

'I want them to see that I feel normal': three children's experiences from attending consultations in paediatric rehabilitation

Wenche Bekken

Faculty of Health Sciences, Oslo and Akershus University College of Applied Sciences, Norway

Keywords: children's experience; decision-making; embodiment; disability; involvement; paediatric rehabilitation

Points of interest

1. The article presents children's experiences of taking part in consultations at a paediatric rehabilitation unit.
2. The children describe how they are involved, and what they find important to talk about during a consultation.
3. The results demonstrate how disability in this context holds to a biomedical understanding, while the children request more focus on how they participate in activities and manage their social life.
4. The article illustrates the importance of listening to children's experiences to see their competence.

Abstract

This article describes and analyses three children's experiences of taking part in consultations at a paediatric rehabilitation unit in Norway. The analyses focus on how the children express themselves through social life experiences during the consultation. It is

discussed how the children apply their embodied knowledge and experience in identifying themselves as normal, and what challenges this identification during a consultation. The analyses emphasize what the children's experiences can mean, and how these experiences represent professional practice and structural constraints in paediatric rehabilitation. By investigating the child's embodied knowledge during consultations, a focus on biomedical issues may overshadow the child's own perceptions of issues related to functioning in everyday life. The children's descriptions are relevant for advocating children's participation in matters concerning their own lives, and for disabled children's participation in decision-making more specifically.

Introduction

All children with disabilities in Norway are enrolled in rehabilitation programs for regular assessments and evaluations. The specialists at the health services do also set diagnosis and initiate rehabilitation programs. Once or twice a year the children attend consultations at the paediatric rehabilitation unit for medical and physical follow-up by a paediatrician and a physiotherapist. At these consultations, decisions are made on treatment programs and/or whether surgery is needed. The community health services implement interventions in cooperation with professionals from school or nursery/kindergarten, and/or the social services. Research conducted on outpatient paediatric consultations shows marginal communicative involvement from children during consultations (Cox and Raaum 2008; van Dulmen 1998). Concerning children's perspective on participating in health care decisions, research documents that they want to participate in decision-making (Moore and Kirk 2010). Children report that they feel valued and less anxious about what is happening when included in decisions and when asked directly about matters concerning their treatment (Moore and Kirk 2010). How children participate during a consultation does, however, vary depending on the stages of the consultation (Taylor et al. 2010; Bekken 2013). There is scarce in-depth

documentation on how children with impairment experience participation and involvement in decision-making concerning their own rehabilitation.

The United Nations Convention on the Rights of the Child, Article 12 (1989), states the child's right to be heard in matters that affects their lives. Norwegian legislation incorporated the convention in 2003. The right applies to all children who are capable of forming a view. In Norway, the practice in medical interventions is to involve children in decisions from the age of twelve years. The law does not demand that practitioners have a conversation with the child before medical treatment is decided on (Sandberg 2009). How to involve the child in an adequate way in decision-making in medical practice is complicated. It has been suggested that professionals at hospitals lead the way in respecting the child's right to participate; however, in clinical practice this may be difficult because what the professionals find to be the best interest of the child in medical terms might conflict with the child's wishes (Moore and Kirk 2010). Tisdall (2012) emphasizes that "disabled children's views may be undermined by questions about their ability to have clear views," and thereby their involvement in decision-making can become even more difficult.

Involving children in decision-making implies promoting the children's feeling of autonomy and acknowledging their experiences and knowledge. Autonomy is understood as acting according to one's own interest and integrated values, and experiencing one's behaviour as an expression of the self (Ryan and Deci 2004). Autonomy is very much guided by support from the environment, and is dependent on and related to competence (Koestner and Losier 2004). Competence refers to *feeling* effective in one's on-going interactions with the social environment and *experiencing* opportunities to exercise and express one's capacities (Ryan and Deci 2004). Feelings and experiences are embodied knowledge, and it is important that children be able to express such knowledge, verbally or non-verbally, when participating in consultations. Adults can encourage children in expressing their opinions;

however, to do so adults need information from children themselves about what they find relevant to talk about during consultations. Therefore, it is pertinent to investigate the experiences and feelings children express during a consultation and to discuss how this competence may inform the paediatric rehabilitation practice.

To give children the opportunity to talk about their experiences of participating in consultations may contribute to improving our insight into how children perceive themselves in interaction with professionals. Research on children's experience reflects an interest in children as persons who can act with intention and as agents in their own lives (Greene and Hill 2005; Connors and Stalker 2007). Studying children's experiences captures the richness of individual lives, and it may capture views that adults might not be aware of as important. The focus on experience in disability studies is about embodiment, about the experience of living with a disabled body in a society. Embodied knowledge is personal experience and emotions, but also reflects cultural values held by society on how to understand and treat persons with bodies that are different from those of majority.

Theoretical framework

Paying attention to how children experience attending consultations may contribute to discussions on the use of standards and norms of what is normal or typical. The word typical is often preferred since normal is associated with its dichotomy abnormal (DePoy and Gilson 2011). In paediatric rehabilitation, children's bodies are evaluated according to medical standards measuring the body functions as typical or atypical development. Interventions are planned according to these evaluations. Understanding children's development according to a specific developmental direction may overshadow children's own experience and children's agency (Burman 2008). Many disabled children need support to participate in daily life activities, however their needs, preferences, priorities and aspirations are in many ways like

any other children (Stalker et al. 2012, 173). The interviews in the present study are about how three children communicate their identity as social persons during consultations in paediatric rehabilitation. Their experiences will be analysed using a sociocultural perspective of embodiment, where the embodied experience represents socially, or culturally held values (Scheper-Hughes and Lock 1987).

In their often cited article “The mindful body” (1987), the two medical anthropologists Margaret Lock and Nancy Scheper-Hughes emphasize how body perceptions and practices are learnt from and affected by culture. Their studies of bodily practice in different cultures demonstrate how the body consists not merely of universal biological or natural functions, but notably also of cultural perceptions that change over time. Scheper-Hughes and Lock recommend a three-fold analysis with focus on individuals’ experience of their body, what sociocultural values the body may represent, and the structural constraint that controls the body (the body politic). Representation, sociocultural values, and sociocultural and political control are broad concepts, and must be refined according to the object and context of study.

To understand the body in a social sense is to focus on how it is to live with a body in society. How individuals experience their body can reflect a society’s values or norms of what is a beautiful body, a natural body, or even a normal body for the majority. Seen in this way, the meaning an individual gives its body may symbolise a collective norm. A symbol has the capacity to convey meaning to people, both common or shared meaning among people, and an individually held meaning (Cohen 1989). The relationship between the subjective and objective collective understanding forms a person’s identity building. In the following, how the children understand and express themselves in the context of paediatric rehabilitation gives insights into what constitutes their identity. Scheper-Hughes and Lock use of body politic is “referring to the regulation, surveillance, and control of bodies (individual or collective) in reproduction and sexuality, in work, and in leisure, in sickness and other forms

of deviance and human difference” (1987:8–9). In the following analyses, the body politic is seen as the power and control of the individual body in paediatric rehabilitation, and in treatment of children with impairment. Scheper-Hughes and Lock state, “Cultures are disciplines that provide codes and social scripts for the domestication of the individual body in conformity to the needs of the social and political order” (1987:26). Applied to paediatric rehabilitation, it is relevant to highlight some of the constraints directing rehabilitation of “bodies with impairment.” It also opens for questions on embodiment in relation to how it fits in a certain context, which Rosemarie Garland-Thomson (2011) states “can lead to and demand for a recognition of better fit” (2011:600). In the summary discussion, Garland-Thomson’s use of *misfit* (of the body) will be applied, by attention to how the discrepancy between the body and the world produces misfits and fits (2011:593).

In disability studies, attention to how it is to live with impairment has rendered insight into how the relationship between biomedical and sociological dimensions is always present. However, the context and personal experience of being disabled affect which dimension is foregrounded (Hughes and Paterson 1997; Neville-Jan 2004; Shakespeare 2006, 2004; Shakespeare and Watson 1997; Watson 2012; Thomas 1999). The following analyses will discuss how the children’s experiences from attending consultations elucidate the relation between biomedical and social dimensions of disability.

Purpose

The purpose of this article is to:

1. Present children’s experiences from attending consultations in paediatric rehabilitation.
2. To describe what the children want the professionals to focus on during a consultation.

3. Contribute to the development of professional work in involving children in decision-making.

Method

Excerpts from interviews of three children are included in this paper: two 11-year-old boys and a 15-year-old girl. They are selected from a study on paediatric rehabilitation consultations, containing researchers' observations of professionals during 40 consultations, group interviews of the professionals by researchers, and interviews with nine children about their experiences from taking part in paediatric consultations. Other results from this study are already published (Bekken 2013). During a consultation, evaluation and decision-making are central themes, and the three selected interviews are based on in-depth descriptions of these themes. The three children want to contribute with their experiences to improve professional practice in paediatric rehabilitation.

The interviews were 45 to 90 minutes long. Two of the interviews are carried out at their homes and one at the researcher's work place, as a matter of convenience for the boy and the family. In one of the interviews, the mother was present, commenting on some of the boy's descriptions. She let the boy talk freely. Her comments are included, and are seen as a complementary perspective to the boy's (Greene and Hill 2005).

The interview method is inspired by the life mode interview (Haavind 1987; Gulbrandsen 1998). The interview method proves to be a suitable mode of interview when talking with children about everyday life (Ulvik 2007). The starting point for the interview is the day before today. In this study it is applied to the paediatric rehabilitation context and the last time at a consultation. The interviewer asks for a detailed description about routines, activities, and experiences during the consultation. Unusual happenings are in focus, and how the child thinks routines and activities should be (Ulvik 2007).

Rereading the transcriptions and listening to the audio tapes several times prepared the interviews for analysis. The first step in the analysis was to identify expressed emotions or perceptions related to attending consultations. Activity, assessment processes, and decision-making emerged as important themes. The children described these themes with reference to their embodied knowledge and to a feeling of being normal. Theories on embodiment from the field of disability studies and medical anthropology seemed relevant for analysing the material.

Ethical considerations

To acknowledge the child's experiences as competence and to involve children in research has altered the perception of the child as being extremely vulnerable, and opened up for seeing fewer differences between doing research with children and adults (Hill 2005).

However, the difference in social status between adults and children may influence the child's subordination during the research process. Other factors that might be influential include considering under what terms the children give their consent, how children are affected by the adult-child relationship during interviews, and how the children are presented in publications (Hill 2005). Age and individual differences may affect vulnerability. Everyone, the three children and their parents, received an information and a consent letter, and a shortened and non-academic letter adapted for children. In addition, their parents informed their children orally. Children and parents gave their consent. The children were not asked questions on sensitive issues related to their private family life.

The paediatric rehabilitation unit recruited the children; meanwhile, their professional contacts at the unit were unaware of the children's participation in the study. Regional

Committee for Medical and Health research Ethics of Southeastern Norway approved the study.

Findings

Tom, 11 years old

Tom finds it okay to attend the rehabilitation unit for consultations:

Tom: I find it fun to show what I can do [to perform activities to show his abilities] and stuff like that. (...)

I: Can you tell me a bit more about what [the professionals] ask you when you sit [point at the drawing] here in the consultation?

Tom: If I'm ok. ...

I: What do they ask you for finding out if you are okay?

Tom: They ask, "How are things at school, and how are things at home?"

I: Do you talk about your leisure time?

Tom: Yes, how I manage at leisure time and stuff like that. I say, "Yes, currently I do lots of activities" – because that's what the physiotherapist wants to hear about. She asked what kind of activities I do, and I answered, "I used to play soccer, but quit this summer because both my knees failed. But now I'm scouting, swimming, horse riding, singing in choir, and also I joined a drama and theatre group that I'll perform with next week.

I: So, do you tell them about how it is to participate in these activities?

Tom: It's good. I feel that horse riding is good for my back.

I: What makes it okay for you to join these activities?

Tom: It's important for me to keep in shape.

(...)

I: What do you think of the physical measurements?

Tom: It's cool [laughs a bit].

I: What is cool?

Tom: That I get to demonstrate what I can do.

I: You like to demonstrate what you can do, okay. (...), and what do you experience then?

Tom: No ... it's like; I don't feel myself as the others with the same disease. ... I feel normal.

I: When you get the chance to show what you can do, then you feel normal. Is that what you mean?

Tom: Mmm [nods yes].

Tom's story illustrates the importance of a supportive environment for experiencing autonomy (Koestner and Losier 2004), and also how feeling at ease during a consultation affects involvement (Taylor et al. (2010). In addition, Tom communicates his competence concerning bodily pain, functional loss due to his progressive impairment, and his abilities.

Activity is a repeating theme in Tom's description, and it is relevant to investigate what Tom's descriptions of activity can mean, and why activity is related to his perceptions of feeling normal (Scheper-Hughes and Lock 1987). Understanding *activity* as a symbol is useful because symbols can convey meaning to people in several ways (Cohen 1989). In the context of the consultation, Tom likes to demonstrate to the professionals his physical abilities. By doing so, he feels normal because it distinguishes him from the others with the same diagnosis. In studies of embodiment, the concept of the *others* is central (Lock 1993), and refers to processes of identification either through association with a group or by disassociating from a group. Tom uses the latter. He disassociates himself from others with the same progressive disease by focusing during the consultation on his skills and participation in activities. A progressive diagnosis means to lose skills and function, in this case, to experience that the muscles get weaker and affect the level of activity, and may cause significant changes in life. Being active or able to do activities is part of what he normally does, which he values, and Tom says:

My impairment makes my muscles get weaker. If I'm to be active as an adult, I need to be active as child.

At the paediatric rehabilitation unit, the professional examines possible loss of muscle strength, and he wants to present his strength and skills to the professionals. He says:

... I just get better and better at things. So it's good that I'm followed up by them [the professionals], so they can see what I can do. So ... next time they can see what I have learnt, and what I can do better. (Tom)

The progressive impairment is a fact he seems to be aware of. In the context of the consultations, activity represents being able to live an active life with this impairment.

Investigating why a child wants to display skills in a certain way enables professionals to better understand the child's own perception of what it is like to have a specific impairment.

Professionals may interpret way of being active as if the child were not having insight or were repressing reality. However, Tom is self-reflective about eventually losing functions, and the professionals must talk with him to reveal his perceptions and motives for his self-representation in order to support and involve him in decisions.

Tom has a positive experience of attending the consultation. The focus on daily life functioning and on capacity to perform seems meaningful for Tom. How the professionals work with children reflects the rehabilitation system in practice (Scheper-Hughes and Lock 1987). Tom knows that the professionals' job is to evaluate children with the same diagnosis as he has. The professionals have competence concerning how his impairment will affect him, and it seems that convincing the professionals that he manages well living with his impairment makes him feel normal. Thereby, the meeting with the professionals actualises the disassociation from the others with the same diagnosis. Tom gives a positive example of how paediatric rehabilitation can work positively; however, for children with a different

impairment, and with other needs, their experiences might highlight the professional practice differently.

Lisa, 15 years old

Lisa describes negative experiences when asked what she thinks or feels when going to the rehabilitation unit:

I've never liked to go there. I really don't find it nice because I'm not very happy with telling that I have a disease. I feel like I function very well, and I don't need much adjustment or assistive technology for functioning in daily life. (...) It has been better the last times I've been there, because now I'm more grown up, and they treat me more like an adult. I believe it was okay when I was younger, except from when I was injected with Botox in my legs. (...) I experienced it more as fun to be there, you know. But when I realised that I was there to be evaluated and tested, it wasn't just about fun anymore.

I: How old were you when you found out about that?

Lisa: 6–7 years old.

Lisa does not like to talk about her impairment, and does not like the attention to her impairment, because she feels that she functions well in daily life activities. The professionals focus on her impairment does not give meaning to or support her own experience of functioning well in daily life, because she does not need technical aid. She wants more focus on how she experiences herself in daily life.

Moore and Kirk's review study (2010) reveals a lack of focus on daily life functioning in paediatric rehabilitation. To a certain extent during consultations, the professionals ask Lisa questions regarding her social life, but according to Lisa, the evaluations and tests have priority. The focus is on Lisa's foot, a focus she does not like. She likes professionals to focus on other things in her life:

Yes. Then I forget it [the impairment] for a moment. In addition, the better they are at not mentioning it [the impairment], the more okay it is to be there. As for example when I've gotten the chance to join ... and understand what happens, then it has been better. I feel that I function very well in daily life, and don't really have serious special needs. So when they manage to focus on something else, not just the medical part. ... I think it is okay to talk about my legs in ordinary situations where things work out well. If they manage to direct it [the conversation] towards how things are in the daily life, then it's easier, then it's not so scary. The last consultations have been better because the conversation has been about daily life activities, not just the medical/theoretical part. (Lisa)

In this extract, she emphasizes again the importance of paying attention to daily life activities, and not merely to the physical functioning of her foot. Attention to physical function connotes a negative experience, whereas more attention to how she lives her life with impairment and feels about her life gives her a positive feeling. Lisa's descriptions is in line with disability research focusing on the importance of investigating how a person experience *being* a person, and what the person does of activities, the *doing* (Thomas 1999, 2004). Lisa emphasizes her *being* when she states that she feels she works well in daily life. Studying personal situated experience can give information about a person, and one could say that separating the experience of *being* from *doing* does not give a complete picture of a person. At a cultural level of understanding, Scheper-Hughes and Lock (1987) emphasize this point when saying that separating the body from certain forms of experience may have consequences for the perception of what is normal, and therefore pertinent to reveal. Understood from Lisa's experience, it does not make sense to her to focus on the disabled part of her body, when her experience is that she feels abled in daily life. Lisa's experience exemplifies that what goes on

during a consultation may challenge one's self-perception. Her experience gives response to what children may want the professionals to focus on during a consultation.

In addition, Lisa highlights that to understand what the professionals talk about makes it more okay to participate in consultations. Having information that makes sense depends on understanding what the professionals talk about, which can open up for better involvement of the child during consultations (Moore and Kirk 2010). The negative experience from attending consultations is explained by too much attention to the physical dimensions of impairment separated from the experience of living with the impairment in daily life, and not understanding what the professionals talk about. Medical evaluation is required during a consultation, where the doctor has a central role. The physiotherapists do perform assessments, which involve several tests on body functioning and body structures in order to guide the goal-setting process, and to implement these goals into the child's daily activities (Langeland and Øien 2008). The purpose of rehabilitation is to facilitate participation in daily life activities. In Norway, this approach has removed the word *medical* in definitions of rehabilitation in governmental and legal documents. This is a strategy to pay more attention to facilitating daily life activities and to the relational understanding of disability, including how social barriers can hinder participation in activities. The present results, however, indicate that in the context of a consultation, the practice holds to a medical understanding of disability.

Tom and Lisa's stories exemplify the usefulness of seeing competence as experience. Their stories provide insights about how professional practice may have both positive and negative impacts on them, and about what might be improved by way of accepting children's experiences and knowledge. It is relevant also to give an example of how a child's involvement in decisions affects the experience of attending consultations.

Peder, 11 years old

Peder had a surgery two years ago. He found the surgery and postoperative period exhausting and challenging. The surgery required an exercise program three times a week to achieve a good result. The surgery changed his normal daily routines, a change he disliked. Peder says in the interview:

I: Before you went to the rehabilitation unit last time, what did you feel or what did you think of?

Peder: Last time ... I dread to go there.

I: What was not okay for you?

Peder: Because ... when I'm there, the physiotherapist tells me to do this and that, and I get like... it feels like I must do it. She makes new rules and stuff like that. I was very afraid (...) because I didn't like it. I don't know why, but I didn't like it because I actually think it was too much. Maybe not for the physiotherapist, but for me it was.

(...)

I: Was it exhausting to do the exercises?

Peder: Yes, it used to be three days, (...) and that was hard. Now it's only once a week and I feel that I get more results now than when I exercised three times a week.

Peder's feels that his experience is not used as relevant information for planning the training program. This is in accordance with research findings on children in rehabilitation after a multilevel surgery, their feeling of never being adequate (Capjon and Bjørk 2010). Peder describes the training, being exhausted, and not being listened to, as *too much* for him. He is aware that the physiotherapist might not have thought so. Peder's various negative feelings elicit a negative feeling towards the professionals, and anxiety about what they will decide *for* him during consultations. This is relevant information for the professionals. Peder's mother explains during the interview:

(...) When the professionals understood that he worried a lot for what they would say to him [during the consultation], they felt sorry for him. The professionals said, “It cannot be like this; we must do something about it.” Therefore, the professionals decided that Peder had to get more involved in decisions concerning his own rehabilitation. Together they took a decision to take a break from physical training at school and leisure time, and then reduce the amount of training per week. Reducing the training schema took away Peder’s irritability.

Peder agreed with his mother’s account, but added that he was not completely sure if they did involve him:

Peder: (...) Now I understand the point, now I understand how, but before I didn’t. Yes, but not completely, but I have the chance, in a way.

I: ... Have the chance?

Peder: (...) now I feel that it works better for me.

(...)

I: Was it too much (training)?

Peder: Yes.

I: So you feel that you have the chance to say how you like it to be?

Peder: I feel (...) before everybody was around me (...). Now I feel that everything is much easier. Now when I’ve done it (the training), I feel proud in a way ... now I can decide much more myself. It’s much easier now. I feel in a way that I’m normal. Hardly anyone decides for me, compared to when I had the surgery.

Moore and Kirk (2010), found in their literature review that children want to participate in decisions concerning themselves. Peder’s experience gives content to what wanting to participate can mean to children. Being involved in decisions makes Peder experience pride after doing the exercises, and he can decide more himself, which he

describes as feeling normal. It can be relevant to dwell on the description of not being involved, and to analyse what this description can represent at a structural level.

A routine during the consultation was that Peder had to leave the room so his parents and the professionals could talk alone (about further decisions concerning *his* body). This made him feel negative about himself. He says:

That [being left outside the room] made me feel very bad because I had thoughts about them hiding information from me, and I thought that I didn't mean much to them. I used to shout and bang on the door.

Experiences can, as Scheper-Hughes and Lock (1987) emphasize, represent a *cultural* practice, or professional practice in this case. Structural conditions like profession, guidelines for rehabilitation in practice, and patient acts, affect the professional's treatment of children during consultations. The involvement Peder experiences in decisions can be a representation of power between a child and the adults. While outside the room, he resists by shouting and calling for attention, because he gets worried when he cannot participate in the conversation. Gallagher (2008) emphasizes with reference to Foucault how power always inhibits control and resistance; Peder's reaction can be seen as resistance to the professionals and parents controlling whether he can participate in the conversation. Peder is explicit about his uneasy feeling when he cannot hear what the adults say about his physical function. In the Foucauldian tradition, power is action played out in network, rather than something one possesses, and can thereby focus attention on how children can contribute with insights that can alter the adults' status as always knowing what is best for the child. To give children actual influence implies to acknowledge their actions and experiences. This is in accordance with Gallagher (2008) who emphasizes that persons can be given agency, whereas to become an independent actor with agency requires some sort of acceptance from the society. Peder's experience and his objections give information about a professional practice. The

professionals do not inform the child about why the adults want to talk alone. They do not ask the boy what he prefers, and thereby it is difficult to see that the child's autonomy is accepted.

Peder's story highlights questions on legislation concerning the child's right to participate and to be heard in decisions concerning the child's health, and concerning the questions of what is in the best interest of the child. In medical matters in Norway, the right to be heard starts at the age of 12 (Sandberg 2009). Younger children have the right if they are able to form their own view. The weighting of the child's right to be heard should increase with age and maturity, but not necessarily with a "greater weight" as in the Children and Parent Act (Sandberg 2009). According to the Patients' Rights Act, the patient has the right to participate in decisions on how to carry out the treatment, while for children below 16 years of age, the parents' consent is necessary. Professionals seeing the child as vulnerable can hinder the child from participating in conversation. The professionals did not ask Peder, or inform him about the reason for excluding him from the discussions on evaluation.

Concerning children with impairments, it can be relevant to think critically about *how* having impairments may reinforce their perceptions of vulnerability. For example, does the child "need" to be protected from hearing the consequence of its own impairment? Wendell remarks the challenges involved in having an open dialog about impairment (Wendell 2001), and the question could be addressed by listening to what children themselves have to say about the topic. Peder's resistance can be interpreted as asking for an open dialog, which can include experience and thought about how he wants to live his life.

Peder, Lisa, and Tom do not like to be reminded of their physical conditions, which might get worse. Being involved in the conversation with the professionals, and contributing with experiences from daily life and with explanations of how they think of themselves, may decrease their vulnerability, and strengthen their self-perceptions of being abled.

Summary discussion

This article presents three children's experiences from participating in paediatric consultations. The children use embodied knowledge to argue for their experiences and the importance of activity, evaluation, and decision-making. The experiences are analysed as knowledge the children have from living with their impairment, which is embodied. Their experiences represent different ways of communicating their identity, and it reflects their experience of professional practice in the specialist healthcare system on children with impairment. Analysing the material reveals that the distinction between attention to physical experience of impairment and social experience of living with impairment is important. Even though experience and daily life activity have received increased attention in the medical rehabilitation system (Langeland and Øien 2008), the children's experiences reveal that attention in consultations is still mainly related to the medical and physical dimension of impairment. The analyses demonstrate that the children's perception of being abled or normal is strongly related to how they experience themselves in daily life with others, and that they want the professionals to consider this experience when judging their physical functioning. Their told experiences are strong arguments for professionals to listen to and talk with children.

The children's experiences, their resistance, and their wishes constitute a critique of the professional practice, and the adult child relationship in paediatric rehabilitation. Too much attention to physical or biological dimensions related to disability in paediatric rehabilitation may narrow the understanding of ability and what is felt as normal for persons (Scheper-Hughes and Lock 1987). Rosemarie Garland-Thomson (2011) uses the concept of *misfit* and the relation between *fit* and *misfit* to describe the floating meaning of *disability* in practice. Garland-Thomson says, "The discrepancy between body and world, between that which is expected and that which is, produces misfits" (2011:593). Especially Lisa and Tom

demonstrate how their own perception of *to fit in* daily life activities is important. To fit in implies to be part of a defined majority, and is crucial for self-perception and identity building for people (Garland-Thomson 2011). In addition, they want to implement their daily life experiences and knowledge of living with impairment into the rehabilitation program. For children with impairment, attending consultations is often a lifelong series of experienced evaluations, from their infancy or toddler age. Therefore, to improve and adapt the encounters to the child's needs, to listen to and see the child as a person with competence to express views and participate in decisions is crucial. The balance between fitting in and not fitting in is negotiable when the professionals listen to the children's opinions and experiences. When misfit is recognised and acted upon, change is possible. Listening to the experienced constraints the children tell about, and acting upon them, may contribute to children's participation in medical decisions.

Children's right to participate in decision-making involves promoting their autonomy and acknowledging their competence. Experience is embodied competence and autonomy. The children state that they want acknowledgement of their feeling normal and functioning well in daily life. The analysis demonstrates how consultations may develop to meet with children's needs through addressing both evaluation of physical impairment and embodied experiences of functioning in everyday life from the child. Listening to the children's stories from participation in consultations opens up for reflections on decision-making, as already discussed; in addition, it also underlines the role of context in studying children's participation. Experience opens up to see individual variation and similarities, and variation related to context.

The article builds on three interviews and cannot be generalised on to a wider population. In addition, these descriptions give content to how children attending consultations may experience participation in consultations, and are relevant for advocating

children's participation in matters concerning their own lives, and for disabled children's participation in decision-making more specifically.

Conclusion

Paying attention to three children's experiences from attending consultations reveals how they experience themselves during consultations, and what they want the professionals to pay attention to. By investigating what they like to talk about or like to do during consultations, the need for improvements in professional practice becomes visible. The analyses reveal that a balanced attention of the child's impairment and the child's social functioning in daily life is important in this context. How the children perceive themselves in daily life reflects what normal life is for them. The material demonstrates that feeling normal or feeling capable in social life is important to communicate to the professionals. This is relevant information for the professionals when planning the child's treatment program. These findings are relevant for the study of children's participation in general, and are relevant to the discussion on children's right to participate in health care decisions, more specifically. It also emphasizes the importance of talking with children.

References

- Bekken, W. 2013. "The role of objects in understanding children's participation in paediatric rehabilitation." *Scandinavian Journal of Disability Research*:1–20. doi: 10.1080/15017419.2012.761155.
- Burman, E. 2008. *Deconstructing developmental psychology*. London: Routledge.
- Capjon, H., and I. T. Bjørk. 2010. "Rehabilitation after multilevel surgery in ambulant spastic children with cerebral palsy: children and parent experiences." *Developmental Neurorehabilitation* no. 13 (3):182–191.
- Cohen, A. P. 1989. *The symbolic construction of community*. London: Routledge.
- Connors, C., and K. Stalker. 2007. "Children's experiences of disability: pointers to a social model of disability." *Disability and Society* no. 22 (1):19–33.
- Cox, E. D., and S. E. Raaum. 2008. "Discussion of alternatives, risks and benefits in pediatric acute care." *Patient Education & Counseling* no. 72 (1):122–129.
- DePoy, E., and S. F. Gilson. 2011. *Studying disability: multiple theories and responses*. Los Angeles: SAGE.

- Gallagher, M. 2008. "Foucault, Power and Participation." *International Journal of Children's Rights* no. 16 (3):395-406. doi: 10.1163/157181808x311222.
- Garland-Thomson, R. 2011. *Misfits: A Feminist Materialist Disability Concept*. Wiley-Blackwell.
- Greene, S., and M. Hill. 2005. "Researching Children's Experience: Methods and Methodological Issues." In *Researching Children's Experiences*, edited by Sheila Greene and Diane Hogan. London: Sage.
- Gulbrandsen, L.M. 1998. *I barns dagligliv : en kulturpsykologisk studie av jenter og gutters utvikling [In the children's daily life: A cultural psychological study of girls' and boys' development]*. Oslo: Universitetsforlaget.
- Haavind, H. 1987. *Liten og stor : mødres omsorg og barns utviklingsmuligheter [Small and large: maternal care and child development]*. Oslo: Universitetsforlaget.
- Hill, M. 2005. "Ethical Considerations in Researching Children's Experiences." In *Researching Children's Experiences*, edited by Sheila Greene and Diane Hogan. London: Sage.
- Hughes, B., and K. Paterson. 1997. "The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment." *Disability & Society* no. 12 (3):325–340. doi: 10.1080/09687599727209.
- Koestner, R., and Gaëtan F. Losier. 2004. "Distinguishing Three Ways of Being Internally Motivated: A Closer Look at Introjection, Identification, and Intrinsic Motivation." In *Handbook of Self-Determination Research*, edited by Edwards L Deci and Richard M. Ryan. New York: The University of Rochester Press.
- Langeland, H., and I. Øien. 2008. "Fysioterapi." In *Habilitering: Tverrfaglig arbeid for mennesker med utviklingsmessige funksjonshemninger [Habilitation: Interdisciplinary work for people with developmental disabilities]*. edited by Stephen von Tetzchner, Finn Hesselberg and Helle Schjørbeck, 291–309. Oslo: Gyldendal akademiske.
- Lock, M. 1993. "Cultivating the body: Anthropology and epistemologies of bodily practice and knowledge." *Annual Review of Anthropology* no. 22 (1):133–155.
- Moore, L., and S. Kirk. 2010. "A literature review of children's and young people's participation in decisions relating to health care." *Journal of Clinical Nursing* no. 19 (15–16):2215–2225. doi: 10.1111/j.1365-2702.2009.03161.x.
- United Nations. 1989. Convention on the Rights of the Child.
<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>.
- Neville-Jan, A. 2004. "Selling your soul to the devil: an autoethnography of pain, pleasure and the quest for a child." *Disability & Society* no. 19 (2):113–127. doi: 10.1080/0968759042000181758.
- Ryan, R. M., and E. L. Deci. 2004. "An Overview of Self-Determination Theory: An Organismic-Dialectical Perspective." In *Handbook of Self-Determination Research*, edited by Edwards L Deci and Richard M. Ryan, 3-37. New York: The University of Rochester Press.
- Sandberg, K. 2009. "Children's right to participate in health care decisions." In *Human rights, dignity and autonomy in health care and social services: Nordic perspectives*, edited by Henriette Sinding Aasen, Rune Halvorsen and António Barbosa da Silva. Antwerpen: Intersentia.
- Scheper-Hughes, N., and M. M. Lock. 1987. "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology." *Medical Anthropology Quarterly* no. 1 (1):6–41.
- Shakespeare, T. 2004. "Social models of disability and other life strategies." *Scandinavian Journal of Disability Research* no. 6 (1):8–21. doi: 10.1080/15017410409512636.
- . 2006. *Disability rights and wrongs*. London: Routledge.
- Shakespeare, T., and N. Watson. 1997. "Defending the Social Model." *Disability & Society* no. 12 (2):293–300.
- Stalker, K., team on behalf of the Guest Editorial, David Abbott, Bryony Beresford, John Carpenter, Roy McConkey, and Nick Watson. 2012. "Researching the Lives of Disabled Children and Young People." *Children & Society* no. 26 (3):173–180. doi: 10.1111/j.1099-0860.2012.00430.x.

- Taylor, S., S. Haase-Casanovas, T. Weaver, J. Kidd, and E. M. Garralda. 2010. "Child involvement in the paediatric consultation: a qualitative study of children and carers' views." *Child: Care, Health & Development* no. 36 (5):678–685. doi: 10.1111/j.1365-2214.2010.01076.x.
- Thomas, C. 1999. *Female forms: experiencing and understanding disability*. Buckingham: Open University Press.
- . 2004. "How is disability understood? An examination of sociological approaches." *Disability & Society* no. 19 (6):569-583.
- Tisdall, E.K.M., 2012. "The Challenge and Challenging of Childhood Studies? Learning from Disability Studies and Research with Disabled Children." *Children & Society* no. 26 (3):181–191. doi: 10.1111/j.1099-0860.2012.00431.x.
- Ulvik, O.S., 2007. *Seinmoderne fosterfamilier: en kulturpsykologisk studie av barn og voksnes fortellinger [Late modern foster families: a cultural psychological study of child and adult stories]*. Oslo: Unipub.
- van Dulmen, A. M. 1998. "Children's contributions to pediatric outpatient encounters." *Pediatrics* no. 102 (3):563.
- Watson, N. 2012. "Theorising the Lives of Disabled Children: How Can Disability Theory Help?" *Children & Society* no. 26 (3):192–202. doi: 10.1111/j.1099-0860.2012.00432.x.
- Wendell, S., 2001. "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities." *Hypatia* no. 16 (4):17.