

EMPIRICAL STUDIES

**Being hospitalized with a newly diagnosed chronic illness—
A phenomenological study of children’s lifeworld in the hospital**ELSE MARI RUBERG EKRA, PhD Student^{1,2} & EVA GJENGEDAL, Professor¹¹Department of Public Health and Primary Health Care, University of Bergen, Bergen, Norway and ²Department of Health and Nursing Sciences, Faculty of Health and Sport Sciences, University of Agder, Grimstad, Norway**Abstract**

The impact of a hospital environment on children has rarely been investigated. Recently, however, the perspective of hospitalized children has been taken into account. Being hospitalized and facing an illness represent a dramatic change in a child’s daily life, and the quality of the environment may influence the child’s experiences. The aim of this study was to investigate the experiences of children being hospitalized with newly diagnosed type 1 diabetes and to obtain an increased understanding of the environmental influences on the children’s lifeworld. The study used a hermeneutic phenomenological approach. The design is a combination of observation of the participant, interviews, and photographs. Nine children, aged between 7 and 12 years, participated in the study. The data were collected between October 2008 and February 2010 and analysed in accordance with thematic analysis as described by van Manen. The children experienced change through recognition and adaptation. They perceived the environment as strange but still comfortable because of the “child-friendly” atmosphere, close contact with their relatives, and access to private space. The children were gradually able to adapt to their new life; they perceived their illness through bodily changes and developed practical skills and understanding. The findings underscored the necessity for an emphasis on the mutual relationship between the body and its environment. Bodily changes that occur during illness may lead to changes in one’s perception of the environment. Children seem to be particularly affected when the body appears alien and the hospital environment is unfamiliar. A well-adapted environment, active involvement, and the incorporation of new habits are significant elements of gradually returning to a more familiar life. However, the child’s new life requires alertness to the body’s signals and acclimation to a demanding diabetes treatment regime. All these factors remind children of their body’s needs and experiences and influence their lifeworld.

Key words: Hospitalized children, lived experience, hospital environment, type 1 diabetes, bodily changes, hermeneutic phenomenological method

(Accepted: 21 July 2012; Published: 17 August 2012)

Being ill and hospitalized represents a dramatic change in a child’s daily life. The quality of the physical and social hospital environment may influence a child’s experiences (Fridell, 1998; Norton-Westwood, 2012).

Most hospital wards for children have traditionally been built and designed around adults’ understanding of children’s preferences and needs. However, children’s views of what is important might be quite different from those of adults (Birch, Curtis, & James, 2007). More recently, children’s perspectives of the hospital environment have been taken into account in research, which has underscored the importance of paying attention to children’s own

views and experiences (Coad & Coad, 2008; Coyne, 2006; Pelander & Leino-Kilpi, 2004). A recent study showed that hospitalized children experienced fear of the unfamiliar environment, health professionals, and treatments, and they were concerned about disruptions of their daily life away from family and friends (Coyne, 2006). The children in the hospital tried to find some type of connection to their lives at home, for example, through meals, games, and TV or videos (Carney et al., 2003). Another study described children’s expectations of the quality of nursing care, including aspects of the environment, such as nice rooms, privacy, activities, and the availability of other children to play with

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Citation: Int J Qualitative Stud Health Well-being 2012, 7: 18694 - <http://dx.doi.org/10.3402/qhw.v7i0.18694>

(page number not for citation purpose)

(Pelander & Leino-Kilpi, 2004). Coad and Coad (2008) explored children's preferences regarding colour and thematic design in the hospital environment and found preferences for a pale blue-green colour and simplicity in design. For example, children preferred themes related to the sea, water, and nature. Furthermore, a study that explored the children's view of the hospital environment found that they were concerned about noise, the opportunity to control the light in the bed area, and the age- and gender-associated features of the environment (Birch et al., 2007). Although the children felt that the children's ward was child-friendly, they required time to become familiar with the environment. Hospitalized children might experience unpleasant aspects more keenly when they spend fewer days in hospital and undergo more intensive treatments (Ekra, 2004).

Although children's perspective of the hospital environment has been illuminated to some extent, there are very few studies that take the body and bodily changes into consideration. Assuming that the illness itself may influence the experience of being hospitalized, in this study children with type 1 diabetes were used as an illustrative group. We chose diabetes because it is quite a common illness in childhood. The Nordic countries have some of the highest diabetic incidence rates in the world, and in Norway, the prevalence of the disease has increased dramatically among children (Aamodt, Stene, Njølstad, Søvik, & Joner, 2007). Hence, the aim of this study was to investigate the experiences of children being hospitalized with newly diagnosed type 1 diabetes and to obtain an increased understanding of the environmental influences on the children's lifeworld. The research questions were the following: How do children experience the hospital stay? What impact does the environment have on these experiences?

Methodology and methods

To investigate the meaning associated with children's experiences of being ill and hospitalized, the study

used a hermeneutic phenomenological approach focusing on the children's lifeworld (van Manen, 1997). The lifeworld is a concrete, preverbal human world of everyday lived experience that we take for granted, inhabit, and share with others (Bengtsson, 2001, 2006). There is a fundamental mutual connection between human beings and the world (Heidegger, 1996), and we perceive our surroundings through the body (Merleau-Ponty, 2002).

Participants and context

The children were recruited from two Norwegian hospitals with children's wards. The staff nurses selected participants who were between 6 and 12 years of age and who had recently been diagnosed with diabetes. Five boys and five girls consented to participate in the study; however, one girl later declined (Table I). Each of the two children's wards had facilities for playing, school rooms, dining rooms, sitting areas, one- or two-bed patient rooms with a TV and an attached bathroom, child-related décor on the walls, and outdoor spaces.

Design and data collection

Data were collected from October 2008 to February 2010. The first author met with the children in different contexts: in the ward during their first hospital stay, in the outpatient clinic, or when they were admitted for an insulin pump education program (Table I). The study period extended from the point of admission until approximately 6 months after the children were diagnosed with diabetes.

To gain insight into the children's lived experience, the study was designed as a combination of close observation, in-depth interviews, (van Manen, 1997) and photo-voice (Darbyshire, Dougall, & Schiller, 2005; Freeman & Mathison, 2009). Being present in the hospital context with the children provided an opportunity to become familiar with them and observe events, interactions, and their

Table I. Data of the participants (all names are fictional).

No	Name	Age	First meeting	Second meeting	Purpose of hospital stay
1	Maria	7–8 years	Outpatient clinic	Ward	Checkup/insulin pump therapy education
2	Therese	11–12 years	Outpatient clinic	Outpatient clinic	Checkup
3	Johan	11–12 years	Ward	Ward	Insulin pump therapy education
4	Andre	7–8 years	Ward*	Ward*	Hospitalized at initial diabetes diagnosis
5	Henning	11–12 years	Ward	Ward	Insulin pump therapy education
6	Lars	9–10 years	Ward	Ward	Insulin pump therapy education
7	Emma	11–12 years	Outpatient clinic	Outpatient clinic	Checkup
8	Eva	11–12 years	Ward*	Ward*	Hospitalized at initial diabetes diagnosis
9	Mads	9–10 years	Outpatient clinic	Outpatient clinic	Checkup

*Several meetings.

relationships with their physical environment and other people. The first author spent time with the children while they were playing and receiving information. Additionally, she observed treatment situations, outpatient consultations, hospital school activities, and patient room settings. The length of the observations varied from a few hours in the outpatient clinic to approximately 14 h over several days in the children's unit. Each child was interviewed twice with one of their parents present. The main focus was on the children's narrations, but the parents who stayed with their children were also important contributors. The interview topics focused on experiences and understanding associated with the illness and treatment, the physical and social environments, and the children's interactions with their family, the staff, and other children in the ward. After the first interview, the children were invited to take pictures of the hospital surroundings. The photo-voice portion of the study was conducted by giving the participants a camera that they could use to take pictures of places, things, and activities that they perceived to be important. These images provided the basis for the second interview and were helpful in contextualizing and reminding the children of the rooms and situations they had experienced. The second interview took place before discharge or at the time of their next appointment at the hospital. The first interview lasted from 10 to 45 min, and the second lasted from 20 to 80 min. The first author, who is an experienced nurse and has worked for several years in a children's ward, conducted the interviews.

Ethical considerations

The hospital's chief physicians, the Regional Committee for Medical Research Ethics in western Norway (No. 066.08) and the Norwegian Social Science Data Services (No. 19087) approved the study, which was designed in accordance with the Helsinki declaration. The children and their parents received written information about the study and an invitation to participate. The parents and children older than 10 gave written consent, and all the children gave verbal consent. Discussion of a hospital stay or an illness may evoke negative experiences or memories; however, it may also be a way to process lived experiences. Although the hospital staffs were available for the children, none of the children needed assistance after the interviews.

Data analysis

Both interviews were audiotaped and transcribed verbatim. van Manen's (1997) description

of thematic analysis was applied to grasp the meaning and formulate thematic aspects of the phenomenon. Each interview and field note was read several times to gain an understanding of the text as a whole and to grasp the fundamental meaning of the children's experiences. Notes were written in the margins, and phrases and quotes that seemed to reveal the study's aim were underlined. The meaning of the text was then condensed. Furthermore, condensed sentences or clusters of sentences was carefully read and reflected upon, and the meaning was interpreted by asking what they revealed about the nature of the experience as seen from a nursing perspective. Preliminary themes were formulated for each interview and field note. These preliminary themes from all the interviews were compared, and a thematic meaning structure, consisting of two main themes and several subthemes, emerged (Table II). The pictures, taken by the children, underscored what emerged in the themes. The data analysis process was characterized by an openness and sensitivity to the text and a movement between the whole and the parts and the whole (Dahlberg, Dahlberg, & Nyström, 2008; van Manen, 1997). During the data collection and analysis, we tried to hold our pre-understanding "deliberately at bay" by making the assumptions explicit and maintaining a reflective attitude toward the phenomenon (van Manen, 1997, p. 47).

Findings

Change through recognition and adaptation

The context of the hospital seemed strange to the children. It was challenging to them to be faced with a chronic, lifelong illness. Nevertheless, a well-adapted and child-friendly environment, as well as the presence of their parents, gave the children a somewhat comfortable feeling. However, through active participation in their treatment based on their ability to adapt to a new situation, the children were gradually able to manage their new circumstances.

Table II. The thematic meaning structure of the phenomenon, as illustrated by main themes and subthemes.

Change through recognition and adaptation	
An unfamiliar but comfortable environment	Gradually adapting to a new life
<ul style="list-style-type: none"> ● A "child-friendly" atmosphere ● A private space ● Close to relatives 	<ul style="list-style-type: none"> ● Facing illness through the body ● Dealing with practical skills and understanding

An unfamiliar but comfortable environment. The children said that they were anxious, afraid, and insecure at the time of their admission to the hospital. When their body appeared strange and the environment was new to them, the children were uncertain about their situation. Although they had felt unwell for a while, many were surprised and unprepared when they were subjected to acute care hospitalization. Children who had previous bad memories or had never been hospitalized seemed especially anxious. Seeing and hearing other sick children made a strong impression on them. Eva thought it was scary when she met a girl in the hospital school who was given a blood transfusion. She said, "She had a bag with lots of blood ... It's okay with tiny glasses, but such a huge bag."

Nevertheless, all the children seemed to feel the children's wards were child-friendly. They liked the interior and appreciated the décor on the walls, and the photographs underscored their feelings. The pictures taken by the children highlighted the interior of the entrance to the ward, the walls and floors, as well as the artwork and the aquarium. A previous hospital stay made Johan afraid of doctors, the hospital, and injections, and he commented on one of his pictures, which was taken of a painting with a smiling figure on the entrance wall, "I could not understand how they could have a smiley face; there is not really anything positive about the hospital." The picture represented a contrast to the mood he was in when he was admitted to the hospital; however Johan enjoyed the aquarium very much:

I spent much of the time looking at the aquarium ... It had a calming effect on me ... There were some big snails that went along the glass and cleaned the algae.

Furthermore, photographs of different locations were often combined with images of specific items or special activities. For example, the children were concerned about the food, and in the dining room, they photographed the buffet, the toaster, the microwave oven, and the dining tables. In some cases, the pictures were related to the children's illness; for example, images of the scale were used to represent their weight loss.

Food was important to the children. Many of them suddenly became very hungry when they were started on insulin, and they said that they ate much more than usual. The food was familiar and good; however, when the children needed some variation in their fare, toast was especially popular. The buffet service in the dining room and the menu options at dinner were also popular. For instance, Therese

boasted of the food and the service, saying, "The food was very good ... It was almost like being in a hotel." It was good for the children to eat in their own rooms when they felt sick or tired. "My room" was a term the children used for the patient rooms. They felt a sense of ownership of their room, where they could be with their parents, receive visits, retreat, relax, and keep their belongings. To have a private space where they did not have to consider or be disturbed by fellow patients seemed to be important.

It was significant to be close to relatives, and that closeness created confidence and was a great support for the children. One of their parents was always present, which was also important for maintaining a daily routine. The children seemed to take it for granted that their parents would stay with them, and it was difficult for them to put the importance of their parents' presence into words. When Emma was asked how it felt to have her mother with her, she said, "I enjoyed it ... It would have been a little bit scary if my mam could not be here and sleep here." The children did not like to go to bed alone without their parents, and it could also have been frightening to be alone if a medical incident related to their diabetes were to occur. The children were aware that their parents behaved differently than before and that they were sad when their children became ill. Johan spoke about the first evening in the hospital: "Something I remember very well was that I lay in my bed and suddenly heard my mom crying ... It was not very nice, but she must also be allowed to be sad."

Being hospitalized involved missing family and friends. It was important for these children to receive visits and stay in touch with their friends, and the availability of a mobile phone was crucial.

The children were ambivalent about time during the hospital stay. Several of the participants described a need for rest and time to calm down. Eva felt tired and found it wonderful to be in the hospital, stating,

It has been so good to be here because I really have been able to rest ... I just wanted to relax all the time ... Normally I think it is so boring to be alone, and when I am home, I always like to go out and find something to do.

The hospital rhythm and pace were quite different from the children's active daily lives in school, in sports, and at leisure. The children's perception of time varied according to whether they had something to do. For instance, when they were engaged in activities in the school or the playroom or when they

were making friends among the fellow patients, the time seemed to speed up. Therese said,

In the beginning the time passed slowly ... after I found the playroom, the time flew ... Sometimes, I just wanted to go home because it was so boring, but it was very fun there as well.

Gradually adapting to a new life. As previously mentioned, being hospitalized can be a challenge, but the children's greatest concern was related to the new chronic illness. It was difficult for them to understand that they had to live with this illness for the rest of their lives.

Compared with their normally active lives, many of the children did not have as much energy. They noticed that they were thirsty and visited the bathroom more frequently than before and experienced facing illness through the body. Eva drank a lot of water at school; other liquids tasted strange. She said, "It became so embarrassing to constantly ask the teacher for permission to go to the bathroom." The children also described different types of symptoms; for example, they felt tired and were hungry, and they lost weight and were afflicted with headaches and stomach pain. Lars said,

I was so thirsty, so thirsty and so thirsty, and I visited the bathroom constantly. After school I was so tired, and I also got headaches and had great stomach pain.

Hypoglycaemia was a strange experience for the children, and they described it as feeling dizzy, hungry, sweaty, or grumpy; however, an induced hypoglycaemic episode with a nurse present could also be considered exciting. Eva related that her siblings and parents were invited to attend this event.

It was so fun; we ran and raced against each other in the garden ... I competed with the nurse and my sister with a skipping rope, and then I began to tremble, and when I saw myself in the mirror, I was white as chalk.

The diagnosis of diabetes required the children to be more aware of signals from their body, especially in relation to low and high blood sugar. The children were anxious about developing hypoglycaemia at night, in school, during activities, or when they were alone. They felt that the illness was a part of them, but at the same time, it could be demanding to manage. Therese said,

I try not to think about it when I play or do other things. When I swim, I always have to measure my blood sugar first in case it is getting low ... It has almost become a part of me, a routine. Sometimes I feel low when my blood sugar is eight, and my mum said that I am too aware.

Diabetes treatment involves injections and blood tests, about which many of the children expressed fears; however, they must get used to needles. The children described different types of pricks, such as small, hard, and painful depending on how the professionals performed the procedure. Blood collection from the armpit or a venous infusion cannula was worse than pricks performed with their own equipment.

The children learned to deal with practical skills and understand their diabetes. From the very beginning, they received practical training in injection technique and blood glucose measurement. The nurses showed them how to handle the new medical equipment, and they gradually managed to prick themselves. Johan, who had previously been very afraid of needles, said,

It has been my greatest fear, injections and blood tests ... He (the nurse) told me how to manage the needles ... First, he showed me how to do it on himself. When I needed to do it myself, I only held the needle. He pushed my hand and pulled it down.

Although the treatment was frightening and demanding, the children also experienced the new medical equipment as exciting, with its non-intimidating design. For example, the blood glucose monitor looks like a small mobile phone that can be decorated with stickers. The girls were proud of the small bags in which they kept their equipment. It was important that the measuring device be accurate; however, the children were also concerned with its design and usability. Therese described her experience with blood sugar monitoring and insulin therapy, saying, "Now that I am used to it ... I do it almost automatically."

Most of the children had heard of diabetes but had a limited understanding of the disease. The children articulated different notions about what the disease meant, especially the older children. When the doctor told Johan he had diabetes, he became quite afraid because he had heard that people died from diabetes. He said, "I thought it was dangerous and that I had to undergo surgery on the pancreas." Henning already knew that he had diabetes before he came to the doctor. He said, "I thought I could manage it." His father suffered from the same illness,

and he saw that his father lived quite well with it. Therese, who was familiar with diabetes, had concerns other than the injections: "I would certainly not want diabetes ... I cried ... because I thought it was so much to manage ... How I could keep my blood sugar stable ... I love sweet cakes."

The children believed that they had learned the most when the education program was adapted to them and the staff used audio-visual equipment, such as films, brochures, illustrations, and figures. Emma said,

They used a figure that could be opened when they explained the pancreas. They did it in a child-like way, and it was simpler to understand ... about the elephant and a key.

"Adult talk," can be difficult to understand and boring for children. Many of the children tried to find something else to do instead of following the diabetes education program with their parents. Mads said, "I thought the time passed so slowly in the 'doctor's hours' ... but then I took a walk on the children's ward." In their daily lives, the children were given a great deal of responsibility for the management of their illness, and they managed quite well. At home, it seemed that it was good for the children if the parents took over the responsibility and controlled the blood sugar late in the evening or at night.

The children looked forward to returning to school, especially those who had made PowerPoint presentations about diabetes in the hospital school, which they would present to their classes. The children's teachers and classmates also received information from nurses or the parents. At school, the children had to manage their diabetic on their own. In the beginning, they felt unsure and were concerned that it would be difficult to get everything done. The mobile phone was useful for reaching their parents to discuss, for example, how much insulin they needed to inject. Emma experienced the situation as challenging:

In the beginning, it was far from easy to deal with everything. I probably spent five minutes measuring and injecting the insulin ... I had to call too (parents) ... It took some time, and we had only fifteen minutes to eat before we had to go out ... But I was allowed to finish eating.

The children did not enjoy the attention that was given to the disease, but they felt safe when their teachers, classmates, and friends knew how to deal with hypoglycaemia. Therese felt the support from her classmates:

I do not believe the class thinks about me as having diabetes. They do it only when I eat ... If we have gym and I just sit on the bench, they ask if they should get glucose or if I'm low ... I feel very confident with them.

Discussion

This study adds to existing knowledge by revealing how children's experience with illness and treatment influenced their perception of their environment. The findings underscore the mutual relationship between the body and the lifeworld. Traditionally, a distinction has been made between the "internal" and "external" body, the biological processes related to a strict medical understanding of the disease and health, and the environment (Fjelland & Gjengedal, 2008). To obtain a deeper understanding of the lived experiences of the children in this study, our discussion takes a phenomenological point of departure by focusing on the embodiment of illness and an unhomelike being-in-the-world (Svenaues, 2000, 2005).

Ambiguity

Initially, the situation was difficult for the children to face; the body seemed alien, and the hospital environment was unfamiliar. Normally, we do not notice our body. When we are healthy, the body is "absent" from our consciousness (Leder, 1990). Confronted with a chronic disease, the children in our study had already noticed some changes in their body and experienced obstacles in school and sports activities. According to Merleau-Ponty (2002), the lived body is the seat of subjectivity and the point from which the world is perceived and understood. The lived body is ambiguous in that it exists as both object and subject. Consequently, bodily changes associated with illness may affect how the environment is perceived. In illness, the body may become an obstruction and prevent participation in daily activities. The body becomes the object of our attention, and the relationship between the lived body and the world changes and may even be disrupted; the world appears unhomelike to oneself (Svenaues, 2000, 2001, 2005).

The impact of the illness seemed to be a challenge to the children and did not necessarily provide meaning, especially in the beginning. This is in line with the study of Forsner, Jansson, and Soerlie (2005), who found that children did not recognize their body during illness and were therefore more vulnerable. They described the children's experiences of being diagnosed as a normal grief reaction.

This description parallels our study, in which the children articulated how difficult it is to face a lifelong disease.

When the body is felt as an obstacle, patients might have altered needs related to their environment. The present study underscores how children may benefit from retreating to the patient room, being close to their parents, and finding a balance between activity and rest. The importance of privacy to children in a hospital is also described in the studies of Boyd and Hunsberger (1998) and Pelander and Leino-Kilpi (2004). To have a room of one's own seems to be especially important. Activity and play may still be needed, but so are peace and quiet. Accordingly, it seems significant that the health care providers had to consider this new ambiguity. Children should be taken care of as ill but still healthy. Despite their illness, they still needed to be seen as active children.

Homelikeness

The alien body is a source of anxiety to children with diabetes, and the older children seemed to have more concerns about the future. Additionally, the hospital surroundings seemed to constitute unfamiliarity, and this resulted in feelings of fear and uncertainty when the children entered the hospital. This finding is in line with the study of Carney et al. (2003), who found that children's anxiety was related to hospital admission rather than to the hospital stay and that anxiety increased with age.

In spite of the unhomelike feeling, the children gradually experienced an improvement in their situation. They became more familiar with the hospital environment and its rules and routines, and they were actively included in their own treatment.

A well-adapted and child-friendly environment seemed to be significant and contributed to an optimal living space that created comfort for the children. A homelike feeling is often associated with home and family. The study emphasized mutuality in the relationship between the parents and their children. Most importantly, it was necessary for the parents to be there for the children when they needed them; at the same time, the children took the parents' presence for granted. The parents were great supporters and important contributors to the children's wellbeing and experience of homelikeness in the hospital, regardless of their age. This result is in accordance with Winther's (2006) study of homelikeness, which noted that a homelike atmosphere is moveable and can be created if one feels at home with the people around him/her and the place is recognizable. Hence, the transition from a feeling

of homelessness to homelikeness seems to depend on both a well-adapted environment and external support.

Incorporating new habits

Merleau-Ponty (2002) claimed that the lived body is a premise for human life and that embodied intelligence enables us to grasp the meaning of a situation and develop practical skills (Benner & Wrubel, 1989). Benner and Wrubel (1989) emphasized that using a tool for the first time often results in clumsiness and strong attention being given to the task itself until the skill is gradually internalized. Our study underscored the importance of including the children in the education program and their own treatment from the very beginning. The children learned how to deal with their illness in a concrete way by doing, seeing, and experiencing. Gradually developing independence and understanding seemed to give the children self-confidence. According to Wennick and Hallström (2006), they identified the period after diagnosis as "an on-going learning process."

Visual tools and the opportunity to share their knowledge were obviously the best ways for the children to learn. Furthermore, it was difficult to engage the children by talking when the doctors and nurses taught them about the disease; the theory went over their head. This finding is in line with the study by Ekra (2004), who found that children felt that they did not learn when the staff used only verbal and written sheets without illustrations. "Knowing how" and "knowing that" are two different types of knowledge; the first is related to practical skills, while the second relates to theoretical knowledge (Ryle, 2000). Embodied intelligence and "knowing how" contribute to making the world recognizable and homelike (Benner & Wrubel, 1989).

Incorporating new habits and adapting to the illness may lead to a gradually achieved homelike state of being-in-the-world. At the same time, having diabetes can also be hard work, and the children knew it was impossible to escape or get rid of. The ill body may be compared to a broken tool. The difference is that a tool can be replaced, but the lived body cannot (Carel, 2008; Svenaeus, 2000). This new life involved being alert to the body's signals. The children in this study adapted to strict time schedules for the procedures, and the diabetes-related tasks did not always fit easily into their daily activities, such as playing and sports. Other studies have reported similar findings (Hema et al., 2009; Herrman, 2006; Wennick & Hallström, 2007). According to Carel (2008, p. 82), in illness,

“the transparency and taken-for-granted nature of the body are now replaced with an acute sensitivity to the body’s demands and limitations it places on the ill person.”

Attention from people around them was experienced as both positive and negative by the children. Family and friends could be a great support; however, attention from others about issues related to mealtime, injections, and measurements resulted in feelings of being different from others and provided a reminder of the body. Being seen as a child with diabetes, as opposite to a diabetic, was important. As underscored by Wennick and Hallström (2007), living with diabetes may be characterized as an ordinary life, but at the same time, it is a different and more demanding life. However, being able to meet the new challenges by incorporating new habits and being supported by others seemed to contribute to a sense of achievement.

Limitations and strengths

This study is, to some degree, limited by the fact that the children were interviewed at different time points in their illness; some were newly diagnosed and still in the hospital, whereas others had lived with the illness for up to 6 months. Nevertheless, a broader perspective of their situation was achieved. The observation time was relatively short, and the study could have been strengthened by a longer duration; however, the children were interviewed twice. The strengths of this study may be the mixed data collection and that the children’s voices were taken into account. The observation period gave the first author the opportunity to get to know the children before the interviews. The children also felt more confident during the interviews. The photographs were an important tool; they created increased interest in the interview situation and made it easier for the children to describe their experiences.

Conclusions and implications

This study underscored the importance of taking the body into account to understand the impact of the environment on children’s experiences. Changes in the body influence how children inhabit their hospital rooms. Hospitalized children seem to be stricken by a double homelessness because the body appears alien during illness and the hospital environment is new and strange. A well-adapted and child-friendly environment, the presence of parents, and active involvement in the illness and the treatment are important for children in the hospital. Adaptation, recognition, and incorporation of new habits are significant elements of change and

gradually returning to a more homelike state of being. The present study focused on a chronic illness; further research on children admitted to the hospital with acute or serious illnesses would also be interesting to investigate.

Acknowledgements

The authors would like to thank the children, their parents, and the staff nurses for their participation in this study.

Conflict of interest and funding

There are no financial or other conflicts of interest for any of the authors.

References

- Aamodt, G., Stene, L. C., Njølstad, P. R., Søvik, O., & Joner, G. (2007). Spatiotemporal trends and age-period-cohort modeling of the incidence of type 1 diabetes among children aged <15 years in Norway 1973–1982 and 1989–2003. *Diabetes Care*, 30, 884–889. doi: 10.2337/dc06-1568
- Bengtsson, J. (2001). *Sammanflätningar: Fenomenologi från Husserl till Merleau-Pontys* [Intertwinings: Phenomenology from Husserl to Merleau-Ponty]. Göteborg: Daidalos.
- Bengtsson, J. (2006). En livsverdenstilnærming for helsevitenskapelig forskning [A life world approach for health science research]. In J. Bengtsson (Ed.), *Å forske i sykdom- og pleieerfaringer* [Researching experiences of illness and care] (pp. 13–58). Kristiansand, Norway: Høyskoleforlaget.
- Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*. Menlo Park, CA: Addison-Wesley.
- Birch, J., Curtis, P., & James, A. (2007). Sense and sensibilities: In search of the child-friendly hospital. *Built Environment*, 33, 405–416. doi: <http://dx.doi.org/10.2148/benv.33.4.405>
- Boyd, J. R., & Hunsberger, M. (1998). Chronically ill children coping with repeated hospitalizations: Their perceptions and suggested interventions. *Journal of Pediatric Nursing*, 13, 330–342. doi: [http://dx.doi.org/10.1016/S0882-5963\(98\)80021-3](http://dx.doi.org/10.1016/S0882-5963(98)80021-3)
- Carel, H. (2008). *Illness* (1st ed.). Durham, UK: Acumen.
- Carney, T., Murphy, S., McClure, J., Bishop, E., Kerr, C., Parker, J. et al. (2003). Children’s views of hospitalization: An exploratory study of data collection. *Journal of Child Health Care*, 7(1), 27–40. doi: 10.1177/1367493503007001674
- Coad, J., & Coad, N. (2008). Children and young people’s preference of thematic design and colour for their hospital environment. *Journal of Child Health Care*, 12(1), 33–48. doi: 10.1177/1367493507085617
- Coyne, I. (2006). Children’s experiences of hospitalization. *Journal of Child Health Care*, 10, 326–336. doi: 10.1177/1367493506067884
- Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2nd ed.). Lund, Sweden: Studentlitteratur.
- Darbyshire, P., Dougall, C. M., & Schiller, W. (2005). Multiple methods in qualitative research with children: More insight or just more? *Qualitative Research*, 5, 417–436.
- Ekra, E. M. R. (2004). *Sykehus – et beboelig sted for barn? En fenomenologisk studie om omgivelsenes betydning for hvordan barnet opplever en sykehusinnleggelse* [The hospital – a habitable place for children? A phenomenological study of the

- significance of environment for how the child experiences hospitalization]. Unpublished master thesis, University of Oslo, Oslo, Norway.
- Fjelland, R., & Gjengedal, E. (2008). Livsverden, arkitektur og sykdom [Life world, architecture and illness]. In E. Gjengedal, A. Blystad, & A. Schiøtz (Eds.), *Helse i tid og rom* [Health in time and space] (pp. 99–124). Oslo, Norway: Cappelen Akademiske Forlag.
- Forsner, M., Jansson, L., & Soerlie, V. (2005). Being ill as narrated by children aged 11–18 years. *Journal of Child Health Care*, 9, 314–323. doi: 10.1177/1367493505056485
- Freeman, M., & Mathison, S. (2009). *Researching children's experiences* (1st ed.). New York: Guilford.
- Fridell, S. (1998). *Rum för vårdens möten: om utformning av fysisk vårdmiljö för god vård* [Spaces for the encounters of care: On the forming of the physical environment for good care]. Stockholm, Sweden: Institutionen för arkitektur och stadsbyggnad, Kungl. tekniska högskolan.
- Heidegger, M. (1996). *Being and time: A translation of Sein und Zeit*. Albany, NY: State University of New York Press.
- Hema, D. D., Roper, S. O., Nehring, J., Call, A., Mandleco, B., & Dyches, T. (2009). Daily stressors and coping responses of children and adolescents with type 1 diabetes. *Child: Care, Health and Development*, 35, 330–339. doi: 10.1111/j.1365-2214.2009.00937.x
- Herrman, J. W. (2006). Children's and young adolescents' voices: Perceptions of the costs and rewards of diabetes and its treatment. *Journal of Pediatric Nursing*, 21, 211–221. doi: <http://dx.doi.org/10.1016/j.pedn.2005.07.012>
- Leder, D. (1990). *The absent body*. Chicago: University of Chicago Press.
- Merleau-Ponty, M. (2002). *Phenomenology of perception* (Reprinted ed.). London, UK: Routledge.
- Norton-Westwood, D. (2012). The health-care environment through the eyes of a child – Does it soothe or provoke anxiety? *International Journal of Nursing Practice*, 18, 7–11. doi: 10.1111/j.1440-172X.2011.01995.x
- Pelander, T., & Leino-Kilpi, H. (2004). Quality in pediatric nursing care: Children's expectations. *Issues in Comprehensive Pediatric Nursing*, 27, 139–151. doi: 10.1080/01460860490497778
- Ryle, G. (2000). *The concept of mind*. London: Penguin Books.
- Svenaesus, F. (2000). The body uncanny—Further steps towards a phenomenology of illness. *Medicine, Health Care and Philosophy*, 3, 125–137. doi: 10.1023/A:1009920011164
- Svenaesus, F. (2001). The phenomenology of health and illness. In S. K. Toombs (Ed.), *Handbook of phenomenology and medicine*. Boston: Kluwer Academic Publishers.
- Svenaesus, F. (2005). *Sykdommens mening: og møtet med det syke mennesket* [The meaning of illness: And encounter with the human being]. Oslo: Gyldendal akademisk.
- van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). Ontario, CA: Althouse Press.
- Wennick, A. & Hallström, I. (2006). Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus: An ongoing learning process. *Journal of Family Nursing*, 12, 368–387. doi: 10.1177/1074840706296724
- Wennick, A., & Hallström, I. (2007). Families' lived experience one year after a child was diagnosed with type 1 diabetes. *Journal of Advanced Nursing*, 60, 299–307. doi: 10.1111/j.1365-2648.2007.04411.x
- Winther, I. W. (2006). *Hjemlighed: kulturfenomenologiske studier* [Homelikeness: cultural phenomenological studies]. København: Danmarks pædagogiske universitets forlag.