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Professional Caregivers' Perceptions of Providing Information to Parents within Pediatric Oncology

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Abstract

Information has been described as a critical part of the care for parents of children with cancer, but not much is known about how staff makes decisions about informing parents. This study aims to illuminate professional caregivers' perceptions of providing information to parents of children with cancer. Twenty caregivers at a Swedish pediatric oncology ward participated in four focus group interviews. The interviews were transcribed verbatim and subjected to qualitative content analysis. Two themes were found: Matching the amount of information to the parents' needs concerned situations where the amount of information provided according to the caregivers' assessment of the parents' needs is deemed too small, appropriate, or too large. Navigating through a vague structure dealt with a disrupted setting, unclear responsibilities within the team, difficult timing, unintelligible information, and underused tools for communication. Implications for intervention development are discussed.

Key words: *information to parents, caregivers' perceptions, pediatric oncology, focus groups, content analysis.*

Introduction

Parenting a child with cancer is a challenging mission characterized by uncertainty (Björk, Wiebe, & Hallström, 2005; McGrath, 2002; Woodgate & Degner, 2002), which creates psychosocial distress in parents (Pai et al., 2007). Information has been described as a critical part of the care (Björk et al., 2005; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; Ljungman et al., 2003; McGrath, Kail-Buckley, & Philips, 2007; von Essen, Enskär, & Skolin, 2001). The situation within the family can be described as “a broken life world,” where parents experience an unreal situation with an immediate risk of death. The family immediately starts “striving to survive” using information, among other supportive resources, to reduce the chaos they are experiencing (Björk et al., 2005). Receiving the diagnosis, in particular, is regarded as an extreme strain that puts parents into shock (McGrath, 2002; McGrath et al., 2007). This reaction makes providing information more difficult, as parents can have a worse recollection of medical information when under stress (Jedlicka-Köhler, Götz, & Eichler, 1996).

Providing information within a nursing context is a complex phenomenon that has been described variously as being part of social support (Stoltz, Andersson, & Willman, 2007) and patient education (Piredda, 2004), and as a precursor to knowledge in the context of empowerment (Leino-Kilpi, Mäenpää, & Katajisto, 1999). There is no clear definition of information, as such, and the boundaries with other concepts like the ones mentioned above are blurred. In this paper, information is understood as a wider concept than patient education and disclosure of diagnosis, and includes what parents are being told about the disease, its treatment, and skills they need to take care of the child throughout the disease trajectory.

McGrath et al. (2007) studied informational issues for parents of children with acute lymphatic leukemia and described how parents face a steep learning curve with a rapid increase in knowledge. The parents literally have to learn a new language when the child's treatment starts. They claimed that information helped them cope with the situation, but the

amount of information needed differed between individuals. Some parents felt they were under-informed, whereas, others got too much information, thus increasing anxiety in both cases. Parents mostly used nurses as a source of information, due to their immediate availability. The Internet is another source for some parents (McGrath et al., 2007). Even if information is considered as an important factor of care, both from the parents' and the caregivers' points of view (von Essen et al., 2001), parental satisfaction with information may not be optimal. In a recent Swedish study investigating parents' perceptions of satisfaction with care, information provided by both physicians and nurses was low valued compared to other components of care (Pöder & von Essen, 2009).

According to nurses, the most important topics to inform parents about are treatment, myelosuppression, symptom management, self-care, and chemotherapy (Kelly & Porock, 2005). Concerning information to *adolescents* with cancer, medical information is rated more important by caregivers than psychological information. Nurses rate information as more important than do other health care professionals (Bradlyn, Kato, Beale, & Cole, 2004). Caregivers also express that the need for information changes over time (Bradlyn et al., 2004; Kelly & Porock, 2005). However, we have not found any descriptions in the literature of how caregivers decide which information should be provided to parents within pediatric oncology, or how it should be delivered.

To recapitulate, informing parents is an important part of pediatric oncology care. Parents are often in severe stress, and information has to be given in an ongoing crisis, further challenging the caregivers' information skills. This study is part of a project aimed at developing an information intervention for parents within pediatric oncology. However, to design successful interventions, it is critical to have the caregivers' point of view, which is sparsely examined in the literature. The purpose of this study is to illuminate professional caregivers' perceptions of providing information to parents of children with cancer.

Methods

This is a qualitative, descriptive study, based on focus group interviews, using qualitative content analysis to derive caregivers' perceptions of providing information to parents. In addition to this study, we will perform focus group interviews with parents and participant observations of information sessions. These three studies will lay the foundation to develop an intervention that will be tested.

Participants

All professional caregivers (some 30 people) at a Swedish pediatric oncology ward were informed about the study by the first author. In total, 20 caregivers participated by choosing one interview session from a list on a notice board in the ward. Of those participating, 11 were registered nurses with a university degree, 2 were pediatric enrolled nurses with a high school diploma, 6 belonged to the allied health personnel group, and one was a physician. Two of the 20 participants were male. The participants' median age was 48 years, ranging from 27 to 64 years. The median number of years in the profession was 19½ years (range 2 to 43) and the median number of years in pediatric oncology was 8 years, ranging from 2 to 39. Another three participants enrolled, but dropped out at the time of the interview due to workloads on the ward.

Focus Group Interviews

We conducted four focus group interviews. A focus group interview is a group interview on a specific topic, facilitated by a moderator. We selected this method for its ability to elicit qualitative data from a large number of people by using the interaction between group members to enhance discussion, and thus generate rich data (Peek & Fothergill, 2009).

The interviews took place in a conference room in the hospital. Group sizes varied from 3 to 7 participants, and the duration of the interviews from 76 to 85 minutes. The first author (AR) moderated the focus groups, while the third author (UHG) observed and kept mind-map notes of the content of the interviews. Before finishing each interview, we reviewed the mind

maps with the group, and invited the informants to make remarks and amendments (cf. Kylmä & Juvakka, 2007).

To facilitate discussion in the focus groups, the participants were asked to tell about actual situations. Three broad questions were posed to the groups: "Could you please tell me about a situation where the information to parents worked well?" "Could you please tell me about a situation where the information to parents worked badly?" and "How would the information to parents work at its best?" If the participants did not spontaneously reflect upon their answers or if there were no discussion, probing follow-up questions were posed, for example, "Why do you think it worked well or badly?" or "What do the rest of you think? Do you recognize this situation?" The interviews were recorded on a digital voice recorder and transcribed verbatim.

Qualitative Content Analysis

The interviews were analyzed by means of qualitative content analysis, a method that can be used to systematically analyze the content in communication, such as interviews. It emphasizes similarities and differences in data and is, therefore, useful for revealing various aspects of the same phenomenon (Graneheim & Lundman, 2004; Krippendorff, 2004). The interviews were read several times to get an initial understanding of the whole. The text was then divided into meaning units, each one representing a single item of content. These units were condensed into shorter elements, while still preserving their core content, and each meaning unit was assigned a code. The codes were then sorted into categories, from which broader themes were developed. This process was not linear, but rather signified by a forward-and-backward movement between the whole and parts of the text. We also reviewed the mind maps from the interviews several times during the analysis to facilitate the analysis and validate the results. Finally, two themes with eight categories were defined.

Ethical Issues

This study was approved by the Regional Ethical Review Board in Umeå (Dnr 08–029M). As in all interviewing, there was a risk that participants would experience distress from the

interviews. We were aware of these potential problems, and all participants received oral and written information about the study. They were informed about the confidential nature of the interviews, and they were assured that they could terminate their participation at any time. Written informed consent was obtained.

Findings

The findings in this paper consist of two themes: *Matching the amount of information to the parents' needs* and *Navigating through a vague structure*, in both cases focusing on issues that could be addressed to improve communication, as described by the professional caregivers.

Matching the Amount of Information to the Parents' Needs

This theme consists of three categories, by which the amount of information provided according to the caregivers' assessment of the parents' needs is deemed too small, appropriate, or too large. The caregivers reported that they often developed a feel for reading the parents, and that it was important to be sensitive to parents' needs. Yet, it could be quite difficult—at times, almost impossible—to gauge the parents' needs, and both over- and under-provision of information occurred. In some situations, the caregiver simply gave the information he or she assumed the parents would need. One caregiver ironically wished that it were possible to assess their information needs with help from the laboratory:

Well, you take a blood sample called information in serum, and then you check the result.

The child's need for information could differ from the needs of the parents. If the child was old enough to understand the information, caregivers reported that information to parents was often mediated through the child.

Providing too little information

The caregivers perceived that they did not provide as much information as needed. For example, parents who were seen as experienced, as at a relapse of the disease, could,

according to caregivers, be given too little information. The same was true for parents who worked within health care. As for families from other cultures, caregivers also experienced a risk of giving too little information, because their preferences for information were not always clear to the caregivers. The caregivers further perceived that, in families where the same parent always accompanied the child at the ward, there was a risk that the parent who stayed home got too little information. The caregivers found it important, although complicated, to cater to both parents' needs in these cases; likewise, with divorced parents.

To search for information about subjects seldom discussed by the caregivers, such as complementary and alternative medicine and the prognosis of survival expressed as a percentage, or to double check the information they got on the ward, some parents reportedly turned to the Internet. The caregivers found this problematic, as it could be difficult to judge the quality of the information the parents found. Some parents concealed the fact that they looked for information elsewhere.

The fundamental rule was that parents should be offered all information available. The caregivers reported that they always strived to be as honest as possible by never withholding information and that parents appreciated this approach. They wanted parents to feel that they got straight answers from the caregivers, and they were aware that parents could easily sense if one did not tell the whole truth. There was, however, sometimes also a need to limit information, when revealing the whole truth might cause distress and insecurity in parents. Those situations were described as exceptions to the rule.

...Certainly, you say everything, but I still believe that you shouldn't be honest and tell sort of all ifs and buts and perhapses and so's, but rather that, "Well, we know this, we've taken these tests now, we know this far." But then, you're not really honest 'cause, well, there is a suspicion that it could be something else, or the possibilities and risks indicate something else, too. But maybe you don't really need to tell such things after all.

In some cases, there was a conflict between what information had to be given from the caregivers' point of view and what information the parents wished to have. In such situations, where the caregivers, for example, intended to give tough information, some parents avoided it:

I believe that the mother in some way had stated... She—I think it was an MR scan she did not want them to do—or she did not want [her son] to have the results. The examination, or whatever it was. So the mother hinted that now, I do not want to know this.

Such avoidance was described as an ethical problem, as when dying children are not allowed to know that they are dying. Even if one believes that the child actually understands the situation, it causes discomfort for the caregivers not to be allowed to communicate openly about the child's condition to both the child and the parents.

Providing an appropriate amount of information

At most occasions, the caregivers felt that they provided the correct amount of information to parents, whose needs they described as insatiable. They described parents as eager to get information, motivated, keen to learn about the child's illness, and full of questions.

There was this father not so long ago when I had the night shift... who stayed up until half-past four with us and talked about this and that, and he had really great needs, I think. Because... there was time then. So at four-thirty, we sent him to bed and said that perhaps you need a few hours of sleep (laughs).

Parents were also encouraged to seek information for themselves, for example, by writing questions in advance or talking to other parents.

Providing too much information

The caregivers described situations in which they provided the parents with too much information. One nurse related an instance of this. The parents of a severely ill child at the

intensive care unit had got a very long and intricate report on the child's condition from a physician, who finally concluded that the child was to be transferred to another hospital.

But then, when the doctor had left, I stayed with the family. And then the mother looked at me with tears in her eyes, and then she says, "Do you know... I... I don't know what the doctor said, but I do know that we'll leave here."
That was what she had picked up.

The ward was described as being accessible to parents who wished to ask questions, and caregivers aspired to immediately cater to parents' information needs. On the one hand, that level of access was generally seen as positive, but on the other, as conditioning parents to have their questions answered promptly. This ready availability caused extra work, because the caregivers were interrupted with questions that could have waited until later, and it was an obstacle to making parents as independent as possible.

Navigating through a Vague Structure

The caregivers identified a number of areas where the structure for providing information to parents was too informal and could be improved. The categories in this theme are a disrupted setting, unclear responsibilities within the team, difficult timing, unintelligible information, and underused tools for communication.

A disrupted setting

One aspect of the vague structure was that information sometimes was imparted in a disrupted setting. Instead, one should choose a quiet place and reserve enough time. The caregivers reported that much information was given while they were busy doing other things, for example, managing the child's intravenous infusions, and because of this, they were not focused on giving information.

A good place to give information is the patient's room or a special meeting room, according to the caregivers. The important thing is that it be quiet and have a door that can be shut. All potential disturbances should be eliminated, and mobile phones and videogames turned off.

The importance of choosing the right place to convey information is illuminated in the following example. One participant referred to a situation with an experienced physician who caught the parents in the stairwell:

He... he could cope with most things. But he couldn't cope with this and then, he ran... He, he caught them in the staircase and said that this was not... I can't... this is inoperable. And that was the same case. It was quite difficult to take care of this family afterwards.

The workload on the ward was also described as playing a part in the quality of information provided. If there was a high strain on the ward and the caregivers were stressed when giving information, they reported doing a poor job of it. Parents might, in consideration of the staff, postpone their questions, if the staff were busy. The caregivers further expressed dissatisfaction with their work if too little time were available for conveying information. Clearly stating the time available for a meeting was mentioned as a good strategy to create realistic expectations, if one were busy.

Unclear responsibilities within the team

It was seen as crucial to have good routines for information provision on the ward—some sort of checklist was suggested. Almost every family had its own primary nurse, who was responsible for planning information and notifying other members of the staff of parents' information needs. Another valued person was the consultant nurse (a specialist nurse at each pediatric oncology ward in Sweden), as she had a separate, explicit responsibility for information. She visited schools and daycare centers and informed teachers and classmates about the disease, in cooperation with the family.

Another problem in the structure on the ward was that it was sometimes unclear who was responsible for giving medical information to the parents. The caregivers stressed that, to ensure that everyone was working in concert, important information from the physician should always be given with at least one nursing staff member present, preferably both a registered nurse and a pediatric enrolled nurse. However, some of the caregivers reported

that the pediatric enrolled nurse was sometimes replaced with another physician. One situation was described in which a physician on his own told a mother that nothing more could be done for her child.

And all of a sudden, the mother is out in the corridor screaming and is completely heartbroken, and we have no clue of what had happened and what has... Well, we don't even know what he [the physician] had said.

This situation was also seen as problematic by the caregivers when considering the parents' trust in the staff—the worst possible outcome had struck the family, and none of the nursing staff seemed to know anything. Having a physician, a registered nurse, and a pediatric enrolled nurse in the room when giving information could, according to the caregivers, be an issue in terms of power relationships, but in general, the advantages were deemed to outweigh the possible problems.

Caregivers referred to issues that arose because the division of responsibilities between caregivers was not clearly defined. For example, immediately after surgery, a very experienced surgeon abruptly told the parents of a small child that the tumor was inoperable and there was nothing more to do. The parents were shocked. But this matter had not been discussed with the oncologists, beforehand, and even though there later proved to be some treatment available, the parents were not able to grasp this new information. The initial information should have been given differently:

Well, you could perhaps have seen to it that... that the physicians involved could come together, for example. Or that they could have some information among themselves. Or some... some discussion before, and then, well, but now, this could not be operated, is there anything else to do?

Another example of lack of communication within the team is when a caregiver inadvertently speaks to a family about something they have not been officially informed about. In the following situation, a decision had been made to amputate a child's leg. The nurse had not

attended the initial meeting with the family, but was erroneously informed that they knew about the amputation before she was to see them:

I know that they had heard it, full information. Well, so I start to talk about amputation—"What?" they said. [Interviewer: But what happened then?] Well, it exploded—there were sparks. And crying.

Difficult timing

The vague structure also affected timing of the delivery of information. Parents' needs for information were seen as changing during the illness trajectory and did not necessarily decline as time passed. The caregivers expressed that they wanted to give information at the very time when the parents really needed it. To do so, they said that they both assessed the parents' readiness and used their own intuition about the appropriateness of the timing.

The caregivers also stressed that the initial crisis reaction when parents are told about their child's disease can render them incapable of assimilating information. They hear just the words *cancer* and *death*. In extreme cases, parents may even forget having met a caregiver:

One night when we admitted a child... and I felt it was quite good, like we had a lot of time for this, this family, that was a mother and a little boy. And I explained and played with the boy and told the mother several times. The next time I saw her, she didn't even recall having met me. Could not remember me. She was so... in such a great shock that she couldn't grasp it.

The caregivers believed that only the most essential information should be given at times like this. The rest should be postponed to a later phase when parents are prepared to receive it.

At some occasions, parents' reactions are unpredictable, and may be considered inadequate by the caregivers. The delivery of information may be well planned, but parents' responses to the information might not be what the caregiver expects. Even if one were very familiar with different crisis reactions, one could still be taken by surprise, thus disrupting the flow of information.

...Well, I can't say, before what I had expected, but... but I do feel at once if the answer wasn't as expected. If they should start laughing or hahaha, what fun, we get to be here [in hospital] a lot.

The process of telling the parents about the definitive diagnosis was deemed easier if parents already had some preliminary information concerning a suspected diagnosis, according to the caregivers. The time until the final diagnosis was difficult for the caregivers to handle, as they could neither start to give information, nor help parents to deal with their situation:

Well, you get, you just sort of just walk in, in a sludge all the time 'cause you can't sort of start working through anything or help them to start working through anything.

Information from physicians should, according to the caregivers, not be given late in the afternoon, since the physician responsible may not be available to answer questions in those cases.

The caregivers reported that information had to be repeated many times and that it was better to have frequent short information sessions. Conversely, information could also be repeated too often, making the caregiver appear tedious. The long time the families spent in hospital made it possible to plan and reiterate the information, yet there were still cases when the child suddenly was to be discharged from the ward, and one discovered that the parents, nevertheless, were insufficiently informed.

Unintelligible information

Another issue related to the vague structure was that caregivers sometimes found that they failed to provide information in such a way that parents were able to understand it. The information could, for example, be too advanced, especially if it concerned serious or complex matters. There was a risk of giving information on a nearly academic level, for instance, by discussing different doses of drugs or theoretical scenarios that perhaps were not relevant to the parents. Using comprehensible language in each specific situation was

deemed as important by the caregivers, and was accomplished by avoiding difficult or frightening words.

When meeting parents from non-Swedish-speaking backgrounds, the caregivers experienced that it was more complicated to give understandable information, due to the language barrier. Critical information could be conveyed through an interpreter, but a lot of the more casual information and communication posed problems, because the interpreter was available only by appointment. Caregivers expressed that there was a significant risk for non-Swedish speaking parents to lack knowledge about the disease, because they simply could not understand the information provided.

Underused tools for communication

There were various aids and tools available to assist in presenting information on the ward; however, these resources were not used as much as they could be. This fact also contributed to the sense of a vague information-handling structure. One teaching kit, originally aimed at the ill child, was useful for parents, too, and helped families to review the information later on their own. Pictures and real specimens of, for example, central venous catheters and percutaneous endoscopic gastrostomies were useful to show before implantation. Doing practical exercises with the parents was also seen as a good strategy.

Another communication strategy used was continuous feedback, meaning that the caregivers tried to ensure that the parents really had understood the information given, which was not always the case. Sometimes, parents believe they have understood the information, but according to the caregivers, the opposite may be true. In other cases, parents may pretend to understand the information. Therefore, the caregivers deemed it important to continually check whether the parents really had understood the information and to correct and fill in the gaps, if necessary. Caregivers also pointed out that their former experiences of giving information were quite useful when facing new situations, including being able to learn from bad examples.

At the ward, group support meetings with parents, moderated by a staff nurse, were held weekly, and the caregivers believed them to be important for parents. The caregivers also desired more organized group information sessions.

Discussion

The aim of this study was to illuminate professional caregivers' perceptions of providing information to parents of children with cancer. To design meaningful interventions for imparting information, one should be aware that there is a risk of over-informing, as well as under-informing, the parents. Structural issues should be taken into account, such as clearly establishing responsibilities for information, creating an uninterrupted setting, using adequate tools, and timing the delivery of information correctly.

Virtanen et al. (2007) described the empowering discourse. Empowerment begins with mutually negotiating the content of the discourse and clarifying the needs of the patient. The discourse is steered by the nurse, but patients are encouraged to participate actively and get feedback and advice from the nurse. Throughout the discourse, the patient determines the content of the information. The tone is calm and confidential, and the relationship is balanced and respectful. Equality and shared power between the nurse and patient are also emphasized. In this study, the mutual negotiating of the content and clarifying of needs was described by the caregivers in the theme *matching the amount of information to the parents' needs*, where a successful assessment of parental needs helped in determining the correct amount of information to be given. The calm and confidential tone in an empowering discourse was emphasized in the category *a disrupted setting*, in which the caregivers expressed that the setting for giving information was not always calm. On the contrary, information was sometimes given in hectic situations. Within a pediatric context, empowerment has been described by Gibson (1995) as an intrapersonal process, whereby mothers develop and use knowledge, competence, and confidence to make their voices heard when caring for their ill children. The mothers in Gibson's study were empowered when they were full participants in the care of the child.

The caregivers expressed that, in certain situations, they avoided giving all the available information. It was argued that complete information might cause unnecessary anxiety and insecurity. One example was the reluctance to talk about a child's prognosis in percentage terms. However, it seems that parents have a strong wish to be thoroughly informed. There are results showing that the more upset parents were by the prognosis, the more important it was to them to learn about it (Mack, Wolfe, Grier, Cleary, & Weeks, 2006). Still, some parents report being both over- and under-informed (McGrath, 2007).

The caregivers also reported that some parents tried to limit the information given, in order to protect the child from bad news about, for instance, an incurable disease. There can be numerous reasons that parents wish to withhold distressing information, for instance, to protect the child or to avoid their own fear of talking about it with the child. The caregivers, on their part, experienced this withholding of information as an ethical dilemma, wherein the child's right to be informed was threatened. Previous research has shown that no parents who talked to their dying child about death regretted doing so, while one-fourth of those who did not talk about it regretted their choice (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). Still, this is a delicate topic, and one, perhaps, has to trust the parents' judgment and let them have the final word.

The caregivers' concern for parents' use of the Internet has some support in the literature. Many parents trust information found on the Web, and far from all are able to assess the quality of the Web sites they use (Wainstein, Sterling-Levis, Baker, Taitz, & Brydon, 2006). Internet research may be risky, since much information found on the Web, for example, about complementary and alternative medicine, is inaccurate (Walji et al., 2004). On the other hand, many parents report benefits from using the Internet to find information (McGrath et al., 2007; Wainstein et al., 2006), and there are methods by which nurses can support parents in evaluating online sites (Anderson & Klemm, 2008).

In this study, the caregivers also described that much of the information for parents was given informally, either while doing other things, such as managing intravenous infusions, or

indirectly, through what was being said to the ill child. Gregor (2001), writing about patient education in quite a broad sense, claims that much of the conversation nurses have while taking care of patients, indeed, has an educative purpose, even if it is neither viewed so by the nurses, nor intended to be patient education in the traditional sense. Conducting participant observations about how information is given to parents would be valuable for gaining a deeper understanding of how informal education might work in a pediatric setting.

As Clarke and Fletcher (2003) argue, both the disease itself and the parents' dealings with the health care system can cause distress. With respect to the illness, acting as a container for the anxiety and worries of the parents is perhaps the caregivers' most urgent task (Fulton, 2008). Yet, distress may spring also from factors within the health care system, such as conflicts concerning relationships, structure, and values (Clarke, 2004; Moore & Kordick, 2006), or badly given information. For example, parents who did not understand the information had more psychosomatic symptoms (Sloper, 1996). A number of obstacles to giving good information are reported in this paper, and it may seem that this is a "mission impossible," with numerous pitfalls. However, even if the information and other psychosocial support were perfectly organized, one could still not expect parents to be without distress. Sometimes, the caregivers' need to inform a family about, for example, a bad prognosis, has to be prioritized, even if the parents actively avoid hearing the information, due to the agony it will evoke. In those situations, it is fundamental to support the caregivers in containing the parent's distress.

Methodological Reflections

A strength of this study is that the majority of the professional caregivers on the ward participated in the interviews and that several types of professions were included. All data were collected in a single ward, which may limit the generalizability of the results.

Using focus groups to collect data worked well. In the focus group literature, there are differing opinions both on recommended group sizes (from 3—5 members up to 8—12 members) and whether or not the participants should know each other (Ekblad &

Bäärnhielm, 2002; Peek & Fothergill, 2009; Sim, 1998). We had fairly small groups (3–7 participants), in which all participants worked at the same ward and, thereby, knew each other. We found that most participants took an active part in discussions and that the climate in the groups was tolerant, self-critical, and open. This corresponds well with the experiences of Peek and Fothergill (2009).

Using mind maps both for validation vis-à-vis the group being interviewed and as a means to facilitate the analysis worked well and probably strengthened the quality of the analysis (cf. Kylmä & Juvakka, 2007).

According to Krippendorff (2004), a text never implies one single meaning, just the most probably meaning from a particular perspective. Thus, this is one interpretation of caregivers' perspectives of providing information in this context. Furthermore, Krippendorff (2004) emphasizes that categories should be internally homogeneous and externally heterogeneous. However, in this analysis, institutional factors run through all categories. Because human experiences tend to be intertwined, it is not always possible to create mutually exclusive categories (Graneheim & Lundman, 2004).

The level of abstraction of the results is a delicate issue. Interpretations that are either too abstract or too concrete are meaningless. In this study, we have strived to keep the interpretations on a concrete level, as we believe they could be more useful as a basis for an intervention.

Conclusions and Implications for Designing Interventions

Professional caregivers within pediatric oncology should be conscious of the difficulty in providing an appropriate amount of information. Carefully balancing the amount of information given, as well as ensuring that it is correct, consistent, understandable, and given at the right time can also be empowering to the recipient. Clearly establishing the responsibilities for giving information could enhance the process. Acknowledging that much information is given informally is important to gain a comprehensive understanding of the information given to parents. The problematic use of the Internet was considered in this

study. However, if parents were provided with quality-assured sources of information on the Web, these supplementary sources could be a good complement to information given by caregivers, having also the advantage of being immediately accessible at the parents' own convenience.

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