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What Was on the Parents' Minds? Changes Over Time in Topics of Person-Centred Information for Mothers and Fathers of Children with Cancer

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ABSTRACT

Acquiring information about one's child's cancer diagnosis is a complex and ever-changing process, and parents' needs change over time. As yet, we know little about what information parents require at different stages of their child's illness. This paper is part of a larger randomized control trial studying the parent-centered information given to mothers and fathers. The aim of this paper was to describe the topics addressed in person-centered meetings between nurses and parents of children with cancer and how those changed over time. Using qualitative content analysis, we analyzed nurses' written summaries of 56 meetings with 16 parents and then computed for each topic the percentage of parents who brought it up at any time during the intervention. The main categories were Child's disease and treatment (addressed by 100% of parents), Consequences of treatment (88%), Emotional management for the child (75%), Emotional management for the parent (100%), Social life of the child (63%), and Social life of the parent (100%). Different topics were addressed at different points in time, and fathers raised more concerns about the child's emotional management and the consequences of treatment than mothers. This paper suggests that parental information demands change over time and differ between fathers and mothers, implying that information should be person-centered. Registered at Clinicaltrials.gov (NCT02332226).

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Introduction

Information about their child's disease is vital to parents, but its delivery is a complex and difficult task (Carlsson et al., 2019). The Person-Centered Information for Parents in Pediatric Oncology (*Personcentrerad information till föräldrar inom barnonkologin*; PIFBO) study was designed as a randomized control trial to provide person-centered information to parents of children with cancer (Ringné et al., 2015). In this paper, we focus on the topics addressed in meetings between the intervention nurses and the participating parents and show how those changed over time and differed between mothers and fathers.

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Learning about one's child's cancer illness involves more than merely hearing the diagnosis. Rather, it is an extensive process that includes learning about planned treatment, self-care, and future expectations. Information about the disease is necessary to a parent's ability to cope during the illness (Sisk et al., 2020) and its delivery has been described as a core part of nurses' caring practice (Enskär et al., 2020). Furthermore, parents' preferences about information may differ from their ill child's (Yamaji et al., 2022; Zwaanswijk et al., 2010) and change over time (Ringnér et al., 2011). Mothers and fathers also show different ways of coping with the information flow during the child's illness, where mothers being more emotion-focused and fathers more practical and problem-focused (Clarke et al., 2009; Gibbins et al., 2012).

The literature reports a variety of topics that parents need information about or that are addressed by health care providers. Medical topics include the child's specific illness, prognosis, examinations, treatment, side-effects, and late effects. Topics on parental care of the child include nutrition, pain, complementary and alternative medicine, and palliative care. Psychosocial topics include the consequences on the family, emotional and existential concerns, and the child or adolescent's schooling (Kelly & Porock, 2005; Kılıçarslan Törüner & Akgün Çıtak, 2013; C. Rodgers et al., 2018). These informational needs are complex and comprehensive, and they change along the illness trajectory. Parents ask for information about diagnosis, chemotherapy, and clinical trials more often at diagnosis, while information about coping strategies and immunosuppression gets increasingly important later in the treatment (Kelly & Porock, 2005; Kılıçarslan Törüner & Akgün Çıtak, 2013; C. C. Rodgers et al., 2016).

A high proportion of unmet information needs is also associated with psychological distress (McCarthy et al., 2018); however, little is known about how information needs change over time or differ between fathers and mothers. Most studies in this area are cross sectional, with data collected at different times post diagnosis (Maree et al., 2016), often assessed by proxies (Haugen et al., 2016; C. Rodgers et al., 2018), usually focused on the time of diagnosis or cessation of treatment (Aburn & Gott, 2011; Wakefield et al., 2012). Few, if any, have studied what information parents actually request along the treatment trajectory.

The PIFBO study was designed to deliver person-centered information to parents, according to their self-identified information needs, at four meetings starting two months post diagnosis. We previously conceptualized person-centered information as information about social, emotional, existential, and medical topics related to ill health and disease that is grounded in the person's present knowledge, preferences, and needs, and that seeks to empower the person to participate in the care of the sick individual. In the intervention, we were able to track the person-centered information given to parents in regular meetings with nurses (Ringnér et al., 2015). Participating parents in the PIFBO study reported satisfaction with the intervention (Ringnér et al., 2021, 2022) and felt that having a moment just for themselves helped them gain a deeper understanding of the situation, learn more, and move forward (Ringnér et al., 2021).

Aim

The aim of this paper was to describe the topics addressed in person-centered meetings between nurses and parents of children with cancer and how these topics change over time.

Materials and methods

This paper is a part of the process evaluation (Moore et al., 2015) of the PIFBO intervention (Ringnér et al., 2015).

The PIFBO intervention

In the intervention we used the representational approach to patient education developed by Donovan et al. (Arida et al., 2016; Donovan & Ward, 2001). The approach builds upon two theories. First, the *common-sense model of illness representations* (Diefenbach & Leventhal, 1996) structures the nurse's assessments of the parents' preexisting understandings. Based on these assessments, the nurse plans individual education for each parent. This is performed according to the theory of *conceptual change* (Posner et al., 1982), which emphasizes the consequences of pre-education knowledge gaps, misunderstandings, or confusion. The representational approach has been used successfully with both patients and family members for clinical concerns such as brain tumors, cancer symptom management, and cardiac rehabilitation (Arida et al., 2016).

In the PIFBO intervention, parents of children with cancer had one-to-one meetings with an intervention nurse (IN) four times, starting 2 months post diagnosis and spanning another three months. Each meeting (total $n = 56$), either face-to-face ($n = 37$) or by telephone ($n = 19$), began with identifying each parent's information needs. The INs first explored information gaps and/or misunderstandings in the parents' existing knowledge, guided by the dimensions of the *illness representation model*: identity, cause, timeline, consequences, cure/control, and emotions (Diefenbach & Leventhal, 1996). Next, they addressed the consequences of the identified gaps or misunderstandings to create the conditions to conceptually change any associated representations. Finally, INs introduced new information about the relevant topics in reflection with the parent. After the meeting, the parent received a written summary by e-mail to reinforce the topics discussed (Donovan et al., 2007).

The INs all had several years' experience in pediatric oncology nursing, were educated to the master's level, and had been trained in a 3-day workshop (Ringnér et al., 2015). The mean number of meetings for parents was 3.5 and the mean time for each meeting was 51 minutes (range: 15–105 min).

Participants

We recruited parents from two pediatric oncology tertiary centers in Sweden from 2015 to 2017. Included parents had (a) a child diagnosed with a first-time occurrence of a curatively treated malignancy within the past 2 months, and (b) enough fluency in Swedish to participate without an interpreter. Patients were consecutively invited by a designated nurse at each center 1 month post diagnosis. After we obtained written informed consent and baseline data, we randomized 32 parents into either the PIFBO intervention ($n = 16$), who constituted participants in this paper, or into the control arm ($n = 16$). Demographic data are presented in Table 1.

Table 1. Demographic data for parents and their children.

Parents	<i>n</i> = 16
Sex	
male	6
female	10
Age (years), mean	40.1
Age (years), range	29 – 65
Lives in community >50k population	8
Cohabiting	16
Currently working or studying	10
University education	12
Socioeconomic group	
worker	5
salaried employee	10
self-employed	1
Shared care with local hospital	4
Children	<i>n</i> = 12
Sex	
male	4
female	8
Age (years), mean	6.6
Age (years), range	1 – 15
Diagnoses	
leukaemia	9
solid tumor	2
brain tumor	1

Data collection

The INs wrote a summary of each meeting, which they sent to the parents via the e-mail system of each hospital, and then entered, together with other data about the intervention, into our trial management database. The summaries were then extracted from the database and used as primary data in this paper. Demographic data were obtained from parents at the study's baseline.

Data analysis

We analyzed the 56 summaries ranging from 191 to 1,182 words (*md* = 579 words), using an inductive qualitative content analysis approach (Graneheim et al., 2017; Graneheim & Lundman, 2004). First, we identified meaning units representing a single unit of content related to the aim. As the text was already more concise than interview texts, no condensation was needed. Each meaning unit was assigned a descriptive code. These codes were sorted into categories describing the main contents. Coding was performed by CO and AR, and MB joined in the creation of the subcategories and categories. We also coded the meaning units with the number of the meeting for each parent, enabling us to see how the distribution of categories changed over time. This is presented as the separate percentages of mothers and fathers addressing each topic at each point in time. The analysis was facilitated by Microsoft Access and Microsoft Excel, *Professional Plus 2019* version.

Ethical considerations

This project received approval from the Ethical Review Board in Umeå (Dnr 2014-167-31 M) and was registered at Clinicaltrials.gov (NCT02332226). We obtained written informed consent from all parents, stating that participation was voluntary and could be ended at any time. All data were coded to ensure confidentiality. The primary data were stored on a secure server at the university and processed only by the research group. The data remains archived at Umeå University and will be deleted after 10 years according to European and Swedish legislation.

Results

The analysis resulted in four categories of topics. Two of those, *Child's disease and treatment* and *Consequences of the treatment*, were related to the child alone, and two, *Emotional management* and *Social life* were related to either the ill child or the parent. The distribution of topics over time, overall, and by fathers versus mothers is demonstrated in [Table 2](#). These variations are described for each category.

Child's disease and treatment

This category addressed aspects of the disease and its treatment, ranging from before the diagnosis into future concerns, such as follow-ups, prognosis, and fears of relapse. All parents talked about issues in this category at least once during the intervention (83–100% of fathers per meeting; 60–100% of mothers per meeting).

Parents discussed the child's prognosis and their own worries about relapse, what to do if they suspected a relapse, and worries about a nonsuccessful initial treatment. They also raised issues about the current treatment, treatment monitoring, future follow-ups, and how to coordinate their child's care among different hospitals and outpatient clinics.

Parents and INs discussed various treatment modalities including chemotherapy, other drugs such as steroids, transplantations, and surgery. Parents also asked for and received information about treatment-related procedures such as blood sampling, central lines, and sedation. They also talked about the effects of the treatment, what to expect in the next phase or at treatment cessation, and their questions about clinical controls and investigations during and after the treatment.

Consequences of treatment

This category dealt with the child's present or foreseeable side-effects and complications. These topics were brought up by 88% of parents (fathers = 100%; mothers = 80%) sometime during the intervention, ranging from 67% to 100% of fathers per meeting and 50% to 75% of mothers per meeting.

Topics brought up by parents included worries about deranged blood counts, restrictions due to increased risk for infections, and parental fears of chickenpox, but also the joy of resuming everyday activities when the lab values improved. Other typical complications of cancer treatment such as alopecia, nausea and nutrition problems, tube feeding, elimination problems, pain, and the child's sleep and fatigue were also addressed.

Table 2. Distribution of topics over time, overall, and by fathers versus mothers.

Topic	All parents					Fathers					Mothers				
	T1	T2	T3	T4	Any T1-T4	T1	T2	T3	T4	Any T1-T4	T1	T2	T3	T4	Any T1-T4
Child's disease and treatment	88%	75%	100%	82%	100%	83%	100%	100%	100%	100%	90%	60%	100%	71%	100%
Consequences of treatment	69%	56%	75%	73%	88%	83%	67%	75%	100%	100%	60%	50%	75%	57%	80%
Emotional management, child	44%	63%	50%	64%	75%	67%	83%	75%	75%	100%	30%	50%	38%	57%	60%
Emotional management, parent	100%	94%	75%	82%	100%	100%	100%	75%	75%	100%	100%	90%	75%	86%	100%
Social life, child	31%	38%	67%	18%	63%	50%	17%	75%	50%	67%	20%	50%	63%	0%	60%
Social life, parent	88%	94%	75%	82%	100%	83%	100%	75%	100%	100%	90%	90%	75%	71%	100%

Note: T1-T4: planned meetings at 56, 77, 98, and 154 days post diagnosis. Any = addressed in at least one meeting. The intensity of the cell shading is proportional to the percentage.

Parents also discussed long-term consequences of the treatment such as fertility, cardiac follow-up, and minimizing long-term side effects.

Emotional management

Emotional issues, including experiences and management for both the child and the parents, were the focus of this category. All fathers (100%) and 60% of mothers (75% of parents) discussed the child's emotional management at some time, ranging from 67% to 83% of fathers per meeting and 30% to 57% of mothers per meeting. All parents mentioned their own emotional management at some time during the intervention, ranging from 75% to 100% per meeting for both groups.

Topics about the child's well-being and feelings in this category included supporting the child through physical losses and changes in appearance, understanding the effects of ordinary child development during the illness trajectory, and learning to focus on the child's emotional needs.

Different strategies for the child and parent to handle different situations were addressed in the meetings. Ways of coping with procedures for the child included parents' being in the present, taking one day at a time, finding time of their own, and relying on an inner strength. In discussions about how information could best be provided to the child and the parents, it was considered important to be honest but also to adapt the information to the child's developmental level, while parents needed to balance being informed and knowledgeable with protecting their own psychological well-being.

Understanding crisis response and stress reactions also fell under this category. Parents discussed how to cope with concerns about the future, manage the effort and sadness around the child's illness, and still do everything as normally as possible.

Social life

This category comprised aspects of the children's and parents' social life, such as school, work life, parenting, and external sources of support. Of all parents, 63% talked about the child's social life (67% of fathers and 60% of mothers) at some time during the intervention, for fathers ranging from 17% to 75% per meeting and for mothers 0% to 63% (mothers) per meeting, and all parents mentioned their own social life at some time during the intervention, ranging per meeting from 75% to 100% (fathers) and 71% to 90% (mothers).

Parents discussed how to plan for and support the child's social life, including preschool or school participation, meeting friends outside of school time, and having hobbies. Concerns about the risk of infections were considered as well as the benefits of maintaining a satisfying social life.

Other topics brought up in the meetings concerned the parent's social life, work life, and arrangements to work from home or differently to accommodate their need to support and care for their child. The family's economic situation was also addressed during the meetings, with some parents needing advice on how to handle the Swedish Social Insurance Agency bureaucracy after months without economic compensation.

Another broad topic was parenthood and taking care of the parents' own relationships as couples, specifically how to hand over responsibilities for the sick child to the other parent,

how to support each other in parenting, and how to support the ill child's siblings and each other.

Parents asked for information about different kinds of external support they could access and how to navigate the relationship with the health care professionals, and they talked about the support they had – or did not have – from family and friends.

Discussion

The aim of this paper was to describe the topics addressed in person-centered information meetings between INs and parents of children with cancer, as written in the summaries provided by the nurses, and how those topics changed over time. The topics of the meetings fell into two main types: (a) the child's illness, treatment, and mood, and (b) the parents' needs, abilities, and coping strategies. Interestingly, parents' focus on various topics differed by sex. The fathers were more focused on topics related to parenting, such as how to support the child's emotional and social well-being, while mothers focused more on their own well-being and management of the situation.

A number of the recommendations published to guide health care professionals about what information to give to families (Duffy et al., 2021; Rodgers, et al. 2017) include most of the topics found in this paper. However, several other topics in the guidelines, primarily practical skills such as temperature taking, changing a central line dressing, or safely handling chemotherapy medications at home were not addressed in our intervention. This probably reflects the timing of the intervention, which began just 2 months after diagnosis.

However, parents also raised topics in this paper that were not explicitly included in the previously mentioned recommendations, such as how to recognize symptoms of a relapse, long-term effects of treatment, how to coordinate care between different health care systems and institutions, and ways of looking after the parents' partner relationship. Some of these topics, for example, symptoms of a relapse and long-term effects, are recommended for survivorship clinics (Beaupin et al., 2018), but were clearly relevant to parents even at this earlier stage. Others reflect the evolution of information needs along the treatment trajectory.

These similarities and differences suggest that parental information needs do not always harmonize with those conceptualized by health care professionals, and they do not cease over time. As information needs are dynamic and change along the treatment trajectory, it seems necessary to adopt a person-centered approach that should be sustained over time. Listening to a person's story and building up a partnership with them is at the core of person-centered care (Ekman et al., 2011). These components are also key in the PIFBO intervention, which starts off with parent's own information needs and descriptions of relevant topics in a trustful conversation with a nurse (Ringnér et al., 2021). This means the INs assessed the information needs of each parent in the family and planned accordingly, rather than assessing the needs of the family as a whole or simply providing information according to predetermined checklists. We argue that checklists should be used early in treatment, primarily to ensure that parents receive vital basic information, although even those should be as individualized as possible. However, after this initial phase, parents' information needs should be regularly and directly assessed, and their education should be planned according to those individual needs.

In this sample, fathers were more likely than mothers to raise issues about the child's emotional management and the consequences of their treatment (Table 2). This may be in line with research that reports that fathers of children with cancer conceptualize their role as that of the “rock” of the family – the breadwinner and the source of strength and sustenance – but they have difficulty expressing feelings and focusing on medical aspects of the child's disease (Polita et al., 2018; Robinson et al., 2019). They may also have found it easier to ask new questions when given the opportunity for a private and uninterrupted discussion with the IN. Mothers on the other hand, may already feel a traditionally primary responsibility for raising their children (Evertsson et al., 2018) and thus focus on their own well-being as in this paper. Further investigation of gender differences in information needs and concerns should be an area for future research.

Methodological considerations

A strength of the PIFBO study is the longitudinal design that collected data on parental information demands 2 to 5 months after the child was diagnosed with cancer. To our knowledge, this is the first study that accounts for this systematically. Most studies so far have a proxy perspective, that is, clinicians have defined parents' information needs. Although the sample size was relatively small, with 16 participating parents, the results could be useful when developing further information interventions in pediatric oncology care. Fathers are often under-studied in pediatric oncology research (Nicholas et al., 2020), but our inclusion of both fathers and mothers enabled us to demonstrate gender differences. Three out of four participants in this paper had a university education, which is more than the 44% in the population aged 25–64 years (Statistics Sweden, 2021), possibly mirroring that higher socioeconomic status plays a role in willingness to participate in research (Jang & Vorderstrasse, 2019). All parents in this paper were cohabiting. This may have influenced our results, considering that single parents taking care of a child with cancer face an increased burden and more often have to cope single handedly with both emotional and informational issues (Granek et al., 2014). Future studies should apply strategies to increase sample diversity from both these perspectives (Vuong et al., 2020).

A possible shortcoming of the material is that the summaries were written by the INs, who may have introduced bias. However, these INs had considerable training in the intervention method and were aware that the summaries should mirror the topics addressed in the meetings. Furthermore, the summaries were sent to the parents, who had an opportunity to make clarifications if needed.

Conclusion

Parents of children with cancer have ongoing and evolving information needs not only at diagnosis, but also throughout the disease and treatment trajectory. Information for parents should be highly individualized due to the many factors influencing their information needs, such as their sex and individual preferences and the child's treatment, well-being, age, and maturity.

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