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Losing a close person following death by sudden cardiac arrest: Bereaved family members' lived experiences

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ABSTRACT

The death of a close person has profound impact on people's lives, and when death is sudden there are no possibilities to prepare for the loss. The study aimed to illuminate meanings of losing a close person following sudden cardiac arrest. A qualitative interpretive design was used, and twelve bereaved family members were interviewed. The results show a transition from pending between life and sudden loss during resuscitation and proceeding with life after the sudden loss. These results of being in liminality illuminate the family members' essential narration and the importance of compassionate care throughout this challenging transition.


Introduction

The high incidence of cardiac arrest in combination with poor survival makes cardiac arrest one of the leading causes of mortality in both Europe and in the United States (Wong et al., 2019). Death by cardiac arrest implies a stressful situation for family members who have to handle the loss (Mayer et al., 2013; Zalenski et al., 2006), and sudden death allows no time for family members to prepare themselves. A review by Kristensen et al. (2012) shows that when death is experienced as sudden it affects the process of bereavement, making the death more complex to manage than an expected death. In addition, the process of bereavement may be slower and last longer when the loss is hard to grasp and grief reactions might intensify as the shock gradually wears off (Kristensen et al., 2012).

Loss and grief are natural and inevitable parts of human life. Grief is a normal emotional reaction following a loss, but the processing of grief varies between individuals (Lindemann, 1944; Parkes, 1998). In recent years there has been a change in bereavement research: from viewing grief as a trajectory leading from distress to "recovery," toward viewing the grieving process as an oscillation between avoiding and engaging in grief work. The idea of "letting go"

of the deceased has changed into maintaining a healthy bond to the deceased. Hence, the stage theory of grief has been shown to be incapable of capturing the complexity of bereavement and does not address the multiplicity of physical, psychological, social, and spiritual needs of bereaved persons (Hall, 2014). More recent models view grieving as a process where a world of meaning has been challenged by the loss and needs to be reconstructed in life (Neimeyer et al., 2014).

Despite grief being a natural part of life, studies have shown that grief is associated with increased emotional distress, physical disease, and mortality (Prior et al., 2018; Shah et al., 2013; Stroebe et al., 2007). The lack of preparedness among suddenly bereaved persons has been shown to be associated with higher mortality among the bereaved than when the deceased had a known preexisting morbidity (Shah et al., 2013). Furthermore, qualitative interview studies have shown that witnessing a cardiac arrest at home puts the family member in an involuntary traumatic situation, and family members experience a close person's cardiac arrest to be extremely stressful. The circumstances surrounding the sudden loss sometimes presents an obstacle to moving forward in the process of bereavement and affects their future well-being (Bremer et al., 2009; Mayer et al., 2013; Thorén

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et al., 2008). Further, to be present during resuscitation is challenging to family members, and the experience might cause psychological reactions such as posttraumatic stress (Compton et al., 2011).

Although there is a substantial amount of research on bereavement, only the study of Mayer et al. (2013) focused on families' bereavement following cardiac arrest, focusing on their stories of losing a male family member. Further research is thus needed to contribute to the understanding of bereaved family members' experiences and their narration of life after the sudden event of cardiac arrest and sudden loss. Hence, the aim of this study was to illuminate meanings of lived experiences of losing a close person following death by sudden cardiac arrest.

Methods

Design

This study is part of a research project focusing on bereaved family members following sudden cardiac arrest. The present study had a qualitative interpretative design, and a phenomenological hermeneutical method (Lindseth & Norberg, 2004) inspired by the French philosopher Paul Ricoeur (1976) was used to illuminate the meanings of lived experiences among family members.

Procedure and participants

Inclusion criteria for the research project were to be adult (≥ 18 years of age) Swedish-speaking bereaved family members of adult deceased patients who had died from sudden cardiac arrest reported as owing to probable cardiac or lung disease (and not, for example, accidents). Deceased patients in a county council in the southeast of Sweden were identified through the Swedish Register of Cardiopulmonary Resuscitation (2018), in which patients receiving CPR are included. Bereaved family members were then identified through the deceased patients' medical records. Family members initially participated in a survey study, which included a question about participation in an interview study. To achieve credibility and reach participants with various experiences of the phenomenon, purposeful sampling was employed (Patton, 2015). The first researcher contacted potential participants based on a heterogeneous purposeful sampling regarding relations, age, and sex to reach various experiences. Four of the participants contacted the researchers on their own and volunteered to participate after finding out about the study in a local

Table 1. Characteristics of the family members and the deceased persons ($N = 12$).

	<i>n</i> (%)
Sex	
Family members	
Female	8 (67)
Male	4 (33)
Deceased persons	
Female	4 (40)
Male	6 (60)
Relation	
Spouse	4 (30)
Daughter/son	7 (54)
Sibling	1 (8)
Daughter in law	1 (8)
	Mdn (Min–Max)
Age	
Family members	50.5 (25–78)
Deceased persons	73.5 (33–83)

Note. ^aOne family member had lost two close persons.

newspaper and/or on the radio. The participants were included as they consented to be contacted, and finally a total of 12 participants were interviewed, which generated a large amount of rich data. The characteristics of the family members and the deceased are shown in Table 1. Three family members were present during the phase of initiating CPR, one of whom performed CPR. The other family members met up (on scene outside the hospital or in the hospital) during CPR or after death was confirmed. The cardiac arrests occurred at home, in a caravan, in a car, in an ambulance, and in hospitals at different emergency departments, medical wards, and intensive care units. Two of the deceased persons suffered the initial cardiac arrest in the hospital, and eight persons suffered the initial cardiac arrest out of the hospital. Three of the deceased persons were not taken to the hospital.

Data collection

Twelve open, in-depth qualitative interviews were conducted with family members concerning their lived experiences during the event of cardiac arrest and the time after losing a close person. The interviews were conducted face to face by the first author 6–16 months after the close person's death and lasted between 32 and 107 min (median = 51 min). All participants were interviewed once, and the interviews took place in a private and quiet room according to the participants' choice—three at the university and nine in private homes. Initially and during the interviews the interviewer strived to create a permissive climate of trust and inquired about their experiences following their loss by an open-ended question: "Could you please tell me your story in your own words and I will

interrupt as little as possible. I'll ask you some follow-up questions. So, when you feel ready, you may start to tell me." The question was kept open so that the participants could choose where to start and tell their narrative. If they did not know where to begin, they were asked to narrate about their everyday life in the present. Follow-up questions were asked to encourage family members to freely narrate their experiences, thoughts, and feelings during the time of the death and the time that has passed. Examples of follow-up questions were "Do you have an example?", "What did you feel then?" or "Please, can you tell me more about ...?" Time was spent before and after to ensure that the family member could cope with the situation. The interviews were conducted from April 2018 to March 2019, and were audio recorded and transcribed verbatim by the first author.

Data analysis

The phenomenological hermeneutical method consists of three phases—naïve understanding, structural analysis, and comprehensive understanding (Lindseth & Norberg, 2004). After all interviews had been conducted, the transcribed interviews were read several times as a whole with openness and closeness using a phenomenological attitude to reach a first understanding of the meaning of the family member's lived experience. This resulted in a naïve understanding, from which the structural analysis was guided. In the next phase, the structural analysis was the methodological instance for interpretation. The whole text was divided into meaning units, which were condensed, abstracted, and thereafter sorted into subthemes and themes by three of the authors. All the authors then discussed and reflected upon the subthemes and themes, which were then found to validate the naïve understanding. In the third phase, to reach a comprehensive understanding, the naïve understanding and structural analysis were reflected upon as a whole in relation to the aim of the study, relevant literature, and the authors' different pre-understandings (e.g. clinical and research experience in nursing and ethics in areas such as cardiac arrest, sudden death, emergency care, and palliative care, including family members' health, well-being, and bereavement).

Rigor was established through carefully following the analysis steps (Lindseth & Norberg, 2004). To strengthen credibility, the authors strived to be as open as possible when interpreting the text, making each other's and their own pre-understanding visible and reflected upon during the interpretation of the

phenomenon under study. Awareness of pre-understandings was also increased by the three-phase method. In the early phases the researchers were open to lived experiences and new meanings and avoided judgments. In the last phase, the comprehensive understanding, the pre-understanding was engaged. In order to reach an in-depth interpretation, there was a movement between the methodological phases, the whole and the parts, and between closeness and distance in the text (Lindseth & Norberg, 2004; Ricoeur, 1976).

Ethical considerations

Formal ethical approval was given by the Regional Ethical Review Board in Linköping, Sweden (No. 2017/525-31). All participants were given written and oral information about the study before the interviews informing them that participation was voluntary, that they had the right to withdraw participation, and that they were guaranteed confidentiality.

Findings

Naïve understanding

Losing a close person following cardiac arrest means that life as it is known suddenly changes. The sudden event of cardiac arrest creates feelings of unreality and is hard to comprehend. The CPR attempts evoke hope of survival, despite some understanding that the person is dying or even already dead. Family members find themselves having to rely on healthcare professionals, and they evaluate the professionals' actions as well as their own. The sudden loss involves being left with questions, some without answers. The death is a reminder that life might suddenly end, and this can cause anxiety and worries about one's own health and the health of others. Losing a close person means suddenly having to take care of all kinds of practical things. It means seeking consolation and starting a grieving process but also pushing away feelings in order to keep functioning in everyday life. Suddenly activities in everyday life become pointless when being alone. Losing a close person means needing to be together with others talking and remembering good times, keeping the loved lost one close and a part of the family. Nevertheless, it also means needing time to be alone with one's thoughts and feelings. Losing a close person inevitably means being apart and suddenly losing the future as it was once intended. It also entails feelings of love and thankfulness for the time spent together, and compassion for others in similar

Table 2. Themes and subthemes in the structural analyses.

Themes and subthemes
Pending between life and sudden loss
Fluctuating between hope and despair during resuscitation
Needing to feel meaning in the act of resuscitation
Wanting to feel taken care of by healthcare professionals
Needing to know that everything possible was done
Proceeding with life after sudden loss
Being left with questions, some without answers
Seeking consolation in the sudden nature of death
Being reminded of death as a part of life
Experiencing an unfamiliar body
Wanting to be acknowledged as a bereaved family member
Suddenly losing life as it was known

situations increases. Suddenly losing a close person following a cardiac arrest involves feelings of injustice while also acknowledging death as natural and seeking comfort from the idea that dying from cardiac arrest avoids prolonged suffering.

Structural analysis

The findings of the structural analysis resulted in ten subthemes and two themes. The theme “Pending between life and sudden loss” involved four subthemes: Fluctuating between hope and despair during resuscitation; Needing to feel meaning in the act of resuscitation; Wanting to feel taken care of by healthcare professionals; and Needing to know that everything possible was done. The theme “Proceeding with life after sudden loss” involved six subthemes: Being left with questions, some without answers; Seeking consolation in the sudden nature of death; Being reminded of death as a part of life; Experiencing an unfamiliar body; Wanting to be acknowledged as a bereaved family member; and Suddenly losing life as it was known (Table 2).

Pending between life and sudden loss

Fluctuating between hope and despair during resuscitation means involuntarily ending up in a vacuum between life and death and in a strange and “difficult-to-interpret” sequence of events that is beyond the family members’ control. CPR could initiate feelings of hope, both when being performed by healthcare professionals and by oneself. When there was a pause in the CPR performed by the healthcare professionals, this was emotionally draining, not knowing if it meant that the person was alive or dead. Hope also fluctuated during CPR because the heartbeats could get going and then cease again. However, hope was kept alive by a strong desire that the person would survive,

even when the chances were understood as minimal, until death was acknowledged. A spouse said:

Then they [the rescue team] had said that he was dead; however, the last words our neighbor said to me were, ‘They’re holding on. So, there can be...’ The neighbor gave me a little shred of hope and we drove to the hospital. Maybe he will be sitting there acting as if nothing has happened.

Being dependent on the healthcare professionals’ and/or others’ ability to describe and explain what was happening involved feeling out of control, and recognizing the risk of suddenly losing a close person awoke feelings of despair and panic. Family members fluctuated between hope and despair during CPR at the same time as the hope in and meaning with the resuscitation attempts gradually faded away.

Needing to feel meaning in the act of resuscitation means that the act itself was connected to a sense of meaning among the family members. When realizing that the person was unquestionably dead, the meaning of CPR was lost and it felt offensive and disturbing to be prompted to start CPR. A spouse narrated how she found her husband dead in bed and when she called the dispatch center the emergency medical dispatcher (EMD) repeatedly insisted that she must start CPR. In the end the spouse only pretended to initiate CPR.

It was an unnecessarily difficult thing for me because they made me feel... I just felt as if she didn’t think I wanted him to live. Do you understand? And that gave me such a bad conscience! - Do you realize he’s dead! - ‘Yes, but you do not know,’ she says [the EMD]. - Well, I know! Then it was just as if I was thinking, ‘Don’t you think I want him to live or?’ Yuk! [shiver]. And I just felt that I knew I was doing right [to not start CPR].

The local rescue service that arrived shortly afterwards confirmed that her husband had been dead for several hours. The lack of empathy and understanding when being doubted by the EMD worsened her experience both during the situation and afterwards.

Wanting to feel taken care of by healthcare professionals means that the involved family members want to be shown respect and be given a chance to take part in the course of the events. Hence, staff that were attentive and provided information both during and after resuscitation were considered supportive and caring. A daughter felt that her wishes were respected when her mother suffered from repeated cardiac arrest:

Dad and I sat there [bedside] and the staff asked: ‘If she gets a cardiac arrest, do you want to stay or do you want to leave the room?’ I answered: ‘Then we

will leave.’ ‘Then you can leave now’ [the nurse said], as mother got another one [cardiac arrest]/.../We went out in the family room and waited there and then they came out and said: ‘You can come back in now.’

Such experiences were mediated by different professionals, for example, an EMD, emergency services such as the local fire brigade, ambulance, or police, or healthcare professionals at the hospital. However, the presence of the police could be perceived as bothersome because of worries about what neighbors (or other people) might think.

When death was certain and there was nothing more to do for the deceased, the family members preferred that the health care professionals would have shifted their focus on to them. They wished for a peaceful and quiet atmosphere to spend time with the deceased and a chance to say their farewells. In this unreal and difficult situation, they needed to feel supported and cared for by the healthcare professionals. This was expressed, for example, as feeling permitted to ask questions, being offered something to drink, not being left alone, and that the deceased was treated with respect and as a person. A woman explained that a physician through a phone call had announced the death of her mother. The physician then called her back in a few hours to check if she had any questions. This made her feel supported and cared for.

In contrast, family members expressed feeling unsatisfied and abandoned when the involved professionals were unable to show compassion or showed a lack of caring for the family members. This was experienced, for example, when things were perceived as being done in a hurry, such as not taking time to talk to family members or asking for their wishes, such as removing jewelry from the deceased without asking first. A family member described the situation when the family was referred to a room in the hospital to stay in during the resuscitation attempt and after their loss:

The staff said: ‘You may stay as long as you want’./.../Nobody really asked ‘How are you?’ or ‘Do you need anything?’/.../It almost felt like... that we were in their way, because they were short on staff and... we didn’t feel taken care of.

The professionals’ actions were of significance for family members’ experiences of the event of the loss and their processing of the event, the loss, and the grief.

Needing to know that everything possible was done means that family members needed to know that the death was indeed inevitable. This was understood through the healthcare professionals’ actions during the resuscitation regarding both the deceased and the

family members. In the hospital, some family members were given the opportunity to choose to be present during CPR, which could help their understanding of the situation. The understanding and feeling that everything was done could also be communicated to family members who had not been present at the cardiac arrest when being told about the course of events. A woman narrated how a physician phoned her and told her about her mother’s death in the hospital:

That bit [her mother dying in the hospital] felt good, I thought. Rather than her [the mother] lying dead alone at home./.../Now we basically knew minute by minute what had happened and how it had happened.

Getting to know as much as possible concerning the event of the death helped her in the sudden situation of loss.

Proceeding with life after sudden loss

Being left with questions, some without answers means that the unexpected death and its sudden nature raised many questions and that answers could not always be given. Family members struggled to get an idea of the event of death, to know what really happened and what caused the heart to stop. Hence, they looked for answers and missing parts of their own understanding and narrative of the sudden loss and expressed the importance and relief when they had the opportunity to talk and ask questions and to get at least some answers. When answers were missing because of healthcare professionals’ mistakes or shortcomings, it was important that they showed empathy and acted with respect toward the family members in order to regain family members’ confidence. In this case, to not follow up with information later as promised was experienced as disrespectful and extremely hurtful. However, the sudden loss also provoked family members’ questions and regrets about their own actions. A son said: “Could I have done something different, could she have been alive today?” Being left with unanswered questions also involved living with doubts and thoughts of things that had not been said or done.

Seeking consolation in the sudden nature of death means that although it was an abrupt and shocking death for the family members, they sought consolation in that the sudden nature of death in cardiac arrest avoids suffering for the deceased. A spouse said: “Peaceful for him [to die in his sleep] with no torment, but totally, totally shocking for us.” Family members also sought consolation in that death was

perceived as more merciful this way than if the person had survived with, for example, a severe brain injury. Furthermore, participants expressed that consolation had to be sought where it could be found. For example, a spouse found consolation in the fact that her husband had not suffered the cardiac arrest in a public place in front of strangers.

Being reminded of death as a part of life means that the sudden death aroused thoughts about life's fragility and reminded the family members of mortality, both others' and their own. The sudden death, especially of a younger person, meant that anyone could suffer a cardiac arrest and die. It was hard to comprehend why a seemingly healthy person had died and a certain sense of safety in life was then lost. A daughter said: "Now I think very much about if something should happen to mom. Who is there then? And then you think about yourself/.../that you are not immortal." Death was regarded as a natural part of life, except that it should not happen now, so suddenly and unexpectedly on a day that had begun just like any other day. It was difficult to grasp the loss, and it was incomprehensible how a person could suddenly cease to exist. A spouse said: "He's completely dead and gone! How can this happen? You go to work in the morning and there is a man alive./.../Then, he's just gone."

Severe illness could have aroused previous thoughts about death and dying, but when living close to illness this became everyday life and thus the death still came as unexpected. A daughter experienced her mother's death as shocking and unexpected the day it happened, although her grief process had started several years earlier when her mother had suffered a severe illness. Instead of grief, she now felt the absence of her mother when being left with time to reflect and realizing the emptiness.

Experiencing an unfamiliar body means that grief came in waves and influenced family members' well-being. After the loss it could suddenly feel like their heart was beating harder and they felt nauseated and had tingling in their hands and feet, and they could also experience cardiac symptoms such as chest pain, which caused worries and fear of dying. Thus, several of the family members had sought emergency care. A spouse said:

I thought I was having a heart attack. So, then they told me that it was stress and anxiety. I would wake up in the middle of the night and feel my heart beating./.../I was calmer simply finding out that it wasn't a heart attack.

Family members felt relieved when they were medically examined and informed that they did not have heart disease. However, the sudden loss caused an increased awareness and worry about one's own health and others' health. Experiencing an unfamiliar body also involved family members expressing feeling tired after the loss because going through the grief process with emotions took a lot of time and energy. Not knowing how to handle or process emotions could result in ignoring them or pushing them away, and it was difficult to know when to look for help. Bereaved family members expressed trying to be strong and to cope, even when not knowing how. A daughter said:

If you are in pain, you go to the healthcare center. Except, this is a bit harder to know. When is it time to go? ... Then, you think, you can handle it, or ... You ought to. You try to be strong ... Somehow you survive!

Wanting to be acknowledged as a bereaved family member means being able to be oneself and to express feelings of grief and to share stories but also to be allowed to sometimes withdraw and be left alone. Family and friends had a great significance in the grief process, and family members emphasized the importance of narrating and being listened to. The possibility to express grief and talk of the deceased was also a way to still feel closeness to the deceased person. Family members expressed both the importance of being able to talk and share the story of their loss and the importance of others, even unacquainted persons, and sharing their stories and memories with them. A daughter said:

It can be someone who knew him, someone you don't know yourself, then you appreciate it a lot if that person talks about him. Instead of not doing that, being afraid of awakening emotions; it's better to keep him alive in that way.

However, a sense of solitude could be experienced in the company of others if the family members felt restricted in expressing their grief. Primarily the younger family members expressed how they felt constrained in talking about their grief, both at work and among friends.

Suddenly losing life as it was known means facing an abruptly changed everyday life and future without the deceased. The participants expressed that worries and concerns on different levels were suddenly aroused, all at the same time, and that this both hampered and steered their grief. Life became unreal and could feel like being in a bubble as when suddenly having to plan a funeral. In this chaos after the loss it felt valuable to visit the mortuary where the family

members could see the deceased and say farewell. Furthermore, family members unexpectedly found themselves with new responsibilities when having to take over the deceased persons' previous obligations, which could be challenging and worrying. At the same time, everyday chores like cooking or cleaning lost their earlier significance. A spouse said:

Sometimes (sigh) ... I think it is so pointless. That's what so hard. I can sit and know that I should do that, and that, but ... There's no one who ... / ... /you get no appreciation or see someone else become happy, so it is ...

Family members felt sorry for themselves, but they struggled to not feel that way. In the home, the loss was constantly present, for example, through photos or the deceased's belongings, and feelings ranged from it being nice to remember them to being hard and hurtful to be constantly reminded of the loss. Family members were living with the fear of forgetting but also the fear of getting stuck in pointless ruminating. They struggled to find a sense of meaning and coherence in everyday life without the deceased. Losing life as it was known also means changing relationships within the family after the loss. Family members shared the loss together, but the experience and their narrative of the loss and the event were in many ways deeply individual. It could be hard for family members to relate to the different individual expressions of grief and to understand each other within the family. At the same time, family members could feel responsible for other family members' grief and wellbeing. Thus, they not only had their own grief since they also lived with others' grief. A woman narrated how her son tried to provide her comfort and how she in turn acted as if she felt comforted as a way to provide him comfort, although she did not feel any comfort herself.

My son says: 'Now grandma is out of pain'. He says it was good for grandma. I have to bite my tongue stopping myself from saying something, for his sake. I have had him around me but it has not helped.

The grief process proceeded at an individual pace. Sometimes, this involved feelings of disappointment when others moved on. Over time, gratitude grew for having shared life with the deceased, although feelings of injustice over the sudden loss remained. The new-found experiences of life after loss generated compassion for others who had also suffered a profound loss.

Comprehensive understanding and reflections

Meanings of losing a close person following sudden cardiac arrest came forth in the themes of "Pending

between life and sudden loss," as being in the borderland of existence in an emotional space between life and death, and "Proceeding with life after sudden loss" as being forced into movement and transition, searching for coherence and meaning in the suddenly changed life.

The findings illuminate that the lived experiences of the sudden loss in the borderland of existence are intertwined with the search for coherence and meaning in the transitions that are needed to proceed with life. This intertwined interaction may be understood as being on a threshold, in liminality (Turner, 1967, 1969). Liminality is described (Turner, 1967) as being neither here nor there, as being in a non-space in "betwixt." Losing a close person following death by sudden cardiac arrest is understood as suddenly being in a liminal space in the borderland in-between life and their loved one's death. Liminality is illuminated in narrations of family members, pending between life and sudden loss, who describe "being in-between." Their sudden loss means losing life as it was known being forced into a non-space, left with questions as coherence and meaning in life is suddenly challenged.

In the present study, based on Turner's (1967, 1969) thoughts about liminality, the lived experiences of the sudden loss in the liminal space came forth. The family members need to grasp paradoxes of emotions and cognitive understandings in liminality to integrate these paradoxes reaching coherence and meaning. Family members are suddenly forced into a movement from a familiar state to an unknown state but ending up in-between, betwixt. Standing on the threshold while other forces in life pull toward reengaging in life involves a fear of forgetting while also sensing a fear of getting stuck in pointless ruminating, as a prolonged state "in-between." Standing on the threshold also implies a need to be acknowledged for one's loss and to be able to express grief without feeling restricted by other persons and, hence, face extended liminality. When continuing with life, the family members continue to illuminate liminality, for example, when living without answers and experiencing unfamiliar thoughts and feelings. Lacking answers might be understood out of liminality as remaining standing on a threshold.

In the liminal space, family members responded to the unreal situation of the cardiac arrest event through their own interpretations of what was happening. Individual interpretations are illuminated by the philosopher Merleau-Ponty (2004) when describing that we as humans are our body and that we experience the world through our subjective and lived

body in the physical, psychological, and spiritual and existential dimensions all at the same time. This is consistent with family members' experiences of an unfamiliar body and their existential thoughts due to the sudden loss. The present findings show that it can be difficult for family members to understand each other's expressions and pace of grief. This may also be understood in the context of Merleau-Ponty (2004) who says that all humans have an individual way of understanding and approaching other humans and the world in which we live. However, intersubjectivity provides the possibility for humans to approach other humans' experiences because through other humans we develop and reflect on our own subjective experiences. This is seen in the present findings as grief is both a universal and an individual experience, and family members share the experience of the loss, but the significance of the loss is different for each individual family member.

When standing on the threshold in liminality, the present findings show the importance of narrating and being listened to when reaching toward incorporation of the sudden loss. According to Neimeyer et al. (2014), the story of the death entails both the *event story* and the *backstory* of the relationship to the deceased. Through the stories we tell and share, and through others' stories about us, our identity is established. Furthermore, as a process of establishing meaning in the death, the narration is shared and expressed within the context of society. Meaning is understood between and within people, and the bereaved seek validation of the significance of their loss from others. In the narration and interaction, the bereaved either reflect on or reject the significance of the loss in the context of the societal and cultural environment and norms (Neimeyer et al., 2014). This is in line with the present findings that point to the significance of being acknowledged as bereaved by family members, friends, coworkers, and other significant persons. However, the narration could also be discouraged and cause distress, which is consistent with studies (Mayer et al., 2013; Pitman et al., 2018) showing that the experience of sudden death involves experiences of stigmatization and social awkwardness.

In the present study, living without answers came forth as constraining the search of coherence to proceed life, hence, continuing liminality and remain standing on the threshold. Sudden death by cardiac arrest left family members in the present study with unanswered questions, which is also in line with earlier studies (Bremer et al., 2009; Mayer et al., 2013). Merlevede et al. (2004) found that family members

confronted with a sudden and unexpected death were left with questions regarding the cause of death and whether the deceased felt pain before their death. Other questions involved self-blame concerning questioning whether having done the right things or concerning the actions of others such as healthcare professionals. Family members also felt new and overwhelming feelings and had questions about their grief process. According to Neimeyer et al. (2014), persons who make the effort to make sense of the troubling transition seem to undergo bereavement in a less complicated way than those who do not seem to find answers to their existential questions (Neimeyer et al., 2014). This highlights the significance of family members being listened to, and providing information about what is known about the cardiac arrest event adds to their narration of the event and the sudden death. Furthermore, losing a close person following cardiac arrest involves no time to prepare or to say farewell before death, sometimes even in spite of a known illness in the person. This might add to questions and to the challenge when making sense of the death.

Experiences of health care professionals as caring or uncaring toward the lost person or themselves were significant and influenced the transition toward coherence and meaning. Hence, family members in the present study expressed a need to be acknowledged and to feel cared for. However, studies both in hospitals (Rafiei et al., 2018) and out of hospitals (Bremer et al., 2012) have shown the complexity of caring in this context, both during the event of resuscitation and when caring for bereaved family members. Uneasiness and short-comings have been described as barriers by healthcare professionals, for example, a lack of courage to face different reactions among family members and one's own vulnerability (Bremer et al., 2012; Rafiei et al., 2018). Walker and Deacon (2016) also show that caring for the suddenly bereaved is experienced as a source of tension and unease by healthcare professionals. The present findings show that compassion and a feeling of being cared for had to be mediated through both verbal and nonverbal communication. Even though Merleau-Ponty (2004) does not write about caring, intersubjectivity as the interaction between subjects might be seen as a possibility for providing care. Bereaved family members could benefit from support 'here and now' since emotional and psychological support might prevent psychological disorders (Soleimanpour et al., 2017; Youngson et al., 2017). However, supportive care also needs to be available over time (Walker & Deacon, 2016). Support

in the longer term includes, for example, follow-up meetings at 2–4 months to answer questions in order to move on in life after the loss (Voisey et al., 2007).

Methodological considerations

Credibility in this study was strengthened by the variation in the characteristics (e.g. relations, age, and sex) of the family members willing to share their lived experiences, thoughts, and feelings, which provided richness of the data and facilitated the understanding of the phenomenon from different perspectives. However, a possible limitation is the exclusion of participants who lost a child due to cardiac arrest. Inclusion of them would have increased sample heterogeneity but would also have created difficulties in recruiting participants. Excluding children younger than 18, or accidents and suicide victims as reasons for death, was also important to balance heterogeneity with homogeneity. Still, our aim to reach a broader understanding by also including different contexts for the cardiac arrest events is considered to illuminate variations of the lived experiences, both in and out of the hospital. The study was performed with great thoughtfulness and respect for the participants' vulnerability by giving them time to reflect, and the interviewer strived to create a permissive climate of trust and to be compliant to the participants' narratives, which strengthens trustworthiness. According to Ricoeur (1976), there are various possible interpretations of any text. However, to strengthen credibility, different interpretations of the text were argued and discussed during the analysis until agreement was reached on the most probable interpretation. Hence, the authors' different pre-understandings enriched the critical reflection during the analysis process and strengthened trustworthiness. The use of representative quotations will help readers to assess the authenticity and validity of the results and interpretations. We consider our findings to be transferable to similar contexts if they are recontextualized (cf. Lindseth & Norberg, 2004), and the readers' judgments of transferability are facilitated by the description of the participants and the context.

Conclusions

Losing a close person following cardiac arrest means suddenly being in the borderland in-between life and death. These experiences are intertwined with the search for coherence and meaning in the transitions to proceed with life. This means being on a threshold,

in liminality; neither here nor there, in a non-space in between. In these transitions, the narrations of the cardiac arrest event are essential when reaching toward incorporation of the sudden loss and reestablishing meaning in life. The liminal space between life and death is individually experienced but also shared by family members and the involved professionals as they become part of the family members' stories. Thus, healthcare professionals have a unique opportunity to provide support and show compassion, both 'here and now' and over time. Through structural support such as follow-up meetings, professionals can provide family members with answers that facilitate a coherent narration of their loss.

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References

- Bremer, A., Dahlberg, K., & Sandman, L. (2009). Experiencing out-of-hospital cardiac arrest: Significant others' lifeworld perspective. *Qualitative Health Research*, 19(10), 1407–1420. <https://doi.org/10.1177/1049732309348369>
- Bremer, A., Dahlberg, K., & Sandman, L. (2012). Balancing between closeness and distance: emergency medical services personnel's experiences of caring for families at out-of-hospital cardiac arrest and sudden death. *Prehospital and Disaster Medicine*, 27(1), 42–52. <https://doi.org/10.1017/S1049023X12000167>
- Compton, S., Levy, P., Griffin, M., Waselewsky, D., Mango, L. M., & Zalenski, R. (2011). Family-witnessed resuscitation: Bereavement outcomes in an urban environment. *Journal of Palliative Medicine*, 14(6), 715–721. <https://doi.org/10.1089/jpm.2010.0463>
- Hall, C. (2014). Bereavement theory: Recent developments in our understanding of grief and bereavement. *Bereavement Care*, 33(1), 7–12. <https://doi.org/10.1080/02682621.2014.902610>
- Kristensen, P., Weisaeth, L., & Heir, T. (2012). Bereavement and mental health after sudden and violent losses: A review. *Psychiatry: Interpersonal and Biological Processes*, 75(1), 76–97. <https://doi.org/10.1521/psyc.2012.75.1.76>
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101(2), 141–148. <https://doi.org/10.1176/ajp.101.2.141>
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145–153. <https://doi.org/10.1111/j.1471-6712.2004.00258.x>

- Mayer, D. M., Rosenfeld, A. G., & Gilbert, K. (2013). Lives forever changed: Family bereavement experiences after sudden cardiac death. *Applied Nursing Research*, 26(4), 168–173. <https://doi.org/10.1016/j.apnr.2013.06.007>
- Merleau-Ponty, M. (2004). *Phenomenology of perception*. Routledge.
- Merlevede, E., Spooren, D., Henderick, H., Portzky, G., Buylaert, W., Jannes, C., Calle, P., Van Staey, M., De Rock, C., Smeesters, L., Michem, N., & Van Heeringen, K. (2004). Perceptions, needs and mourning reactions of bereaved relatives confronted with a sudden unexpected death. *Resuscitation*, 61(3), 341–348. <https://doi.org/10.1016/j.resuscitation.2004.01.024>
- Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies*, 38(6–10), 485–498. <https://doi.org/10.1080/07481187.2014.913454>
- Parkes, C. M. (1998). Coping with loss, bereavement in adult life. *BMJ (Clinical Research ed.)*, 316(7134), 856–859. <https://doi.org/10.1136/bmj.316.7134.856>
- Patton, M. Q. (2015). *Qualitative Research & Evaluation Methods* (4th ed). Sage Publications, Inc.
- Pitman, A. L., Stevenson, F., Osborn, D. P. J., & King, M. B. (2018). The stigma associated with bereavement by suicide and other sudden deaths: A qualitative interview study. *Social Science & Medicine* (1982), 198, 121–129. <https://doi.org/10.1016/j.socscimed.2017.12.035>
- Prior, A., Fenger-Grøn, M., Davydow, D. S., Olsen, J., Li, J., Guldin, M.-B., & Vestergaard, M. (2018). Bereavement, multimorbidity and mortality: A population-based study using bereavement as an indicator of mental stress. *Psychological Medicine*, 48(9), 1437–1443. <https://doi.org/10.1017/S0033291717002380>
- Rafiei, H., Senmar, M., Mostafaie, M. R., Goli, Z., Avanaki, S. N., Abbasi, L., & Mafi, M. H. (2018). Self-confidence and attitude of acute care nurses to the presence of family members during resuscitation. *British Journal of Nursing (Mark Allen Publishing)*, 27(21), 1246–1249. <https://doi.org/10.12968/bjon.2018.27.21.1246>
- Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Christian University Press.
- Shah, S. M., Carey, I. M., Harris, T., DeWilde, S., Victor, C. R., & Cook, D. G. (2013). The effect of unexpected bereavement on mortality in older couples. *American Journal of Public Health*, 103(6), 1140–1145.
- Soleimanpour, H., Sadegh Tabrizi, J., Jafari Rouhi, A., Golzari, S. E., Mahmoodpoor, A., Mehdizadeh Esfanjani, R., & Soleimanpour, M. (2017). Psychological effects on patient's relatives regarding their presence during resuscitation. *Journal of Cardiovascular and Thoracic Research*, 9(2), 113–117. <https://doi.org/10.15171/jcvtr.2017.19>
- Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *Lancet (London, England)*, 370(9603), 1960–1973. [https://doi.org/10.1016/S0140-6736\(07\)61816-9](https://doi.org/10.1016/S0140-6736(07)61816-9)
- The Swedish Register of Cardiopulmonary Resuscitation (2018). *The Swedish Register of Cardiopulmonary Resuscitation annual report 2018*. Retrieved February 1, 2019, from <https://www.hlr.nu/svenska-hlr-registret/>
- Thorén, A.-B., Danielson, E., Herlitz, J., & Axelsson, B. Å. (2008). Spouses' experiences of a cardiac arrest at home: an interview study. *European Journal of Cardiovascular Nursing*, 7(1_suppl), 7–167. <https://doi.org/10.1016/J.EJCNURSE.2008.01.014>
- Turner, V. (1967). *Betwixt- and-between: The liminal period in the forest of symbols*. Cornell University Press.
- Turner, V. (1969). *The ritual process: Structure and anti-structure*. Aldine De Gruyter.
- Voisey, S., Davies, J., Parry-Jones, J., & Stallard, N. (2007). Five years experience of critical care bereavement follow-up. *Critical Care*, 11(Suppl 2), P494. <https://doi.org/10.1186/cc5654>
- Walker, W., & Deacon, K. (2016). Nurses' experiences of caring for the suddenly bereaved in adult acute and critical care settings, and the provision of person-centred care: A qualitative study. *Intensive & Critical Care Nursing*, 33, 39–47. <https://doi.org/10.1016/j.iccn.2015.12.005>
- Wong, C. X., Brown, A., Lau, D. H., Chugh, S. S., Albert, C. M., Kalman, J. M., & Sanders, P. (2019). Epidemiology of sudden cardiac death: global and regional perspectives. *Heart, Lung & Circulation*, 28(1), 6–14. <https://doi.org/10.1016/j.hlc.2018.08.026>
- Youngson, M. J., Currey, J., & Considine, J. (2017). Current practicies related to family presence during acute deterioration in adult emergency department patients. *Journal of Clinical Nursing*, 26(21–22), 3624–3635. <https://doi.org/10.1111/jocn.13733>
- Zalenski, R., Gillum, R. F., Quest, T., & Griffith, J. L. (2006). Care for the adult family members of victims of unexpected cardiac death. *Academic Emergency Medicine: Official Journal of the Society for Academic Emergency Medicine*, 13(12), 1333–1338. <https://doi.org/10.1197/j.aem.2006.06.029>