

## ORIGINAL ARTICLE

# Mothers' lived experiences of support when living with young children with congenital heart defects

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The progress made within earlier diagnostics, surgery, and postoperative care has been said to increase constantly the number of survivors with congenital heart defects (CHD). It is possible to determine the majority of childhood diagnoses before the child begins school, and many medical complications that are encountered can be rectified. Yet more complex malformations require intense, long-term follow-up, and therefore necessitate repeated interventions and investigations (Wren & O'Sullivan, 2001).

The impact of health problems has been found to be greater within several domains for these children than for healthy children. Children with health problems might experience a reduced ability in autonomy, and motor and cognitive functioning (Krol et al., 2003), as well as experience various psy-

**Abstract**

**Purpose.** The purpose of this study was to illuminate the meanings of support as disclosed by mothers of children with congenital heart defects (CHD).

**Design and Method.** Narrative interviews were conducted with 10 mothers of children with CHD. A phenomenological-hermeneutic method was used for interpretation of the transcribed interviews.

**Results.** The comprehensive understanding of mothers' lived experiences of support emerged as the experiences of receiving good support, receiving "poor support," and absence of support.

**Practice Implications.** Mothers receiving person-centered and family-centered care feel more supported and are more likely to adapt to the stresses of parenting a child with CHD.

chosocial challenges in their lives (Fredriksen, Diseth, & Thaulow, 2009). It has also been found that children with severe CHD and children with other complications in addition to any level of CHD have higher levels of social or communication impairment than children with mild to moderate CHD (Brandlistuen et al., 2011). These children's problems can also lead to an increased level of distress in their families (Carey, Nicholson, & Fox, 2002). However, studies have shown that many children can adjust to their life limitations by learning various coping strategies and can come to perceive themselves as being as equally capable as other children (Bjorbaekmo & Engelsrud, 2008).

It can be a great burden for parents to be informed that their child is suffering from heart disease. The whole family might be affected and might undergo a

stressful adjustment process (Lan, Mu, & Hsieh, 2007), experiencing challenges such as attempting to understand the disease's effects, coping with uncertainty, and seeking reassurance from health-care providers (Stratton, 2004). Experiences such as somatization, depression, anxiety (Yildiz, Celebioglu, & Olgun, 2009), distress, hopelessness, and social isolation can also arise (Lawoko & Soares, 2004). Mothers might also feel guilt and might wrongly blame themselves (Lan et al., 2007; Nyström & Axelsson, 2002), or they might feel frustration over not having a healthy baby. Those who have multiple children might additionally experience neglecting the healthy children (Lan et al., 2007).

Each parent has a unique reaction and varying levels of anxiety, but in a study by Yildiz and colleagues (2009), mothers seemed to be more strongly affected by the child's disease than the fathers. After conducting this quantitative study, Yildiz and colleagues drew the conclusion that mothers spend more time on and are more actively engaged in care for the child with CHD. Lawoko and Soares (2006) also found that mothers are at an increased risk for chronic psychosocial problems in terms of depression, anxiety, somatization, and feelings of hopelessness. Studies that have analyzed differences in gender and interactions between health status and the total workload of paid and unpaid work stated that mothers in Sweden generally take greater responsibility for child care than fathers do (Berntsson, Lundberg, & Krantz, 2006; Krantz, Berntsson, & Lundberg, 2005).

The need for support among mothers of children with CHD can begin with the diagnosis. At the point of diagnosis, healthcare professionals have the important task of encouraging parents and providing them with relevant information in simple terms. Parents need to be prepared for their children's upcoming treatment, what it means, and what to expect (Upham & Medoff-Cooper, 2005). This dimension of support is considered to be tangible and concrete (Stoltz, Andersson, & Willman, 2007).

Another dimension of support is the type of relationships mothers have with others (cf. Stoltz, Udén, & Willman, 2004). This dimension is referred to as social support and can consist of emotional support, such as advice, consolation, and caring from the people who have a close relationship with the mother. Social support is considered to be very important for mothers who are in crisis. Spouses, children, grandparents, next of kin, friends, and colleagues are examples of contacts who can provide

support by listening and discussing (Laakso & Paunonen-Ilmonen, 2002). Social support also appears to have a protective function against a variety of pathological states for persons in crisis, although it may accelerate their time for recovery (Cobb, 1976). Hupcey (1998) studied the subject of social support and found it to be complex; likewise, researchers and theoreticians have been attempting to define and describe aspects of social support but have not achieved clarity. Hupcey gave an example of one of the more specific definitions in the literature, which was originally presented by Cobb (1976), who defined social support as information that leads someone to believe that he or she is cared for, loved, esteemed, and a member of a network of mutual obligations. Lawoko and Soares (2003) found that the more caregiving time a mother spent on behalf of the child, the less possible it was for her to obtain social support. Tsai and Wang (2009) conducted an investigation into the correlations between health and caring for sick children, and found that the more effort a mother spent on caregiving time, the greater was the level of strain that she experienced. Furthermore, the greater her level of strain, the worse her health status was. In contrast, the study indicated that mothers who received higher levels of social support experienced lower levels of strain.

Some studies indicated that high levels of support are available for mothers during the hospitalization of their premature infants in neonatal intensive care units (Mok & Leung, 2006), as well as for mothers of hospitalized children at pediatric sites (Sanjari et al., 2009). Other studies showed that mothers reported high levels of satisfaction with the support they received from the healthcare team, especially from the nurses (Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002; Tran, Medhurst, & O'Connell, 2009). Nevertheless, mothers still reported a desire for more support than what they received, even though they reported that healthcare professionals provided adequate services (Mok & Leung, 2006). Disappointment in the care process can arise from too few opportunities to speak to healthcare professionals and a lack of information (Nyström & Axelsson, 2002). Tran and colleagues (2009) found that mothers desired more empathy and understanding from healthcare professionals, along with more time to discuss issues related to their children's care. In order to offer good support for mothers, healthcare providers must determine what the needs of the mothers are, what kind of actions they perceive as helpful, and what will help

them feel satisfied and supported (Lawoko & Soares, 2003; McKenzie, Wade, & Davidson, 2010; Miles et al., 2002). Thus, the purpose of this study was to illuminate the meanings of support as disclosed by mothers of children with CHD.

## METHODS

### Design

To reach an understanding of the phenomenon, a qualitative research design, with a phenomenological-hermeneutic interpretation method inspired by Ricoeur's (1976) interpretation theory, was used (Lindseth & Norberg, 2004). Phenomenology strives to seek the essence of a phenomenon and what it means for the humans who experienced it (Polit & Beck, 2010). A phenomenon may have another meaning than what may appear on the surface. Thus, the method seeks to explain the lifeworld, the experience as it is apprehended in reality (Husserl, 1931). Hermeneutics is closely related and focuses on meanings and interpretations of texts. The sense of a text is something disclosed, and that something is pointing toward a possible world (Polit & Beck, 2010). These two philosophies are equally important to reach a full understanding of texts (Ricoeur, 1976). Within a phenomenological-hermeneutic interpretation method, the researchers followed the texts' movement, from what it said to what it talked about, instead of listening to the discourse as it initially occurred. This method of interpretation can, through comprehensive understanding, reveal and provide new possibilities for being in the world.

### Participants and procedure

The head of a children's cardiac clinic in northern Sweden gave permission to recruit participants for the study. A nurse from the clinic agreed to cooperate with the recruitment by selecting the participants consecutively from the visitor register of a pediatric cardiac outpatient clinic in northern Sweden. Both the clinic and the mothers gave their consent to record and carry out the interviews. In accordance with research ethics, the mothers were assured that all information would be kept confidential. The study was approved by the university's research ethical review board.

The selection procedure was performed by the nurse at the pediatric outpatient clinic. The selections were taken from the visiting register at the pediatric outpatient clinic during the year 2009. The

criteria given to the nurse for selecting the participants for the research study were mothers of children diagnosed with CHD, and children who were born between 1996 and 2006 (i.e., 3–12 years old as of 2009). We chose not to include mothers of adolescents in this study because we expect that children undergo a liberation process from their parents in adolescence, which we believe can affect the meanings of support for mothers. The mothers needed to speak Swedish. The children needed to visit the pediatric cardiac outpatient clinic on a regular basis, at least once per year. Mothers of children with mental retardation were excluded as those children were expected to have other types of needs.

The mothers were asked to participate in an interview concerning their experiences of support in connection to their children's heart defects. The written request, with information about the aim of the study and how it would be implemented, was sent to the mothers' home addresses. They were informed about the confidentiality of the study and that participation was voluntary. They were also informed about their right to withdraw from participation without explanation or consequences for continuing care. They were asked to return their responses in pre-addressed envelopes, with names and phone numbers in a reply form, along with a clearance form indicating whether or not they were willing to participate.

The mothers were contacted by phone, which gave them the opportunity to ask questions and determine a time and place for their interviews. Ten mothers agreed to participate, and of them, one wanted to carry out the interview together with her spouse. (The selections of parents, both mothers and fathers, were made at the same period. The fathers' experiences are presented in another study.) All mothers lived in northern Sweden. Three of the mothers lived in an urban area, six mothers lived outside urban areas, and one mother lived in the countryside. Six mothers had a university education, and four mothers had upper secondary school education. One mother was unemployed, and one mother had taken early retirement; the remaining mothers were employed. Their mean age was 38 years. Their children had the following diagnoses in different combinations: anomalous pulmonary venous return, aortic and mitral valve insufficiency, atrial septal defect, atrioventricular septal defect, coarctation of the aorta, discrete subaortic stenosis, double outlet right ventricle, hypoplastic left heart syndrome, single ventricle heart defect, tetralogy of Fallot, and ventricular septal defect.

### **Narrative interviews**

Collecting data by interview is an appropriate procedure to reach an understanding of human actions and experience (Polit & Beck, 2010). Mishler (1986) stated that by narration, respondents can highlight issues that are most important to them.

Between March and June 2009, the participants were interviewed individually, except for one married couple who wanted to be interviewed together. All interviews were conducted by one person in the research team (EB), and encouraged the mothers to provide deep and richly described stories. The focus was on the mothers' experiences of support. Each interview was between 50 min and 2 hr, taped digitally and transcribed verbatim. All interview locations were chosen by the respondents. This was arranged in order to let them feel as comfortable as possible so they also would be better able to narrate their emotional experiences of support. One interview was conducted in a parish house in the mother's village, three in a student room at the university, one at the mother's office, and five in a conference room at a library. All locations chosen were kept secluded from disturbing surroundings.

The same interview guide was used for all interviews. The open-ended questions led the informants to freely narrate their experiences of support in their own words. The following questions were asked: (a) Can you please tell me what support means to you in your situation of being a parent to a child with a heart defect? (b) Can you please describe a situation in which you and your child received the desired support? (c) Can you please share with me a situation when you and your child received what was meant to be "support," but, as you experienced it, was not the desired support? Probing questions such as "Whom?" "When?" "What do you mean?" and "Could you tell me more?" encouraged detailed explanations.

### **Data analysis**

A phenomenological-hermeneutic method of interpretation was used to interpret the interviews (Lindseth & Norberg, 2004). The interviews were transcribed verbatim into a text. The development into a deeper understanding moved in a spiral rather than a linear formation. This occurred in a three-phase process, from naïve understanding, to structural analysis, and finally toward comprehensive understanding. The first step to understanding the phenomenon included several readings of the text as

a whole in order to apprehend the entirety and create a first naïve understanding. The first phase then guided the second phase of interpretation. The second phase, the structural analysis, was done to clarify the text and to validate the first naïve understanding. The third phase of the interpretation reached a comprehensive understanding. In this phase, the research question was reflected on in relation to the understandings that had developed during the previous two phases, taking the researcher's pre-understanding into consideration.

## **RESULTS**

### **Naïve understanding**

The interpretation began by reading the interview text several times from a phenomenological approach to reach a first naïve understanding. The purpose of this procedure is to let the text speak, and thus create an overall sense of the material's content (Lindseth & Norberg, 2004).

The mothers of children with CHD need support to gain understanding of the disease and the situation. They have a desire to receive competent care and support that allows their everyday lives to function well. The mothers need support in the forms of sympathy, confidence, being treated with respect, and being taken seriously. They need these forms to come partially from health professionals, as well as from relatives and friends. Uniting with other mothers who are in similar situations can also provide invaluable support. Confidence is created not only with an assured diagnosis, proper treatment, and follow-up, but also with the feeling that competent, updated healthcare professionals will devote their time to the child and coordinate a dynamic and effective care plan with a holistic perspective. The mothers' desires to gain support give rise to their need for privacy and for calmness, as well as their wishes that others will have the time to listen to them so that they feel affirmed and important. The mothers appreciate guidance that will enable their children to acquire resources and tools that facilitate their lives.

### **Thematic structural analysis**

The second step of the interpretation, the thematic structural analysis, was guided by the naïve understanding, and it aimed to validate that as well. The text about the meaning of support was divided into meaning units, and then condensed and further

**Table 1. Example of Structural Analysis of Two Themes**

Meaning unit	Condensed statements	Abstracted statements	Subtheme	Theme
Yes, support, it can be so much, it could be from mother and father, that they take care of her for an evening so you can get some sleep, *laugh,* or just sit, and, and take it easy, get some time to socialize with, well, with my cohabitant, well, so we can be alone sometime.	Support can be when the grandparents take care of her for an evening so you can get some sleep, or have some time to socialize alone with my cohabitant.	Sense of support in everyday life when relatives are babysitting.	Needing to prioritize oneself	Requesting privacy as support
We joined the heart association for children to meet like-minded so to speak, and get, it's not that often you meet a family with children with heart defects so, so that, but through this association then, we had very much, it felt like you had, yes, the possibility to be able to keep your sense in some way, it came from there, so and there are several who have it much, much worse.	We met like-minded in heart association for children where we got to meet others, and thereby we got help to keep our sense in some way. There are others who have it worse.	Feeling of support in the community with like-minded and insight too that others can have it worse.	Feeling supported by parents of other children with heart defects	Supportive confirmation

abstracted (Table 1), and grouped into subthemes and themes (Table 2). The findings of the structural analysis present 11 subthemes that fall under four themes. The first theme describes how the mother must make changes to her life and must make sacrifices for the good of the child. This theme also includes the dissatisfactions and difficulties that come with living with a child with special needs, and the mother's desire for support to manage this. The second theme clarifies the way that the mother sees herself as the manager of her children's care due to the limitations of the system, and her desires for relief concerning this. The third theme represents the mother's need for support to reach tranquility,

privacy, and integrity. The fourth theme summarizes the common exchange of support that the mother has with others in the same situation. She experiences a need to be near her children and also an appreciation for the professional support that is available.

The quotes that are illustrated in the structural analysis are selected from among all 10 interviewees who participated in this study.

**Theme 1: Needing support to overcome limitations in daily life.** *Feeling inhibited due to the child's condition* reveals how the child's illness forces the mother into an unwanted, limited lifestyle. Mothers can rarely prioritize their own interests and social activities. One reason for this limitation is the feeling of fatigue that occurs as a result of managing and structuring every activity around the child. Their intention is to help make the child's existence as favorable and as positive as possible. Mothers experience a guilty conscience when their own stress and sense of overload affect their ability to satisfy the needs of the child's healthy siblings. Mothers must stay at home for a long period of time when the child is ill because the recovery time for children with heart defects is prolonged. In the time before the child is diagnosed, mothers might have reduced financial resources, with no access to long-term compensation for being at home with their seriously ill children. The negative effects on their household economy also limit what they can afford to do. Thus, mothers need support to overcome their fatigue, bad conscience, and economic compensations.

**Table 2. Themes and Related Subthemes**

Theme	Subtheme
Needing support to overcome limitations in daily life	Feeling inhibited due to the child's condition
	Feeling concerned about the situation
	Feeling vulnerable
Desiring coordination of care within the society as support	Requesting routines in coordinating care for the child
	Feeling significant for the care of the child
Requesting privacy as support	Needing to prioritize oneself
	Losing privacy
Supportive confirmation	Being pleased with the support that is available
	Feeling supported by parents of other children with heart defects
	Feeling proud and relieved about the knowledge gained through having a sick child
	Feeling satisfied in being close to the child

. . . it has meant that I am, 9 years later, on the verge of burnout, uh, because it's so much that we actually have to constantly work with.

*Feeling concerned about the situation* implies that mothers feel concerned about their children's well-being and health. They feel helplessness and stress when the child is weak and when diagnosis takes a long time to complete, or they feel shock and despair when the diagnosis of a heart defect is totally unexpected. Mothers fear losing their children and find it overwhelming to be asked to take part in difficult decisions about giving the child life-saving treatments. When they lack information, the worry and fear is the worst. They sometimes wonder whether they have done something wrong that could have caused the child's illness. Given the mothers' fragile conditions, healthcare professionals should neither provide information that can be misinterpreted nor disagree with one another over decisions concerning the child.

It is painful for mothers to see their children under strict supervision. It can also be emotionally trying to see the children's fear of treatments and painful procedures. Mothers feel grief over their children's illnesses and can even feel anger and injustice if they are unable to accept the situation. Feelings of disappointment can appear when they are unable to provide for their children's basic needs, and they suffer from guilt when they do not always have the opportunity or strength to be at the child's side. They also feel concerned about the risks for complications. The differences in the healthcare professionals' competence make them feel insecure. Mothers become anxious if the healthcare professionals cannot supply instructions regarding how to facilitate the child's activities in their daily lives. They feel frustration when people do not understand the implications of their situation, and thus will not adjust to the instructions given for the child's sake. They worry that their children will not be given access to tools to make their lives easier. This worry takes a lot of their time, and their confidence in healthcare professionals decreases when the latter do not take these modifications seriously.

The child's lack of insight into his or her own illness can result in family conflicts. Mothers feel mutual grief for their children's limitations but are simultaneously forced to be stern in setting limits for their children. Mothers feel concern about the future, and the child's medical history might lead them to be overprotective. Mothers also have concerns over the other family members' needs for

support. Thus, mothers need support to have the strength to support their whole families.

These years, when he should be having fun and playing, being a child and shamble around in long underwear and having fun in kindergarten, they're gone, because he's lying at home sick, and I have a 3 year old who's begun to ask if his friends are sick just as much. Oh, why am I sick so much? Because he starts to feel it himself . . . that he's not coping.

*Feeling vulnerable* refers to the feeling that arises when healthcare professionals do not take the mothers' concerns seriously, and when children's prolonged and unhealthy conditions become normalized. Mothers feel exposed when they notice gaps in coordination between institutions, and when healthcare professionals, both within and outside of the healthcare industry, such as the school personnel, have insufficient knowledge. It is frustrating for them when their children's cases are given low priority; moreover, they want the opportunity to participate in decisions within all areas concerning their children's care. Mothers have to take the initiative to demand resources and support to facilitate their children's daily life activities. They perceive themselves as being ignored when they experience an absence of holistic care and a lack of respect for their suggestions. They also feel lonely when their friends distance themselves. Thus, mothers need support in the form of competent and coordinated care.

If they would do as I say, I think he would get better support. If someone said: let's do this, fast in the arm, we'll stick you and then we are finished . . . I think that would be better support for him, instead of standing there with clowns trying to get him to think of something else.

## **Theme 2: Desiring coordination of care within the society as support.**

*Requesting routines in coordinating care for the child* concerns the mothers' desires for better cooperation from those who have the primary responsibility for the care of their children. Mothers encounter major flaws in the transfer of information between child care and health care. There is a request for more preventive thinking about the children's needs as they change over time. Mothers wish to avoid responsibility for being the link between instances, and request a greater number of dynamic solutions that would also take the family's opportunities into consideration. Getting guidance in what it takes to receive financial help, or to organize, plan, and obtain relief, is perceived as valuable support for mothers.

. . . A better follow-up in some way, would I like . . . from institutions that the child belongs to, from the counties and municipalities in the first place, because that's where the child is, in child care and schools, and even then in health care. Yes. So that a cooperation in between and a better follow-up . . . that you have prevention in mind . . . It takes a long time before a parent might realize that this is not quite right . . . and other parents do not really know what they should do . . . then the care won't be fair . . .

*Feeling significant for the care of the child* is based on the mothers' feelings of needing to act as a manager for their children. Mothers claimed that they took most of the responsibility for the care of their children and that they spent a great deal of effort organizing their children's treatment. Mothers need to instruct, correct, or make suggestions to healthcare professionals in what to do and how to handle the child's condition, which contributes to their loss of respect for and confidence in the healthcare professionals, although it is important for them to have this faith in order to feel safe during the children's care. Mothers have noticed that healthcare professionals have insufficient knowledge, which is why they must find more specific information from other sources. Thus, mothers experience support when the healthcare professionals are updated.

. . . The parent is like a coordinator and must carry the information between departments, and that isn't the parent's role, according to me, that's where I really think that health care has gaps . . . I shouldn't have to have all that stuff in my head all the time, I need to be able to feel safe, that this physician, which we are now meeting, has read the journals so well that I shouldn't have to add something, but no, that has never happened.

### **Theme 3: Requesting privacy as support.**

*Needing to prioritize oneself* means that mothers cherish their personal integrity. It is common that they need time to themselves after being notified about their children's medical conditions. Mothers experience support when they are being left completely alone or are able to choose to be together with someone they have a close relationship with. Mothers lack strength to answer questions in the early days of their children's diagnoses, which may collide with relatives' wishes to display their participation by keeping in touch. Healthcare professionals who cannot see the mothers' need for privacy may be perceived as pushy. Living with a child with a heart defect requires highly intensive care, and therefore the mothers appreciate receiving some help and relief in order to be able to recover. They

are grateful for opportunities to spend time in environments other than home and to have time to think more about themselves for a while.

. . . I was so exhausted in the beginning when we got home, and I, yeah, I turned off the phone, to, just that all my friends, all friends, they all wanted to call and ask and, well like almost every day, and I said it, I can take it, we turn off the phone, so, most people knew that we didn't answer, for I, I couldn't talk on the phone, I couldn't manage anything, and by then the closest family was enough . . .

*Losing privacy* refers to mothers feeling offended as a result of others telling them what to do. Mothers feel that they do not need to specify or to explain their concerns to outsiders. When certain treatments for their children need to take place at other facilities, the resulting unexpected and instant transportation of the child can come as a surprise. It can be perceived as uncomfortable, and when the mothers are forced to expose themselves to unknown persons, they can feel as if they no longer have self-determination or a private life. When there is no possibility to choose or to refuse actions and treatments, they feel very defenseless. Being able to defend their privacy means support to the mothers.

It has been such a frustration to the max, I had also myself, uh, when you begin to realize it, that I am not only a parent, I am apparently also just a human with limitation, and I cannot going around around the clock and at the same time doing my job, . . . as it has been for me, my mother was babysitting, so I could go to sleep or work, no question about that I maybe would have to go out or going to the movies, that has never been prioritized because of the economy and then I do not have any energy either.

### **Theme 4: Supportive confirmation.**

*Being pleased with the support that is available* means that the mothers feel grateful to receive specialized care for their children from professional healthcare providers (nurses, physician, psychologist, social worker, occupational therapist, and physiotherapist). Getting a gracious explanation and having time made for their needs create a feeling of safety. It is important for them to be taken seriously. Mothers appreciate the availability of healthcare professionals who can clearly explain and give information. They also value the honesty of healthcare professionals. When healthcare providers have the time and flexibility to meet their specific needs, they feel well respected and thus supported. They feel empowered by being involved in the care of their

children, and they feel a great appreciation for the support and resources provided to facilitate their needs in everyday life. If they get help with coordination and planning, then they feel grateful and relieved. It is important that holistic care is practiced. Excellent support occurs when caregivers follow up on events. It is also vital for mothers to maintain their social networks.

I don't know if there is a difference . . . those who work with children or those who work with adults, I have no idea . . . they are so amazingly soft and nice and they are so good with parents, knowing that it regards their children, who are the most important thing in life . . . It felt like that they were handpicked, really . . . it really is the right healthcare professionals to work with parents who are in crisis.

*Feeling supported by parents of other children with heart defects* means that mothers have a desire to get in touch with these other parents. The feeling of being alone in the situation decreases when they have the opportunity to meet with others who are in the same position. They feel it easy to be understood by others who have had similar experiences, and thereby understand the implications of the process that they are undergoing. The mothers' insight increases, and they become strengthened and supported by sharing and by the community spirit.

We joined the Association for Children's Hearts to look for like-minded people . . . it's not so often you run into a family with children with heart defects . . . but through this association we gained a great deal. It felt like it was, yes, the ability to be able to keep the head clear in some way . . .

*Feeling proud and relieved about the knowledge gained through having a sick child* refers to the mothers' feelings of satisfaction in the knowledge they have acquired. These feelings are associated with the sense of pleasure that the mothers gain from being able to share knowledge and advice with other parents who have undergone similar situations. Mothers feel that they are important, and they gain confidence when they are requested to become a contact person for other parents. Mothers who also are able to meet and manage their own children's needs obtain a feeling of well-being.

As a contact person . . . then I know their situation. They need to talk to someone who knows what a saturation meter is and who knows about pressure in lung veins. Well, it is that kind of stuff that . . . you become quite familiar with, and we who have children with these heart defects are quite . . . quite skilled . . . know a lot about hearts and so . . .

*Feeling satisfied in being close to the child* indicates that the mothers have a need to be near their sick children in the first place. Mothers appreciate and feel supported when the healthcare providers understand and confirm their desires to be together with the children, and when health care is coordinated in such a way that the mother and child are not separated from each other. Mothers feel tremendous pleasure and relief when healthcare providers allow them to hold and handle their children, and to be involved in the care for their children.

I remember the first time they removed a few tubes so I could sit and have him in my arms, you know, I remember that I told them that I hadn't even been allowed to change a diaper on him either, nothing . . . after a while I got to begin assist, changing diapers, to dress him, wash him and things like that . . . it felt great, actually.

## COMPREHENSIVE UNDERSTANDING

Comprehensive understanding is the third step of the interpretation. This deeper understanding of the text as a whole is based on the researcher's naïve understanding, structural analysis, and pre-understanding in relation to the research question. In addition, relevant literature has been used to widen and deepen understanding (Lindseth & Norberg, 2004).

The meaning of support for the mothers of children with CHD is to receive assistance to get their needs and desires satisfied. Support has a multitude of dimensions for them. On one hand, they are grateful for and feel relieved by the support that has been given to their families. On the other hand, they become victims in different ways under the circumstances and as a result of a lack of support. Each mother's need for support is unique and changes over time. The comprehensive understanding of this study's mothers' lived experiences of support is presented in the following three ways: the experience of receiving good support, receiving "poor support," and the absence of support.

### The meaning of "receiving good support"

Mothers need support to regain their psychic well-being and strength. They need free space and time on their own to reload and to build new energy. They need to be encouraged to seize their human right to care for themselves because they cannot care for their children if their mental faculties are failing. Support also means to have both privacy and community with others. When the mothers meet other



parents in the same situation, they feel understood and are comforted by not being alone in their situation. When their need to vent is satisfied, they feel lighter and more relieved.

To some degree, the mothers want to be involved and have insight, but they do not want to take full responsibility for the quality and constant vigilance of their children's medical care. The mother's strength, time, and knowledge are too limited to play every single role in the life of the child with CHD. Support means to be relieved from what they feel are their healthcare responsibilities so that their role as a mother can play a dominant part in their relationship with the child. Mothers feel a great deal of pressure when their presence and participation are constantly required to coordinate their children's care. Support means to feel safe and supported when they have access to expertise and relevant knowledge, and when they meet skilled healthcare professionals who are honest with them. When they receive help or resources to ease their everyday lives, they are grateful for the attention.

Respect and a need for privacy are important subjects. Support means to be offered privacy after receiving the news about the child's diagnosis and the confirmation of the child's critical condition. During this time, relatives and friends want to keep in contact to share their sympathy and to receive information. Playing the role of communicator can be too much for mothers during the initial period of grief. Therefore, support means to understand and accept the mother's desire to be left alone, and then provide support in the form of company when the mother needs it. This conclusion is in line with the claims of Tak and McCubbin (2002), who maintain that perceived social support is a key resource that helps the parents of children with CHD cope during times of crisis.

Support means to be given confidence to be involved in the care as soon as possible. Mothers associate the ability to hold and to provide for the child's basic needs for the first time with a wonderful feeling of joy and a sense of being a capable mother, and their self-confidence grows when healthcare professionals allow them to participate in the care. These findings are similar to those of Hopia, Tomlinson, Paavilainen, and Åstedt-Kurki (2005), who emphasize the important role of healthcare professionals in helping mothers of chronically ill children clarify mothers' role and reinforce their parenthood. This can be done through encouragement and by giving positive feedback during hospitalization.

One way that mothers met other parents of children with CHD was joining an organization.

Mothers' feelings of being alone with their problems decrease when they have the opportunity to vent. Other parents who are familiar with similar situations and terms have a different kind of comprehension than, for example, friends who have had no such experience. Thus, support means to receive other types of advice and tips than they would have received from healthcare professionals. Good social support has been found to reduce the risk of suffering from depression (Gjesfjeld, Greeno, Kim, & Anderson, 2010). Similar to mothers of children with cancer (Fletcher, 2011), the mothers in this present study also valued the support of a like-minded community, while another study of parents of children with physical disabilities noted that healthcare providers should help parents maintain social support (Cavallo, Feldman, Swaine, & Meshefedjian, 2009).

After the child's condition has been stabilized, mothers worry more than before about being able to maintain a smoothly functioning everyday life. They claim that they struggle against barriers that result in frustration and fatigue. Thus, mothers end up in a kind of victim role and are placed in a dependent position. This problem is by no means specific to mothers of children with congenital heart diseases but generally appears when mothers have a child with special needs (e.g., when the child is living with cancer, Fletcher, 2010; or brain injury, Jones, Hocking, & Wright-St Clair, 2010; or when the child has disability, Sen & Yurtsever, 2007). Support, thus, means that mothers are offered to be involved in the caring of their children, and this involvement will relieve them from the experience of being in a victim role.

### **The meaning of "receiving 'poor' support"**

Mothers of children with CHD feel worry and hopelessness when the children are critically ill. Mothers feel sad when they are not able to care for the child's basic needs, such as breastfeeding, washing, or giving comfort. They need to be near their children, even if they cannot do anything but watch. They become insecure when they believe they are in the way of healthcare professionals who work with the child. Therefore, support means the opportunity to understand the implications of the treatment and the status of the child's condition. McCusker and colleagues (2009) found during their intervention study that maternal anxiety reduced when mothers received assistance with meaning-making; with processing of difficult emotions, such as grief over the loss of a "healthy child"; with the promotion of the mother-

child relationship in the care of the child; and problem-solving strategies for dealing with their concerns. The results in the present study show that "poor" support was given when the mothers could not understand or absorb the given information. One explanation for this lack of understanding might be that the shocking news blocked their ability to digest and comprehend the given information when it came immediately after diagnosis. Stinson and McKeever (1995) recommended that healthcare professionals provide information gradually throughout the child's hospitalization for cardiac surgery, and this information should be combined with written documents, illustrations, or videotaped information.

Mothers felt frustrated when they encountered deficiencies within the healthcare organizations. The mothers also found the transfer of information among the healthcare setting, preschool, and school setting to be problematic. They continually had to coordinate and transmit information among these institutions. Anderson (2009) also highlighted the finding that healthcare professionals at school were rarely prepared to receive children with special needs and communicated with the mothers infrequently. Ray (2002) found that the health and social services system could take up to half of the caregiving time, and they considered the structure of the system to be more difficult to work with than working with individual healthcare professionals. Similar to the findings of the present study, Ray showed that parents of children with chronic illnesses desire a more flexible system and a more holistic approach to their children's care.

Each mother of a child with CHD is forced to make major changes due to the child's condition and accompanying problems. The life that the mother once had has been displaced, and her social and personal life depletes alongside her decreasing strength and stamina, and the disease's negative effects on the family's financial situation. The mothers' plans for their daily lives have faded away because of these diminishing resources and support. All these sacrifices were made out of love and goodwill for their children. Even though the child's well-being is important, a mother cannot indefinitely displace her own needs. Support means to be appreciated and prioritized, but when mothers felt invisible, they experienced a lack of support.

### **The meaning of feeling "absence of support"**

The large readjustment that happens in life after giving birth to a child is quite challenging for most

mothers, in general, and can strongly affect their quality of life (Hill & Aldag, 2007). The results of the present study claim that mothers, moreover, suffer from strong anxiety for the child's health because of the encountered complications. It is clear that during the initial, most critical phase, mother's worries primarily concern the child's survival and well-being. Through this first period of uncertainty and fear, mothers are very fragile and feel psychologically unwell. If no one takes their fragility into account, they do not feel supported. These findings were confirmed by Doherty and colleagues (2009), who found that the mothers of children with CHD experienced elevated levels of psychological distress 1 month after the child's birth. According to Lawoko and Soares (2006), psychosocial morbidity can be chronic for a significant proportion of mothers who have children with congenital heart disease.

The present study shows that mothers of children with CHD must make numerous sacrifices in their lives. Their social activities and personal lives shrink as they perform additional work for their children's illness-related needs. This shrinkage leads to decreasing strength and stamina. The household economy is also affected negatively when the possibilities to work drastically decrease compared with what they were before the child was born or diagnosed. All these changes result in expectations for and visions of daily life fading away. Mothers feel fatigue and experience reduced joy in their lives because of these changes. Bourke-Taylor, Howie, and Law (2010) had comparable findings; they discovered that mental health issues as well as emotional distress are possible consequences of these kinds of challenges for mothers of children with disabilities. Enskär, Hamrin, Carlsson, and von Essen (2011) also found it surprising that many of the parents of children with cancer experienced severe financial strain even though social insurance covers absence from work and a good deal of the healthcare costs. There appears to be a lack of economic security for those with sick children. This assumption is in line with the experience of lack of economic support in our study.

In the present study, absence of support means that mothers need to battle to get respect from school personnel. A child with CHD does not have as much stamina as healthy children have, so if the school does not follow the limitations in the child's activities, then the family might need to change its leisure plans. This problem clarifies the importance of medical healthcare professionals providing information to healthcare professionals within other

contexts, such as the school, who are also involved in the care of the child. Otherwise, the mothers see themselves as the managers of their children's health care. They also feel more tied up in their homes than before due to the extra needs of children with CHD. Their opportunities for relief are so brief and rare that they are not beneficial for them. Yantzi, Rosenberg, and McKeever (2007) interviewed mothers of children with long-term care needs and found that sometimes even the immediate family members did not have the knowledge or expertise to relieve the mothers of their responsibilities. The results of our study indicate that mothers experienced a similar lack of transmission of information from healthcare professionals to school personnel, as well as a lack of understanding from society, which they experienced as an absence of support.

## CONCLUSION

The meaning of support for the mothers of children with CHD is to receive assistance to get their needs and desires satisfied. As the needs for support by mothers of children with CHD are dynamic and change over time, it is very important that healthcare professionals are aware that these mothers will be under great pressure for many years to come. Mothers have a desire to be near their children, but they also have a need for privacy and time to reload their energy to cope further with their situations. Therefore, at regular intervals, healthcare professionals should put effort into contacting and informing the healthcare professionals in other fields who might need to provide the child with support. Getting confirmation and having contact with competent healthcare providers who practice personal and holistic care that stretches beyond the hospital walls was highly important for the mothers in this study. If they do have these contacts, then they have opportunities to release their control and to experience reduced stress and burden. The findings in our study have also shown that offered support is more than a positive resource that is produced and given to a receiver who needs support. Support can also be seen from different perspectives: provided, perceived, and received support. The phenomenon of support has been shown in studies in the positive and negative presence and in its absence, and Hupcey (1998) made the observation that all intended support that is provided is not always perceived as positive by the recipient.

The mothers experienced support that was provided as well as not provided. They did not always

perceive the provided support as the caregivers had intended, and there was also sometimes an absence of desired support. The findings in our study show that the intended support given was also experienced as negative when it was not required by the mother, or when the mother required it but did not receive it in a desired way. The mothers desired different "ways of provided support" when they were in different circumstances. A specific "way of provided support" could be perceived as "good" in one situation but as "poor" or even an "absence of support" in another situation. If support was not adjusted to the mother's needs and desires, resulting in a specific "way of support" not being provided (i.e., not adjusted to the specific circumstance), then the mother experienced "poor support" or the absence of support, and thus suffered from incompetent care (cf. Sundin, Axelsson, Jansson, & Norberg, 2000) and from nonsupportive interactions. Neufeld, Harrison, Hughes, and Stewart (2007) study about nonsupportive interaction among women who were the caregivers of their sick family members (an infant or an adult) showed that nonsupportive interactions were negative actions that undermined the women's credibility as caregivers, interactions wherein the intended support was ineffective, or interactions in which the expected support was absent.

## Methodological Reflections

This study's trustworthiness is discussed on the basis of the concepts of qualitative research (i.e., credibility, dependability, confirmability, and transferability; cf. Hanson, Balmer, & Giardino, 2011). The strength of the present study is its method. We identified the phenomenological-hermeneutic method (Lindseth & Norberg, 2004) as an appropriate method for this study because our intention was to illuminate the meaning of support as disclosed by mothers of children living with CHD.

Prolonged immersion, reading the data multiple times, vertical and horizontal comparisons, and peer debriefing among the researchers supported the credibility of the findings. All three researchers were involved in the process of interpretation and discussed the work along the way in order to verify comprehension. Employing reflexivity was salient as one's own preconceptions may affect the results, and a self-critical attitude on the part of the researchers is required to uncover and acknowledge these preconceptions.

The participants in the present study consisted of a convenience sample of mothers purposely selected

and recruited from the visitor register of a specialist pediatric cardiac outpatient clinic. The participants were mothers of children from 3 to 12 years of age. The reason for the chosen age range was that these children fall within the preschool and school age years. By the time the child passes 3 years of age, she/he has been diagnosed and undergone the first treatments related to CHD. In addition, the children and their mothers have had time to meet life as a family with a child with CHD. This adequate experience with CHD can contribute to the processing and understanding of their experiences, so they can put their experiences into insightful words.

Ten narrative interviews were performed, each of which represented a variety of diagnoses of varying severities. Together, they contained many diverse experiences, and along with the quality of the interviews conducted, this diversity strengthens the study's credibility. A written request was sent to 25 mothers' home addresses. They were asked to return their responses in pre-addressed envelopes, with names and phone numbers in a reply form, along with a clearance form indicating whether or not they were willing to participate. Only 10 mothers replied that they were willing to participate. The number of participants satisfies what the method claims, and the mothers provided many rich narratives of the meanings of support that they associated with being a mother of children with CHD. The questions mothers were asked concerned their lived experience of support. The findings show that for mothers of children with CHD, support means getting their needs and desires fulfilled.

A clear audit trail that outlined sampling, data collection, and interpretation, as described in the Methods section, supported the dependability of this study and established the rigor of the study by providing the details of data collection and interpretation and some of the decisions that led to the findings. The trustworthiness and confirmability of the analysis lie in the method's nature because the dialectic between explanation and understanding is validated through three phases. One of the researchers (KS) has extensive knowledge and experience on this type of interpretation from her research of relatives' experiences of care, and the interaction between healthcare professionals and patients; she is also proficient in the research method used. All of the researchers are registered nurses. Two of the researchers (EB, CL) in this study are graduate pediatric nurses with several years of experience in pediatric care at a pediatric clinic. This mediates some understanding about the culture, the pediatric care,

and the phenomenon studied (i.e., similar understanding gained through prolonged engagement).

The limitation of this study is arguably that the findings may not be generalized to other populations, but these findings may be transferable to other mothers of children with CHD. Member checking, which is considered one of the most robust ways to assure credibility, was not done. This may have strengthened the rigor of this study.

#### How might this information affect nursing practice?

The findings in our study support the opinion that families receiving person-centered and family-centered care feel more supported and are more likely to adapt to their dramatically different lifestyle that occurs when a child requires extra care. This is in line with Pelchat and Lefebvre's (2004) study, which describes a holistic intervention program developed in collaboration with the families of children with disability. The program gave attention to each family member's well-being and was based on a family-professional partnership. The parents received support in their adaptation to the child's disability, and Pelchat and Lefebvre confirmed this support to be effective in facilitating the families' adaption. Likewise, Rempel, Rogers, Ravindran, and Magill-Evans (2012) conceptualized a model of five facets of parenting a child with hypoplastic left heart syndrome to find an intervention model that would fit those parents' needs. The model points to a social support intervention that includes a genogram (i.e., a visual depiction of family structure) and an ecomap (i.e., a visual depiction of sources of support and nonsupport) at the time of diagnosis to determine the family's lifelines and to encourage immediate support mobilization. This means that healthcare providers review and pay attention to the unique family situation, and the mothers may experience a fundamental prerequisite for adequate support.

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