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Firm handling; the information exchange interaction by parents in paediatric care – An observational study

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Abstract

Background. Information exchange is fundamental in the paediatric care encounter. Health care professionals need further background knowledge to encounter the parents/guardians from their perspective in their minors' paediatric care. The parents'/guardians' ability to manage the situation is dependent on their receiving optimal information, which is why it is important to study how information is exchanged.
Aim. The aim of this study was to identify, describe and conceptualize how parents/guardians resolved their main concern in information exchange with health care professionals in paediatric care situations involving their minors.
Methodology. Glaser's grounded theory method was used and all data were analysed using constant comparative analysis. The observational study took place at three paediatric outpatient units at a university hospital and 24 parents/guardians participated. Data sources were field notes from 37 observations of paediatric care situations and five adherent excerpts from the minors' medical records. Grounded theory is a method of conceptualising behaviour, which is why an observational study of parents'/guardians' information exchange and social interaction in the context of nursing care is relevant as research design.
Results. Firm handling was revealed as the way the parents/guardians resolved their main concerns when they were exchanging information about their minors' paediatric care. Firm handling is built on five inter-related categories: representative advocating, collaborating, aim sharing, supportive resourcing and minor bypassing.
Conclusions. This knowledge suggests possible ways for health care professionals to design paediatric care that supports, facilitates, strengthens and improves the parents'/guardians' firm handling. The key issue is to find ways to support parents/guardians and minors so they can participate in health care encounters according to their preferences. Firm handling gives an opportunity to both reinforce parenthood in paediatric care and invite minors to participate.

Keywords: grounded theory, health care professional, information exchange, interaction, minor, observation, paediatric care, parent/guardian

Introduction

Information exchange in paediatric care involves providing understandable information to child and parent, asking them for information, and advising them how and where to obtain information. This process is assessed as being important and related to child and parental satisfaction with their care (King, King & Rosenbaum 1996). Sometimes parents feel defenceless in a hospital environment, and their ability to manage the situation is dependent on receiving optimal information (Hallström, Runeson & Elander 2002). Parents are vulnerable, as they have the responsibility to support and care for their child as well, as the right to be informed and decide in the child's best interests, as stated in article 3 in the Convention on the Rights of the Child (UNCRC) (United Nations 1989). Basically, it is essential to find out how parents handle the information exchange interaction when they visit a paediatric outpatient unit with their child.

Information exchange in paediatric care

There have been changes in paediatric hospital care for both children and their parents in recent decades. In the early days, the parents were separated from their child, while nowadays the parents participate and sometimes even feel totally responsible for the care of their child (Coyne & Cowley 2007). Simultaneously, the development of the right of the child to participate in decision-making about their own care may imply that the grown-up might have less power than previously (Alderson & Montgomery 2001). At the same time, the child's existential need of being close to his/her parents is shown as loyalty towards the parents, and the child thereby adapts the dialogue to what is accepted by the parents (Hindberg 2003). Paediatric care should integrate the child's particular needs and the needs of the child's family. Children and their families should be treated with respect and should be informed, so that they are able to understand and cope with the illness and its related treatment (Department of Health 2003).

Becoming a parent is an important adult development, and development as parent is contemporaneous to the development of children (Westman 1999). Parents may uphold any rights because of the value of family integrity within society (Paul 2007). The UNCRC supports the parents in their parenting role in articles 5 and 18 (United Nations 1989).

The influence of a child's illness on the family can be seen both on the family as a unit and in individual family members (Hopia, Paavilainen & Åstedt-Kurki 2005, Hopia et al. 2005, Sarajärvi, Haapamäki & Paavilanen 2006). However, partnership in paediatric care involves creating a relationship that is concerned with both the family and the health care professionals (Coyne & Cowley 2007). Both children and their families have a need for care, and that makes it fundamental for the family to become involved and to participate in a child's care (Silveira & Angelo 2006). When the child receives paediatric care, it is necessary for the parents to be informed to manage their situation (Cegala, Coleman & Turner 1998).

There is a common understanding that information exchange is the central point of a medical encounter (Cegala, Coleman & Turner 1998). Information exchange is about seeking, giving and verifying information, which means to ask questions, to answer questions and to confirm that what is said is understood by all concerned. The discourse is what is said, how it is said, and in turn, the interaction between the parties (Tates et al. 2002). It seems reasonable to consider the health care professionals' skill in communication as being as important as other clinical skills in caring (Alexander 2001). In a study of parents and their children, (aged 9-21) perspectives on physician communication in paediatric palliative care and information exchange were some of the most important findings (Hsiao, Evan & Zeltzer 2007). Parents find information exchange, involving mutual trust, with health care professionals to be essential when their child (1.4–9 years) needs care (Nuutila & Salanterä 2006). Brykcyńska (1987) discusses information in the ethical practice of nursing, and stresses the importance of giving and receiving information in order to make facts available.

Aim

The aim of this study was to identify, describe and conceptualize how parents/guardians resolved their main concern in information exchange with health care professionals in paediatric care situations involving their minors.

The parent/guardian is responsible for bringing up the minor, whether they are the biological parent or not. Paediatric nurses, enrolled nurses and paediatricians are called 'health care

professionals' (HCP). 'Care situations' are all situations that occur in an outpatient paediatric unit, such as examinations or taking blood samples. A 'child' is any person up to 18 years old (United Nations 1989). 'Minor' is used here instead of child, because a minor is a person who has not reached the age at which full constitutional rights are accorded (Rynning 1994).

Methodology

This study used the grounded theory method according to Glaser, where the theory emerges from the empirical data (Glaser 1978, Glaser & Strauss 1967). While grounded theory can be used as a systematic method to conceptualize behaviour, observational studies of information exchange in the context of paediatric care are relevant to the method. The goal of grounded theory is to achieve at least the third level of concept: firstly, collecting the empirical data, secondly, generating categories, and thirdly discovering the core category. The latter organises the categories that revolve around the participants' main concern (Glaser 2002). The minors' medical records were studied after the observations were completed and the text related to the observation was selected for reading. With grounded theory, any type of data or combination of data can be used (Glaser 1998). The constant comparative analysis method verifies the participants' main concern and is where categories and theory are generated (Glaser 1978, Glaser & Strauss 1967).

Settings

The observations were performed at three outpatient units at a university hospital; the paediatric day care unit, the paediatric neuro – urology and bowel disorders unit (PNUT), and the paediatric diabetic clinic. The observations were performed in surgeries, treatment rooms, wards, consulting rooms, corridors and waiting rooms.

Sample

Inclusion criteria were to be a parent/guardian of a minor, ten to 17 years old, and to give informed consent to participate (Swedish Codes of Statutes 2003). Ethical approval was received from the Regional Ethical Review Board. When using the grounded theory method, it is not possible to say in advance how many participants are needed to achieve saturation in the categories (Glaser & Strauss 1967). Saturation was achieved at observation 32. The selected participants were 20 female and four male parents/guardians of 20 minors. The minors were aged between 10 – 16 years and had various diseases and/or were undergoing different examinations (Table 1). No parents/guardians of minors aged 17 were included in the study since these minors visited the unit by themselves. Sixteen HCPs took part in the observations.

In order to guarantee trustworthiness in grounded theory, the categories have to fit, work, have relevance, and be modifiable (Glaser 1978, Glaser & Strauss 1967). Fit is when the result is grounded in data and the categories express what is happening in the empirical situation. Work is when the categories predict what is going to happen and how these participants are going to act. Having relevance is when the result can be used in practise in care situations.

Modifiability is when the results can be used in future research and can be modified by new results. Trustworthiness is guaranteed as the data is systematically collected (Glaser 1978). In order to convey credibility, the researcher can quote directly from conversations (Glaser & Strauss 1967).

Data collection and data analysis

Thirty seven observations were conducted. Each observation started as soon as the HCP was physically with the minor and/or the parent/guardian, and ended when they separated from each other. During the observation, the observer was placed in the periphery of the paediatric care situation, writing down observational field notes. Immediately after the observation, the observer recorded a description of the observation using a tape recorder. Field notes bring observation and analysis together and are the most usual way of making observations (Spradley 1980).

Table 1 **Characteristics of 20 minors to 24 parents/guardians in 37 observations**

Gender[a]	Visit[b]	Minor's diagnosis or examinations	Time[c]	Number[d]
Female	10	Type 1 diabetes	63	2
Female	19	Type 1 diabetes	45	1
Female/Male	14	Type 1 diabetes	38	1
Male	55	Relapsed acute lymphoblastic leukaemia	38	1
Male	1	Pubertas tarda	20	2
Female/Male	28	Type 1 diabetes	31	2
Female	-	24-hour ph monitoring	15	2
Female	7	Cystometry	114	4
Female	9	Renography	25	1
Female	-	Mb Hodgkin's	34	5
Female	5	Myelomeningocele	30	1
Female	7	Enuresis	13	2
Female/Male	-	Magnetic Resonance Imaging	16	1
Female	-	Leukocyte scintigram	6	1
Female	5	Pyelonephritis	15	1
Female	21	Type 1 diabetes	28	3
Female/Male	1	Benign teratoma	5	1
Female	2	Type 1 diabetes	52	3
Female	-	Magnetic Resonance Imaging	17	2
Female	11	Computerized Tomography Brain	12	1

[a] The gender of observed parent/guardian.

[b] The number of previous visits by the minor to the unit before observation.

[c] The total time of observation of the parent/guardian in minutes.

[d] The total number of observations of the parent/guardian during the visit

Data analysis and data collection took place simultaneously due to the constant comparative analysis method (Glaser 1978). At first, open coding was carried out, and data were read and analysed line-by-line. Open coding is used to compare incident to incident, to compare concept to incident, and to compare concept to concept (Glaser 1978). The codes were sorted into groups of codes with similar substance and substantive codes. In order to generate categories, the substantive codes were compared to one another. A category is substantive codes with the same meaning and content. The core category, which is to be seen methodologically as the resolving process, was identified as *firm handling*.

Results

Firm handling is the core category and is seen in and includes every category. The five categories are; representative advocating, collaborating, aim sharing, supportive resourcing and minor bypassing.

Firm handling

The parents/guardians firmly handle the information exchange with the HCP because they are dedicated to their minor. While they exchange information, they are representatively advocating in their minor's best interests. The parents/guardians, minors and HCP are collaborating together within the situation and in a responsive approach when aim sharing. When the parents/guardians are supportively resourcing, they are helping the minor to the greatest possible extent. Representative advocating and supportive resourcing differ in that supportive resourcing is something that is required by the minor, as opposed to representative advocating where the parents/guardians take the place of the minor without asking for permission. Minor bypassing is where the communication is only between the adults, and the relation is between parents/guardians and the HCP, which is an interaction aside from the minor. When parents/guardians are mainly engaged in representative advocation for their minor, then the parents'/guardians' natural reaction of supportive resourcing must be demanded by the HCP. The HCP might encourage the minors to participate by asking for their opinion and inviting them into the conversation to start the collaboration between all the parties. This mother of a minor, who is prepared to undergo computed brain tomography, is using firm handling in the information exchange:

> Mother – The test results, when do we get the results?
> HCP – We do not give the results, it is the treating endocrinologist who does
> that. You will meet him and the oncology radiologist next week. (The HCP then
>> explains how the teams are organised between the oncology radiologist, the endocrinologist and the day care unit.)
> Mother – He needs some more medication.
> HCP – You have an appointment with … you can discuss it then.
> Mother – I must also talk to the doctors then.
>> HCP – The parents or guardians of all children undergoing radiation treatment may talk to the oncology radiologist at the meeting next week.
> Mother – It is most important for me to talk to the doctors.

Representative advocating

Representative advocating is where parents/guardians take over the conversation and usurp the minors' possibility to explain their own situation to the HCP, which they might be capable of doing. Representative advocating is when parents/guardians replace the minor in discussion when discussing diseases and medication with the HCP. In general, representative advocating can be described as the situation where parents/guardians talk over the heads of the minors without involving them. There follows a discussion about high levels of blood-glucose and eating sweets between a HCP and a mother of a minor who has been diagnosed with type 1 diabetes:

> HCP to the minor – There are different kinds of people, some people are 'sweet people'. I think you have to make up your mind.
> Mother – It is not true that we eat sweets all the time at home. The children eat sweets but also other foods. We have different strategies concerning food, different alternatives without sugar, but it does not always work.

Collaborating

Collaborating is where parents/guardians and the minor communicate together and cooperate during the visit, as when the HCP asks questions and they are answered in union by the parents/guardians and the minor. It is also when the parties cooperate in a common dialogue concerning the symptoms of the minor's disease. Such a collaborative conversation is held in a situation of mutual respect in which the participants give and take. Here, a father of a minor diagnosed with Relapsed Acute Lymphoblastic Leukaemia is collaborating. The minor suffers from occasional palpitations and is trying to explain how this affects him:

> HCP – What do you feel when you have palpitations?
>> Minor – If I have palpitations when I am watching the TV, everything moves at double speed for me, compared to normal.
> Father – Ah, you mean that everything rushes?
> HCP – I am not quite sure it is the heart.
> Father – Is it the brain?

Minor – No, sometimes it is the heart.

Aim sharing

Aim sharing is where parents/guardians and minors agree on common objectives on the minor's behalf. It is when parents/guardians are being confirmative and supportive to the minor while at the same time receiving support themselves. During an examination, advice might be given to the minor by the parents/guardians in order to make the minor's situation manageable in spite of inconvenience. Parents/guardians respond to the minors when being given the objectives and details of the treatment the minor may undergo. What is required is a feeling of concern and perhaps curiosity in order to find the best way of dealing with the feelings and possible fears of the minor who is about to undergo a procedure. Aim sharing is illustrated below in an example taken from a medical record involving a minor with type 1 diabetes. It concerns the handling of the minor's low blood-glucose level in the evening in order to avoid hypoglycaemia during the night:

> It emerged that the parent often serves extra food in the evening if the minor's blood-glucose level is below 6 – 7 mmol/l.

Supportive resourcing

Supportive resourcing is where parents/guardians support the minors during paediatric care situations. It is when parents/guardians encourage their minor and commend through stressing what the minor is proficient in. It also includes reading through the information presented by the HCP and explaining it to the minor. While discussing the disease with the HCP, mutual feelings of affinity and tenderness within the families become apparent. The parents/guardians may sometimes feel irritated when their minor does not comply with the directions given them, but as a family member they also understand the frustration and behaviour of the minor. Being supportive resourcing also means praising the minor for good behaviour, cooperation, and willingness. In the following, the minor, who was being prepared for magnetic resonance imaging, is being supportively resourced by the mother:

> The mother fills in the form about the Magnetic Resonance Imaging, while the minor is watching and also reading the form.

Minor bypassing

Minor bypassing is the situation where the minor is overlooked. It is a communication between parents/guardians and HCP and without the minor's participation. Mostly, this situation arises when the HCPs verbally encourage the parents/guardians to participate in the ongoing activities. The HCP communicate the minors' status directly to the parents/guardians, without the minors' direct involvement. The following shows minor bypassing between an HCP and the mother of a minor diagnosed with Mb Hodgkin's. The minor is receiving his chemotherapy at the paediatric day care unit for the first time:

> HCP – How brave you are. Most parents just sit in a corner.
> Mother, smiling – I am a little bit curious, you know.
> HCP – You are a brave mother.
> Mother – Well, this is not funny but … it is interesting.

Discussion

Parents/guardians can find themselves in an exposed situation when their minors are undergoing medical treatment and they are in need of understandable information and have the possibility of a continuous informative dialogue with the HCP. An issue is if parents/guardians are required to make a great effort to obtain information and thereby have to stay close to the minors. Maybe HCPs should be more informative generally and more attentive specifically to the individual family member as well as the whole family and their special needs. This need to exchange information is made concrete in *firm handling*, where the parents/guardians respond to the expectations as loving caregivers.

Parents/guardians act in their minors' best interests, and thus they engage in *aim sharing* with their minor and *representatively advocate* for them. Perhaps parents/guardians create a sense of delimitation concerning their minors, just in order to establish the most protective and best atmosphere for the paediatric care. Companionship in care implies equality among partners, information sharing, negotiation of care and shared responsibility as in *aim sharing* (Coyne & Cowley 2007). This might be one of the causes of *representative advocating*, in which parents/guardians speak on behalf of their minor. Parents/guardians have a need to be supported and facilitated by HCPs when *firm handling* their minors in paediatric care situations, which Silveira and Angelo (2006) presented as interaction in a previous study. Parents/guardians have a need to inform, to be informed and they also want to talk and agree with their minor in order to be *collaborating*. To be *collaborating* is most important to the minor as a developing person; to become a responsible grown-up the minor needs *firm handling* by adults.

It might be assessed as challenging by an HCP to encounter the family as both a unit and as consisting of individuals. This is where *minor bypassing* occurs; a

way for the adults to communicate in order to have a nice, pleasant conversation to create a warm and tender environment. By *minor bypassing* the parents/guardians create a state of authorization within the situation and thereby express their need of confirmation.

Representative advocating is a way for parents/guardians to engage in *collaborating*, when communicating in proxy, and an expression of *supportive resourcing* when sponsoring the minor in *aim sharing*. *Representative advocating* fitted the category of family influence in an observational study of minors' information exchange in paediatric care, and the impact of family appears to be universal (Mårtenson, Fägerskiöld & Berterö 2007).

Parents/guardians respect their minor's integrity when *supportive resourcing* in *firm handling* in different paediatric care situations. There is a strong commitment to include family, and thus to be *collaborating*, in all aspects of health care that impact children and their families (Landis 2007). To be *supportively resourcing*, parents/guardians have to get knowledge, and that is why it is essential to explore the information exchange by parents/guardians (Tates et al. 2002).

This study has limitations, as there are no follow-up interviews because the parents/guardians and their minors were often in a hurry to attend another appointment or they had limited time. The results are analysed by the observer and the co-authors and there is no confirmation of the participants' views. There were no minors aged 17 with accompanying parents/guardians and, perhaps the results would have differed if there had been.

The results create possibilities for reinforcing parenthood by supporting parents/guardians and minors so they can participate in health care encounters according to their preferences. The results may provide some guiding principles for HCPs regarding awareness of the vulnerability of parents/guardians. It is of great importance to be aware of the weakness and the need of support of the parents/guardians and encourage them to engage in firm handling their minor. If it is obvious that the parents/guardians and minors do not cooperate with one another, it might be possible for the HCP to focus on aim sharing to create an opportunity for the individuals to start collaborating. If the parents/guardians are mainly representatively advocating, the HCP might encourage the minors to participate by asking for their opinion and inviting them into the conversation. This may to start the collaboration and thereby encourage their parents'/guardians' natural feeling of responsibility to be supportively resourcing. In order to support the parents/guardians and their minor, written and computer based information ought to be easy to access when visiting a paediatric care unit. This is also valuable to the HCPs, since it facilitates and emphasizes their information exchange. The information must be suitable and understandable to both the parent/guardian and the minor, and should be provided in their first language.

There is a need to continue research in this specific area. What is needed is further knowledge about how minors and parents/guardians interact when they are in paediatric care. Furthermore, it would also be of interest to find out how health care professionals interact among themselves.

Conclusion

Reconstituting firm handling explains information exchange when parents/guardians are with their minor in paediatric care. The results indicate a pattern of how parents/guardians come closer to the minor in diverse ways. This knowledge makes it necessary and possible to design paediatric care situations in such a way as to support, facilitate, strengthen and improve the parents'/guardian's firm handling. Information exchange is a subject to parents/guardians to be practised by firm handling and this ought to be identifiable, well-known and manageable by health care professionals.

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