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Feeling responsible but unsupported: How relatives of out-of-hospital cardiac arrest survivors experience the transition from hospital to daily life – A focus group study

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Abstract

Aim: To generate knowledge about how relatives of out-of-hospital cardiac arrest survivors experience the transition between hospital and daily life. The research question was “how do relatives of out-of-hospital cardiac arrest survivors experience collaboration and communication with healthcare professionals, and what is emphasized as important in the transition from hospital to daily life”.

Design: Qualitative design.

Methods: Six semi-structured focus group interviews were conducted with 23 relatives of out-of-hospital cardiac arrest survivors who participated in a residential rehabilitation course. Data was collected between November 2018 and March 2019. Transcripts were analysed using a phenomenological hermeneutic approach.

Results: The analysis generated three themes “a necessary presence,” “communication with healthcare professionals on the cardiac ward” and “the abrupt disappearance of the system.” Relatives of out-of-hospital cardiac arrest survivors feel a great responsibility when coping and adjusting to their new life. In the transition to daily life, a focus on systematic involvement and collaboration with relatives should be an essential part of the post-cardiac arrest pathway.

KEYWORDS

communication, focus group, healthcare professionals, healthcare system, out-of-hospital cardiac arrest, relatives

1 | INTRODUCTION

Surviving an out-of-hospital cardiac arrest (OHCA) is a traumatic event that is felt beyond the survivor. Relatives too may struggle to deal with the consequences caused by the cardiac arrest (Haywood & Dainty, 2018). A recent scientific statement on sudden cardiac arrest survivorship recommends that post-cardiac arrest care should involve the relatives as a central and active part of the post-cardiac arrest pathway (Sawyer et al., 2020). Previous studies have suggested a lack of support and information increases anxiety during

the transition phases involved in these post-cardiac arrest pathway (Larsson et al., 2013; Wallin et al., 2013).

1.1 | Background

Survival after OHCA is increasingly common (Myat et al., 2018; Porzer et al., 2017). Extensive investment in research, infrastructure and training have led to improvements in bystander resuscitation, pre-hospital care and acute medical management (Hassager

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et al., 2018). In North America and Europe, more than 700,000 people suffer OHCA every year and approximately one in ten of these people will survive until hospital discharge (Wong et al., 2019).

A lack of oxygen to the brain during an OHCA means that survivors risk suffering some degree of cognitive impairment (Cronberg et al., 2020). Current literature reports one year post-arrest cognitive impairments in 30%–50% of all OHCA survivors leading to problems returning to daily life (Cronberg et al., 2020; Moulaert et al., 2015). Further, survivors may suffer emotional trauma reactions, anxiety about the future and chronic fatigue (Green et al., 2015; Moulaert et al., 2015; Wagner et al., 2020).

Relatives of OHCA survivors are often deeply involved in the survivor's recovery and their return to daily life. This period of transition from hospital to daily life can be a difficult emotional process. The traumatic event can cause feelings of inadequacy, uncertainty and hopelessness for relatives (Bremer et al., 2009; Haywood & Dainty, 2018; Wallin et al., 2013). This may lead to anxiety and depression (Van Wijnen et al., 2017). In one study, trauma-related stress was still present in one third of relatives two years after OHCA (Hofland et al., 2018).

Survivors may need more support with daily life tasks due to cognitive impairments, with memory, attention and problem solving abilities most commonly affected (Cronberg et al., 2020). Significantly, mood disorders such as anxiety and depression have been found to be more prevalent in relatives of OHCA survivors with cognitive impairments (Van Wijnen et al., 2017). In addition, a recent interview study with critically ill patients and their family members found very different recollections of events during the period of critical illness (Page et al., 2019). Finally, research shows that relatives of OHCA survivors may experience increased responsibilities and restrictions in social life (Wallin et al., 2013).

Relatives are considered by healthcare providers to serve a central role in supporting a patient's transition from hospital to home (Hahn-Goldberg et al., 2018). Considering the potential emotional and practical burden suffered by relatives of OHCA survivors, an understanding of how relatives experience this transition would help identify the need for specific support or interventions over and above those offered to OHCA survivors.

1.2 | Aim

The aim of this study was to generate knowledge about how relatives of OHCA survivors experience the transition between hospital and daily life. The research question was "how do relatives of OHCA survivors experience collaboration and communication with healthcare professionals, and what is emphasized as important in the transition from hospital to daily life".

1.3 | Design

The qualitative design for this study was chosen in order to explore the experiences of the participants and was inspired by a

TABLE 1 Demographic and clinical characteristics of the participants ($N = 23$)

Characteristics	N
Gender, men	6
Age (year)	
31–40	2
41–50	5
51–60	8
61–70	5
71–80	2
81–90	1
Family relation	
Mother-in-law	1
Partner / non-cohabitants	1
Married/cohabitants	11
Married/ cohabitants with children	10
Time between OHCA and interview (months)	
<4	2
4–12	6
13–24	7
25–48	1
49–72	3
73–96	1
97–120	1
121–134	2

phenomenological hermeneutic approach. The method of data analysis was inspired by Paul Ricoeur's qualitative analysis (Missel & Birkelund, 2019).

2 | METHOD

2.1 | Setting and participants

Data were collected through focus groups as these are capable of producing concentrated data in a social context about the participants' expressed experiences and norms on a topic chosen by the researcher (Halkier, 2016). Participants were attending one of three, three-day residential rehabilitation courses for OHCA survivors and their relatives at REHPA The Danish Knowledge Centre for Rehabilitation and Palliative Care in Denmark. All twenty-three participants (31–89 years old, 17 women) (Table 1) were close family members of attending survivors, predominantly spouses or partners, a single participant was the mother-in-law of a survivor. The focus groups were mixed according to gender and age of participants. The time since OHCA varied from 3–134 months (≈ 12 years) (Table 1).

The Danish healthcare system is universal and based on the principles of free and equal access to health care for all Danish citizens, in regard to both hospital treatment and rehabilitation. The

primary sector, known as municipalities, is responsible for rehabilitation outside hospitals. Hence, after the medical treatment at the hospital, OHCA survivors are referred to rehabilitation in their municipality. The Danish healthcare system offers high-quality services, the majority of which are financed by general taxes (Ministry of Health & Healthcare Denmark, 2017). The residential rehabilitation course at REHPA for OHCA survivors was offered in addition to usual care.

2.2 | Data collection

The first author (CD) moderated all the interviews. CD has a background as a cardiology nurse with extensive clinical experience with OHCA survivors and their relatives. CD also had knowledge of some of the participants and the healthcare teams involved in their care. In addition, an experienced researcher with a health professional background participated in each interview as an observer (CB). Their role was to make observations, write notes and ask supplementary questions. Six interviews were conducted using a semi-structured interview guide comprising open-ended questions (Table 2). Participants were encouraged to share their experiences in their own words and to describe what was important to them. An open-minded approach was fostered through active listening. Before the interviews, the purpose of the study was explained to the participants and they were asked if they would like to take part. The participants had already met each other as the interviews were conducted on the second day of the rehabilitation course. All six focus group interviews were on average one hour long. Two interviews were performed in November 2018 and four in March 2019. The interviews were recorded and transcribed verbatim.

2.3 | Data analysis

The scientific theoretical position was inspired by Paul Ricoeur's phenomenological hermeneutics, whereby we emphasized both the experiences and phenomena connected to participants' lifeworld and the dialogues between the participants. The starting point in the analysis of the six transcribed interviews was Ricoeur's interpretive theoretical framework, which consists of three levels: a naive reading, a structural analysis and a critical analysis (Missel & Birkelund, 2019). At the first level, three authors (CD, MKW and CB) individually read all the interviews to create an overall impression. A broad range of themes was found; therefore, only those relevant to the aim of this study will be presented here. At the second level, we divided data into meaning units, where the units of meaning from the individual interviews were paired with similar units of meaning from the other interviews. At the third level, we interpreted data in a dialectical movement between explaining the meaning of the text and understanding the meaning of the text. This was conducted in a circular process where identified units of meaning were reread in their primary context and perhaps gathered into other units of meaning with similar themes, resulting in the final themes (Table 3).

3 | RESULTS

Overall, this study found that relatives often take an active part in the survivor's situation and that they need to be fully involved in the transition of the survivor from hospital to daily life. The findings indicate that both communication and collaboration between healthcare professionals and relatives are essential to support the transition. However, this communication and collaboration changes

TABLE 2 Semi structured interview guide

Research question:	
The aim of this study was to generate knowledge about how relatives of OHCA survivors experience the transition between hospital and daily life. The research question was "how do relatives of OHCA survivors experience collaboration and communication with healthcare professionals, and what is emphasized as important in the transition from hospital to daily life"	
Research areas	Interview questions
Experiences in the hospital	<i>Can you describe the first thing that comes to your head when you hear the word cardiac arrest? Thinking back at the cardiac arrest, can you tell us about your experiences in that context? What do you find important for healthcare professionals to consider during the hospital stay and around discharge to support the relatives?</i>
Experiences in daily life	<i>Can you elaborate on your concerns, and what have been your most important concerns after the cardiac arrest? Can you describe how you have experienced your daily life after the out-of-hospital cardiac arrest?</i>
Levels of information	<i>How were your experiences of support after discharge from the hospital? And would anyone like to share your experiences of rehabilitation? Can you describe what kind of information and help that you needed to make it easier returning to daily life? Did you experience a need of seeking support for you self and your loved ones?</i>
Loved ones and relatives	<i>Have you learned something according to your loved ones surviving a cardiac arrest? How would you describe relations to other people after the cardiac arrest? Do you experience that your values and priorities in life have changed after the cardiac arrest?</i>
Practically aspects	<i>Are you interested in having the results of this study sent when it is completed?</i>
Rounding off the interview	<i>Thank you for your participation</i>

throughout the survivor's time in hospital – especially pre-discharge – in a way that does not support the relatives. The results are presented in three interconnected themes: “A necessary presence”, “communication with healthcare professionals on the cardiac ward” and “the abrupt disappearance of the system.”

3.1 | A necessary presence

Confronted with the healthcare system, the participants found themselves in a serious situation dealing with important questions of life or death. Many participants experienced the system as well-organized with a high level of professionalism, taking good care of their relatives, especially in the chaotic acute phase. The focus of the participants in this phase was mainly on the survival of the survivor. The participants described deep concerns and anxieties during the hospital admission. Most of the participants felt they carried an emotional burden on top of the traumatic experience and described how being close to the survivor was important.

It was fantastic (being present at the hospital). Personally, it meant that I had less unanswered questions. I was there all the time (...) until he was more recovered

As this participant points out, being present at the hospital was a high priority allowing them to follow the survivor's recovery closely. Like this participant, several participants described being present at the hospital as an emotionally difficult time. However, they also pointed out that being away from the hospital would have been even harder.

Another concern the participants shared was the uncertainty about a future with their loved ones suffering from a cardiac disease and cognitive impairments with the potential consequences this would have for daily life. During the hospital admission, the participants described how the survivor permanently or periodically appeared with a different personality. One female participant stated:

He was like a child when he woke up, you know with his memory. I felt the need for my presence, to keep track of information (11)

As illustrated, the participant felt her presence was necessary. These experiences of an abnormal behaviour created feelings of insecurity and unpredictability – not only in terms of the cardiac disease but in terms of the overall postarrest consequences. Participants found the survivor waking up with cognitive impairments causing difficulties understanding their current situation. Hence, the participants described a great responsibility to “keep track” of communication and to be the ones in control of the collaboration with healthcare professionals.

3.2 | Communication with healthcare professionals on the cardiac ward

Overall, participants found it was important they received information from healthcare professionals to help them cope with feelings of anxiety and responsibility during hospital admission. Daily communication with healthcare professionals was emphasized as important to understand both the cardiac condition and the cognitive impairments as they appeared during hospital admission. This was described as especially valuable when the participants were handling the unpredictable situation simultaneously with protecting the survivor. The participants felt safe leaving the hospital to see to their own needs. One said:

I felt safe walking home from the hospital. I was able to follow what was going on. The next step was always told to me and we (relatives) did not need to think about it. In that way I felt that we were very well informed (22)

This sentiment was echoed by several other participants who also described the need to take the full responsibility for understanding the instructions from healthcare professionals. Participants emphasized the importance of receiving support and understandable information from healthcare professionals.

Across the interviews, participants expressed how they experienced different challenges in the transition from hospital admission to daily life. Most of the relatives described how the survivors gradually recovered both physically and neurologically. At the same time, they experienced that healthcare professionals mainly focussed on

TABLE 3 Example from the structural analysis

Citations	Themes
<i>He was like a child when he woke up, you know with his memory. I felt the need of my presence, to keep track of information. He had no idea (11)</i>	A necessary presence
<i>I would rather had known this earlier. They (healthcare professionals) make it sound like you (patients) will be as normal as usually in a short time. I don't think they (patients) need to have those information (8)</i>	Communication with healthcare professionals on the general ward
<i>Support, it's really difficult to locate. I really don't think the system is geared to handle this. I mean you can have a lot of technical instructions; you can have an Implantable Cardioverter Defibrillator and so on. That's where they [healthcare professionals] give you good instructions. However, to help people to move on (relative crying). That's where you are alone. (15)</i>	The abrupt disappearance of the system

the cardiac condition and treatment, and less on the overall risk of OHCA consequences. One said:

I would rather had known this earlier. They (healthcare professionals) made it sound like you (OHCA survivors) will be as normal as usual in a short time (8)

As this quote illustrates, several participants described how difficult it was that healthcare professionals did not address the possibility of suffering hypoxic brain injury during OHCA potentially causing long-term cognitive impairments.

3.3 | The abrupt disappearance of the system

The majority of participants experienced that the consequences of any cognitive impairments did not form a part of the communication during discharge from the cardiac ward. Besides experiencing a lack of information, the relatives felt the discharge to be a premature process described as an abrupt break from the professional care and communication they received during the hospital admission. This female participant described:

He (my husband) was so different than I knew him before. I felt there was no help. He was angry with me because I asked the doctors if they felt sure about sending him home. I felt better when he was there (at the hospital). They send you home early, as fast as possible. That was hard (8)

This quote illustrates how the participant experienced the transition from hospital admission to daily life as difficult. Suddenly being alone at home with the responsibility of the survivor without professional help was described as unsafe but also with mixed feelings. On the one hand, it was a relief to have the survivor back home, but on the other hand feelings of doubt, powerlessness and frustration on how to manage daily life together were prevalent.

Several participants described the hospital discharge as a forced prioritization by the healthcare system and that there existed an incongruity between participants need for healthcare support and the ability of the healthcare system in primary care to provide this support for the participants. One participant said:

Support was really difficult to locate. I really don't think the system was geared to handle it. I mean you can have a lot of technical instructions; you can have an Implantable Cardioverter Defibrillator and so on. That's where they [healthcare professionals] give you good instructions. However, to help people to move on (relative crying), that's where you are alone. (15)

This experience of being alone in the transition of moving on in daily life is shared by most participants in this study. Support from

healthcare professionals was not systematically offered after discharge and several relatives agreed on the experience of difficulty in locating support. Furthermore, they experienced that healthcare professionals deprioritized sharing information on the overall and long-term consequences of OHCA. Furthermore, participants described how in retrospect that they could have used this important information at the time of discharge. One male participant stated:

So much focus on the heart. As if the heart works then everything works (laughing ironically). "Do as you usually do", as if everything is normal. My wife has been alone with this grief and has asked herself; "Have I become more stupid? I can't do what I used to". She thinks it's difficult to recognize herself in this new situation (9)

The participants shared the experience of feeling uneasy with the survivor after discharge. Not having any tools or instructions on how to support the survivor with cognitive impairments made the participants feel powerless. Often the survivor was not able to contribute to practical work at home at the same level as before the OHCA, leaving the relatives with a coordinating role in daily life. Many participants expressed how they would secretly double check the calendar and the grocery list to make sure everything was carried out properly. These altered roles created a significant change in family structures leading to stress. One said:

It is in daily life that all these problems are shown. That's the hard part. You experience them coming home with the wrong things from the grocery list. My husband has problems with his memory. We can agree on something and then the next second he does the complete opposite of what we just agreed (11)

Several participants described being the first person to notice how serious the cognitive impairments seemed to be. Participants found healthcare professionals did not address the cognitive impairments and consequences at discharge and hence, they found themselves with a great responsibility to identify and address these cognitive changes themselves.

4 | DISCUSSION

The aim of this study was to generate knowledge about how relatives of OHCA survivors experience the transition between hospital and daily life. In this study, we present the experiences of relatives in three themes describing the transition between hospital and daily life from different perspectives. The first two themes "a necessary presence" and "communication with healthcare professionals on the cardiac ward" describes the experiences of the transition from the hospital side. These two themes relate to the relatives' experiences of collaboration and communication with healthcare professionals

and points to the importance of information and support from healthcare professionals. The third theme “the abrupt disappearance of the system” describes the experience of the transition from the hospital to home when relatives experienced a lack of support from healthcare professionals in primary care.

This study describes how relatives of OHCA survivors feel a great responsibility in coping and adjusting to the new life situation – both on behalf of the OHCA survivor and for themselves – making relatives of OHCA survivors especially vulnerable. Relatives experience a lack of involvement around the discharge and that it happens too abruptly with little support on how to deal with the cognitive impairments in particular. This feeling of a great lack of support continues when the survivor returns home to daily life where the impact of cognitive impairments becomes even clearer.

The feeling of a major responsibility to “keep track” of care and treatment and instructions from healthcare professionals has also been described in previous studies involving relatives of OHCA survivors (Bremer et al., 2009; Pußwald et al., 2000; Wallin et al., 2013). Findings from our study also highlight that support from healthcare professionals is crucial to relatives, who need guidance in relation to the cardiac situation, risk for cognitive impairments and considerations for the future. This was found to be particularly important during discharge, being the last contact with hospital healthcare professionals before arriving home. Relatives found that the collaboration and communication with the healthcare professionals on the cardiac ward focused on the cardiac care and less on the long-term cognitive impairments, which they regarded as problematic. Other studies confirm that cognitive impairments are sparsely addressed by healthcare professionals (Moulaert et al., 2014; Wallin et al., 2013). A study of adults with acquired brain injury and their families found that cognitive impairments can be very difficult to diagnose and following hospital admission become evident as challenges in daily life (De Goumoëns et al., 2018).

Despite evidence showing cognitive impairments are common after surviving OHCA (Cronberg et al., 2020) and guidelines on post-resuscitation care recommending rehabilitation, it has not been established who is responsible, to identify cognitive impairments in OHCA survivors and to refer for further rehabilitation if needed (De Goumoëns et al., 2018; Nolan et al., 2015). This may explain why healthcare professionals do not focus on cognitive impairments in the transition between hospital and daily life. However, our study demonstrates this lack of focus and information on cognitive impairment may create unnecessary challenges for relatives during the transition to home and adjustment to daily life.

Another reason for the lack of attention and communication on cognitive impairments could be that the healthcare system is highly specialized and the patient pathway bio-medically organized (Lock & Ngyen, 2010) making the heart and the brain two different specialties. Relatives of OHCA survivors often experience a focus on the cardiac medical specialty in the post-cardiac arrest pathway, instead of a more holistic view on the overall consequences after surviving OHCA. In addition to this, the healthcare system

is organized into different sectors, where the post-cardiac arrest pathway is divided between the acute hospital and primary care – making discharge a particularly vulnerable time of transition (Meleis, 2010). On the cardiac ward, the professionals’ focus is perhaps on the “here and now” and not so much on daily life after hospital discharge. After discharge, relatives felt left alone with the care of the survivor and requested more information “on life after surviving OHCA”. The present study points to a need for healthcare professionals to think about the post-cardiac arrest pathway as a whole as opposed to separate parts in relation to disease, treatment, recovery and relatives.

Finally, this study found that relatives experienced a lack of support and communication which may reflect healthcare professionals’ approach towards relatives. Studies show that relatives are considered important in nursing care in relation to being a resource for the patients. However, support for relatives themselves is often inadequate, especially in a highly patient-centred healthcare system where there is a lack of systematic relative involvement (Bernild, 2018; Wallin et al., 2013).

This study has several strengths and limitations. 23 participants were included in six focus group interviews; this was considered enough as after the fourth interview we identified repetitive perspectives from participants, pointing towards data saturation (Polit & Beck, 2010). To ensure we did not miss important new topics, we conducted two further focus group interviews. Both showed repetitions from participants.

A limitation to focus group interviewing is that social control might occur and that it can be difficult for each individual to share life situations with others. In this study, we chose small focus groups to prevent social group control and to provide the necessary facilitation allowing time for each participant to talk about emotional topics (Halkier, 2016). Furthermore, many of the participants described that it was helpful to be able to earnestly share their experiences with other like-minded relatives.

Participants had a wide variation in time since OHCA and hospital discharge [<4 –134 months]. This is potentially a limitation due to the length of recall time differing between participants. However, as they had all experienced the same event: hospital admission and discharge home, we do not consider that this would greatly influence the results.

Another possible limitation in this study is the sampling strategy where the inclusion took place during a rehabilitation course sought by the participants. Thus, our participants may be more resourceful and engaged in the OHCA survivor’s situation than the general population of relatives of survivors. Another consideration is the participants were relatives of survivors who all self-identified as having rehabilitation needs, again making them different from the general population of relatives of OHCA survivors.

To ensure validity, we made the study process as transparent as possible by using Ricoeur’s interpretation model (Table 2) and frequent, direct quotes. Through the third phase of interpretation: explaining the meaning of the text and understanding the meaning of the text, we move from what is being said to what is the meaning.

In this way, we found the final analytical themes, which we consider having relevance for other relatives of OHCA survivors, beyond the study participants.

Through a discussion of the study findings, we suggest different reasons for the lack of involvement of relatives in considering the future impact of cognitive impairments. Firstly, the difficulty diagnosing and addressing cognitive impairments and lack of guidelines is described. Secondly, it is suggested that the focus on the cardiac dimension of the situation is due to the medically specialized healthcare system. Thirdly, the divided healthcare pathway across secondary and primary health sectors contributes to the difficult transition for relatives. Finally, we suggest that the lack of systematic involvement of relatives is due to a patient-centred healthcare system. Future research should focus on screening and referral for cognitive impairments with interventions that include relatives as well as a focus on follow-up interventions that include the screening of relatives for emotional problems.

5 | CONCLUSION

Relatives of OHCA survivors describe the transition from hospital to daily life as being left responsible but unsupported. In the transition to daily life and especially during discharge from hospital, a focus on systematic involvement and collaboration with relatives should be an essential part of the post-cardiac arrest pathway. Healthcare professionals need to understand and communicate with relatives of OHCA survivors during the whole pathway, including both the cardiac situation and the risk of cognitive impairments with their potential impact on daily life.

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CONFLICT OF INTEREST

The authors report no conflict of interest. No private funding.

ETHICAL Approval

The participants were informed that all data would be anonymized. All transcripts were kept confidential (Polit & Beck, 2010). The study did not require approval from an ethics committee (Ref. No: 20192000-66) which is normal for this type of research in Denmark. Nonetheless, the study conformed to the principles of the Declaration of Helsinki. The study was reported to the Danish Data Protection Agency I-suite nr. 6,423 and follows the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007). Relatives of OHCA survivors are potentially a vulnerable group; hence, the interviewer endeavoured to ensure participants felt safe while sharing private and emotional experiences. At the start of the interviews, the possibility that strong emotions might be raised and that a break during the interviews may be needed was discussed with participants.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

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