

INTRODUCTION:

The purpose of this paper is to examine the views and experiences of parents of children with life-limiting conditions on out-of-home respite care and to present a proposed new model of care based on the findings of this research. Parents provide the majority of care to children requiring palliative care with mothers often fulfilling the role of primary carer (Heaton *et al.* 2005; Monterosso *et al.* 2009; Remedios *et al.* 2015). Initially lacking confidence, experience and skill, parents become adept at caring for their child, often becoming the 'expert' carer (Kirk & Glendinning 2002), with varying degrees of support from healthcare providers and in some cases extended family members. The majority of care is provided in the family home however, assistance with care often depends on diagnosis and geographical location (Davies *et al.* 2004; Thomas & Price 2012). The unremitting responsibilities of caring for a child with a life-limiting condition effects all aspects of family life (Steele & Davis 2006; Rodriguez & King. 2009). Attending to care needs impacts on parental health (Steele 2002), causes social isolation (Thomas & Price 2012) disrupts family routines (Eaton 2008), and can lead to marriage difficulties (Stein *et al.* 1989; Steele 2005; McConkey *et al.* 2007). Marital strain can be further exacerbated by other factors related to caring such as strained finances, sleep disruption (Eaton 2008) and limited employment opportunities (Redmond & Richardson 2003; Champagne & Mongeau 2012; Thomas & Price 2012). In order to sustain the energy required to meet their child's care needs many parents require respite.

Respite, or 'short breaks' are often cited as an essential component of children's palliative care (Craig *et al.* 2008; ACT 2009; Remedios *et al.* 2015) providing a break from the routine of caring for both the child and family (Eaton 2008; Grinyer *et al.* 2010). Benefits of respite have been acknowledged as being multidimensional, in which it allows parents to: sleep (Eaton 2008); spend with partner/spouse (Olsen & Maslin-Prothero 2001; Champagne & Mongeau 2012); be with their other children (MacDonald & Callery 2007); or carry out everyday tasks (Olsen & Maslin-Prothero 2001). For respite to be acceptable to parents they require assurance that their child is safe and being well-cared for (MacDonald & Callery 2004). This may potentially be more challenging for parents when respite is provided out-of-home in locations such as hospital, hospice or a designated respite centre. Utilisation of out-of-home respite is dependent on a number of interlinking factors.

METHODS:

Research design:

Findings reported here are drawn from a larger longitudinal, qualitative case study exploring the respite needs and experiences of parents caring for a child with a life-limiting condition requiring palliative care in Ireland and reporting reflects the COREQ guidelines (Tong et al, 2007). Potential participants were selected by and accessed through the case-load of a palliative care team based in a tertiary children's hospital who distributed information packs to prospective eligible participants. Parents were interviewed between one and three times with a total of eighteen semi-structured parent interviews recorded.

The nature and composite of respite in children's palliative care is multifaceted and often complex involving a myriad of different people and services. Case study methodology captures and takes account of these factors. Multiple methods of data collection were utilised including: semi-structured in-depth interviews; participant observation; review of documentary evidence; and researcher notes. Children's palliative care is multifaceted and often complex involving a myriad of different people and services; case study is versatile and provides the structure to explore a range of issues making it the appropriate method for this study.

Sample:

In this research, parents were the 'case'. Inclusion and exclusion criteria were purposely broad. Purposive maximum variety sampling was selected in order to achieve a mix of cases that met a range of criteria and demographic characteristics. This paper focuses on data obtained during interviews with parents (nine mothers and three fathers) of children with life-limiting conditions. The children's ages ranged from 6 months to eighteen years, all were under the care of a children's palliative care team.

Data collection:

Using an interview guide, all interviews were undertaken with the parents of children with life-limiting conditions in their location of choice, with their consent all were audio recorded. Data collection took place over twenty-four months from June 2010. Some parents were

followed through to the time their child died whilst other children survived beyond the duration of the study.

Ethical considerations:

Ethical approval was granted by both the university and children's hospital ethics committees in June 2010. The process of gaining informed consent was carried out reflected the researchers' ethical responsibility to both the research process and the participants. All participants signed a consent form. All efforts were made to maintain confidentiality and anonymity including the use of pseudonyms and each case was assigned a number.

Data analysis and rigor:

All interviews were transcribed verbatim. Thematic analysis was employed for interview data following the steps of coding, categorisation and clustering. Initial analysis was informed by the analytical and theoretical ideas developed during the research, the process of data reduction through clustering enabled each individual case to be viewed clearly and data were categorised into themes. Themes specifically relating to out-of-home respite are shown in Figure 1. The process of constant comparison throughout the data analysis process was utilised. An audit trail was developed which provided a chain of evidence to enhance rigour and trustworthiness. Every effort was made to ensure that this research was designed, conducted and analysed rigorously (Sandelowski 1993; Hewitt 2007). Although findings of case study research are not statistically generalisable (Stake 1995; Yin 2009), cross-case comparison was undertaken to: compare commonalities and differences; identify shared and similar experiences; and to capture emerging conceptual issues and analytical themes.

RESULTS:

To emphasise the emergence of data from the findings, themes are presented and supported by direct quotations from participants. One of the themes identified in cross-case comparison, namely, "utilisation of out-of-home respite from a parental perspective" is the focus of this paper and forms the foundations for a proposed new model of care for out-of-

home respite. Of 17 parents approached by gatekeepers, 10 parents made contact with the researcher and nine were recruited, two of their children died during the study period.

Theme 1. - Parental need for respite

Parents reported the unremitting nature of caring for their child who often required care throughout the day and night. Parents demonstrated the level of skill and experience they had developed to provide care. Past experiences heavily influenced parents decisions regarding utilisation of out-of-home respite and their expectations of care delivery.

Becoming 'expert' carers

This was a process that occurred over a period of time. In many instances, this process was fraught with difficulties.. Although initially novice carers, parents quickly acquired and developed the skills that enabled them to become carers. Often demonstrated by healthcare professionals or learnt through experience, skills included sometimes complex technical care such as suctioning as described by one father: *"...we were shown a couple of times...supervised and that was it, you had to do it ... if we didn't manage that he'd die so that's...an awful responsibility"* (3D)

Impact of caring

The presence of a child with respite needs in the family changed the norms of family life. While the demands of care were inherent within the full day, it was not surprising that there was an impact on the parents in their quest to provide, what they considered, quality care. Exacerbated by stress and worry about their child, the majority of parents reported regular sleep disturbance and many reported sleeping with their child in their bed as one mother reported *"...most nights she's in the middle of the bed...so I can just reach out (6M)*. This occurrence was not unusual, as is demonstrated by another parent who commented. *'sometimes you'd have to physically get up and bring her downstairs and sit with her'* (2M)

Family help

It became evident that family support varied among participants. While generally there was a concerted effort to support parents as they cared for their child, it was not uncommon for participants to note a change over time; *"...family support was fantastic...gradually they fell*

back to their own lives so you know you are left on your own with your child like to try and muddle along” (1M). .Parents recognised the anxiety that caring for their child caused to others often impacting on their ability to offer help “...my mother ... was with me a few times when he had little turns...she hasn’t kind of offered...they’re just I suppose afraid” (8M). Cross-case comparison revealed that extended family members who were trusted by parents to provide support shared several key features: all had provided care from soon after birth or diagnosis, many felt confident in their ability to provide care.

Previous experiences of in-patient care

Previous experience of in-patient care in any location influenced parental decision-making regarding the utilisation of out-of-home respite. Home was unequivocally the location of choice particularly if their child was unwell and time was perceived as limited. Parents found inevitable hospital admissions more stressful than providing care at home... “we have to stay there...it is impossible to give the care she needs in a busy ward where children are going to theatre and there’s infections and it is just the worst scenario for us is if (she) ends up in hospital” (1M). All parents explicitly stated that regardless of the length of admission they would not leave their child alone in hospital.

Others were critical of the standards of care their child received “when he’s in hospital it’s a killer... you have to be with your child all the time, you won’t get the care because they’re (staff) so busy... (mother) is so used to looking after him now, she’d be nearly left to her own devices...they know we know better than they do a lot of the time” (3D). With another parent simply saying “...because she doesn’t get looked after properly...she would be left in the bed all day basically “ (2M) Decisions regarding utilisation of out-of-home respite care were broadly based on four interconnecting factors: previous experiences; standards of care; acceptability and accessibility; and fears.

Out-of-home respite was utilised by some parents in residential respite centres primarily established to provide care to children with disabilities. Some families had out-of-home respite care tailored specifically to meet their child’s needs “They have a room that’s only for (our child)... painted pink...all her clothes are there...it is her siblings second home” (1M).

As care needs became more complex parents reported that the majority of extended family no longer provided care for their sick child. As their child grew older and heavier not only did parents struggle to meet their child's physical needs, grandparents also reported this to be a key factor in whether they were able to provide support and thus their child's respite needs changed over time. This last paragraph seems misplaced here – Would it fit better above within the family section

Theme 2. Parental perception of standards of care:

Parents reported benchmarking the care provided out-of-home against their own standards. *"I just really feel that when she goes somewhere else that she won't get the same care"* (2M). Reassurance was needed that staff were skilled and able to provide high quality care *"There are so many situations ... that I make quick decisions about...they could be right or wrong but I make them and that's it they're made, where as in there (respite) they would have to seek medical advice and then the GP would certainly refer to the hospital...then she would end up in hospital"* (1M). Parents also clearly expressed a need and expectation that carers respect their child, family and home and acknowledge parental knowledge as expert carers.

Staff turnover

Parents were concerned about staff turnover and continuity of care valuing consistency in staffing and the stability this brought for their child. While it is acknowledged that *"...regular staff...better for continuity"* (1M). Familiarity with the child and their routine were of importance to parents who raised concerns about new or different staff *"...that they wouldn't know anything about him ... and what if he took these turns during the night"* (3P). There was an effort made by parents to avoid out of home respite as much as possible in some situations. Disruption to routine and the need for familiarity were cited as reasons for not using out-of-home respite. *"Feeding times were not important...we wanted respite to be continuation of the home ...We still have a huge problem with handing her over because we know that routine is so important ... that if you don't give her everything on time then she will suffer"* (1M)

Exposure to infection

It was recognised that these children were susceptible to infection, which, if acquired for some, would have been fatal this was an added concern for parents when considering out-of-home respite settings *"you are very housebound ...because if you are bringing her in and out she is going to pick up stuff...it seems like we mollycoddle her but it is the best way for her because we are limiting her bugs...we are limiting her time in hospital – since we have taken (her) out of school...trips into hospital have gone down dramatically"* (2M).

Theme 3. - Acceptability and accessibility

In order for parents of children with life-limiting conditions to consider out-of-home respite it is essential that the respite offered to them is provided in an acceptable format and location. All participants had been offered some form of out-of-home respite but found it to be unacceptable *"... the way I see my family is here I don't see my child in a respite place but that's not saying that I don't think it is right for other people but you know ... I wouldn't judge someone else for using respite that's the way they are ...they mightened have as much support maybe with their family as I do..."* (2M)

Travel and distance to respite centre

Where acceptable, local, accessible respite was important to parents. Significant travel was a deciding factor. In one case parents described their use of a service two hours from their home *"...there was no respite in the area... we would sit in the car and wait 3 hours to pick her up..."* (1M)

Some parents referred to school as respite, this has been recognised by others where it provides a natural break from caring (Johnson & Steinhorn 2012). In this research all children who were of school age, either had, or continued to attend school. For parents, even their child's need for complex care did not deter them (For example, one child attended the local school with a ventilator). The symbolism of their child doing something normal such as attending school and being part of the wider community was often a motivating factor for parents. As an example one parent who was concerned about what the neighbours thought, sent her daughter to the local school rather than sending her on the "special bus" to a "special school" this was particularly an issue for those who lived in small rural communities.

Fears

Parents reported a number of concerns that influenced their decision regarding the utilisation of out-of-home respite. Often based on information either given to them by healthcare professionals or sourced independently, parents were reluctant to leave their child if they feared that time was limited *“I don’t know how much time we’re going to have ... I’d hate to be gone if something happened, you’d want to be here” (3M- 141).*

Trust in carers

Parental ability to trust the staff providing care in out-of-home locations was viewed as essential. Parents sought consistency in staffing and the development of trust before they were able to handover their caring responsibilities to others. Parents were concerned about the competency and experience of staff providing care to their child *“you always assume that no one is going to look after her like you” (2M) and “... I would trust them but I suppose they are not going to love her like we love her...you know it’s a job like and they treat it as a job” (1M).*

Safe from harm

Parents also sought assurance that no harm would come to their child from other child-users of the respite service *“(they would)... keep the room with (our child) locked to keep autistic children out from harming her... it’s important that children going in are matched with (my child) I...see respite is very delicate because if there was a hair on her head harmed when she was there we would say were not sending her in next time” (1MIV1-305).* Another mother commented *“you can’t put her in where there’s a group with challenging behaviour, active...throwing things...she can’t cope with loud noises and she gets upset” (6P).* A teenage girl with cancer being discharged to a respite centre where the majority of other children had intellectual and physical disabilities found the other residents behaviour upsetting *“...for children without mind this is very good place ...wrong place for children who understand...everything is perfect...food everything is great...not for child who understands” (4M).*

DISCUSSION:

Findings from this research provide the foundation for a proposed new model of care shown in Figure 2. Based directly on findings from this research, the model demonstrates the multifactorial nature of decision-making for parents considering out-of-home respite for their child with a life-limiting condition. Clearly identified in the model are key factors including: the child's prognosis; the skills and experience of staff; and trust in carers and the maintenance of routine that impact on parental decisions regarding the utilisation of out-of-home respite.

Prognostication in children's palliative care is inherently challenging, despite evidence from parents of children with cancer suggesting that parental prognostication overestimates survival (Wolfe et al. 2000). Findings of this research clearly suggest the opposite with parents frequently reporting that their child had outlived all medical expectation. This impacts on parental decision-making which is also heavily influenced by past respite experiences.

In this research caring skills frequently taught by healthcare professionals or gained through experience provided an element of control in the face of much uncertainty. Overtime both respite and care needs of children change as does the level of support provided by extended family members who resorted to helping in other ways such as providing financial assistance or babysitting for well siblings. These confirm the findings of research findings with children with disabilities (Katz & Kessel 2002; MacDonald & Callery 2004).

Parental trust was gained only when carers could pragmatically demonstrate that they were capable of meeting parental care expectations and standards. Parents continually assessed and judged carer's clinical skills and manner (Thompson *et al.* 2003; Monterosso *et al.* 2007a). Parents value mutual respect (Heller & Solomon 2005) and in this research they especially valued carers who were friendly, treated them and their child with respect, were not patronising and who respected family privacy. In particular they expressed negative feelings towards carers who portrayed pity or who did not address the child directly. Trust was not dependent on the age, gender, professional qualifications or past experience of the carer but was judged by the parents during their interactions over-time. Previous research has indicated that all those caring for children with a life-limiting condition should have specific paediatric experience and skills (Monterosso *et al.* 2007b), however participants in

this research suggest that parents considered other factors to be of greater importance than qualifications. Parent's resented the process of repeatedly training new staff to care for their child. Similar findings are reported by parents of children with disabilities (Robinson *et al.* 2001b) and those whose children received hospice care (Eaton 2008) and highly valued carers respecting the child's routine. This research identifies all of these components as they relate to respite in childrens palliative care in one model.

Overall evidence suggests that familiarity with staff and routine, are essential components in enabling parents to relinquish some control over their caring responsibilities and allow others such as those working in out-of-home respite to provide care however past experiences of out-of-home care strongly influence respite care decisions.

In this research parents did not equate hospitalisation of their child with a break, conversley finding this more stressful than providing care at home. Utilising the model it is possible for healthcare professionals to identify past experiences and address parental concerns. Transporting medically frail children and the equipment made travel challenging therefore proximity was a key factor in decision-making.

The proposed model

The proposed model will take cognisance of parents' experiences of respite care and help to consider the influencing factors that parents are challenged to go through as they consider the overall model of respite they are planning for their child. It will provide a framework for healthcare professionals to assess options with families enabling them to identify barriers and facilitators to respite care and to thus tailor respite that meets the families individual needs and preferences.

STRENGTHS AND LIMITATIONS:

Strengths:

The basic tenets of children's palliative care are that the child and family are viewed as one unit of care. Enabling families to get a break from the routine of caring is fundamental to their well-being and continuing ability to care over often sustained periods of time. The concept and delivery of respite in children's palliative care has not been specifically

examined from a parental perspective. This research and specifically the proposed model of care adds to the body of evidence on respite as it specifically relates to children who have a life-limiting condition regardless of diagnosis and age. This is the first research of its kind in Ireland and provides a unique view of respite in children's palliative care.

Limitations:

This research is limited to the experiences of nine specific families in one country with its own unique culture. Parents experiences were explored through case study methodology and therefore findings cannot be generalised, however cross-case comparison revealed commonalities within and between cases. Participants were selected by gatekeepers resulting in a need to determine if the experiences of parents who were not referred differ from findings presented here.

A new model of care:

This model is empirically based on the views and experiences of parents living with a child with a life-limiting condition. By encompassing the factors impacting on their decisions identified by parents longitudinally, it provides healthcare providers with a framework within which to assess, plan and deliver effective respite care to children and their families outside of the family home. Whilst provision of respite varies within and between countries this model incorporates findings from international literature and may therefore be transferable. The model provides a systematic process through which those caring for children with life-limiting conditions can assess and address parents concerns and by utilising this model it is possible to identify areas where parents may require further action, support and reassurance before handing over their caring responsibilities to others.

Policy and practice implications of the research and the new model:

Children's palliative care is a relatively new specialty where there is a paucity of evidence to support practice. This research and specifically the proposed model of care highlight the factors that parents take into consideration when choosing to accept respite care for their children with life-limiting conditions. Location of care has implications for healthcare planners and providers and this research may help to focus developments in the location of

parents choice. Pragmatically this model could be used as part of the assessment process for parents caring for a child with a life-limiting condition.

Further research:

Further testing of this model will be required, however it appears to be flexible enough to support its consideration for broad application in children's palliative care and in particular in assessing suitability of out-of-home respite care. This model of care may also be useful in underpinning a larger quantitative study of out-of-home respite in children's palliative care.

CONCLUSION:

When parents have a child with a life-limiting condition requiring palliative care they are most often not only the primary carers but also the experts in the care of their own child. Despite the need for respite, handing over responsibility for caring for their child is challenging. Findings of this research provide the basis for a new model of care for out-of-home respite in children's palliative care. Based directly on the barriers and facilitators identified by parents as influencing their utilisation of out-of-home respite, this research clearly demonstrates the myriad of factors that influence parent's decisions on utilisation of out-of-home respite. The model provides a pragmatic approach for healthcare professionals enabling them to clearly identify and effectively address the issues impacting on parents decisions regarding the utilisation of out-of-home respite for thier children with a life-limiting condition.

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