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Rodriguez, Alison and King, Nigel

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Sharing the care: the key-working experiences of professionals and the parents of life-limited children

Rodriguez, A. & King, N.

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Abstract

Aims: To explore the lived experience of caring and care planning for a child with a life-limiting condition (LLC). **Method:** Using van Manen's conceptualisation of hermeneutic phenomenology, three focus groups were conducted with 21 paediatric palliative care professionals, and interviews were conducted with 20 parents of children with LLCs.

Findings: Parents' expectations for support were raised by the diagnosis, but the reality could disappoint, which put pressures on professionals. Current service designs with respect to key working did not always coincide with family preferences. Both parents and professionals found that the care journey required them to shift personas to respond to different contexts. **Conclusions:** The findings are limited by the sample characteristics, but they provide insight for current policy and practice initiatives. The key worker needs to be mindful of historical care arrangements and be prepared to step into the family 'team' arrangements.

Key words: Children | Life-limiting conditions | Key-working | Family-centred care | Care planning | Qualitative

In the UK there are over 23 000 children and young people who are not likely to reach their adult years (Together for Short Lives, 2011). These children are classified as having life-limiting conditions (LLCs) or life-threatening conditions. It has been suggested that a life-threatening condition is one for which there is a possibility that a medical intervention might prove successful (even if the treatment poses a threat to life). Conversely, LLCs are those for which there is currently no available cure and the condition is likely to lead to the child dying prematurely (Together for Short Lives, 2013). In practice, the distinction is often arbitrary as an individual child may oscillate between the two definitions, especially during acute exacerbations of the illness, for example in children with cystic fibrosis. Palliative care for children is a comprehensive multidisciplinary approach to care that seeks to enhance the life of children and families living with LLCs. It involves a holistic approach embracing symptom management, psychosocial/spiritual care, and bereavement support (Together for Short Lives, 2013). The need for palliative care begins as soon as it is clear that a child has an LLC. Whether the palliative care is community-led, disease-specific, or specialist, individually-designed approaches are sought to support the child and their family to lead lives that are as normal as possible. Children's palliative care differs in a number of ways from adult palliative care (Malcolm et al, 2008). The LLCs are unique to childhood and there

can often be difficulties in providing a prognosis. Palliative care can span a longer period than would be expected in adult populations, and can also be episodic and unpredictable. Indeed, children can endure a number of what might seem to be terminal phases. Care is always aimed at being family-centred, as parents need supportive interventions to care for their sick child and other dependants. Conditions can be hereditary and therefore the family may already be bereaved or caring for other family members with the same condition. Unlike with adults, the extent to which the child understands the nature of their condition is dependant on their age and developmental stage.

In the UK there is now a plenitude of community-based and in-patient services to support children with LLCs and their families. However, there remain inconsistencies in provision across the country, and families often have to suffer the consequences of poorly coordinated care or a lack of provision (Noyes et al, 2013). Community nursing teams are often the supportive framework for palliative care services, enabling children to be cared for and to die at home. However, government-funded 24-hour nursing support is difficult to achieve. One of the major challenges for paediatric palliative care services in terms of both funding and planning is to provide services for a relatively small patient population who have high levels of dependency and complex needs (Downing et al, 2012). Uncertainties in prognosis and communication barriers between professionals and families are also said to impede care (Davies et al, 2008). Recently, a study by Whiting (2013) explored the experiences of parents caring for children with varied needs, including children with LLCs. A key theme was that of the carer experience being a 'battle' to get a diagnosis, meet respite criteria, and obtain funding. These findings concur with those of Rodriguez and King (2009), who discussed negative mental health effects of parenting children with LLCs, not just because of the nature of the children's conditions but also because of the daily demands and stressors related to fighting for help and services.

In 2010 the Department of Health (DH) made £30 million available for paediatric palliative care services to bid for projects that could enhance the lives of children with LLCs and/or to develop services. A review of this funding programme by Forbat and Adams (2011) highlighted the need for each child and family to have a dedicated professional in a key-worker role leading their care. Such a person would act on behalf of families, focusing on their unique needs and ensuring that they have access to the most appropriate services. Further research is needed around future planning for children with LLCs. There has been little guidance for professionals to draw on when working with families and supporting decision making (Noyes et al, 2013). Noyes et al (2013) recently documented intervention work in which they created 'my choices' booklets. These booklets address key milestones in care planning (ACT (now Together for Short Lives), 2007) and have been designed to facilitate family thinking about and involvement in care planning. Hence, there is beginning to be a supported approach to key working for professionals and families. However, explanatory models stress the importance of context, and so the authors of the present paper argue that this requires a close focus on the everyday experiences of families and the professionals who work with them. Consequently, the core research question for the study reported here was: what is it like caring and care planning for a child with an LLC? This broad question encompassed a number of research objectives:

- To investigate the roles and care experiences of professionals working in paediatric palliative care
- To explore the lived experiences of parents of children with LLCs
- To highlight where these perspectives do or do not converge.

Method

Design

The interpretive/hermeneutic phenomenological research methodology of van Manen (2001) was adopted for the research design. This method was chosen because it advocates an inductive approach to research, the goal of which is to describe the nature of lived experience.

Ethical approval

Ethical approval was granted by the Calderdale and Huddersfield NHS Foundation Trust (N0083102889 and N0083117158) and the University of Huddersfield.

Sampling and recruitment

The study was conducted in one UK county with both urban and rural localities. Recruitment of participants was sought after managerial approval and via link professionals, who included a senior community paediatric palliative care nurse, a lead person from a children's hospice, and a consultant paediatrician. These link professionals provided participants with information packs detailing the study. Professionals involved in palliative care in their day-to-day practice were invited to attend a focus group ($n=35$). Link professionals contacted parents who they felt would be able to participate in an interview discussion ($n=25$). They excluded any they thought would find the research process too distressing. Professionals and parents interested in the study filled out and returned forms agreeing researcher contact. The lead researcher then contacted potential participants informing them of focus group discussion dates or to determine times for interviews. The focus group dates and times were pre-arranged, giving a 3-month notice period. Unfortunately, this meant that some interested professionals were not able to participate owing to other commitments. Parent interview dates, times, and locations were mutually decided by each parent participant and the lead researcher. Unfortunately, owing to the unpredictable nature of childhood life-limiting illness, three interviews were not conducted. In each instance this was because of the child's need for acute or tertiary care. Each participant provided written consent prior to data collection.

Data collection

The study involved three focus groups with 21 professionals ($n=11$, 5 and 5) working with children with LLCs (*Table 1*). In addition, 20 individual semi-structured interviews were conducted with the parents (18 mothers and 2 fathers) of children diagnosed with an LLC. Of these children, 4 had been given cancer diagnoses (1 brain tumour, 1 bone cancer, 2 leukaemia) and the remaining 16 had been given other diagnoses (3 cerebral palsy, 1 muscular dystrophy, 1 congenital, 1 neurological, 10 rare genetic). A further stage of the research that involved interviews with life-limited children will be reported in a subsequent publication.

Analysis

Each focus group discussion and interview was digitally recorded and transcribed verbatim. The transcripts were then read and re-read, searching for themes. A line-by-line approach was followed (van Manen, 2001) and selected statements were attached to labelled units of meaning. These were the foundations for constructing interpretive summaries. The written accounts of the themes organised in template form facilitated a hermeneutical interpretation of the text (van Manen, 2001; King, 2012).

Findings

Three broad interrelated themes were found to characterise the shared care experience and perceptions of the professionals and parents: great expectations—and disappointments, the right help from the right person, and changing faces. Here, the structure of the experience of care shared between parents and professionals is found to be personal, transactional, communicative, and profoundly social.

Great expectations—and disappointments

Diagnosis of an LLC held both positives and negatives for parents. Immediately after receiving the diagnosis, parents commonly felt lost and full of despair about their child's future. However, they also had hopes and expectations that they would receive all the care and support needed. The reality of what services were available and the level of help, care, and support they could draw on was a shock.

'I think the oncology group, they've got some idea of how long they will need care and therefore you can kind of plan services. With the neurodegenerative conditions and in fact every other diagnosis ... you don't know how long they are going to live. Therefore, people are reluctant to put in care ... families are then left with very limited assistance.' (Paediatrician)

'My son has a lot of behavioural problems and a condition that has been determined to be genetic but we know little about ... this means we are left not being able to put him in a box.' (Parent)

Some parents reported feeling isolated and wanting more help. Professionals often felt pressured to deliver a good service against all odds, working longer than salaried hours and being involved in tasks outside their remit.

'My conscience often won't let me leave a family ... sometimes just going that bit further can help them massively.' (Community paediatric nurse)

The extra help offered was greatly appreciated by parents, especially if staff could intervene in communicating with other agencies or professionals.

'We have had over 20 professionals in our home ... and we have had to tell each and everyone of them about our child and their illness history and what the plan is, it's exhausting.'
(Parent)

'... if you've got a child with an LLC, the last thing you want is loads of different people ... You need to know that even if they can't solve a problem there and then they can do it on your behalf.' (Occupational therapist)

Relaying information led to anxiety for some families. Professionals realised the importance of parental reporting and the variance between parents in their ability and preparedness to do this.

'I think sometimes with some parents it's hard for them to keep telling the story, it's emotional, it's even harder then for them to be expected to take on care planning and related decisions.'
(Paediatric hospice nurse)

Nevertheless, professionals tried to encourage parents to take the lead in care planning to ensure family-centredness, despite knowing that this was not always appropriate or possible. Indeed, from the perspective of the parent, at times the goal of empowering families actually required professionals to take more of a lead, not less.

'If professionals are thinking about us, our needs as a family, then they need to see that we want to be aware of all our options but we are not medics or qualified nurses, we need them to say what help we need or what decision we would be better taking.' (Parent)

The right help from the right person

Professionals and parents discussed organisational barriers and the competencies of health-care providers affecting families' experiences. Some parents felt they were not being supported as well as they could be.

'When she [the child] first had her PEG [percutaneous endoscopic gastrostomy] put in we were sent home and left to get on with it ... [it was] quite scary to think we were sent home not knowing how to deal with this properly.'
(Parent)

In some cases, parents argued that their key worker was not as relationally close to the family as a given other professional. This was noted particularly when families had built strong relationships with professionals but had been given key workers who had not had much involvement with them previously.

'Some families will only accept one person that they get on with ... I think you need that ... but to perhaps also have someone else who can help out, also if there are problems that arise.'
(Community paediatric nurse)

'Professionals don't seem to talk to each other ... we were allocated a key worker who could help us with this process ... they hadn't worked with us before and they struggled to take on board the total circumstances of our family unit and life ... we were happy for this girl to become part of our team but not be given a lead helping role.' (Parent)

In these instances, parents continued to rely on the professionals with whom they were most confident and comfortable. Note the participant above referring to the professionals as 'our' team. Professionals were happy to continue their levels of involvement irrespective of whether they had 'official' key-worker status.

'I had one family and they said: "They've told me my child is going to die" ... their child had got just 2 weeks to live ... The week after they were going off to the coast in a caravan and their attitude was she could die at home or she could die at the coast, so I said: "Well if you want to go as a family then you go, I'll make sure you've got everything to take." I contacted a GP where they were going and said: "... you know there's this child coming, you know where the nearest hospital is ..." It was something I could get done to help them.' (Health visitor)

Often, parents stated they needed unforeseen help and were appreciative of professionals whom they said 'really cared' and were able to act in a timely fashion. Frequently these professionals were said to be the more experienced health professionals, whose care was said to be very personalised.

'The consultant is very good ... he will sometimes pop in to see how we are doing ... it is nice to know that he cares, he has seen us struggling sometimes and has done his best to help us out

when he can.’ (Parent)

Professionals also talked about the need for someone to be in a position to take responsibility for the needs of families.

‘What we need is someone who can see the bigger picture, who can take on board family needs and professional needs and sort things out ... so they are accessing all the cares they are entitled to and so that we are supported too.’ (Community paediatric nurse)

Importantly, across the parent interview data there was a desire to be involved in care planning and care decisions but not always to be the ones who had to flag issues or be making the final decisions. The burden of care is so great that the further energy needed for forward planning or ‘second guessing’ (parent) or just to orchestrate required discussions was felt to sometimes be too much for parents. To feel reassured that they were in ‘good hands’ (parent), even if they were aware of a lack of provision, would ease their day-to-day burden.

Changing faces

Being everything to everyone was a common notion across the two participant groups. For parents this was with regard to their maintaining relations with other family members and friends while also being a parent, carer, and ‘nurse’ to their ill child. For professionals this was related to working within and outside their job descriptions to facilitate family-centred care. One mother spoke of how she had researched her child’s illness and was aware of the diagnosis before it was given. Although she had trust in the professionals involved in her son’s care, she talked of knowing her son best, of being the one most alert to changes. The role of parent-as-expert was coupled with intense caring responsibilities.

‘I see to all his meds, we need to use suction quite a lot, otherwise it is keeping him comfortable now, he cannot be alone so we tend to work shifts through the night.’ (Parent)

The professionals appeared to accept the parent as-expert.

‘I can remember when I came into this role I was adamant that we needed to be finding trained nurses to help these kids that were needing a lot of technology, [but] over the years it has not failed to surprise me how many parents can just get on with it and really they end up doing a lot that we would consider skilled nursing care.’ (Paediatrician)

Despite the day-to-day care and emotional demands, trying to maintain a perceived level of

normality was important for parents and professionals alike. Parents felt the need to try and maintain closeness with their partners but acknowledged difficulties in affording time for each other and living the wife or husband role. For some families this lack of time for each other had led to marriage breakdown. The focus for normality was more heavily channelled toward siblings, so that they did not feel isolated. Professionals tried to nurture parents' thinking around normality for both the sick child and their siblings. The relinquishing of active treatment sometimes made it easier for the families of children with cancer to achieve 'normality'. Attention could now be paid to what the child liked to do or eat, for example, rather than being focused on treatment regimens and their side effects. But this movement was coupled with fear and upset in knowing the end could be in sight. Professionals in these instances talked about the need to be 'good cop/bad cop' (paediatrician) to try and encourage families to focus on family activities for the sake of all having happy final memories.

'... it is nice when they can talk about what they managed to cram in in those final days and they are comforted with it ... And we can all think about that and smile and then we can see why we have to really really try to rally parents on in their time of total despair.'
(Community nurse)

Guilt was expressed by parents who said they could not devote enough time to their other children. One mother talked about how her older children had become carers for her two younger children with health difficulties, not least because of periods when she struggled to cope. Parents acknowledged that it was difficult to share their time and that this led them to feel emotionally vulnerable. Professionals recognised this vulnerability and discussed lack of respite availability and supportive services for siblings. Where both the mother and father were at home, it was sometimes possible that one parent could spend a day out with a sibling on a weekly basis, and this time was cherished.

'We try and make sure his sister has one of us at least one day a week. She needs a break from the routine and to have the attention and childhood we think ... It is something like going to the cinema or going swimming or just having some food out. It does her ... [a] world of good and it does us [a] world of good ... you switch off ... we are just mum or dad to anyone else ... out with our daughter, no explaining, no ignoring, no struggling, a bit of a relax and she's not left out ... and with one of us away our son gets the other to himself too.' (Parent)

An additional role of 'business manager' was also implied, and not just to manage daily routines and demands. Both parents and professionals spoke of times when they needed to be expert negotiators.

'We often have to fight for these kids, we have a team and so we can get together and think and plan strategically, but we know not all families have a local team they can rely on.'
(Health visitor)

'Everything is a fight, from fighting to get specially fitted shoes to getting respite care to prevent us breaking down.' (Parent)

Difficulties were encountered owing to funding and service constraints, especially if a child did not quite fit certain service criteria or if a lot of funding was needed for equipment that is not generally funded. Parents could feel that their already-pressured time was consumed with filling out forms and arguing their cause. Professionals close to families in such circumstances could find themselves stepping out of their job roles to help parents, e.g. to help them look for potential sources of charitable funding or to help them frame their written arguments. Professionals talked of how complex their relationships sometimes became with families —akin to that of a friend or even a relative in some cases owing to the number of years of involvement. Stepping out of their professional identity and providing generalist help was therefore not something they would feel awkward about. This relationship closeness was especially difficult once the end of life for the child was near or when the child died.

'What do you say to the family? What are we going to say to mum you know? He's dying; how am I going to deal with it?' (Paediatric physiotherapist)

All of the participants discussed how important it is that service providers and funders are aware of the pressures families are under and the extent to which professionals are facilitated or inhibited by their level of closeness or familiarity with given families.

Discussion

Caring encompasses parents' lives, and professionals' roles are blurred by the close relationships that are formed. The emotional journey is fraught with complex decision making and communication. Field and Behrman (2003) highlighted that professionals need to realise that parents do not or cannot absorb every piece of information on first telling. If limited attention is given to information provision then there are risks of parents feeling unsupported and misunderstood by others in their care network whom they then have to relay information to. Time needs to be afforded for professionals to work with families to revisit goals, to assess their understanding of information provided, and to explore phases of their child's illness trajectory. Field and Behrman (2003) argued that no one professional can navigate decision making and that families need to work together with a number of specialists to explore how goals can be redefined and met. However, the current study argues that relaying information, having many professional contacts, and having to carve out their own packages of care can be very stressful for families. Wright et al (2009) stated

that it should not be taken for granted that the perceptions of families mirror those of professionals. They recognised that some parents will always want to be active decision makers whereas others will want to defer decisions or ask professionals to make choices for them. On the basis of the present study the authors argue that family advocates or assigned key workers could take a lot of the burden of information relay and the need to revisit goals with a number of specialists away from parents. This may be especially relevant in relation to advance care planning or end-of-life planning. Parents want to be focused on immediacy and periods of wellness; it may be too difficult to think about the end of life until the prospect is very near, by which time opportunities to ease suffering may have been missed. Again, appropriately assigned family key workers could be the ones to have early supportive end-of-life planning discussions with families.

Davies et al (2008) conducted a survey with hospital-based nurses and physicians to assess barriers to paediatric end-of-life care. Uncertainties in prognosis were associated with differences in treatment goals between professionals and parents. It was suggested that professionals need further education in communication skills and palliative care for children. Paediatric providers need to see and accept that uncertainty is unavoidable in the care of seriously ill children and there is a need to work through it with families. The current study goes further, suggesting that an uncertain prognosis is a sign to commence palliative care and key working rather than to delay them. Once parents enter the palliative care world, they desperately try to maintain their ties to their previous life. They particularly struggle with a level of guilt in having to neglect their spousal relationship and in feeling that they are not able to provide their other children with equitable time (Rodriguez and King, 2009). Where relationships are good, parents and professionals negotiate care and work together to engage more help and assistance. Where relationships are limited, parents can feel lost. Effective support for professionals requires an understanding of the complexities of relationships in each individual family, as also noted by Mehta et al (2009); this in turn requires a more subtle understanding of the professional role—especially the key-worker role—than simply an emphasis on ‘empowerment’. Indeed, what professionals may see as empowerment, e.g. in promoting choices and enabling parents to undertake more of the care for their child, can in reality make parents feel overburdened. Emphasis on parental autonomy can be seen as potentially undermining a familycentred approach (Mehta et al, 2009). Instead of promoting collaboration and joint decision making, it can be seen as shifting an excessive burden of responsibility onto parents. As Forbat and Adams (2011) concluded, there is a need in paediatric palliative care for a professional to take leadership of care for all, to promote familycentredness.

It is also apparent that parents try to define their own key workers, regardless of who is formally assigned to this role. They want to maintain a sense of ownership of ‘their’ team, and this may be hard to achieve if they feel an unfamiliar and/or inappropriate professional is assigned to them. Parents and first-line professionals are happy to maintain their caring relationships and close bonds; someone given the key-worker role could maintain a protective distance and yet support parents and front-line professionals together in their shared care endeavour. In this instance the ‘my choices’ booklets (Noyes et al, 2013) or similar discussion guide tools could be used to help families to organise their thinking around issues and to educate professionals with less experience with the family.

Limitations

The small sample size, influenced by the study's methodological stance, means that strong probabilistic generalisations cannot be made. In addition, the use of a gatekeeper for parent recruitment means that the sample may not have been representative. However, the premise was that there would be no bias and that information packs would be sent to all families meeting the study criteria. A further limitation to the parent sample is the lack of ethnic and racial diversity.

Conclusion

The current study adds insight into the more nuanced aspects of the requirements for key workers. Families need specialist help but they also need to maintain their bonds with current front-line and experienced members of their team. Key workers need to be mindful of family team arrangements and develop knowledge and understanding of issues key to each family. This will enable them to work with specialist agencies on behalf of the team. Undoubtedly, owing to the complex nature of these childhood conditions, the key worker may need additional specialist training to be successful in their role. They also need to show their readiness to be accepted as a team member rather than someone sitting just outside of it. With these families there is no generic model that can be applied to shape or formulate the key-worker role. What we can do is draw further on how these families perceive good family-centred care. For them, it is not about families being independent; it is about them maintaining a close-knit first-line team where care decisions and support can be negotiated between and among all parties. For some families at some points in the illness trajectory, being autonomous is too burdensome. Hence key working needs to have a creative team ethos, fostering support and respect for shared decision making. The key worker is therefore working with and not for the family and should not be dictatorial or over-burdening in encouraging independence. This can be a difficult balance to strike. Further research is required to better understand the practices, training needs, and service organisational arrangements that will best enable it to happen.

Declaration of interests

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