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**‘Starting Out in Haziness’: Parental Experiences Surrounding the
Diagnosis of their Child’s Non-Malignant Life-Limiting Condition in
Ireland.**

Abstract

Purpose

To explore parental experiences surrounding the diagnosis of their child's non-malignant life-limiting condition.

Design and Methods

A qualitative descriptive study design using single-occasion one-to-one semi-structured interviews collected data from twenty-three parents of children diagnosed with non-malignant life-limiting conditions.

Findings

'Starting out in haziness' was the central concept when parents' recounted the time they learnt of their child's diagnosis. Analysis revealed three main distinct but interconnected themes within this concept helping us better understand the experiences of parents at this particular time, those being: 'Entering a whole new world', 'Acquiring a learner permit' and 'Navigating the unknown territory'.

Conclusion

Learning of their child's diagnosis was highly distressing for parents and was marked with emotional chaos. Parents' process of realization regarding the diagnosis was related to the diagnostic process. Information and communication needs should be individualized accordingly. The findings have implications for service provision, particularly with regard to how supportive care is delivered at this time.

Keywords life-limiting, parents, children, diagnosis, experience

The term 'childhood life-limiting condition' encompasses children with non-malignant as well as malignant conditions with the range of conditions being extensive (Siden, 2018). The United Kingdom (UK) charity Together for Short Lives (TfSL) has, however specified four categories of childhood life-limiting conditions (TfSL, 2018). The classifications include: possibly curable (Category 1), conditions associated with periods of good health, but limited-life; (Category 2), progressive conditions without curative treatment options (Category 3) and non-progressive conditions causing severe disability (Category 4). (Table 1). There has been a significant increase in the number of children living with life-limiting conditions an increase which is forecasted to continue (Fraser et al., 2020).

Children with non-malignant life-limiting conditions (NMLLCs) constitute the largest proportion of children requiring palliative care (Siden, 2018). This is partly due to technological advances, resulting in growing numbers of these children experiencing improved survival as well as improved survival rates for children with cancer (Nageswaran et al., 2018). When a child is diagnosed with a NMLLC the lives of the parents and the family are individually, collectively, and permanently altered (Fullerton et al., 2017; Postavaru, 2019). The challenge is one of being thrown into an abnormal unready world which compels one to consider the paradoxical temporality of the here and now. Relationships within the family and with the healthcare team become crucially important (Bailey-Pearce et al., 2017; Ekberg et al., 2018). However, little is known about parental experiences surrounding the diagnosis of a NMLLC. More research exists regarding parental experiences of having a child diagnosed with cancer (Caprini & Motta, 2017; Siden, 2018). Whilst these studies are insightful there is a need to specifically understand parental experiences surrounding the diagnosis of a NMLLC. While some elements of care overlap other elements, especially prognosis and trajectory, have nuanced differences (Nageswaran et al., 2018; Siden, 2018). Caring for a child with a NMLLC is a multifaceted experience for parents. Parents face the enormous challenge of being a parent and providing the best care, while at the same time processing their situation and acting accordingly (Verberne et al., 2017). However, the

majority of studies have focused on caring for a child throughout the trajectory with little emphasis on the time surrounding diagnosis (Collins et al., 2016; Randall, 2017; Spiers & Beresford, 2017). Such understanding is paramount for healthcare professionals who support parents at this time. Parents must contend with the possibility of their child's death in the context of negotiating a path (Bailey-Pearce et al., 2017). How parents process their situation and adapt ultimately affects the child's and family's well-being (Koch & Jones, 2018). This paper explores parental experiences specifically surrounding the period of diagnosis. This paper is part of a larger study which explored the experience of caring for children with NMLLCs including, accessing services and decision-making surrounding the child's care.

Table 1

Categories of Life-Limiting Conditions and Life-Threatening conditions (TfSL 2018, p.11).

Categories

Category 1

Life-threatening conditions for which curative treatment may be feasible but can fail.

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration or threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

Examples: Cancer, irreversible organ failures of heart, liver, kidney.

Category 2

Conditions where premature death is inevitable.

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples: Cystic fibrosis, Duchenne muscular dystrophy.

Category 3

Progressive conditions without curative treatment options.

Treatment is exclusively palliative and may commonly extend over many years.

Examples: Batten's disease, Mucopolysaccharidoses.

Category 4

Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.

Examples: Severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injuries.

Methods

Research Design

A qualitative descriptive study design was adopted to gain a comprehensive insight into parental experiences surrounding the diagnosis of their child's NMLLC and to keep participants' perspectives central to the study.

Recruitment and Sampling

Purposive sampling was used for the recruitment of participants. An Advisory Group, comprising of healthcare professionals in the field of Children's Palliative Care (CPC) and academics involved in CPC research on the island of Ireland oversaw the implementation of the research playing a key role in advising re recruitment. Five organizations were identified from which to recruit participants, including a Children's hospital, two children's units within regional hospitals, a respite facility and a children's hospice. The organizations were situated in Ireland (two urban and two rural) and one situated in the north. The decision to include representation from different providers and geographical settings was made in an effort to learn about a diverse range of experiences. Efforts were likewise made to include parents of children of varying ages and diagnoses. Recruitment took place through gatekeepers at each organization. Eligible parents (both mothers and fathers) were over eighteen years from a broad socio-demographic spread. Fluency in the English language was required. All gatekeepers were experienced Children's nurses.

Sample Size and Participant Characteristics

Interviews were conducted with parents until data saturation. No additional data or themes emerged at this point and the interviews were stopped. This culminated in a sample of twenty-three parents representing twenty-two children (as both mother and father of one child chose to participate). Overall, this comprised of eighteen mothers and five fathers. (Table 2). The children had a wide variation of conditions, including Cerebral Palsy, Duchenne Muscular Dystrophy, Spinal Muscular Atrophy and undiagnosed metabolic disorders. They had a range of complex medical and care needs. (Table 3).

Ethical Approval

Ethical approval was obtained from the Ethics Committee in the relevant University and also from the five organizations on the island of Ireland involved in recruitment.

Data Collection

Data were collected using single-occasion one-to-one semi-structured interviews with parents. Twenty out of the twenty-three parents were interviewed in their home. Three parents chose other venues. A topic guide was used. The guide was developed by the first author after reviewing several studies and following consultation with the second and third author. The guide was designed to support parents to reflect on the time when their child was diagnosed and to facilitate discussion regarding the impact of same and their experiences of support. An initial pilot was conducted with one parent to sense check the topic guide.

Data Analysis

Braun and Clarke's (2006) six-phase thematic analysis framework was used to guide data analysis. The recorded interviews were transcribed verbatim, checked for accuracy, and entered into NVIVO 10 for data storage and management. Initially open coding identified themes which were then refined, cross-checked, and adjusted as needed through discussion with the second and third author, who independently coded the data, until reaching consensus. Finally, exemplars were identified and chosen through selective coding. To assure trustworthiness, the first author conducted all interviews and kept memos detailing the interactions.

Findings

'Starting out in haziness' was the central concept when parents recounted the time they learnt of their child's diagnosis. Analysis revealed a crucial part of parents' stories was the emotional chaos which appeared to emanate from the shock of the seriousness of their child's condition. Analytically described as the concept of 'Starting out in haziness' three main distinct, but interconnected themes contributed to this concept those being: 'Entering a whole new world', 'Acquiring a learner permit' and 'Navigating the unknown territory'. Given the importance of describing parents' overall experiences in this paper, the findings are presented in detail at the theme level. Additional quotes that illustrate each theme are represented in Table 4.

Table 2*Participant Characteristics*

Characteristics of the participants	n= 23
Parent gender	
Female	18
Male	5
Marital status	
Married	18
Single (never married)	2
Separated	2
Widowed	1
Education	
No formal education	1
Primary education	2
Lower secondary education	3
Upper secondary education	1
Technical/vocational courses	7
Bachelor Degree or National Diploma	8
Professional qualification	1
Employment	
Full time carer	20
Working for payment/profit	3
Ethnicity	
White	23
Residence	
Urban	15
Rural	8

Table 3*Child Characteristics*

Characteristics of the children	n= 22
Child gender	
Male	14
Female	8
Categories of life-limiting conditions	
Category 1	1
Category 2	1
Category 3	11
Category 4	9
Age	
0-4yrs	11
4-8yrs	7
8-12yrs	1
12-16yrs	3
Time since diagnosis	
0-4yrs	11
4-8yrs	8
8-12yrs	1
12-16yrs	2
Required artificial nutritional support	
Yes	20
No	2
Required medical technology (mechanical ventilation/respiratory support)	
Yes	22
No	0
Required regular/intermittent medications	
Yes	22
No	0

The Central Concept: Starting Out in Haziness

'Starting out in haziness' represented the time period from diagnosis or recognition of a life-limiting condition and marked the beginning of an unknown journey filled with emotional turmoil. For some parents the diagnosis came early either antenatally or shortly after the birth of their baby. The unexpectedness and speed of the diagnosis often left parents feeling ill-prepared to deal with the harrowing situation. Other parents faced a long and arduous search for a diagnosis which sometimes took months or years. Receiving a named diagnosis appeared very important for these parents evidenced by a determination to arrive at a diagnosis, which they hoped would enable them to make sense of their situation: "*we fought for a diagnosis.*"[P2]. Parents felt that a diagnosis would provide a degree of clarity or direction as they were starting out on their unknown journey. Sometimes, however the specific diagnosis was never found. This lack of a named condition often left parents feeling in limbo. Parents who did finally receive a named diagnosis realized that it did not in fact offer a solution to the multiple challenges that they, their child and the whole family faced.

Whilst parents' stories were all individual and the presentation of their child's condition different what was clear was the diagnosis of a life-limiting condition turned their life upside down. It shattered dreams, transformed lives and propelled most into recognizing that their parenting experience would be forever different: "*I had to bury my dreams of what he was going to be.*" [P2]. Additionally, it appeared that this was the first time in their lives that they had encountered such an overwhelming inability to alter or influence events. Thus, parents reported feelings of complete powerlessness. Profound emotional distress was core to parent accounts. Such emotional distress appeared to trigger the haziness. Parents described how they were utterly shocked at this time. As a result, they could not comprehend the information that was imparted to them. Grasping the immediate and long-term implications of the diagnosis was a complex process for all the parents. Parents spoke of having uncertainty; of not knowing the extent of what having this condition meant for them

and their child and of feeling that they had no real conceptualization of what the future may bring.

Parents described the initial months following diagnosis as life-altering and all-consuming as they started their journey in the emotion, shock and disbelief that created the haziness. They reported the unremitting nature of caring for their child often throughout both day and night led to profound exhaustion. Parents described how meeting their own needs became secondary to meeting their child's care needs. Low parental mood was a particular issue shortly after diagnosis in the haziness that marked their lives. Some mothers and fathers recounted being prescribed antidepressant medication in the months following diagnosis. Parents grieved the loss of a healthy child as well as the loss of their aspirations for their child. Even with a backdrop of overwhelming emotion parents recognized that life as they knew it was permanently altered: *"we thought our world was going to fall apart."*[P15]. Despite the haziness there was an awareness on the part of parents that they were 'Entering a whole new world'.

Theme 1: Entering A Whole New World

Simultaneously to 'Starting out in haziness' parents possessed an awareness that they were 'Entering a whole new world' one characterized by hospitals, appointments, medical investigations and equipment. Parents had an awareness that they could not stop their entry into this world, but they knew for definite it was a world they did not want to be in: *"I entered a wee world that I didn't know existed beforehand. I never ever wanted to be part of. And you are part of it."*[P6]. Moreover, entering the new world was a journey marked with unfamiliarity and a degree of intimidation. Their personal world had become completely uncertain and unpredictable: *"everything's all new to you."*[P11]. Additionally, their hopes, dreams and plans no longer seemed to pertain as the world that they once knew was altered irrevocably.

On entering this new world parents entered a world of decision-making that they had never known. Parents faced numerous challenging decisions, including decisions regarding ventilation, surgery and invasive treatments. Parents revealed decisions that created incredible stress for them and their families: *“we were told if she didn’t have the operation she would die but there was a possibility that she could die in surgery also. So... we just had to take that lifeline and hope for the best.”* [P12]. Within a single conversation, parents were often given the diagnosis, possible prognosis and then presented with a complex array of decisions. Despite the specific diagnosis and differing circumstances leading to the diagnosis, all parents were driven by the desire to give their child every chance of survival. Parents were often faced with the immense, heart-breaking responsibility to withdraw life-sustaining treatments on diagnosis, with a number later regretting these decisions as they proceeded on their care journey.

Sometimes the outcome of certain decisions could not be predicted. This is described in the following scenario: *“we made a decision to take him off the ventilator, because the longer we left it, the worse it was going to get.”*[P10]. The infant, however, survived following the withdrawal of ventilation. Decisions were made easier when parents trusted healthcare professionals caring for their child and perceived them as caring: *“they didn’t push me.”* [P22]. However, the haziness undoubtedly had a significant impact on the parent’s ability to make decisions often making such decisions in moments of profound emotional turmoil.

Theme 2: Acquiring a learner permit

As parents were ‘Starting out in haziness’ in this ‘new world’ they had to acquire a new range of knowledge and skills as they learnt to parent in a new and unexpected way. Learning to care for their child was often perceived as an experiential undertaking:

As I always say we're only learning...we haven't been actually trained to do this... we're teaching ourselves. We haven't got it wrong yet but there's no saying we won't get it wrong, but we'll not deliberately get it wrong. [P15].

Parents often experienced an overwhelming sense of fear in the early days of learning to care for their child. This fear generally stemmed from their perceived lack of knowledge, the fragile nature of the child and the health status of the child: *"we were worried sick about him, because he was very, very small."*[P19]. Parents discussed specific fears for example, fears of dislodging endotracheal tubes and oxygen tubing and of those fears, then contributing to reservations about touching or holding their child. Feelings of being overwhelmed pervaded parents' stories, particularly in the early stages of coming home from hospital with their child. Parents learned ways to respond to their fears, for example, holding their infant/child despite the worry of dislodging tubes, constantly checking the infant/child or making a conscious decision not to sleep. However, the need to remain constantly alert and sleep deprivation without doubt exacerbated the haziness.

Providing care at home necessitated that all parents learned skills akin to those usually performed professionally by nurses. In most cases the level of specialized care required by the child precluded obtaining help from family or friends. Parents described the challenges of providing technical care and recalled having concerns during the period in which they were being trained for and/or took on responsibility for a procedure. Many parents reported that they were extremely anxious at this time. Parents reported having concerns about the safety implications of undertaking certain procedures and as a result, they often needed reassurance from healthcare professionals:

They showed me the PEG how to clean it one day and I nearly got weak. The nurse was lovely. She was really nice. She showed me how to do it about ten times. I said, 'what if it comes out?' she said, 'it won't.' She was really good, like, in fairness to her. [P1].

The responsibility for a procedure that was potentially life-threatening if mishandled was daunting. However, support from healthcare professionals made 'Acquiring a learner permit' easier.

It was clear that parents felt overwhelmed and ill-prepared in learning to care for their child. However, support from healthcare professionals and social support certainly made the experience easier. The parents were grateful to the few healthcare professionals that went above and beyond their role to help them feel supported during times when they felt most vulnerable. Sensitive healthcare professionals were able to enter the life world of parents and understand it from their perspective. Parents were also faced with the issue of accessing services and support for their child at this time. Communication with healthcare professionals played a significant role in how parents began the process of 'Navigating the unknown territory'.

Theme 3: Navigating the Unknown Territory

Navigating the unknown territory refers to the process that the parents were required to undertake in order to access services and support whilst caring for their child. It was clear from the parents' stories that the experience of caring for a child with a NMLLC was also overwhelming in terms of finding and accessing services and support.

Parents' ability to navigate the unknown territory was strengthened through the provision of information in a sensitive and timely manner. However, for many parents, the communication process at the time of diagnosis was fraught with difficulty. Insensitive use of language impacted significantly on parents as they started out in haziness: "*they basically said that my son had been born a vegetable, and that's the word that they used...they told me that he was going to have no quality... absolutely no quality*". [P10]. While learning the diagnosis, parents were also processing the emotional impact of this unexpected, life-changing situation. Initial information was often given at a time of intense emotional distress. Many parents described how they were given heart breaking information without any follow-

up support. For some parents, the stress of the diagnosis was heightened by their perceived lack of professional support:

We were actually told; you've got a diagnosis. And the exact words were, I suppose you'll have to go home now and make the best of the time you have. I think that was far more devastating. It was the fact that because when it's (name of condition), there's nothingthere's no treatment and there's no cure. It was the nothingness of it. [P18].

Furthermore, many mothers in particular described scenarios where they were given distressing information when alone and unsupported.

Many of the concerns expressed by parents involved a need for more information on diagnosis, with many commenting that healthcare professionals lacked knowledge regarding their child's condition: *"He just said, your son has (name of syndrome) and there's a leaflet. I don't know anything about it. You'll have to wait and talk to another consultant from the metabolic unit and sent me on my way."* [P22]. Parents also described how they were not given enough practical information, with some perceiving a reluctance among healthcare professionals to share information with them. Parents likewise described clinical practices that reflected a technocratic approach to care. This was characterized by poor communication, interpersonal and time management skills as well as a lack of human understanding and compassion:

The neonatal doctor ... he would never answer my questions. He'd come in and go, so today we've got the Newcastle Work up and the bloods.... I hadn't a clue what all this meant.....and when I asked questions...he'd be gone. [P4].

Parents were frustrated with the lack of information and themselves sought out further information soon after receiving their child's diagnosis. In some cases, they talked about needing to do so partly because healthcare professionals had given them insufficient information, but for all of them it seemed to be a useful coping strategy, a feeling they were taking charge of the haziness in this new world.

Table 4

An Overview of the Themes outlining the Parents' Experiences

Themes	Illustrative quotations
<p>Theme 1 Entering a whole new world</p>	<p><i>Because it's a different world, you know. When you go into one of those rooms, it's a live-or-die room. It's an alien world because you've never been in to an intensive care unit, and you don't understand what it's about. [P15].</i></p> <p><i>he was on life support and lying there, and we had told the doctors, you know, no matter where you have to take him, just try and keep him safe. [P14].</i></p> <p><i>We decided not to shunt him, and we brought him home. I don't know was that the best decision? In hindsight, now, I regret that we didn't shunt him earlier, because his head got bigger and bigger and bigger, and we didn't shunt him until he was seven weeks old, and his head, now, at that stage, was massive, so it was, which in hindsight I regret. I wish we had. [P19].</i></p> <p><i>We decided to have him christened the next day and we got his godparents together and they came into the hospital. We got all our family together to say goodbye, because they gave us an indication that he wouldn't survive. So, they all came in and said their goodbyes and we had him christened at about 5 o'clock and everybody left, and then at 7 o'clock we took him off the ventilator and he started breathing by himself. [P10].</i></p>
<p>Theme 2 Acquiring a learner permit</p>	<p><i>I just got to hold him, it was a mixture of relief, love, and worry that, you know, am I going to knock his tube out here? What if he stops breathing on me? [P14].</i></p> <p><i>when we first came home, I didn't go to the toilet. I was terrified. [P3].</i></p> <p><i>and we got him home the day before Mother's Day which was quite nerve-racking and in fact the first night we didn't sleep a wink because we stayed up and kept checking him in the cot, worrying is he breathing, is he alright? [P14].</i></p> <p><i>I never learnt to do it like. I just did it once and it really upset him and I caused him problems. It didn't work out right. I couldn't do it again. Maybe now I would be able to do it. I couldn't do it at the time. [P1].</i></p>
<p>Theme 3 Navigating the unknown territory</p>	<p><i>He came to us and said, basically, your child will never walk. He will never sit up. He will be a vegetable. He will be on a sofa, on a ventilator 24hrs a day for the rest of his days. That is the condition that is the future. [P16].</i></p> <p><i>They brought me up to a room to have a wee chat with me. Again, a lot of it is hazy, but I feel like I'm angry that they didn't wait until (husband's</i></p>

name) was there and bring both of us up. I would be very angry with them. [P4].

So, the lovely neonatologist pointed at me and said, is he your child? And I said, no, she's my child. And he said, well, there's something wrong with her. We've done an ultrasound. There's fluid on her brain. It's very serious and she'll be off to (name of Children's hospital) in the morning. So, of course, me, 24 hours after giving birth, no husband with me, and no idea what was going on? [P21].

I didn't realize there was parents' accommodation either. Nobody told me about that. At the time I didn't know there was such a thing as parents' accommodation. I never asked. I didn't know. I was driving home at night; it would have been better if I could stay. I might have left the hospital sometimes at twelve or one o'clock.... going home, expressing, going to bed and getting back up again. [P4].

Discussion

'Starting out in haziness' was undoubtedly the central concept when parents' recounted the time they learnt of their child's diagnosis. This time signified a key moment in each parent's experience and marked the end of their previously known and familiar world. Likewise, parents of children with NMLLCs in other studies revealed that the initial diagnosis is a very traumatic and deeply personal experience (Bailey-Pearce et al., 2017; Somanadhan & Larkin, 2016). In keeping with earlier research (Sabzevari et al., 2016), parents in this study reported a range of intense emotional distress such as shock, fear, low mood and guilt at this time. Sometimes this was coupled with a sense of relief that their child had ultimately survived. The emotional impact on parents and the combination of positive and negative emotions were immensely noteworthy at this time. A complex interplay of factors relating to the internal world of the parents and to the external world, such as the support, compassion and assurance they received at the time of hearing the diagnosis influenced the nature and the extent of this emotional impact.

The manner in which the diagnosis was delivered left a lasting impact with parents able to vividly recall how, when and by whom the information was provided. Poor delivery of

information was commonly reported and appeared to be associated with a much more complex period of adaptation and adjustment to the diagnosis. This involved overwhelming parents with too much information, insensitive communication and apparent lack of awareness of the significance and impact of the information communicated. This was clearly evident in the theme 'Navigating the unknown territory'. Comparable findings have been reported in other studies and recommendations made to enhance communication between healthcare professionals and parents at the time of diagnosis (Ekberg et al., 2018; Hill & Coyne, 2012; Lemacks et al., 2013). Our study clearly illustrates that poor communication from healthcare professionals at the time of diagnosis is still a concern for parents of children with NMLLCs. In addition, the findings support the literature that poor communication during the time leading up to and including diagnostic disclosure can result in serious consequences and can increase distress for parents even over the long-term. The parents in this study experienced aggravated grief, anger and/or frustration when healthcare professionals failed to be thorough, empathetic, offer any hope or deal with their emotions and stress during the diagnostic disclosure. Parents perceived that healthcare professionals were unable or unwilling to enter their life world and understand it from their perspective.

The majority of parents had no previous experience of care provision for a sick child prior to their child's diagnosis. This was unveiled across the three themes. They relied on healthcare professionals to teach them and to support their decisions regarding their child's care. The findings highlight some shortcomings in this process, including parent dissatisfaction with communication resulting in lack of trust in healthcare professionals which ultimately impacted with preparation for their caregiver role. Consistently parents referred to the stress associated with the experience of learning to care for their child. For some, this stress was undoubtedly eased by the support they received from healthcare professionals. The formation of satisfactory alliances, based on mutual respect and good communication early in the trajectory, was found to be instrumental in coping and in competence development. Such similar findings were reported by Brenner et al. (2015) albeit with a different cohort that being parents of children with complex needs. Regardless, parents

described the enormity of the caregiver role on diagnosis. They described being both physically exhausted and mentally weary as a consequence of caring. The shift in focus towards home and community-based care could explain this finding. In the past, many children would have spent prolonged periods of time in hospital due to the complexity of their care needs (Hunt et al., 2015). However, the development of a range of devices to support children at home and greater knowledge about the long-term management of childhood life-limiting conditions have meant that children are now cared for primarily at home by their parents (Guglieri & Bushby, 2015). Consequently, parents are increasingly taking responsibility for the management of their child's condition early in the trajectory and providing many elements of care previously carried out by healthcare professionals.

The complexity of care provided in this study is akin to that reported in previous research incorporating children with life-limiting conditions (Smith et al., 2015). The current study, however, also identified the lack of professional support for parents in relation to their role as caregiver which led to parents feeling overwhelmed in the period following diagnosis. There was little evidence of care negotiation between the parents and service providers surrounding this period. This was particularly evident in the themes 'Acquiring a learner permit' and 'Navigating the unknown territory'. Likewise, parents of children with chronic conditions described needing more reassurance and support from healthcare professionals through this time in order to undertake their new care giver responsibilities and alleviate anxiety (Geense et al., 2017; Rankin et al., 2016). Parents in this study felt they had no choice other than to deal with the situation they found themselves in, yet when they reflected back they questioned how they had survived in the haziness that then characterized their lives. Preparedness for caregiving has been found to moderate negative effects and promote wellbeing in family caregivers in adult palliative care (Holm et al., 2015). While the concept of preparing parents and families is advocated in CPC it appears that the focus is primarily on preparation for end-of-life care (Hoell et al., 2018).

The findings from our study provide new and interesting insights regarding clinical expertise and the concept of the healthcare professional as expert. Benner's model of skill acquisition is widely used in nursing practice. Benner (1982) detailed the acquisition of expertise and proposed five possible expertise levels: novice, advanced beginner, competent, proficient, and expert. Aligned with Benner's model it would appear from the findings here that it is essential for the healthcare professionals to have a comprehensive knowledge base in order that they can support parents and families. They also required an intuitive grasp of each situation based on deep knowledge and experience surrounding the period of diagnosis. However, the concepts of relational practice and family-centred care were also important and appeared to give rise to the very clinically competent expert within this specialized field of practice. This was apparent across the three themes. The concept of relational practice broadly refers to the art of authentically being with people and includes reciprocity (Bjornsdottir, 2018; Magen & DeLisser, 2017). Understanding clients in their context, what they need and how you can best respond to that need are part of relational practice (Fyers & Greenwood, 2016).

Practice Implications

Parents' stories identify the need for multifaceted supports, including psychological and social supports surrounding the diagnosis of their child's life-limiting condition. Healthcare professionals can assist parents to understand the diagnosis, work through their concerns and refer them to other healthcare professionals if necessary. Children's nurses, for example, are ideally situated to lead the required care and refer parents from a psychological perspective. Assessing parents will identify where families are potentially struggling and require intervention to optimize child, parent and family outcomes. Communicating with parents, particularly at the time of diagnosis is extremely challenging for healthcare professionals (Wool, 2015). The findings from our study indicate that the skills required, especially techniques for effective communication in emotionally charged

situations, need to formally enter the pre-registration curricula for healthcare professionals. Communication is often taught in a behavioural way, as a set of skills to be mastered; this can be useful for novice practitioners (Ferreira-Padilla et al., 2015). However, relational practice requires much more of healthcare professionals in terms of knowing how and when to use the skills (Fyers & Greenwood, 2016). The enhancement of these skills will have the potential to increase parental satisfaction and coping abilities, and thereby improve quality of life in families'. Children's nurses need to be given the opportunity to develop the skills with support. Novice nurses need substantial education and support from experienced nurse mentors to learn and acquire effective communication skills necessary to engage in caring and sensitive discussions. Being present is a vital component of care. There is clearly a case in favour of 'being with' parents specifically surrounding the period of diagnosis, but it is challenging to do so in practice. Healthcare professionals may, consciously or not, avoid difficult conversations, opportunities to engage and situations perceived as stressful. To be present, healthcare professionals need clinical supervision and support. Healthcare professionals need to be cognizant and assess the 'haziness' for each individual parent prior to starting to teach them the new way of caring for their child, a way as a parent they never thought they would have to do.

Limitations

Despite being open to both parents, the sample encompassed mostly mothers, given very few fathers volunteered to partake. Thus, when interpreting the findings, it is important to note the over-representation of mothers which may have obscured gender perspective differences. This is, however reflective of previous research in the area. In terms of roles, research suggests that the role of primary caregiver is often assumed by mothers (Smith et al., 2015). Hence, research is regularly dominated by the perspectives of mothers (Sabzevari et al., 2016). The data were dependent on recall and perception of parents surrounding the diagnosis of their child's NMLLC. The time since diagnosis varied considerably. While for the majority this occurred in the previous four years others reflected on this period which occurred many years earlier. The parents were however able to reminisce and share rich details regarding their experiences, including detailed descriptions of their interactions with healthcare professionals. Consequently, this could alternatively be viewed as a strength of the study. Holloway and Galvin (2017) suggest that qualitative research is primarily concerned with what resonates with the person. Despite efforts to recruit participation from a diverse range of respondents, there was little cultural diversity among parents in this sample. The sample was homogenous in terms of ethnic profile with all parents White and of Irish ethnic background. Perhaps the need for English fluency may have affected this. Future researchers need to be more proactive in terms of seeking the views of those from different ethnic backgrounds, particularly as Ireland has rapidly changed into a multicultural society. Nonetheless, this study makes an important contribution to an understanding of parental experiences surrounding the diagnosis of their child's NMLLC.

Conclusion

This study highlights parental experiences surrounding the diagnosis of their child's NMLLC; a topic that has in recent times been underexplored and under-researched in CPC literature. Although the presence of pain, discomfort and loss of control featured across the interviews, and should not be underestimated, these aspects were overshadowed by parents' struggle and search to make sense and meaning of their experience and the world that they had unwillingly become part of. The nursing role is central in providing support to parents surrounding the diagnosis of their child's NMLLC. Children's nurses have a valuable opportunity to enhance a family's experience. The experiences of these parents prove that healthy therapeutic relationships are vital to the care of children with life-limiting conditions, helping to remind parents that they were not alone in their struggles. Future research should endeavour to further elucidate the perspectives of fathers surrounding the diagnosis of their child's NMLLC.

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