

Peer support among parents of children with congenital heart defects: A qualitative analysis of written responses submitted via an online survey

Tommy Carlsson^{1,2}  | Anna Klarare^{2,3} | Elisabet Mattsson^{2,3}

¹The Swedish Red Cross University College, Huddinge, Sweden

²Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

³Ersta Sköndal Bräcke University College, Stockholm, Sweden

Correspondence

Tommy Carlsson, MTC-huset, Dag Hammarskjölds väg 14B, 1 tr, SE-75237, Uppsala, Sweden.
Email: tommy.carlsson@kbh.uu.se

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Abstract

Aim: To explore experiences of peer support among parents of children with congenital heart defects.

Design: A study analysing written responses to open-ended questions about peer support, collected via an online survey distributed in Sweden.

Methods: Respondents were recruited during 3 months in 2018 by means of convenience sampling, through ads via the Swedish foundation for families with children who have heart defects and two closed Facebook groups for peer support. An online survey containing open-ended questions was distributed and responses were analysed with systematic text condensation.

Results: Peer support was grounded in a mutual understanding among parents and involved highly appreciated emotional support. Listening to the stories of peers meant an opportunity to gain useful insights about what life is like for parents of children with heart defects. Receiving and providing peer support was described as rewarding on a personal level. Negative aspects of peer support were also described, which sometimes led to psychological distress and withdrawal from peer support activities.

Conclusion: Peer support is emotionally relieving and appreciated among parents of children with congenital heart defects, who consider providing the support a rewarding responsibility. While peer support activities may have considerable benefits for individuals, it may also lead to psychological distress for some.

Impact: This study addressed peer support among parents of children with congenital heart defects. The main findings illustrate the potential impact peer support can have on individuals and calls attention to the experienced benefits related to peer support activities, while also providing some insights regarding potential negative aspects. The findings have relevance for nurses, midwives, and other health professionals working in settings providing care for these families.

KEYWORDS

congenital heart defects, life change events, nursing, parents, peer support, social support

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1 | INTRODUCTION

Congenital heart defects (CHD) are the most common birth defects, with a global incidence ranging between 4-50 per 1,000 live births (Dolk, Loane, & Garne, 2011). There is variability in severity of the defect and the incidence of severe defects range between approximately 0.4 and 2.3 per 1,000 live births (Miranović, 2016). To successfully identify newborns who need prompt care, pre- and postnatal screening routines are now widely recommended in clinical settings (Ewer, 2014; Lytzen et al., 2019; Mohammed & Chinnaiya, 2011). Many countries have implemented nation-wide routines for screening, including obstetric ultrasound examinations and pulse oximetry measurements of newborns.

Regardless whether the diagnosis is established prenatally or postnatally, parents experience considerable psychological distress at the time of diagnosis (Carlsson, Starke, & Mattsson, 2017; Carlsson & Mattsson, 2018; Lalor, Begley, & Galavan, 2009) and after the birth (Bratt et al., 2019). Treatment often entails advanced intensive care, prolonged hospital stays, and repeated cardiac interventions, involving further stressors (Kosta et al., 2015). Research consistently shows that being a parent of a child with CHD is associated with psychosocial morbidity (Lawoko, 2007), psychological distress (Bratt et al., 2019; Franich-Ray et al., 2013; Uzark & Jones, 2003), and reduced quality of life (Arafa, Zaher, El-Dowaty, & Moneeb, 2008). The daily life of parents is negatively affected when having a child with CHD, including participation in social activities (Wray & Maynard, 2005).

1.1 | Background

Coping with family life is associated with perceived social support among parents of children with CHD, indicating that those who receive social support are more likely to cope with their situation (Tak & McCubbin, 2002). There are various types of social support, including peer support defined as the provision of emotional, informational, and appraisal support by an individual considered equal (Dennis, 2003). Research indicates that peer support is desired among parents of children with CHD (Carlsson, Melander Marttala, Wadensten, Bergman, & Mattsson, 2016; Jacobs, Boyd, Brennan, Sinha, & Giuliani, 2016; Sood et al., 2018) and that it has the potential to offer validation of feelings and insights on how to manage psychological stress (Mok & Leung, 2006). Parents articulate a need for peer support following the diagnosis of a birth defect, either in face-to-face settings or through distance-spanning technology (Carlsson, Melander Marttala, et al., 2016).

Parents of children with birth defects establish networks to come in contact with peers, either face-to-face or via the Internet (Carlsson, Landqvist, & Mattsson, 2016; Hall, Ryan, Beatty, & Grubbs, 2015). In many countries, families of children with birth defects turn to organizations that facilitate contact with peers. The peer support gained via these organizations may have various benefits for parents. However, the provision of the support often relies

on internal resources in the organizations and may not be delivered as part of healthcare services. Knowledge concerning potential benefits and risks associated with the peer support is needed in clinical practice, taking the considerable support needs articulated by parents into account. However, little is known about peer-to-peer communication between parents of children with CHD.

2 | THE STUDY

2.1 | Aims

This study aimed to explore experiences of peer support among parents of children with congenital heart defects.

2.2 | Design

This study used written responses to open-ended questions about peer support, collected via an online survey distributed via a national foundation and closed Facebook groups.

2.3 | Sample

2.3.1 | Study context

This study was conducted in Sweden. Sweden has one national foundation dedicated to families that have children with CHD (Swedish name: *Hjärtebarnsfonden*). The foundation is a nation-wide independent organization offering emotional and financial support for its members. The organization involves 12 local peer support groups dispersed throughout Sweden. Yearly camps for family members are offered in the organization. In addition to the national foundation, Swedish parents of children with CHD also manage closed virtual peer support groups via the social media platform Facebook. While there are many closed Facebook groups for Swedish parents of children with CHD, two larger and active groups were identified through the clinical network of the last author. One of these groups were for families of either living or deceased children, which had approximately 900 members at the time of data collection. The other group were for parents of deceased children, which had approximately 100 members at the time of data collection. Both groups were closed, meaning that they were only accessible by members and were not publicly accessible.

2.3.2 | Sampling procedure

Respondents were recruited by means of convenience sampling. An advertisement containing an invitation to participate in the study as well as a link to the online survey was published in a newsletter from the Swedish foundation for families with children diagnosed

with CHD and the two Swedish Facebook groups for parents of children with CHD (detailed in study context). To gain access to the peer support groups, one parent was identified from the clinical network

TABLE 1 Sample characteristics (N = 61)

Characteristic	N (%)
Age of respondent (years)	
20–39	31 (51)
40–59	26 (43)
60–69	4 (7)
Gender of respondent	
Mother	57 (93)
Father	4 (7)
Highest educational level of respondent	
High school	17 (28)
University/College	40 (66)
Not disclosed	4 (6)
Diagnosis of child/ren	
Prenatal	14 (23)
Postnatal	46 (75)
Not disclosed	1 (2)
Status of child/ren with heart defects	
Has one living child	33 (54)
Has one deceased child	25 (41)
Has several children, some alive and some deceased	2 (3)
Has several children who are alive	1 (2)
Age of living child (years), n = 36 parents of living child/ren	
<7	17 (28)
7–12	9 (15)
≥13	8 (13)
More than one child, both aged 13–18	1 (2)
More than one child, both aged 1–6	1 (2)
Age of child when death occurred (years), n = 27 parents of diseased child/ren <7	
7–12	0 (0)
≥13	4 (15)
Interventions of child ^a	
Heart catheterization	22 (36)
Heart surgery	51 (84)
Peer support group membership ^a	
Member of closed FaceBook group	55 (90)
Member of Swedish foundation for congenital heart defects	37 (61)
Experience of peer support ^a	
Web-based support	53 (87)
Telephone support	12 (20)
Face-to-face support	40 (66)

^aMore than one alternative possible

of one of the authors. This parent was a member of both Facebook groups and posted messages in each group containing invitations to participate in the study. In total, 61 parents submitted a response to the survey. Table 1 presents sample characteristics. When specified by the respondents, one had a child who died in the 1970's, two a child who died in the 1980's, two a child who died in the 1990's, four a child who died in the 2000's, and thirteen a child who died in the 2010's.

2.4 | Data collection

2.4.1 | Structure and content of questions in the survey

The survey was distributed during 3 months in 2018 via SurveyMonkey, a web-based tool used to collect data via online surveys. In addition to questions about respondent background, five open-ended questions were asked concerning experiences of peer support: (a) what has it meant for you to come in contact with others who share similar experiences (answered by 49 respondents); (b) what examples do you have of received support from members in the peer support groups (answered by 41 respondents); (c) what examples do you have of negative experiences or lack of support from members in the peer support groups (answered by 35 respondents); (d) is there something that is lacking in the support groups that you participate in (answered by 31 respondents); and (e) what are your experiences of providing support to other parents either with a living child or who have lost a child with a heart defect (answered by 33 respondents). Twelve respondents did not answer any of the open-ended questions. A translated version of the survey is presented in Additional File 1.

2.4.2 | Technical settings of the survey

The order of the questions in the survey was fixed and not adapted, i.e., questions were not randomized or changed depending on participant characteristics. The questions in the survey were distributed over two web pages following an initial page containing information about the study and a question about approval to participate (detailed in ethical considerations). The first page after the initial page contained questions about the respondent's backgrounds. The second page contained the open-ended questions about their experiences related to peer support. Respondents could go back to previous pages and were encouraged to write as much or little as they desired. No limits regarding number of letters or words for the responses were applied. The survey was open, meaning that it was accessible without a need for a password. Due to the anonymous design and to make it possible for two parents in the same family to respond using the same computer, IP addresses were not recorded and no limit was set in regard to how many surveys could be collected from the same IP address.

2.5 | Data analysis

The written responses were analysed with systematic text condensation, a descriptive approach for thematic cross-case qualitative analysis. The method is considered a pragmatic approach, focusing on what the respondents are saying, as expressed by them, rather than exploring and identifying underlying meanings. Systematic text condensation has an explorative purpose (Malterud, 2012). It is not restricted to any specific type of empirical data and is suitable when analysing qualitative data as written answers to open-ended surveys (Bjorkman & Malterud, 2012).

The analysis involved the steps detailed as follows. First, all responses were read repeatedly to gain an overall comprehension, being careful to keep an open mind towards the experiences of the participants. Having read the complete data set, preliminary themes were identified, portraying an initial overarching understanding of the content. Second, meaning units were identified in the written responses, defined as fragments of text that contained information related to the research question. This step involved reading the responses line-by-line, identifying relevant meaning units corresponding to the aim of the study. Third, meaning units were sorted in code groups inspired by the preliminary themes. Code groups were defined as decontextualized collections of meaning units connected by a similar content. During this iterative process, the analyst tried to be as flexible and creative as possible, allowing changes as the analysis moved forward. Fourth, subgroups were identified within each code group by reviewing the meaning units in each code group, illustrating the different components within a particular code group. Fifth, condensates that illustrated the content of each subgroup were developed, defined as an artificial quotation written in first-person format. The condensates were written so that as much as possible of the original wordings of the respondents were retained. Having formulated condensates, the analyst then identified at least one illustrative quote portraying the condensate. Sixth, condensates were reconceptualized as synthesized descriptions, written in third-person format, and symbolizing the cross-case synthesis. Lastly, the essential aspects of each code group were formulated as category headings, serving as precise and expressive statements that portrayed the most significant findings within the code group.

The analysis was data driven, meaning that no theoretical framework was used as a template to guide the analytic process. The analytic process was flexible and iterative, meaning that steps were repeated when needed and the analysis was reviewed in relation to the raw data during all steps. The first author performed the qualitative analysis. Nvivo for Mac was used to organize meaning units into code groups and subgroups. The second author read all responses and scrutinized the results to approach the data from another researcher's perspectives.

2.6 | Rigour

An online survey was used because it is considered a suitable method when aiming to describe experiences and generate hypotheses

through inductive methods. Another reason behind the methodological choice was that knowledge gained from online surveys has the potential to provide data grounded in the social and cultural context of interest, resulting in in-depth knowledge of particular groups (Eysenbach & Wyatt, 2002). These aspects imply that an online survey is an appropriate option, considering the aim and the fact that a particular population is of interest, i.e., parents with experience of peer support. Written narratives were collected to promote reflective thinking and gain responses not influenced by any interviewer (Handy & Ross, 2005). We strived for as much variation in the sample as possible. Thus, no limitations were articulated with regard to how long ago the child was diagnosed, was born, or when a deceased child died. The respondents could choose to answer only some of the questions and decide how much sensitive information they wanted to provide, meaning that they had the opportunity to remain anonymous if they so desired. These methods were chosen to promote honest answers. The online tool did not include any time limit when accessing the survey.

To address problems with interpreting data in a transparent way, i.e., interpretative rigour, we used systematic text condensation and visual meaning making for analyses in accordance with the aim of the study (Malterud, 2001; Malterud, 2012). Researcher qualifications, backgrounds, and reflexivity are important aspects in qualitative studies (Tong, Sainsbury, & Craig, 2007). All authors are registered nurses and researchers with experience of qualitative analyses. The first and last authors are also registered midwives, having conducted previous research in the field of foetal and paediatric cardiology, particularly about parental experiences following a prenatal diagnosis. The first author, who was responsible for the primary analysis, has formal training and previous experience of conducting content analyses.

3 | ETHICAL CONSIDERATIONS

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden (approval number: 2016/366). Respondents were provided written information about the study before approving participation. The information was provided in the initial web page when accessing the link to the survey. The text contained information that participation was completely voluntary and anonymous, the estimated time to respond to the questions and that the duration depended on how much they wanted to write. Information was also provided concerning confidentiality (i.e., only involved researchers would gain access to the data) and that the complete data from would be analyzed cross-case, but that individual quotes would be presented. Details how to contact the principal investigator were also provided. At the bottom of the initial page after the written information, participants were asked to check a box indicating that they approved participation before gaining access to the questions. No monetary or other incentives for participation were provided.

3.1 | Findings

Respondents articulated a need to build a community among peers, grounded in mutual understanding. The respondents had experience of face-to-face gatherings as well as Internet-based peer-to-peer communication. Receiving and providing peer support had been a rewarding effort that provided emotional relief. Providing emotional support for parents of children born with CHD was seen as a duty and responsibility of peers. Peer support presented an opportunity to vent feelings and experiences related to sensitive topics, resulting in benefits on psychological well-being. However, instances were also described when behaviours were destructive or distressing to the peer support community, leading to psychological distress and withdrawal from peer support activities. In the following sections, the findings are elaborated further under three category headings.

3.2 | Building a supportive community grounded in mutual understanding among peers

In total, 42 respondents left written responses about building a supportive community grounded in mutual understanding. Participating in peer support made respondents feel a sense of community and belonging. Various communication routes for peer support were described, including via the Internet, telephone, and face-to-face gatherings. Several expressed that Internet-based communication made it easier to get in touch with peers. Use of the Internet for peer support was varied with regard to background characteristics, including respondent age. Having peers that they could contact at any moment was highly appreciated among respondents. On the other hand, Internet communication was also seen as sometimes being a hindrance for face-to-face gatherings, which were considered an essential part of peer support. The importance of welcoming parents to the groups and receiving peer support at the right point in time was emphasized, illustrating a need to build an available community by constantly adding new members. Respondents expressed a need for peer support close in time to the diagnosis:

My friend and I have a silent agreement that we can always contact each other, regardless of time or day. The most important part of that contact is that we both know that the other one understands exactly how it is. (Respondent 5: mother of living child)

Supporting parents who are in emotional crisis was seen as a responsibility and duty of peers, which was articulated both among parents of living and dead children. Several called attention to the satisfaction and joy they felt when providing peer support. Supporting other parents was rewarding on a personal level, described as a *pleasant feeling*, that it *made it easier to process their own experiences* and that it *made them feel less alone when helping others*. Respondents made conscious efforts to communicate that they cared about the well-being of peers, such as making sure that at least one peer answered messages

posted on social media and sending messages of emotional content to support parents of critically ill children. Respondents with longer experience of caring for a child with CHD wanted to communicate the positive aspects related to having a child diagnosed with one of these defects, to convey hope among parents of children with a recent diagnosis:

If I can, I am happy to calm other parents down by telling them about our experiences – especially when everything has gone well! We have so many positive experiences of health care and want to spread word about that, as a contrast to those with negative experiences [...] I am also happy to share how I personally feel and about the support I have received (or missed). (Respondent 25: mother of living child)

Being able to vent feelings and experiences with peers meant a great deal for respondents, as it entailed the chance to talk about sensitive topics together with persons having similar experiences. Peer support was seen as essential when feeling depressed and low in spirit, illustrating benefits on psychological well-being. Interacting with peers was considered more allowing than other social interactions, as peers did not react to in the same manner and did not make a big deal about things said. Respondents mentioned that peers showed more understanding and could relate to their stories to a greater extent, compared with non-peers who were considered to not have the same ability:

For someone who has not gone through a similar thing, it can be very difficult to understand my situation. I have also experienced that many find it difficult to talk about topics related to the heart defect. (Respondent 40: mother of living child)

3.3 | Gaining affirmation and useful insights by interacting with experienced peers

In total, 39 respondents left written responses about gaining affirmation and useful insights, including parents of living and dead children, with a range in age of their living child or at what age their child died. Respondents appreciated the opportunity to gain information and advice from peers, as it led to valuable insights into daily life for parents of children with CHD. Some described that they received clearer and more valuable information from peers than they did from health professionals, in particular about practical issues when caring for their child. Meeting experienced peers felt comforting, as it made respondents feel hopeful about their own future when listening to their stories. Drawing from the experiences of peers, respondents could relate to others and gain deeper perspectives of how life would turn out as a parent:

The older children became role models, it made us feel hopeful that our little girl could grow up and

become an adult too. We went to our first meeting feeling worried and went home with a wide smile and feeling hopeful about the future. (Respondent 27: mother of living child)

Respondents expressed a need to interact with experienced peers and wanted support groups dedicated for parents who share a similar situation, e.g., those with experience of similar CHD, with a critically ill child, who have a deceased child, who have grown-up children, and those expecting a child with a prenatal diagnosis. In particular, parents with a deceased child wanted and appreciated having an arena where they could interact with other bereaved parents. This was related to difficulties talking about their loss because it was considered a sensitive and uncomfortable topic to discuss with parents of living children. Bereaved parents tried to avoid stirring up fears and emotions among other parents and, thus, felt they had little or no opportunity to talk about this topic. Having few opportunities to vent feelings about the death made them feel alone and excluded from peer support activities. Bereaved parents also experienced that peers started to withdraw and excluded them when their child died:

Because my child died, I did initially feel that I did not dare to share [my feelings], since it all became so real for everyone else, the fear you always live with that you can lose your child with a heart defect. I felt that [other parents] withdrew a little when I told them that I was a parent of a dead child. (Respondent 30: mother of dead child)

3.4 | Aspects of peer support that result in psychological distress and withdrawal

This category heading was discussed by 13 respondents, who varied in regard to their backgrounds, including whether their child was alive or dead, educational levels, and experience of different modes of peer support. While peer support was highly appreciated, it also occasionally involved negative aspects and psychological distress. Reading stories from parents who recently lost their child set internal thoughts in motion and reminded them of their previous hardships, resulting in increased anxiety. An articulated concern was that some parents could get stuck in their grief and may thus not be able to move forward in life. Moreover, one mother felt discomfort when interacting with expectant parents who considered terminating the pregnancy after a prenatal diagnosis. Another experienced psychological distress when other parents wrote about superficial things during a time when her child was critically ill:

It's heartbreaking [to provide peer support]. Even if you don't 'know' the parent who lost their child, it hits so close to home and starts a lot of anxiety in yourself, at the same time you're trying to support the afflicted

in every way you can. (Respondent 10: mother of living child)

Destructive and unfriendly behaviours in the peer support community were described, which led to psychological distress and withdrawal from peer activities. Some peers were considered to spread negativity in the networks, leading to lowered spirit among members. At times, respondents felt that no one listened to them, increasing feelings of exclusion and loneliness. Related to this, some who had lost their child felt ignored and not listened to by leaders when articulating a need for gatherings dedicated for bereaved parents. Some recounted situations when peers had been aggressively confronted or excluded from the community because they articulated opinions that challenged the norm within the peer support networks. We also received recounts that respondents felt that leaders had taken undeserved credit for projects initiated by other members of the peer support networks. Respondents also described feeling caught up in administrative work, which took time away from helping families and making respondents take less active roles in providing peer support:

[The members of the peer support group] showed a strong internal admiration and when members had the smallest deviating thought they were excluded [from the community]. The chairman took all the credit for the initiatives made by the other members. (Respondent 37: mother of living child)

4 | DISCUSSION

This study explored peer support among parents of children with CHD by analysing written answers from respondents recruited through convenience sampling. The analysis revealed a need to build a community among peers, grounded in mutual understanding. Receiving and providing peer support was a rewarding and provided emotional relief. However, peer activities also involved instances of negative and unsupportive behaviours, leading to psychological distress and withdrawal.

Communicating with peers involved an opportunity to receive emotional and informational support, which was highly appreciated among the respondents. In line with these findings, previous research in other health-related contexts suggest psychological benefits when participating in peer support (Dennis et al., 2009; Raharjo et al., 2020) and that Internet-based peer support between parents involves emotional as well as informational support for mothers of ill children (Niela-Vilén, Axelin, Salanterä, & Melender, 2014). Our findings further illustrate the positive effects that parents experience when participating in peer support activities. Interestingly, some respondents were bereaved parents who had lost their child several years before the time of data collection. Other studies have similarly identified parents who continue to communicate with peers long after the diagnosis (Carlsson et al., 2017). The findings in this study suggest that peer support may serve as a complement to

professional psychosocial support for parents of children with CHD, even long after the death of their child. However, there is still a need for more research in the field of peer support between parents (Dias et al., 2019; Tully, Shneider, Monaghan, Hilliard, & Streisand, 2017).

Little has yet been reported about negative experiences or harmful effects when participating in peer-to-peer interactions. The few studies that have been reported describe some negative aspects related to Internet-mediated peer support, including technical issues, off-topic posts, lack of physical contact, time requirement, misinformation, and lack of replies (Niela-Vilén et al., 2014). Studies suggest that online peer support may involve processes of instances of critique, polarization, increased prejudice, and a temptation to revel in illness (Carlsson, Landqvist, et al., 2016; Niela-Vilén et al., 2014; Parsell, 2008). While a proportion of the total sample described negative aspects of peer support, our findings call further attention to the potential psychological distress some parents may experience due to peer interactions. This includes psychological anxiety because the communication reminded them of previous hardships, feelings of exclusion and loneliness, being met with aggression in the peer community, and detrimental cultures within the social networks. It is possible that the convenience sampling resulted in a self-selection of persons with mostly positive thoughts about peer support. This implies that negative or harmful experiences need to be further explored further in future studies.

Previous studies report that fathers of children with CHD experience emotional stress, but try to hide their feelings to support others (Carlsson & Mattsson, 2018; Clark & Miles, 1999). We are unsure why few fathers participated in our study, considering it has been noted that parents of ill children do indeed express a need for social support, including fathers (Carlsson, Melander Marttala, et al., 2016; Jacobs et al., 2016), and that social support is predictor of family functioning (Tak & McCubbin, 2002). Little research has yet been reported regarding coping processes among fathers of children with CHD. One study report that most parents participating in online peer support are mothers (Jacobs et al., 2016) and another study suggests that fathers turn to peers primarily for informational support (Sood et al., 2018). These aspects could explain the sample characteristics in our study. It is possible that fathers' turn to specific peer networks for support not used for recruitment in this study, or that they experience less need of peer support than mothers. We encourage more research that explores how fathers cope when having a child with CHD.

4.1 | Limitations

This was a qualitative study using convenience sampling to collect written responses from parents participating in peer support activities, via the national foundation for families with children who have CHD or via online peer support groups. Few fathers participated in the study and the fact that we recruited respondents via advertisements implies a risk that the findings do not represent experiences among parents who do not experience a need for peer support or

have left peer support activities because of negative experiences. Recruitment via the Internet has a risk of self-selection, implying that those who are interested in answering the topics asked may be more inclined to do so. These methodologies are more suitable for addressing inductive research questions that aim to provide in-depth information about experiences grounded in social and cultural contexts (Eysenbach & Wyatt, 2002), which was the purpose of this study. Another aspect is the potential non-representative characteristics of Internet users. While it is possible that the online recruitment influenced characteristics of respondents that participated, our intention was not to provide generalizable conclusions but rather to gain deeper understandings and generate hypotheses. Worth noting is the substantial Internet access in Sweden (98%) and the fact that 74% of Swedish Internet users have used Facebook (The Swedish Internet Foundation, 2019). Nevertheless, we acknowledge that the methodological limitations related to the online recruitment and data collection are important when interpreting the transferability of the findings.

The data collection was performed with an online tool distributing a survey containing written questions. It is possible that this could have resulted in honest responses without the influence of an interviewer (Handy & Ross, 2005). On the other hand, some parents may prefer to talk about their experiences or are unable to answer written questions due to language difficulties. Because of the convenience sampling through ads, it is not possible to know the number of parents who read the invitation and the proportion of these who then decided to participate. However, we had a rather high completion rate with a median of four of the five open-ended questions answered and a total of 21 respondents having answered all open-ended questions. With regard to richness of the data, our view is that the responses were condensed, which is expected from written narratives, but contained valuable information that were useful during the analysis. The range of allocated subgroups for the respondents was one to six of the total seven identified subgroups, the median number of allocated subgroups was three and 42 respondents provided answers that were coded in at least two subgroups. The responses we collected ranged from 1-428 words (median = 83 words), which represent a data size similar to that of another published study analyzing data with systematic text condensation (Maeland, Magnussen, Eriksen, & Malterud, 2011). These aspects illustrate that the respondents provided rich answers that spanned across several topics, indicating a breadth of experiences covered in the collected data. Nevertheless, we acknowledge that the data collection involves limitations, including not being able to ask follow-up questions.

This study needs to be considered as a complement to other studies using other recruitment strategies and data collection methods. The first author performed the analysis and the second author scrutinized the findings in relation to the collected data. This approach involved an opportunity to confirm the findings from the perspective of another researcher. Nevertheless, we acknowledge that the analysis could involve some bias or misinterpretations.

5 | CONCLUSION

Peer support between parents of children with congenital heart defects involves emotional relief and mutual understanding. In particular, parents appreciate the opportunity to gain insights on how life can turn out when being a parent of a child diagnosed with a heart defect. Providing support is viewed as a responsibility of peers and those who provide peer support experience it as rewarding process on a personal level. In addition to the various benefits described by parents, peer support can involve instances of distressing, destructive, and unfriendly behaviours. Experiencing negative aspects of peer support activities may result in psychological distress and withdrawal from peer activities. Health professionals should consider discussing the option of reaching out to peer support networks and participating in peer support activities when consulting parents. More research is needed to further explore potential negative aspects related to peer support in this context.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHOR CONTRIBUTIONS

TC conceived and designed the study, collected the data, analysed the data, and wrote the manuscript. AK analysed the data and reviewed the manuscript. EM conceived and designed the study, collected the data, analysed the data, and reviewed the manuscript. All authors approved the final version of the manuscript.

PEER REVIEW

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ORCID

Tommy Carlsson  <https://orcid.org/0000-0003-4141-8692>

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