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“A Really Really Almost Impossible Journey” Perceived Needs and Challenges of Families Impacted by Pediatric Cancer: A Qualitative Analysis

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ABSTRACT

Caring for a child with cancer can place a number of burdens on families, however it is unclear the extent to which health-care professionals (HCPs) and other personnel supporting families are aware of these burdens. This study sought to explore the needs and challenges encountered by families impacted by pediatric cancer in Ireland from the perspectives of both parents and the personnel who support them. Twenty-one participants, comprising seven parents (one male, six females), and 14 supportive personnel (nine hospital-based volunteers and five HCPs) took part in in-depth semi-structured interviews via Microsoft Teams (December 2020 to April 2021) to obtain a perspective of the needs, challenges, and currently available support for families. A reflexive thematic approach to analysis was employed. The need to *navigate a new normal*, a sense of *riding the wave* and *reliance on others* were perceived to be the primary challenges encountered by families. Participants reported a need for *community service provision*, *connectivity* across the health-care system and more *accessible psychological support*. High levels of overlap across themes were found for parents and supportive personnel, particularly HCPs. Results highlight the significant challenges encountered by families impacted by pediatric cancer. Themes voiced by parents were frequently echoed by HCPs, suggesting this group is attuned to broader family needs. As such, they may be capable of providing insight where parent perspectives are unavailable. While further analysis including children’s voices is needed, findings highlight key areas toward which support for families should be directed.

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Introduction

Each year in Ireland, over 200 children are diagnosed with cancer, with rates growing by over 20% since 1994 and 2019 (National Cancer Registry Ireland, 2022). This rate is in line with global precedence rates, with one in 285 children worldwide experiencing a cancer diagnosis (World Health Organization, 2021), in comparison to one in 334 children in Ireland. For parents, taking on a dual role of parent and care manager may cause emotional strain (Jantien Vrijmoet-Wiersma et al., 2008; Williams et al., 2006), with fatigue, fear, and stress on marital relations commonly experienced following diagnosis (McKiernan & Balfe, 2019; Pierzynski et al., 2020). Family coping may be

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supported by information provision, psychosocial support (Aziza et al., 2019), peer support networks (McKenzie & Curle, 2012), improved communication with health-care professionals (HCPs), and coordinated follow-up care (Keats et al., 2019). However, barriers to accessing such supports are common, often due to under-resourced services (Hegarty et al., 2018; Olsson, 2016), and logistical challenges (Warner et al., 2015). In Ireland, for example, incidence rates of pediatric cancer are evenly spread across the country (National Cancer Registry Ireland, 2017), but treatment is delivered through centralized hospitals, requiring significant travel and disruption for families. For parents who reside far from their child's hospital, loss of income, travel time, and cost cause concerns (Shepherd & Woodgate, 2011). Negative impacts persist following treatment, including challenges returning to employment, managing family responsibilities, and maintaining relationships (Peikert et al., 2018). As such, the effects of pediatric cancer on families appear significant and enduring.

Growing emphasis has been placed on the value of child and family-centered care within pediatric illness (Phiri et al., 2020). However, while the importance of the family in care provision is acknowledged, research has focused on patient needs alone. For example, past systematic reviews examining psychosocial interventions for pediatric cancer have highlighted the absence of analysis of the family unit (Enskär et al., 2015; Meyler et al., 2010; Steele et al., 2015). Furthermore, in Ireland, while there is recognition of the importance of supporting the quality of life (QOL) for cancer survivors (Hegarty et al., 2018), little work has examined the needs of families coping with pediatric cancer specifically (Barrett et al., 2019). This sentiment has been echoed globally, with a recent WHO report highlighting the need to support the QOL of families impacted by pediatric cancer (WHO, 2022).

In trying to understand the needs of families, there may be value in exploring the perspectives of the stakeholders involved in supporting them. Through such a multi-perspective approach, a more fulsome exploration of the convergence and divergence of views on past experiences and perceived areas of need can be obtained (Mulligan et al., 2019). Notably, a range of HCPs are involved in pediatric cancer care, each supporting different areas of child and family health. As each of these HCPs interacts in different manners with families, they may encounter a wide breadth of family experiences. In addition to HCPs, within Ireland, hospital-based outreach programs rely on volunteers to provide services (National Cancer Control Programme, 2018). Again, these individuals may be well suited to provide insight into commonly reported family experiences and challenges. However, while exploration of the views of supportive personnel such as these may offer valuable perspectives on the needs of families, questions remain as to whether these perspectives would be reflective of the experiences of families themselves. As such, there is a need to consider the perspectives of supportive personnel, in tandem with those of parents, to determine if they are attuned to families needs.

Qualitative analysis may be particularly useful in this context, as it can allow for whole-some discussion of complex human experiences (Van Dongen-Melman et al., 1998). For example, a qualitative systematic review by Mu et al. (2015) explored the needs of families impacted by pediatric cancer in the year following diagnosis, revealing how needs experienced included family turmoil, positive future planning, the importance of family support, and HCP communication. However, as this review focused on the year following diagnosis, long-term needs were omitted. This suggests a need for analysis in this area to allow for more fulsome identification of the needs of families, which in turn may allow for the

development of more appropriate support. Furthermore, little qualitative research has explored the perspectives of HCPs in understanding family needs.

For service provision to be effective, the context and content should reflect individual needs and resources (Halpern et al., 2014; Mullen & Hanan, 2019). However, to ensure supports are available to meet individual needs, service providers must establish a clear understanding of what those needs are, as well as the extent to which they are met. The primary aim of this study is to explore the needs and challenges encountered by families impacted by pediatric cancer through the perspective of parents, with a secondary aim to consider the perspectives of those who work to support these families. Through exploring the perceived unmet needs experienced by families affected by childhood cancer recommendations for future support can be made.

Materials and methods

Research design

This study formed part of a series of studies with Public and Patient Involvement (PPI) in the design. An inductive qualitative approach was used to undertake a series of semi-structured interviews, with data analyzed using a reflexive thematic approach. Three separate participant groups undertook interviews, namely parents of children with cancer, HCPs, and hospital-outreach volunteers. This multi-perspective approach is in line with past research (Mulligan et al., 2019). Ethical approval for this study was obtained through the Maynooth University Social Research Ethics Subcommittee (reference number: SRESC-2020-2414528). Full informed written consent was obtained from participants using a consent form and information sheet.

Participants

Participants were recruited using an exhaustive purposeful sampling strategy, with invitations to participate disseminated through social media groups, voluntary organizations, patient advocacy groups and service providers in pediatric cancer. Eligibility criteria included being 1) the parent/caregiver of a child with cancer who was at least 3-months post-diagnosis but less than 5 years from their last active treatment session, 2) a HCP with experience in pediatric cancer, or 3) a volunteer at a hospital-based therapeutic recreation service in pediatric cancer with at least 1 year's experience. Supportive personnel, namely volunteers and HCPs, were included to explore their perspectives in addition to those of parents, to determine what additional insight such perspectives may offer. In line with the reflexive thematic approach to analysis (Braun & Clarke, 2019; Braun et al., 2019), richness of data, rather than data saturation, was used to determine sample size. Of the individuals approached, no individuals declined to participate.

Epistemological approach

This research sought to reflect the needs and experiences of families in Ireland impacted by pediatric cancer, from the perspectives of parents and the staff that support them, while also acknowledging the reflexive influence of the researcher on analysis. In line with this, reflexive thematic analysis (Braun & Clarke, 2006) was chosen for as it allows for participant

perspectives to be openly considered while acknowledging participant subjectivity and the researchers' own reflexive influence in analysis. The interview process was developed using a recursive approach and continuous reflection on biases through open discussion. The world view perspective of the researcher is one of a “doctoral researcher and behavior analyst, with no experience as a HCP, parent or with childhood illness,” with an emic ontological position.

Interview guide and data collection

In-depth semi-structured interviews with parents and supportive personnel were conducted to obtain a perspective of the needs, challenges, and currently available support for families, in addition to some demographic information. To allow for this, an interview guide was developed, though specific wording and order were not firmly adhered to, to allow participants space to raise unconsidered areas. The first interview with each group (HCPs and parents) served as a pilot, with feedback gathered from participants following the interview. This feedback was then applied to subsequent interviews. Additionally, three questions on needs across health-care services, mental health, and financial advice were also asked (see Table 1). Interviews took place using Microsoft Teams and lasted an average of 38.16 for parents (range: 23.36–56.48 min), 32.43 min for HCPs (range: 31.05–35.46 min), and 28.29 for volunteers (range: 19.46–44.36 min).

Data analysis

Interviews were transcribed by the researcher and replayed to check for accuracy. While interviews were recorded using Microsoft Teams, the transcription function was not used due to university requirements. A reflexive thematic analysis was used (Braun & Clarke, 2006, 2013), as it allowed for theoretical flexibility and an inductive analysis of data (Braun & Clarke, 2006). A recursive approach following Braun and Clarke (2006) was employed. Prior to analysis, all interviews were transcribed into Microsoft Word by ED. Firstly, familiarization with the data occurred through re-reading transcripts. Next coding occurred with codes pertaining to relevant or important aspects of the data given to pieces of the transcript. QDA Miner Lite (a qualitative data management software program; Provalis Research, 2022 version), was used for coding and theme development. A researcher, a female PhD student with no past experiences in childhood cancer, completed the coding. Analysis of codes in the absence of transcripts occurred to confirm that they were accurately worded. To enhance the quality of findings and ensure the rigor of analysis, a second researcher (a researcher with experience of

Table 1. Semi-structured interview questions.

Semi-structured interview questions		Groups asked
Did you feel your family's needs were met?	Service Needs? Mental Health? Financial Advice?	Parents
Unmet needs of families impacted by pediatric cancer	What do you feel are the needs, challenges, and currently available supports for parents, children and families impacted by pediatric cancer? Do you feel these needs are met? If not, why? What additional services do you feel are needed?	Parents Volunteers HCPs

qualitative analyses, with no experience of pediatric cancer) supported coding, theme development, and data analysis. To support accurate coding and theme development, a sample of transcripts (1 per participant group) was independently coded by the second researcher. Following this, the researchers met to openly discuss the independently determined codes and themes arising and determined key themes. While no major disagreements occurred, minor disagreements were resolved through discussion. Arising from this, themes were determined based on the data, and codes allocated to relevant themes. A review of themes in the absence of coded text was completed independently by both researchers to ensure data was appropriately captured. As per Tong et al. (2007) consolidated criteria for reporting qualitative research, themes were not anticipated in advance. Themes were then defined and named, and analysis written. To support analytic rigor, ongoing reflections on data during collection and credibility checks following analysis were conducted, in line with best practice (Tong et al., 2007; Wu et al., 2016).

Results

Demographics

A total of 21 individuals consented to participate – seven parents, five HCPs (one nurse, two doctors, one social worker, and a physiotherapist) and nine volunteers. Volunteers (four males and five females) had volunteered for an average of 3.39 years. HCPs (two males and three females) had on average 17.6 years of experience. Parents (one male, six females) had a mean age of 38.8 years. Due to the relatively small number of individuals in each participant group, demographic details of individuals are not reported to protect their anonymity. Parents were primarily married/cohabitating ($n=6$) and lived in small towns ($n=6$). Children had a mean age of 8 years (range = 4–12) and most had finished active treatment ($n=5$). Diagnoses included Acute Lymphocytic Lymphoma ($n=2$), Rhabdomyosarcoma ($n=2$), Pilocytic Astrocytoma, Wilms tumor, and Hepatoblastoma. Most had siblings ($n=5$; mean siblings = 2.6, range 1–4). Travel to local care centers took parents an average of 22 min (range 10–30) and 132.5 min to the primary treatment center's (range = 40–210 min).

Themes

Six key themes are presented. Of these, three pertained to challenges experienced by families, namely *navigating a new normal*, *riding the wave* and *reliance on others*. Three themes related to the needs of families, namely the *need for community*, *connectivity*, and *accessible psychological support*. Distribution of themes discussed across participant groups is reported in Figure 1. High levels of overlap across themes were found. For HCPs specifically, an emphasis was placed on challenges navigating the health-care service, both during treatment and when transitioning back to their local communities. While themes pertaining to reliance on family and de-prioritization of own needs were noted for parents, these were not reflected on by supportive personnel.

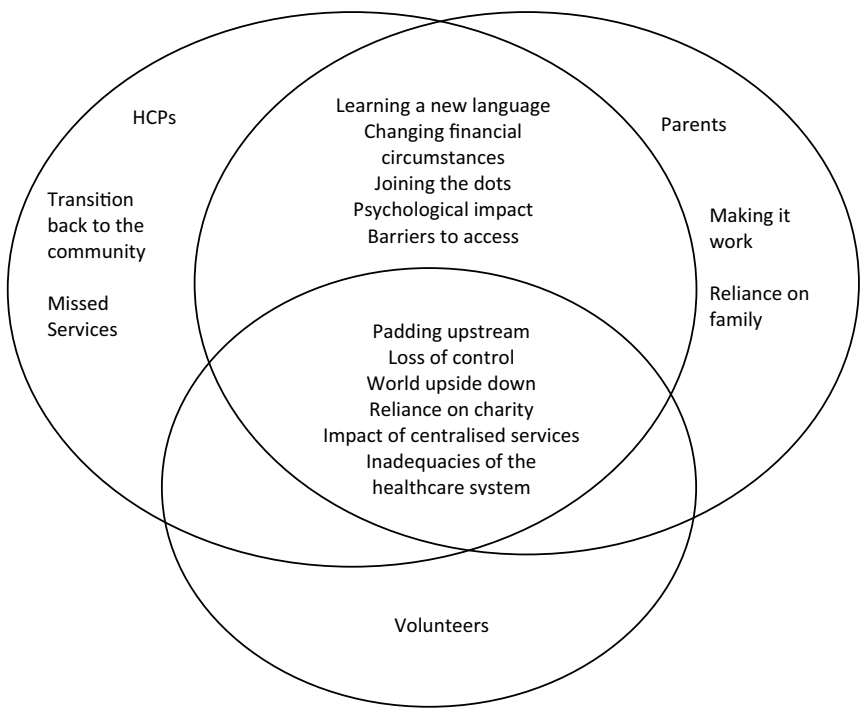


Figure 1. Distribution of themes across participant groups.

Navigating a new normal

A common theme across participant groups was the need to navigate a new normal in response to their child’s diagnosis. This necessitated a swift learning curve to determine what is needed of them and to learn the language of their child’s care.

Paddling upstream. Significant difficulties were perceived to be faced by families in seeking financial, informational, and other supports. At diagnosis, parents reported feeling overwhelmed and unable to determine needed supports.

I remember you know getting home from the hospital after being in for a week or more and sitting at my kitchen table, and I had papers and forms, and there was just stuff everywhere. . .I remember sitting here and crying like because I just didn’t know where to start. P2

All participant groups noted that administrative burdens associated with accessing support led to emotional distress in many instances. Where services were obtained, families faced continued requests to demonstrate eligibility, causing concern.

We got the medical card. Six months later they were asking for more proof. They put it on hold, and we had to, it was like reapplying again. P2

Families new to the health-care system were seen by all participant groups to be particularly at risk.

A lot of the other things you're kind of left to figure out for yourself . . . I could see families and maybe English wasn't their first language. I could see how it could be a really really really almost impossible journey for some people. P7

Learning a new language. A further feature was the need to learn a new medical language pertaining to their child's diagnosis and treatment. As the prevalence of many pediatric cancers is low, parents reported difficulties finding peers or appropriate information sources.

Particularly for some of the more rarer cancers, there's often not that many other families or children going through treatment for the same diagnosis at the same time. HCP3

As parents often served as care coordinators for their children, a steep learning curve was encountered, a sentiment echoed by HCPs.

And then there's a whole new language there yknow it's, one knowing what they're doing and then you have to, we learnt to, she was on a tube feed, like how to do that so we could come home. P3

Changing financial circumstances. Post-diagnosis, families identified the severe impacts of pediatric cancer on their finances.

It has hit us financially. . . . I reckon we were probably down about 30-40 grand. P3

This financial impact was often further exacerbated by a loss in income, with one parent taking leave from employment. Mothers appeared to be disproportionately affected by this, taking leave in most instances, as noted across participant groups.

Financially, usually from my experience one of the parents will give up work. More often than not it's the mother. . . And things like mortgages bills have to be paid, they don't have work and then in hospital it's very expensive. HCP4

High anxiety around the family budget was noted, with free time spent seeking financial support or identifying ways to manage finances. For single parent families, increased financial burden was particularly evident.

As a single parent I just felt that I, it's better I continue working. That was very hard on the mental health then but then at least if I'm independent I don't have the added worry of finance. P1

Riding the wave

Another theme reported by parents was the loss of control in the face of the disruptive impacts of pediatric cancer.

Loss of control. A common sentiment was parents' loss of control over their day-to-day lives and those of their children. Upon diagnosis, child health and wellbeing is placed in the hands of the medical team, with high uncertainty surrounding outcomes.

You can't do anything and you're having to rely on yknow medical experts. Well basically to see if you can save your child really. P3

HCPs echoed this loss of control over medical care and outcomes.

And to cope with the eh I would guess constant source of disappointment as things continue to “go wrong” is a description that is often used. It’s not entirely true in that these are expected adverse consequences of the therapies. HCP1

Loss of control was also perceived for children themselves. Children were quickly thrown into a world in which they have little say, particularly around medical interventions. This loss of autonomy was felt to have lasting effects.

Even though he’s a child like he’s still went through a trauma of yknow needles and operations and it it’s something that he learned to get used to . . . when he was getting everything out he had a bit of like Stockholm syndrome. P5

World turned upside down. All participant groups noted disruption and shock following diagnosis, with family life thrown off course.

A child can be playing hockey on Thursday and diagnosed on Monday with em osteosarcoma, bone cancer. So there can be quite a sudden, it usually is quite sudden. And there aren’t very overt signs of something being wrong. HCP5

Parents faced uncertainty in how to manage their child’s health, questioning the severity of even small changes.

It felt like bringing a new baby home from the hospital and you’re like ok what do I do now. P1

Volunteers particularly voiced the tendency for families to become split as one parent cares for the ill child, causing strain.

Often families are split so you would have yknow. Dad up with the child mom at home with the rest of the kids or vice versa so I suppose the strain on the families that they’re quite separated. V7

Making it work. One approach to this new circumstance, as reported across participant groups, was the focus on supporting their child, pushing other considerations aside.

I suppose if it’s your own child you’ll do whatever has to be done. V1

Parents alone noted this focus on their child often came at the expense of their own needs, with stigma attached to acknowledging these needs. This avoidance of own physical and mental wellbeing often resulted in negative effects over time.

I think I was just on raw energy all the way through. And then after treatment, she then got sepsis and then em I just then had to take another month of work. And I just crashed basically. P3

Reliance on others

A common feature noted was the absence of adequate support from the state and healthcare system, requiring families to seek needed support from other sources. While reliance on charity was echoed by supportive personnel, HCPs specifically raised the inadequacies of the healthcare system.

Inadequacies of the healthcare system. While participants reported having high-quality medical care, challenges engaging with the healthcare system were reported. Under-resourced services lead to high wait times, low service volume and a perceived need to fight for services.

You know there's a whole wide range of things and chemo can leave you with a lot of side effects but I suppose then when the oncologist is referring the child for them it's not urgent it's not considered urgent to anybody so they can't get bumped up the list. But sometimes it could be quite debilitating to the child. P4

HCPs emphasized how this absence of services was felt, particularly as families transitioned back into the community following treatment.

And where we failed, and where there is a plan to do group work is at end of treatment cos we know that that's another traumatic time that we didn't attend to because of capacity. HCP1

Reliance on charity. Charity groups were relied upon to provide supports often considered within the care pathway, such as on-ward psycho-social support.

They donated a lot of money to the service to try and help the psychosocial needs of patients and parents and em that is in the next year hopefully going to happen with a specific em eh project manager on the ward to help with psychosocial issues and help co-ordinate resources for them. HCP2

For HCPs, however, concerns were raised regarding this reliance on external entities to provide services in hospitals due to inequalities in service provision and risk of closure.

If they're family-initiated charities you've really concerns about their survivorship, can they keep going. . . We run into the problem we provide a service that people have become used to and now financially we don't have support to do that. HCP4

HCPs noted an absence of alignment across charities delivering supports, leading to service gaps and areas of overlap. For families, additional effort was required to navigate the numerous charities to determine which may meet their needs.

What you often find happening is different charities are doing the same thing . . . So em you might find that they're offering the same support but then there's gaps in the system that they're missing. HCP4

Reliance on family. A further external support are extended family. While in hospital, extended family members were often relied upon to maintain things at home, as reported across all participant groups.

There's one little guy he comes now a lovely little fella . . . and he's a tough little nut now, and his, I'd say they might be either uncles or big brothers. . . they left at quarter past 6 or something in the morning, to be up for a 9 o'clock appointment. V1

However, not all could rely on this support.

You're thinking god there's other people that don't have the support network that we have and there's nothing out there for them. P5

Needs of families

Connectivity

Parents noted a need for increased connectivity across the system and support with service navigation. Often absences of communication across care services led to burden falling on parents to either seek services or manage care.

Joining the dots

Caring for a child with cancer requires a large multi-disciplinary team, with communication needed between and within these teams. However, an absence of communication was noted by all groups, particularly at diagnosis.

It would have been difficult in the beginning like, cos you would've felt like there wasn't much joined up thinking as you're being told one thing and then you met the next person and then that's not the case and like what's going on here yknow. P6

This lack of connection led to a reliance on parents as a source of information, requiring them to re-tell their story across service providers.

I was the database I felt. You restarted the story every time you met someone; you started the story from the beginning. P6

Managing alone

This absence of connectivity led to a pressure on parents to serve as the conduit through which connection was achieved. A fear of falling through the gaps was noted by many, with pressure on parents to ensure their child obtained needed services.

I was responsible for making sure NAME was well cared for because you'd fall between stools your trying to bringing the staff in the hospitals with you, while also not being pushed over yknow. P6

For single-parent families, or those with limited support, pressure to manage care was felt more acutely.

I mean the nurses are there the doctors are there, but with chemo every single day he has to take pills, he has to take liquids. . . So you feel like you are the only one responsible for that and if it happens that you maybe you don't have that strength any moreWhat will happen if I just wasn't able to get out of bed one day you know. P1

Missed services

HCPs highlighted that the complexity of the system and the effort required to navigate it often led to missed services. Those who could effectively navigate the system were seen to have an advantage with inequalities in access noted.

Some people get so much support cos they know how to access it and where it is. Others don't know that, or they don't have the energy to find out. HCP4

Community-based services

A core need reflected on by parents was the burdens imposed by centralized services. Removal from communities for medical care was seen to contribute greatly to family disruption and the absence of support to re-integrate.

Impact of centralised services

Medical services are delivered in a center of excellence, requiring families to travel to receive treatment and outpatient care. With traveling these distances came significant financial costs and disruption, as noted by all participant groups.

Often families are split so you would have yknow dad up with the child. Mom at home with the rest of the kids or vice versa. V7

Sibling routines were impacted as they attended appointments with their ill sibling, resulting in missed education.

There was one family who came up from Sligo . . . but there was three other kids came as well. So you're sort of thinking well, they've all had to come out of school, and the parents have had to give up what they're doing for the day. V1

Children missed school and other activities to attend appointments, impacting their development and peer relationships. HCPs noted that many of these factors could be addressed through community-based service delivery.

There's a much more normal sort of family life for the sick child and the siblings if some of the treatment could be administered locally. So, we are in a constant kind of catch up trying to deal with the consequences of that I think. HCP5

Transition back to the community

A key timepoint at which greater links to community were needed was at the end of treatment. An absence of connectivity between hospitals and community-based services to support this transition was noted by HCPs particularly. Again, parents formed the conduit through which communication flowed in these instances.

There is this psychologist connected to the ward who would be a specialist so we told her obviously we need to get somebody locally so we sourced our own play therapist locally and even like she said oh I'll connect with her . . . but even at that we weren't even able to get that that that kind of connection yknow. P4

Many communities lacked clinicians sufficiently knowledgeable in pediatric cancer. Seeking clinicians with relevant experience proved difficult, with families relying on hospital supports.

Depending on the public health nurses or their GPs but most of them have only seen a child once in their lifetime with cancer so their experience is limited. Not their fault, it's just the nature of the thing and therefore parents often feel quite alone dealing with this. HCP4

Universal psychological support

Due to stigma and accessibility challenges, a need for access to universal-level psychological support within the care pathway for families was noted. While this theme was echoed by HCPs, it was not noted to the same extent by hospital volunteers.

Psychological impact

Parents described a need for family psychological support following their child's diagnosis.

And the day came for his end of treatment bell, and I felt no different. I'm like, you nearly feel bad for celebrating because it's still right we got over this hurdle were in remission now, now it's to stay in remission. And it's that constant worry and it's the constant god he looks very pale today. God, he says he's not feeling well. P5

For children, a need for psychological support was also noted. While treatment is key to survival, children were often unprepared for procedures leading to mistrust in medical professionals. While parents attempted to support these needs, often this was not sufficient.

As much as I could prepare him there wasn't enough support medically for his, for his mental health to help him prepare even more for all those situations. P5

Barriers to access

Parents noted that psychological services were often inaccessible, associated with long waitlists or difficult to find. Significant effort is needed to find supports, often at times where families may not have the capacity to seek services.

The services weren't there unless we actively went searching for them, and it wasn't you would've had to really been looking for it like they weren't easily in my grasp sort of thing. . . And sometimes you don't know you need it so it was hard. P2

Parents also did not recognize or prioritize their own needs. For many, psychological support was only obtained following a mental health crisis or through medical staff identifying their urgent need. Further, some parents felt stigma in seeking support when their child had survived.

You're kind of half afraid to go. And you get, I've often heard people say oh isn't it lucky that he's still here, and isn't it lucky that, I can't believe what you went through, as if it's a past tense thing, but it's not its constantly going to be in your present. P5

Discussion

This study explored the challenges and needs of families impacted by pediatric cancer from the perspective of parents and those who support them. The results highlight the numerous impacts that living with pediatric cancer can have on the family unit, with families often facing significant disruption to routines, relationships, psychological wellbeing, finances, and household management. Building on this, however, the results also highlight several avenues through which families may be better supported.

Lambert et al. (2008) noted that children with cancer want information presented in a clear, accessible, and honest manner. Our results suggest that this also holds for parents.

Specifically, parents in our study expressed a clear need for accessible, comprehensive, and reliable sources of information. Similarly, previous research has highlighted a need for information on child health (Aziza et al., 2019; Vetsch et al., 2015), to support decision-making (Mckenna et al., 2010; Yoshida et al., 2014) and to coordinate follow-up care (Keats et al., 2019). The present study also highlighted the need for additional information on service pathways, care co-ordination, and on child health. Due to the time commitments and worries associated with caring for their child, parents in our study faced difficulty in accessing required information due to conflicting or untrustworthy sources. This therefore suggests a need for trustworthy and comprehensive sources of information that are easy to access. The need for support to traverse the complex health system is also clear from our results, with transparency around service pathways and increased communication between HCPs needed to reduce parental anxiety around care management. In addition, the results highlight the importance of frequent communication with HCP, consistent with past research findings (A. J. N. Tan et al., 2021; Zwaanswijk et al., 2007). Taken together, there is a need for increased consideration into how best to support the information needs of families.

The results also highlight the potential role of community-based services as a means of reducing some of the negative impacts of pediatric cancer on families. Traveling for care was perceived to significantly impact family functioning, finances, and relationships, in addition to sibling wellbeing and parent employment. The financial impacts of a cancer diagnosis are consistent with past research (Irish Cancer Society, 2015; Kelada et al., 2020), with common areas of expenditure associated with travel and lost income. The absence of medical support within local communities can increase parental pressure to manage their child's health at home, and to co-ordinate or inform care should they need to visit local health-care services. Past research echoes the need for increased community-based service delivery, since parental job-loss, reduced hours, and extended leave may be required by those living further from treatment centers (Cheng et al., 2022; Roser et al., 2019). For such parents, loss of income, travel time, and cost present as concerns (Shepherd & Woodgate, 2011). The need for increased communication between hospitals and local HCPs and upskilling for local doctors may be some potential ways of improving care in local communities (Martiniuk et al., 2021; Tonorezos et al., 2018), which would likely reduce negative experiences for families.

The identified need for increased psycho-oncological support for families is also consistent with past research (Ay Kaatsız & Öz, 2020; Aziza et al., 2019; Christen et al., 2019), particularly for those based in rural areas (Barrett et al., 2020). Poor peer support and risk of isolation for rural survivors was highlighted by Barrett et al. (2020), in keeping with present findings. The results differ somewhat from those of Hegarty et al. (2018), who found higher access to psycho-oncological supports for pediatric cancer across Ireland. However, this may be attributed to the profile of the families in our study, who predominantly resided outside of urban areas. Hegarty et al. (2018) noted only 25% of non-Dublin patients had access to psycho-oncological support, which is more consistent with the present findings. Interestingly, in contrast to Christen et al. (2019) who found that needs for psychosocial support were greatest during treatment, participants in this study suggested that needs for support are greatest when transitioning back into the community following treatment. This may be facilitated through increased communication between primary and local care providers.

A comparison of themes across parents and supportive personnel suggests a good degree of agreement in the perceived challenges and needs experienced by families. This was particularly clear for themes pertaining to the negative impacts of cancer on the family unit (e.g., experiencing a loss of control, paddling upstream, feeling that the world is upside down), difficulties in navigating services (e.g., impact of centralized services and inadequacies of the healthcare system), and reliance on charity for support. This suggests that supportive personnel have a good general awareness of the challenges and needs experienced by families. This differs somewhat from past analyses in different cultural contexts, in which misalignment between HCP and parent perceived informational needs was found (C.-E. Tan et al., 2022). It is of note, however, that, while HCPs voiced all but two of the subthemes noted by parents, volunteers differed, with only eight of the 16 subthemes mentioned by this group. In particular, the need for “accessible psychological support” and “changing financial circumstances” were not emphasized by volunteers. This is somewhat to be expected as their encounters with families may be more limited than HCPs. These results suggest that while supportive personnel may be in tune with the needs of parents and families, gaps in awareness, particularly for volunteers, may hamper their ability to fully capture family needs. However, as the work of volunteers tends to focus primarily on children themselves, the omission of some themes is to be expected.

Several parent-specific themes were also noted. One such example was the need to “make it work,” or the emphasis on child wellbeing over other areas of life. This may pose a challenge when considered in the context of the HCP–parent relationship, should HCPs be unaware of parental struggles which they may be unwilling to share. This may lead to supports for parents being missed, either through them not being offered by HCPs or being dismissed by parents due to an unwillingness to prioritize own needs. This highlights the need for health-care systems to reduce any “activation bump” encountered by parents when seeking services by making them freely and easily available and highlighting the importance of self-care. The importance of extended family members was also highlighted by parents alone. As families may lack family support systems on which they can rely, additional supports may be needed to bridge this gap. Increased awareness of this reliance on family is needed for supportive personnel to ensure those families who may lack broader family support are identified and provided appropriate support.

There are several limitations to the present study, most notably the absence of children’s voices. The views of both children with cancer and their siblings were not captured here. Future research should seek to capture these perspectives to determine needs more fully. A further limitation was the sample size and composition, with a relatively small number of parents, particularly fathers, participating in interviews. The differing child diagnoses across parent participants may have resulted in very different treatment pathways and experiences. However, the range of perspectives obtained provides a good insight into the diverse experiences that may be encountered by families. Future analysis may benefit from more in-depth analysis of the needs of families impacted by different forms of pediatric cancer to evaluate more specific needs for support. Furthermore, as these interviews were completed in the context of COVID-19, which had significant impacts on the health-care system, the needs and challenges experienced may have been impacted by this. As most children had finished active treatment prior to the pandemic, the impacts on results are likely limited.

Recommendations for practice

Several recommendations for practice can be made arising from the current manuscript. First results obtained highlight the clear need for increased community-based services to mitigate the negative effects associated with centralized treatment, as well as increased connectivity in terms of service navigation and communication across the health-care system, and a need for universal psychological support. Efforts to address these needs within existing or emerging care pathways is needed. Second, the results obtained cast positive light on the insight of HCPs into the needs and challenges encountered by families living with pediatric cancer. Results obtained suggest strong overlap across both parent and HCP reported needs and challenges, suggesting that HCPs may be able to provide some insight into the experiences of this group. However, caution is needed, particularly in the context of psychological needs, where overlap across HCPs and parents was lesser. A further recommendation arising from the current analysis is the need for clear communication and information sharing across treatment and survivorship to reduce the burden on parents. By ensuring information is clearly and accurately shared between care teams and families, the pressure on parents to serve as informal care managers may be reduced. This is particularly necessary to reduce the burden on those at particular risk, such as single-parent families or those new to the healthcare context.

Conclusion

To conclude, this study highlights several challenges and unmet needs experienced by families impacted by pediatric cancer. For families, key challenges include navigating the hospital landscape, managing their child's care, and accessing services within an under-resourced healthcare system. There is a clear need for increased community-based services to mitigate the negative effects associated with centralized treatment, as well as increased connectivity in terms of service navigation and communication across the healthcare system, and a need for universal psychological support. While further analysis of the experiences of families impacted by pediatric cancer is needed, these findings highlight several key areas toward which support should be directed.

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Ethical statement

Ethical approval for this study was obtained through the Maynooth University Social Research Ethics Subcommittee (reference number: SRESC-2020–2414528). Written informed consent was obtained from all participants.

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