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Belonging to a community of care: Mothers' experiences of online peer support groups for parents having lost a child with congenital heart defects

Anna Klarare^{a,b} , Tommy Carlsson^{a,c}, and Elisabet Mattsson^{a,b}

^aClinical psychology in healthcare, Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden; ^bDepartment of Health Care Sciences, Ersta Sköndal Bräcke University College, Stockholm, Sweden; ^cThe Swedish Red Cross University College, Huddinge, Sweden

ABSTRACT

The aim was to study mothers' experiences of online peer support groups after the death of a child. Participants ($N = 8$) were recruited through a newsletter for the Swedish association for families/children with heart defects, and two closed support groups on Facebook (900 and 100 members) and interviewed by telephone. Transcripts were analyzed with qualitative content analysis. The groups were available around the clock, regardless of support need, and mothers joined both to receive and provide support. Participation in online peer support groups may provide a sense of belonging to a caring community and serve as a valuable complement to healthcare.

Every year, approximately 4 out of 1000 children worldwide are born with complex congenital heart defects (Dolk et al., 2011; Hoffman & Kaplan, 2002). The diagnostics, treatment, and care for pediatric heart disease around the world have improved (Jortveit et al., 2016). In developed countries, mortality for pediatric heart surgery is approximately 4% (Tchervenkov et al., 2008) and children who die with complex heart disease often do so in intensive care units (Morell et al., 2012), even though early provision of palliative care has been advocated (Bertaud et al., 2016). Families experiencing a lack of support after the death of a child has been highlighted and documented (Segal et al., 1986). Parents report feeling unprepared to provide for the child's medical and emotional needs at the end of life, and want increased communication with healthcare professionals (Segal et al., 1986). Having a child with a congenital heart defect involves a significant impact on psychological health (Wei et al., 2015), including fear, grief, stress, and uncertainty (Bally et al., 2018). When a child dies due to a severe illness, bereaved parents have an increased risk of long-term psychosocial morbidity, lasting several years after the death of their child (Rosenberg et al., 2012). Resuming life and living after the death of a child is challenging, and parents struggle to cope with their loss (Segal et al., 1986).

Consequently, the identification of effective psychosocial interventions that aim to help bereaved parents cope is needed (Rosenberg et al., 2012).

In many countries around the world, parenting support groups for the general population have been implemented as a part of standard care. One reason why parents participate in these groups is to come in contact with peers and experience a sense of belonging (Hjelte et al., 2015). For bereaved persons, social support has the potential to buffer against the impact of the loss and facilitate recovery (Stroebe et al., 2005), including following the death of one's child (Jaanieste et al., 2017). Four sources of support have been identified among parents of children with congenital heart diseases: spouse/partner, peers, professionals, and religion (Lumsden et al., 2019). Peer support is defined as the mutual exchange of assistance and encouragement between two or more individuals who consider each other as equals. Identified attributes of peer support include emotional, informational, appraisal and practical support (Dennis, 2003), with emotional being suggested as the most common in online interactions between parents (Carlsson et al., 2016). The Internet is now used around the world to communicate distance-spanning support between peers (Beaunoyer et al., 2020). Studies report high levels of activity in online communities about parenting, where a wide range of

CONTACT Anna Klarare  anna.klarare@kbh.uu.se  Erstagatan 1C, 116 28, Stockholm, Sweden.

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intimate topics are discussed (Sjöberg & Lindgren, 2017). A substantial proportion of bereaved persons seek support from friends and community groups as ways to cope with the grief (Aoun et al., 2015), including parents of children with anomalous aortic origin of coronary arteries (Agrawal et al., 2017). Further illustrating the large volume of parents who participate in online communication, one cross-sectional study identified 54 Facebook groups dedicated to families with four different types of congenital defects comprising more than 16,000 members in total, with the most common being heart defects. Most of the members in these groups were mothers who joined with the intention of participating in peer support activities (Jacobs et al., 2016). Indeed, the social media platform Facebook has now become a site of communication about death and mourning (Brubaker et al., 2013).

The literature indicates potential benefits of online peer support for bereaved persons, referring to the positive attributes associated with being part of an understanding community (Robinson & Pond, 2019). One qualitative study exploring experiences of online peer support among four bereaved mothers who lost their child because of heart failure revealed that they communicated emotional, cognitive and community support, concluding that online peer support is a viable option for grieving parents (Aho et al., 2012). Another study showed that virtual communities may help bereaved parents cope with their grief and support their life-long needs in new and previously unavailable ways (Hård af Segerstad & Kasperowski, 2014). However, there is still a need for further qualitative exploration of experiences related to online peer support (Robinson & Pond, 2019). To the extent of our knowledge, very little is published with regard to the experiences of bereaved parents who have lost a child with a congenital heart defect. In-depth knowledge about this type of online support may have clinical relevance in many settings, such as pediatric and palliative care, providing insights into how to appropriately support the grieving process that bereaved parents go through. The aim of this study was to study and describe mothers' experiences of participation in online peer support groups after having lost a child with a congenital heart defect.

Method

Study design

This descriptive, qualitative interview study was performed with Swedish mothers who lost a child with a congenital heart defect.

Setting

In Sweden, families of children diagnosed with congenital heart defects are provided care at state-driven hospitals, primarily pediatric cardiology units. These units offer psychosocial support by psychologists and social workers/counselors for parents in need, and facilitate contact with the Swedish umbrella association for children with heart defects. In addition to the state-driven care, parents may also turn to various offline and online peer networks administered outside of the health care system, ranging from publicly available popular virtual communities about parenthood in general to closed peer-to-peer networks specifically for bereaved parents. There is no published formal compilation about how many and what types of Swedish online peer-to-peer networks there are for parents of children with heart defects. Two closed Swedish Facebook groups were used for recruitment in this study, which we knew about based on clinical experience. One group was mixed, comprising both parents with living children with a heart defect, as well as parents who lost a child with a heart defect (approximately 900 members). The other was only for bereaved parents who lost a child with a heart defect (approximately 100 members). Both groups were closed; that is, users could not view or write posts until their membership was granted.

Recruitment of participants

Convenience sampling was used. Participants were recruited through the Swedish association for children with heart defects and their families (*Hjärtebarnsfonden*), as well as the two aforementioned Facebook groups. Inclusion criteria were having lost a child with a heart defect and having experience of online peer support groups. Participants expressed interest in participating in the interview as they took part in a prior online survey about peer support (reference blinded for peer review). The survey was advertised in a newsletter from the association and posts in the two Swedish Facebook groups. A mother who had lost a child due to a congenital heart defect and who was a member of both groups acted as a contact person for the present study. The group administrators were contacted with a request to post an invitation to participate in the study to members of each group. Oral and written information about the study was provided to the group administrator, who subsequently consented to post the invitation. When the participants in the online survey, including 7% fathers (Carlsson et al., 2020), had

Table 1. Sociodemographic characteristics.

Characteristics	Total (n = 8)
	Mean (SD)
Mothers age at time of interview (years)	46.7 (9.0)
Time elapsed since child's death (years)	11.6 (11.6)
	n (%)
Education	
University degree	5 (63)
Upper secondary	3 (37)
Child's age at death	
<1 year	5 (63)
1–3 year/s	1 (12)
13–18 years	2 (25)
Membership	
Member of one Facebook group ^a	3 (37.5)
Member of more than one Facebook group ^b	5 (62.5)

^aFacebook group for parents who have lost a child with a heart condition.

^bFacebook group for parents who have lost a child with a heart condition & Facebook group for parents with a child with a heart condition (n = 2); Facebook group for parents who have lost a child with a heart condition, Facebook group for parents with a child with a heart condition & member of the Swedish umbrella association for children with heart defects (n = 2); Facebook group for parents who have lost a child with a heart condition & member of the Swedish umbrella association for children with heart defects (n = 1).

submitted their responses, they were asked if they were interested in participating in a telephone interview, i.e. the data that this study is based on. Eleven mothers expressed interest in participating in this interview study, while none of the fathers who participated in the online survey volunteered for an interview. When contacted, three mothers did not respond to phone calls or e-mails. Thus, eight mothers constitute the sample. See Table 1 for a presentation of socio-demographic characteristics of the included mothers.

Mothers' ages ranged from 33 to 62 years (median 48 years) and the majority had a university degree. The time elapsed since the child's death ranged from 2 to 32 years (median 6 years). All mothers were members of the closed Facebook group for parents who lost a child due to a heart defect and over half were members of more than one group for parents of children with heart defects.

Data collection

The eight mothers who wanted to participate were contacted for informed consent and to schedule a time for the telephone interview. At the start of each interview, informed consent procedures were reiterated verbally. The interviews were semi-structured, conducted with the aid of an interview guide involving three main questions about online peer support: "how did you come in contact with the peer support group on Facebook," "how have you experienced having contact with other parents of children with a heart

defect," and "how have you experienced being the one who offers support to parents of children with a heart defect." The interviewer asked about positive as well as negative experiences of online peer support. Follow-up questions were asked to encourage the participants to elucidate their answers further. Interviews were audio recorded and lasted from 22 to 62 min (median 33 min). All interviews were performed by the last author, a registered nurse-midwife and professor with previous experience of conducting telephone interviews. All interviews were transcribed verbatim and checked against the recordings.

Data analysis

For data analysis, a qualitative content analysis was conducted by the first author (Graneheim & Lundman, 2004). The first author started the analysis with reading and re-reading transcripts to become immersed in the data and to initiate analysis, discerning patterns and finding meaning units relevant to the aim. Each interview was de-contextualized and analyzed individually by initial coloring of meaning units in the text, pasting meaning units into a separate document, and condensing, interpreting and coding. De-contextualization is the process of breaking the interview transcripts into pieces, separated from their original context and illustrating the observable manifest content (Lindgren et al., 2020). The process then continued with re-contextualization, meaning that identified de-contextualized units were combined to form new patterns emerging as sub-themes and themes illustrating the interpreted latent content (Lindgren et al., 2020). Themes and sub-themes emerged inductively from the data, meaning that no preconceived theory or model was used to guide the analysis. The construction of sub-themes and themes was inspired by Sandelowski and Leeman (2012), in formulating thematic statements intended to convey the essence of the results to readers. We allowed different levels of interpretation represented in the sub-themes; meaning that some could illustrate a more latent underlying meaning while others could illustrate a more manifest content. Please see Table 2 for examples of the analysis process. When themes and sub-themes were identified, the second and last authors scrutinized the results and were involved in discussions until all authors felt the results adequately reflected the content in the interviews.

Regarding reflexivity in qualitative research, the first author does not have a background in peer support for parents of children with heart defects. The

Table 2. Examples of the steps involved during the analysis.

Meaning unit	Condensation	Interpretation	Sub-theme	Theme
I saw a post on Facebook where someone posted and I commented on it, someone replied and then I wrote that I too had lost a child. That in turn led to the group administrator inviting me to join. Someone wondered what kind of songs or texts would be suitable for burying a teenager	I commented on a post and was invited to the group by the administrator. A question regarding songs and texts for a teenagers' funeral	Invitation to the group after post	<i>Channels and membership for online peer support</i>	Belonging to a community of care promotes resilience and continued life
Yeah, it happens all the time, that someone says, well, it's been 5 years, 10 years since my child passed. When does it get easier? And someone with 20 years since the loss can write that: it has gotten a lot easier, but that there still are really tough days ...	Some wonder when it becomes easier since it's been 5 or 10 years since the loss. Even after 20 years there can be tough days.	Practical support for planning funeral The grief is ever present, but it gets easier with time, but even after 20 years, there are tough days. It is a comfort to hear from other and to know that others are like me.	<i>Attributes of online peer support</i> <i>Belonging and resilience with continued life and living</i>	

second and last authors have previously conducted qualitative research in the field of pediatric cardiology and the last author has clinical experience at one unit for pediatric cardiology. The analytic process was adopted to dissuade previous knowledge from permeating the results, as the first authors' naiveté was utilized to promote the trustworthiness of the results. The authors are registered nurses specialized in palliative care (first author), intensive care (second author) and pediatric care (third author). The second and last authors are also registered midwives.

Ethical considerations

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden (approval number: 2016/366). All participants were provided written and oral information about the interview study before consenting to participate.

Results

The overarching theme is that participation in online peer support groups provides a sense of belonging to a community of care, which promotes resilience and continued life, even though the worst imaginable, the death of a child, has occurred. The following three sub-themes emerged: (1) *channels and membership for online peer support*, (2) *attributes of online peer support*, and (3) *belonging and resilience, with continued life and living*. The first sub-theme presents the different channels mothers turned to when wanting to communicate with peers, which channels they chose depending on the need, and how they discussed membership within the groups, while the second presents the characteristics of the support that was communicated. The last sub-theme presents the personal impact that mothers experienced related to the online peer support communicated in the groups. The first two sub-themes discuss a more manifest level of content, while the last sub-theme discusses a more latent level of interpretation.

Channels and membership for online peer support

The mothers participated in different peer support channels, involving public groups, closed groups, and through private messaging, deciding which channel to write in depending on the intended recipient. When communicating in channels accessible to parents of living children, mothers felt they could not be completely honest, because they did not want to deprive

them of hope. There was a desire to protect parents of living children, since they still hoped that their child would be cured and well. Communicating with bereaved mothers was perceived as more honest and open, since they shared the experience of losing their child:

There's a big difference between groups, because you can write more openly in the lost-group, than in the group where they still have their child. You wouldn't want to scare them, and I certainly wouldn't write about the last days of my child's life to them... (Mother 2)

Mothers gained membership to the groups via an invitation from the group administrator or another member. Commonly, they had written something regarding their ill or deceased child on social media and were then invited to join. Mothers described different kinds of groups that they were members of, such as a group for parents having lost a child in general (car accident, cancer, suicide etc.), groups for parents who have a living child with heart disease, and a group for parents who lost a child due to a congenital heart condition. Member eligibility was seen as an important aspect of the soundness of the closed groups. Related to this, there were examples of persons lying about having a child with a heart condition to gain group access, which was regarded as morbid curiosity and showing blatant disrespect for the affected families. In these instances, the person was immediately evicted from the group. Before becoming a member of a group, mothers described screening for eligibility, for example that one has a living or dead child with a heart condition:

I posted something telling about my son's heart condition, and the administrator of a group for parents having lost a child wrote: You are welcome to our group... That's how it happened. (Mother 6)

Mostly, communication in the online peer support groups was between mothers, as fathers were not prominent members in any of the peer support groups. When discussing reasons for fathers being absent, the mothers provided three possible main reasons: they do not want to discuss private things in a public arena, they do not need to discuss emotional issues, or the online peer support groups do not meet their needs:

My husband, he might react like 'Good Lord, it happened 30 years ago, haven't you moved on??' He sorts of gets provoked by all the emotions in a forum like that, thinks they should move on and not keep re-living the trauma over and over... (Mother 1)

Attributes of the online peer support

The support that mothers experienced from being in online peer support groups dedicated to parents of children with congenital heart defects was emotional, appraisal and informational. When needed, the online peer groups provided respondents with informational support, as the groups contained the collected knowledge of many parents with varied backgrounds and experiences. For example, informational support could involve advice on arrangements around funeral services, family lawyers or alternative treatments:

And suddenly, when their child died, the absent father appeared and wanted his share of the child's trust fund... so I gave the name of the lawyer I'd used... Someone else asked about what kind of songs or texts are suitable for the funeral of a teenager... (Mother 4)

Emotional and appraisal support was a large part of the communicated support in the groups. It revolved around reading and commenting on someone's post, sending an image of a heart or hugs, or writing brief feedback such as: "thinking of you," "sending strength," or "you are not alone." Needs for support from the online peer support group varied over time. Initially, mothers needed to put words to their experiences and talk about or discuss the death of their child. In this instance, the group provided support and a "digital" shoulder to cry on. With time passing, many described how they had energy and resolve to give support instead of receiving it:

In the beginning, it wasn't easy to give support to others, I was so caught up with my own grief... (Mother 1)

Belonging and resilience, with continued life and living

One of the positive aspects of belonging to an online peer support group was the experience of understanding from other members. A foundation of the peer support in the groups was building on similar experiences. The sense that someone with experience of having a child with a similar condition was listening and knew what they were going through was experienced as supportive and as sharing the burden. Mothers described having felt completely alone with a terrible loss, and then realizing that others had similar experiences and that they were not alone. Mothers felt a need to censure themselves when talking to others about the death of their child, since they either ended up comforting the other person who had not lost a

child, or to making light of the experience so that the listener would not be uncomfortable. When communicating in the peer support group, mothers felt they could tell the truth, without worrying about how it would be received. In the online peer support group, the fact that the death of one's child is horrendous was accepted and confirmed, without trivializing or glossing over it. Mothers described it as very supportive that someone else understood and was aware of what they were going through:

It's great to talk to someone where it doesn't get personal, just telling is straight forward, no sugar coating, just the honest truth. In some groups people feel sorry for you, which is not helpful, but in the lost-group it's more like 'yeah, I know how you feel, it sucks!' ... you get more honesty (Mother 5)

The online peer support group was available at any time and place, as long as an Internet connection was available, regardless whether someone has been active in the group recently or not. Mothers described how the need for peer group support varied over time and depended on different circumstances. After an initial period, closer to the death of a child, need for support often waned, but could flare up again around the child's birthday, holidays or funeral day. It was described as comforting knowing that someone was always there for you:

That's just how it is, there are good days and there are bad days ... even if it's been 10 or 15 years, there will still be days (when I need support) ... maybe birthdays or death days, that's to be expected. (Mother 4)

A requirement for participation was having lost a child with a heart condition, and this contributed to mothers finding themselves in a group of peers and experiencing a community of care. One mother said that she scans different posts in the online peer support group and ensures that she responds to the ones that no one else has responded to. This was done to ensure that everyone in the group is seen and heard. The emotional support did not necessarily need to be expansive, as even small utterances of emotional support often were communicated. Several told how they sincerely posted a heart symbol or a digital hug as a resounding message that mothers in need of support are not alone.

There's no judging or spiteful comments, just sooo much understanding and caring for each other. ... I guess that's what I feel, and it's enough to just go in and read a few posts and comments, and you see the support and caring that everyone gives. (Mother 7)

Discussion

Bereaved mothers described that online peer support groups provided a sense of belonging to a community of care, which promoted resilience and continued life. They were introduced to the closed groups by means of an invitation to join and thereafter continued to communicate emotional, appraisal as well as informational support. These findings were expected and confirmed what is already established in the field of peer-to-peer communication (Dennis, 2003; Robinson & Pond, 2019). Participation in the peer support groups was associated with a sense of belonging to a community of care involving mutual understanding among the members. While similar findings have been reported in other contexts and populations (Hjelte et al., 2015; Robinson & Pond, 2019), our study brings new knowledge about bereaved mothers who have lost a child with a congenital heart defect. This study contributes with an in-depth understanding how bereaved mothers of children with congenital heart defects in particular cope with their loss by participating in online peer support. Our study complements the previous reports about parental peer-to-peer interactions following bereavement, providing an expanded knowledge about parents of children with heart defects and confirming much of what has already been reported concerning peer-to-peer interaction following bereavement in other fields.

In Sweden, professional psychosocial support provided by psychologists and social workers/counselors is available to parents within the scope of state-driven care. However, bereaved parents may not feel a need for support from professionals and instead turn to peers for support (Aoun et al., 2015). Four factors characterize use of health-related information on the Internet, namely browsing, acquiring information, communicating and networking (Magnezi et al., 2015). Peer support filled an emotional need among the included mothers, echoing what has been reported in other contexts (Aho et al., 2012; Hård af Segerstad & Kasperowski, 2014; Robinson & Pond, 2019). Our findings confirm other qualitative studies reporting that bereaved mothers use Facebook to receive support, identify with other mothers, and express their feelings (Perluxe & Francisco, 2018). Further, the findings illustrate that mothers not only received, but also provided peer support. Studies suggest that providing social support has a potential to enhance psychological health (Midlarsky, 1991) and involve positive intrapersonal changes, including feeling more confident and less psychological burden (Solomon et al., 2001). Future studies should continue to

investigate the potential positive effects of receiving, as well as providing peer support among bereaved mothers who have lost a child with a heart defect. Overall, the findings suggest a need to test an intervention offering online peer support in a private setting where mothers can communicate emotional support unconstrained.

The mothers belonged to a community of care, where they could communicate without constraints among others who understand them. Overall, the findings echo what has already been reported about the potential usefulness of online peer support for bereaved persons (Robinson & Pond, 2019), and confirm that the positive effects also apply to parents seeking support following the death of their child with a congenital heart defect. The mothers felt they could speak freely and share their thoughts without censoring themselves in the closed online support group. This finding emphasizes the importance of gaining access to safe and private groups when experiencing a need for peer support. The Internet has introduced new and promising distance-spanning ways to communicate with peers that may live far away or are otherwise difficult to identify (Eysenbach et al., 2004). As of yet, generalizable evidence remains inconclusive regarding the potential effects online peer support may have on grief-related symptoms (Robinson & Pond, 2019). Nevertheless, empirical qualitative studies including this study repeatedly illustrate the impact it can have in the lives of bereaved parents in various contexts (Robinson & Pond, 2019). In light of the findings of this study, participating in online peer support groups may complement healthcare after the death of a child with congenital heart defects, and may serve as one contribution to bereavement care in our communities. Our findings give further weight to the notion that health professionals who counsel parents following the death of their child should inform them about the potential positive impact of online peer support. More studies are needed that further investigate the effects of online peer support among bereaved parents who have lost a child with a congenital heart defect. We encourage future research among fathers, who were not represented in this study.

There are several limitations with this study. All members in the two Facebook groups were invited to participate by means of convenience sampling. Only eight mothers were interviewed, and we had no direct access to the groups, meaning that we have limited knowledge about the larger population. This makes it difficult to draw conclusions about the transferability

and representativeness of the results. We have no way of knowing the extent to which the mothers who participated in this study represent parents who communicate peer support via Facebook. The sample is varied in regard to age and time since the death of their child, but most had studied at a university/college implying that more research is needed that explore experiences among those with less education. We are unsure why more educated persons expressed an interest in participating, but it is possible that parents with less education do not seek peer support in their grieving process. Only mothers elected to participate and no fathers, making the transferability to fathers' experiences difficult. Taken together, the convenience sampling used in this study implies limited transferability and representativeness. The findings of this study should be interpreted with this in mind, and primarily be seen as hypothesis generating for future research in the field.

Performing telephone interviews can be liberating for participants, making it easier to talk about difficult topics (Novick, 2008). However, it may also be more challenging to create an atmosphere of trust conducive to sharing deeply personal narratives (Carr & Worth, 2001). Our impression is that the participants appreciated the approach of data collection, and that their experiences could be explored by telephone. We nevertheless acknowledge the possibility that face-to-face interviews could have generated other findings and encourage future qualitative research employing other data collection methods. Moreover, group dynamics can vary depending on the social norms constructed within the community. We did not collect any material written in the peer support groups, meaning that we still know little about how support is communicated between bereaved mothers who have lost a child with a congenital heart defect. Future research could build on the findings of this study by analyzing the content of the support communicated in peer support groups.

Conclusions

This study provides in-depth understandings about online peer support among bereaved mothers of children with congenital heart defects, adding to and confirming much of what has already been reported in other fields in regard to peer-to-peer interactions following bereavement. The results of this study indicate that participation in an online peer support group after having lost a child with a congenital heart defect may contribute to a sense of not being alone and of

belonging to a community of care. This may promote resilience and continued life, even though the loss and the grieving are life-long. Online peer support can be a valuable complement to health and social care and promote health. The findings may provide new insights for professionals providing care to parents experiencing the death of their child with a heart defect. Future research should explore how bereaved fathers experience peer support. The findings of this study illustrate a need to test an intervention offering online peer support to bereaved parents who have lost a child with a congenital heart defect.

Disclosure statement

No potential conflict of interest was reported by the author(s).

ORCID

Anna Klarare  <http://orcid.org/0000-0001-7935-3260>

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