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“The challenge of managing insecurities”: Parents’ experiences with the care for their child with congenital diaphragmatic hernia

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Abstract

Purpose: Last decennia remarkable advances have been made in decreasing the mortality rate of children with congenital diaphragmatic hernia (CDH), resulting in a relatively growing patient group with long-term complications and complex care needs. These consequences have a huge impact on the quality of life of both children and their families. To provide practical recommendations for improving the quality of care for this patient group, the present study sought to obtain insights into the experiences and needs of parents with a child with CDH.

Design and Methods: A qualitative study was conducted on the experiences and needs of parents with a child with CDH living in the Netherlands. Data was obtained by means of a discourse analyses of 17 weblogs written by parents and three online focus groups with 8–12 parents per group ($n = 29$). The data was analysed thematically and structured by using the model of Lawoko (2007) on parental satisfaction with care.

Results: Although parents were generally satisfied with the delivered care, they frequently encountered challenges in managing insecurities throughout the care process. Besides the unpredictable disease progress, insecurities were exacerbated by: (a) limited specialized knowledge of long-term consequences, (b) logistical problems, and (c) nontransparent communication. Providing security through, for instance, a clear care plan and by engaging parents in the decision-making process helped them feel more in control.

Practice Implications: This study showed that parents’ main challenge was to manage insecurities. Creating securities by providing a care plan and involving parents in the decision-making process helped parents to feel more in control. To improve quality of care for children with CDH, future measures should, therefore, focus on reducing insecurities by managing expectations, improving transparency and stimulating engagement.

KEYWORDS

congenital diseases, family-centered care, parents’ perspectives, patient-centered care, pediatric care, pediatric nursing, qualitative research, quality of care

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What is currently known?

Research into parental experiences with the care for their child with Congenital Heart Disease show that parents are in general satisfied, but judge information provision as too insufficient to manage their child's illness. Differences in parents' satisfaction of care were explained by parents' well-being. Although children born with congenital heart disease and congenital diaphragmatic hernia both cope with long-term hospitalization and health consequences, the type of health problems and disease trajectories differ.

What does this article add?

This study is the first to investigate parental experiences with the care for their child with Congenital Diaphragmatic Hernia. We found that insecurities of the care process, caused by nontransparent communication, logistical problems, and a lack of specialized knowledge among professionals, resulted in psychological distress and subsequently a negative effect on parental satisfaction. Improvements should, therefore, focus on increasing parents' well-being by diminishing insecurities and stimulating self-management.

1 | INTRODUCTION

Congenital diaphragmatic hernia (CDH) is a defect in the diaphragm that allows abdominal organs to "herniate" into the thoracic cavity, leading to underdevelopment of both lungs. The defect occurs in 1 per 2,000 to 3,000 live births (Badillo & Gingalewski, 2014; McGivern et al., 2015). Until recently around 40–50% of the children with this condition died shortly after birth (Langham et al., 1996; Peetsold et al., 2009). Owing to remarkable advances in neonatal resuscitation and new postnatal treatments, the mortality rate decreased to 1 per 5 babies born with the condition (Peetsold et al., 2009; van den Hout et al., 2011). The greater survival of children with CDH, leads to a growing patient group with long-term CDH-associated complications such as gastrointestinal abnormalities and severe lung impairments (Danzer & Kim, 2014; Keijzer & Puri, 2010; Peetsold et al., 2009). As a result of these complications, children with CDH have often complex care needs and are repeatedly hospitalized for longer periods. Later in life, behavioral, social and psychological problems have also been reported (Danzer & Kim, 2014). These consequences have a huge impact on the quality of life of children and their parents. Parents, and especially mothers, show significantly higher overall parental stress rates than other parents (Öst, Nisell, Frenckner, Burgos, & Öjmyr-Joelsson, 2017).

To provide good quality care, it is important to be responsive to patients' wishes and needs (Carman et al., 2013; Latour, Hazelzet, & van der Heijden, 2005). This is especially important in cases of intensive and frequent hospitalization periods. Since babies and small children lack the ability to express their needs, parental experiences can serve as a proxy for the quality of pediatric care from a patients'

perspective (Meterko & Rubin, 1990). Various studies have investigated what parents consider important in pediatric care (Haines & Childs, 2005; Latour et al., 2005; Miceli & Clark, 2005; Nuutila & Salanterä, 2005; Tenniglo et al., 2017). Parents' experiences with the care for their child with CDH have only been briefly mentioned in relation to those whose child has a rare and life-threatening disease (Gengler, 2014). Furthermore, parental experiences regarding a child with a congenital disease are, to the best of our knowledge, only investigated with regard to congenital heart disease (CHD; Kendall, Sloper, Lewin, & Parsons, 2003; Lawoko, 2007; Lawoko & Soares, 2002). Although children born with CHD and CDH cope with long-term hospitalization and health consequences, the type of health problems and disease trajectories differ. Moreover, studies mostly evaluated parents' experiences with the care for their child with a congenital disease in quantitative terms. Especially in the case of long-term and complex care trajectories, knowledge of parents' underlying perspectives is needed. Qualitative studies would allow for a deeper understanding of these perspectives (Gray, 2013). Therefore, the present study sought to obtain insights into parental experiences to improve the future quality of care for children with CDH.

2 | METHODS

In the period April 2015–March 2016, a qualitative study was conducted on the experiences and needs of parents with a child with CDH living in the Netherlands. Data was obtained by means of a discourse analysis of parents' weblogs followed by online focus groups (OFGs) to deepen and broaden the analysis of the weblogs.

2.1 | Discourse analysis of weblogs

For this study a discourse analysis of weblogs was used to identify parental experiences regarding the care for their child with CDH. Spending a lot of time in the hospital, these parents often use weblogs to easily inform family and friends. These weblogs describe parents' experiences in a longitudinal way and are an interesting source of their perspectives.

To collect the weblogs, a message was posted in two secure Facebook groups and a structured online search was conducted using the tool Coosto¹ and search engines Google, Yahoo, and Bing. For the search syntax, initially a combination of Dutch terms for the concepts CDH, weblog, and child, were used. Subsequently a few weblogs were analyzed to get a better understanding of the parents' language. Commonly used words, such as sleeping, drinking, physician, nurse, lungs, father/mother, were selected to broaden the syntax. In total, 64 weblogs were collected. Weblogs were included when publicly available and written in Dutch by parents of children with CDH that were living in the Netherlands. Other inclusion criteria were that the

¹This tool has been developed to analyze posts placed on Dutch media, news and blog websites and forums.

TABLE 1 Characteristics selected weblogs (*n* = 17)

Aspect	Category	Amount
Writer	Mother	4
	Father	1
	Both	12
No of posts	1–9	2
	10–25	5
	26–100	8
	≥100	2
Year of birth	2007–2010	7
	2011–2015	10
Mortality	Alive	13
	Deceased	3
	Unknown	1
Sex	Boy	8
	Girl	9
Number of children	One	7
	Two	7
	Three or more	3
Prenatal diagnosis	Yes	13
	No	4
Hospital	Erasmus MC (Rotterdam)	9
	Radboud UMC (Nijmegen)	5
	UZ Leuven	4
Duration hospitalization	≤1 month	8
	1–3 months	5
	>3 months	3
	Unknown	1

treatment had taken place in the Netherlands or the CDH expert centre in Belgium and the blogs focused on the care process of a child born with CDH after 2006. Since the adoption of a routine 20-week ultrasound scan in the Netherlands in 2006, the prenatal detection rate of CDH increased significantly. As a result, precautionary measures could be taken during pregnancy and delivery to increase the babies' survival chances. Based on the inclusion criteria, 17 weblogs were selected. After the selection process, the diversity of the characteristics of the weblogs was studied. Because there was a great variety in characteristics and all potential subgroups based on previously identified categories were represented, there was no need for further collection. An overview of the characteristics of the selected weblogs can be found in Table 1.

2.2 | OFGs

To validate and deepen the findings from the weblogs, three OFGs with parents of children with CDH were organized in November–December 2015. For the OFGs a specific OFG tool,² a secure online website to conduct group discussions, was used (Tates et al., 2009). Because

parents live in different regions in the Netherlands and are often tied to their home due to young children, OFGs were considered a useful tool (Tates et al., 2009). Lung Foundation Netherlands recruited participants in collaboration with two Dutch CDH expert centers, Erasmus MC and Radboud UMC. A letter was sent by post to all parents whose child was born after 2006. Furthermore, a message was posted in two secure Facebook groups and on the website of Lung Foundation Netherlands. In total, 43 parents sent an e-mail expressing their willingness to participate. The same inclusion criteria as for the weblogs were used. Parents whose weblog had been included in the study were excluded from the OFGs. In total 29 parents participated in an OFG. The selected participants were divided into three groups: two groups of parents whose child is still alive and one OFG with parents whose child has died. The groups comprised respectively 12, 11, and 7 participants. Prior studies have showed that this is a good number of participants for online discussions (Zwaanswijk & van Dulmen, 2014). In dividing the participants in the first two groups, attention was paid to the diversity of the participants. Table 2 shows an overview of the characteristics of the participants of the OFGs.

The OFGs were held asynchronously. Over a period of 10 days participants could log in anonymously 24hr a day. The first author facilitated the OFGs. On specific days and times new questions were posted. These questions were focused on the main challenges or points for improvement parents experienced in three timeframes: during pregnancy, the stay in the hospital and when returning home or concerning the death of their child. Through the questions insights could be obtained on the main bottlenecks, needs and wishes participants experienced. Specific questions on for instance specific decisions or steps in the care process were posted to test participants' views on the topics brought forward in the weblogs. In this way the main aspects highlighted in the weblogs could be validated and deepened. To stimulate interaction, the moderator posted supplementary questions to obtain a more in-depth explanation or description or asked other participants about their view on a certain subject. When a participant was rather silent, his or her opinion was explicitly solicited.

2.3 | Data analysis

The weblog texts were analyzed line by line using an extended discourse analysis to identify parents' descriptions of their experiences and needs (Gray, 2013). Codes were derived via open coding. Subsequently the codes were compared via the qualitative analysis software program MAXQDA 2007 and sorted into categories by a continuous comparative method. The categories were clearly defined and mutual connections were mapped. To increase the validity, the codes and categories were discussed with a second researcher. The coding scheme was subsequently used to manually analyze the results of the OFGs by deductive coding. Moreover, the results of both the weblogs and the OFGs were discussed with a steering

²For this study an OFG tool developed in by Nivel, Netherlands Institute of Health Services Research, was used.

TABLE 2 Characteristics participants online focus groups (n = 29)

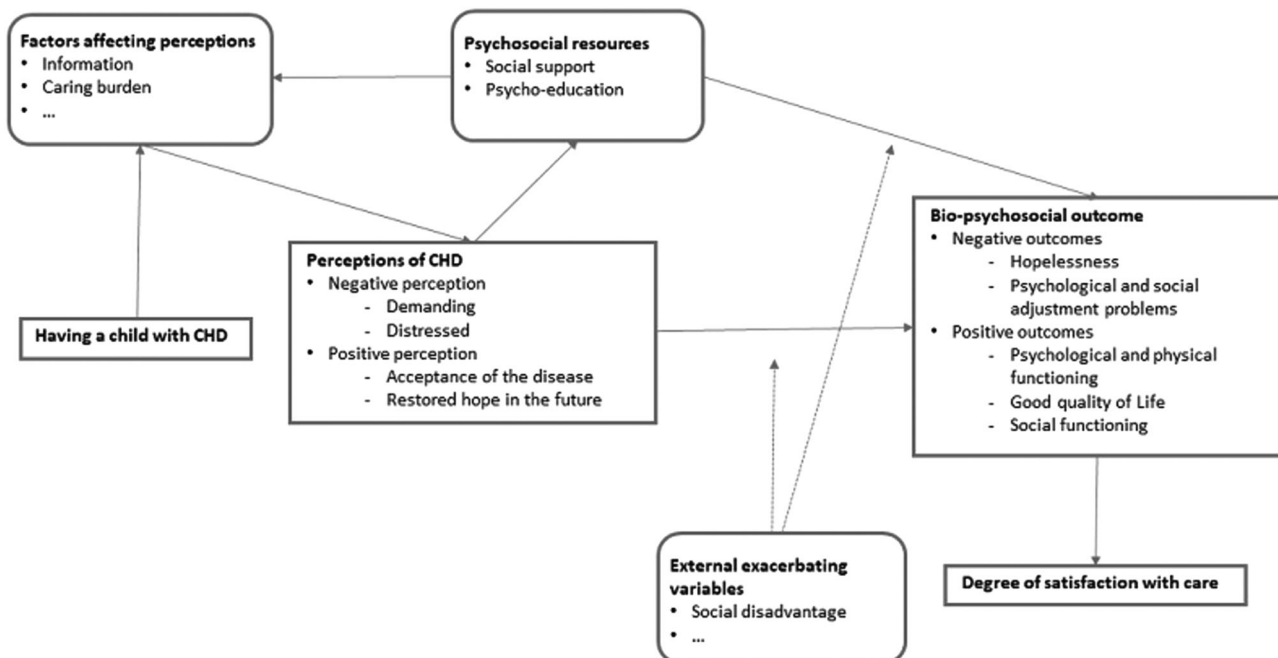
Aspect	Category	FG1	FG2	FG3	Total
Participant	Mother	8	8	3	19
	Father	1	1	0	2
	Both	2	2	4	8
Year of birth	2007–2010	6	5	3	14
	2011–2015	5	6	4	15
Mortality	Alive	11	11	0	22
	Deceased	0	0	7	7
Sex	Boy	5	7	3	15
	Girl	6	4	4	14
Number of children	One	5	4	2	11
	Twins	0	1	0	1
	Two	5	5	1	11
	3 or more	1	1	4	6
Prenatal diagnosis	Yes	6	8	7	21
	No	5	3	0	8
Hospital	Erasmus MC (Rotterdam)	6	7	3	16
	Radboud MC (Nijmegen)	5	4	4	13
	UZ Leuven	1	2	1	4
Duration of hospitalization	<1 month	4	4	5	13
	1–3 months	6	4	1	11
	>3 months	1	3	1	5

committee to check potential misinterpretations by the researchers. The steering committee comprised of parents of a child with CDH, a pediatrician, neonatal specialist and staff members of <Name organization>.

To identify, analyze and report patterns within the segmented codes thematic labeling was used (Braun & Clarke, 2006). The model of Lawoko (2007), see Figure 1, was used to structure the themes and to get a better understanding of the interrelatedness between the themes. This holistic model was based on a review of the experiences of parents of a child with CHD. Following the model, the satisfaction of parents with the quality of care can be explained from their well-being (referred to as the biopsychological outcome). This biopsychological outcome is the effect of a complex interaction between parents' psychosocial resources and perceptions of CHD, factors affecting these perceptions and external exacerbating variables (Lawoko, 2007). The model helped in placing the findings in a broader perspective. This contextualization is needed to formulate measures to improve the quality of pediatric care for children with CDH. By applying the model, this study also adds to its further development beyond the CHD context.

2.4 | Ethics

According to Dutch law, ethical approval from a formal medical ethical committee was not required for this study. This study does not concern clinical research (because respondents are asked about their experiences with the care provided) or research with people under the age of 18 years. The researchers adhered to the national

**FIGURE 1** Holistic model demonstrating factors influencing satisfaction of parents of a child with congenital heart disease (Lawoko, 2007)

Code of Ethics for Research in the Social and Behavioral Sciences involving Human Participants (VCWE, 2016). In advance all OFG participants received written information about the aim of the study and of the possibility to withdraw from the study at any given time. Several weeks after the OFGs, a summary was sent to the participants for a validity check. Participants' suggestions for changes and additions were taken into consideration. Moreover, the weblogs were publicly available and the results of both the weblogs and OFGs were analyzed anonymously.

3 | RESULTS

To structure and explain parental experiences with the quality of CDH care, the results are described in line with the model developed by Lawoko (2007). First will be elaborated on the final outcome of the model, parental satisfaction with the care provided. Subsequently the parental bio-psychosocial outcome linked to parents' satisfaction and the psychosocial resources and parents' perspectives on CDH that influence and explain the psychosocial outcome are discussed. Examples are illustrated by quotes. Quotes from the weblogs are identified with (WL <number>). The number indicates a specific weblog. The quotes from the OFGs are identified with (OFG <number> and RD <number>), where RD stands for respondent.

3.1 | Parental satisfaction with care

In general, parents were satisfied with the care for their child with CDH. However, their satisfaction differed with regard to certain aspects of care. These aspects could be divided into *technical* (structures, materials, and protocols of the health organization) and *social* (relating to the interaction with health care professionals) aspects. Four technical aspects were mentioned by parents in their evaluation of the care provided: (a) the residence, (b) the medical activities, (c) the internal logistics, and (d) the transfers between different departments or organizations. Parents were generally positive about the patients' residence. Expressions of dissatisfaction were only made by almost half of the weblogs when the needs for privacy and direct availability of personnel were unbalanced. This balance depended on the health status of the child: when less direct care was needed more privacy was preferred. A high proportion of the parents of the weblogs and four of the OFGs, who stayed in a nursing home, spoke about it in very positive terms. It gave parents the possibility of staying close to their child. However, the nursing home was sometimes still experienced as being distant (compared to rooming-in) because of the mother's limited mobility or the emotional distance. After a longer period, some parents missed their own belongings and felt like nomads. In the majority of the weblogs and by nine OFG participants, complications with medical activities influenced parents' satisfaction with care. Wrongly administered medication, insufficiently attached patches, and problems with drips and probes caused stress for the baby. Dissatisfaction with the

internal logistics at the hospital was expressed in many weblogs and by a few OFG respondents. A majority of the respondents experienced long waiting times, difficulties with scheduling appointments and uncertainty about the timing of certain activities.

The surgeon promised to return an hour later and we decide to wait together. Eventually it is after 6 o'clock in the evening before a surgeon informs us about the surgery and what will happen next (WL 9).

Moreover, five weblogs and 13 OFG participants referred to the lack of consensus within the team or between different care organizations as tiring. The evaluation of the transfers between different care organizations varied. Some OFG participants evaluated the transfer as timely, quick and accurate, with a clear task division. However, five weblogs and eight OFG participants mentioned dissatisfaction with disorderly or prematurely planned transfers.

Unfortunately, there is quite some misunderstanding today. The High Care department thought they only had to be sure there was space available and that the rest would be arranged. The other department expected that the High Care department would also assist (WL 2).

Parents mentioned four social aspects in their evaluation of the care provided: (a) involvement, (b) emotional support, (c) expertise, and (d) communication. Parents' experiences with their own involvement in managing their child's care were variable. Parents of a third of the weblogs and a few OFG participants were satisfied with the opportunities to express their wishes and for self-management, such as feeding, and shared decision-making. However, many weblogs and some OFG respondents mentioned the wish to be more involved in the decision-making process of planning transfers, treatment options and steps, especially in relation to the quality of life. Almost all the weblogs and many of the respondents of the OFGs were positive about the emotional support provided by care professionals, showing affection and empathy. Only in a few weblogs and by a few OFG respondents more negative experiences were mentioned, specifically referring to more old-fashioned personnel who were less aware of patients' perspectives. Parents of most weblogs and a high proportion of the OFG respondents were positive about the expertise of the health care professionals. The expertise of health care professionals at local hospitals and first-line care, and specifically on eating problems, was less valued.

Insufficient care of general practitioners. I understand that they have limited knowledge on CDH, but sometimes you have to return 3 times before any action is taken (OFG1, RD1).

Almost all weblogs and some OFG respondents expressed negative experiences with regard to the communication with health care professionals. These respondents described situations in which

they did not receive information or the information was last-minute or unclear. A lack of transparency caused feelings of loss of control and stress for parents.

We spoke with quite some people in the hospital today, but it didn't provide us the necessary clarity (WL 2).

3.2 | Parents' biopsychological outcome

In this study, almost all respondents expressed psychological distress with regard to their child with CDH. Not being able to manage insecurities, and therefore, not feeling in control were identified as a main cause for distress expressed by feelings of sadness and hopelessness among parents. Uncertainties played a role in all phases of the clinical care pathway. During pregnancy and the first days, weeks, and sometimes even months after birth, uncertainties about the prognosis and survival chances of the baby were caused by the complex and erratic disease process.

Coping with all the uncertainties was probably the biggest challenge. You hear percentages and survival rates and what the physicians will be doing, but how it will be for you and your child, is hard to estimate (OFG2, RD4).

Later on, insecurities arose about the complications of the disease and the duration of hospitalization. On returning home, respondents felt insecure about their own abilities to care for a child with CDH and the long-term consequences of the disease. Besides insecurity, parental distress was caused by combining life at the hospital with their normal life. In combination with the business of managing different tasks, a lack of sleep, mother's recovery from the delivery and the constant flow of both positive and negative emotions, staying healthy was a challenge for parents. More distress related to a more negative stand on the part of the parents. It was, however, unclear what caused what: whether less satisfaction caused more distress or the other way around.

3.3 | Parents' psychological resources

Psychological resources influenced the respondents' biopsychological state. Coping strategies formed the most important resource, but also their social network and in a few cases professional help were important. Parents' distress was influenced by the extent they were able to cope with their emotions and mainly their feelings of insecurity. These strategies differed between parents and over time and influenced parents' perspective regarding the disease and care process. During pregnancy most parents developed a similar strategy: to hope and have trust in a positive outcome after delivery. The days and weeks after birth, when there was still uncertainty about the baby's chances of survival, parents developed four different strategies. The majority of the weblogs and some OFGs respondents mentioned trying to stay positive and hopeful by holding onto existing securities, such as medical facts and the current status

by, for instance, check-ups and follow-up steps. However, due to setbacks or unexpected insecurities, some parents unconsciously were disappointed and became more negative to be prepared for the worst. For a few respondents of the weblogs, religious faith was a way to stay hopeful. Their trust in God and led to resignation. A third strategy mentioned in the majority of the weblogs and by some participants was the relationship with the baby. Parents became energized by feeling responsible towards the baby, but also by being in contact during (breast) feeding and pouching. Eight OFG respondents expressed difficulties in building a relationship with the baby because they could not touch the baby and/or due to a self-protection mechanism.

Because I was afraid of losing her, I found that distance comforting. Unconsciously I thought that if she won't get closer, it will be less painful when it will go wrong. Quite weird actually but I did not dare to build a relationship with her (OFG1, RD7).

A fourth strategy was "being active." Actions ranged from performing medical or caring practices, practical arrangements, praying, burning candles, singing, playing music or writing a weblog. By being active and engaged, parents did not have to think about the situation and by creating a routine they generated a feeling of being in control. Factors such as logistical problems, lack of communication of misunderstandings that undermined this feeling of security or created additional insecurities, contributed to respondents' psychological distress.

3.4 | Social context

All the weblogs and most OFG respondents said that they received both practical as well as psychological support from their social network. Knowing that you are not on your own, thanks to the presence of family and friends, gave most parents of the weblogs a good reason to proceed. A lack of support from the social environment, but also handling their well-meant but unwanted reactions, led in a few weblogs and for most OFG participants to more distress and less energy to carry on. A few weblogs and some OFG participants indicated that they specifically valued the support of fellow sufferers because they have a more shared understanding than family or friends.

Most of the support we received was from fellow sufferers via the Facebook group of CDH. Those people know exactly what you are going through. With family and friends I found it difficult. They only wanted it to be well, but your child is born with a severe illness so everything is not completely well (OFG2, RD9).

Several respondents indicated that the practical and mental support from a social worker helped them with feeling in control. Two others were less positive, because the conversations were said

to be unneeded, paternalistic and vague. Receiving professional help from a psychologist was only mentioned by one of the respondents, who was very much helped by Eye Movement Desensitization and Reprocessing (EMDR) therapy, a psychotherapy approach for treating trauma.

3.5 | Perceptions of CDH

Parents repeatedly described the disease as a factor of insecurity, which can unexpectedly cause various negative consequences for their child and themselves. Most respondents indicated that they were not prepared for continuing uncertainty about prognosis and survival. Quite a few parents of the weblogs and OFG participants indicated that they were not informed about the consequences of the disease, because CDH had not been diagnosed before birth. Even when it had been diagnosed, respondents had limited knowledge about some long-term and nonphysical consequences of the disease. Six weblogs and six OFG participants described the consequences of the disease as demanding. Parents have to adapt their life rhythm to the meetings with care professionals. These meetings and the long waiting times result in organizational challenges for parents: running from one place to another (home or nursing home, the hospital and work). They do not have time to keep on top of household matters or take care of themselves. Also, when they return home, the medical caring activities are exhausting. These perceptions were influenced by parents' coping strategies, their personal situation and the disease and care process.

3.6 | External exacerbating variables

From the data, there is no indication that the experiences of mothers and fathers differed significantly. The weblogs were often written by both parents and therefore it was difficult to distinguish the views of mothers and fathers. With regard to the educational level or other possible external variables, no distinctive correlation was found. The only factor that seemed to influence parents' perspectives was the duration of the hospitalization. A longer period of hospitalization imposed a larger burden on parents, influencing their mental state but also their expectations with regard to the care provided.

4 | DISCUSSION

This study is, to the best of our knowledge, the first to investigate parental experiences of a child with CDH. The findings show that managing insecurities was the most important challenge for parents. Feelings of insecurity were caused by the complex and erratic process of the disease and uncertainties of the care process. The way parents were able to cope with these insecurities influenced the way they experienced the disease and care process.

In general, parents were very satisfied with health care professionals' support and showed trust in their competencies and services. Limited expertise and support was only experienced

regarding long-term consequences, such as eating problems, and first-line care. Other perceived starting points for improvement related to long waiting times and problems with planning appointments and transfers. Also limited, nontransparent communication or mixed messages due to contradictory views among professionals or between organizations, caused frustrations. Lastly, parents indicated the wish to be more engaged in the decision-making process and possibilities for self-management. These findings are generally in line with studies on parental experiences with pediatric care of hospitalized children suffering from other diseases (Haines & Childs, 2005; Latour et al., 2011; Lawoko, 2007). In these studies logistic and communication problems were also regularly brought forward.

Parental experiences that caused dissatisfaction were often mentioned in relation to feelings of uncertainty. Logistical problems, nontransparent communication and a lack of specialized knowledge created insecurities about the disease and care process, resulting in frustrations and feeling powerless. Managing these factors can help in creating security. For instance developing a clear care plan or providing transparent medical information made parents feel more secure. Engaging parents in the care process not only improves transparency, but having an active role also increases feeling of being in control. This positive effect of engagement, by parents' advocacy, is also mentioned by the review of Rafferty and Sullivan (Rafferty & Sullivan, 2017). The factors found to cause insecurities go beyond the seven triggers of that heighten parental uncertainty in chronic, life-threatening childhood illness of Cohen (Cohen, 1995). Three of these triggers were, however, also mentioned within this study. Routine medical appointments triggered uncertainty mainly during pregnancy and the trigger "changes in therapeutic regime" was brought forward when parents were not involved in the decision-making process. Night-time absence was only mentioned as a trigger of uncertainty after returning home. Differences in disease types and subsequently care process or a different study approach, could explain why different triggers were found.

Because of the essential role of insecurities in parental experiences, we opt for measures that take psychosocial components, and specifically coping, into account. To date, studies regard parents' insecurities mainly as an interpersonal component and not related to the evaluation of care (Arockiasamy, Holsti, & Albersheim, 2008; Uhl, Fisher, Docherty & Brando, 2013; Hopia, Tomlinson, Paavilainen, & Åstedt-Kurki, 2005; Stratton, 2004). Managing insecurities has only been linked to the provision of information (Balling & McCubbin, 2001; Carey, Nicholson, & Fox, 2002; Dixon, 1996; Farrell & Frost, 1992; Miles, 2003). This study showed that also other aspects relating to the care process can cause uncertainties. We, therefore, recommend that four types of measures are improved: (a) specialized knowledge, (b) logistics, (c) transparent communication and (d) possibilities of empowerment. By giving transparent information at set times about the current status and future care steps, parents have a clear idea about what to expect. Furthermore, managing expectations about waiting times and clear transfer protocols, could help in improving current logistical experiences. Also, flexibility on the part of health care professionals

towards individual needs (both mental and practical), parents' expectations and coping strategies, can help parents to remain positive, tackle setbacks and stay healthy. Empowering parents, by including their experiential knowledge in the decision-making processes or providing self-management measures, can help them to feel in control. These four measures would diminish current insecurities and help parents feel more in control. These measures are expected to be also relevant in other congenital diseases with an unclear prognosis and for which children are hospitalized for a longer period of time.

The Lawoko (2007) model was helpful in organizing the relations within respondents' experiences. Following the model, the degree of satisfaction of care is directly explained by parents' biopsychological outcome. This study however showed that it is not the biopsychological outcome, but parents' coping strategies which create their frame of reference. Moreover, the model is mainly focused on explaining differences within experiences and less useful for identifying the factors that determine the degree of satisfaction in general. More attention for (care) factors that affect perceptions, could be starting points for potential improvements by health care professionals. Based on the findings of this study, a new model (depicted in Figure 2) is proposed. Following the model, parents' situation differs in terms of their personal background and their child's disease and care process. These factors influence the psychological resources and thus the potential coping strategies of parents. The way parents cope with the situation subsequently influences their biopsychological outcome and their perceptions on the disease and the delivered care, which are interrelated. Future studies are needed to test this model outside the CDH context.

This study has a number of limitations that need to be addressed. Using only digital recruitment and data-collection tools could have caused some selection bias. However, parents with children born after 2007 are expected to be skilled in using online tools. Because the analyzed weblogs were publicly available, parents could have censored certain information. Managing difficulties with their social network was, for instance, not mentioned in the weblogs, but emerged in the OFGs. Regarding the OFGs, there was limited interaction between respondents. Respondents mainly answered questions or responded to statements made by the moderator. Moreover, various probing questions were not answered. As a result, the extent to which some findings are broadly supported by respondents is unclear. Other options, like sending a notification to specific people or posting an announcement, could have been helpful. Although the experiences of a heterogeneous group of parents were included, there was an overrepresentation of mothers within the OFGs (30 mothers and 10 fathers). Nonetheless, the data does not give an indication that the experiences of mothers and fathers were substantially different.

In conclusion, this study shows that with regard to CDH, parental experiences largely correspond to those of children with other diseases. However, it specifically addressed the relationship between parental satisfaction with care and the extent insecurities were managed. Furthermore, this study validated and adds to the model of

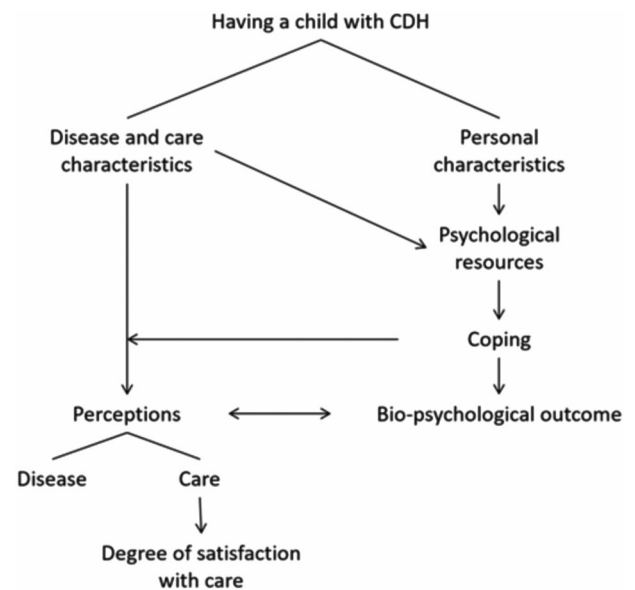


FIGURE 2 Model demonstrating factors influencing satisfaction of parents with a child with CDH

Lawoko (2007) for structuring and explaining the satisfaction and well-being of parents of a child with a congenital disease.

5 | HOW MIGHT THIS INFORMATION AFFECT NURSING PRACTICE?

Babies and young children with CDH cope with intensive and frequent hospitalization periods. To provide good quality care for this patient group, it is important to be responsive to their parents' wishes and needs. By staying with and watching their child, parents have acquired experiential knowledge about their child's experiences and needs. Moreover, as future caregivers the empowerment of parents within the care process is of great importance. This study showed that the most important challenge for parents was to cope with the insecurities caused by the erratic process of the disease and uncertainties of the care process. We provide four concrete recommendations for health care providers to diminish these insecurities. First, logistical experiences could be improved by managing expectations about waiting times and using uniform transfer protocols. Second, by giving transparent information at set times about the current status and future care steps, will help parents to anticipate on potential future scenarios. Third, support with long-term and nonphysical consequences of the disease could be improved by increasing specialized knowledge of professionals on these topics. Fourth, involving parents in decision-making processes and providing them tools for self-management and coping, can help parents feel in control, tackle setbacks, and stay healthy. These measures are expected to be also relevant in other congenital diseases with an unclear prognosis and for which children are hospitalized for a longer period of time.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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