



University of Southern Denmark

## Understanding the lived experiences of short- and long-term consequences on daily life after out-of-hospital cardiac arrest

### A focus group study

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## Title page

- **Short informative title**

Understanding the lived experiences of short- and long-term consequences on daily life after out-of-hospital cardiac arrest. A focus group study

- **Short running title**

UNDERSTANDING SHORT-AND LONG-TERM CONSEQUENCES AFTER OHCA

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### Author contributions

Criteria	Author Initials
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Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	MKW, SKB, LHT, DSS, CH, MM
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	MKW, SKB, LHT, DSS, CH, MM

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**Understanding the lived experiences of short- and long-term consequences on daily life after out-of-hospital cardiac arrest. A focus group study**

## Abstract

**Aim:** To explore and gain in-depth understanding of how out-of-hospital cardiac arrest survivors experience the short- and long-term consequences on daily life.

**Design:** A qualitative exploratory design.

**Methods:** A purposive sample of 32 survivors of out-of-hospital cardiac arrest. Data from six audio-taped focus group interviews was collected in either November 2018 or in March 2019. Analysis and interpretation of the transcribed texts was performed using a phenomenological-hermeneutic approach guided by Ricoeur for unfolding lived experiences.

**Results:** Three narratives were identified. The survivors narrated how they in the early phase after the cardiac arrest experienced: (1) 'a fragmented memory at the mercy of the system'. The analysis further showed how the participants were: (2) 'living in the shadow of anxiety and mixed feelings' and with the: (3) 'lost sense of self' up to several years after survival.

**Conclusion:** The participants in our study experienced distinct bodily impairments, suffering and the lost sense of self in the return to daily life from early on to several years after resuscitation. There seem to be an urgent need for an early initiated post-arrest transitional care program led by an expert cardiac arrest nurse. In particular, the healthcare professionals need to pay attention to survivors in employment and with children living at home. Facilitated cardiac arrest peer support groups might minimize the long-term suffering, heighten the self-image and install a new hope for the future.

**Impact:** To ease the post-arrest return to daily life for out-of-hospital cardiac arrest survivors it seems important that a transitional care program from the in-hospital setting to the community consist of: 1) screening for and education on bodily losses at an early stage, 2) provision of support on the often prolonged emotional reactions, and 3) referring for further individual and targeted psychological and neurological follow-up and rehabilitation if needed.

**Keywords:** Cardiac arrest, out-of-hospital cardiac arrest, phenomenological hermeneutic, focus groups, interview, lived experiences, nurse, daily life

## 1 INTRODUCTION

Out-of-hospital cardiac arrest (OHCA) remains a common global medical condition as several hundreds of thousands annually are resuscitated. Up to 80% of OHCA's are caused by coronary artery disease (Porzer et al., 2017; Wong et al., 2018). The OHCA survival rate is still poor (Myat et al., 2018). In terms of morbidity and accompanying health deficits OHCA is a major public health issue as the disability-adjusted life years following adult OHCA rank third in the US (Coute et al., 2019). As an increasing number of lay people are trained in cardiopulmonary resuscitation (CPR), and the number of and the accessibility of Automated External Defibrillators (AED's) is increasing, the survival rates might improve in the coming years (Gräsner et al., 2016). In line with an expected rise in survival there is a growing awareness that a cardiac arrest is an obvious life changing event and a significant burden to the survivor (Haydon et al., 2017; Sawyer et al., 2020).

## 2 BACKGROUND

Residual cognitive impairments and mental health problems frequently occur in the aftermath of a cardiac arrest (Cronberg et al., 2020; Sawyer et al., 2020). This is caused by an interruption of the blood supply to the brain during cardiac arrest, as well as responses to the acute traumatic event. These high rate disabilities are reported to negatively affect daily activities, the ability to interact in social life, the return to work (Lilja, 2017; Lilja et al., 2018) as well as quality of life after survival (Moulaert et al., 2010). Studies have investigated resuscitation experiences in a broad population of sudden cardiac arrest survivors (Bremer et al., 2019; Brännström et al., 2018; Forslund et al., 2014; Forslund et al., 2017; Ketilsdottir et al., 2014; Sawyer et al. 2016). However, looking solely at OHCA survival, data in these studies have been collected early after the event (Forslund et al., 2014, Forslund et al., 2017).

These previous studies have found that OHCA survivors experience emotional challenges, memory loss and an enhanced focus on what is important in life. Despite these significant insights, it is not well described, how patients adapt to, are troubled by and manage later effects in daily life after resuscitation. Moreover, most previous studies have taken a non-theoretical approach in the intertextual interpretations (Brännström et al., 2018; Forslund et al., 2014; Ketilsdottir et al., 2014; Sawyer et al., 2016; Bremer et al., 2019). To our knowledge only one study has used theory to deepen the understanding of surviving OHCA (Forslund et al., 2017). However, when it comes to investigating the return to daily life after OHCA, the literature is insufficient. As the cardiac arrest survival increases, and as there is a lack of studies that provide a more in-depth understanding of experienced consequences after survival, there is a need to explore both the short- and long-term impact of cardiac arrest on daily life more comprehensively. Thus, broader in-depth insights are needed to nuance and support the development of future tailored supportive and rehabilitative intervention programs targeted cardiac arrest survivors.

### **3 THE STUDY**

#### 3.1 Aims

The aim of this study was to explore and gain in-depth understanding of how out-of-hospital cardiac arrest survivors experience the short-and long-term consequences in daily life. The research question was 'how do cardiac arrest survivors experience daily life and what do they emphasise as important in their return to daily life after resuscitation?'

#### 3.2 Design

This study had a qualitative explorative design using focus group interviews. Focus group interviewing gave the opportunity to express tacit and pre-reflective knowledge in collective discussions (Kitzinger, 2005). A phenomenological-hermeneutic approach inspired by Ricoeur's philosophy created the epistemological stance for exploring lived experiences of participants (Ricoeur, 1976).

#### 3.3 Participants

The Danish Heart Foundation and the Danish Cardiac Arrest Survivorship (DANCAS) network (Tang

& Zwisler, 2019) invited cardiac arrest survivors to participate in a three-day cardiac arrest rehabilitation course at the national research clinic REHPA in the Region of Southern Denmark. The original setting for enrolment at a course was a self-reported rating of own rehabilitation needs. This was inspired by the validated scale Distress Thermometer; an instrument developed to assess rehabilitation needs in cancer patients. Underpinned by the literature and knowledge from the DANCAS network expert group supplementary questions on potential problems cardiac arrest survivors may experience were added (figure 1) (Cronberg et al., 2020; Sawyer et al., 2020). Eligibility criteria for participating in a course are shown in Table 1. All 33 patients applying for a course were offered to participate either in November 2018, or in March 2019. A purposive sampling strategy was as such applied including participants from the course. Participants were broadly represented by demographic and clinical characteristics (table 2). The data collection was carried out until data saturation was reached.

### 3.4 Data collection

Data was collected in focus groups at REHPA. As the interviews were conducted at the end of the courses, the participants were familiar to each other at the time of interviewing and a trusting atmosphere was created. To ensure social recognition, and thereby create a safer environment during interviewing, the participants were divided roughly into groups based on age, gender and family type (table 2). Based on the November 2018 interviews, and to enhance the design and programme of future cardiac arrest courses, a few questions were added to the interview guide in March 2019 regarding daily living. Table 3 present the interview guide with topics based on curiosity regarding how the participants managed their daily life and health. Previous research indicate that this patient population might experience post-arrest consequences in daily life and a concomitant decline in health and health-related quality of life (Sawyer et al., 2020). The interviews were conducted in an undisturbed room and lasted between 60 to 90 minutes. The first author had the responsibility of enabling everybody to introduce themselves, share their experiences, and carefully moving on the discussions so that all topics were covered (table 3). The interviews were performed with an experienced assistant MM and LHT. The assistant was responsible for the audio recorder, handling of the environment conditions and logistics and was prepared to respond to unexpected interruptions. The assistant could also ask additional questions or follow-up on topics of interest. The guide helped focus the interviews and



included questions on the survivors' experiences and concerns after returning to daily life (Green & Thorogood, 2014). The introductory question was "Can you describe how you have experienced your daily life after the cardiac arrest?". To collect a variety of information the participants were asked to elaborate on meaningful post-arrest experiences. As the interviews progressed relevant probes were used to gain insight into issues that were raised.

### 3.5 Ethical considerations

The study is registered with the reference number: 20192000-66 and conform to the basic principles of the Declaration of Helsinki. All participants gave written and informed consent to participate. The study objectives, confidentiality of data, and recording of interviews were explained to the participants prior to the interviews. Furthermore, it was explained that they could withdraw from the study at any time. During the interviews some participants experienced strong emotions (e.g. crying). These participants were offered to resume later on and debrief at the end of the interviews. Data were made anonymous by means of identification codes.

### 3.6 Data analysis

The interviews were audiotaped and transcribed verbatim. Analysis and interpretation of the transcribed texts was performed using a phenomenological-hermeneutic approach inspired by Ricoeur's philosophy (table 4). According to Ricoeur new insight of being-in-the-world can be achieved by understanding the meaning of lived experiences by utilising an interview text and applying critical interpretation. (Ricoeur, 1976). The analysis includes three main levels of textual analysis and interpretation; naïve reading, structural analysis, and comprehensive understanding. In the naïve reading the transcripts were read several times to gain an understanding of the meaning of the texts as a whole. The structural analysis organized the transcripts into meaning units. To interpret the meaning units at a deeper level and go beyond naïve understanding the aim of the structural analysis is to open up the text and pointing towards essential themes as a distanced objectivity and explanation of what is said. The process is a hermeneutic spiral moving from of what the texts say to what they talk about. The aim is to reach a comprehensive understanding of the texts by relating to theory and research. This comprehensive understanding transformed the texts to an interpreted whole where three narratives were constructed. The analytical levels in the critical interpretation are illustrated in Figure 2. The

consolidated criteria for reporting qualitative research (COREQ) checklist provided guidance during the reporting of this study (Tong & Sainsbury, 2007).

### 3.7 Rigour

The trustworthiness was established following the criteria of Lincoln and Guba (Lincoln & Guba, 1985). Credibility was ensured, as the course created a community for the participants with a mutual understanding of one another in which they were all valued as individuals with a significant story to share (Isaksen & Gjengedal, 2000). Furthermore, the researchers had all prolonged engagements in the research setting. All interviews were conducted by the first author MKW, an experienced clinical nurse specialist within cardiology and familiar with interviewing. Credibility and dependability were increased, as the interviews were facilitated by two experienced qualitative researchers. A second set of eyes and ears increases both the total accumulation of information and the validity of the analysis (Krueger & Casey, 2015). Confirmability was ensured through a detailed audit trail of the three main levels of textual analysis and interpretation. To strengthen transferability of the findings, description of the setting, sampling strategy and change of research questions between the two inclusion periods are provided. Substantiation of the findings and transferability was also increased by the rich inclusion of participant quotes (Lincoln & Guba, 1985; Ricoeur, 1976). The first author coded and conducted the data analysis in collaboration with the last author, an experienced researcher. Findings were discussed with all authors.

## 4 FINDINGS

Six focus group interviews were conducted involving 33 out-of-hospital cardiac arrest survivors (25 men and 8 women) with a mean age of 59 (range 40–83 years) from all regions of Denmark. Divided in groups of 4 to 7 participants, 17 survivors took part in the interviews in 2018, and 16 survivors in the 2019 interviews. More than a third of the participants had children living at home, only three were living alone and 22 were employed before the cardiac arrest. The median time between cardiac arrest and interview was 16 months (table 2). One male participant withdrew from the study right after the interview and was excluded. Three main narratives illuminate the participants' experiences of the hospital phase, their returning to daily life and the long-term follow-up after resuscitation: 'a *fragmented memory at the mercy of the system*'; 'living in the *shadow of anxiety and mixed feelings*';

and 'the lost sense of self'. The narratives, along with the researchers' interpretations, are presented in the following.

#### 4.1 Narrative (1): A fragmented memory at the mercy of the system

This narrative describes how the acute cardiac arrest phase still dominated the participants outlook in daily life. Clearly stated was experiences of partial memory loss in the time period just before and during the acute critical phase and up to weeks after hospital discharge. The remaining experiences of the acute treatment and care were fragmented and filled with perceptions of mixed sounds, colors with white light or darkness, ambience and surroundings with a high pace. Being a body that is handled at the mercy of the healthcare system is narrated as traumatic and has taken a hold (with)in the survivors. Survivors described this period as a surreal experience with shifts between experiencing nothing or being in an awake and chaotic state.

What the heck is going on? I really felt it like that. In that way it [the cardiac arrest] is an intense and traumatic experience - an out-of-body experience. I remember that I was fighting a battle... They almost needed to lie on top of me, the ones trying to help me (8).

Being a body that is handled within the healthcare system leaves the participants with mixed feelings of frustration, lack of control and powerlessness. Using strong words as traumatic, intense, fight and shouting emphasise that the cardiac arrest is a paramount and frightening experience. These feelings seem to hold a very strong position in the survivor's daily life narratives and are all still highly present even up to 11 years after the event.

Even though the acute management is an unpleasant and overwhelming event, the participants also highlight feelings of gratitude toward the healthcare system and their rescuers. A female participant describes how she experienced gratitude to the people who had acted in that situation: "Ten minutes went where I was actually dead. They fought and never gave up". (4). This sense of gratitude for being saved has taken hold in the consciousness of the participants. Although they have experienced how their bodies have been handled by the healthcare professionals, they have also experienced getting their lives back.

#### 4.2 Narrative (2): Living in the shadow of anxiety and mixed feelings

This narrative describes how the participants are struggling with continuous emotional reactions in daily life. These challenges restrict daily life and participants are living in the shadow of anxiety and feelings of sadness and restlessness. Participants narrate how they are “feeling down” and in “a black hole” without joy. The implications of these feelings for the survivor are distinct meaning that common day-to-day routines are suddenly troublesome and an obstacle to managing daily life.

It is so hard.... *To be with your children and family... (crying). I have trouble going into my bedroom where it happened [cardiac arrest]. I cannot sleep in there.... I'm having a hard time with ambulances, the sound of the computer, and when people are running. It sounds like when you are having a cardiac arrest. It is in my head(7).*

Not having the mental surplus to socialize with the family and avoiding reminders of the cardiac arrest dominated daily life. Several participants spoke about a sustained vulnerability as both intrusive thoughts and bodily reactions occurred frequently if reminded of the event. These reactions often first arose after discharge from the hospital but seemed to persist long-term. Furthermore, feelings of insufficiency, loneliness and guilt were present. Especially guilt and worries about the impact of the cardiac arrest and the course of the illness on the closest relatives. A male participant stated:

The worst thing is that you wake up to a traumatised wife and kids. My biggest challenge has been to relate to my family before I have been able to relate to myself (17).

This guilt of having caused the family a major traumatic experience, weighs down on the participants and is casting a shadow over their daily life. Several close relatives had been present during the most critical phase at the hospital, perhaps also found the survivor unconscious, called for help and performed the initial cardiopulmonary resuscitation (CPR). Moreover, the participants are especially concerned about their children. In particular, if their children are at risk of having inherited the cause of the cardiac arrest; a worry they did not have before the event, but which is suddenly very present.

Overall, the participants' narratives were emotional and surrounded by a shadow of suffering and

embedded sorrow and at times, the emotional chaos was overwhelming. During the interviews several participants spontaneously expressed an inadequate emotional support during the illness trajectory which they felt could have helped them in managing daily life. What the participants expressed was missing was a support to help deal with individual challenges, to talk problems through and to deal with hereditary issues. Such emotional issues like talking about death and related thoughts about death was expressed as very sensitive to bring up around close relatives. Therefore, the participants often chose not to burden relatives in this regard. Instead talking to peers was emphasized as a possible and valuable supplement to manage daily life.

#### 4.3 Narrative (3): The lost sense of self

This narrative describes the long-term experiences of having 'lost yourself' after the cardiac arrest. The struggle to hold on to some kind of normality and balance within the changed life was frustrating and confusing, especially among the younger and middle-age participants who were still employed.

I do not feel self-control, only frustration. It is hard to acknowledge that nothing will be as before. I have felt like Alice in Wonderland who enters this totally new world. Who am I now and what is this? I do not know whether to go left or right or which door to open. It has been and is a huge work for me to find out who I am and what I am going to do (10).

As illustrated in the quote above, it was difficult to come to the realization that nothing would be as before, and that the participant's life situation had changed by the event. Before the cardiac arrest this woman was physically active, both in her leisure time, at the house, at work, and with sports. The feeling of losing this basis of her identity, her sense of self and how others pictured her was described as difficult. Other participants also narrated about a life before the cardiac arrest where work was a substantial part of their identity. In particular, the search for acceptance from colleagues within a certain working community subsequently became crucial for returning to daily life.

This is what is important and what we live for now, when we work. Respect from our colleagues. I was afraid that I would be put in a corner. But they still need me and what I do (6).

A persistent challenge for the participants was experiences of extreme and long-term fatigue accompanied with concentration difficulties, lack of focus and mental resources, short-term memory problems, headaches and feeling irritable and irrational. These impairments had an impact on the individual's self-perception. The participants described how they felt losing parts of themselves and their identity.

I work fulltime. Not much is going on before I get confused and I feel like I am banging my head against the ceiling. I cannot cope with as many things and continue the same pace as before. There are days where I can't do anything (8).

This overwhelming feeling of fatigue disrupts daily life leaving the participants in a powerless position and with a call for help. Contrary to this participant a few others received support and guiding to help manage their acquired impairments.

...my neuro psychologist tells me that I have to adapt to daily life and try not to be worn out. It means that I need breaks when one hour has passed. It is hard, but if I *don't* do this, I will be totally worn out after three hours (9).

The participants unanimously agreed that the sooner a professional helping hand was initiated, the disrupted and altered daily life was somewhat easier to deal with.

## 5 DISCUSSION

In the following, we elaborate on what might be at stake for survivors of a cardiac arrest, derived from the identified themes. Selected aspects of theory are used to interpret the findings to achieve a further, deeper and comprehensive understanding of the participants' lived experiences (Ricoeur, 1976).

During the acute phase of the cardiac arrest, participants both experienced and lived through their bodies. Looking back at the hospitalisation, the experiences were fragmented, traumatic and with glimpses of a body being handled within the mercy of the healthcare system. Being a body that is

handled by others mercy may evoke experiences of alienation and as a threat to one's self with a risk of suffering. This changed sense of own body might though be formed by the responsive approach from others (Storli, 1999). In a medical approach to the body, Lock and Ngyen state that the clinicians inevitably focus on the physical body in an acute critical situation of a cardiac arrest. For the affected person this standardised medicalisation focusing on the body can seem reductionistic. However, survival is the main target and the most important cardiac arrest outcome (Lock & Ngyen, 2010). Despite this fact, our study showed that in the medicalised environment, during treatment and care, the state of mind of our study participants were of a more comprehensive nature underpinned by feelings of a changed body and fear as well as lack of control and out-of-body experiences. As such the participants spoke about their bodies as more than just physical boxes. Løvås has described how the body during critical illness might be experienced without boundaries and as unrecognizable (Løvås, 1988). However, such accompanying consequences of a cardiac arrest might not be realized at hospital discharge. Recent research though reported that addressing bodily changes in a stable but early phase after the event may help the patient in an acceptance of the new situation and the consequences of bodily impairments (Sawyer et. al., 2020).

Our study further illuminated how the participants were living a daily life in the shadow of anxiety and mixed feelings from early on to several years after the cardiac arrest. Burdened by emotional reactions they expressed how they did not have the mental surplus socializing with their families. Health issues is reported to be an area of significant concern for survivors of OHCA (Haywood & Dainty, 2018; Wilder Schaaf et al., 2013). A pronounced issue for the participants in our study was the feeling of guilt over having inflicted a traumatic experience on the family which casted a shadow over their life. Other studies report difficulties in meeting such emotional needs of survivors (Haydon et al., 2017; Haywood & Dainty, 2018; Lilja et al., 2018). From a caring perspective, nurses must minimise and relieve suffering during a course of illness. According to Morse two broad and divergent behavioural conditions are present in suffering; enduring where emotions are suppressed and suffering where emotions are released (Morse, 2001). Enduring persists while the suffering is still pre-reflective and unspoken, and all energy is used to maintain control while adapting to this new situation. Enduring can induce long-term anxiety and depression. Emotional suffering is however the opposite and is a condition where suffering is acknowledged and expressed. Emotional suffering is often characterised

by feelings of sorrow and sadness, as the individual comes to the realisation of what is lost and what this means in daily life (Morse, 2001). For cardiac arrest survivors who are living in the shadow of anxiety and mixed feelings, and an acknowledgement of a new daily life, Morse emphasises the significance of nurses being empathic, asking about suffering, meeting patients in articulating worries and taking action on feelings and thoughts to support these people (Morse, 2001). Participants in our study speak about post-arrest suffering in daily life up to 11 years. This suffering is a threat to the well-known daily life. Therefore, it has to be expressed and acknowledged together with finding time and space to live through the suffering (Eriksson, 1995; Morse, 2001). By focusing on psychosocial well-being (Sawyer et al., 2020), the individual might be ready to move on with a reorientation and new meaning in life.

Participants in our study experienced a lost sense of self after the cardiac arrest. According to Bury “illness interrupts the expectations and plans that individuals hold for the future” (Bury, 1982, p. 169) and “requires a fundamental rethinking of the person’s biography and self-concept” (Bury, 1982, p. 177). Experiences related to the cardiac arrest were for our participants indeed a disruptive event. Facing daily life with acquired impairments such as fatigue, concentration difficulties and short-term memory problems resulted in an altered daily life where the survivors felt being alone with their interrupted biographical experiences. We found that the younger participants, who were employed and with children living at home, were trying to ignore, minimise and struggle against the fatigue and impairments for a long time. This resulted in a feeling of ‘banging the head against the ceiling’. As stated by Charmaz, people may ignore a certain illness and additional consequences if they e.g. want to keep a certain job (Charmaz, 1995). Through this theoretical lens our findings emphasize that especially younger cardiac arrest survivors need special attention, as they struggle against impairments and ignore them for a long time in an effort of returning to their previous daily life. As illuminated in our study, this strategy however has consequences leaving the survivors in a protracted powerless position. Developing education programs and referring for individualized and targeted psychological and neurological follow-up and rehabilitation is therefore urgently needed.

#### 5.4 Limitations



We collected data from a relatively large number of OHCA survivors aged from 40 to 83 years with a majority of men, from all regions of Denmark, and from all groups of society. As two thirds of cardiac arrest patients in Denmark are male (Wissenberg et al., 2014), with a wide age range, this sample might thereby reflect the population in general, making transferability of findings possible. Participants were however recruited from a population of OHCA survivors who themselves chose to sign up for the course. The sample in this study might therefore reflect participants who had more resources to narrate about their experiences and act upon their situation. Moreover, a potential study limitation is the generous timespan of 3 months to 11 years from cardiac arrest to time of interviewing. This means that some variations are expected in how the participants experience the consequences on daily life after OHCA. On the other hand, this study explore what the participants emphasize as important from early on to long-term in their return to daily life after resuscitation.

## 6 CONCLUSION

Characterized by distinct bodily impairments, mental suffering and the lost sense of self, patients surviving OHCA experience a disrupted daily life from early on to several years after resuscitation. The findings suggest that the role of a post-arrest healthcare-team is emphasized as significant to the return to daily life after resuscitation. In particular, the findings highlight that a transitional care program led by a coordinating expert cardiac arrest nurse between the in-hospital setting and the community might be the needed organizational link to reconcile with early bodily losses and accompanying prolonged emotional reactions, suffering and a lost sense of self. To ease the return to daily life it seems important that screening for and education on bodily losses is given at an early stage, support is provided on the emotional reactions, and referral for further psychological and neurological follow-up and rehabilitation is addressed in a systematic manner. In particular, for the survivors in employment and with children living at home the cardiac arrest seem to have a considerable impact on the experiences of the return to daily life in the aftermath after resuscitation. Besides the important role of the transitional healthcare professionals, facilitated peer support groups might provide a perspective of shared experience and emotional support among cardiac arrest survivors that minimize the long-term suffering and heighten the self-image which instill a new hope for the future and improve the return to daily life after resuscitation.

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**Table 1; Eligibility criteria for participating in a course**

<b>Eligibility criteria</b>
Out-of-hospital cardiac arrest survival
Willingness to convey and engage fully in a course
Needs help to find a foothold in life after cardiac arrest
Without severe neurological disabilities
Independent in activities of daily living
Able to speak and understand Danish

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**Table 2: Demographic and clinical characteristics of participants**

Category	Focus group 1	Focus group 2	Focus group 3	Focus group 4	Focus group 5	Focus group 6	Total
<b>Time for focus group interview</b>	November 2018	November 2018	November 2018	November 2018	March 2019	March 2019	
<b>Participants, n</b>	5	5	7	6	4	5	<b>32</b>
<b>Male : Female</b>	3:2	3:2	6:1	3:3	4:0	5:0	<b>24:8</b>
<b>Median age [IQR]</b>	62[53-76]	41[40-60]	53[44-63]	55[51-63]	72,5[68-83]	70[62-76]	<b>60[40-83]</b>
<b>Median duration since OHCA (months)</b>	12[3-24]	18[8-24]	14[7-132]	12[8-58]	57[7-64]	16[12-120]	<b>16[3-132]</b>
<b>Aetiology of the OHCA</b>							
Ischemic heart disease, n	3	2	6	3	4	3	<b>21</b>
Arrhythmia others, n	2	3	1	2	0	2	<b>10</b>
Unknown to participant, n	0	0	0	1	0	0	<b>1</b>
<b>ICD implanted after OHCA, n</b>	4	5	6	2	1	3	<b>21</b>
<b>Family type</b>							
Alone, n	0	0	0	1	2	0	<b>3</b>
Living with spouse/or partner, n	3	2	3	3	2	5	<b>18</b>
Living with spouse/ or partner and children, n	2	3	4	2	0	0	<b>11</b>
<b>Residence of region in *Denmark</b>							
Capital Region of Denmark, n	1	1	2	1	0	4	<b>9</b>
Region Zealand, n	0	3	2	0	0	0	<b>5</b>
Region of Southern Denmark, n	0	1	2	4	2	0	<b>9</b>
Central Denmark Region, n	2	0	1	1	1	1	<b>6</b>
North Denmark Region, n	2	0	0	0	1	0	<b>3</b>
<b>Education</b>							
Elementary school, n	1	2	4	2	3	3	<b>15</b>
High school, n	1	2	3	2	1	2	<b>11</b>
≥ College, n	3	1	0	2	0	0	<b>6</b>
<b>Employment</b>							
Before OHCA, n	3	5	6	6	0	2	<b>22</b>
After OHCA (reduced ability to work), n	3	4	4	5	0	1	<b>17</b>
Retired (8) or on sick leave (1) before OHCA, n	2	0	0	0	4	3	<b>9</b>

**OHCA: Out-of-Hospital Cardiac arrest**

\*Denmark consists of five regions

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**Table 3: Interview guide**

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	<b>Open-ended questions asked to the cardiac arrest survivors</b>
Introduction	<p>The aim of the study is explained to participants</p> <p>Clarifying the roles as participants and researchers</p> <p>Can you describe how you have experienced your daily life after the cardiac arrest?</p> <p>Can you describe the impact of the cardiac arrest on your daily life?</p> <p>Can you tell about your concerns, and what have been most important for you after your cardiac arrest?</p> <p>Can you tell if and what kind of support you might have needed from your surroundings and health professionals after the cardiac arrest?</p>
Closure	<p>Is there anything else you would like to share before we end the interview?</p> <p><b>Supplementary questions for the March 2019 interviews</b></p> <p>Overall, how would you describe your work-life after the cardiac arrest?</p> <p>If you are a pensioner. How do you think this influence your daily life after the cardiac arrest?</p>

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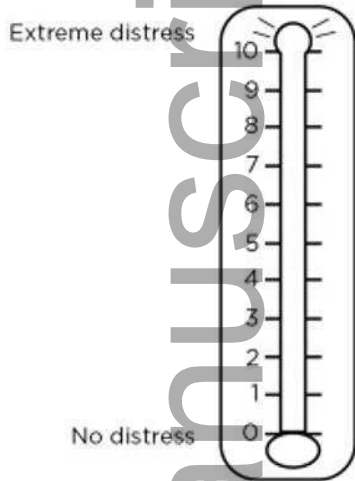
**Table 4:** Example of a Structural Analysis

Meaning units	Condensation/essence	Sub-theme	Theme
<p>I do not feel self-control, only frustration. It is hard to acknowledge that nothing will be as before. I have felt like Alice in Wonderland who enters this totally new world. Who am I now and what is this? I do not know whether to go left or right or which door to open. It has been and is a huge work for me to find out who I am and what am I going to do (10).</p> <p>I cannot cope with as many things and continue the same pace as before. Because I work fulltime, I feel like I am banging my head against the ceiling. Not much is going on before I get confused. There are days where I can't do anything (8).</p>	<p>The participants experience a struggle in their return to daily life in relation to the fact that the cardiac arrest has changed who they have become compared to who they were. The participants are frustrated, confused and searching for the sense of self.</p>	<p>Loss of self-control</p> <p>Frustration</p> <p>Confusion</p> <p>Loss of identity</p> <p>Helplessness</p>	<p><b>The lost sense of self</b></p>

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**Distress Thermometer**

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



**Problem list**

Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

**YES NO Practical Problems**

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

**Family Problems**

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

**Emotional Problems**

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

**Spiritual/Religious Problems**

- 

**YES NO Physical Problems**

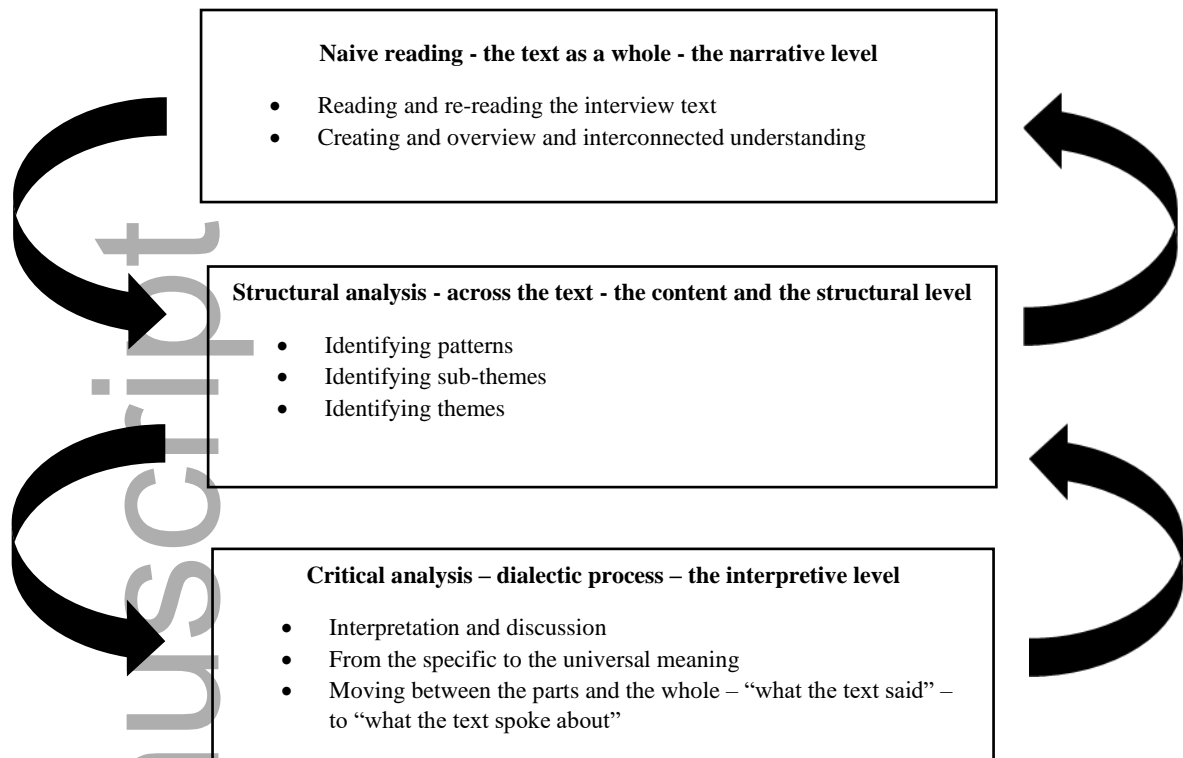
- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentrate
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance use
- Tingling in hands/feet

**Other Problems** \_\_\_\_\_

**Supplementary questions: Do you have cardiac arrest related problems regarding:**

- |                               |                          |  |                          |
|-------------------------------|--------------------------|--|--------------------------|
| Concentration                 | <input type="checkbox"/> | Reading                                | <input type="checkbox"/> |
| Attention                     | <input type="checkbox"/> | Writing                                | <input type="checkbox"/> |
| Memory and learning abilities | <input type="checkbox"/> | Epilepsy                               | <input type="checkbox"/> |
| Problem solving               | <input type="checkbox"/> | Hypersensitivity in noise              | <input type="checkbox"/> |
| Keeping appointments          | <input type="checkbox"/> | Interacting socially with other people | <input type="checkbox"/> |
| Orientation/ finding your way | <input type="checkbox"/> | Changed behaviour                      | <input type="checkbox"/> |
| Understanding                 | <input type="checkbox"/> | Other problems _____                   |                          |
| Linguistic skills             | <input type="checkbox"/> |  |                          |

**Figure 1:** Self-reported rating of own rehabilitation needs



**Figure 2** Analytical levels in the interpretation of findings.