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Clinical paper

“We don’t talk about his heart”: Narrative sense-making and long-term readjustment among older out-of-hospital cardiac arrest survivors and their spouses



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ABSTRACT

Aim of the study: Globally, there has been an increase in the survival rate and the average age of survivors from out-of-hospital cardiac arrest (OHCA). However, little is known about the joint OHCA-associated experiences among older survivors and their spouses in a long-term perspective. The aim of this study was to explore how narrative sense-making processes following OHCA shapes everyday life in a long-term perspective among older survivors and their spouses.

Methods: Five older male survivors and their female spouses were interviewed individually using narrative methods. Arthur Frank’s theory on illness narratives informed the analysis. Participant observation at two meetings for survivors and relatives regarding cardiac arrest was used for qualification of the interview guide.

Results: Five married couples participated. The mean age of the survivors and spouses was 70,4 and 71,4 years respectively, and time since OHCA varied from 12 to 66 months. Two themes of the dyadic experience emerged: 1) experiences during OHCA, and 2) experiences in life following OHCA. Subthemes differed with survivors emphasising a desire to return to the same life as before the OHCA, and the spouses narrating feelings of anxiety. Potential complications of the OHCA were often explained with reference to ageing processes, and the OHCA was contextualised in relation to previous life-changing events.

Conclusion: In a long-term perspective, OHCA shapes the life trajectory of both the survivor and the spouse, and the relationship between them, underscoring a need for patient-centred care with a greater focus on the relationship of the dyads.

Introduction

With an ageing population and increasing survival rates following out-of-hospital cardiac arrest (OHCA), a growing proportion of older survivors is expected.^{1–7} Potential consequences following OHCA include negative neurological outcomes such as severe disability or vegetative state that are adversely affected with increasing age, making this population particularly vulnerable.^{7–10} In addition, the survivors’ relatives may experience anxiety, depression, and burden of care.^{9,11,12} As a consequence, spouses may experience a lack of social, emotional, and practical support, leading to isolation.⁹ Older survivors and relatives may readjust to the negative outcomes differently than younger survivors, which may reflect that age impacts the sense-making processes.¹² However, a qualitative meta-ethnographic synthesis of sense-making among survivors

and relatives argue, that little is known about sense-making processes among older survivors and relatives.¹³ This underscores a need for more insights to inform provision of age-friendly supportive services that empower older adults and their relatives following OHCA.¹⁴ Yet, research has focused mainly on the experience of either the survivor or the spouse with the exception of a recent qualitative study exploring unmet needs and experiences among both survivors and their partners 3–12 months following OHCA.^{15–21} To our knowledge, no previous research has explicitly explored the everyday life experiences among older survivors and their spouses in a long-term perspective.

The aim of this study was to explore how narrative sense-making processes following OHCA shapes everyday life in a long-term perspective among older survivors and their spouses.

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Methods

Design

A qualitative narrative approach to explore the illness narratives was used including participant observations and narrative interviews. This enabled in-depth exploration of the participants' experiences situated in the biography and context of the individual, thereby supporting reflexivity, sense-making and interpretation.^{22–24} According to Danish guidelines, no ethical review is needed of studies not involving biological material. This study adheres to the principles outlined in the Declaration of Helsinki and all aspects of the General Data Protection Regulation.²⁵

Sample

The study was carried out in Denmark from February to July 2019. Inclusion criteria were based on: 1) age (≥ 60 years at the time of the OHCA), 2) married couples with both the survivor and spouse willing to participate, and 3) resuscitation taken place ≥ 1 years ago. An information letter was shared on relevant websites and as printouts across 17 activity centres for older adults. Three couples were recruited using snowball sampling with researchers sharing information letters within relevant social networks. Two couples were recruited through national news media and social media. To gain in-depth knowledge of sense-making and everyday life, the aim was to have a sample of five couples, which is a sample size that corresponds with the narrative approach.²² Thus, 10 individuals participated in this study.

Data collection

The objective of the interviews was to gain insight into the survivor's and spouse's different perspectives on the same event. Due to the sensitivity of the subject and our interest in a dual perspective, the in-depth narrative interviews were conducted separately, thus ANJ and KBB interviewed the survivor and spouse in separate rooms simultaneously, enabling the participants to share their narratives in private.²⁶ All couples were interviewed in their homes upon own request. The 10 interviews lasted 60–105 minutes and were guided by a topic guide initiated by the question, "Can you please tell me how you experienced the process right up to and during the OHCA?".²⁷ This open-ended question enabled the participants to control the content and direction of their narratives.²⁷ The follow-up questions concerned their experiences during hospitalisation and their sense-making processes in everyday life. During the interview, clarifying and exploratory questions were used. All narratives were audio recorded.

Participant observation was conducted in part at two meetings held by the Danish Heart Association concerning cardiac arrest for survivors and their relatives and in part in the context of the narrative interviews. The overall objective of the observations was to gain a deeper insight into the discontinuity and the experiences shaping everyday life after OHCA. Therefore, the observations during the meetings were used to inform the development of the topic guide used in the proceeding narrative interviews.²⁸ None of the interviewed couples had participated in the two meetings. Observations were also conducted before, during, and after each narrative interview to: 1) form a trusting relationship with the participants, 2) use the informal conversations as references during the interview, for example, "Prior to the interview, you told me that ...", and 3) gain insight into the couples' home as a setting, in particular in relation to their medication and Implantable Cardioverter Defibrillator-monitor (ICD-monitor). These observations were used as contextual information during the analysis.

Analysis

The 10 narrative interviews were transcribed verbatim by ANJ and KBB. Afterwards, the transcripts were exchanged and double-checked.

Table 1

Characteristics of survivors and spouses

Survivors (n=5)	n
Gender	
Male	5
Age ¹ (years)	
60-69	2
70-79	3
Retired	
Yes	5
Time since OHCA ² (months)	
12	1
13-29	3
≥ 30	1
ICD	
Yes	4
No	1
Induced hypothermia after OHCA	
Yes	5
Spouses (n=5)	
Gender	
Female	5
Age ³ (years)	
60-69	2
70-79	2
80-89	1
Retired	
Yes	4
No	1

¹ Survivors' mean age (years): 70,4.

² Mean time since OHCA (months): 29,8.

³ Spouses' mean age (years): 71,4.

Using the methodological approach of narrative analysis, the narratives were carefully read through and then each researcher individually analysed each narrative systematically and iteratively as a whole to maintain the structure and flow of the individual narrative.²² The analysis was thematic as meaningful excerpts were identified, coded, and linked together using NVivo 12.²² Elements from Arthur Frank's concept of illness were used as a theoretical framework, enabling exploration of sense-making processes and the effect of sociocultural factors on readjustment to everyday life.^{23,29} Frank argues that serious illness disrupts lives necessitating sense-making processes and readjustment to a changed everyday life. Sense-making processes may involve storytelling by which the individual restores order in an otherwise fragmented and chaotic life.²³ Emerging findings were discussed in the author group to ensure intercoder reliability.³⁰ Field notes were conducted during the observations and following each interview and analysed thematically.

Results

Characteristics of the 10 participants are presented in Table 1. During the analysis two themes cross-cutting the survivors' and the spouses' narratives emerged: experiencing OHCA and experiencing life after OHCA. Each contained several subthemes (Fig. 1).

Experiencing OHCA – survivors' perspectives

Lack of memory

The survivors described the OHCA occurring suddenly, without warning, and narrated they had no memory of the event. They further explained that they did not perceive the "event itself" to have affected their lives emotionally due to their lack of memory of it with several survivors stating that they had 'lost' a short period of their lives.

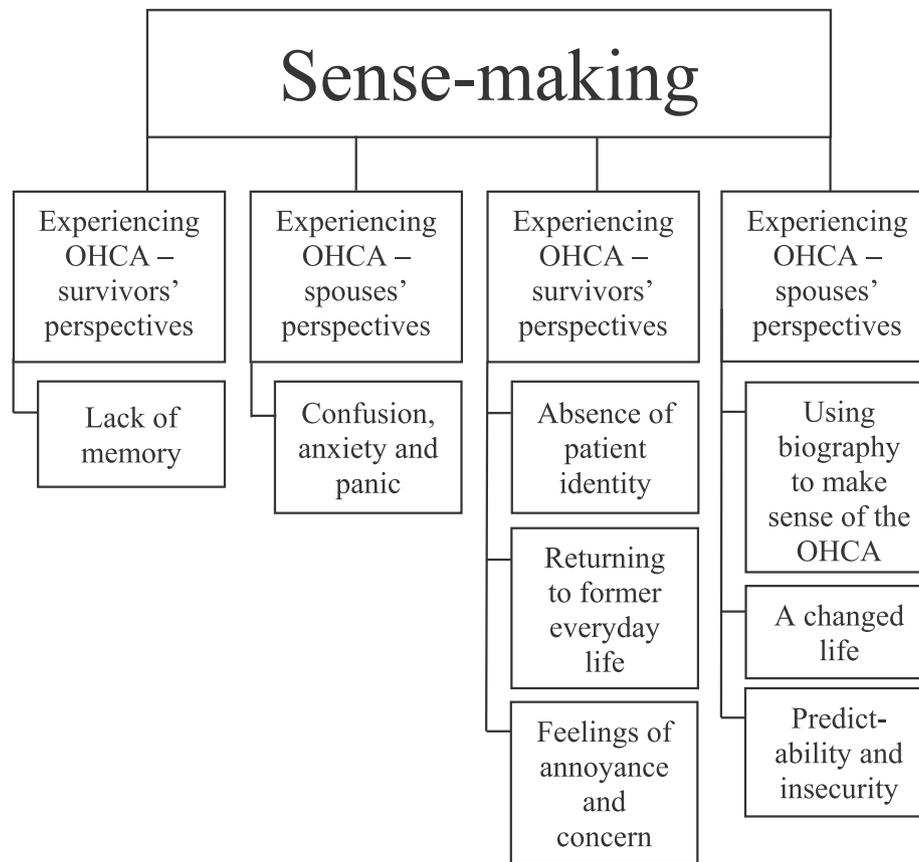


Fig. 1. Themes and included subthemes.

Experiencing OHCA – spouses' perspectives

Confusion, anxiety and panic

When describing the OHCA and hospitalisation, the spouses' narratives reflected confusion, anxiety, and panic, underscoring the unexpected nature of the event. From our observations, it was evident that the event was still present among the spouses who, during the interviews, became emotionally affected, were pausing for thought, and expressed concerns. The period was characterised by a lack of control, expressed in confused thoughts regarding uncertainty as to whether their husbands would survive in a vegetative state. As the survivors were awakened from their coma, the spouses' confused thoughts lessened. Their narratives highlighted that the risk of losing their husbands was reduced and hope emerged shaped by encounters with healthcare professionals whose positive assessments of the prognosis helped them regain a sense of control.

Experiencing life after OHCA – survivors' perspectives

Absence of patient identity

The survivors distanced themselves from identifying as 'patients'. They emphasised that they had not been assigned to a cardiac ward after the discharge and therefore did not consider themselves to be ill. One survivor said that he purposely wanted to break out of the patient role.

Returning to former everyday life

After discharge, the survivors expressed a desire to regain control of their bodies. They focused on having achieved this by being able to live an unchanged life with the same physical abilities as before. They perceived their bodies to be 'repaired' during the specialised hospital treatment, and in particular through their ICD. However, changes

affecting everyday life became apparent during our observations in their homes with medication and ICD-monitors present. Further, changes surfaced in their narrated experiences of cognitive challenges, such as fatigue and reduced memory, making everyday tasks harder to perform. The survivors' attempts to re-establish life and search for coherence and meaning after the OHCA made them draw on various alternative explanations for these cognitive changes, which were most often explained as common features of growing older.

Feelings of annoyance and concern

Survivors frequently narrated that their spouses had a continuous need to monitor their daily activities, which most often caused annoyance since they perceived it as unnecessary overprotection. Moreover, the survivors emphasised how their spouses experienced daily anxiety, which they believed to be closely related to the spouses' experiences of the acute event. Hence, the survivors believed the spouses to be more affected by the OHCA than themselves.

Experiencing life after OHCA – spouses' perspectives

Using biography to make sense of the OHCA

The spouses most often related the OHCA to previous life-changing events and compared their current situation to friends' and family members' serious illnesses, surgeries, and deaths. Previous life-changing events had shaped their view of the OHCA, helping them accept it. Thus, the OHCA was meaningfully incorporated into their biographical narratives with previous life experiences shaping their approach to life.

A changed life

The spouses expressed that the OHCA had affected their life by making them more anxious, fearing the death of their husbands. Their

Table 2
Narratives of survivors and spouses.

Theme	Subtheme	Example
<i>Experiencing OHCA – survivors' perspectives</i>	Lack of memory	"Before collapsing that day ... I hadn't experienced anything [unusual]. Nothing at all. Suddenly, I was just 'puff' – gone." (survivor 2).
<i>Experiencing OHCA – spouses' perspectives</i>	Confusion, anxiety and panic	"I have no negative experiences. I have no emotional experiences about what has happened. Therefore, I've lost about two weeks of my life, and I don't know what those two weeks contained. And that doesn't bother me. I've continued where I left off and I feel great about it". (survivor 1) "(...) Well, quickly you'd start thinking: if he survives in a vegetative state, then it's better if he doesn't survive (...)". (spouse 3)
<i>Experiencing life after OHCA – survivors' perspectives</i>	Absence of patient identity	"I was just hoping [for the best at the hospital], and I tried to tell myself, "It'll be okay." And they [healthcare professionals] provided us with hope, pointing out that he was in good shape and that it seemed as if he would be okay". (spouse 2) "Well, I don't see myself as a patient. (...) because I've been kicked out of the system in a positive sense. No one is keeping up my patient file apart from when checking the technicalities of the ICD (...)". (survivor 3)
	Returning to former everyday life	"I want to strip myself of it [the patient role] right away. Get away from the hospital as soon as possible. See my general practitioner instead of the hospital. I mean, I didn't get to consider myself as a patient except from when I got the ICD". (survivor 2) "I've noticed I may have some cognitive changes related to my memory". (survivor 1)
	Feelings of annoyance and concern	"I don't notice any complications. If I did notice anything, it would be something to do with my brain but ... also the fact I've aged. Therefore, I'd say that some of my doubts about my functions could be a post-cardiac arrest reaction, which has affected the brain. But it could also be caused by my old age". (survivor 3) "She still sometimes comes out from the shower and pushes me a bit [while in bed]: 'Well, his toe is moving, so he must be okay'". (survivor 4)
		"If I need to get something at the bottom of the closet, she comes running, 'Let me, I'll do it'. I get a little annoyed because she is overly good to me". (survivor 5)
<i>Experiencing life after OHCA – spouses' perspectives</i>	Using biography to make sense of the OHCA	"Sometimes it has caused her [spouse] to be a little scared. I was hardly allowed to go down into the basement alone in case I didn't come up again". (survivor 5) "Sure, I was sad when I lost my son and quite miserable sometimes. However, I can't keep thinking about it. It spoils everything for everyone around me, right? You have to carry that in your heart". (spouse 1)
	A changed life	"Well, who goes through life without any obstacles?". (spouse 3) "I have become a slightly sadder person. I get sad more often. I think it was because of the shock. Just standing there and seeing how life just disappears". (spouse 5)

(continued on next page)

Table 2 (continued)

Theme	Subtheme	Example
		"I can wake up at night like: Is he here? It haunts me ... I never really sleep anymore. And he can't leave the bed either. If anything happens to him ... I've been seized with fear". (spouse 1)
		"[I said] 'Be careful and please don't do this, all right?' And the children as well: 'Please don't do this and that, okay? Please, sit down.' And at last he said: 'Well, I can't live this way.' And of course, he couldn't". (spouse 1)
	Predictability and insecurity	"We don't talk about his heart. If I ask, he says, 'I'm fine. And I promise to let you know when I'm not'". (spouse 1) "(...) we'd benefit from a follow-up from the municipality. There's been nobody [healthcare professionals] in our home since the first year. I'd have liked it if they'd ... visited one year after their first visit, so we could've had a chat about how everything was going". (spouse 4) "We've just been to the hospital [for ICD checking, which very much gave me peace of mind. Because they [healthcare professionals] told us that everything is okay [with the ICD-device] and that it will last for another 6 years. It has sort of given me some peace". (spouse 1)

anxiety was expressed through a continuous need to monitor the survivors for signs of life. After the survivors' hospital discharge, the spouses started to provide more care for their husbands by monitoring their energy levels and limitations in everyday activities, offering increased help, and taking over several of their husbands' duties. Thus, the spouses provided care based on their concern, which at times annoyed the survivors, which in return affected the spouses emotionally.

Predictability and insecurity

The narratives reflected a newfound need for predictability and control among the spouses. Among the couples where the survivor had an ICD implanted, this had created a sense of security, as another OHCA would not have fatal consequences. The spouses described the ICD as "trustworthy" since it involved annual medical check-ups and as it had a direct connection to the emergency medical services. Moreover, the spouses developed feelings of insecurity in their everyday life after their husbands' hospital discharge, reflected in fear of performing new caring duties such as taking care of the medication and changing bandages. The spouses' narratives reflected a need for further support, and some expressed a desire for follow-up meetings with healthcare professionals to jointly examine the survivor's present health status. (See Table 2)

Discussion

Our study highlights the influence of age and relationship dynamics on sense-making and readjustment to everyday life in a long-term perspective as it surfaces in narratives among OHCA survivors and their spouses.

Life following OHCA may be affected by cognitive changes with studies indicating that survivors experience reduced memory, fatigue, and lack of endurance, all in accordance with this study's findings.^{11,31,32} These consequences may limit daily activities and quality of life.^{9,11,15–17,31} Our study provides novel insight into everyday life in a long-term perspective, and thereby adds to a recent qualitative study exploring unmet needs among OHCA survivors and their partners in a short-term perspective with more emphasis on the perspectives of survivors suggesting that recovery was complicated by several challenges that disrupted the perception of 'normality'.²¹ Thus, our study expands on the existing literature with its explicit focus on readjustment to

everyday life among older survivors and spouses in a long-term perspective. Contrary to Whitehead et al.²¹ we found that the survivors' narratives did not reflect uncertainty or fear of death. Rather, the long-term perspective revealed a development in sense-making and readjustment to everyday life among survivors, shaped by various explanations. First, the survivors considered the OHCA as an acute yet isolated event, limited to the OHCA itself, the hospitalisation and the time following immediately after hospital discharge. The survivors associated this absence of anxiety to their lack of memories from the event. Our study underscores that the acuteness of the event may have enabled the survivors to distance themselves from the "patient" role. Second, the lack of identification with the patient role further enabled the survivors to explain potential complications of the OHCA as a natural part of ageing processes highlighting age as a factor mediating the individual experience of illness.³³ Thus, age became a positive resource in readjusting to everyday life. This might explain why the survivors most often regarded these cognitive changes as common features of growing older, rather than OHCA-related complications.

The survivors' OHCA-experiences contrasted with the spouses' experiences. The acute nature of the OHCA was reflected in the spouses' narratives of anxiety, despair, and fear of death. These emotional challenges among close relatives are well known in the existing literature.^{11,19–21,32} The concerns created a need for the spouses to monitor the survivors' activities, since they worried that the survivors would overstrain themselves. This monitoring practice was noticed by the survivors and perceived to be overprotective and unnecessary, resulting in tensions among the couple, also reflecting findings elsewhere.^{11,19,21,32} In line with existing research, the spouses in our study narrated their concern about leaving the survivors alone or visiting friends.^{11,34} The fear of loss further affected most of the spouses during the night, as they were alert towards signs of life and irregular breathing in the survivors. Among heart failure relatives, this alertness has been found to adversely affect spouses' sleep.^{34–37} Further, the ICD resulted in conflicting feelings among the spouses. It made them feel secure as it prevented a new OHCA from being fatal.¹¹ Conversely, the ICD also reflected the disruption of their biographies as it underlined the fragility of life. The ICD represented a newfound need for control, and situations, where they were not in control made them panic. Upon their husbands' hospital discharge, the spouses experienced insecurity when given new caring duties by the

healthcare professionals, indicating that the spouses have unmet needs for support. Overall, these findings highlight how OHCA shapes the life trajectories of both the survivor and the spouse, and the relationship between them, emphasising that the couple should be offered various types of supportive interventions such as relationship counselling.^{19,21}

Finally, when people experience a disrupted biography, for example caused by a cardiac arrest, they may seek cognitive adaptation and therefore engage in sense-making processes.^{16,23,38} A search for meaning by creating a timeline consisting of the past, present, and the future is evident in narratives.^{22,23} In line with this, our findings indicate that the participants' sense-making processes were shaped by their biographies, as earlier life events such as severe illness and loss of family members affected their experience of the OHCA.³³ However, across the individual narratives, we identified collective narratives reflecting societal values as described by Arthur Frank.²³ Frank²³ argues that a narrative focusing on recovery is often dominant in Western societies, which might explain the participants' desire to return to their former way of life. This study argues that the participants' narratives of recovery and determination to regain their previous life are created in a dyadic process within the couple and in encounters with healthcare professionals. In our study, the narratives were shaped by societal values, expressed through the participants' use of positive comments from healthcare professionals who anticipated that the survivors would be able to return to normal everyday life, also reflected elsewhere.³⁹ Bremer et al.¹⁹ found that relatives of OHCA survivors experience that friends and family expect them to show gratitude that the survivor had survived. These expectations may explain why relatives' failure to thrive is not recognised to the same extent as that of the survivors. These findings suggest that a narrative, explorative approach in clinical, municipal, and civic societal encounters could strengthen the support for both survivors and spouses.

This study adds important insights into the complex dynamics in sense-making processes following OHCA. The dyadic design with separate in-depth narrative interviews contributed to detailed descriptions of the event, as dual perspectives were covered.⁴⁰ Through this dual-perspective approach in an understudied group of older adults, the study adds to the limited existing evidence and enabled the identification of differences in the narratives within the couples.⁴⁰ Inclusion of solely the survivors' or the spouses' narratives, would have created loss of valuable insight into a life event that deeply affects both parties and their relationship.

The study has some limitations. As the study does not include repeat interviews, its ability to explore sense-making processes over time is limited. Also, conducting interviews jointly as a survivor-spouse dyad may have contributed to uncover the interactive, collective, and intersubjective components of the sense-making and everyday life.⁴¹ Moreover, the study focuses on older married couples, and the findings should be interpreted according to this, as this study underscored the importance of age and biography. Further, the participants may have been more resourceful than those declining to participate, leading to selection bias. Finally, this study only included male survivors and female spouses. Future longitudinal research is needed as well as studies exploring sense-making following OHCA in jointly survivor-spouse dyads, in more diverse groups of survivors and spouses including diversity in gender to gain a more comprehensive understanding of life after OHCA.

Conclusion

This study contributes to a nuanced and in-depth understanding of life following OHCA. The OHCA is experienced as a severe event and a biographical disruption which the participants attempt to mitigate and accept through various explanations. The survivors' experiences of cognitive changes were explained as age-related. This enabled the embedding of the OHCA into the participants' biography in a meaningful way, which further enabled readjustment to everyday life. Thus, it should be recognised that OHCA among older adults is embedded within their biography as part of the life course. However, everyday life following

OHCA is a complex, and dynamic dyadic process between the survivor and spouse leading to challenges resulting in unmet needs, especially among the spouses. Thus, it should be acknowledged that OHCA shapes the life trajectory of both the survivor and spouse and the relationship between them. This study underscores the necessity of providing patient-centred care responsive to the individual needs of both survivors and spouses. A greater focus on the dyadic relationship of OHCA using a narrative approach may improve clinical encounters, positively affecting quality of life following this critical event.

Credit author statement

Andrea Nedergaard Jensen: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Writing – Original Draft, Writing – Review & Editing, Visualization, Project administration
Katrine Bruun Bonnén: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Resources, Writing – Original Draft, Writing – Review & Editing, Visualization, Project administration
Maria Kristiansen: Conceptualization, Methodology, Writing – Review & Editing, Supervision.

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Declaration of competing interest

None.

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