

# **Comparing needs of families of children dying from malignant and non-malignant disease: an in-depth qualitative study**

## **Contributorship**

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This study was taken from Jayne Price's Doctoral Study. All data was collected by Jayne Price, analysed by Jayne, with blind analysis being carried out by the entire research team. The first draft of the paper and the rewrite were written by Jayne Price and each member of the team commented on these and revised later drafts.

## **Data Sharing Statement**

No additional data

## **ABSTRACT**

**Objective:** To examine the experiences of bereaved parents concerning the care provided to children who died from cancer compared to those who died from a non-malignant condition.

**Design:** An in-depth qualitative study with bereaved parents of children who died as a result of a life limiting diagnosis, recruited through two regional centres.

**Results:** Although parents' accounts displayed commonalities, key differences were discernible. Typically, parents of children with cancer considered care at the end of life as well resourced and responsive to their and their child's needs. In contrast, parents of children with non-malignant conditions reported under-resourced and inadequately responsive services. Although both groups of parents called extensively on military metaphors such as 'battle', 'fight' and 'struggle', the focus of their respective energies was different. In the one case the adversary was disease and illness; in the other it was service providers and service provision.

**Conclusions:** Community based services for children and young people with cancer at the end-of-life were perceived by parents as responsive to parent and child needs. Conversely, community services for children and young people with non-malignant conditions were experienced as ad hoc and under-resourced. Community services for children with non-malignant conditions may require further development if they are to meet the levels of support offered to parents of children with cancer. If improvement is to be achieved, the need to raise awareness regarding hospice services, hospice referral and eligibility criteria across the entire gamut of service providers is essential.

## INTRODUCTION

Palliative care for children has emerged as a distinct area of practice in recent years,<sup>[1]</sup> as numbers of children requiring such care increases. Despite this growth, the evidence base to inform practice remains limited.<sup>[2]</sup> Within the context of a vast spectrum of clinical need (see Figure 1), existing research focuses predominantly on care of children with cancer. However, children with non-malignant conditions constitute 60% of those requiring palliative care<sup>[3]</sup> and early indications suggest distinct needs related to the protracted and sometimes unpredictable nature of their conditions.<sup>[3-9]</sup> Accordingly, there is a clear imperative for evidence that differentiates between the needs of children with cancer and those with non-malignant conditions, including that relating to parental and wider familial involvement in care<sup>[3]</sup>.

A systematic search of the literature revealed only two studies that sought to differentiate the experience of parents caring for children with different types of conditions. In the first study, unmet needs of Australian parents caring for children with a range of conditions were identified with the aim of informing service provision.<sup>[10]</sup> For parents of children with non-malignant disease, unmet need was related to lengthier duration of care, fewer hospital admissions, less support from extended family, managing nutritional needs, administering medication and securing clinical assistance with care. Contrastingly, unmet needs of parents of children with cancer related to lack of disease-specific information, financial security and limited access to staff out of hours<sup>[10]</sup> In the second study, conducted in the UK, the framework shown in Figure 1<sup>[3]</sup> was used to classify 26 children based on their medical condition.<sup>[11]</sup> Findings demonstrated a more sudden decline among children in category 1 (predominantly with cancer), in comparison to children in the remaining categories who were more likely to experience slow deterioration. Furthermore, issues relating to information provision and pain management were less relevant to children in categories 1 and 4 than for those in categories 2 and 3, for whom genetic counselling emerged as particularly significant.<sup>[11]</sup>

Although these two studies are important in highlighting the diverse clinical challenges faced by carers of children with life-limiting conditions, their findings could be seen compromised by the presence of parents at different stages of their child's life and death. Thus whilst some families were still actively caring for their children, the entire caring trajectory had not been captured. As such, all parents could not report on issues and experiences pertinent to the time leading to their child's death. Findings reported in this paper are taken from a larger study (PATCH) that sought to overcome such limitations by including only bereaved parents whose child had died from a life-limiting condition. This study aimed to explore parents' experiences of caring for a dying child in relation to the entire illness trajectory and concomitant care, with a view to making recommendations for improving care and practice.

## METHOD

### Design

The study adopted a qualitative approach, involving in-depth interviews with bereaved parents at one point in time.

### Participants

Twenty five parents (16 mothers and 9 fathers) talked about the life and death of 16 children. Stratified purposeful sampling<sup>[12]</sup> was used to ensure the inclusion of parents whose children had died from both cancer (n=6) and a non-malignant condition (n=10), all between 6 and 24 months prior to participation (see Table 1). This time frame was chosen in order to facilitate recall, as well as being sensitive to the emotional requirements of parents.<sup>13-14</sup> Recruitment of parents of children with cancer was via a regional children's cancer unit and those of children with a non-malignant condition via a regional children's hospice, both in the same constituent part of the United Kingdom (UK). Initial contact was made by intermediary nurses already known to parents. The majority of parents (n=10) were interviewed individually; at their request three couples were interviewed together. Despite the challenges associated with conducting joint interviews,<sup>[15]</sup> the accounts offered by parents interviewed together were consistent in all essential respects to those of parents interviewed alone. That is, although analysis revealed differences in what parents talked about, these differences were not dependant on whether they were interviewed together or individually, but rather on core features of their child's illness, trajectory and concomitant caring experiences.

Table 1: Characteristics of children (n=16)

Characteristic	Category	Frequency (n)
Sex	Boys	8
	Girls	8
<i>Age of child at death</i>	Under 1 year old	5
	1- 10	1
	10-18	9
	Over 18	1
<i>Diagnosis</i>	Cancer	6
	Non cancer *	10
<i>Location of death</i>	Hospital	3
	Hospice	3
	Home	10
<i>Time from death (at interview)</i>	6 -12 months	1
	13 -18 months	7
	19 - 24 months	8

\*One of the children within the non malignant grouping had a haematological condition and was cared for in the cancer centre.

### **Data Collection**

Data were collected between November 2007 and September 2008. Using in-depth interviews parents were encouraged to tell their own stories about the period of their child's illness and subsequent death. All interviews were audio-recorded (with permission) and transcribed verbatim. Interviews began by asking "Could we start by telling me a little about your child and his/her life?". Thereafter, a series of open-ended questions used as necessary enabled parents to talk about their experiences of caring in terms of what they considered to be important (Figure 2). As such, all relevant issues were raised spontaneously by parents. Strategies were developed to provide post interview support to parents if required. Ethical approval for the study was granted (07/NIR02/72).

### **Data Analysis**

Thematic analysis<sup>[16]</sup> was conducted as follows. Repeated readings of interview transcripts allowed a detailed familiarization with their content. Thereafter, the comparison of interview data both within and across parents' accounts enabled the gradual identification of patterns of 'themes' that cross-cut the entire dataset.<sup>[17]</sup> This inductive approach to analysis ensured that these themes and their constituent properties were wholly derived from parents' accounts.

Analytical rigour was achieved through a number of processes, including comprehensive treatment of data, shared analysis to promote the full possibilities for analytical insight<sup>[18]</sup> and memo-writing to further enhance the development of analytical ideas.<sup>[19]</sup> NVIVO 7 was used for data management, thereby maintaining a clear audit trail of the analytical process.

### **FINDINGS**

Core similarities across parent accounts demonstrated how losing a child caused profound changes to parent biographies and family dynamics. In responding to their child's illness and death, parents exhibited an unremitting need to actively 'do' for their child and wider family – for example providing ongoing physical care for their child whilst attempting to preserve some normality within family life. Thematic findings from the PATCH study have been provided elsewhere<sup>[20]</sup> Here we focus on six interrelated differences discernible in parents' accounts (see Figure 3) that exposed an intractable *inequality* in experiences, rooted in the nature of their child's condition and associated service provision.

For parents of children with cancer, caring experiences were framed by treatment, periods of remission and hope for cure. In contrast, parents of children with non malignant conditions tended to experience a protracted progression towards death, with less emphasis on the possibility of cure. Although all parents were involved in providing medical care to their child, those of children with non-malignant conditions were typically involved in complex care interventions over an extended time period.

All parents talked about the uncertainty that characterized their day-to-day living throughout their child's illness. Uncertainty was described by parents as fluctuating, according to, for example, periods of remission or relatively stability. However, the focus of uncertainty differed. Parents of children with cancer recounted an oscillation between hope for recovery, fear that cure was impossible, and eventual knowledge of impending death. Although some parents of children with non-malignant conditions discussed hope for cure, their uncertainty focused not on *if* their child would die, but *when* and *how* death would occur. The rarity of many of these conditions and relative lack of professional knowledge concerning, for example, symptoms, intensified the uncertainty experienced.

Based on the nature of uncertainty, parents' accounts captured wholly different experiences leading to their child's death. Parents of children with cancer talked about becoming increasingly aware of the inevitable 'march' towards death, as when, for example, curative treatment options were exhausted. That said, the certainty of death was typically challenged, with many parents describing their refusal to give up hope. Parents of children with non-malignant conditions gave much less 'tidy' accounts, so that death was rarely anticipated. Many described their child's survival (sometimes, repeated) of 'near death' moments, encouraging them to believe that recovery from 'the brink' could occur indefinitely.

*'On the Monday night we thought this was it and when they resuscitated her again we didn't think... 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)

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

Although all parents talked of the struggles or battles inherent in caring for their child, the nature of these battles differed. For parents of children with cancer, the 'enemy' was the illness itself, waged against a backdrop of possible biomedical cure. Their accounts emphasized a determination to conquer the disease, evidenced through the deployment of such metaphors as 'beat this' 'overcome' or 'win'.

*'She was knocked back because she heard she had cancer But she says "Well then we fight it you know I will beat this".'* (15M)

*'But Susan did ask me when she come home was she going to die and I did say no she was going to fight this.'* (3M)

Parents of children with non-malignant conditions, where cure was never a possibility also used military metaphors but in an entirely different context. They described expending huge amounts of emotional and physical energy in their 'battle' for adequate service provision, aware of having to struggle on what they saw as two related fronts: bureaucratic ineptitude and inadequate resources.

*'Well that's when the fights started ((laughs))  
Well the sort of...the struggle for care you know. (1D-LL)*

*'We had social workers come out and... it was a fight we had to take ...our local board to the High Court to seek a judicial review over the level of care that Cormac was gettingem eventually we did get a care package that we were happy with but it took months of fighting.'* (4D-LL)

Consequently, frustration and resentment characterized these parents' accounts, particularly in relation to acquiring services to facilitate home care. They highlighted a disorganized and uncompassionate approach on the part of formal service providers, coalescing around the assessment process for eligibility to services. In this context, their experience of children's hospice services, both community and hospice based, was of a 'lifeline'.

*'Community nursing we found incredibly frustrating...they had actually appointed so many people 7 carers Amelia couldn't come home until these carers had been interviewed vetted and everything work their 3 months notice in their present jobs then had to be trained but by this stage Amelia died before they got this all done so she never got home'* (1M+D-LL)

*'It was continuous and when I asked then social services for more help they said there wasn't help out there and at that stage you were tearing your hair out because... there is only so much you can do and you need your sleep... so then when the hospice opened it was brilliant absolutely brilliant a life line really'*(2M-LL)

That said, delayed referral to hospice services featured in the accounts of parents in the non-malignant grouping. Late referral was particularly resented since potential time with their child at home was lost. Taken overall, these delays carried greater significance for the parents of children with non-malignant conditions for several reasons. Firstly, due to their need for hospice services over an extended time period and secondly, because of their relative lack of access to mainstream health-care support.

*'Em so we ended up getting him home for two weeks effectively whereas we could have had him home... for probably seven or eight weeks you know even after all the training we'd done if somebody had have referred us to it earlier it was really only until we found out this was terminal and it was very terminal at that stage did we find out that em the hospice was a real option here.'*  
(6D-LL)

Interestingly, no parents of children with cancer used any military metaphors in relation to accessing services. Rather, their accounts highlighted experience of

comprehensive and responsive services, concerning both hospital and community-based care. Although they could identify weaknesses, these tended to be in relation to specific aspects of care (for example, cleanliness) rather than its actual provision. Accordingly, few parents of children with cancer utilized hospice services, and those who did were more likely to acquire hospice home care. Furthermore, these parents were less likely to talk about (the need for) respite care.

*'CLIC Sargent have always been very good em with helping us and then they sent [[family worker]] along...we had her when Ruth was first diagnosed for a while when [[mum]] had the baby and then towards the end [[family worker]] would come in once a week to do the ironing or a few wee jobs we also had ...and that was really helpful...'* (10D)

*'[[Macmillan nurse]] always seemed to be there...she never seemed to leave my house she always seemed to be here for me ...when Susan seen her coming Susan felt safe.'* (3M)

Of particular importance for those in the non-malignant grouping was the availability of respite care, which allowed parents to invest time in family related activity. This activity often focused on other children about whom parents felt guilt over their perceived 'neglect' in the context of caring for their ill child. In addition, such breaks helped mothers, especially, combat the mental and physical fatigue stemming from the typically prolonged nature of caring. Consequently, it tended to be the parents of children who had used hospice services, (typically, but not exclusively, those with non-malignant conditions) who talked about their drive to 'pay back' the goodwill and support they had received during their child's life. Their gratitude was often displayed in very tangible ways, such as via multiple fund raising activities.

Parents talked about their reluctance to discuss death with their ill child based on a desire to protect them from additional distress. Such communication issues appeared particularly problematic for parents of children with cancer, possibly because the majority of children with non-malignant conditions were either babies or cognitively impaired.

*'No I think she knew in her own heart and she didn't want to hurt me and I couldn't say to her you know but I wouldn't have lied to her you know.'* (15M)

For all parents, difficulties remained concerning talking to siblings about death; some entered into discussions and others avoided them.

*'They gave her a kiss and said their goodbyes for they didn't know Ruby was dying I never had told them.'* (8M)

*'They knew like she was going to die we told them a few weeks beforehand ...and they adapted well you know.'* (4M-LL)



Whether or not parents broached the subject of death with their children (the ill child and/or siblings), it was clear that their primary motivation was protection from distress, which made talking about death uniquely challenging.

## DISCUSSION

Military metaphors are apparent in other literature concerning the perceived 'war' against cancer, in relation to both adult <sup>[21-23]</sup> and child populations.<sup>[24]</sup> and in relation to the disease itself as well as with professionals. These metaphors are also discernible in the literature pertaining to children with a range of other life-limiting conditions.<sup>[11,25]</sup> Our findings uphold the relevance of such metaphors for understanding parents' caring experiences and go further by revealing the details of this experience for other groups of ill children and their parents. In so doing, they demonstrate the implications of these differences for service development.

Although all parents talked about battles faced caring for their ill child, their focus differed significantly according to whether the child had cancer or not. The accounts of parents of children with cancer focused on their 'heroic's' child's fight against the 'enemy' (illness). Similar to literature focusing on adult cancer, parents of children with cancer in this study talked about their 'hero' child's war, involving of battles, losses, enemies and victories.<sup>[23]</sup> This study however highlights significant differences in the use of such metaphors between adult cancer and children's cancer. When an adult is battling cancer the relatives/family members of the cancer sufferer are as involved in the fight in a largely supportive capacity.<sup>[23]</sup> In this study, parents tended to talk about their role as more immediately involved, as they sought to battle the disease on behalf of their child. It was however possible for them to reflect positively on well-established and mostly effective services that were anticipatory of and responsive to their child's and family needs. Parents of children with non-malignant conditions were unable to construct such a narrative. Although their accounts were also littered with military metaphors, invariably, these focused on a seemingly never-ending battle to access services. For example, in the face of parents' strenuous efforts to bring their child home, protracted referral processes, including police checks and staff training, meant children having to remain in hospital. Such processes tended to amplify parents' stress and sense of helplessness serving to further ignite their perceived need to 'battle' for services to secure optimum care for their child.<sup>[11]</sup>

Our findings are similar to previous research<sup>[26]</sup> indicating that children's hospices are rarely used by children with cancer, since most oncology centres have the infrastructure to support home care. Hospice services were most commonly used by parents of children with non-malignant conditions, providing them with respite care to combat the exhaustion they routinely experienced<sup>[10]</sup> as well as other forms of support amidst the ongoing struggle with statutory services. Unfortunately, referral to hospice services for this group were often delayed. Although this delay may in part be explained by parental reluctance to avail of hospice care as they associate this with the immediate end-of-life.<sup>[27-28]</sup> our evidence also suggests a failure to inform parents of their entitlement for hospice care and that such services existed. Late referral created significant problems, in that a therapeutic relationship was formed

over a shorter period of time, when the child was close to the end-of-life and with their family in a period of acute crisis. What was unclear from parents' accounts was whether professionals other than those working in the hospice were unaware of the criteria for hospice referral<sup>[28]</sup> or, rather, were reluctant to mention hospice care to parents due, for example, to its perceived link with death. Such issues need to be explored both in practice and future research.

By contrasting parents' accounts the evidence suggests a disparity in both service provision and organisation. Service reviews and strategic documents have identified the exemplary nature of palliative care for children with cancer in the UK, seeing it as a cornerstone for future developments in Europe.<sup>[29]</sup> However, children with non-malignant disorders constitute the greatest number of children requiring palliative care<sup>3</sup> but have only recently been recognised as a discrete group.<sup>[30]</sup> Our findings suggest the need for a corresponding impetus for tailored service development to meet their needs.

Whilst two earlier studies<sup>[10-11]</sup> provided insights of differences in unmet needs of parents depending on their child's diagnosis these studies involved a mix of parents - some bereaved and other parents currently caring for their sick child. Our findings endorse policy and strategy for England and Ireland,<sup>[31-34]</sup> which suggest there is a clear need for continuing development in children's palliative care service provision. Such development as this research study indicates includes raising public and professional awareness of what a children's hospice is and the different types of care it provides if referral processes and pathways are to be improved. Secondly, given the lack of statutory health service staff with appropriate expertise to support home care, community children's nursing teams need to be expanded, with out-of-hours cover and adequately trained professionals who could be called upon in the event of a child needing urgent transfer to home. Built upon a collaborative approach between professionals and parents such a service would complement that currently provided by children's hospice services. Finally, the need for timely and responsive assessment processes has been highlighted, potentially using a standardized assessment tool focused on the individual needs/wishes of the child/family. Taken together, such care and service provision would aid reducing parental isolation and desperation, helping to counter the perception of a need to 'battle' to provide for and protect their child in the case of children dying from non-malignant disease.

## **CONCLUSION**

This study provides clear evidence that differences in the illness trajectories for children with cancer and those with non-malignant conditions give rise to different kinds of challenges. It is also clear that the facilities and resources upon which the two groups of parents can draw in order to effectively deal with these challenges would appear to be inequitably distributed. In the main, parents of children with cancer have a well developed, sensitive and flexible set of services on which to draw. In large part, it is this well developed infrastructure that enables such parents to focus their energies on fighting 'the illness'. For parents of children with non-malignant conditions, the infrastructure is less well-developed, less easily accessed and less flexible. As we have shown, these inequities are reflected in the ways that

parents talk about their experiences of caring, in particular, how parents of children with non-malignant conditions repeatedly talk about having to 'fight' for resources. The message for service planners and service providers is clear – 'we [should all be regarded as] equal in the presence of death' (Publilius Syrus 1<sup>st</sup> century BCE).

Figures 1-3 in PDF as instructed



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