

Feeling understood for the first time:

experiences of participation in rehabilitation after out-of-hospital sudden cardiac arrest

Wagner, Mette Kirstine; Berg, Selina Kikkenborg; Hassager, Christian; Joshi, Vicky; Stenbæk, Dea Siggaard; Missel, Malene

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Mette Kirstine Wagner (1) 1*, Selina Kikkenborg Berg (1) 1,2, Christian Hassager (1) 1,2, Victoria Louise Joshi³, Dea Siggaard Stenbæk (1) 4, and Malene Missel (1) 5

¹Department of Cardiology, Copenhagen University Hospital, Rigshospitalet, Blegdamsvej 9, DK-2100 Copenhagen, Denmark; ²Department of Clinical Medicine, University of Copenhagen, Blegdamsvej 3B, 33.5.18-21 DK-2200 Copenhagen N, Denmark; ³Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA), Southern Denmark University, Odense, Vestergade 17, DK-5800 Nyborg, Denmark; ⁴Department of Neurology, Neurobiology Research Unit, Copenhagen University Hospital, Rigshospitalet, Inge Lehmanns Vej 6-8. DK-2100 Copenhagen, Denmark; and ⁵Department of Cardiothoracic Surgery, Copenhagen University Hospital, Rigshospitalet, Blegdamsvej 9, DK-2100 Copenhagen, Denmark

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Aims

Survivors of out-of-hospital sudden cardiac arrest (SCA) may suffer from long-term cognitive, psychological, or physical post-arrest consequences impacting and disrupting daily life. To adjust to and manage daily life is critical, and therefore a tailored rehabiliation programme was introduced to the participants. The study aimed to explore the lived experience among cardiac arrest survivors.

Methods and results

Data were gathered through six focus group interviews during a cardiac arrest rehabilitation programme. Thirty-three out-of-hospital SCA survivors (8 women and 25 men) participated. Time since cardiac arrest was on average 12–57 months. An exploratory qualitative design inspired by Ricoeur's phenomenological hermeneutics was applied. Two main themes emerged from the analysis and interpretation: (i) a lack of support from the health system in the transition from hospital to daily life; and (ii) feeling understood for the first time. The findings revealed that out-of-hospital SCA survivors experience a knowledge gap struggling for support. Attending the programme, gaining knowledge and experiencing peer support was described as a revelation for them.

Conclusion

The findings suggest that out-of-hospital SCA survivors felt understood for the first time when attending a cardiac arrest rehabilitation programme. A post-arrest pathway is needed led by a coordinating cardiac arrest specialist nursing service together with allied healthcare professionals. Focus on hypoxic brain injuries, emotional burdens, and supportive strategies are essential in the transition to daily life. Facilitated peer support is warranted.

Keywords

Sudden cardiac arrest • Phenomenology • Hermeneutics • Focus groups • Rehabilitation

Implications for practice

- Systematic follow-up and referral for rehabilitation after sudden cardiac arrest (SCA) survival (if needed) requires early organization by a
 cardiac arrest nursing service.
- Participating in a tailored cardiac arrest rehabilitation programme can contribute to a better understanding of the cardiac arrest-induced risk of hypoxic brain injury, emotional burdens, and the need for supportive strategies.
- Attending a cardiac arrest rehabilitation programme may help SCA survivors towards a healthy transition to daily life after survival.
- In future cardiac arrest rehabilitation programmes, peer support is warranted.

^{*} Corresponding author. Tel: +45 35453143, Email: mette.kirstine.wagner@regionh.dk

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Introduction

Out-of-hospital cardiac arrest (OHCA) is a sudden life-threatening condition associated with significant morbidity and mortality rates. ^{1,2} In North American and European populations, the overall annual incidence of sudden cardiac arrest (SCA) approximately 50–100 per 100 000 in the general population. ³ Coronary artery disease is the predominant cause of SCA in those who are 35 years of age and older, while younger patients present with primary arrhythmia and inherited cardiomyopathies. ⁴ To maximize the chances of surviving a cardiac arrest, improvements have been made in several links of the chain of survival. Despite geographical differences, epidemiological findings point to increased survival with a reasonable neurological status indicated by mild or no noticeable post-arrest neurological disabilities. ^{2,5}

Life after SCA involves several complex challenges for resuscitated patients. Due to the risk of cardiac arrest-induced hypoxic-ischaemic brain injury and trauma reactions, protracted cognitive consequences as short-term memory problems, attention deficits and executive function disorders, and emotional reactions as anxiety and depression are prominent in survivors.^{6,7} Studies have also demonstrated that these challenges are negatively affecting the return to daily life activities, vocational reintegration, and quality of life. ^{7–9} To aid recovery and prevent further illness, rehabilitation is therefore recommended after cardiac arrest. 10,11 Traditionally, cardiac arrest survivors are referred to standard cardiac rehabilitation which addresses and provides education in cardiovascular disease risk factors. 11 Although international recommendation further suggest neurological rehabilitation as a part of an integrated care pathway after resuscitation, 12 only few studies are describing follow-up programmes for cardiac arrest survivors with hypoxic brain injury. To our knowledge, one early neurologically focused rehabilitation intervention for cardiac arrest survivors has systematically addressed cognitive and emotional challenges. 13 From this current literature, it is evident that screening for cognitive and emotional challenges, provision of support and information, promotion of self-management strategies, and referral to specialized care improved quality of life 1-year post-arrest. 13 Still, there is a scarcity of evidencebased cardiac arrest rehabilitation interventions and no consensus on the content and timing of post-discharge services for these patients. Expanding our knowledge to find a more optimal pathway of care to help sudden OHCA survivors adjust to and manage daily life is critical, as the number of cardiac arrest survivors is expected to grow in the future. Therefore, this study aimed to explore the lived experiences among out-of-hospital SCA survivors.

Methods

Design

This study had an exploratory qualitative design using focus groups. A phenomenological-hermeneutic approach inspired by Ricoeur's philosophy for unfolding the lived experiences was applied. The consolidated criteria for reporting qualitative research (COREQ) checklist provided guidance during the reporting of this study.

Study participants, recruitment and setting

Participants were recruited from those taking part in a cardiac arrest rehabilitation programme held at the Danish Knowledge Centre for Rehabilitation and Palliative Care's (REHPA) research clinic in the Region of Southern Denmark. Eligible participants in the programme were: adult (≥18 years) sudden OHCA survivors from all regions of Denmark. They were recruited via purposive sampling through information posted on the Danish Heart Foundation website and via members of the Danish Cardiac Arrest Survivorship (DANCAS) network¹⁵ based in the five Heart Centres in Denmark. Participants took part in a 3-day multidisciplinary rehabilitation programme organized by REHPA and the DANCAS network. Eligibility criteria for participating in the programme, including the interviews are summarized in *Table 1*. To apply, a detailed application form identifying the survivor's rehabilitation needs, goals for rehabilitation and co-morbidities was completed by the applicants and their doctor. Eligibility for the rehabilitation programme was assessed from this application form.

Thirty-three survivors participated in the programme and interviews; 8 women and 25 men aged between 40 and 83 years of age. Twenty-six survivors attended the programme together with a close relative. The relatives did participate actively in the rehabilitation programme but did not attend the focus group interviews for OHCA survivors. *Table 2* summarizes the demographic and clinical data from the participants. The programme was designed based on current evidence on the consequences of cardiac arrest. The structure of the programme is summarized in *Table 3*.

Data collection

Data were collected in November 2018, and in March 2019 in an undisturbed meeting room at REHPA. The data collection was guided by the principles of data saturation. Besides the interview data for this study, data were collected by questionnaire before attending the programme. This is summarized in *Table 2*.

Focus group interviews

The participants were grouped on the basis of age, gender, and family type to ensure social recognition, group dynamics, a safe atmosphere, and dialogues during interviewing (*Table 2*). As one participant withdrew consent from the interview study, 32 survivors participated in interviews divided into six groups. Focus group interviewing was chosen as a comprehensive method to generate ideas within this social context, ¹⁷ and furthermore for exploring complex and unexplored areas. ¹⁸ The focus groups were scheduled at the second day of the programme. While the first group of participants shared their experiences in the group, the remaining rehabilitation participants followed the programme. Then the groups switched. The focus groups were facilitated by the first author and co-facilitated by an experienced co-researcher. The facilitator was responsible for creating a safe and comfortable setting before and while introducing the questions, to ensure that the participants interacted, and that the conversations were balanced between the

Table I Eligibility criteria for participating in the programme including the interviews

Inclusion criteria 1 Sudden out-of-hospital cardiac arrest

2 Self-identified need for rehabilitation

3 Willingness to convey and engage fully in a course

Exclusion criteria 1 Severe neurological disabilities

2 Dependent in activities of daily living

3 Unable to speak and understand Danish

Table 2 Demographic and clinical data on participants in focus group interviews (n = 32)

Category Focus group 1 Focus group 2 Focus group 3 Focus group 4 Focus group 5 Focus group 6 Total							
Category	Focus group 1	Focus group 2	Focus group 3	Focus group 4	Focus group 5	Focus group 6	Total
Number of participants	5	5	7	6	4	5	32
Male:female	3:2	3:2	6:1	3:3	4:0	5:0	24:8
Age, median (IQR)	62 (53–76)	41 (40–60)	53 (44–63)	55 (51–63)	72.5 (68–83)	70 (62–76)	60 (40–83)
Duration since first CA to	12 (3–24)	18 (8–24]	14 (7–132)	12 (8–58)	57 (7–64)	16 (12–120)	16 (3–132)
interview, median (months)							
Aetiology of the CA							
Ischaemic heart disease, n	3	2	6	3	4	3	21
Arrhythmia others, n	2	3	1	2	0	2	10
Unknown to participant, n	0	0	0	1	0	0	1
Family type							
Alone, n	0	0	0	1	2	0	3
Living with spouse/or	3	2	3	3	2	5	18
partner, n							
Living with spouse/or	2	3	4	2	0	0	11
partner and children, n							
Residence of region in							
Denmark ^a							
Capital Region of	1	1	2	1	0	4	9
Denmark, n							
Region Zealand, n	0	3	2	0	0	0	5
Region of Southern	0	1	2	4	2	0	9
Denmark, n							
Central Denmark Region, n	2	0	1	1	1	1	6
North Denmark Region, n	2	0	0	0	1	0	3
Education							
Elementary school, n	1	2	4	2	3	3	15
High school, n	1	2	3	2	1	2	11
≥College, n	3	1	0	2	0	0	6
Employment							
Before CA, n	3	5	6	6	0	2	22
After CA (reduced ability	3	4	4	5	0	1	17
to work), n							
Retired (8) or on sick leave	2	0	0	0	4	3	9
(1) before CA, n							

^aDenmark consists of five regions.

 Table 3
 The rehabilitation programme for sudden out-of-hospital cardiac arrest survivors

Day 1	Day 2	Day 3
 Arrival, short welcome and presentation Introduction to the schedule Meeting peers and professionals Cognitive screening tests (neuropsychologist) Introduction to possible cardiac arrest late complications as fatigue (neuropsychologist and occupational therapist) 	 Physical training exercises (physiotherapist) Joint walk and talk sessions in small peer groups (nurse) Discussion group on cardiac arrest and psychological reactions (psychologist) Conversations on spiritual matters and identity (priest) 	 Sessions on mindfulness (physiotherapist) Individually face-to-face consultations together with close relative (medical doctor, nurse, and social worker) to discuss personal topics and daily life concerns as mental and family reactions, children, sexuality, shock from ICD, economy, and/or job situation Closing session

participants. Furthermore, the facilitators retained an active listening posture in each interview. With the aim of gathering the participants' indepth narrative accounts of their lived experiences of participating in the programme, open questions were used, such as: 'Could you please tell me about your intentions of signing up for the programme'? and 'Could you please tell me about your experiences during the programme'? The aim of asking the participants to narrate how they experienced participation in the programme was to allow the phenomenon to appear as it was experienced and not to control their articulation of it. Additionally, the participants were also encouraged to narrate about formal things such as: challenges related to participation, unexpected or unknown reactions during and after the sessions, and how they experienced the content and duration of the sessions and the overall cardiac arrest rehabilitation programme. The open approach throughout the interviews helped to keep focusing on the survivor's lived experiences of taking part in the programme and enabled exploration of the participants' views and perception of what they found meaningful or mattered most to them. To facilitate progression of the interviews, relevant probes for answering the aim of the study were used. The interviews lasted between one and one and a half hours each, were audio recorded and transcribed verbatim.

Ethical considerations

As the study explored the meaning of very personal, possible traumatic and painful experiences on sensitive topics, the participants were informed that participation was voluntary. Furthermore, their right to refuse to answer questions and withdraw from the research at any time was explained. The study is registered with the ethics committee reference number: 20192000-66 and conform to the basic principles of the Declaration of Helsinki. Written informed consent was obtained from all participants before attending the overall programme.

Data analysis

A phenomenological-hermeneutic approach inspired by Ricoeur's philosophy was used in the analysis and interpretation of the transcribed texts. 14,19 The steps of the analysis consisted of the following levels: naïve reading, structural analysis, and comprehensive understanding (Table 4). In the naïve reading, the texts were read several times to make a general sense of the whole. During the structural analysis, we moved from what the texts said to what they talked about and identified themes. According to Ricoeur, the structural analyses are a dialectic process between understanding and explanation of what the texts are about. 14,19 The comprehensive understanding was directed at the meaning and range of the texts statements where new perspectives from literature and research were included and critically discussed to unfold and deepen understanding of the findings. ¹⁹ The analytical levels are illustrated in *Figure 1*. Two authors (M.K.W. and M.M.) analysed and interpreted the interview response narratives independently. The structural analyses with quotes and themes were presented for all authors to discuss and validate the interpretations.

Table 4 An example of a structural analysis process from meaning units, condensations, and subthemes to illumination of the first theme; a lack of support from the health system in the transition from hospital to daily life

Meaning units (what is said)

• 'have been off track for two years now [after the cardiac arrest]. There was no overall plan prescribed for me when I left the hospital, and no one mentioned what was important to prioritize when you need to get on track again. Nobody talks to you about that' P6.

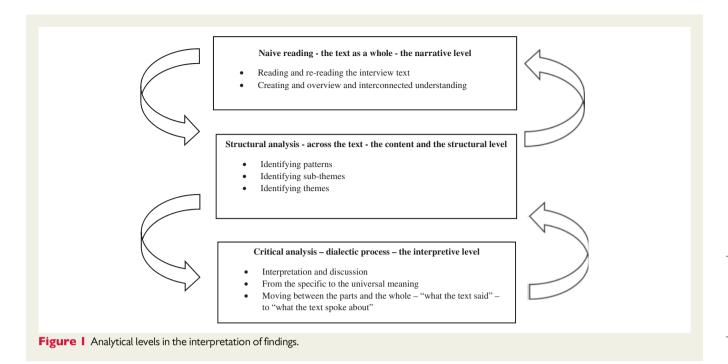
- 'I do not think that I have been informed about the consequences to expect after I survived. Therefore, I started working just after discharge from the hospital. If only somebody had said: We need to form a plan together with you on how to get back. I see now that I did not have the surplus of mental resources myself to ask for help' P3.
- 'Why is there a difference in the help you get after cardiac arrest? You actually have the same symptoms as a brain injured person. Why should there be no standard schedule for rehabilitation to patients like us' P7.
- 'I often loose the thread. It does not work when I receive information. If I have to remember three things said, then I am lucky if I can remember one thing. Fatigue is a huge problem. Without support I had to stop working. Now it's all about making my daily life work' P22.

Condensation (what is talked about)

- The participants experience a struggle in the transition to daily life in relation to the fact that they after the discharge from hospital were on their own.
- The participants are suffering, concerned, feel distressed, frustrated with less mental capacity and they all have difficulty with concentration.
- They reflect on the absent information on consequences after survival and the lack of support in managing work and overall daily life.
- In the group they are reflecting upon their experiences of the differences of possible help when recovering after a cardiac arrest and the lack of systematized rehabilitation targeted their specific needs. The participants describe their challenges due to a paramount fatigue and experiences of a lack of guidance and plans.

Subthemes

- The challenging transition from hospital to daily life
- Being on your own
- The suffering survivor
- Lack of support
- Lack of information
- Lack of coordination
- Lack of systematized interventions
- Lack of guidance and plans



Findings

The analysis and interpretation of the interviews revealed two overarching themes (i) a lack of support from the system in the transition from hospital to daily life; and (ii) feeling understood for the first time.

A lack of support from the system in the transition from hospital to daily life

A pervasive theme of the lived experiences among the participating cardiac arrest survivors were related to a crucial lack of guidance on how to return to and manage daily life with changing demands of deteriorating health. Participants experienced both long-term physical and mental health challenges which caused distress, suffering and concerns in daily life. Despite profound changes in the participants' daily lives, usual healthcare attention did not emphasize communication or systematized planned interventions towards these acquired challenges. Influencing factors on the experience of the lack of support from the system were identified as absence of coordination and responsibility between institutions.

'I have been off track for two years now [after the cardiac arrest]. There was no overall plan prescribed for me when I left the hospital, and no one mentioned what was important to prioritize when you need to get on track again. Nobody talks to you about that' P6

As illustrated in this quotation, participants were left without a meaningful direction in the transition to daily life. Continuing a life after resuscitation with nobody to guide and point out possible paths raised frustration among participants. The information on what to expect, and how to prepare for daily life fail to happen.

'I do not think that I have been informed about the consequences to expect after I survived. Therefore, I started working just after discharge from the hospital. If only somebody had said: We need to form a plan together with you on how to get back. I see now that I did not have the surplus of mental resources myself to ask for help' P3

Participants described in different ways their experiences of absent support, and with no preparation for the transition to the home environment. One participant stated: 'There is no help [from the hospital]. You just come home. And then you are on your own' P14. Another participant agrees: 'Exactly, there is nothing' P16. Regarding the experienced information gap at discharge from the hospital, the participants especially pointed out receiving none or limited knowledge on potential hypoxic brain injury acquired during the cardiac arrest. Nobody talked to the participants about the concomitant consequences. Such consequences were experienced as irritability, problems with memory and concentration, being tired all the time, not being able to manage work, loss of energy to deal with social responsibilities together with heavy emotional challenges. Especially, emotional challenges appeared to occur early on and last for several years post-arrest. Although few participants received some help and support after the event, they were however questioning the inequality in the help being offered.

'Why is there a difference in the help you get after cardiac arrest? You actually have the same symptoms as a brain injured person. Why should there be no standard schedule for rehabilitation to patients like us?' P7

Some participants succeed to establish contact to supportive services themselves. Others were surprised that they with their individual

rehabilitation needs did not fit in somehow. During the focus group interviews, the participants reflected on how less painful their transition to home and daily life might have been, if they had known where to address their suffering. Several participants emphasized the need for a matching of expectations within a transition programme between the healthcare system at the hospital, the municipality and their place of employment.

Participants with a labour market affiliation expressed a wish for but did not receive any individualized planning and support in their return to work. Although motivated to return to work, these participants spoke primarily about their experience of less mental capacity and an overriding fatigue in the aftermath after survival and described the difficult struggle of trying to get back to work without support:

'I often loose the thread and if I have to remember three things said, then I am lucky if I can remember one thing. Fatigue is a huge problem. Without support I had to stop working. Now it's all about making my daily life work' P22

The presence of brain-related health consequences can be so significant that participants' priorities have shifted so that they are reorganizing all or part of their daily lives.

Feeling understood for the first time

The participants narrated how the opportunity of participating in the rehabilitation programme and discussing their cardiac arrest experiences with both healthcare professionals and other survivors of cardiac arrest was meaningful. In particular, they highlighted the affirmation, that mental symptoms and concomitant consequences on daily life were present for a long time, as a relief. Receiving and exchanging experiences and knowledge about especially the brain-related consequences as mental exhaustion was experienced as an eye-opener for the participants. But at the same time, it was emphasized as frustrating to experience that nobody seemed responsible for identifying these problems from the start and refer to additional early care and rehabilitation to support and help moving on with daily life.

'I had eight cardiac arrests in a row. Why has nobody ever told me that after what I experienced, the more you stress yourself, the more chaos you experience, will trigger losing your focus. Yesterday's tests [cognitive tests] have given me a huge answer' P7

The quote illustrated that information about brain-related consequences is important in supporting the survivors, and that the participants without this knowledge may be challenged when trying to adapt to daily life. Understanding and reflecting on these challenges seemed to facilitate an increased understanding of what it means to live with long-lasting cardiac arrest consequences.

As participants were given the chance to mutually tell their illness stories and subsequent challenges to each other and experienced that the other survivors also struggled with cardiac arrest consequences in daily life it raised a new hope for the future. The participants furthermore spoke particularly about the fatigue and how that caused them to criticize themselves and feeling inadequate. This led to

feelings of guilt when they experienced not being able to participate fully in the family life, work, or other social activities. Sharing their stories both during the cardiac arrest rehabilitation programme but also in the focus groups made the participants feel that they had been left alone without strategies to cope with and manage the cardiac arrest impairments. Having the opportunity to talk to peers about these experiences was described as liberating.

'After two years...this is the first time I experience and realize how identical our experiences are [in the group]. Just being so tired all the time makes you feel sad. I cannot do anything. I can be nothing to anyone; I cannot contribute anything. Not manage either work, sports or any social arrangements. I'm a complete failure' P11

This new experience of a social community between participants led to the perceptions of healing for the participants and was expressed as positive. This community evoked experiences of feeling understood for the first time.

'I have felt lost in the Siberian wilderness, and then all of a sudden when I listen to your stories, I experience that you all have the same symptoms as I have and it seems like you have the same problems... It feels good to share these experiences with you' P15

It was thus a recurring feature in the participants' narratives that being recognized, understood, and confirmed was really something that the participants had missed; perhaps even without being aware of it before it was articulated:

'I think there is an actual need of equals to talk to, I just didn't know that before now. You all know how I feel... You understand, and I really have missed someone to understand. It really means a lot' P12

To exchange these narratives in peer group dialogues, made the participants talk about the necessity of having the opportunity to talk these issues through initially. Not just focusing on passing the acute hospital stay and the cardiac illness. Provision of a clear model of cardiac arrest aftercare supporting both the physical recovery, brain-related consequences, and the significant exchanging of experiences and narratives seemed important to the survivors.

Discussion

Focus group interviews were conducted during a cardiac arrest rehabilitation programme to explore the lived experiences among SCA survivors. The findings revealed that the resuscitated patients experience a knowledge gap striving for support towards especially the brain-related consequences in their transition from hospital to daily life. Cognitive and emotional problems were found, as in previous studies, to be common and led to major disruptions in the return to daily life. ^{9,20} In particular, an absence of information and guidance regarding the possibility of cardiac arrest induced impairments and

referral to further rehabilitation was found as important shortcomings in the aftermath. These experiences of lack of communication, guidance and information on what to expect in the transition from hospital to daily life are complementing other studies on missing systematic interventions after surviving cardiac arrest. 21–25 Together it is suggested that post-arrest support needs to be more organized and that follow-up programs are essential in the transition to a changed daily life after resuscitation. Using Meleis' transition theory, the shift from a state of a healthy human being to a person with changed abilities in need of aftercare and rehabilitation can be seen as a health-illness transition with a loss of former roles.²⁶ According to Meleis, a transition process is characterized by (i) a passage from one fairly stable state to another fairly stable state, and (ii) a process triggered by a change.²⁶ To support a healthy transition towards stability and healthy outcomes, Meleis argue that it is fundamental that the ill person is supported by care of expert professionals understanding this role transition; she further argues that nurses may play a significant role in this respect.²⁶ In a recent systematic review, Haydon et al.²⁷ state that there is a need to develop more holistic clinical pathways, focusing on both physiological and psychological functions in cardiac arrest survivors. Further, a Dutch study stresses that integrated rehabilitation treatment between cardiac and neurological rehabilitation departments is recommended for these patients.¹³ Our findings expand these studies by suggesting that participating in the cardiac arrest rehabilitation programme supported the survivors towards a healthy transition which they experienced relieving. By receiving and exchanging experiences and knowledge with healthcare professionals and the other survivors, they learned about hypoxic brain injuries, emotional burdens, and supportive strategies and thereby felt more able to deal with their perceived problems. In order to meet these survivors post-arrest transition challenges, after-care and rehabilitative interventions should be utilized much earlier in the clinical pathway to reduce the risk of suffering and to support a healthy transition process to recovery which is evidenced in other research as well.^{6,27} According to Meleis, nurses are in the most opportune position to assess and enhance the patient's psychosocial needs during a healthillness transition, and furthermore, support and develop the patient's identity reformulation in their communication and interaction.²⁶ To bridge the experienced health-illness transition gap between the hospital, the municipality and the place of employment this study shows that there is an urgent need for a coordinating effort. Based on the empirical and theoretical contributions from our study, a cardiac arrest specialist nursing service are suggested to be integrated already in the patients' transition from hospital to home and further in the time between hospital and rehabilitation. Addressing and supporting the individual survivor along with coordination of needed specialized care and knowledge is significant competences to include in such nursing services. The participants in the present study furthermore perceived the community in the rehabilitation group liberating. This shared community evoked feelings of being really understood for the first time after the cardiac arrest and raised a new hope for their future. This meaningful peer support has been described in studies of other patient populations as well as a crucial part of the transition to recovery.²⁸ Hence, it is worth highlighting that this group of cardiac arrest survivors, although vulnerable themselves, can help facilitate role transition back to daily life which should be integrated in future rehabilitation programmes.²⁶

Methodological considerations

This study has several strengths. According to Lincoln and Guba, trustworthiness of a study involves establishing: credibility, confirmability, dependability, and transferability.²⁹ The rich quotes from the participants strengthen the credibility of the study. The recording of interviews and verbatim transcriptions increased the confirmability of the findings, as well as ensured their dependability. Dependability was further strengthened as the first author conducted all interviews and described the analytical process in detail. The structural analysis was, according to Ricoeur, 14 further validated, as the analysis was discussed within our research group and thereby confirmability and credibility ensured. Furthermore, transferability of findings was increased as participants were from a range of age groups, sociodemographic backgrounds, and regions of Denmark. However, this study also has several limitations. The participating group was heterogeneous in age which can be seen as a limitation, but which on the other hand allowed us to explore relevant themes across differences. The recruitment process was by self-referral with self-identified rehabilitation needs, survivors with cognitive problems may not have become aware of the programme or be able to apply. Furthermore, survivors needed to be self-caring with the support of their relative and therefore survivors with severe cardiac arrest sequelae would not have participated. Moreover, other reasons as heart failure for the post-arrest consequences may exist. These facts can influence the relevance to a broader range of cardiac arrest survivors.

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Conflict of interest: none declared.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author. The data will be available in Danish.

References

- 1. Myat A, Song KJ, Rea T. Out-of-hospital cardiac arrest: current concepts. *Lancet* 2018;**391**:970–979.
- Hassager C, Nagao K, Hildick-Smith D. Out-of-hospital cardiac arrest: in-hospital intervention strategies. Lancet 2018;391:989–998.
- Wong CX, Brown A, Lau DH, Chugh SS, Albert CM, Kalman JM, Sanders P. Epidemiology of sudden cardiac death: global and regional perspectives. Heart Lung Circ 2019;28:6–14.
- Krokhaleva Y, Vaseghi M. Update on prevention and treatment of sudden cardiac arrest. Trends Cardiovasc Med 2019;29:394

 –400.
- Moulaert VRMP. Life After Survival of a Cardiac Arrest: The Brain is the Heart of the Matter. The School for Public Health and Primary Care: CAPHRI, Department of Rehabilitation Medicine, and School for Mental Health and Neuroscience of Mastricht University; 2014.

Cronberg T, Greer DM, Lilja G, Moulaert V, Swindell P, Rossetti AO. Brain injury
after cardiac arrest: from prognostication of comatose patients to rehabilitation.

Lancet Neurol 2020:19:611–622.

- 7. Sawyer KN, Camp-Rogers TR, Kotini-Shah P, Del Rios M, Gossip MR, Moitra VK, Haywood KL, Dougherty CM, Lubitz SA, Rabinstein AA, Rittenberger JC, Callaway CW, Abella BS, Geocadin RG, Kurz MC; On behalf of the American Heart Association Emergency Cardiovascular Care Committee; Council on Cardiovascular and Stroke Nursing; Council on Genomic and Precision Medicine; Council on Quality of Care and Outcomes Research; and Stroke Council. Sudden cardiac arrest survivorship: a scientific statement from the American Heart Association. *Circulation* 2020;141:e654–e685.
- Green C, Botha J, Tiruvoipati R. Cognitive function, quality of life and mental health in survivors of out-of-hospital-cardiac arrest: a review. Anaesth Intensive Care 2015;43:568–576.
- Lilja G. Follow-up of cardiac arrest survivors: why, how, and when? a practical approach. Semin Neurol 2017;37:88–93.
- Nolan JP, Soar J, Cariou A, Cronberg T, Moulaert VRM, Deakin CD, Bottiger BW, Friberg H, Sunde K, Sandroni C; European Society of Intensive Care Medicine. European Resuscitation Council and European Society of Intensive Care Medicine 2015 guidelines for post-resuscitation care. *Intensive Care Med* 2015;41:2039–2056.
- Tang LH, Joshi V, Egholm CL, et al. Are survivors of cardiac arrest provided with standard cardiac rehabilitation?—Results from a national survey of hospitals and municipalities in Denmark. Eur J Cardiovasc Nurs 2020;1-10. doi:10.1177/147451 5120946313.
- Boyce LW, Goossens PH, Moulaert VR, Pound G, van Heugten CM. Out-of-hospital cardiac arrest survivors need both cardiological and neurological rehabilitation! Curr Opin Crit Care 2019;25:240–243.
- 13. Moulaert VRM, van Heugten CM, Winkens B, Bakx WGM, de Krom MCFTM, Gorgels TPM, Wade DT, Verbunt JA. Early neurologically-focused follow-up after cardiac arrest improves quality of life at one year: a randomised controlled trial. Int J Cardiol 2015;193:8–16.
- Ricoeur P. Interpretation Theory: Discourse and the Surplus of Meaning. Fort Worth: Texas University Press; 1976.
- Tang L, Zwisler A. Rehabilitation after out-of-hospital cardiac arrest—we can definitely do it better! Danish Cardiol Soc Cardiol Forum 2019:30–37.

- 16. Morse JM. "Data were saturated. . ." Qual Health Res 2015;25:587-588.
- Breen RL. A practical guide to focus-group research. J Geogr High Educ 2006;30: 463–475.
- 18. Powell RA, Single M. Methodology matters-V focus groups. *Int J Qual Health Care* 1996;**8**:499–504.
- Missel M, Birkelund R. Ricoeur's narrative philosophy: a source of inspiration in critical hermeneutic health research. Nurs Philos 2020;21:1–6.
- Elliott VJ, Rodgers DL, Brett SJ. Systematic review of quality of life and other patient-centred outcomes after cardiac arrest survival. Resuscitation 2011;82: 247–256.
- 21. Forslund A-S, Zingmark K, Jansson J-H, Lundblad D, Söderberg S. Meanings of people's lived experiences of surviving an out-of-hospital cardiac arrest, 1 month after the event. *J Cardiovasc Nurs* 2014;**29**:464–471.
- Forslund A-S, Jansson J-H, Lundblad D, Söderberg S. A second chance at life: people's lived experiences of surviving out-of-hospital cardiac arrest. Scand J Caring Sci 2017;31:878–886.
- Ketilsdottir A, Albertsdottir HR, Akadottir SH, et al. The experience of sudden cardiac arrest: becoming reawakened to life. Eur J Cardiovasc Nurs 2014;13: 429–35
- Brännström M, Niederbach C, Rödin AC. Experiences of surviving a cardiac arrest after therapeutic hypothermia treatment. An interview study. *Int Emerg Nurs* 2018;36:34–38.
- Palacios-Ceña D, Losa-Iglesias ME, Salvadores-Fuentes P, Fernández-de-las-Peñas C. Sudden cardiac death: the perspectives of Spanish survivors. Nurs Health Sci 2011;13:149–155.
- Meleis Al. Transitions Theory—Middle Range and Situation Specific Theories in Nursing Research and Practice. New York: Springer Publishing Company; 2010.
- Haydon G, Van Der Riet P, Inder K. A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest. Eur | Cardiovasc Nurs 2017;16:475–483.
- Palm P, Missel M, Zwisler A-D, Svendsen JH, Giraldi A, Berg SK. A place of understanding: Patients' lived experiences of participating in a sexual rehabilitation programme after heart disease. Scand J Caring Sci 2020;34: 370–379
- Guba EG, Lincoln YS. Naturalistic Inquiry. Newbury Park, CA: Sage Publications; 1985.