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The Core of Parents' Main Concerns When Having a Child With Cataract and Its Clinical Implications

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ABSTRACT

Purpose: To investigate the main concerns associated with being a parent of a child with cataract and how the parents deal with these concerns.
Design and method: Twenty-three parents; 6 mothers, 5 fathers and 6 couples with a child with cataract were included in this study. The parents included some with a personal experience of cataract and some without. Data was collected through 17 in-depth interviews, which were recorded and transcribed verbatim for analysis by the method of Grounded Theory developed by Charmaz.
Results: The Grounded Theory describes the parents' efforts to balance the child's inability and ability in order to maintain their social functioning and lead a normal life through a process comprising four main categories; *Mastering, Collaborating, Facilitating, and Adapting*. This process makes the path of transition evident, starting when the child is diagnosed and continuing for several years during her/his growth and development.
Conclusion: The core of parent-child interaction is mastering the balance between the child's disability and ability in order to achieve the best possible outcome, visually and habitually. The interactions changes through a process towards adjustment and acceptance. All the parents emphasized that you do what you have to do to achieve a successful visual outcome of the child.
Clinical implications: The model provides a comprehensive understanding of parental self-management that can be used by a case manager, preferable a nurse, to pilot the parents through the process.

Introduction

Having a child with a congenital cataract is rare but very demanding for the parents. The shock of having a child with a condition most people associate with older people throws the parents into a world of uncertainty and demands. If not treated, the eye with the cataract will become blind, requiring early surgery (within three months) followed by many years of visual training through patching, contact lenses, and/or glasses.

With an incidence of 1–3 per 10,000 live births, congenital/infantile cataract is a rare, but sight-threatening condition if not treated (Foster & Gilbert, 2003). In Sweden, 40 children are diagnosed with a cataract every year. The most severe cases of congenital cataract require surgical intervention and very early treatment (Haargaard et al., 2015). The etiology behind unilateral pediatric cataract is usually isolated sporadic incidents and can be associated with ocular abnormalities. Bilateral cataracts are often inherited and associated with other diseases. A study by Magnusson et al. (2002) shows that less than half of all children who have undergone bilateral surgery in western Sweden achieved sufficient visual acuity to obtain a driving license (Magnusson et al., 2002). For unilateral cataracts, good visual acuity (0.2 or more) was only achieved in children who underwent cataract surgery by the age of 3 months and who adhered to the occlusion therapy schedule (Lundvall & Kugelberg, 2002). After surgery, occlusion therapy is often prescribed to enhance vision in the affected eye, but can be extremely demanding for both children and their parents. Some children become completely passive and apathetic, while others become frustrated and angry (Dixon-Woods, Awan, & Gottlob, 2006; Koklanis, Abel, & Aroni, 2006). Occlusion treatment is often prescribed for several hours/day for many years during childhood, making the parents responsible for the outcome of the treatment and causing dilemmas and tensions in the family. These tensions can affect the relationships in the family, as described by the family function system theory (Benzein, Olin, & Persson, 2015; Persson & Benzein, 2014; Wright & Leahey, 2013). Research shows that when having a child with a disability, parents experience grief related to the loss of an expected future. Also, early diagnosis may have adversely affected parents ability to get to know their newborn without worry or sadness (Gilliver, Ching, & Sjahalam-King, 2013).

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Responsibility for the treatment lies mainly with the parents, which is implicit in healthcare today. Little is known about the process of change experienced by these parents when their child is diagnosed with a cataract. Previous research reveals that parents desire more information (Gyllén et al., 2015; Rahi, Manaras, Tuomainen, & Hundt, 2004; Rahi, Manaras, Tuomainen, & Lewando Hundt, 2005; Speedwell, Stanton, & Nischal, 2003). Also, for the parents of children with disabilities, the sense that they make of their situation plays a pivotal role in determining how parents experience the impact of disability and the help for need and support (Whiting, 2014). Parents also worry about their child's visual progress, something happening to the non-affected eye and if they are doing enough to promote visual progress (Castaneda et al., 2016).

This study stems from the assumption that human beings are social and interactive by nature. Parents of children with a cataract exist in a social context with or without a number of close relatives. In order to improve current clinical practice, the aim of this study was to investigate how parents deal with the main concern associated with being a parent of a child with a cataract.

Design and methods

We chose to work inductively using Grounded Theory (GT) according to Charmaz (2014).

The focus of this study was the parents' experienced process of change in their interaction with their child with a cataract within their family and social context from the time that the child was diagnosed with a cataract until the interview. Thus, this is a study about the parents' experiences of interacting with their child with a cataract expressed through in-depth interviews. No observations of the parent-child interactions were performed. The constructivist model enabled the researchers to theorize on the informants' interpretation during the interview. Our pre-understanding stems from long experience of caring for children with pediatric cataract and their families as well as from many years of conducting qualitative research. During the whole research process we strived to be open to the informants' main concern. The constructivist approach resulted in a deeper understanding of the main concern one of which was trying to balance the child's inability and ability in order to achieve the best possible visual outcome.

Selection and recruitment

Inclusion criteria were parents of a child diagnosed with pediatric cataract that had been operated on at one of the two hospitals in Sweden appointed by the Swedish National Board of Health and Welfare to perform National Specialized Medical Care of children with a congenital cataract and who could verbally share their experiences. Interview data collection was conducted between 2016 and 2017 in the form of interviews at a place chosen by the parent. The parents were sent information about the study and asked to return their written consent if they were willing to participate. The selection was performed in a step-wise fashion:

1. The first step involved adopting a so-called "*point of departure*", in which we defined the informants and inclusion criteria based on previous research, our clinical experience, and accessibility, which resulted in the initial three interviews with mothers and one couple. When interviewing the couple a gender difference was observed concerning the father's more salutogenetic approach to the child's disability.
2. The second step comprised the focused selection. Here, the authors also wished to gain a clear understanding of the fathers' main concern as they were a part of the emerging phenomenon, resulting in five interviews with fathers.
3. The third and final step was the remaining four interviews with the couples and two mothers. This theoretical selection was based on the notion that there seemed to be gender differences in the emerging model that we wished to expand on by interviewing fathers and mothers in the same family together. These insights were used to modify and achieve saturation in the emerging model.
4. In order to achieve saturation we invited a mother, a couple and a father to validate the model that had been developed into a theoretical construct and to elaborate on our conceptualization of the findings. The mother in the sixteenth interview and the couple in the seventeenth interview had vast experience of caring for a child with a cataract, hence these interviews were included in the analysis. Finally one father was re-interviewed with the aim of validating the model.

The first validation interview with the mother resulted in re-labeling of the second main category. After the changes, the model was tested again by the couple and the father, who all agreed with it. The process ended here as the model had been verified and theoretical saturation occurred, i.e., no new sub- or main categories emerged from the interview data.

A total of 23 parents of a child with a cataract, six mothers, five fathers and six couples, with a mean age of 39 years (range 33–46 years) were included in this study (Table 1), of whom three had personal experience of having cataract. In most families there were siblings, not having a cataract. Interview data was collected through 17 in-depth interviews, which were recorded and transcribed verbatim for analysis by the Grounded Theory method developed by Charmaz (2014). After written consent had been obtained, the interviews were performed in a location and at a time chosen by the informants, i.e., at the hospital ($n = 4$), in their own home ($n = 7$), via the telephone ($n = 2$) or in a public setting, e.g., library, café ($n = 4$). No parent was excluded or declined participation after the initial contact.

Data collection

The informants were asked to recall thoughts, emotions, and actions from the time their child was diagnosed with a cataract up to the present. The open-ended interviews lasted on average 50 min (range 22–87 min) and were recorded with a digital voice recorder. The recordings were transcribed verbatim after each interview.

Ethical approval was obtained from the Regional Ethical Review Board (No. 746-14).

Data analysis

Following the recommendations of Hallberg (2010) and Glaser (1998), we first established whether previous studies with a GT approach and similar aim had been conducted within this particular context. No such study was found. Secondly, initial line-by-line coding was performed by the interviewer to find words or phrases indicating important categories, qualities or contexts related to the research question (Charmaz, 2014). Memos about each interview were logged, including reflections that emerged during the analysis and coding processes. In order to detect and perhaps explain the most significant codes, the third step involved focused coding, which illuminated the main concern. In turn, theoretical coding performed in collaboration between two of the authors, revealed relationships between the codes generated from the focused coding. The constant comparative method (CCM) (Charmaz, 2014) was used simultaneously on interview data, codes, and categories. The interviewer who performed all interviews is a clinical nurse specialist at the pediatric ophthalmology clinic who had no caring relationship with the informants. In line with Charmaz's constructivism (Charmaz, 2014), the categories and theory were developed from the patterns revealed by the researchers' theoretical constructions of the parents' subjective experiences.

Table 1
Demography.

nr	Parent	Age	Age	Child	Laterality	Age at diagnosis	Age at interview	Location of interview	Parent had cataract
1	Mother	39		Daughter	Bilateral	6 months	1,5 years	Hospital	No
2	Mother	42		Daughter	Unilateral	1 week	8 years	Hospital	No
3	Mother	41		Son(s)	Bilateral (both)	1–2 years	5 and 7 years	Hospital	Yes
4	Couple	39	41	Son	Bilateral	1 week	10 years	At home	No
5	Father	33		Son	Unilateral	6 months	2 years	At work	No
6	Father	33		Daughter	Bilateral	1 week	6 years	Cafe	Yes
7	Father	38		Daughter	Unilateral	2 months	7 years	Telephone	No
8	Father	46		Daughter	Unilateral	1 week	9 years	Telephone	No
9	Father	34		Daughter	Unilateral	1 week	4 years	Hospital	No
10	Couple	42	42	Son	Bilateral	1 week	11 years	At home	No
11	Couple	40	41	Daughter	Bilateral	4–5 years	10 years	At home	No
12	Couple	45	51	Daughter	Bilateral	1 week	8 years	At home	Yes
13	Couple	37	38	Daughter	Unilateral	1 week	4 years	At home	No
14	Mother	38		Son	Unilateral	1–2 months	8 years	Library	No
15	Mother	39		Son	Unilateral	1 week	4 years	At home	No
Testing the model									
16	Mother	37		Daughter	Unilateral	1 week	5 years	At work	No
17	Couple	33	32	Son	Unilateral	1–2 months	3 years	At home	No
18	Father	38		Daughter	Unilateral	2 months	7 years	Telephone	No

Results

The core category ***balancing the child's inability and ability*** summarizes a process whereby the generated Grounded Theory contains the four main categories; ***mastering***, ***collaborating***, ***facilitating***, and ***adapting***. Through this process a clear path of adaptation is evident, starting with the child's diagnosis and continuing for many years during the child's growth and development. Additionally, the main categories contain several subcategories revealing the strategies used to achieve a balance. An outline of the results is presented in Table 2 and Fig. 1.

The common denominator was the active efforts of all parents to promote the best possible outcome for their child diagnosed with a cataract. As a parent, one does what is necessary to achieve the best treatment outcome and an everyday life that functions and promotes the child's autonomy and abilities. There was an overall salutogenic driver of this process to maintain a balance between the child's inability and ability, i.e., the focus was more on health than illness and abilities rather than disabilities. However, clear gender differences were evident where fathers predominantly focused on health, goal setting, and the child's performance accomplishment while mothers were generally worried more about the child's inability and future consequences. The need to master emerged immediately on hearing the diagnosis, as the parents were overwhelmed by the child's visual inability and the unknown consequences. As the prognosis became clearer, the parents often chose to view their child as healthy, feeling grateful for her/his abilities instead of focusing on the visual inability. The treatment places many demands on parents and collaboration is essential. Parents often chose to see everything as normal as possible, hence they maintained structure, continuity, and played down the impact of the inability. A functioning family life despite the child's visual inability was important throughout the whole treatment process, demanding extensive parental facilitation. The parents finally balanced their expectations and learned how to adjust their everyday life in order achieve an optimum balance between the child's inability and ability at various developmental stages in her/his life. When this optimum level was fairly well maintained, the parents achieved self-efficacy and acceptance became a part of their everyday family life.

> "*Things could be much worse. One needs to reflect on the fact that it could be much worse. She can actually manage without one eye. We will do everything to make it work, but even if it's not working, she is not blind. She has a healthy eye*!"
>
> [(*Mother of a daughter diagnosed in the first week after birth*)]

Each of the four main categories contains various subcategories that illustrate the different strategies used in the process.

Mastering

Immediately after receiving the diagnosis, often the within the child's first week, the parents started ***seeking knowledge***. They tried to comprehend by searching on the Internet, posing questions to healthcare professionals, and realizing that it was necessary to ***trust*** the ophthalmological team. The most common mastering strategies were ***being optimistic*** and ***making choices*** regarding mastering strategies, treatment options, and how to manage the child's first phase of life. The parents soon realized the importance of ***creating structure and continuity*** in order to manage their care giver burden. It was a matter of remaining focused, feeling optimistic, and acknowledging the fact that everyday life actually worked from time to time. During the intense phases of occlusion treatment the mastering strategy of choice was ***staying determined*** and focusing on the possible success of the treatment. The ability to remain determined and master in various ways with the occlusion treatment and lenses was hampered by set-backs

Table 2
Model of the Grounded theory Balancing the child's inability and ability anld its' underlying categories.

Core category	Balancing between the child's inability and ability			
Main categories	Mastering	Collaborating	Facilitating	Adaptation
Subcategories	Seeking knowledge Trusting professionals Being optimistic Making choices Creating structure and continuity Staying determined	Accepting Adhering Keeping appointments Performing the treatment Staying patient and persistent	Paving the way Setting goals Creating options Facilitating self-confidence Promoting autonomy Increasing stimuli Changing optician	Accepting Adjusting everyday life Involving school, grandparents and siblings Sharing responsibility Adjusting family roles

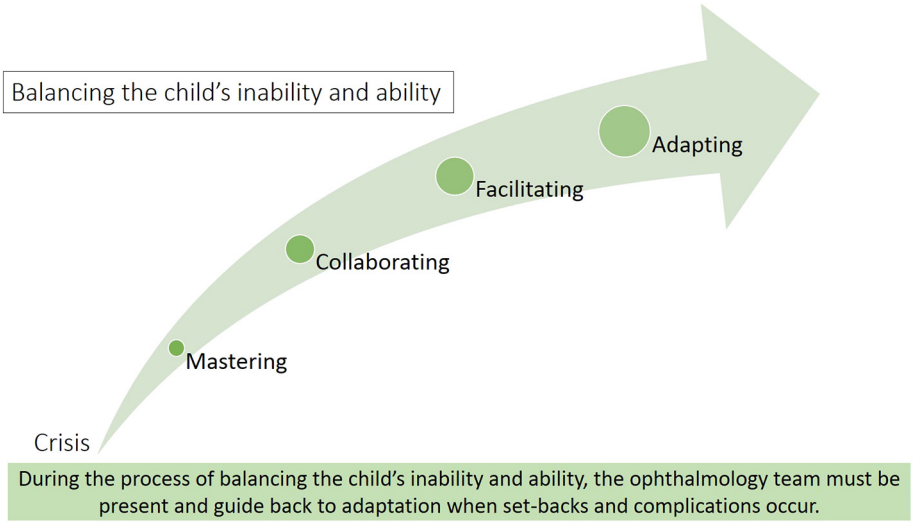

Fig. 1. Model of the grounded theory Balancing the child's inability and ability.

and complications, leading to uncertainty. The situation often became overwhelming and a wish to give up emerged. Thus, mastering was dependent on the ophthalmological team confirming the performance accomplishment and providing both instrumental and emotional support. The diagnosis, treatment, and endless visits to the clinic required either a gradual or an immediate adaptation of the parents' mastering strategies in order to achieve some kind of balance.

> "*I do believe it totally depends on one's attitude from the start. It is like a combination of a will to win, being positive and how one thinks how one successfully thinks ahead. Time passed after her surgery, it was an intense, reflective, absorbing time for us… and then we realized that we had managed it, we did it. It is possible to work hard at it and make it better.*"
>
> [(*Couple with a daughter diagnosed in the first week after birth*)]

Collaborating

The parents started to collaborate immediately when the surgery and other treatment options were presented. They had to ***accept*** what the specialist physician suggested and did not oppose or question the treatment plan. They ***adhered*** to every detail and carried out their part of the treatment. When the child was an infant, the main collaboration was with the clinic and the parents developed ***patience*** and ***persisted with*** the occlusion treatment and putting in the lenses. As the child developed the efforts to collaborate were directed towards her/him. The parents achieved a balance between the child's inability and ability when the collaboration worked with both the child and the clinic. During phases when they had to force the treatment on the child and collaboration was impossible due to her/his immaturity the collaboration with the clinic served as the primary motivation for persisting with the treatment. Collaboration was also essential in order to facilitate the child's performance and abilities.

> "*At first it was the regular visits to the clinic for checkups. They were very frequent during the first year, I would say 6–8 times, and we had to constantly return to the hospital eye-clinic. I remember clearly when they said now you can book your check-ups for every 6 months, and I felt WHY? It was part of our routine to visit the clinic to find out how things were, especially as things had gone so well for her during these checkups. Her results reminded us how hard we worked and how well she was doing. It was very important for us. It was stressful to hear that twice a year was enough because things were going well. We did it together so why is there such a long period between visits?*"
>
> [(*Father of a daughter diagnosed in the first postnatal week*)]

Facilitating

Having moved on from the demanding initial period of the diagnosis, surgery, and intense treatment with lenses and occlusion, the parents started to think about everyday life, which demanded extensive facilitation. They moved from uncertainty, mastering, and requesting collaboration to focusing on ***paving the way*** for the child's growth and development. A strategy mainly adopted by the fathers was to set goals for the child's achievement and for the parents' own efforts. Both mothers and fathers ***created options*** for their child in order to make the time in pre-school as positive as possible or enabling play activities both at home or outdoors.

> "*The thing that I was obsessed about was him damaging his healthy eye! I bought sunglasses for him because he was sensitive to light. It worked until he turned two and then he refused to wear them. My intention was to protect his healthy eye from sticks and sand in the sandpit etc.*"
>
> [(*Mother of a son diagnosed in the first week after birth*)]

Strategies for focusing on the child's abilities included ***increasing self-confidence*** and ***promoting autonomy***, which involved the parents setting their fear aside and encouraging the child to go out, explore her/his opportunities and be part of a group with children of the same age.

> "*He is doing really well as a matter of fact. I would say superb! He chose other activities and is busy doing things he should not be doing with his impaired vision. There is the kick bike, U-ramp, things like that… he just goes for it, he dares, and truly he does, he jumps from 1/2 meter without hesitation! Even though he does not improve his sight through these activities it's still exciting. He does what he does, he is good at it, and it shows. It is great that he has built up his self-confidence, solved his visual challenges on his own terms and is doing as well as other children of his age. We never imagined that his motor skills could be at that level. To tell the truth, when he was younger we felt so sorry for him… what will his future be like?*"
>
> [(*Couple with a son diagnosed in the first week after birth*)]

Other strategies involved ***increasing the stimuli*** in order to promote visual performance and the child's abilities. The parents showed various toys, introduced different items in the environment, pointing,

demonstrating, continuously explaining and repeating, while patiently awaiting the results. If they felt dissatisfied with the attention and help they received, for example with glasses, they could ***change the optician*** in order to facilitate the child's autonomy. Facilitation was a vital part of adaptation.

Adapting

The fourth part of the balancing process involved strategies to adapt to everyday family life with a child diagnosed with a cataract. The parents sometimes stopped seeing friends due to the demanding treatment. However, as the years went by and the child developed, they changed from taking parental leave to ***adjusting everyday life*** by working full time, enrolling the child in day care and ***accepting*** the fact that the child's abilities were greater than her/his inabilities. Instead of working alone they learned to ***involve the pre-school***, ***grandparents***, ***and siblings*** in facilitating the treatment. After initially doubting the future, the parents reported that after several years they viewed their whole life in a new perspective by simply going from day to day, appreciating the small things in life and the fact that only one eye was affected by cataract.

Adaptation meant a clear shift from the mother being the primary care giver and responsible for the occlusion to ***shared responsibility*** between the parents and an overall ***adjustment of family roles***. However, there were gender differences between mothers and fathers regarding how to balance the child's inability and abilities, where mothers tended to focus more on the child's inability while fathers used goal setting, reasonable expectations, and the child's performance accomplishment as markers of health and ability. As parents they did whatever it took to achieve the best possible visual outcome of the occlusion treatment and an everyday life that functioned both for the child and the whole family. The perspective on life as a whole and what is important changed after the child was diagnosed with a cataract, with facilitation becoming the number one issue. The parents emphasized their gratitude towards the ophthalmological clinic that had supported them throughout the whole illness and their transition towards adaptation and balance. However, no longer being dependent on the clinic was also considered a relief. They had moved from dependence on the clinic to achieving a balance between the child's inability and ability by themselves.

> "*We have had the privilege to travel as parents for a month, we worked mornings until lunchtime. After that we had family time, no work, no daycare, no eye-patch. We soon noticed how much our family enjoyed these afternoons and became strengthened by a break from the everyday routine. We spent time with each other. I had struggled a lot to be able to relax and spend my time seeing her for the person she is, instead of "is her pressure high, must I polish her glasses" etc. I could let go and enjoy our family. The children enjoyed our time together and I could see that we were a family like any other family. This was important for me to realize. Because we are caregivers for her visual impairment it may be even more important to have fun and enjoy each other's company*."
>
> [(*Mother of a daughter diagnosed in the first week after birth*)]

To some extent, the diagnosis of cataract clarifies the family's priorities. Despite all the challenges, setbacks, and complications, it seemed possible to eventually achieve an optimum balance between the child's inability and ability.

Discussion

Methodological considerations

We performed this study in line with the four criteria of good quality in GT-research described by Charmaz (2014), i.e., originality, trustworthiness, resonance, and usefulness. The interview data collection took place during 2016–2017 through written memoranda, digital recordings, and verbatim transcription. Parents of children of various ages diagnosed with a cataract were selected from a single center. As a research team, we tried to ensure credibility by analyzing the interviews independently of each other. During data collection and data analysis, theoretical saturation was clearly evident after 15 interviews. By the end of the analysis process, the subcategories and the main categories confirmed the findings rather than adding any new data. Nevertheless, we wished to ensure saturation by also trying to confirm the theory, thus two additional informants were included.

The Grounded Theory was, achieving a balance between inability and ability has generated a new understanding of parents' process of adaptation and balance when having a child with a cataract. The main categories constitute new condensed concepts of how parents master the process of regaining balance and a functioning everyday family life. The social implication of this theory is a more specific understanding of the strategies parents adopt to adjust to their new life situation. This study both generates new hypothesis and confirms established knowledge. New research questions about the parents' strive for balance were formulated. The importance of understanding the parents' process is highlighted. The study also goes one step further by clearly identifying the main concern during the process of adaptation to life with a child diagnosed with a cataract.

Quotations from the parents support the principle that the theory stems from the coding process. We chose not to overload this paper with quotations in order to make it more reader friendly. We have continuously checked the developed concepts, as well as the theory against the data in order to confirm and optimise the result. We consider the theory relevant, firstly to the parents included in this study, and secondly to parents in developed countries where both state funded care and employment are important parts of their everyday life. After further testing the Grounded Theory of this study might be applicable within the area of ophthalmological care.

Reflection on the findings

To our knowledge, this is the first ever attempt to use a truly inductive method to understand the core of parents' main concern when having a child with a congenital cataract. We have explored the inside perspective of parents with children who have cataract and synthesized their experiences. The process started when their child received the diagnosis. Most parents shared vivid memories of where and when they first noticed that something was wrong or the period of uncertainty due to the signs that something was wrong, which lasted until the ophthalmologist confirmed the diagnosis. The analysis of the interviews shows the parents' constant struggle to achieve a balance in life. The child's performance sets the pace and place on the balance scale. Whenever there is a setback or complication, they find themselves back at square one and need to master. In this ongoing process collaboration with the ophthalmological team gives them responsibility as a co-caregiver. They facilitate everyday life by means of goal setting and forward thinking for the child's best development. The last stage of the process is adapting to make everyday life function.

This constant struggle on the balance scale is ever present and also described by family system theory; when a change occurs in a family, the disturbance can cause a shift to a new balance (Benzein, Hagberg, & Saveman, 2012; Wright & Leahey, 2013). A change in one family member affects all family members, which is also seen in this study. If somebody contributes in a positive way, it will affect everybody in a positive way (Wright & Bell, 2009; Wright & Leahey, 2013). This reciprocity is visible in a family in that if one member is having a bad day, so will the rest of the family. Thus the family can contribute to better health and reduced suffering for everybody (Benzein et al., 2012; Bylund, 2017). Healthy family functioning is essential to positively adapt to change and facilitate sustained familial health and well-being (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Healthy family

functioning can support patients and help them adhere to treatment regimens. Moreover, it maintains the physical and emotional health and that of the family as a unit (Bylund, Arestedt, Benzein, Thorell, & Persson, 2016). The mothers and fathers in this study had a different approach; the fathers being more salutogenetic and the mothers in general were more worried about problems and future risks. This balance between a salutogenetic and a pathogenic approach probably promotes the transition towards acceptance. Our understanding is that this gender difference between mothers and fathers can be useful for creating balance in a family. Being the parent of a child with an illness/inability will put strain on the relationship and change the roles in the family. The nurse/ophthalmological team can recognize the challenges and enhance the role of mothers through interventions to make the fathers more involved. The family nursing system model has different intervention methods such as family health conversations (Benzein et al., 2015; Persson & Benzein, 2014; Wright & Leahey, 2013) or the Calgary Model by Wright and Leahey (2013).

Overall the mastering strategies were constructive, suggesting a shared problem solving approach. This is highly useful in the present context, as after a while the parents focused on the child's abilities rather than her/his inabilities. This is also true for parents of children with intellectual disabilities (Broberg, 2011), where the parents identified themselves with the majority group, emphasized normality, and described themselves as no different from other parents. The parents in this population seemed able to adopt Antonovsky's concept of sense of coherence, telling us that "there is a high probability that things will go as well as one can expect" (Antonovsky, 1987), which is applicable to the parents in our study. After each setback, most parents gradually found different positive, constructive ways of looking at the situation.

To do so, the parents enhanced the collaboration, which is about mutual agreement, between themselves and the ophthalmological team. It started right after surgery when they were given the responsibility for handling contact lenses and patching. They were willing to go to great lengths to fulfil their part of the agreement, even if it meant having to force treatment on the child. Therefore, attachment between the child and the parent is important for a successful visual outcome. The attachment theory is evolutionary and the goal of the attachment system is protection at times of danger, which is achieved by seeking proximity and contact with the primary caregiver to ensure safety and survival at times of fear, distress, anxiety, and abandonment (Bowlby in Howe (2006)). It is not a child's disability per se that is associated with insecure attachments but rather "an interaction between children with disabilities and the caregiver's state of mind with respect to attachment" (Howe, 2006). Howe further suggests that it is important for healthcare professionals to help parents to understand their child's disability, which in turn increases their resilience. It is essential to acknowledge the parents' will and efforts (Howe, 2006). The parents in this study all showed enormous determination and goal setting to ensure the best possible outcome for their children.

All parents exhibited great creativity when it came to facilitating their child's treatment in everyday life. They also provided suggestions for the ophthalmology team regarding how to take more responsibility for this facilitation (Table 3). How can the health care system be more active in facilitating the various stages of the process? As suggested by Gyllén et al. (2015), person-centered care is recommended. By regularly listening to the parents' narrative, a structured care plan can be developed through mutual understanding and collaboration (Gyllén et al., 2015). Research suggests that a key worker might be valuable for confirming that the healthcare system has taken its responsibility seriously by being pro-active (Greco, Sloper, Webb, & Beecham, 2007) and promoting facilitation and the treatment outcome (Rahi et al., 2004; Sloper, Greco, Beecham, & Webb, 2006).

Facilitating is followed by adapting, which requires that a transition has taken place. According to Kralik et al., transition occurs by knowledge and understanding about the ways people incorporate the consequences of illness into their lives (Kralik, Koch, Price, & Howard, 2004). Kralik et al. further conclude that self-management is a dynamic, active process of learning, trialing, and exploring the boundaries created by illness, which is applicable to the parents in this study. As Meleis, Sawyer, Im, Hilfinger Messias, and Schumacher (2000) point out, changes in the health and illness of individuals create a process of transition, and clients in transition tend to be more vulnerable to risks that may in turn affect their health. Identifying these risks may be enhanced by understanding the transition process (Meleis et al., 2000). By making the parents aware of this process, the ophthalmology team can guide them towards acceptance, as has been shown in other populations (Almgren et al., 2017). Despite setbacks and complications, the parents can return to the stage of adaptation if they are provided with assistance to master with the temporary uncertainty that emerges in such situations.

Table 3
Parents' suggestions.

•Provide information about how to contact a case manager
•Provide information about how to contact another parent with similar experience
•Provide a structured individualized care plan
•Provide a tutorial video on how to put in contact lenses and practice on oneself
•Provide information about what to expect at each visit to the clinic
•Provide information about insurance, sick leave, etc.
•Provide practical tips from other parents about patching
•Ensure that the same care providers are present at each visit to promote continuity
•Stimulate the child's existing vision
•Provide a booklet documenting the vision and eye pressure
•Provide a schedule for the different eyedrops prescribed (to mark when given)
•Provide information about the child's vision that can be given to the preschool/school
•Do not search for information about pediatric cataract on the Internet prior to the first visit

Limitations

At the time of the interviews all the parents in this study had been through the challenging stage of patches, handling contact lenses, and all other stages of the process and had achieved adaptation. The result of the study would most likely have been enhanced if the informants had been at different stages of the process. Furthermore, the sample reflects families where the patching treatment was more or less successful, thus the perspective of those who gave up patching is missing. The informants also represent a limited ethnicity, as no parent was non-European. Although the inclusion criteria allowed for non-Swedish speaking informants, the final population only included Swedish speaking parents, which could be a limitation.

Clinical implications

Knowing and understanding the process of balancing between inability and ability enables the parents to comprehend the changes that occur after having a child with pediatric cataract. The ophthalmological team would be enhanced with a case manager who can pilot the family and set up an individualized care plan for each child, which will be regularly updated and changed. The team needs to pay attention to the parents' facilitation, since that is such an important part of balancing between the child's inability and ability. To enhance facilitation, the case manager can give them practical guidance of contact lenses, provide written information that can be handed to preschool/school, what regulations there are about insurance and sick leave and how to get in contact with other parents. Also, a digital application in a smart phone or another device containing self-management support would be helpful to provide easy accessible information to each parent. The ophthalmological team needs to be present through the process and guide the parents back to adaptation. The mutual agreement for collaboration, where both parents and the healthcare providers take full

responsibility, is a prerequisite for a successful visual outcome for a child with a congenital cataract.

Conclusion

This novel study provides a deeper understanding of the main concern of parents of children with a cataract. The model of balancing between inability and ability can be used as a point of departure when refining the care for families of a child with a congenital cataract.

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