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TALKING VIA THE CHILD

Discursively Created Interaction Between Parents and Health Care Professionals at a Pediatric Oncology Ward

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Keywords

Discursive psychology, health care professional-parental interaction, participant observations, pediatric oncology.

Bios

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Abstract

The aim of this study was to describe discursively constructed interactions between parents and health care professionals (HCPs) at a pediatric oncology ward. Field notes from 70 focused participant observations and 16 informal interviews with 25 HCPs interacting with 25 parents of children with cancer were analyzed using discursive psychology. Six dominant interpretative repertoires (flexible parts of discourses used in everyday interaction.) were found. Repertoires used by the HCPs were child-, parent-, or family-oriented, mirroring the primary focus of the interaction. Parents used a spokesperson repertoire to use their own expertise to talk on behalf of the child; an observer repertoire, in which they kept in the background and interfered only when needed; or a family member repertoire to position themselves on a level equal to the ill child. The results are discussed in relation to philosophies influencing pediatric nursing, such as family-centered nursing and child-centered nursing.

Background

During the first half of the 20th century, parents were routinely excluded from the care of ill children in hospital. There were several motives for this, including the fear of contagion, but also the belief that the moment of separating from parents caused more damage to the child than separation itself. This notion was challenged during the latter half of the century, starting in the UK with work by John Bowlby on the damage to a child from separation from its mother, and by Joyce and James Robertson, who implemented and developed Bowlby's theories in the context of children in hospital (Alsop-Shields & Mohay, 2001; Davies, 2010; Robertson & Bowlby, 1952). At about the same time in the USA, Gofman et al. (1957) described how parents suffer from being separated from their ill child, but also from a lack of information about their child's condition. This incipient understanding of the harm of separation, both to children in hospital and to their parents, resulted in 1959 in the first governmental recommendation (by the UK Ministry of Health) of parental involvement in the care of children in hospital (Davies, 2010; Platt, 1959). Implementation of the recommendation was slow; in Sweden, generous visiting hours began in the 1970s, when parents were enabled and encouraged, especially with the introduction of parental benefits, to live in hospital with their child (Arbetsgruppen för samhällets barnomsorg, 1975).

Models of family-centered care (FCC) within pediatric nursing began to evolve in the 1980s in the UK and the US, with precursors such as parental involvement, partnership in care, and care-by-parent (Coyne, 1996; Jolley & Shields, 2009). FCC has been defined as a "way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients" (Shields, Pratt, & Hunter, 2006, p. 1318).

Although FCC is a cornerstone of many areas of pediatric care services, its effects and whether it is actually implemented are matters of debate (Shields, 2010).

Another model of pediatric care, supported by the Nordic Association for the Needs of Sick Children, is child-centeredness, which emphasizes children's participation in their own healthcare and focuses on the child's perspective. Allowing children to participate in decisions increases their competence and informing and preparing them for procedures and treatments enhances their ability to participate in care (Söderbäck, Coyne, & Harder, 2011).

The treatment for malignant cancers in children is long term, often spanning years. It almost always involves an intensive treatment regime, and parents may have to spend long periods in hospital with a child who may be very ill and suffer badly from the heavy treatment (Björk, 2008). During this period, parents can develop important relationships with health care professionals (HCPs), characterized by feelings of closeness with those who help them to feel safe as they adjust to and cope with their child's diagnosis. On the other hand, when HCPs are in a hurry or several HCPs are involved in the care of their ill child, that can lead to feelings of loneliness and lack of attention (Björk, Wiebe, & Hallström, 2005; Jackson et al., 2007).

At home between hospitalizations parents are responsible for much of the supportive care, including relatively advanced tasks such as treatment of pain and nausea, looking after central venous catheters, and supporting the child's nutrition. This means parents need not only a great deal of medical knowledge to understand the principles of the treatment regime, but also the practical skills necessary for the care of the child (Kelly & Porock, 2005; Pyke-Grimm, Kelly, Stewart, & Meza, 2011).

Thus, to support parents, pediatric departments need to convey both information about the child's disease and treatment, and instruction in the skills needed to take care of the child at home, so that parents can bring that knowledge into the family, reduce chaos, and create an environment of normality (Björk, et al., 2005; Woodgate & Degner, 2002). However, the transfer of information to parents can sometimes be problematic.

HCPs may have difficulty judging the amount of information that parents need, and this can be further complicated because informational needs develop and change as the disease evolves. The complexity inherent in the diseases makes it difficult to explain them clearly, and stress and lack of informational structures only add to the difficulty (Ringnér, Jansson, & Graneheim, 2011a, 2011b). Even though HCPs themselves emphasize the need to use plain or lay language, they may use the advantage of their professional knowledge to decide what they think the family needs to know (Hallström & Elander, 2005).

Söderbäck (1999) has studied how nurses deliver practical knowledge to parents in general pediatric care. She reports that in interactions with parents, nurses use four different action styles: assumptive, demanding, eliciting, and collaborative. These styles were characterized by differences in such areas as understanding of parents, relationship to parents, and verbal and non-verbal interaction. The different styles also influenced how parents were enabled to participate in care: in the assumptive style, they were rather taken for granted, whereas in the collaborative style parents were perceived as equal partners, bringing unique knowledge about the child into the encounter.

A complicating aspect is the different information needs and preferences of individual parents and children. In a Dutch study (Zwaanswijk et al., 2010) about one third of the children treated for cancer and their parents preferred separate information sessions. The parents' wish for separate sessions decreased with the child's age. Likewise, four out of ten children and half of the parents stated that information to the child should only be given when the child wished for it (which also was associated with the child's age). Similar results have been reported elsewhere (Soanes, Hargrave, Smith, & Gibson, 2009).

In two previous studies within this research project, we have interviewed HCPs and parents about their perceptions and experiences of information within pediatric oncology. HCPs reported that the amount of information given was often mismatched to the parents' needs and

that the structure for giving information was vague. Parents felt either acknowledged as a person of significance, usually during the early phases of treatment, or treated as an unwelcome guest, usually during the latter phases (Ringnér, et al., 2011a, 2011b). Few studies have examined the socially constructed interaction between HCPs and parents with children suffering from cancer. To better understand what in the interaction creates the difficulties reported by HCPs and parents, and what social norms that steer that interaction, we conducted an observational study aimed to describe the discursively constructed interactions between parents and health care professionals at a pediatric oncology ward.

Methods

This paper is based on field notes from participant observation of interactions between HCPs and parents of children with cancer, and transcripts of informal interviews with the participants, all analyzed from the perspective of discursive psychology.

Discursive psychology

Paradigmatically, our stance is a social constructivist view of reality. According to this, knowledge is not something eternally objective; rather it is socially constructed by people depending on their historical and cultural surroundings. Social constructivism also criticizes the notion of essences, that is, genuine and persisting qualities. On the contrary, in each situation, reality is constructed by the people in it. Social practices always take place within a discourse and what happens within a certain practice, such as parent-health care professional communication, is governed by that specific discourse. The discourse rules what can and cannot be said and how a thing can be said in a given social interaction. The scope of a discourse covers language in a broad sense: written language, spoken language, and body language. Discourses are thus culturally and historically specific, powerful resources that

directly influence interaction between people, such as HCPs and parents (Winther Jørgensen & Phillips, 2002).

Discourse analysis is the study of discourses in social practice. There are several ways of doing discourse analysis and for this paper we have been inspired by the works on discursive psychology by Potter and Wetherell (2001). Within discursive psychology, the term interpretative repertoires is often used to put forward how people as actors navigate between different rhetoric possibilities. In everyday discursive practices interpretative repertoires refer to a flexible part of discourse. Interpretative repertoires can thus be seen as cultural resources consisting of concepts, descriptions, and ways of speaking that distinguish them from other ways of speaking and, thus, from other interpretative repertoires. People use interpretative repertoires to make sense of experience, and to create meaning and identity. When people position themselves or become positioned in certain interpretative repertoires, they also construct their identity, a way of self-definition, deriving from the particular interpretative repertoire. Because there can be many interpretative repertoires available, the person in each situation is offered several discursively created identities, and different situations offer different identities (Edley, 2001; Winther Jørgensen & Phillips, 2002).

Setting

The observations were performed at a pediatric oncology ward at a university hospital in northern Sweden. The ward is the principal treatment centre for about half the area of Sweden and covers roughly 10% of its population. Approximately 30 children each year are diagnosed with malignancy at the ward. All major treatment is given at the ward, however, some milder treatments and most supportive care is also given at the child's local pediatric department/clinic. The long distances to the ward—for some children over 350 miles (600 kilometers)—leads to long hospital stays, especially for families from rural areas living far

away from the nearest hospital. There are 12 beds at the ward and the occupancy rate can vary widely, at times leading to overcrowding and a shortage of beds.

The ward employs an average of 22 registered nurses, 6 pediatric nursing assistants, and 6 physicians. The work at the ward is organized according to a primary nursing system, with one or two primary nurses (RN and/or pediatric nursing assistant) for each family. No corresponding system exists for the physicians, although most families consider the physician in charge at diagnosis as “their” physician. There are also two consultant nurses, responsible for visits at the child’s kindergarten or school to inform the teachers, the other pupils, and other pupils’ parents.

During our observations, the ward relocated from a building in the 1970s to a completely new building; no observations were performed during the months around the move. The two wings of the ward were organized along two parallel corridors around a central core with patient rooms on the window sides. The nurses’ station was in the central core.

All patient rooms were single patient rooms. At the old ward, each room had contained two hospital beds, one for the child and another one for a parent. At the new ward, there was also a folding bed for another parent or a sibling. The rooms also each had a table and some chairs. The ward policy is that at least one parent should always attend the hospitalized child, including at night. Siblings and other relatives and friends are also welcome at the ward.

Participants

Participants in this study were recruited in two steps (cf. Moore & Savage, 2002). All HCPs on the ward received written and oral information about the study and were invited to participate. 25 HCPs agreed to participate and one HCP who was asked verbally declined.

The participating HCPs then asked parents whether they wanted information about the study and those who were interested were informed about the study by us and received an invitation

letter. Criteria for eligibility were that the child was being treated for a malignant disease at the ward and was not critically ill at the moment. Parents for whom the caregivers deemed the disadvantages of participation might outweigh the benefits were not invited. Further, parents of children at a very low level of nursing and/or medical intervention, e.g. those awaiting transport home, were also excluded. A total of 25 parents representing 16 children agreed to participate. Written informed consent was obtained from both HCPs and parents. Although the ill children were not subjects of the observations, those who were deemed old enough were asked verbally for their assent (Carnevale, MacDonald, Bluebond-Langner, & McKeever, 2008). There were also signs on the ward with information about the study. Demographic data of both HCPs and parents is presented in Table 1.

Insert Table 1 about here please

Data collection

Our main data source was participant observations performed at the ward (Roper & Shapira, 2000). The observations were conducted by the first author (AR) with guidance during the initial observations by the third author (MB). Both observers had long experience of pediatric oncology nursing. At the time of the observations, AR worked at another ward at the clinic and was familiar with the ward in question, whereas MB had no previous connection to the ward. Neither had previous knowledge of any of the families. The aim of the observations was known to all participants. We tried to be as reticent and quiet as possible when observing, for example we did not interfere in the interaction, but if we were addressed, we answered. To differentiate ourselves from health care staff, we dressed in normal street clothes. Observed interactions included formal situations such as medical rounds and informal situations such as small-talk during procedures. We tried to observe one or two families each day. Every time a participating HCP entered a ward room, we followed.

The focus of the observation was the communication, including both spoken and body language, used by HCPs and parents. During the observations, field notes were taken either on paper or on a laptop computer. After each observation, the notes were typed, edited, and elaborated upon. The primary observer (AR) is a skilled typist, which made it possible to take down detailed notes of interactions without using a recording device.

The observations took place between 6:45 AM to 9:30 PM on both weekdays and weekends. In total, 121 hours were spent at the ward, and 70 focused observations comprising a total of 8 hours were transcribed. The median observation time for each focused observation was 5 minutes (range 1 to 36). In all situations observed, the ill child was in the room.

We also performed 16 informal, electronically recorded, interviews after some of the observations, in which the HCPs or parents were asked to reflect upon the situation just observed (cf Lindgren, Öster, Åström, & Graneheim, 2011). The parts of these interviews referring to the observed situation were transcribed and used to validate the interpretation of the observations and to obtain data that could not be obtained by observing. These interviews ranged from 2 to 22 minutes (median 4 minutes).

Data collection was stopped when it became apparent that information redundancy was achieved from the last sessions of observations (Cutcliffe, 2000).

Analysis

The observations and interviews were analyzed by focusing on the variations and patterns of interpretative repertoires which constructed the interaction between parents and HCPs at a pediatric oncology ward.

To identify the dominant interpretative repertoires, the primary data was read carefully several times, and possible repertoires and variations between those were sought and written down.

The several readings resulted in a pattern of repertoires. The observed data was divided into

passages, each of which represented an intersection between two dominant repertoires: one used by the HCP and one by the parents. Each passage was coded with the specific repertoires, and some of the initial repertoires were merged. We also identified typical situations from the data that illuminated all specific repertoires. All authors participated in scrutinizing the observational data and elaborating the text until consensus was achieved. Finally, we established descriptions of the interpretative repertoires used by both parties and then sought possible consequences of the interaction constructed by the intersections of the different repertoires (Winther Jørgensen & Phillips, 2002).

Ethical considerations

All participants in this study were informed and consented to participation. The children, who were not a focus of the observations, were also asked for their assent. We were alert to the possibility of anyone being observed seeming disturbed by our presence, and prepared in those cases to discontinue the observation. However, this was never necessary. To protect the identity of the participants, all names are pseudonyms. The study was approved by the Regional Ethical Review Board in Umeå (Dnr 08–029M).

Results

We identified six dominant interpretative repertoires in this material: three used by the HCPs, and three by the parents. In total, 93 passages were identified in the field notes. Table 2 shows the number of passages for each of these repertoires. In Table 3, the parents' and the HCPs' repertoires are cross-tabulated, showing the number of passages for each combination. We have also classified the material by the children's age: parents of younger children (up to 12 years, $n = 9$ patients) and parents of teenagers (13 years and elder, $n = 7$ patients). These age groups will be used below.

In almost all the passages observed the ill child was present in the room. The atmosphere was usually calm and relaxed and we observed no apparent tension or conflicts. For each repertoire, we describe their dominant themes and consequences and then give examples of the repertoires in use.

Insert Table 2 about here, please

Insert Table 3 about here, please

Interpretative repertoires used by the HCPs

The different interpretative repertoires used by the HCPs are grounded in the focus of the HCP's attention: the child, the parent, or the whole family. Many of the interactions occurred in passing, typically during procedures such as changing the intravenous infusion set or giving the child oral medication.

The child-oriented HCP

In most of the observed situations, the HCP used a child-oriented repertoire with parents of both younger children and teenagers. This repertoire is characterized by the HCP facing and talking directly to the child using age-appropriate language, as with this seven-year-old boy suffering from severe nausea:

The nurse sits on a chair next to the boy's bed, the nursing assistant stands at the foot of the bed, and the mother is in the parent's bed next to the boy. The nurse is about to give the boy an anti-emetic in his gastric feeding tube to relieve his nausea.

Nurse (addressing the boy): Do you want to choose which one of us will give you the medicine?

Nurse assistant (also to the boy): Should mummy, daddy, or <the nurse> inject it?

The boy: I feel really sick.

Mother: But if you need to throw up, you just have to.

Nurse (to the boy): It's tough, but you will feel better afterwards.

Mother: And if you throw up the tube, we will just put it back.

Nurse (to the boy): Does it happen often?

The boy nods.

Mother: It has happened both here and at the hospital in <their town>.

Nurse (to the boy): What tricks do you use? What is the best way of doing this?

For older children, the HCPs used a more abstract language, assuming more knowledge of the child, as with this teenage girl just after her first chemotherapy treatment:

Physician (looking at the girl): But you pee quite well, and your pH is good. You had one dose this morning, didn't you? You had it at nine yesterday and at nine this morning. Good. The creatinine, the kidney test, is decreasing all the time; it is 78 today. That is, after all, a sign that the kidneys are recovering.

In the interviews, parents stated that they appreciate the child-oriented interpretative repertoire used by the HCP:

Mother: Everyone always turns to him and talks to him. If sometimes somebody does not talk directly to the patient, I get very annoyed.

Interviewer: If they turn directly to you?

Mother: Precisely.

The HCPs also emphasize the rule of keeping the children in focus even if it is not always possible to speak directly to them.

Nurse: You always try to turn to the child, but still, sometimes you end up talking over the child's head. It just happens sometime.

The parent-oriented HCP

This interpretative repertoire was characterized by the HCP turning directly to the parent, bypassing the child. This was more common for younger children and is illustrated in this example at the end of the medical round for a seven-year-old girl:

Mother: Well, we're out of questions now I guess. We pop off today, and we are thinking about going to my aunt's cottage over the weekend. If she is feeling all right, that is ok, isn't it?

Physician: You know what medicines she takes and so on?

Mother: Well, she only has Movicol [laxative]?

Physician: (laughs) I need to have a look at her chart, these things change so swiftly.

Mother: But we won't have to worry, the values won't decrease that quickly, will they?

Physician: No, that is all right. And <physician at the hospital in their town> will look after you.

Mother: Yes. So we will go for the first blood samples on Monday?

Physician: Yes.

The HCPs took a vast knowledge of medical drugs for granted, but also helped parents gain more competencies about the child's disease. That is apparent in situations such as this one, where the HCP answers complicated questions that would probably be difficult to discuss directly with the child:

Father: If you consider chemotherapy versus surgery? The chemotherapy is the main treatment but dangerous, so why don't you start with surgery? It is a difficult question, of course, but how do you decide?

Physician: Well, the answer is that both are needed. At first, you want to make sure that the tumor is operable at all, that you can remove it. That depends on what areas are affected, how it grows, and so on, and there are only just a few surgeons who can judge whether it is possible to operate and what are the risks. Rapidly growing tumors respond quickly to the treatment, so they are easier to shrink and then remove, so that is the way of removing them, by first giving chemotherapy so they leave hold of things in the body that you cannot live without.

[...]

Father: Well, radiation, then, you might not give radiation to a big tumor? What is the difference between chemotherapy and radiation?

Physician: Both of them destroy tumors.

HCPs can switch swiftly between using a child-oriented and parent-oriented interpretative repertoire. They may for example start by explaining something to the child, then turn to the parent to provide a more in-depth explanation:

The mother starts talking about vaccinations. The ill girl wonders why she has not had her influenza shot. The nurse explains to the girl the principles for vaccinations in a simple manner and tells her why she did not get the shot.

The nurse (looks at the mother): We use to take a blood sample called viral serology to see how many antibodies you have. And then you should have above a certain number to be regarded as immune. I have to check her chart. But in general, you should be in the community, in school, and on public buses if you have the strength.

The family-oriented HCP

Using a family-oriented interpretative repertoire, the HCPs constructed themselves as people who interact with the whole family as a unit; they talked to and about all family members present, even in matters that were clearly about the ill child. This repertoire was used

somewhat more often when interacting with parents of teenagers, as illustrated in this excerpt of a situation in which the nurse handles the intravenous drip of a girl aged 15, while talking about what was being said at the medical round.

Nurse: I brought you a new infusion bag because this one will soon run out. I was going to ask you, what did <the physician> tell you when he visited?

The girl: Well, it's starting tonight and going on for five nights and days.

Father: And then there are drops in the eyes three times a day?

Nurse: Indeed, eye drops, and you will also take cortisone tablets for five days. The same ones you had before in a lower dose.

Father: So more tablets but not more often?

Nurse: No, not more often but more tablets.

Father (to his daughter): And then you are going to be a bit speedy?

Nurse: Yes, you might be like that, and then you will be hungry too, but you might already have noticed that?

The girl: Well, yes I have (everyone laughs).

In this example, the nurse addresses the individual members and the whole family as “you,” and both the child and the parent participate in the discussion. This interpretative repertoire is the least frequently used by the HCPs in these findings.

Interpretative repertoires used by the parents

The parents use different repertoires depending on their level and style of participation in the interaction with the HCP and the ill child.

The spokesperson

When the parents use an interpretative repertoire as a spokesperson, they make use of their expertise within their lived experience of the child's disease. This repertoire was more commonly used by parents of younger children. The parents often talk on behalf of the child and answer almost all questions. The child is given a theoretical opportunity to enter the conversation, but seldom does. The content of interactions using this interpretative repertoire is characterized by factual issues concerning the child's disease and treatment. In this

example, the mother shows great insight into the upcoming treatment for her one and a half-year-old girl:

The nurse sits on a stool in front of the bed and works with the central venous catheter (CVC). The mother talks to her and the nurse switches between looking at the CVC and the mother. There is a calm atmosphere in the room.

Mother: Well, and she's having Zofran [an anti-emetic], isn't she?

Nurse: Well, yes she should be having that.

Mother: What about Bactrim [an antibiotic]? Will she have that during this treatment?

Nurse: Yes, you will give her that too.

Mother: Ok, we'll do that then. What time is she scheduled for her heart examination?

Nurse: At 11.30. We'll wait for the results from her blood samples during that.

Mother: Ok, and then she'll have the Dauno [antineoplastic drug] after that? How long do we have to wait until it arrives from the pharmacy?

Nurse: I don't know, but that's why we take her blood samples so quickly, so we can have it here as soon as possible. The physicians have to order it and then the pharmacy has to prepare it, so it is really hard to say how long you have to wait for it.

The mother is very active. She asks, almost interrogates, the nurse about the different drugs to be given and examinations to be done. She double-checks with the nurse that all the necessary preparations will be made so they will not have too long to wait on the ward.

Parents may use a spokesperson repertoire when they want to help the child. In this example, as the HCP interviewed the child about pain and mobilization, the parent directed questions about pain medication to the child and the child answered. However, on the more sensitive topic of bowel movements, the parent came to rescue:

The head physician asks the boy about his bowel movements and the look of his feces.

Physician: "Is it hard? We are always worrying about that you know."

The boy does not answer, but the mother does instead: "He has no problems with that."

In this repertoire, the parents have such a good understanding of the child's treatment protocol that all excess information can be stripped from the interaction between the HCP and the parent. In the following excerpt the nurse is giving a medication to a crying child, and just in passing informs the mother about the latest methotrexate concentration in serum:

Nurse: Have you heard the results of the blood sample?

Mother: No.

Nurse: 0.61.

Some parents reported that they appreciated this kind of thorough knowledge about the biomedical aspects of the disease, but that it could be difficult to obtain, as this father states in a follow-up interview.

Father: If you could start by telling us a little more, I mean, begin with talking about what happens with the blood cells during the treatment and so. We have, if you are interested in science, you rather soon understand the effects of these drugs. But you could describe that from a medical perspective, too.

The observer

When parents use the observer repertoire, they stay in the background, perhaps in their own bed watching television, yet still keeping an eye on what is happening and what is being said in order to intervene if it seems necessary. This repertoire was more common in parents of older children and teenagers. In this example, the nurse is changing the dressing of an 11-year-old boy's CVC:

The father and the boy are in their beds. The television is switched on and the father seems to be surfing the internet on his laptop. It is rather dark in the room. The nurse enters and positions herself on a stool next to the boy's bed.

The nurse talks with the boy about the food, which she noticed that one of the nursing assistants was about to prepare. She is turned towards the boy and preparing things to change the dressings on the boy's CVC. They then talk about how he has just been in the shower and how he likes the special dressing they use to fix his CVC.

The father looks up from his computer, watches the nurse remove the dressing, and leans forward over the boy's bed.

Nurse: There is some clotted blood here, but there is no redness.

The father watches quietly. The nurse and the boy discuss a bruise over the tunnel of the CVC. Both the boy and the father watches.

Father: I have not seen that before, but on the other hand, I haven't been here for a few days. (Reclines in his bed).

The nurse and the boy continue to chat while the dressing is being changed, and the father goes on watching television and surfing the internet.

In the above example, the father remains in the background, but as soon as the critical moment of the procedure comes—the nurse’s assessment of the catheter entry site—the father engages and enters the interaction. Then he reclines again and continues his activities.

The family member

When using an interpretative repertoire of family member, parents position themselves at an equal level with other family members, including the ill child. This repertoire was used somewhat more often by parents of teenagers. When addressed by an HCP, the parents’ answers are more leisurely than in the other interpretative repertoires and parents are involved in a joint conversation with the HCP and the ill child.

In this excerpt the nurse, the father, and the ill nine-year-old girl talk about her medication and how she dislikes the taste of some of it.

Nurse: So you approved Betapred [corticostereoid] after all. I have brought a tiny, tiny tablet for you. It’s a Purinethol [antineoplastic drug].

Father: That’s only a quarter of a tablet, isn’t it?

Nurse: Exactly, a quarter.

Father: (to the girl) And you have had your Alvedon [anti-pyretic/analgesic] but you skipped lactulose [laxative] because both you and Mother thought that your bowel movement was in good shape.

Girl: I think it was a bit loose.

Father: But mummy found it to be ok, so you didn’t take it then.

Nurse: Good, well, let us skip that then. Are you doing well apart from this?

Girl: I’m doing fine.

Nurse: Well, just contact us if there is anything else you need.

In this conversation, the parent does not take charge of the situation but remains as an equal family member of the ill child who participates fully.

Discussion

The aim of this study was to describe discursively constructed interactions between parents and health care professionals at a pediatric oncology ward. The HCPs used interpretative

repertoires that were child-oriented, parent-oriented, or family-oriented; parents also had three available repertoires: the spokesperson, the observer, or the family member.

The different interactions constructed when the repertoires intersect also have different consequences for the parties. When spokesperson parents meet parent-oriented HCPs, they are able to meet at an advanced level; the parents gain both competency and the opportunity to share their lived experience of the child's illness. In this situation, the child is subordinated in the interaction. Observer parents meeting child-oriented HCPs signal competence and confidence, rather than willingness to be subordinated. However, this situation is possible only when the HCP uses a child-oriented repertoire. Should the HCP address the parent directly, it would probably be impossible to maintain the observer repertoire. When spokesperson parents meet child-oriented HCPs, both the child and the parent are subordinated. It can become almost absurd when the HCP asks questions of the child, but the parent answers; they seem to be talking at cross-purposes. In this situation, the parent can act as an advocate for the child and take over. The situation of family-member parents meeting family-oriented HCPs seemed in this material to be relatively rare. Finally, when spokesperson parents meet family-oriented HCPs, the parents can seem to subordinate the child by trying to control the conversation.

In an absolute majority of the observed interactions, the HCPs used a child-oriented repertoire. In previous research, ill children have reported both over- and under-involvement in their care. Some children want to participate in all decisions and have all information available, whereas others desire the opposite, and yet others have preferences in between (Coyne & Gallagher, 2011; Zwaanswijk, et al., 2010). Just as children have a right to receive information about their illness, they must also be entitled to abstain from information; in those cases it is the parents' responsibility to deal with the information provided by the HCPs.

The second most common repertoire used by the HCPs was a parent-oriented approach. Although it may appear that the child is being disregarded in this repertoire, it may be an effect of the ill child voluntarily using the parent as a buffer between themselves and difficult information, as described by Coyne and Gallagher (2011). This repertoire could be said to have its roots in the notions of parental involvement and partnership in care, concepts which can be seen as precursors to FCC (Coyne, 1996; Jolley & Shields, 2009).

Shields (2010) argues that family-centered care can seem difficult to achieve in practice. One reason for this may be that it requires constant assessment of the needs of all parties: the ill child as well as the parents and other family members. Although HCPs have reported that assessing parents' needs is crucial but difficult (Ringnér, et al., 2011b), in none of our observations was it apparent that HCPs were consciously making that kind of assessment. This lack of assessment may cause both over- and under-involvement for both children and parents.

From this study, one can assume that both family-centered and child-centered philosophies influence the interaction on the ward. We agree with Franck & Callery (2004, p. 268), who argue that "there are tensions between the interests of children and other family members" and that one should be careful not to force information upon either party (Hallström & Elander, 2005). In a thoroughly child-centered philosophy (Söderbäck, et al., 2011), parents might be marginalized and alienated. The solution should be a pragmatic approach that puts the needs of neither of the parties aside, but strives to meet the needs of all involved partakers. Making use of all these repertoires when appropriate may then be a step towards family-centered care as conceptualized by Shields (2010).

In almost all situations the topic of the interaction was medical or everyday conversation topics: drugs, treatments, the family's plans for the day, etc. Topics of a more psychosocial-emotional character were rare in this material. Pediatric oncology services are indeed a highly

specialized part of the health care system, and there seems to be a profession for each specific need. Could this specialization be a threat to holistic care, however, and reduce nurses at the ward into infusion specialists, while all psychosocial care is handled by social workers and psychologists on the ward? Many of the interactions occurred in passing while procedures were being conducted, and there seems to be a lack of a tradition, especially among nurses, to earmark time for conversations with the parents.

In previous studies, parents reported that their information needs were not always attended to (Björk, et al., 2005; Ringnér, et al., 2011a). As long as the HCPs maintain a child-centered ideology, it will be difficult for them to satisfy specific parental needs for information that do not correspond to the needs of the child. Therefore, there is a need for interventions that cater to individual parental needs as well as to the needs of the child and the family as a unit. The results from this study show the need for interventions that give parents an opportunity to deepen their knowledge about the child's disease and their own management of it.

Methodological reflections

A main strength of this study is that the observations were performed by two independent observers, thereby increasing the validity of the data collection. Combining observations and interviews also contributes to confirming our interpretations. One might argue that video recording the observations would have produced richer data, but the ethical difficulties of obtaining informed consent were too serious considering that the parents were observed in public areas as well as in their own patient rooms. It would be virtually impossible to get consent from everyone who might appear on the video tapes, as opposed to obtaining it only from those who would be at the focus of the observations.

A possible limitation might be that the HCPs recruited parents. Some of the HCPs expressed concern about themselves being observed before the study started. We therefore took care to

allow the HCPs to give consent before each observation. We had very few observations of situations with any psychosocial or emotional tension: could it be that the HCPs avoided inviting us into potentially tense situations? None of the parents or the children withdrew their consent or assent during the observations. It should also be noted that some of the observations and interviews were only 1 to 2 minutes long, but this simply reflects the fast-paced clinical reality.

The main observer (AR) had worked at the ward but resigned one year before the data collection started. This could be both a possible strength and a weakness of the study. The HCPs might have felt comfortable because they knew the observer, but this new relationship of observer/observed versus co-workers may also have been perceived as awkward. Knowing the setting, however, was an advantage as it helped us to select quickly grasp the context of meaningful situations. We are also aware that there is a risk that the participants changed their behavior due to our presence, however, we tried to be as quiet and invisible as possible; there is also some scientific evidence showing that the attendance of an observer does not influence the work of HCPs (Schnelle, Ouslander, & Simmons, 2006).

The analysis of the material from a discursive perspective has helped us to see how the interaction between the parties is constructed and what the consequences are from this. As to our knowledge, this is the first paper describing communication between parents and HCPs from a discursive perspective. The main feature of discursive psychology is the focus on *how* interaction is created rather than *what* was communicated. Consequently, we did not primarily describe the content *per se* in the interactions. Another analysis of the content of this extensive material could provide further understanding of how parents create knowledge.

Conclusions

In this study we have described different patterns of interaction between HCPs and parents at a pediatric oncology ward.. Parents used interpretative repertoires as spokespeople, observers, and family members, whereas HCPs used child-, parent-, or family-oriented repertoires. Depending on the combinations of the repertoires, parents had different opportunities to acquire knowledge about the child's disease. An orthodox application of any of the repertoires could form a threat to the prospects of parents, children, or both getting the information they need. Within a child-oriented repertoire, the parent's needs for information could be neglected; within a parent-oriented repertoire, the child's needs are in danger and, finally, within a strictly family-oriented repertoire, either party's needs could be neglected in favor of the other's. When working according to Shield's definition of family-centered care, therefore, in which all family members are considered care recipients, parents may gain from specific interventions to provide them with information about the child's disease and strategies for their own management of the disease.

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Tables

Table 1. Demographic data of HCPs, parents, and ill children.

		<i>HCPs</i>	<i>Parents</i>	<i>Children</i>
Number of participants (<i>n</i>)		25	25	16
Median age, years (range)		39 (23–62)	37 (31–48)	11 (1½–18)
Sex	male	3	12	
	female	22	13	
Profession	registered nurse	14		
	nursing assistant	5		
	physician	6		
Years within pediatric oncology, median (range)		2½ (0–40)		
Diagnoses	leukemia			7
	lymphomas			2
	other solid tumors			7
Months from diagnosis, median (range)				3½ (0–17)

Table 2. Interpretative repertoires and number of passages for HCPs and parents respectively.

<i>Interpretative repertoire</i>		<i>Passages (n)</i>
HCPs	Child-oriented	46
	Parent-oriented	32
	Family-oriented	15
Parents	Spokesperson	57
	Observer	26
	Family member	10

Table 3. Number of passages for each combination of the interpretative repertoires.

<i>Parents</i> \ <i>HCPs</i>	<i>Child-oriented</i>	<i>Parent-oriented</i>	<i>Family-oriented</i>
Spokes-person	20	32	5
Observer	26		
Family member			10