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Parental experiences of information within pediatric oncology

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Abstract

Parents of children with cancer use information to create knowledge about their child's disease. Information can help parents reduce chaos and create a feeling of control, but there are often obstacles to its acquisition, which has been described as similar to learning a new language. The purpose of this study was to describe parents' experiences of acquiring and using information to create knowledge about their child's cancer during the course of the illness. We used qualitative content analysis on data from focus groups and individual interviews with 14 parents of children with cancer. Two themes were constructed: Feeling acknowledged as a person of significance included feeling safe and secure in spite of uncertainty, having one's hopes supported, and getting relief from other families' experiences. Feeling like an unwelcome guest included feeling abandoned at important milestones, feeling forced to nag for information, and feeling burdened by the obligation to inform others. Parents may need extra attention at important milestones such as treatment cessation, with information meetings grounded in the parents' own needs.

Keywords: content analysis, focus group interviews, individual interviews, information, parental experiences, pediatric oncology.

Background

In pediatric oncology information about the child's cancer is a vital part of the care given to parents. Information can help parents create knowledge and build a meaningful and intelligible understanding of the situation. Information also contributes to reducing chaos, creating normality, increasing the parents' feeling of control, and helping parents to advocate for their child (Björk, Wiebe, & Hallström, 2005; Earle, Clarke, Eiser, & Sheppard, 2007; Holm, Patterson, & Gurney, 2003; Wong & Chan, 2006; Woodgate & Degner, 2002). The concept of information lacks a consistent definition, and the boundaries between information and other concepts such as social support and patient education are blurred (Leino-Kilpi, Mäenpää, & Katajisto, 1999; Piredda, 2004; Stoltz, Andersson, & Willman, 2007). In this study "information" includes every source parents use to create knowledge about the child's disease. Information is seen as an aspect of social support; it is also a broader phenomenon than patient education and disclosure of diagnosis, and it includes for example the parents' own search for information and informal, unstructured ways of acquiring information.

When acquiring information, parents make use of different sources of information, including not only health care professionals (HCPs), but also other parents at the ward, friends, printed material, and information from the Internet (Björk, et al., 2005; Kästel, Enskär, & Björk, 2010; McGrath, Kail-Buckley, & Philips, 2007; Patistea & Babatsikou, 2003; Ringnér, Jansson, & Graneheim, 2011). The process of gathering information continues throughout the whole treatment period and long after treatment has finished. Information needs therefore continually change in terms of both content and amount of information needed (Clarke & Fletcher, 2003; Ringnér, et al., 2011; Woodgate & Degner, 2002).

Obstacles arise for parents not only in attaining, but in using, information. Parents can be overwhelmed by the sheer amount of information available, and the effort to comprehend and manage it all has been described as similar to learning a new language. Medical terminology can be difficult to understand, and this objective obstacle to comprehension may be compounded by the parents' crisis reaction. Occasions when parents are informed about

their child's diagnosis or prognosis can be marked by stress and HCPs may not always give priority to providing information (Björk, et al., 2005; Clarke & Fletcher, 2003; McGrath, et al., 2007; Ringnér, et al., 2011). Parents experience frustration, worry, and stress when they lack information that the HCPs assume they already have (Soanes, Hargrave, Smith, & Gibson, 2009).

The complex combination of crisis, obstacles to comprehension, and changing needs for information makes it difficult for parents to create knowledge from available information and can lead to fear and worry (Kästel, et al., 2010; McGrath, et al., 2007; Sobo, 2004). Parents may be less satisfied with the provision of information than with other aspects of care (Pöder & von Essen, 2009).

Information provision is an important part of pediatric oncology's care for parents. Information allows parents shape knowledge about their child's disease, however, it may be difficult to understand, especially when coupled with the strain of having a critically ill child. Much of the research on parents' experiences of information in this context present secondary findings (eg. Björk, et al., 2005; Earle, et al., 2007; Jackson et al., 2007); studies using an integrated approach are still lacking. Accordingly, the purpose of this study is to describe parents' experiences of acquiring and using information to create knowledge about their child's cancer.

Methods

This study employs a qualitative mixed method, using data from focus group interviews and individual interviews that all underwent qualitative content analysis. In order to get narratives of the parents' lived experience of the topic under study, we combined focus group interviews with individual interviews (Lambert & Loiselle, 2008). The advantage of this approach is that the interaction between the focus group members generated broad, rich data (Peek & Fothergill, 2009), and by adding individual interviews, we also got personal narratives of lived experience. In order to reveal variation in content as narrated by the interviewees, qualitative content analysis was deemed to be a suitable method of analysis

(Graneheim & Lundman, 2004; Krippendorff, 2004). This study is part of a larger project aimed at developing an information intervention for parents in pediatric oncology.

Context

Pediatric oncology services in Sweden consist of six principal treatment centers responsible for diagnosis and treatment, all university hospitals. Patients living far from their principal treatment center can get certain treatments and much of the supportive care at a general pediatric department in a hospital closer to home. Recruitment and focus-group interviewing took place at one of the principal treatment centers, but many of the families also discussed experiences from their local hospital.

Participants

Parents of children with cancer were recruited to the focus groups from the pediatric oncology ward at one principal treatment center. Each week, two study nurses at the ward reviewed the planned admissions for the next week and assessed whether there would be enough parents to start recruiting for a focus group interview. If so, the nurses contacted the parents by telephone, by e-mail, or in person. In total, 32 parents planning to come to the ward were invited to participate. Of those, 2 parents declined and 16 parents were unable to participate because the child was either not admitted as planned or had already been discharged. In total, 14 parents participated in the four focus group interviews.

The parents were 4 men and 10 women between 26 and 53 years old (median 39½ years) with 11 children between 1 and 18 years old (median 8 years). There were 5 children with leukemia, 2 with a brain tumor, and 4 with solid tumors. Four of the children had finished their treatment. One child had a relapse of the disease. The time from diagnosis to the focus group interview ranged from 1 month to 10 years, with a median time of 34 months. All children still had contact with the pediatric oncology ward.

The sample for the individual interviews was a purposive sample of four parents, one from each focus group session. We choose parents who were proficient narrators and well-distributed between children's diagnoses and parents' gender.

Interviews

Four focus group interviews were conducted over a period of 8 months. The interviews took place in a room within the play therapy facilities at the pediatric clinic, so the play specialists could provide child care if necessary. The interviews ranged from 55 to 81 minutes long and included 3 to 4 participants each. The first author (AR) moderated the focus groups. Two broad topics were explored with the parents: situations where information worked well and situations where information worked badly. The discussions swung between these two areas throughout the interviews. When necessary, probing questions such as “Why do you think it worked well or badly?”, “How should it have worked at its best?”, or “What do the rest of you think? Do you recognize this situation?” were posed. All interviews were recorded on a digital voice recorder and transcribed verbatim.

After the initial analysis of the material from the focus groups, we decided to do individual interviews with further reflection upon the results in order to get individual accounts of the themes. This second round of interviews started with the interviewer (AR) reviewing the results of the preliminary analysis of the focus groups. The parents were then asked if they could elaborate the themes from their own experience. The same type of probing questions as in the focus group interviews were asked when needed. Finally, the parents were asked if they thought anything was missing in the themes. These interviews took between 40 and 88 minutes. One of these interviews was conducted by telephone on request of that participant.

Qualitative content analysis

The transcribed interviews underwent qualitative content analysis (Graneheim & Lundman, 2004; Krippendorff, 2004). This is a method that aims at systematically describing differences and similarities in any form of communication, such as an interview transcript. The text from the focus groups interviews were read several times. Meaning units, each one representing a single unit of content, were identified, condensed, and assigned a descriptive code. The codes were sorted into larger sets that eventually formed sub-themes and themes. This analysis moved back and forth dialectically. During the analysis process, codes, sub-

themes, and themes were reflected on and discussed among the authors and in the research group until consensus was reached. This resulted in two themes with six sub-themes.

The text from the individual interviews was also subjected to qualitative content analysis and the data was merged into the previously existing structure after a minor revision of the sub-themes. The same procedure for validation was employed in this phase.

Ethical considerations

The study was approved by the Regional Ethical Review Board in Umeå (Dnr 08–029M). All participants received written and oral information about the study. Written informed consent was obtained and participants were assured confidentiality. We were also aware that people may be upset by interviews about a potentially sensitive topic, and were therefore prepared to discontinue the interviews, but this was never necessary.

Results

The findings in this paper are organized under two themes, “feeling acknowledged as a person of significance” and “feeling like an unwelcome guest.” These two themes reflect two different conditions that parents experienced through the different phases of their child’s treatment, sometimes one right after the other.

Feeling acknowledged as a person of significance

When parents were well informed, they felt safe and secure in spite of the uncertainty, they felt their hopes were supported, and they felt relief learning about other families’ experiences. Altogether, they felt acknowledged as persons of significance. This theme was emphasized in the early phases of the child’s treatment.

Feeling safe and secure in spite of uncertainty

Parents were quite satisfied with the information they received. Despite emotional stress and chaos, they found that the information was well provided. It was given in a calm setting, and complicated matters, such as the treatment protocol, was also given in writing. Parents appreciated that the HCPs were honest and always gave them all the available information.

When parents were dissatisfied with the information, their complaints were taken seriously. Well organized, pre-arranged meetings some time after diagnosis and at the last treatment were useful. Parents found the HCPs (nurses, physicians, and allied health personnel) were obliging and welcoming, and they perceived themselves as people who mattered. These experiences created a sense of security in parents and they felt assured that this ward was the right place to be in these circumstances.

They sat down and explained what it was and what they knew. And it was really a good thing to come up here. They took their time and I could ask my questions and talk about my thoughts and so on.

Father, focus group interview

Feeling safe and secure in spite of uncertainty also meant having the right information at the right time. The parents described their initial reaction to the diagnosis as a state of shock wherein they were unable to process information from the HCPs. They simply did not hear what the HCPs said, or they repressed it. One mother reported not having grasped that her child was to receive cranial radiation until a few months after the diagnosis. At later times of strain in the treatment, such signs of crisis reaction could reappear. Parents also spoke about shutting off their feelings to protect their child and to cope, and that this also could have a negative impact on information processing.

The six first weeks were just a haze—well, you were sad and in grief—before you understood what it was all about.

Father, individual interview

However, the parents said that the HCPs adjusted to this shock reaction and limited information to what the parents could take in. For example, they did not speak about side and late effects of the treatment or the risk of relapse, and they often repeated the information and gave it in small portions so that the parents would be able to comprehend.

Having good continuity of HCPs was also a part of feeling safe and secure. Parents felt that they were given sufficient time for information, and that it was easy to find someone to ask if they had questions. Families were assigned a primary nurse, who had a central role in the information flow and gave the parents confidence. Parents felt that they could ask the nurse even “stupid” questions and telephone the ward at any time to ask questions.

Having one's hopes supported

Positive information from the HCPs, such as the planned treatment and its proven effectiveness, supported parents' hopes. Some parents had suspected the diagnosis in advance, and some had also had bad experiences of cancer themselves. The parents wanted to hear that everything was going to be fine, but they understood that no one could promise that. However, the HCPs managed to maintain hope in the parents, as for this family who had known a boy who died from a similar disease:

It was a nurse who came to us and said, “You know, this is going to be fine, your child does not have what [the dead boy] had, and this will just be OK.” But the doctors didn't say this. But perhaps you can't do that either, because you don't know if it will end well.

Mother, focus group interview

Getting relief from sharing other families' experiences

In addition to the HCPs on the ward, other families of children with cancer acted as sources of information. For example, volunteers from the Regional Childhood Cancer Association, who were mainly parents of children who had been on the ward, served coffee and pastries and were available to talk to the parents at the ward one evening each week. These evenings were highly valued by the parents, who learned from the other parents' experiences. Another arena for parents to inform each other was the weekly Parent's Forum on specific topics (e.g. nutrition, school attendance, central lines) moderated by an experienced pediatric nurse. The skills of the nurse responsible for the forum were highly valued by the parents.

In some situations, parents preferred to ask advice from other families rather than HCPs. Other families' own experiences of caring for an ill child, their knowledge of how to manage at home, and their real-world example were often more useful than the more sweeping, abstract descriptions obtained from the HCPs. For instance, another family's experience of what happened to their child after a specific treatment helped parents better prepare for hair loss, nutritional problems, nausea, fungal infections, and other practical problems. Knowing that other children had suffered from, and families had coped with, similar problems, allowed parents to feel one step ahead and gave them some relief. Learning from other families also helped the parents to see that there were other people who were worse off and to put their own situation in perspective. This mother explains how information from other parents helped her normalize the trouble the family had with the gastric feeding tube:

Well, we were told they would just put the tube in place and it was going to be in the tummy and you can give [the child] food and everything will be all right. Period.

Nobody told us that it could actually be so terribly irritating that she would vomit the tube up all the time so it came out from both her mouth and her nose. Nobody had said that. But it was like that from the start. And then you hear from other parents that it was like that for their children too, so they had to take it away.

Mother, individual interview

However, in some situations other families whose children were not doing well were more of a worry than a help. Parents actively avoided learning from those families, as a parent of a child with a relapse of the disease experienced almost as a deterrent to contact with other families.

As a way of reciprocating the information they received from other families, parents tried to share their knowledge with families who had recently arrived at the ward. The HCPs' policies of patient confidentiality interfered with this intention since parents were not allowed to refer new families to others willing to help. Parents wished the ward could actively establish contact between families with the same diagnoses so that they could help each other.

Feeling like an unwelcome guest

Parents felt like unwelcome guests on the ward when their information needs were not met. They felt abandoned at important milestones, forced to nag for information, and burdened by the obligation to inform others instead of being given information. This theme was expressed most often in the late phases of the treatment and at follow-up visits.

Feeling abandoned at important milestones

Certain events, such as the child's first discharge from hospital, finishing treatment, having a relapse, or returning to the ward for a new treatment after some time at home were very important to parents. Finishing treatment was especially emotional for parents:

Well, I feel that when we return here after two and a half years, we should be greeted with a glass of champagne. Well, something like that. Because this is so special; we have been looking forward to this for so long.

Mother, focus group interview

Parents felt that their information needs at these important events were sometimes neglected by the HCPs. For instance, at end of the treatment, parents wanted a meeting where the treatment was summarized and a written overview of the treatment and possible side effects was given to them. Some parents had such a meeting, but for those who did not, there was a feeling that the treatment had not really come to an end. The same sort of meeting was wished for at the first discharge and, for leukemia, when the maintenance treatment started. In the case of a relapse in the disease, parents emphasized that good information was as important as ever, but that at that point they had to search for information themselves.

The parents emphasized that their needs for information did not decrease as time passed—on the contrary, after some time new and recurring questions left them needing more information. This was especially the case in later phases of the treatment, when the families sporadically visited the ward or the patient only got radiotherapy a few minutes each day. The feeling of being an unwelcome guest forced the parents constantly to be on guard and they

were never able to relax. The insufficient information made parents feel that they had to keep control and could not trust the HCPs.

The feeling of being abandoned could also be due to a lack of structure for the provision of information on the ward. On arrival at the ward, it was not clear when or even if they would have a meeting with their physician. The parents suggested that regular information sessions be merged into the treatment schedules in the same manner as drugs have already been incorporated.

The primary nursing system that had worked so well for providing parents with information earlier was absent in the later stages. The parents missed meeting a primary nurse and physician responsible for informing them and this contributed to their perceived need be on guard. Parents felt that they were low priority, “a piece of furniture” on the ward.

The sporadic information meetings and lack of continuity of information, was another problem for the parents. They felt like unwelcome guests at the ward, ignored as the HCPs rushed past them in the corridor. Medical rounds were short encounters and the parents felt that they should not ask for more time then. In general, the HCPs attended to the ill child, but made no separate time for the parents, who felt that they could not ask any of their many questions when the child was listening. Parents wanted an opportunity to get information from the HCPs on their own, should they have specific questions. They also wanted scheduled follow-up information meetings with the physician, where they could sit down and look at the treatment schedule together, and regular contact with HCPs while the child was back at home. At the same time, the parents did understand that the HCPs were overloaded with work and that they had to focus on the new families.

In some situations, such as while waiting for a preliminary diagnosis or when a child's condition rapidly worsens, the parents felt that the HCPs sometimes limited the information. Parents might, for example, be told only the symptoms but not the suspected disease. They sometimes thought that the nurse had been instructed not to talk to them about the

suspicious. However, even when they were given no information at all, the parents themselves created an understanding of what was happening:

Mother: No, they looked after us a lot, they were like, do you want something?

Father: They knew what the matter was but weren't allowed to tell us. I said to you, it has to be something, because they feel so bloody sorry for us.

Mother and father, focus group interview

Information also seems to be limited during a crisis. When her child's condition was critical, one mother solved the problem herself:

And we did not get enough information about what was happening, so I just took some papers that the doctor had left behind on the table. And those papers were in English, and he had found some studies, so thanks to those papers, I understood what was going on. And after that I just had to think further and ask questions.

Mother, focus group interview

In these situations of limited information, parents also reported browsing the Internet to learn more, despite HCPs' recommendations to the contrary. However, they also said that information from the Internet could be difficult to understand and disappointing to read, because it presented possible complications and side effects that they did not know about earlier.

On some occasions, parents got incorrect or contradictory information from the HCPs. The consequences of this could range from practical problems, such as arriving to the ward one day too early having been given a wrong date, to unnecessary anxiety about a bad, but not necessarily correct, prognosis. Parents said no information at all might be better than incorrect information, but throughout the interviews, lack of information was reported as a great hardship by the parents. The most frustrating situation was when not even the physicians could answer questions; the saddest was during times of relapse when the nurses could no longer offer support for parents' hopes.

Some parents reported strategies for handling the situations when they felt abandoned. Some “put their foot down” and demanded communication with the HCPs, while others tried to cope by not expecting so much information in the later phases of the treatment.

Feeling forced to nag for information

Parents felt that they were under-informed and therefore constantly had to ask for information. They were unhappy about having to be so pressing, but at the same time found that persistence necessary in order to get information.

Sometimes I have nagged at them to give me five minutes, because I don't understand a thing. So they would explain to me for five minutes, then bye-bye. Sometimes I have asked them for a longer talk, half an hour perhaps. Sometimes they don't have time, sometimes they do. That is the only thing that I am disappointed in.

Mother, focus group interview

Some parents felt that it was their right to be informed until they understood; others were reluctant to disturb the HCPs and to take up their time, even when the HCPs did not indicate that they were demanding.

Perhaps you need to hear that you really are welcome to ask questions and that it is all right. You are not a bother. Perhaps you need to hear that to feel that it's ok.

Mother, individual interview

Feeling burdened by the obligation to inform others

This sub-theme illustrates a somewhat paradoxical situation in which parents had to keep the health care system informed about important aspects of the care, as opposed to being provided with information. The information required of the parents was far beyond the typical information parents provide during a regular medical examination or nursing assessment and had to do with what drugs should be given or how the nursing care should be performed. Parents saw this as far beyond what they should reasonably be expected to provide. Parents spoke about having to inform new HCPs about the child's medical history

and current situation, but knowing that the new HCP might be annoyed if they tried to warn her or him against mistakes.

Father: Well, she wanted to give him a sedative in his bum.

Mother: Yes, and the experts here say that he can never even have a thermometer in his bum, nothing ever enters there. And then she gets really cross and thinks that we interfere too much.

Mother and father, focus group interview

There were also situations in which the parents had to inform each other about the child's diagnosis.

Well, so I had to tell him when he arrived, because I could not tell him on the phone, so when he arrived . . . I told him that they are going to do this because they believe that there are tumors. So I had to throw that shit right in his face.

Mother, focus group interview

Discussion

In this study, we described parents' experiences of acquiring and using information to understand and cope with their child's cancer during the course of the illness. We identified two themes, "feeling acknowledged as a person of significance" and "feeling like an unwelcome guest," that reflected two conditions that parents experienced. The first theme expresses a primary goal of information-sharing for professionals in pediatric oncology, while the second illustrates shortfalls in reaching that goal.

This study concerns parental experiences. In a previous study (Ringnér, et al., 2011), we reported issues about information that HCPs in pediatric oncology found to be troublesome, such as the lack of structure on the ward, unclear responsibilities, and the disrupted setting, which are reflected in this study's report of parents' experiences. In some situations, parents in this study felt that the HCPs withheld information, which corresponds well with the HCPs' earlier statements about the difficulty of matching the amount of information to the parents'

needs (Ringnér, et al., 2011). Integrating parents' and HCPs' descriptions of problems with information-sharing should contribute to improving the provision of information to parents.

We considered an alternative, more positive view of the sub-theme "feeling burdened by the obligation to inform others." Parents could be described as expert parents just as expert patients are described within chronic illness research: very well acquainted with their own (child's) illness, competent to systematically reason and interpret clinical signs, and able to educate other parents (Tattersall, 2002). However, we chose to interpret this sub-theme as a burden because the parents strongly emphasized their reluctance to be forced into the role of expert and their expectation that health care professionals should act as experts.

In general, in pediatric care it is seen as obvious that the child has a right to all information and that the family should be seen as a unit (Harrison, 2010). Still, parents in this study reported having questions to which they did not want the child to hear the answer. Especially for younger children, it is reasonable to believe that parents needs for information differ from those of the ill child. Family-centered information interventions in pediatric oncology should therefore acknowledge the different information needs of all family members.

The parents in this study generally reported more dissatisfaction with access to information in the later phases of their child's treatment. However, quantitative data indicate that parental psychosocial distress is at its highest at the time of diagnosis but decreases and approaches norm levels at one year post diagnosis (Pai et al., 2007). Could it be that in situations of high distress, including the initial cancer diagnosis, parents are less likely to identify weaknesses in information provision than they are to be grateful for any information? Exploring why parents seem less satisfied with the information provided when their psychosocial distress improves is an important topic for future research.

Methodological Reflections

We found it difficult to recruit enough participants for each group. We expected five to eight participants for each focus group, however, due to the unpredictable nature of pediatric cancers and patients' treatments being postponed because of leukopenia, we had many drop-

outs at the time of interview (cf. Lowe, Bravery, & Gibson, 2008). This contributed to the comparatively small focus groups sizes. However, we agree with Toner (2009), who claims that smaller focus groups can have unique advantages as a result of their more intimate climate as opposed to larger groups.

The time from the child's diagnosis ranged from 1 month to 10 years, which adds to the variety and breadth of experiences illuminated in this study. Relatively few parents of children with brain tumors participated. This could be because many of these patients undergo surgery only once and do not return for regular treatment.

Combining focus group interviews with individual interviews gave us the opportunity of obtaining both a broad understanding of the phenomenon and deeper genuine accounts of some parents' own experiences. The individual interviews also served to help us confirm the analysis of the focus group data (Lambert & Loiselle, 2008; Wutich, Lant, White, Larson, & Gartin, 2010). Most of the quotations in the text are from mothers. This corresponds to the overall gender distribution of the sample.

Conclusion and implications for practice

Clinicians should try to pay extra attention to parents' informational needs at important milestones such as treatment cessation or relapse of the disease. Continuing information meetings beyond the early phases would be very valuable to parents, as would optimizing the information flow within the health care system so that parents do not feel responsible for conveying important information about the treatment of their child to different actors within the health care system. Gaining a deeper understanding of how parents acquire information in the later phases of treatment may be a topic for future research.

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