

**Parents' Perceptions of Physiotherapy in Primary Health Care With Preterm  
Infants: Normalization, Clarity and Trust**

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## **Abstract**

Having a preterm infant is a life-altering event for parents. The use of interventions intended to support the parents is recommended. In this study, we investigated how parents' perceptions of physiotherapy in primary health care influenced their adaptation to caring for a preterm child. We conducted 17 interviews involving parents of 7 infants, at infants' corrected age (CA) 3, 6 and 12 months. The analysis was a systematic text condensation, connecting to theory of participatory sense-making. The parents described a progression toward a new normalcy in the setting of persistent uncertainty. Physiotherapy that provides knowledge, acknowledges the child as subject and the parent-child relationship ameliorates this uncertainty and supports the parents as they progress toward normalization. Via embodied interaction and the exploration of their child's capacity, the parents learn about their children's individuality and gain the confidence necessary to support and care for their children in everyday life.

## **Keywords**

coping and adaptation; embodiment / bodily experiences; families, caregiving; infants, high-risk; physical therapy;

Requested new keyword: participatory sense-making

Having a preterm baby is a stressful event characterized by fears and doubts (Aagaard & Hall, 2008; Brett, Staniszewska, Newburn, Jones, & Taylor, 2011; Campbell, Vander Linden, & Palisano, 2006). Parents often feel isolated from their child during his/ her hospitalization (Aagaard & Hall, 2008). Following hospital discharge, caring for the child can be challenging and a source of stress (Treyvaud, 2013). Preterm infants are often more irritable and exhibit decreased responsiveness and attention capacity compared with infants born at term (Korja, Lehtonen, & Latva, 2012; Treyvaud, 2013; Wolf et al., 2002). Moreover, uncertainty regarding the child's development is likely to be a persistent concern for parents (Benzies, Magill-Evans, Hayden, & Ballantyne, 2013; Moore, Lemyre, Barrowman, & Daboval, 2013). Hence, parental support as part of the assistance offered to these families is recommended (Benzies et al., 2013; Brett et al., 2011; Spittle, Orton, Anderson, Boyd, & Doyle, 2012; Treyvaud, 2013).

Children born preterm are at increased risk for motor impairments; therefore, physiotherapy is an important intervention for these children. Following hospital discharge, children receive physiotherapy via primary health care. It can be either a preventive or a therapeutic service, with the goal of enhancing the child's motor development (Spittle et al., 2012). In accordance with the principles of family centered care, collaboration, partnership and responsiveness to the family's needs are fundamental elements of this type of intervention (Basu, Salisbury, & Thorkildsen, 2010; Brett et al., 2011; Dirks, Blauw-Hospers, Hulshof, & Hadders-Algra, 2011; King & Chiarello, 2014). However, knowledge regarding how parents perceive physiotherapy is scarce.

Previous studies pertaining to parental experience with physiotherapy for preterm infants have demonstrated that although parents appear to prefer interventions that improve their ability to support their child's development, they might also perceive participation in their child's therapy as stressful (Dusing, Murray, & Stern, 2008; Scales, McEwen, & Murray, 2007).

Additionally, parents who receive therapy might perceive their child as being more vulnerable than parents who do not receive these services (Bartlett, Nijhuis-van der Sanden, Fallang, Fanning, & Doralp, 2011). Hence, attention should be devoted to the possible adverse effects of therapy. In a review regarding parental education and support, relationship-directed approaches based on coaching principles appear to be beneficial for parents and result in lowered stress levels, improved self-efficacy and more positive perceptions of their children's abilities (Kemp & Turnbull, 2014).

Other studies regarding parental experience have demonstrated how healthcare providers can contribute to parents' perceptions and management skills (Knafl & Deatrck, 2003; Pelchat & Lefebvre, 2004; Treyvaud, 2013). They describe the parent's adaption to their new life as a process of which acknowledgement of their situation and achieving a sense normalcy are important elements (Deatrck, Knafl, & Murphy-Moore, 1999; Graungaard & Skov, 2007; Pelchat & Lefebvre, 2004; Pelchat, Levert, & Bourgeois-Guérin, 2009; Piggot, Paterson, & Hocking, 2002; Watson, Kieckhefer, & Olshansky, 2006). Furthermore, these studies confirm the need to create a parent-provider relationship, building on the uniqueness of each family and devoting attention to the family's uncertainty regarding their situation and their evolving needs (Deatrck et al., 1999; Jansen, Ketelaar, & Vermeer, 2003; Kruijsen-Terpstra et al., 2014; McLaughlin & Goodley, 2008; Piggot et al., 2002; Watson et al., 2006).

The existing research indicative various ways in which healthcare professionals can influence parents' normalization and adaptation processes. We wish to expand this knowledge by answering the following research question: How do parents perceive physiotherapy in primary health care, and how does said perception influence their adaptation to raising a preterm child? Our study is relevant to both physiotherapists and other professionals responsible for providing early developmental assistance to families with preterm children. Furthermore, this study

contributes to the current debate regarding normalization in families with children with special needs (Deatrick et al., 1999; Knafl & Deatrick, 2003; Knafl, Deatrick, & Havill, 2012).

### *Theoretical Perspective*

In our investigation of parents' experiences with physiotherapy, we utilized the enactive concept of *participatory sense-making* (De Jaegher & Di Paolo, 2007; Fuchs & De Jaegher, 2009). Building on phenomenological insights, neuroscience and dynamic systems theories (Gallagher, 2012), this innovative perspective addresses how individuals understand each other and make sense of the world via interaction. This process entails the comprehension of a mind-body-world entity in which bodily sensations, expressions and actions are essential and incorporate both thought and communication (Fuchs & De Jaegher, 2009; Gallagher, 2009). With respect to physiotherapy, this implies that both therapeutic actions and embodied interactions can contribute to and enter into processes of participatory sense-making (Nicholls & Gibson, 2010; Øberg, Blanchard, & Obstfelder, 2014).

From the enactive view our human way of making sense is deeply embedded in our being in a world that not only surrounds us but also shapes us and is shaped by us (De Jaegher & Di Paolo, 2007). We connect with our world by devoting attention to what we perceive as significant, the items that make a difference in our lives. It is as if we wear significance goggles, through which we gain perspective of our world, of others and of ourselves. Therefore, sense-making is an active process, driven by our previous experiences and interactions with our surroundings. However, sense-making is not only an individual endeavor but is also a group endeavor and an act of participatory sense-making (De Jaegher & Di Paolo, 2007) in which we connect to one another and devote our mutual attention to what we consider significant. Moreover, participatory sense-making is not a static entity. It can be perceived as a scale with individual sense-making at one end and optimal participatory sense-making at the other end (De

Jaegher & Di Paolo, 2007). In everyday interactions, participatory sense-making will move back and forth along this scale, with matching up of attentions and breakdowns thereof. Optimal participatory sense-making can provide participants with new insights. This entails a mutual exchange in which the participants take into account matters significant to the other participants. Additionally, when the sense-making is truly participatory, the control of the process lies not only within each participant but also within the interaction itself, which has its own energy and influences both the sense-making and the actions of the participants (Fuchs & De Jaegher, 2009).

## **Methods**

### *Study Design*

In this study we emphasized lived experience as a means of developing knowledge (Creswell, 2007). We collected data via individual, semi-structured interviews with parents (Kvale & Brinkmann, 2009) at infants' corrected age (CA) 3, 6 and 12 months. CA is the age the infant would be at if born at term; calculated as the chronological age reduced by the number of weeks born before 40 weeks of gestation (Committee on Fetus and Newborn, 2004). There were some deviations because of late recruitment and the cessation of physiotherapy, resulting in a total of 17 completed interviews. Following the principles of the WMA Declaration of Helsinki (World Medical Association, 2013), the study was approved by the Norwegian Social Science Data Services (NSD), which serves as the internal review board for Norwegian universities and research institutes. This study was part of a larger project in which we investigated different aspects of how physiotherapy in primary health care enhances the development of preterm infants and the parents' ability to care for and support their child.

### *Participants and Recruitment*

This study was performed in Norway, where the health care system is well developed (World Health Organization, 2000). Based on a preterm child's motor development, gestational age and

weight at birth, either hospital personnel or public health nurses will refer the child to physiotherapy. Because physiotherapists participate in frequent follow-up visits with these families, they play an important role in monitoring the child's development and are often involved in uncovering additional needs for both the child and the child's family.

Nine strategically selected parents of seven preterm infants, including one set of twins, were included in this study. Hospital physiotherapists distributed participation inquiries to families who received primary health care physiotherapy. The infants' parents provided written consent via mail. Once informed consent from parents was provided, Håkstad obtained informed consent from the family's physiotherapist. The participants had no prior contact with the researchers.

For all but one family, the preterm infant was the parents' first child. There was great variability in the children's motor function, ranging between no apparent motor delays and CP characterized by severe impairment. The mothers of all of the children and the fathers of four of the children were represented. The sample provided a variety reflective of Norwegian primary health care, where families can receive physiotherapy both as a preventive and as a therapeutic service; and both maternity and paternity leave are accessible via the Norwegian Labour and Welfare Organization (NAV).

#### *Data Collection*

The interviews were conducted by Håkstad, either in the family's home or in a private area at the physiotherapist's location. The interviews ranged from 19 to 89 minutes in length, with the majority of interviews lasting 46 to 68 minutes, with a mean of 60 minutes. All interviews were audio-recorded. The interview guide utilized the following five themes: a) Talk about the child, b) Today's physiotherapy session, c) Physiotherapy in general, d) Experiences from birth – present time, and e) Future priorities. The same interview guide was used for all interviews;

therefore, individual topics were discussed in separate interviews. Within this structure, the interviewer strived to allow the parents to choose the topics they most wanted to discuss and to share their opinions freely (Kvale & Brinkmann, 2009). In preparation for the second and third interviews, the previous interviews were reviewed, and follow-up questions were developed regarding the topics emphasized by the parents, or the topics for which clarification was needed. Across the interviews, we observed a variety with respect to the content of the conversations, which indicated that the parents were able to influence the direction that the interviews took.

Eleven interviews were conducted with only the mother present, three were conducted with only the father present, and three were conducted with both parents present. Whereas the interviews with a single parent allowed for an exploration of parents' individual experiences, the parents who interviewed together gave a picture of the commonalities and differences in both their experiences and their coping strategies. However, we did not emphasize parental mutuality (Knafl & Deatruck, 2003) or gendered differences (Graungaard & Skov, 2007) in our analysis. Rather, we treated the differences among interviews as varying and contrasting descriptions of the parents' experiences (Kvale & Brinkmann, 2009).

In general, the parents were cautious when sharing critical feedback regarding their physiotherapists. When the researcher clarified that any feedback shared during the interviews would be treated respectfully, the parents became more open with their answers.

### *Data Analysis*

Data collection and the initial data analysis overlapped in time; therefore, the data analysis influenced both the focus and the development of the subsequent data collection. The interviews were transcribed verbatim. Additionally, a summarizing text of each interview was generated, a text that included the researcher's impressions and reflections. In the analysis we applied a systematic text condensation approach (Malterud, 2012), with QSR International's NVivo 10



software used as a sorting tool (QSR International Pty Ltd, 2012). We initially searched for themes that emerged from the data, allowing issues that appeared to be significant for the parents to come to light. The next step entailed a detailed coding characterized by the collapse of codes and subthemes and the subsequent condensation of meaning within each theme, resulting in the themes presented in the results section. This was primarily an inductive approach, but theoretical deductions guided the process. We recognized a variety of descriptions, which indicated richness of the material; however, tendencies of repetition at later stages indicated saturation of data (Kvale & Brinkmann, 2009; Malterud, 2001). Håkstad was in charge of the transcription, summarizing and coding, and met regularly with Øberg and Obstfelder to ensure the validity of the findings and interpret the data.

### *Reflexivity*

Both Håkstad and Øberg are experienced pediatric physiotherapists, in primary and secondary health care, respectively. Thus, they share a proximity to the field of investigation which has had an impact on preconceptions, angling of investigation and data interpretation (Malterud, 2001). They also share an interest in the use of interactive processes during physiotherapy. Obstfelder has a background in nursing and sociology and also shares said interest; however, she has challenged established positions within the investigated field throughout the research process.

## **Results**

### *Adapting to the New Life with a Preterm Infant*

The parents in this study were eagerly engaged with how they had learned and still could learn to cope with having a preterm child. The following text describes how the parents attained a sense of normalcy in spite of the changes to their lives. This yearning for normality was a complex process in which their perception of their child and their acceptance of the situation intertwine

and represent the building blocks of a new life. However, the uncertainty surrounding their child might disrupt their pursuit of normalcy.

*Adaptation via normalization.* The return to everyday life represented a pivotal portion of the parents' stories. The perception of having a normal child played a crucial role in this process. The parents illuminated different dimensions of this perception at different stages. During the first months, the removal of medical equipment such as monitors, feeding tubes and oxygen enabled the parents to gradually leave behind the impression of an ill newborn, as one parent said: "When you think back now, that we've been to the hospital and through all that, it just seems surreal, kind of. . . . Because to me, she no longer appears like a hospital baby anymore." During the later stages, monitoring of the child's development fed into the parents' perception that their child was normal. The appearance of age-appropriate motor and cognitive skills were encouraging signs, as follows: "For every milestone we reach, big or small, it is, it contributes to lifting us a little. . . . So I guess it is those things, those small things, yet in sum are really precious."

The children's parents emphasized that in spite of the infant's delays or impairments, their child was normal to them. Given that no obvious signs of pathology were observed, the parents were not concerned with the minutiae of normal child development. Even in the setting of pathology, the perception of their child as normal was crucial to the parents. Recognizing that the child will have to live with some level of impairments, normalcy now entailed accepting the child. One parent shared the following:

Because to me it doesn't matter what he's like; I'm thinking about him; he's the one who's going to live this life. . . . I can carry him back and forth and anywhere it might be, so to me it doesn't matter, but for his sake.

The parents struggled to learn about their child and to gain the perception of their child as normal to them. However, uncertainty about the future might disrupt this process.

*Dealing with uncertainty (and certainty).* The parents expressed their uncertainty about the future in multiple ways and were aware that these concerns will persist for several years. One parent shared the following:

At first you are scared; will the child come home at all, kind of. And then scared that she will come home, but with massive injuries. And then it is kind of what challenges will she face; will she be late; will she be able to run and play; can she attend kindergarten and interact with them, with peers her age, in a normal way? Will she sort of make friends; will she be able to concentrate in school? There is kind of a very large spectrum of possible problems.

Different strategies helped the parents to cope with their thoughts regarding their child's future. They emphasized the advantages of being patient and positive, as well as the necessity of understanding the potential risks facing their child. Close monitoring of the child and the opportunity to address questions regarding the child's development were both crucial elements in the parents' ability to tackle their concerns. Nonetheless, the situation remained challenging, as the following parent described:

No that is the problem right, being stuck in that uncertainty; that is the hard part. . . . It gets pretty exhausting, when you're still in that grey zone where you try to move on, but we haven't really been able to.

In cases in which a child was diagnosed with CP, some certainty existed. Coping with this certainty, however, was a separate issue, in which finding meaning to having a child with special health care needs seems essential. One parent explained:

I don't know; I at least feel privileged to have him in a way. Whatever shape he came in, I kind of feel even more privileged to get someone who needed me. . . . It is not something you have to do; it is something you get to do.

The parents faced uncertainty for multiple reasons and for extended periods of time. Moving beyond this uncertainty appears to be tied to the parents' ability to understand and find meaning in their situation.

#### *Physiotherapy as a Resource in the Building of a New Life*

In their progression toward normalcy, the parents perceived physiotherapy as a potential guiding resource. Provision of clear information influenced the parents' ability to understand how to care for their child and instilled the confidence necessary for them to do so. The parental coping abilities relied on a therapeutic approach focused on learning about and interacting with their child. This learning process became part of the parents' everyday day interactions with their child.

*Clarity – If we get to hear it, we can bear it and address it.* The parents were unanimous in their desire for clear information from healthcare personnel. They wanted to be prepared for possible negative outcomes for their child; however, they also wanted to remain optimistic about their child's development. Although the future was unpredictable, parents wanted to know healthcare professionals' thoughts, as the following parent explained: "It's really nice when someone dares to say 'I think; I don't think; we can't guarantee, but we don't think' . . . that

nuance there has a lot to say for letting your worries go.” Vague responses and limited explanations could leave the parents feeling helpless, as the following parent described:

There is nobody telling me what might happen, what will happen, what is possible, nothing. . . . What is sort of the worst case, and what is the best case, they don't say anything about that. . . . Because when you read about the likelihood of the different things, you wonder, when she today is considered healthy, that is what they often say; 'looks like she's healthy, can't see anything'. But does that mean that all of a sudden something will appear, a sign of CP? Sort of when, and in what way does it appear? We don't know that.

In cases in which the child was likely to have CP, there was little use in withholding information, as the following parent explained:

They wanted to wait until the 9-month consultation, because it was such a negative word, as they said. I said, “You, are you sure he has CP?” “Yes.” “Then write it down”, I said. . . . It doesn't get any worse just because you say it out loud.

The parents emphasized, however, that clear messages had to be conveyed with caution. They were appalled by situations in which bad news appeared to be taken lightly. They expected healthcare personnel to be empathetic and spend time talking with them.

Regarding physiotherapists, in particular, the parents demanded concrete feedback. Although much about the child's development was unknown, parents nonetheless wanted their physiotherapist to help them understand what normal development entails for a preterm infant compared with infants born at term; including the motor skills that have developed appropriately and the motor skills that are either delayed or absent. For the parents, answers to such questions

were necessary if they were to understand and assist with their child's development. Frustration arose when physiotherapists provided evasive responses, as follows: "They talk very generally. I would have liked more of, "He does this, but not this. Then he has to work on that"." However, honest insights and thoughts were greatly appreciated, as follows:

They were very direct . . . and to me that works. I think it should be like that. . . . I don't think anything should be tucked away. . . . You have to prepare for the worst and hope for the best.

The parents expected both clarity and honesty from healthcare professionals, including their physiotherapist. They depended on healthcare professionals' insights to understand their child's development and the range of possibilities for a largely unknown future.

*Finding the child during therapy.* The parents had different experiences with respect to how physiotherapy contributed to the discovery of their child. Some of the parents believed that being involved in therapeutic assignments helped them to better understand their child's capabilities, as the following parent explained:

It is kind of one of the few places where she, where you're challenging her in a way, and not just, not just nurse her, kind of. And it is a good way to, in a way, well get, or at least some help to approach her, I think. . . . That you, yes it kind of gets a touch of normalcy.

Conversely, the parents also recounted situations in which the physiotherapists failed to recognize or acknowledge progress in their child's development, leaving the parents feeling dispirited. Similarly, some of the parents perceived that their child was treated as a marionette, and was moved around by the physiotherapist. One parent shared the following:

I very much feel that she has really been like a marionette, yes, but seriously, she has been a marionette, and it has been about triggering certain parts on her; it has been like in here, there, up, stand right there, park right there.

An additional issue mentioned by the parents was their frustration with situations in which the physiotherapist appeared to be focused on minute details regarding motor function that the parents perceived as irrelevant, as the following parent explained:

They started to see that he was using the wrong muscle groups. . . . It kind of sounded a bit strange when we were told about it. . . . Had it been a term baby, he wouldn't get that [physiotherapy, our insertion]. And then maybe that term baby would also have used the same muscle groups, and it wouldn't have been anything wrong, either. . . . There is nobody to see it, because there are no experts looking. . . . And they turn out to be people, too. Ha, ha, so if it takes a little while until they use just the right muscles, that's not something we emphasize.

Based on these findings, the approach utilized by the physiotherapist played a crucial role in the parents' perception of the physiotherapy sessions as activities of learning, development and engagement. They wanted therapy to teach them about ways to be with their child, and they required acknowledgement of their child's progress.

*Handling the child in everyday life.* When the parents talked about what they had learned from the physiotherapist, they referred to such as tips, activities or adjustments to their child's environment that they applied to everyday life. However, when asked to elaborate further regarding these subjects, they described a large number of techniques intended to stimulate

specific motor functions, as well as extensive exercise routines that they utilized on a daily basis. A parent shared the following: “And then we have two hours on the floor. And it is during those two hours that we get through everything.” Although the activities took up much of their time, the simplicity that they conveyed appears to indicate that they do not consider the activities to be forms of either training or exercise. Rather, the activities are incorporated into their everyday way of being with their child, as the following parent explained:

She follows her own pace, and we just support her and help her to get where she wants. . . . There is no use trying to force anything or change anything, so it is just help to support her and know that we are doing it right.

The means by which the parents incorporated these skills appeared to differ, however. Whereas some parents described the process as something that happened intuitively, others depicted a more systematic approach; in which they dedicated their time and effort to a learning phase, aiming to integrate treatment principles into a playful setting for their child. Irrespective of these differences, all of the parents stated that the process of learning how to support their children’s motor development provided them with both reassurance and confidence with respect to their handling of their children. Moreover, it gave them hope for the future, as the following parent explained:

It is because we want her to have the best conditions possible in life, right? And, of course, everything we do is sort of to help her with that. And then I think that nothing is too much, kind of.

The parents’ trivializing of how they learned to handle their child via physiotherapy harkens back to their initial descriptions of adapting by gradually achieving a sense of normalcy.



However, this section demonstrates that normalization is also about building confidence and hope for the parents, in which the incorporation of handling skills into their everyday routine reassures them that their child is receiving the best possible support.

## **Discussion**

Our analysis demonstrated that the parents of preterm infants are hopeful about the future but also accept the uncertainty surrounding their child's development. Physiotherapists provide parents with knowledge regarding their child's development, as well as the opportunity to discover and develop the skills necessary to interact with their child. Being provided with information and becoming involved in therapeutic activities enables parents to better understand their child's development and how they can support their child. When this process fails, however, parents are often frustrated and less able to recognize the benefits of physiotherapy.

### *Uncertainty is the New Normal*

The parents' search for normalcy represents a means of making sense of their situation; a sense-making that revolves around their ability to perceive their lives with their children as ordinary. This phenomenon is better known as adaptation or normalization (Deatrick et al., 1999; Pelchat et al., 2009); a process in which parents need to accept a new identity with their preterm child, not knowing whether the child will have impairments or not. To establish this identity, understanding the child is of paramount importance and enables parents to acclimate to their new lives. However, uncertainty regarding their child's development might threaten the parents' progression toward normalcy (Deatrick et al., 1999). Certainty, even regarding negative outcomes, is helpful because it provides parents with the necessary knowledge to understand and care for their child. In other words, certainty can facilitate sense-making, whereas uncertainty might hamper sense-making for parents. This idea is supported by the studies by Piggot et al (2002) and McLaughlin and Goodley (2008), in which normalization was found to be closely connected with parents'

abilities to build a vision of their child's future. For the parents of preterm infants, persistent uncertainty regarding their child's development might adversely affect this vision.

Learning about and building a relationship with their child via interaction appears to ameliorate this uncertainty. Interaction provides the parents with personal, embodied knowledge about their child that supports their sense-making. The child's individuality and capabilities emerge through these interactions and create a perception of normalcy for the parents, regardless of the child's medical condition. However, this normalcy does not necessarily entail observing progress or the acquisition of new skills. Rather, these intersubjective connections and interactions between the parents and the child appear to be more significant for the parents of children with more profound developmental problems. For these parents, their relationship and interactions with their child become reliable sources of information and enable them to perceive their child as both capable and normal. The interactions allow parents to look beyond their child's impairments and to trust their child's abilities. Nonetheless, for all parents, uncertainty will most likely persist and must be addressed as a means of shaping each parent's reconstructed vision of the future (Deatrick et al., 1999; McLaughlin & Goodley, 2008).

### *Making Sense of the Child*

As the parents strive toward normalcy, they expect the physiotherapists to provide them with professional knowledge regarding their child's development. However, parents often perceive both physiotherapists and other healthcare professionals as evasive with respect to sharing of information. This evasiveness can be attributed to several factors; the healthcare professionals might be uncertain about a child's development (Watson et al., 2006) or might not believe they are qualified to manage specific issues or situations (Pelchat & Lefebvre, 2004). This behavior might result in a disconnect between the parents and the therapist, in which vague responses and deviating attentions impede the parents' learning about the child's development. Therefore, the

sense-making becomes less participatory (De Jaegher & Di Paolo, 2007). By contrast, there are scenarios in which the physiotherapists are more open about their opinions, even if their knowledge of the child's development is limited. These instances of mutual attention to and clarification of future expectations facilitates participatory sense-making between parent and physiotherapist.

Similarly, clarity can also be communicated via actions during the therapy sessions. Regarding the parent who compared his child with a marionette, our impression is that the positioning of the child's body and the elicitation of specific movements occupied the bulk of the physiotherapist's attention. However, many parents do not find this approach to be relevant. Likewise, the dismissal of the physiotherapist's focus on specific muscle groups is also illustrative of discrepancies in the focus of the physiotherapist and the parent. These physiotherapists appear to consider only the child's motor skills and development, as opposed to thinking of the child as a person. This contrasts with the parents' perceptions of their children as individuals and enactors in the world. Because of these differences in what is perceived significant, the opportunities for participatory sense-making are limited. Nonetheless, these instances do not represent a rejection of the physiotherapist's knowledge, parents rely on said knowledge to understand their situation and subsequently progress toward normalcy. However, this understanding must not be based solely on an objective view of the child's motor function. Physiotherapy must address the child as a whole (McLaughlin & Goodley, 2008) by incorporating the child as enactor in and of the world. The therapeutic approach must accentuate the child's individuality and consider treatment strategies in relation to their applicability in everyday life for both the child and the child's parents.

Making sense of the child can therefore be viewed as a negotiation between the parent and the physiotherapist; a negotiation of what each party perceives as significant, as a means of

helping parents adapt to their new lives caring for a child that they understand and are comfortable supporting. When physiotherapists fail to share their professional knowledge, both verbally and via therapeutic actions, in a way that makes sense to the parents, the physiotherapy sessions appear less relevant and might impede the normalization process. Therefore, physiotherapy can be both a negative and positive contributor to parents' abilities to manage their situation (Knafl et al., 2012), as demonstrated via the enactive view. The physiotherapist's ability to connect and respond to the parents' concerns is crucial in the parents' discovery of their child via therapy and pursuit of a new sense of normalcy.

### *Building Competence and Confidence*

The physiotherapists' sharing of opinions and therapeutic approaches can serve as important sources of information for parents, enabling them to comprehend their child's condition and understand their child as individual. This idea resonates with the study by Watson et al (2006) regarding therapeutic relationships, which demonstrated that care providers are important contributors to the normalization process. This contribution is based not only on verbal conversations but also on "reading cues" such as facial and body expressions (Watson et al., 2006). We further the interpretation of these signals to be not merely cues, but fundamental, enactive means of connecting with and interacting with others.

One such example involves the parent who stated that challenging the child in therapeutic activities contributed to her sense of normalcy. These therapeutic assignments, in which embodied "reading of cues" are incorporated, serve as an opportunity for the mother to perceive her child as a capable individual. A participatory sense-making provided by attention toward the child's body expressions, embodied coordination and interactional engagement; enables an exploration of the child as an enactive being, interacting and engaging with the surrounding world. Moreover, in addition to discovering their child's capabilities, the parents also learn about

their ability to challenge their child in ways that differ from familiar nursing approaches. The active involvement of the parent is a key ingredient in this process, as is a therapeutic approach that acknowledges and supports the dyadic interplay between the child and the parent. By contrast, a parent who is relegated to observing the therapist-child interaction is deprived of the opportunity for an embodied connection and learning. Therefore, therapeutic approaches that focus on body cues, embodied interactions and exploration of the parent-child relationship are more likely to facilitate parental learning. The involvement in therapeutic activities enables parents to believe that they are doing something for their child, which instills confidence and leaves them better equipped to cope with their situation (Graungaard & Skov, 2007).

As therapeutic activities are explored and learned, they gradually become incorporated into the parents' interactions with their child. Whereas some parents perceived this as an intuitive process, others utilized a more systematic learning approach. Regardless of their learning strategy, however, it is crucial that this becomes an integrated, embodied knowledge that instills the parents with confidence regarding their ability to support their child. Therefore, physiotherapy is not limited merely to exercises or assignments that the parent and child must complete together, but entails a learning of ways to interact with the child. Understanding what the child needs becomes an embodied knowledge of how to interpret and coordinate to the child's bodily signals. This use of embodied dialogue enables the parents to learn about their child's individuality and capabilities, as well as their own ability to care for their child. They are building competence in their daily routines with their child, which improves their sense of normalcy and attenuates the perceived burden imposed by physiotherapy (Deatrick et al., 1999; Graungaard & Skov, 2007; Knafl & Deatrick, 2003).

### *Implications for Practice*

The findings of our study indicate that physiotherapists and other healthcare professionals might enhance or hamper the process of normalization within which the parents of these preterm infants were engaged. Healthcare providers should be aware of and find ways to contribute to parents' adaptation and normalization processes. Such an exercise requires sensitivity regarding the parents' concerns, as well as both clear and honest but thoughtful sharing of information and dialogue with families. Regarding physiotherapists, in particular, problem-oriented therapeutic activities might appear meaningless to the parents. Evaluations of a child's motor skills and development in conjunction with specific and effective treatment techniques represent the core of physiotherapy. Nevertheless, therapists must also recognize the child as a person and acknowledge the importance of the parent-child relationship, interacting with both the child and the parent as enactive beings.

### *Study Limitations*

In this study, we have investigated the experience of physiotherapy services for parents with preterm infants. The findings on parents' normalization processes are relevant across a variety of health care settings; however, the contribution of different service providers in these processes will depend on the content and outlining of assistance for each individual family.

Following the families described in this study for a period of nine months has enabled us to recognize changes in their adaptation and normalization processes. However, because both theoretical and clinical studies have demonstrated that parents' experiences and perceptions are likely to evolve with time (Knafl et al., 2012; Kruijsen-Terpstra et al., 2014), it is important to note that our findings are related only to the infants' first year of life.

### *Suggestions for Future Studies*

This study was based on interviews with parents. Observational studies of clinical encounters can expand both clinicians' and researchers' knowledge of how physiotherapy contributes to the adaptation and normalization processes for parents of preterm infants.

### **Conclusion**

Parents' adaptation to life with a preterm child entails finding a sense of normalcy in the setting of persistent uncertainty. To attain this normalization, parents must acquire knowledge regarding their child's development and reconstruct their visions of probabilities and possibilities for the future. Furthermore, they must be confident in their ability to handle and support their child. Via bodily actions and interactions, physiotherapists have a unique opportunity to support this normalization process. Building on the individuality of the child and the parent-child relationship, physiotherapists can facilitate a mutual exploration of a child's capabilities and interactional skills, contributing to parents' relationships with and perceptions of their child; not as a preterm infant with special needs that they are familiar with, but as an individual developing his/her selfhood via interactions with the world.

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