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Available, but not always accessible: a nationwide,
qualitative study of multidisciplinary health care
providers'
experiences with follow-up care after paediatric brain
tumor.

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Abstract

Objective: Paediatric brain tumour (PBT) survivors face high risks of disabling long-term and late-effects. Whether survivors' needs are met in a system with publicly funded services, but in the absence of a formal long-term follow-up model, is uncertain. Empirically-based recommendations for a national model are needed. We explored multidisciplinary health care providers' (HCP) experiences with providing such care.

Methods: We conducted five focus-group interviews and five individual interviews with a nationally representative sample of 33 Norwegian HCPs. Focus-group interviews and individual interviews were analysed using systematic text condensation.

Results: Three main themes were identified: 1) "Providing care above and beyond system constraints", describing a perceived discrepancy between HCPs' knowledge of, and their ability to meet, the survivors' needs. 2) "System barriers to providing optimal follow-up care", describing a perceived lack of routines for communication and coordination between the HCPs and existing care services. 3) "Nurses and shared-care to improve care", including empowering nurses and establishing routines for collaborations and areas of responsibilities.

Conclusion: The current health care system was perceived not to fully meet the survivors' needs. Nurse-led care models, including standardized patient-care pathways, were suggested to increase the accessibility of already existing services and thus to improve long-term follow-up care.

KEYWORDS paediatric brain tumour, survivorship, follow-up care, health care provider, multidisciplinary, qualitative

1 INTRODUCTION

Paediatric brain tumours (PBT) are the second most common type of cancer in children, with a current average five-year survival rate to 75%, largely thanks to great improvements in treatment (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). This results in a growing population of PBT survivors, many whom are at high risk of extended early-onset and late effects compared to other childhood cancer survivors (Turner, Rey-Casserly, Liptak, & Chordas, 2009). Radiation therapy directed towards the developing brain is associated with a high risk of experiencing progressive neurocognitive, physical, psychological, and psychosocial decline (Turner et al., 2009). Neurocognitive late effects include problems related to attention, emotional regulation, organization, and memory. Fatigue, hearing loss, growth deficits, and weight changes are among many of the other physical late effects in this group (Gupta & Jalali, 2017). Educational issues, unemployment (King et al., 2017), and poor relations with peers are also documented, especially for those treated with cranial radiation therapy (Schulte et al., 2018). PBT survivors are also at increased risk of receiving financial assistance (Gunnes et al., 2016), and male PBT survivors are less likely to marry compared to controls (Gunnes et al., 2016). Given the heterogeneity within this group and the wide-reaching consequences of the disease and treatment, providing adequate follow-up care is challenging. Long-term multidisciplinary follow-up care for PBT survivors is recommended (Turner et al., 2009), but there is still no agreement on the best care model (Bowers, Adhikari, El-Khashab, Gargan, & Oeffinger, 2009).

Guidelines and models for follow-up care exist internationally, but the content and use of these vary across and within countries (Brown et al., 2015; Tonorezos et al., 2018). Common follow-up care models for childhood cancer survivors involve either care by a general practitioner (GP) in collaboration with a medical specialist (shared care model), by a specialist physician alone (Singer, Gianinazzi, Hohn, Kuehni, & Michel, 2013; Tonorezos et

al., 2018) or within the context of a multidisciplinary survivorship clinic (Tonorezos et al., 2018). Even when such care is available, several challenges remain in meeting the complex needs of the PBT survivors. From HCPs' perspective, lack of funding and time is significant barriers to provide optimal follow-up care to the PBT survivors (Bowers et al., 2009). From survivors' perspective, commonly identified unmet needs are the lack of access to psychosocial services and lack of information about late effects (Aukema, Last, Schouten-van Meeteren, & Grootenhuis, 2011; Earle, Davies, Greenfield, Ross, & Eiser, 2005; Hoven, Lannering, Gustafsson, & Boman, 2011; Tallen et al., 2015) As a result, PBT survivors' health care and other needs are not necessarily met (Hoven et al., 2011).

The Norwegian health care system is publicly funded and organized in two main sectors: primary health care (e.g. GP, school health, educational and psychological counselling services) and specialist health care (e.g. hospitals and medical specialists) (Romøren, Torjesen, & Landmark, 2011). During and after treatment, patients and their families typically receive care from multidisciplinary HCPs, such as physicians, nurses, physical therapists, psychologists, social workers, and educational services, at the level of both specialist and primary health care services. Paediatric oncologists routinely provide follow-up care for five to 10 years post-treatment or until 18 years of age, after which no national guidelines for long-term follow-up care exist. Children with on-going, complex health care needs are, however, entitled by law to habilitation/rehabilitation services, a coordinator, and an individual plan, a document meant to tailor and coordinate assistance to meet the individual's needs. Ideally, a coordinating group of relevant local care providers (i.e. family support teams) representing all involved services is established, with regular meetings to ensure that the individual plan is enacted (Nilssen, 2011). As such, the Norwegian system, similar to other publicly-funded health care systems, should be well suited to meet the

complex needs of PBT survivors, despite the lack of a formal long-term follow-up care model.

Identifying potential short-comings of current practice is important to inform public policy development and clinical services to ensure care services of high quality. Although several studies have explored the views of HCPs regarding the follow-up care of childhood cancer survivors in general (Aslett, Levitt, Richardson, & Gibson, 2007; Berg, Stratton, Esiashvili, Mertens, & Vanderpool, 2016; Howard et al., 2018; Michel et al., 2017), studies exploring their views of the follow-up care of PBT survivors are lacking. HCPs working with PBT survivors in paediatric oncology have specific knowledge about the survivors' needs, witnessing daily how late effects influence the survivors' lives, and are responsible for initiating follow-up care, including referrals to local care. Their experiences are therefore valuable to identify strengths and weaknesses with the current system (Howard et al., 2018; Michel et al., 2017), and serves as a useful first step towards developing recommendations for a national model for long-term follow-up care. As such, including HCPs' experiences from a nationwide sample were deemed important.

We explored the perceptions of multidisciplinary HCPs from Oslo University Hospital (OUH), Haukeland University Hospital (Hauk), St. Olav's University Hospital (St. Olav's) and the University Hospital of North Norway (UNN) regarding existing challenges and what works well in current follow-up care, and what can be done to improve the current system.

2 METHODS

A qualitative approach using focus group interviews and individual interviews are appropriate to gain an in-depth understanding of a seemingly neglected area, such as HCP's experiences with follow-up care of PBT survivors.

2.1 Study setting and sample

In Norway, the regional distribution of children diagnosed with a brain tumour within the last 10 years is: Oslo (231), Bergen (84), Trondheim (76), Tromsø (47) (Norwegian Children's Cancer Registry, 2019). As such, only a limited group of professionals have experience following the PBT population. To ensure adequate experience, eligible HCPs had to be professionals within the paediatric oncology field, with a minimum of two years' work experience providing follow-up care to PBT survivors. We used purposeful sampling to invite participants with specific experiences with PBT survivors. We identified and invited 41 potential participants from the four largest university hospitals in Norway, representing the four national health regions (OUH), (Hauk), (St. Olav's) and (UNN). A.Å. (RN, MSc, nurse at the paediatric oncology ward, OUH) and E.R (PhD, Professor, MD, Head of the paediatric oncology ward, OUH) are clinicians, working at OUH with access to contact information to relevant staff at all paediatric oncology wards in Norway. They contacted local key staff at the different hospitals for recommendations for suitable participants and to provide their email addresses. A.Å. then contacted the potential participants via email which included a study invitation, detailed study information, and an informed consent form. At one site, participants were invited through the local oncologist. Additional participants were identified through snowball sampling, where already recruited participants suggested further relevant HCPs, which we then contacted.

2.2 Data collection

We used a semi-structured interview guide, based on the authors' clinical experiences and the existing literature concerning follow-up care of PBT survivors. Additionally, three experienced paediatric or oncology nurses and one user representative (a parent of a PBT survivor) assured the relevance and quality of the interview guide questions. The interview guide contained overarching themes regarding HCPs' experiences and challenges, perceptions

of survivors' met and unmet needs in current follow-up care, and suggestions for improvement (see Appendix 1). The same interview guide was used for focus-group interviews and individual interviews. The focus-group interviews and individual interviews were held between November 2017 and August 2018, each with a duration of approximately 45 to 90 minutes. All but one of the focus-group interviews were multidisciplinary (paediatric oncology consultants only). Four focus-group interviews were held in a suitable room at the University of Oslo (close to the hospital) and one focus-group interview at Haukeland University Hospital in Bergen. An experienced female researcher trained in conducting interview studies (H.C.L) facilitated the focus-group interviews. Another female researcher (A.Å, trained by H.C.L), took notes and observed. The semi-structured individual interviews were carried out by H.C.L and/or A.Å, in an office at the University of Oslo or OUH, as desired by the participant. Due to significant travel distances, HCPs from Tromsø and Trondheim were invited to participate in phone interviews conducted by A.Å. Given the small community of experienced HCPs, it was unavoidable that some study participants knew the researchers. However, because the topics to be discussed were experiences with care at the system level, not personal performance, we considered this to be acceptable. We also assured participants that discussions were treated confidentially. Both focus-group interviews and individual interviews started with providing information about the study information on background and aim, and a short introduction of the interviewers including our interests in the field and work background. All participants provided written informed consent before data was collected. The focus-group interviews and individual interviews were audio-recorded and transcribed verbatim by A.Å.

2.3 Data analysis

The analysis was based on Malterud's four steps of qualitative systematic text condensation (STC) (Malterud, 2012), conducted concurrently with data collection. STC is an appropriate

method of analysis when aiming to create knowledge based on experiences and meanings from cross-case analysis of both focus-group interviews and individual interviews (Malterud, 2017). We aimed to understand HCPs' experiences with follow-up care in clinical practice, not generating theories or hypotheses. STC was therefore chosen due to its pragmatic step-by-step nature, which offers structure to the analysis and simplifies the process of transparency and reflexivity, but also provide some flexibility to the process (Malterud, 2012). Step one concerned obtaining a general impression of the data. Two of the project members (H.C.L., A.Å) read the transcriptions to identify preliminary themes, striving to keep an open mind, unconstrained by the study aim. The preliminary themes identified were: "challenges experienced", "survivors" "needs", "experiences with the health care system", and "improvement suggestions". Step two consisted of coding the data. H.C.L. and A.Å. independently coded any meaningful utterances relevant to the study aim in three focus-group transcriptions, and then compared the codes. Disagreements were resolved through discussion. This process resulted in a codebook of 18 codes, used to code the remaining focus-group interviews and individual interviews. In step three, we collated these 18 codes into broader subgroups by grouping units concerning similar nuances of each code, including illustrative quotes. In step four, we produced a brief description for each subgroup that summarized the results, using some of the codes as main headings, organized in logical compliance with the research question. The results were then discussed by the researchers. Finally, a revised summary of the findings was sent to the participants for member checking and validation of our interpretations of the data. No subsequent changes were required. We used NVivo 11 to code and organize the data.

2.4 Ethical considerations

The study was approved by the Data Protection Officer at OUH (18/11728).

3 RESULTS

Of 41 invited, 33 (80%) participated (one did not respond, two were unable to meet, and five felt they lacked sufficient experience). Participant characteristics are provided in Table 1. We held five focus-group interviews consisting of four to 10 participants and conducted five individual interviews with HCPs unable to attend a focus-group interview. We continued recruitment until no new themes were identified in subsequent interviews and we were confident that we had sufficient informational power (Malterud, 2017).

We identified three main themes, including several sub-themes (presented in Tables 2–4 with supporting quotes). The main themes were: 1. “Providing care above and beyond system constraints”, 2. “System barriers to providing optimal follow-up care”, and 3. “Suggestions for improving care: nurses and shared care collaboration”. Main themes 1 and 2 contain both HCPs’ perspective on existing challenges and what works well (presented below in that order).

3.1 Providing care above and beyond system constraints

This topic emerged spontaneously during the focus-group interviews and individual interviews, not prompted by the interviewer. Many participants described an acute awareness of the complex health care needs that some PBT survivors struggled to manage, and found it frustrating that they felt unable to fully meet these needs in the current system. The HCPs also reported that it appeared random as to which survivors they saw for follow-up consultations. This resulted in a lack of continuity of care, both for the survivors and the HCPs. As such, the HCPs talked about a feeling of dissonance between their profound desire to help and care for PBT survivors and their inability to do so reliably. This was experienced as a significant extra burden in addition to their already high workload. Participants wondered if this contributed to some HCPs’ reluctance to care for this population.

Adding to what they described as their feelings of inadequacy in providing quality follow-up care, was the perceived challenge of getting HCPs outside the field of paediatric oncology to recognize “invisible” problems with delayed onset, e.g. cognitive problems. Consequently, facilitating appropriate assistance for survivors at the level of local health care, school, and habilitation/rehabilitation services was seen as challenging.

Despite these challenges, the HCPs in our study expressed a high level of engagement in their work with the PBT population, regarding themselves as their “ambassadors”. The HCPs’ mentioned the PBT populations’ needs, fears, and concerns as important motivational factors for the HCPs’ continued engagement with this group.

3.2 System barriers to providing optimal follow-up care

HCPs described how meeting the complex needs of the PBT survivors required the involvement of many multidisciplinary providers, across the two levels of the health and welfare system, such as oncologists, neuropsychologists, and nurses as well as local school services, GPs, physiotherapists and family support teams. A major concern of the participants centered around the system barriers that made it challenging to provide *access* to the follow-up care they felt the survivors needed, despite relevant health care and habilitation/rehabilitation services often being *available*. This was related to another frequently discussed barrier, overcoming problems due to the fragmented nature of the health care system, with poor routines for collaboration between the specialist health care services and other care providers. For example, perceived challenges in collaborating with regional habilitation/rehabilitation services, local psychological service, or the local hospitals, sometimes resulted in referrals being rejected and “survivors being lost in the system”. Similarly, lack of routines for defining care providers' responsibilities and, at times, a lack of knowledge of the PBT survivors' needs among local HCPs, were perceived as additional challenges to providing good follow-up care. Other barriers described involved complex

issues with communication, information flow, and coordination between the involved multidisciplinary professionals, both within and across levels of care. Some of the HCPs related this to the absence of a common communication platform making access to important information inaccessible, e.g. test results.

Although some HCPs described positive experiences with the local family support teams and their efforts in supporting the survivor and family, this was often attributed to the special efforts of individual HCPs and not to the “system” *per se*. As such, the HCPs described that the lack of a formal system and routines for follow-up care made them feel that the responsibility for providing good care rested on the individual HCP. This made the care provision person-dependent and vulnerable to disruption from the HCPs’ already limited capacity due to heavy workload.

Many HCPs voiced concerns that the timing of the follow-up care was not always optimal, given that the emergent neurocognitive deficits often became apparent as the survivors entered adolescence and affected both schooling and social abilities. The HCPs described how the PBT survivors’ needs and late effects with late onset could often appear as nonspecific and “invisible” to others, thus delaying appropriate support. This delayed, and often unrecognized, need for support was seen in contrast to the tendency for HCPs and other services to express greater understanding for the survivors’ needs directly after treatment.

This, together with the system barriers, contributed to the HCPs' expressed concerns regarding that many PBT survivors are left with unmet health care needs, especially after transitioning to adult health care services. This perceived lack of coordination of care by “the system” was seen by the HCPs to place immense pressure on the parents of the PBT survivors. Parents were described as the “real-life” coordinators, left with the immense responsibility of attending to the needs of their child and coordinating the different care and educational services. Lastly, some of the HCPs were also concerned that too much

responsibility was placed on the survivors and family regarding attending follow-up care. If a survivor failed to attend a couple of follow-up appointments, then they would “fall out of the system” unless the parents or an HCP re-established contact.

In addition to these challenges, we identified some positive perspectives. Some participants pointed out that certain aspects of the current follow-up care worked quite well, such as the routine follow-up consultations at the hospital before survivors reached the age of 18 years and the routines for neuropsychological testing. The follow-up care at the hospitals are led by oncologists with specialist experience and knowledge about follow-up care and survivors’ needs, and some HCPs saw this as the reason for why they were perceived to work well. Additionally, one hospital (OUH) had recently established a nurse-coordinator for PBT patients and survivors, which was highly appreciated by the local staff. It was hoped that this role would mitigate some of the challenges of coordinating care.

3.3 Suggestions for improving care: Nurses and shared care collaboration

The main suggestions for improving current follow-up care concerned the need for increased involvement of skilled nurses, to introduce nurse-led consultations and the use of nurses in coordinating roles. Some HCPs suggested that an optimal model would include a follow-up care nurse in the municipality and one at the hospital with the main responsibility of coordinating the follow-up care for each survivor. Such nurse involvement could help coordinate care with clear delineations of responsibility and facilitate collaboration between involved professionals.

Similarly, the HCPs agreed that there is a need for a more systematic involvement of already existing local care services, such as the family support teams, local coordinators, and schools, to help provide structured follow-up care in the survivors’ home environment. Related to this, the participants emphasized the need for routines that ensure knowledge

transfer between the specialist HCPs at the hospitals and the local providers, to facilitate a common understanding about PBT survivors' late effects and needs.

Furthermore, some of the HCPs desired the routine involvement of the habilitation/rehabilitation services, as they are perceived to be suited to meet the complex challenges affecting many areas of PBT survivors' lives. Some of the HCPs reported a need for the PBT survivors to have a formal diagnosis, eliciting a code in the system (ICD code), once they are cancer-free, e.g. acquired brain injury, to facilitate access to existing care and habilitation resources. In sum, the participants emphasized the need for follow-up care to be more structured and formally organized, drawing on already available health care and habilitation/rehabilitation resources.

4 DISCUSSION

We explored multidisciplinary HCPs' perspectives on the current follow-up care of PBT survivors in Norway. Our findings add to the existing knowledge by providing insight into HCPs' perceptions of what works well in current follow-up care, existing challenges in such care, and suggestions for how to improve follow-up care.

The first main theme – “providing care above and beyond system constraints” identifies existing challenges in providing follow-up care at a personal level. Feelings of “coming up short” when facing the complex health and functional problems of many PBT survivors, were seen to add to the burden of working with the PBT population even for experienced HCPs. This is similar to Canadian HCPs, acknowledging lack of time as a great barrier to provide sufficient follow-up care, leaving the HCPs to make complicated prioritizations (Howard et al., 2018). Additionally, the survivors' “invisible” and delayed-onset problems were seen as an important challenge when advocating for the survivors' needs beyond the field of paediatric oncology. This is in line with research reporting that paediatric

oncologists rate their work as both emotionally and intellectually challenging for similar reasons (Stenmarker, Palmerus, & Marky, 2009). Prior research on HCPs within the paediatric oncology field often points to patient care involving death and palliative care as reasons for burn-out (Mukherjee, Beresford, Glaser, & Sloper, 2009). Our findings suggest that the provider burden in the PBT follow-up care context can also be challenging, evoking feelings of dissonance between the HCP's awareness of the survivors' needs and feeling unable to adequately meet these needs. This sense of dissonance could contribute to significant work stress (Mukherjee et al., 2009). While our participants expressed the desire for more support in their care provision for PBT survivors, systematic approaches to supporting HCPs are currently lacking (Beresford, Gibson, Bayliss, & Mukherjee, 2018).

The second main theme reflects the participants' perceived barriers to quality follow-up care at a system level. These barriers - challenges around communication and coordination, a lack of knowledge and a fragmented system, are similar to those identified by British HCPs regarding follow-up care for optic pathway glioma and other childhood cancer survivors (Berg et al., 2016; Sturgess, Brown, Fraser, & Bailey, 2018). This indicates that fragmentation of services can be a common problem, independent of diagnosis, across different health care systems. In theory, the Norwegian system should be able to meet PBT survivors' complex needs using already-available care services. Existing laws entitle those in need of both coordinated care and habilitation/rehabilitation services (Norwegian Directorate of Health, 2005), and considerable efforts have been made to improve collaboration, coordination, and knowledge transfer between health care sectors (Government White Paper, Report No. 47 (2009). Our results, however, indicate that although services are available "on paper" they are not always accessible to the survivors, for various reasons discussed. A solution to improve access to care discussed, was to make the survivors' and their needs more visible and thus recognised in the system. Cancer survivors, once disease-free, no longer have a diagnostic

code in the system despite the risk of long-term and late effects impairing health and functioning, potentially hampering the recognition of their needs and accessing appropriate care.

PBT survivors' late effects are often associated with extended functional impairments, limiting the survivors' social participation abilities. As such, quality follow-up care should not merely address health-related problems, but also include a habilitation/rehabilitation perspective with a focus on restoring and preserving function, especially for survivors with functional, neurocognitive and psychosocial deficits (Fountain & Burke, 2017). Although a system for including this in follow-up care already exists as described above, the HCPs were concerned that it may be underutilized or not systematically provided. A national model or set of guidelines, including standardized care pathways, could help increase the accessibility of the existing services for every survivor in need, thereby reducing the current reliance on the efforts of individual HCPs. This would also likely reduce the perceived burden on the informal caregivers, who have previously been shown to shoulder most of the responsibility for ensuring their child's needs are met in the system (Aukema et al., 2011; Woodgate, Taylor, Yanofsky, & Vanan, 2016).

In contrast to the many perceived barriers to follow-up care in general, many participants agreed that the follow-up care provided by the treating hospitals worked well. This is similar to the perspectives of Canadian HCPs, which believed that paediatric oncologists are well suited to provide high quality, multidisciplinary, holistic follow-up care to the childhood cancer survivors, given their already established relationship with the survivors (Howard et al., 2018). Similarly, childhood cancer survivors described losing the continuity of care when transitioned to adulthood as something negative (Berg, Stratton, Esiashvili, & Mertens, 2016).

The final main theme identified in this study concerns HCPs' suggestions for improving current follow-up care. Establishing a national care model could overcome many of the system barriers and facilitate a life-long holistic approach that would meet PBT survivors' needs and unburden their parents and HCPs. Such a care model should be based on already-existing resources, improving the coordination and collaboration between the health care sectors, and should include a follow-up care coordinator. As discussed by our participants, at the hospital, this could consist of an experienced nurse who provides nurse-led consultations with survivors and helps coordinate the care provided by the municipality, habilitation/rehabilitation services, and adult health care services as needed. Such a "bridge" across the health care sectors would also facilitate adequate knowledge transfer. Different nurse-led care models show promising results related to improving coordination and continuity around children with different diagnoses but who have complex medical needs in common (Cady, Kelly, Finkelstein, Looman, & Garwick, 2014). A Survivorship Care Passport (SCP) can also be beneficial by providing the survivor, parents, and professionals with information about the diagnosis, treatment, potential late effects, and follow-up care suggestions (Haupt et al., 2018). Although some participants here expressed their concerns that an SCP may be difficult for PBT survivors to use due to potential neurocognitive deficits, it could serve as an important knowledge transfer tool (Haupt et al., 2018).

4.1 Strength and limitations

We used focus-group interviews and individual interviews to gain an in-depth understanding of the current follow-up care of PBT survivors. Our sample was diverse in terms of professions, ages, gender, experience, and geographic location, resulting in rich and nuanced data. The multidisciplinary approach allowed us to gain a holistic view of current follow-up care in the specialist health care sector, as the participants shared their perspectives through the lens of their specific professions. The participants' validation of our interpretations of the

data represents an additional strength of the study. Limitations include the lack of local care providers' perspectives. However, due to the complexity of locally organised care and service providers, collecting their perspectives in a meaningful way was beyond the scope of the current study. Rather, we prioritised to explore the perspectives of specialist HCPs representing all disciplines regularly involved in follow-up care of PBT survivors, across all four health regions within Norway. As such, we hoped to capture discipline-specific experiences and variations in local routines, given the lack of a national model of follow-up care. The relation between some of the participants and the researchers, could potentially bias the findings, such as negative aspects being omitted. To provide for an empathic and non-judging environment during the interviews, we started the interviews with food/snacks and small-talk and guaranteed confidentiality. Our preconceptions from experience and previous work were identified and discussed during the process. Although the study was conducted within the Norwegian health care system, we believe that the findings have relevance for similar health care systems internationally, and for follow-up care of other childhood cancer survivors with complex needs.

5 CONCLUSION

Although, some areas are perceived to work well in the current system, the many perceived barriers to quality follow-up care, both at a personal and system level, high-light the need for a formal, national care model that facilitates a sustainable health care system for the survivors, parents and involved HCPs. Implementing systematic support and continuing education for the involved HCPs might help reduce burn-out and facilitate the recruitment and retainment of future HCP in the paediatric oncology field. On a policy level, national guidelines including standardized care pathways would ensure improved and equal access to already-available health care and habilitation/rehabilitation resources.

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TABLES

TABLE 1 Participant characteristics

| | Overall sample (N= 33) |
|--|-----------------------------------|
| Gender | |
| Female (n) | 30 |
| Male (n) | 3 |
| Age | |
| Range | 32-69 |
| Mean | 52 |
| Profession | |
| Consultant (n) | 10 |
| Median years of experience (range) | 20 (2-35) |
| Nurse (n) | 12 |
| Median years of experience (range) | 17,5 (8-38) |
| Psychologist/neuropsychologist (n) | 2/5 |
| Median years of experience (range) | 7 (2-15) |
| Social worker (n) | 2 |
| Median years of experience (range) | 18 (11-25) |
| Physiotherapist (n) | 2 |
| Median years of experience (range) | 12,5 (10-16) |
| Sites | |
| Oslo University Hospital (n) | 21 |
| Haukeland University Hospital (n) | 10 |
| St. Olav's University Hospital (n) | 1 |
| University Hospital of North Norway (n) | 1 |

Notes. Oslo -- Oslo University Hospital; Bergen -- Haukeland University Hospital; Trondheim -- St. Olav's University Hospital; Tromsø -- University Hospital of North Norway.

TABLE 2 Main theme “Providing care above and beyond system constraints” and sub-themes with supporting quotes.

| Main theme | Sub-themes | Supporting quotes |
|--|---|---|
| <p>1. “Providing care above and beyond system constraints”.</p> | <p>1a. Highly engaged and enthusiastic.</p> | <p>Neuropsychologist11: I have to say that it is a privilege to get to work with these children—the moments when you feel you can bring something positive into their lives, then it is worth it.</p> |
| | <p>1b. Challenging (due to the complexity of patients’ problems).</p> | <p>Nurse33: Sometimes it feels demanding—I especially think of when they struggle with social relations for example, so you feel a little helpless in many situations because of the diffuse things with the patients...it is hard to know what kind of needs they have....</p> <p>Consultant29: [W]e sometimes experience this as demanding. And the work gets to us, and how should we relate to that? Earlier, when I started, I remember we had guidance....</p> <p>Consultant18: Sometimes I think, even though we have them [PBT survivors] for follow-ups, we do not capture the whole patient anyway. Maybe they are at the neuropsychologist and maybe [the neuropsychologist] writes their report to the school, but everything at home, in between, everything they struggle with, who captures that?.</p> |

TABLE 3 Main theme “system barriers to providing optimal follow-up care” and sub-themes with supporting quotes.

| Main theme | Sub-themes | Supporting quotes |
|---|--|--|
| 2. “System barriers to providing optimal follow-up care”. | 2a. Fragmented system. | Consultant7: I was struggling with getting an overview from either the [treatment] protocols or other places on how they should be followed. I felt they just slipped through my fingers: when are they at the neuropsychologist, when are they at the physical therapist and what kind of resources do they actually need?. |
| | 2b. Barriers due to interaction and coordination between services. | <p>Consultant4: [T]he biggest challenge is actually the information flow (...) especially related to MRIs taken during treatment and follow-up care. It is here the information flow is really lacking, and when they come back to us [at the local hospital outpatient clinic], we do not know anything and they [the survivor and family] do not know anything because they have not received the MRI results... It is a shame when parents call and say they got information about some tests that should be done and we know nothing about it.</p> <p>Neuropsychologist2: [W]e experience that it is often “before” and “after” a brain tumour for the family -- it often changes the family situation a lot. To actually pass on the information to the correct services in the municipality, to have the time to do so and listen to what they have to say, as well as arrange for a well-coordinated system around this survivor is challenging....</p> |
| | 2c. Poor timing of current follow-up care. | <p>Consultant1: Those who got treatment when they were children or young adults said they experienced a big difference before and after the age of 18 -- before 18 the follow-up care was delivered by the childhood cancer ward and afterwards they got totally left to themselves... But when you struggle with neurological late effects, you are not able to do that.</p> <p>Nurse3: It appears as many providers or services have a greater understanding of the survivors’ struggling under and right after treatment, with less understanding after some years after the cancer is cured.</p> |

| | |
|--|---|
| | <p>Consultant32: The major problem occurs when they turn 18 (...). As a paediatrician you are trained to have an overall responsibility for the patient, but that is lacking in adult medicine.</p> <p>Neuropsychologist2: They fall between the cracks, because in a way they are a bit too high-functioning --they are not disabled.</p> |
| 2d. Poor distribution of responsibilities. | <p>Nurse33: In today's system, there is no routine, where one person has the main responsibility, so the patients have to relate to so many different people. And with none of them having the main responsibility, things are running out in the sand.</p> |
| 2e. Lack of knowledge. | <p>Consultant4: I think many are struggling to be taken seriously in school because they meet the attitude, 'Now you are well and you have to start to push yourself'....</p> <p>Nurse13: Locally, some professionals are engaged in this and really understand the survivors' situation, and others are less engaged and we [HCPs with the specialist health care service] have to push them.</p> |
| 2f. Some areas work well. | <p>Consultant32: I think there is a lot that is functioning quite well, absolutely... But we need more resources, that is quite clear.</p> <p>Neuropsychologist5: They [PBT survivors] are receiving the medical follow-up in accordance with the treatment protocols, and that is functioning quite well, I think....</p> <p>Nurse13: We are so happy now, with the Childhood Cancer Association's financing of the coordinating nurse role that I think has a very important function....</p> |

TABLE 4 Main theme “nurses and shared care collaboration” with sub-themes and supporting quotes illustrating suggestions for improving follow-up care.

| Main theme | Sub-themes | Supporting quotes |
|--|---|---|
| 3. “Suggestions for improving care: nurses and shared care collaboration”. | 3a. Follow-up care nurses. | Nurse33: That is something we see could be beneficial with nurse consultations, to assess the quality of life [of the survivors] -- with existing tools we could do this, but we need to have the resources to do so and a routine for it. |
| | 3b. Coordinating role. | Consultant29: I think we need a coordinator. I think it is the parents themselves that have to push, or you have a lot of great parents but some are pushing more than others -- some do a huge job themselves trying to fight for things. However, if we could offer them a coordinator at the end of treatment that could help them and guide them, for example.... |
| | 3c. System and routines that ensure cooperation, communication and shared responsibilities. | Social worker22: I have experience working with parents for 25 years and I know that one of the most important things within this work is that we assist them so that they experience a predictable everyday life (...). The big challenge in this work is the fact that the survivors’ situations differ a lot -- someone has a good starting point, someone has a worse [starting point], someone has many late effects, someone has less late effects. Moreover, the more diffuse the late effects appear, the harder it is for the professionals to catch the problems. So, we need good, systematic routines. Consultant17: They [PBT survivors] should get diagnosed with acquired brain injury, because when cancer is cured, then the situation is that they struggle, but this is invisible in the system.... |
| | 3d. Local resources. | Nurse13: I think every survivor needs follow-up care close to where they live, but we are dependent on communication with the local hospital and other resources in the community so that they know what to do. |

| | | |
|--|--|---|
| | 3e. Transfer of knowledge. | Nurse33: There should be more information material available to the professionals outside the hospital to increase their knowledge about this group, because it is a jungle of rights that they have related to getting assistance in school -- it can be a fight. It has gotten out of hand with regards to what they are entitled to get. |
| | 3f. Habilitation/rehabilitation services. | <p>Consultant1: [W]hen you get a brain tumour when you are 7 or 10 years old, you get chemotherapy and radiation, and then your neurocognitive deficit might increase, and this might not be visible until the age of 18 (...). I think every one of these survivors should be followed up by adult habilitation and a neurologist because they are going to need a lot of help. It is not certain that they will, but if they do, they have to get better follow-up then they receive today.</p> <p>Physiotherapist27: ...In the following years after treatment, maybe it is possible for example with one week a year, at a rehabilitation center, to check on how the survivors actually are doing.</p> |

APPENDIX 1

Semi-structured interview guide.

General cues: experiences, challenges, met and unmet needs, suggestions for improvement

Themes:

1. Would you tell us about your experiences with the follow-up care of PBT survivors?
 - Specific tasks in the delivery of follow-up care
2. Would you tell us about what challenges you perceive in the follow-up care of PBT survivors?
 - Perceived barriers
3. Would you tell us about what you perceive to be PBT survivors' needs following disease and treatment?
 - Need for information
 - Need for health care services—practical help
 - What kinds of needs are met in the current follow-up care delivery/what works well in the current follow-up care?
 - What are the unmet needs in the current follow-up care delivery?

4. If you allow yourself to think beyond resources and financial circumstances, what would optimal follow-up care for this group look like? Who should do what?
5. What do you perceive are the survivors' resources? What do they manage without help?