threats to ourselves and our children (Crittenden & Landini, 2011). In addition to this, our ability to reflect on our experiences and structure our narratives meaningfully will be influenced by our attachment strategies and defensive attachment processes, which also shape the narrative content and level of emotionality expressed. Crittenden and Landini (2011) have developed the AAI using their Dynamic Maturation Model (DMM) of attachment which places a greater emphasis on the ability for attachment strategies to change and for complex attachment patterns to emerge in response to extreme trauma. Their version of the AAI (Modified AAI) employs a more elaborate set of questions regarding trauma and loss and replaces the attachment classification 'disorganised' in favour of viewing these as mixed/complex attachment strategies.

This emphasis on the complex states involved with high levels of threat and distress is important, and the AAI has been considered the gold standard for assessing attachment in relation to such situations. However, the AAI focuses on retrospective questions regarding distress and danger in relation to significant attachment figures and places relatively little emphasis on later attachment strategies that come into play when adults become caregivers for their own children. It therefore does not explore how parents may react to significant attachment threats, such as their child being diagnosed with a life-threatening illness. It is arguable that exploration of such specific circumstances may reveal even more fully how complex defensive processes are activated. In a recent study, mothers' experiences of their child's cancer journey were explored through analysis of a narrative interview and compared with attachment strategies identified through administering a full AAI. It was found that these mothers' stories spontaneously revealed their use of attachment strategies which were consistent with those emerging from their AAIs. Importantly, it is also indicated how these strategies were being strained to their limits, or even to breaking point, by the extreme distress of attempting to deal with their child's serious illness (Bishop, Stedmon, & Dallos, 2014). This finding supported Crittenden and Landini's (2011) model that extreme distress and danger can cause a temporary rupture to our preferred attachment strategies, providing a more accurate conceptualisation than to consider attachment strategies as 'disorganised' or 'dysfunctional'.

To date, no research has yet considered how fathers' experiences might similarly be informed by their attachment strategies, predictably activated by the danger of their child's illness. The aims of this study are twofold: to explore the experiences of the fathers who have a child with a life-limiting illness and to explore how fathers' attachment strategies influence their experiences of illness related to threat within their narratives.

Method

Design

A narrative approach was adopted for data collection and exploration of the experiences of, and complex attachment strategies utilised by, fathers throughout the course of their child's illness. The study employed an in-depth qualitative analysis of narrative interviews of seven fathers' experiences of their child's illness. An exploration of fathers' narratives through an attachment lens was undertaken as one simultaneous aspect of the narrative analysis, attending to both the content and process of their narratives, and the identification of attachment strategies and defensive processes shaping their accounts. An assessment of their attachment strategies was also employed using the AAI to provide an independent measure. Comparison across the two data sources was undertaken to seek evidence of corroboration.

Participants' inclusion and exclusion criteria

Fathers aged 18 years and older were recruited so long as they met the criteria of 'father' and their child was under the age of 18 and had been diagnosed with a life-limiting illness for at least 1 year. A father was defined as a male of any age who has some parental responsibility; it refers to biological fathers, stepfathers and adoptive fathers (Phares et al., 2005). A life-limiting condition was defined according to the four definitions by Widdas, McNamara, and Edwards (2009). **IAQ5**

Ethical approval

This study considered carefully the sensitivity of the research topic and its effect on participants. This study was reviewed and given a favourable opinion by the National Research Ethics Service (NRES) Committee South West – Exeter; further approval was sought by the local Research and Development Department. **IAQ6**

Participation and recruitment

Seven fathers, all biological parents of the child with illness, aged between 27 and 54 years of age took part in the study. All the fathers reported that they were currently, or had been, in heterosexual relationships as parents of their child who had a life-limiting illness. All the fathers reported that they were in a relationship with their partners at time of diagnosis for their child. One father reported that during the course of their child's illness, the relationship had finished and attributed this mostly to effects of the illness. A second father reported that his relationship ended quickly after the birth of his child but attributed this to long-term relational dynamics already inherent in the relationship that were likely exacerbated by the additional stresses associated with having an ill child. The remaining five fathers were all currently in a relationship with the mother of their child who had a life-limiting illness. Two fathers reported that they had been married before their current relationship. One father had two children, both with a life-limiting illness. The remaining fathers had one child in the family with a life-limiting illness. Further more detailed information has been omitted to protect the anonymity of the participants.

Participants were recruited via the local community paediatric nursing team who identified 20 fathers meeting the criteria. A letter was sent by the team on behalf of the researcher outlining the study. Enclosed in the letter was an information sheet outlining the aims of the study, consent and confidentiality, and what participation would entail. Potential participants returned the Consent to Contact form with their details in a prepaid envelope. Fathers who did not return the form were contacted by nursing staff and details of interested fathers were passed on to the researcher. The researcher contacted potential participants 1 week later to discuss the research. Consenting participants were contacted 48 hours later, allowing a ‘cooling-off’ period, to confirm their participation and arrange an interview.

Procedure

Each participant was interviewed twice by the lead male researcher, within a private location either within their own home or a National Health Service (NHS) building. Interviews lasted between 45 and 100 minutes and were digitally recorded. The first interview was a narrative interview where fathers were encouraged to tell their story about their experiences with their child’s life-limiting illness. Participants were fully aware of the aims and rationale for the research because of the information provided during the recruitment process and reiterated prior to conducting the interview. Participants were encouraged to tell their story following being asked a narrative-inducing question (Wengraf, 2001): ‘Tell me about your experiences with your child’s life-limiting illness, their treatment and how things are now’. If questioned by the interviewee about where to start, they were encouraged to start wherever they wanted. When participants drew their stories to a close, the interviewer prompted about certain aspects of their story, their experiences of services, emotional experiences and how it had affected them. The second interview was the Dynamic Maturation Model–Adult Attachment Interview (DMM-AAI; Crittenden and Landinin, 2011). Fathers were offered recompense for travel, but all refused.

Analysis

Interviews. All interviews were transcribed by the lead researcher. Fathers’ narrative transcripts were read and reread by the lead researcher. The analysis drew upon Riessman’s (2008) methodology which accommodates both successive and simultaneous narrative analyses over multiple levels and through multiple lenses. Brief summaries of the overall stories were produced (McCormack, 2004) both to assist in identifying overall story structure and to incorporate performative/dialogical elements (Riessman, 2008). Each narrative was coded for themes paying attention to the content of what was said (Braun & Clarke, 2006). A reflective process was maintained and facilitated by utilising reflexive notes from the bracketing interview in order to

Table 1. DMM-AAI discourse makers used in the narrative analysis.

Dismissing	Distancing	Removing self from danger, for example, replacing ‘I’ with ‘you’
	Omitted images	Dry descriptions – events free of images
	Idealisation	Describing relationships in very positive terms
	Memory loss	Inability to recall memories
	Artificial language	Dry distanced language
	False positive affect	Inappropriate use of positive affect
Pre-occupied	Intense images	Images that indicate strong emotions
	Evocative language	Language to evoke feelings
	Blurred circular episodes	Blurring from story to another
	Derogation	Describing others in extremely negative ways
	Involving	Emphasis on feelings inviting listeners to side with the speaker

DMM-AAI: Dynamic Maturation Model–Adult Attachment Interview.

attend to personal and professional conceptualisations which were influencing the analysis. The analysis was supported by the use of a ‘bracketing interview’ completed by the lead researcher before the analysis (Rolls & Relf, 2006). In this, he was interviewed by the second author (J.S.) regarding his own personal and professional experiences and how they related to this area and how his analysis of the fathers’ experiences might be influenced by these experiences. This enabled an in-depth reflective process which in turn enhanced the transparency and accountability of the research process. A reflective diary was kept throughout the research.

Following this analysis, a second layer of analysis was also conducted which employed the DMM-AAI attachment discourse markers (Crittenden & Landini, 2011; see Table 1). As a reliability measure, two narratives were independently coded by the third author (R.D.) for attachment discourse markers which corroborated with the lead researcher’s coding. Once this process had been completed, narratives were compared and contrasted looking at similarities and differences within and between DMM-AAI classifications.

AAIs. The DMM-AAI coding was completed by R.D. who has certified reliability in the administration and scoring of this measure. This analysis consisted of examining the AAIs for evidence of the core attachment discourse markers and also for indicators of unresolved states of trauma or loss.

Findings

DMM-AAI

Table 2 shows the participants (pseudonyms have been used) of DMM-AAI strategies.

David used both A and C strategies in his AAI; however, he displayed more dismissing discourse markers within his narrative interview and therefore was grouped as Dismissing in the analysis.

Narrative analysis

The analysis revealed superordinate themes that were shared across all fathers and were independent of their underlying attachment strategies. The theme ‘gaining knowledge’ pertained to a double-edged sword of seeking information on the illness which while helpful also brought horror. ‘Keeping my child alive’ described how fathers became expert on their children, particularly in cases when their child had a rare condition. With this knowledge, they could voice

Table 2. Participants' DMM-AAI attachment strategies [AQ7]

	DMM-AAI classifications
Nick	Type A: Re-organising to B1
Jason	Type A
Scott	Type A
Liam	Type C
David	Type A and C
Bradley	Type A: Re-organising to B1
Andrew	Type A

DMM-AAI: Dynamic Maturation Model–Adult Attachment Interview.

Table 3. Summary of themes.

Superordinate theme	Sub-ordinate theme
Experience of Diagnosis	‘A shock’ ‘A whirl wind’
Living with the illness	Getting on with it ‘I tried to resume my life – I didn’t’ ‘A unique kind of horror’ ‘It brings you together or tears you apart’
Struggling with emotion	Keep emotions at a distance Overwhelmed with emotion
Relationship with Staff	Difficulty trusting staff Fathers ‘side-lined’ Staff are important

concern regarding treatments and help professionals care for their child. ‘A brighter reality’ described fathers’ attempts to ensure that their child was no different to any other child and to prevent the illness from dominating their views of the future. ‘Giving back’ described how fathers wanted to give advice to others and engage in transforming services. Similar themes have been found by Ware and Raval (2007), and therefore, only themes relevant to attachment theory will be reported here.

The summary below presents each theme shared across the group of fathers with an additional commentary from the second layer of analysis employing DMM discourse markers. This analysis revealed that the fathers articulated broadly shared narratives capturing core features of the experience. However, they then revealed subordinate themes in effect telling the ‘same’ story but emphasising different aspects of it to the point that these essentially indicated subordinate themes. Table 3 shows a summary of superordinate and subordinate themes.

Experience of diagnosis

Structurally, all the fathers' narratives begin with the diagnosis. There were moments of uncertainty while their child either presented with an unusual health issue or were born with an immediate medical need and needed intensive care; this uncertainty continued as their child went through tests. The length of this period depended on the type of illness, and some fathers describe feeling helpless. The impact of the diagnosis was devastating – a shock leaving fathers feeling uncertain about the future and not knowing what to do. There were marked differences in the way that the fathers described the diagnosis.

'A shock'. Fathers employing Dismissive strategies describe the diagnosis with brevity or with distraction to tangential detail. Specifically, they employed minimising 'you're in a bit of shock' (Jason) and distancing language, as highlighted in Andrew's narrative:

The initial um I don't know shock of it I suppose that was a bit that was a bit threw me back . . . it's sort of does hit, hit you hard because you think what is this I don't quite understand it . . . was initially very quiet yeh it hit you hard

'A whirl wind'. In contrast, Liam, who most clearly employed a Pre-occupied strategy, describes his experience with vivid imagery, involving discourse and derogation, which is most amplified in this part of his narrative which escalates in anger as he describes an insensitive diagnosis. The presence of amplified discourse markers, with intense imagery, might be an indication of trauma:

It just went woooooooooosh . . . I remember . . . a weird 70's puke green place with a window that only had about this much gap it was high up and she (Consultant) matter of factly said 'yeh people with (diagnosis) only live till their about 28 uh yeh you're guna need lots of help yeh its awful' . . . I remember . . . thinking you fucking bitch and . . . if that gap in that window was big enough I'd force myself out of it right now cause I can't cope . . . then uh it's like the whirl wind . . . I freaked out . . . I lost my mind, went completely didn't know what to do . . . I was gone.

Living with the illness

Broadly, this theme captured the enormous task of coming to terms with the illness, and fathers revealed that this was a significant and challenging task particularly when the condition was extremely rare, which caused increased uncertainty and isolation. There were clear differences related to fathers' attachment strategies.

Getting on with it. This captures the approach of fathers using Dismissing strategies. Fathers tried to not worry, dealing with difficulties with a positive attitude. Fathers expressed an acceptance of the illness and treatments which manifested in a pragmatic 'getting on with it' approach. Fathers demonstrated this approach after the child's diagnosis, and this continued throughout the child's treatment as observed in Nick's response to operations:

It's a necessary evil which we've got to go up there to do like you know we can't get um there's nothing we can do like about it we just got to go get on with it.

Jason appears to move into this approach after describing a potentially traumatic episode, suggesting this might be a way of creating a manageable reality:

I've seen him die several times but managed to sort of bring him back before the crash team comes in . . . it was just uh I don't know it's just (laughs) you just get on with I suppose you have to just get on sort of with day by day.

'I tried to resume my life – I didn't'. This theme was specific to the Pre-occupied strategy. After the diagnosis, Liam appeared to be searching for mastery and trying to create a manageable reality. However, each attempt made him feel worse, creating a further struggle with the reality of life limiting:

I didn't work for six months after that . . . the more you read the more horrendous it gets . . . I was just putting myself in a darker and darker place really you know it was grim.

Liam often returned to the overwhelming nature of the illness; he appeared to struggle with his child having a life-limiting condition. Liam uses powerful imagery, involving discourse and evocative language to communicate this (indicative of Pre-occupied strategies):

Like the walking dead I felt like . . . I tried to resume my life I didn't . . . I thought she was going to drop dead any minute, I'd be up all night looking at her you know listening to her breathing, you know that sort of state of alertness can't last . . . I did five or six years like that . . . I'm surprised that I'm not fucking dead actually of stress.

'A unique kind of horror'. Fathers described experiences observing their child suffer, which involved invasive procedures, agreeing to operative procedures or watching their child die. Some fathers described these as horrific, in some instances positioning themselves as helpless. Attachment discourse markers were present when describing such events; for example, Scott describes his experience of his child's operations:

Every time you sign that pink slip . . . you could be signing your child's life away and the first couple were so hard . . . you see your child in pain or discomfort you know the only way around it is to do is to let her have an operation you sign the pink slip.

There were indications of trauma within four of the fathers' narratives as indicated by a disruption in attachment strategies. For instance, Bradley frequently returns to images of his child dying, indicative of a Pre-occupying trauma:

When you're watching your daughter die in front of you . . . you become weaker by a long way . . . it was really tough just watching her die in front of you is just the most horrendous thing . . . you become much weaker you know impotent is probably the word.

Given the extreme danger to their child's lives, some fathers' attachment strategies were stretched to the limits. David's attachment strategy (compulsive caregiving and self-reliance) was pushed to its limits as he describes a painstaking routine to remove any threats to his child's illness:

I would literally throw myself into cleaning down to bleaching the walls skirting boards just over the top OCD cause it was how I felt was better for my kids.

'It brings you together or tears you apart'. This theme pertains to fathers' relationships with their partners in the context of the illness. All fathers acknowledged their experiences had placed huge demands on the relationship. Two fathers described how a strong relationship and supporting each other was the key to coping with difficult experiences. Four fathers talked about how the illness had caused arguments as they and their partners both adjusted differently to the demands and routines of the illness, as described by David:

When you have a child with a life-threatening illness the relationship it goes one way or the other it either brings you extremely close or it tears you apart . . . it's been difficult there's been lots of fights um I think a lot of it is both of us getting our frustration out of the whole situation.

The illness was so intrusive on relationships that attachment strategies were stretched, and in some cases, there was an intrusion into the reverse strategy. Jason describes how he tried to keep his relationship together for his child, and when his partner became increasingly unavailable, he appeared to switch to a more Pre-occupied strategy. Liam, when describing the effect the illness had on his relationship, moved into a more Dismissing strategy:

I'd get really upset . . . I'd start Lucy off crying and the last thing you want to do is make your partner really upset you know so I'd just internalise it and it just drove a massive wedge . . . that was the start of the end . . . once you can't communicate about something as big as that . . . your relationship's doomed.

Struggling with emotions

This theme was prominent across all the fathers' narratives with respect to how they coped with the emotional aspects of the illness. Five of the fathers reported they were trying to be strong for their families. This culturally gendered narrative spread across attachment strategies; however, two subordinate themes were found.

Keep emotions at a distance. This theme ran throughout the narratives of fathers using Dismissing strategies. Fathers reported that they preferred not to talk about the illness or the emotional aspects of it to others. For example, Nick described how he could not talk about the illness with others as he became too upset:

I'd be with my friends in the pub . . . of course like your friends want to know . . . and you'd get teary and then all of a sudden I have to leave the pub . . . I could feel myself getting all like emotional . . . I almost felt myself like a bit weak.

Fathers would describe their emotions or emotional experiences in minimised ways. An intrusion of affect was met with strategies, such as reverting back to detailed talk. For example, when Jason described the initial stages of his child's treatments, he used distancing, minimised his experience of shock by using 'a bit' and when talking about the vulnerability of his child, he engages in false positive affect:

You sort of on automatic mode you just do what you can . . . you're in a bit of shock but you think everything is going to be alright because he was absolutely perfect he was just tiny his arm was the same size as my little finger really seriously [laughs] tiny anyway.

Overwhelming emotion. This theme is specific to Pre-occupied strategies whereby Liam had periods of being consumed with emotion within the narrative. Liam describes a time when his child became ill. While he overcame this problem, he describes how he broke down as a result:

I . . . had a breakdown out there . . . I went out and I collapsed . . . I was just holding my hand crying . . . it has fucked me up there's no denying.

Liam described how he is affected emotionally by the illness spontaneously and acknowledges how his emotional world affects his thoughts about the future:

I get really upset about it sometimes often at the most random time yeh you'd be having a completely normal time and then all of a sudden it hits you oh my god.

Discourse markers provide evidence that for Liam the emotional aspects of the illness are overwhelming; he uses evocative language and vivid imagery. Emotional arousal was evident in his narrative, which ran on, and this occurred frequently. At times, Liam used distancing, suggesting that topics had become too overwhelming.

Relationship with staff

All fathers talked about the bonds that they had formed with staff. Broadly, fathers talked about positive experiences with staff; however, fathers also described frustration with some interactions, and particular professionals. Analysis revealed how fathers engaged with, responded to and developed their relationship with staff.

Fathers 'side-lined'. Fathers being positioned on the periphery in comparison with the mothers was a theme across five of the fathers' narratives. Some drew on culturally gendered ideas and suggested the presence of such an issue was outdated as described by Bradley:

I would ask him a question and he would talk to my wife . . . he never ever answered any of my questions . . . I understand that there is this maternal thing and I get it from a male point of view but were not in the eighteen hundreds anymore and actually a lot of fathers are the carers for their child.

Fathers using Dismissing appeared more accepting of the problem. Bradley considered this a '*dangerous*' issue as their child was in a critical condition and it made him feel helpless, but he felt unable to voice his concerns. Bradley uses distancing as he describes this:

If you're not involved in it you're nothing in this equation and therefore you're completely impotent in your help of your daughter . . . not that I ever said to anyone you don't in hospital you just don't cause their looking after your kid and you don't say anything negative ever but it was frustrating.

In contrast, Liam, using Pre-occupied strategies, responded more assertively in response to his perceived unfairness:

You're just a second class citizen sort of what it feels like until you smash your way to the front and 'god dam it you will listen to me' . . . I'm a bit feisty and prepared to get stuck in.

Difficulty trusting staff. This theme is specific to Liam using Pre-occupied strategies and describes a relationship with Doctors using mocking derogation which draws the interviewer in to seeing his point of view. He describes staff being medically knowledgeable but failing to understand the reality of the situation:

Fuck what the doctors tell you a lot of times because they just spend a lot of time looking at this crap they don't live with child they don't understand you know I'm told they've got the latest research papers . . . that's not living at home with someone 24/7 and understanding the condition from the inside out you know you have to it's a fight.

Liam continues to describe how staff do not communicate a hopeful story which is unhelpful, which is emphasised by repetitive use of '*doom*' which is an attachment discourse marker:

You know they doom and gloom you . . . its murder cause I think they have to cover themselves so they say your child's going to live till their thirty . . . it's guna be bad doom doom doom doom doom doom . . . you start to believe that shit it doesn't have to be like that.

'Important relationships'. Fathers talked about positive and trusting relationships with staff. Positive descriptions might have also been indicative of an idealising strategy, as observed in four fathers using Dismissing strategies. Given the extreme attachment 'danger' of losing their child, fathers were left with no choice but to put their faith in medical staff. Fathers talked positively about certain consultants who had supported or advocated for them through difficult episodes. Scott describes how he sought the help of his consultant who met his needs in a critical situation:

I just phoned (specialist hospital) for help . . . I then had a phone call from (consultant) and I told him what was happening and I said, 'I know you're not her consultant at the minute' . . . and he said 'I'm her heart consultant all the time it doesn't matter when' and he phoned (local hospital) she was transferred.

Liam who demonstrated difficulty in trusting staff described one episode when he built a positive relationship with one consultant who supported and reassured him after the diagnosis. Continuity of care was vital to fathers, indicating that the trusting relationships that were built were important for fathers. To have some genuine trust in receiving positive care may indicate a shift towards a more secure strategy. David describes the trust he built with his care team:

When you've got a child with a terminal illness and you first come in the team that you first meet that's the team you kind of get everything from . . . so automatically the trust is there and the kind of patient bond.

Discussion

This study aimed to explore the experiences of the fathers who have a child with a life-limiting illness and how their attachment strategies influence their experiences and telling of their narratives.

The narrative analysis of the fathers' narratives indicated four clustering of narrative themes that captured their experience which largely represented the temporal stages of adjusting that they went through: experience of diagnosis, living with the illness, struggling with emotion and their relationship with staff. The experience of the diagnosis was universally experienced as a 'shock' and a major upheaval in their life. However, the second theme, living with the illness, indicated that the emotional responses and strategies for coping followed a relatively stoic dismissing or minimising pattern, getting on with it and trying to resume their life. This was further underlined by their emphasis on the theme 'struggling' with emotion on keeping emotions at a distance. Given the enormity of the problems faced by these fathers, this was somewhat unexpected. However, there were differences between the fathers, but only one of them used more evocative language and emphasised a story of horror and emotional turmoil.

The second layer of analysis focused on the underlying attachment orientations of the fathers. Attachment processes were evident in fathers' narratives as there were marked differences in discourse markers between fathers using Dismissing and Pre-occupied strategies. Attachment discourse markers were evident throughout fathers' narratives which corroborated with their AAI classifications, such that Dismissing and Pre-occupied markers were present in their narratives, respectively. This provides further evidence that a life-limiting illness will activate attachment strategies in parents, which are observable outside of the formal AAI (Bishop, Stedmon, & Dallos, 2015). **AQ8** Attachment processes appeared to be most prevalent when describing threatening invasive procedures, threats to their child, emotional moments in their story and relationships with staff. This supported the impression of distancing and minimising the emotions in the narrative analysis in that the themes of distancing and minimisation were more evidently employed by fathers who held findings that suggest living with the illness appeared to be readily accepted by fathers using Dismissing attachment strategies. This featured adopting a 'get on with it' approach to the illness. This approach might also feed into 'keeping emotions at a distance' as fathers dismiss worries related to the illness, consequently making it easier to attend to the practical demands of the illness.

More broadly, dismissing strategies represent an attempt to minimise emotions, adopt a position of not burdening others with their problems, self-reliance and focus on others' needs rather than one's own. Such an orientation appeared to fit with the fathers focussing on care of their children but marginalising their own emotional needs. Many of the fathers in this study described their initial experiences using the term 'we' as they shared experiences with their partner, suggesting that this is an experience that was co-constructed. However, they did not refer to turning to their partners for emotional support and instead indicated that they felt they needed to be strong and not burden them with their distress. Possibly, they drew on a common gender discourse of fathers needing to be strong, unemotional and supportive of their family. Only one of the fathers revealed a pre-occupying attachment strategy in his AAI. Although separated at the time of interview, he also appeared to draw on this

discourse in relation to not burdening his partner emotionally. He did not criticise or refer to other family members; however, his narrative suggested he would make his feelings known to medical professionals even to the point of being critical. Interestingly, he also showed some remorse and reflection regarding his ex-wife and consideration of her feelings. Furthermore, attachment strategies were further apparent in the fathers' narratives about effective adjustment in the belief that strong or overwhelming displays of emotion from them regarding their child's illness might contribute to an unhelpful 'overwhelming emotion'. They appeared to fear that this might create an escalating process, making adjustment more difficult. Keeping calm and detached was generally viewed as a better way to navigate the complex demands of adjusting to the illness (Vetere & Dallos, 2008).

The findings suggest that fathers feel 'side-lined' and provide further support that healthcare staff might be positioning fathers on the periphery (Hill, Higgins, Dempster, & McCarthy, 2009). Fathers using Dismissing strategies, while frustrated, were more accepting of and less likely to challenge the issue. Fathers here also generally attempted to tell a narrative of staff 'trying their best', 'being over-worked' and not to blame. In effect, this is a narrative of being just and fair to others. In contrast, in pre-occupying attachment patterns, there is a strong focus on narrative of blame and a resentful sense of injustice towards the self. Only one of the fathers indicated this pattern (Crittenden & Landini, 2011, p. 196).

The theme 'a unique kind of horror' suggests the illness brings potentially traumatic experiences for both parent and child. Kazak et al. (2006) have indicated that various phases throughout a child's treatment are potentially traumatic for both child and parent. In intensive care situations, fathers report the invasive procedures as most stressful in addition to feeling helpless (Board, 2004). Understandable feelings of fear and horror and feelings of helplessness might be exacerbated by fathers' perceptions of being 'side-lined', contributing further to highly aroused states. It is therefore important that further research aims to understand how to support and engage fathers during critical periods of care. It was observed within their narratives that fathers predominantly talked about their child in the context of the illness and rarely referred to their child's subjective experiences or expressed their child's view. The results are similar to those of Bishop, Stedmon, and Dallos (2015), who suggest this might have been a self-protective strategy because reflecting on the child's view was too painful and therefore remains untold. This might be supported by the theme 'a unique horror' where fathers themselves experienced procedures as horrific, and to think about the child's perception would be too emotionally intrusive.

Although the attachment strategies employed by the fathers in their AAIs were clearly evident in how they told their stories about their child's illness, their narratives also revealed that these defensive strategies could be pushed to their limits by the extreme distress that the narrative interview triggered. In some cases, there was evidence of dominant strategies becoming overwhelmed with intrusion into the reverse attachment strategy, such as Liam using dismissing strategies when topics became too emotionally intrusive. Likewise, the fathers using predominantly dismissive strategies showed evidence of at times becoming angry and somewhat emotionally dysregulated as they talked in detail about their child's illness and, in some cases, had been 'let down' by medical staff. This is an extremely interesting and important finding in our study. It provides evidence of how attachment strategies are dynamic and shifting and are influenced and, in some cases, de-stabilised by current demands (Marvin & Stewart, 1990). Furthermore, it supports the idea that in-depth clinical/research interviews, such as used in this study, may reveal in more detail the workings of attachment strategies. The AAIs identified two fathers as reorganising to Type B (Secure). Findings by McNeil (2004) and Hayes and Savage (2008) suggest that a life-limiting condition can increase fathers' emotional involvement in their child's care. The dynamic maturation model of attachment posits that attachment strategies are modified over time based upon life experiences and interpersonal relationships (Crittenden & Landini, 2011). It could transpire that having to be more involved and attentive to a child with increased healthcare needs influences fathers to reorganise towards an integrated and more secure attachment strategy.

Limitations of study and future research

This is the first study specifically to explore fathers and their child's life-limiting condition with a focus on attachment. Fathers appeared to appreciate the opportunity to talk separately from their partners and as a father in their own right. This research demonstrates that fathers are willing to participate if they are engaged. Recruitment rates could have been influenced by a male researcher, in addition to the research emphasising the value of father's views.

This study recruited fathers with an over-representation towards Dismissing strategies and under-representation of secure strategies. Research has suggested no gender differences in attachment strategies (Bakermans-Kranenburg & Van Ijzendoorn, 2009), and therefore, the reason for this remains unclear. Many of the fathers in this study described their initial experiences using the term 'we' as they shared experiences with their partner, suggesting that this is an experience that gets co-constructed. Future research could interview parents together, taking an attachment lens to co-constructed narratives about their child's illness.

Future research could investigate further the identification of attachment classifications from narratives and having another researcher identify attachment classification from an AAI and see whether they corroborate. This

would provide further evidence that attachment discourse markers and strategies are evident in experiences that trigger attachment strategies. If the findings further support this, then training in how attachment strategies present themselves might be helpful to assist staff in recognising the needs of parents and children in order to provide appropriate support.

Clinical implications

This research has clinical implications for health professionals working in the paediatric setting. As attachment strategies were observable within the narratives, it provides support that clinicians could be trained to formulate an idea of the strategies being used by parents to provide appropriate support.

Parents using Pre-occupied strategies might show highly expressed emotion, which will drive their actions; subsequently, this signalling of distress can be overwhelming for health professionals. It is important clinicians are aware of this strategy of dealing with danger, offering time and reassurance about the realities of threats, while remaining consistent in continuing with the most effective treatments (Thompson & Ciechanowski, 2003). Professionals might need to support parents who are emotionally overwhelmed to regulate their distress and to think through treatment decisions in rational ways (Vetere & Dallos, 2008). Parents using Dismissing strategies or the 'get on with it' approach are likely to appear to be coping, and because of the way emotions are expressed, clinicians may be less curious about how the family are really managing. Parents using Dismissing strategies might be less inclined to communicate their upset regarding treatment decisions. Therefore, it is important for clinicians to support parents to voice their views or concerns and to help articulate feelings in relation to their child's illness (Thompson & Ciechanowski, 2003) and to ensure that a positive working relationship remains stable as a result.

This research has highlighted the importance of understanding paternal attachment styles in the context of life-limiting illness. The results of this study confirm that attachment strategies are observable within fathers' narratives. It might therefore be possible to get a broad sense of the strategies being used by each father through sensitive clinical interviews. Identifying clinically viable methods for identifying attachment strategies through the use of questions designed to trigger attachment threat may offer a pragmatic alternative to formal AAIs. This approach provides an important step for developing psychological awareness of how individual differences in attachment style might lead to targeted treatment strategies for supporting families receiving paediatric care.

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