The Physical and Mental Impact of Surviving Sepsis – A Qualitative Open Interview Study

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Research

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Abstract

Background: This study aims to illuminate how sepsis survivors experience sepsis and the impact of sepsis as well as the quality of life thereafter.

Methods: A qualitative open interview study with eight sepsis survivors was performed. A content analysis inspired by Burnard was made.

Results: Four main categories emerged during the analysis; *The experience of health care and being a sepsis patient*, *New circumstances' impact on life*, *Family and social interactions*, and *The psychological impact on life*. The lack of information on how sepsis can impact the survivors' lives and what to expect can lead to prolonged agony. The long recovery time comes as an unexpected and unpleasant surprise to those affected. Initially, the sepsis survivors are almost euphoric that they have survived, which can later lead to chock and trauma when they realize that they could have died. This insight needs to be processed in order to reach reconciliation with how life will turn out after sepsis.

Conclusion: Sepsis has a huge impact on both physical and mental aspects of life. Many survivors suffer from persistent residual symptoms of varying degrees to which they have to adapt. The sepsis survivors need individually adjusted information about the sepsis recovery trajectory and what to expect during and after the hospital stay.

1. Background

Sepsis is a life-threatening condition defined as a dysregulated host immune response to a localized infection. Infections such as pneumonia, wound infections, or urinary tract infections may sometimes trigger the immune system to overreact, leading to damage of vital organs such as the heart, lungs and kidneys [1]. Each year sepsis affects about 48,9 million people all over the world [2] and is also one of the major reasons for admission to hospital and critical care [3, 4]. Sepsis is a critical illness with high morbidity and mortality rates, leading to death for about 10–20% of those suffering sepsis [5]. The incidence of sepsis in adults in Sweden is estimated to at least 40 000 people each year [6]. In May 2017, WHO adopted a resolution stating that sepsis is a global health problem [7]. Updated international definitions and new clinical criteria for sepsis were presented for adult patients in February 2016. According to the new Sepsis-3 definitions, sepsis is defined as a dysregulated host response to an infection leading to life-threatening organ dysfunction [8, 9]. For each hour that adequate treatment with antibiotics, oxygen and fluid treatment is delayed, mortality increases [10], which has led the research field to focus on early detection and treatment of the infection [8, 9, 11]. As a result, the survival rate after sepsis may have increased during the last few years [12, 13].

According to the WHO definition of quality of life (QOL), good QOL is about how the individual perceives his or her life situation in a broader/wider context and in relation to his or her values, expectations and goals. QOL is also linked to the contextually of culture and norms, relationships and family, as well as physical health and mental state [14]. It's important to distinguish between QOL, which is quality of life in a more

general sense, and health related quality of life (HRQOL); hence both of the terms are used in this study [15].

Sepsis survivors experience a reduced health-related quality of life, (HRQoL) and impaired functional status compared to other people in general [16, 17]. In the United States, it's believed that many sepsis survivors are discharged from the hospital with a new, undefined combination of cognitive impairment and physical disability, such as sensory and emotional problems, which has an impact on work and challenging activities [18]. This could explain the deterioration of their HRQOL [19, 20]. The specific entity and manifestation of the complications are, after discharge from hospital, not fully understood [19]. Compared to the average population, sepsis survivors report lower QOL and are less likely to return to work and activities after discharge from hospital [2, 21].

Sepsis can be compared to other critical illnesses [22], for example stroke, where research has shown that early treatment, support and rehabilitation has a major impact on how extensive the residual symptoms are after the disease, which in its turn affects daily life and the reduction of QOL [23].

To focus the research of critically ill patients with sepsis on the impact of early rehabilitation, improved cognitive ability, as well as family, relatives and friends, could be of importance for improved recovery [24]. As the number of survivors of sepsis increases, it's of major importance to gain further knowledge about how these patients experience their HRQOL. To describe the patients' HRQOL trajectory over time, what happens to them after surviving sepsis [19] and what kind of support, care and rehabilitation they could benefit from further research is required [24, 25].

The aim of this study was to illuminate how sepsis survivors experience the impact of the sepsis episode and their quality of life thereafter.

2. Methods

2.1 Study design and sample

Open interviews with eight sepsis survivors were conducted to illuminate the experiences and perceptions of the participants, which also was the aim of this study. A consecutive sample of Swedish speaking participants was selected. To be included in the study the participants had to be between the ages of 18 and 65 and they had to be able to speak and understand Swedish. Furthermore, they had to have had an infection that progressed to sepsis or septic shock, as the severity of the infection is associated with an increased need of healthcare and an increased risk of sequelae. It was also a requirement that the sepsis survivor had only had sepsis once. To be included in the study, at least three months should have passed since the sepsis episode and hospital discharge, but not more than three years. Participants nursed by the author, who is working at an emergency department in the south of Sweden, were also excluded to avoid research bias.

2.2 Data collection

The participants were recruited from the "Sepsis Forum", a closed forum on Facebook, where sepsis survivors and/or their relatives can discuss their situation after sepsis. The administrator of the forum posted information about the study and asked the members to give their approval for the researchers to gain access to the forum. When the ethical approval was obtained, an open request was posted with information on how to contact the author if anyone wanted to participate in the study and those who met the inclusion criteria were contacted by telephone. The participants decided the date and place for the interview. Before the interview, the participants received written information via mail about the aim of the study and that they at any given time could withdraw their involvement, without providing a reason or an explanation. Before each interview they submitted their signed consent for participation in the study.

Four of the interviews were made in person and the other four by telephone and the participants came from the middle and the south of Sweden. Initially demographic questions were asked and then an open overall question: "What does health mean to you"? Thereafter, follow-up questions were asked, for example whether the participants could specify/clarify and/or give more examples, to ensure that all areas of the theme-guide (appendix 1), were referred to in depth. The interviews were audio recorded and transcribed verbatim, with the participants consent. The transcribed interviews were coded so that no third party would be able to identify any of the participants in the study. The transcribed interviews were stored in a lockable cabinet, at the author's home, to which no one else had access.

2.3 Data analysis

The data was analyzed with inspiration from Burnard's 14-step content analysis [26]. In close connection with each interview, notes of topics were made. Throughout the reading, general themes within the transcripts were identified and codes were written down. The category system resulted in 132 codes, similar codes were removed, and categories and sub-headings were worked through thoroughly, Table 1. The co-author listened to the majority of the recordings and read all transcripts and independently coded some of the material. The categories were discussed with the third co-author, and adjustments were made to enhance validity and to minimize researcher's bias. Independent coding was done in some of the interviews by the authors and then compared in order to ensure that the categories covered all aspects of the interviews and the material was then re-read. In each interview codes were identified using the coding scheme. The codes from the interviews were merged and the categories were created. Thereafter the text unit of each code were cut out of the transcripts and put under each category. These steps were taken with caution in order to not lose the context and to avoid altering the meaning of what the participants said. A complete transcript of each interview was kept close at hand during the whole process in order to be able to stay close to the original context and meaning. Step 11 in Burnard's model [26] of content analyzing was to check with participants. This was not done, as the author thoroughly examined the statements made by the participants by asking follow-up questions during the interviews. One of the co-authors participated in the analyzing process to ensure that the correct interpretations and conclusions were made and to validate the process [26, 27]. After the analysis of interview number six, no new topics occurred. All interviews were made by the same author and the same questions were asked.

Table 1
Textunits into categories and subcategories

Category	Sub category	Code	Text condensation	Text unit
Physical impact	Sequelae	Fatigue	Forget things... and I'm so exhausted because I'm not tired really, I'm tired all day, I can't sleep at all and I don't feel like I'm tired from a lack of sleep, just... just exhausted in some strange way.	<i>"and what I told you about how I lose track of conversations, and how I completely forget things... and I'm so exhausted because I'm not tired really, I don't know, it's so strange, I'm tired all day, I can't sleep at all and I don't feel like I'm tired from a lack of sleep, just... just exhausted in some strange way."</i>

Table 2
Demographics of the participants

Age	Gender	Type of interview	Type of infection	ICU	Long-term effects	Comorbidity before sepsis	Comorbidity after sepsis
22	Female	In person	Thrombo phlebitis	No	Pain, fever, fatigue	Chiari-malformation	Postural tachycardia syndrome (POTS)
31	Male	In person	Upper respiratory infection	Yes	Cognitive impairment, amputation, wounds, pain, fatigue, pondering	No	No
38	Female	In person	After childbirth, Sectio	No	Cognitive impairment, impaired short-term memory, fatigue, pondering, depression	No	No
41	Female	Telephone	Erysipelas	Yes	Frailty of the body, fatigue	No	No
45	Female	Telephone	Pneumonia	Yes	Cognitive impairment, depression, loss self-esteem, fatigue	No	No
51	Male	In person	Influenza	Yes	Cognitive impairment, depression, sleeping problems, loss self-esteem	Pacemaker PM/ICD and Sarcoidosis	No
56	Male	Telephone	Pneumonia	Yes	Total loss of HRQoL, dependent on help with ADL pain, wounds	Diabetes	Myocardial infarction
58	Male	Telephone	Pneumonia	No	Pain, fatigue, sleeping problems	No	No

2.4 Ethical considerations

The four ethical principles of the Helsinki Declaration [28] were followed. Ethical approval was obtained (2019-00001) by The Swedish Ethical Review Authority. All participants were provided with oral and written information about the study as well as information about how it's conducted and that the participants could terminate their participation at their convenience.

3. Results

Eight interviews were conducted, and four of them were held over the telephone. The interviews lasted from 45-80 minutes. Four of the participants were female and four were male, the age range was from 22-58 years, and they lived in different parts of Sweden. During the analysis four main categories emerged, *The experience of health care and being a sepsis patient*, *New circumstances' impact on life*, *Family and social interactions* and *The psychological impact on life* (see figure 1).

3.1 The experiences of health care and being a sepsis patient

The participants had difficulties adapting to life both during and after the illness and to managing on their own.

From a common infection to a life-threatening condition

Many of the sepsis survivors described that they had minor symptoms of illness such as influenza, pneumonia, or a simple cold before becoming critically ill. *"I had been complaining that I had a sore throat... but one has that every once in a while, during the year and I, or we, had no reason to believe that it was something different this time around". (Interview 1)*

A few of the participants described that they had contacted the healthcare for guidance but were advised to stay at home and see how things developed. When they finally sought care, symptoms had progressed. *"I don't know what happened: if they forgot about me or if they didn't take me seriously... I didn't get any treatment until seven hours after my arrival... So I had to wait for very many hours and then I just collapsed in the emergency room". (Interview 5)*

Being dependent on others and feeling left out

Overall, the sepsis survivors were positive and felt incredibly grateful for the care they received during the hospital stay, but they also felt that improvements are needed. The importance of positive interactions with the health-care professionals was recurrent in the narratives, because the patients felt dependent on them in every way. *"I told someone [hospital staff] to make sure that the remote control for the bed is nearby... When I woke up... I couldn't reach the remote control, because... they put it far away from the bed... I tried to*

call out for help, and I started yelling louder and louder – I just panicked to be honest...”. (Interview 3) To be able to get back to what life had been before the illness, they motivated themselves and began their rehabilitation by setting goals already at the hospital. This was a crucial part of their journey to come home. During the hospital stay, the information provided was scarce and didn't include individualized information about what to expect after discharge and in a long-term perspective. Many meant that this lack of information caused pondering and unnecessary suffering, thus leaving them mentally unprepared. *“...it was more about the information about what's coming or that it might be this way for a while. Or that it's going to feel this way and that that's normal...”. (Interview 5)* They also felt that an appointment after being discharged would have helped to minimize the sense of feeling left out. Only those who had been admitted to an ICU had a follow-up appointment scheduled at the hospital. *“I haven't had any follow-up from doctors or nurses, or any follow up regarding the sepsis itself at all...”. (Interview 4)*

3.2 New circumstances' impact on life

All participants talked about how their daily living changed after their sepsis episode and they all referred to various sequelae such as difficulties with short-term memory and increased sensitivity to stimuli.

Changed conditions in daily life

Fatigue is major factor affecting this patient group and they described it as complete exhaustion. The fatigue also had negative effects on their sensitivity and on being able to focus when reading or conversing and not being able to concentrate. *“...the brain doesn't work very well after sepsis... my short term memory is very bad. I forget things very easily...” (Interview 2)*

Almost all sepsis survivors described that they needed support at home and that it took an exceptionally long time until they became independent. *“... I couldn't handle everything on my own at that point... I couldn't handle quotidian tasks such as grocery shopping, cooking and cleaning...”. (Interview 7)* The participants also described difficulties with; pain, loss of appetite, sleeping problems, anxiety and difficulties in adapting to the new life conditions. Activities like showering, getting dressed and walking were a struggle. *“...Because I cry sometimes. I cry from the pain of walking, but still I think it's so lovely to be able to walk...”. (Interview 4)* Performing activities that required simultaneous abilities, such as driving a car, was perceived as challenging. Another problem described was the increased sensitivity to stimuli and impressions such as light and sound etc. This sensitivity triggered anxiety, discomfort and stress and caused nightmares and disturbed sleep. Such triggers could be sweating and heavy breathing which occurred during some kind of sport activity or while watching television, and they triggered an underlying memory from the time of the acute illness. They used the knowledge they already had to make strategies and learned how to deal with everyday life from the mistakes they made. The inner drive and motivation for reaching the goals they set pushed them onwards. They were not prepared for the recovery to take so long and this was perceived as mentally challenging.

Trying to manage and adapting to working life

Many of the participants described difficulties in coming back to their original form. Starting to work again was more difficult than they had expected. Fatigue and forgetting things became a clearer obstacle in this context. Others described losing confidence as they returned to work, despite having many years of experience and knowledge. *"...the first time was the worst of course, because I was all wired up, but I managed to do it and had to take a sedative pill before... I haven't felt that way before. Of course, you can be a little nervous, ... but I have never been close to a total collapse just because I was going to talk about something that I know so well..."*. (Interview 3) After the sepsis episode it was difficult to get fit and regain their former strength, despite working out. They felt as if the body wasn't ready for exercise and not being able to exercise properly was a huge disappointment. A physical sense of frailty persisted for some time and led to temporary removal or complete elimination of activities in their professional lives, but it also affected them at leisure. *"... I can't be on the frontline, it feels like they can just blow me away like that. I don't dare to."*(Interview 7)

3.3 Family and social interactions

All participants talked about how important family and friends were during the whole process, but also how it can feel to not be able to be the person you once were and that new priorities must prevail.

The importance of family and friends

The sepsis survivors described how happy they were about the support from family and friends. They helped with all sorts of things, from delivering food to the hospital, if needed, to be supportive but also by helping when health care staff didn't respond adequately. Family and friends created a sense of security *"I don't think I was able to identify it. I just knew that I could sleep when my boyfriend was there – then I could relax – but when he wasn't there I couldn't sleep. My boyfriend went on sick leave. He was with me all the time"*. (Interview 7) All sepsis survivors were able to see that their relationships with family and friends had changed and some even felt closer with their spouses after having sepsis. Many were disturbed by the fact that close relatives had to provide care but also to what extent they had to do so. They thought too much responsibility was placed on relatives. *"... I don't know what I would've done without my wife. She had to learn how to take care of my wounds and how to help me shower..."*. (Interview 4) *"... I live with my mom and dad, so they had to take a lot of responsibility..."*. (Interview 6) They explained that they, to some extent, had become a different person after sepsis and now had other priorities, which led to changed relationships with both family and friends.

Changes and new priorities in life

The participants found it difficult to relate to the new situation. For most survivors of sepsis, the desire to participate in social activities decreased. Partly because of difficulties in staying focused in conversation."

It was important for me to rest and it was very hard for the people in my surroundings to understand that I wanted to be alone, because I wasn't that way before the illness... Right after the illness I found it very hard to attend family reunions and such". (Interview 2) Unfortunately, they perceived others to have difficulties with this change. Being social took a lot of energy and decreasing social interactions was therefore necessary. This often led to feelings of guilt for not being able to help at home, attend family gatherings or visit friends. Keeping up the energy that life required was something that persisted and it had a major impact on the survivors. They thought it was sad to forgo nice activities with family and friends, or to cancel social events. This among other things made it more difficult to see the future in a positive way. It's easy to fall into a downward spiral with dark thoughts and feelings of hopelessness. Progress isn't as clear as failure. This also changed their outlook on life and what they considered to be important, which was difficult for family and friends to understand, sometimes leading to irritation for both parties.

3.4 The psychological impact on life

Many described sepsis as a physical illness and wasn't prepared for the mental part – how to cope and regain their life. They had never heard or believed that sepsis could have any impact on their mental well-being.

Changed state of mind

All sepsis survivors described a lack of patience due to the constant and sometimes big setbacks and how difficult they were to overcome. It took very long before they saw any progress, which had a negative impact on their patience. Sepsis was to them known as a physical illness and the participants were never given any information about how it could have a major impact on their mental well-being, how to cope and how to regain control of their lives. The participants said it took time before they realized how critically ill they had been. As they were able to handle more and more in their life, by themselves, the memories regarding how seriously ill they had been, along with memories from the time they had spent in the hospital came back. *"...and I've taken back more of my life than predicted. My wife said that she never thought I'd get as well as I am now, but then again it was very bad at first, a year ago I mean". (interview 8)* The trauma of being close to death initially created feelings of gratitude and euphoria, having survived, but it later switched into discomfort and anxiety. Going through sepsis had a huge negative impact on their mental status. All the sepsis survivors described great agony and a lot of pondering on what happened or what could have happened. After a trauma comes shock and for some this occurred already before being discharged from the hospital, for others at home. *"...since the doctors said that they didn't know if I'd survive sepsis or not, I even planned my own funeral when they told me...". (Interview 6)*

To start processing and reach reconciliation

The trauma was processed in different ways, for example by; writing a diary, reading their hospital records, meeting other survivors – all to understand what they had gone through, but the healing process of the

trauma of 'being close to death' took a very long time. Exaggerated thinking about what could have happened was also common. For some of them, there was a huge fear of regaining sepsis and becoming critically ill again. A small symptom they recognized from the time of the illness could create a great sense of fear. They even described being a little hypochondriac. *"I'm not a hypochondriac really, but one gets a bit worried. You need to use hand sanitizer all the time and you be more careful. Like, generally you have to be more careful".* (Interview 2) Some wanted to get help from a psychologist connected to the general healthcare services accepted by the Swedish Insurance Fund, so they could afford it, but it wasn't easy to get that help on their own. After processing the trauma and reaching a certain acceptance, they were able to accept that they had been critically ill. All participants talked about the tough times they had gone through and about the tremendous effort required to be able to process the fact that they had been critically ill. Life after discharge was fraught with adversity and trying to get back to a normal everyday life which was a constant struggle. One of the hardest things was to keep up, being hopeful and to look ahead. *"...the psychological part and how it can affect you... I feel that it's a physical illness when I get an infection, when I'm in pain and everything hurts... but... it can really mess with your head as well. I wasn't prepared for that. I wasn't prepared for sepsis at all, I guess, but I was especially not prepared for the aftermath of it".* (Interview 3)

4. Discussion

The sepsis survivors described that the psychological and cognitive impairment with remaining fatigue, lack of concentration, loss of short-term memory, pondering and depression was the worst. Feelings of sadness and depression occurred when the sepsis survivors tried to process the trauma of having been close to death.

4.1 Life after critical illness

Many of the participants experienced a depersonalization, almost like they had become a different person in some situations, which had a negative impact on both family and other social relations. The change was due to the need for rest and tranquility. Much responsibility lays with family and relatives after discharge from the hospital, sometimes with shifted roles. For instance, partners became an informal caregiver when critically ill patients were released from the hospital and the ICU, especially during the first year, [29] and the same was found in this study. Most of the sepsis survivors started to work only a few months after discharge, but setbacks were common and took a lot of energy. Some described it as a loss of self-confidence and an overall frailty of the body. It seemed difficult to get back to the professional role at work. Mainly due to the psychological and cognitive disabilities but also due to being tired, so new priorities in life were required. The same findings are described in other studies [20, 30] for people over 65 years, however many of the sepsis survivors in this study suffered from the same consequences although the oldest participant was only 58 years old.

Sepsis is comparable to other critical illnesses [22], for example stroke, and according to the recommendations for stroke patients, the general health care services should offer multidisciplinary stroke teams for coordinating discharge and follow-up [23]. Teams like this have a positive impact on the

outcome. The sepsis survivors could benefit greatly from a similar program designed for sepsis with a solid plan for their recovery, based on their motivation. Interventions to help recover from critical illness are likely to affect areas such as physical function and social ability, especially during the first year after hospital discharge. [31].

4.2 Questions need answers

Studies talk about the need to feel secure during and after severe illness and how trust between healthcare professionals and patients must be established for this feeling to exist. To be able to do so, healthcare professionals should be supportive, responsive to the patients' needs and they need to empower them [32]. Some of the participants in this study described that they received some information about what to expect after discharge. However, memories from this period were fragmented and therefore the participants had difficulties sorting out what really had happened and as well as their uncertainties about the future. It's possible to assume that some of the participants received information, at least to some extent, but the information was not individually adapted to the sepsis survivors. It probably had an impact on how well the information could be understood, which is an important aspect to take into account when giving someone information. How receptive an individual is to information and how well it can be understood plays a major role [33]. In addition, many described problems with their memory, which may have affected the perception of the information. Even years after their critical illness, the participants wanted information to fill in the missing gaps. They tried to create meaning from both fragmented and scary memories during the recovery, all while wanting to return to a normal life [34]. Previous research shows that during the whole recovery process, patients need a lot of care and support to create existential meaning [35]. Therefore, it's reasonable to believe that sepsis survivors would have benefited from an appointment after discharge with a deeper and clearer information about the hospital stay and what to expect further on.

4.3 The psychological impact on life

Individuals exposed to imminent life threats are at high risk of developing mental illness [33]. Life-threatening events such as being critically ill or near death can cause psychological trauma. A study [36] showed a correlation between the presence of psychological disorders and poor QOL. They also found an association between domains of QOL and various types of psychological complications post-ICU, such as symptoms of post-traumatic stress disorders (PTSD) with anxiety and depression [36]. PTSD is common after critical illness and occurs in between 10–30% of survivors after discharge [37]. The participants in this study also experienced a new sensitivity to various symptoms such as heavy breathing and sweating, which triggered the underlying memory of being seriously ill, this created feelings of great discomfort. Researchers [19, 20] believe that many who survived sepsis are discharged from the hospital with a new, undefined combination of cognitive impairment and physical disability that could explain the deterioration in their HRQOL [19, 20]. It's reasonable to assume that the sepsis survivors in this phase are in some type of crisis. Almost all the sepsis survivors described that not knowing what to expect after discharge was mentally challenging. The fact that it took so long to achieve even the smallest of progress was unexpected and surprising. Previous research [34] found that patients struggled more than two years after discharge with existential reconciliation. To prevent psychological problems after discharge, research shows that during the hospital stay increased communication is beneficial [38] and therefore an important

issue. The participants in this study experienced that they were left alone to cope with the consequences after returning home. Previous research has been focused on critically ill patients post ICU [39, 35, 30, 40–42], however all of the sepsis survivors in this study, post ICU or not, describe similar symptoms of sequelae. In light of the fact that much is unknown about PTSD in connection with the survival of critical illness, the dynamics of recovering physically and psychologically are important factors to consider when planning the care for the sepsis patients [43, 44]. Many in this study expressed that professional help should have been offered in order to deal with this psychological trauma.

4.5 Methodological considerations

A qualitative interview study was selected to elucidate the experiences of sepsis survivors with inspiration of Burnard [26]. Some of the participants were interviewed in person and others by telephone. No differences were found between the interview methods in regard to depth in the material. According to Burnard, [27], interviewing over the telephone gives the participant opportunity to feel anonymous, which can provide a sense of security, since the face was not shown. Other benefits are that there is no geographical limitation. A disadvantage with telephone interviewing could be the risk of missing out on underlying meanings of what was said, because facial expressions and gestures couldn't be observed [27]. However, the author of this study believes that by listening closely to the voice and emotional utterances, it was possible to get similar information from the interviews made by telephone. By using a robust analysis method with clear steps and a well-substantiated category system, the researcher stays true to the participants' intentions for the purpose of validating data. It also increases the opportunity for replication by other researchers [26, 27]. The author and the co-authors discussed and reflected on the material in the study throughout the process. Categorization was done based on giving the narratives and the participants' experiences fairness. The co-authors provided valuable insights during this process.

4.6 Study limitations

The study has some limitations. Firstly, only Swedish speakers participated, therefore no cultural aspects have been considered. The choice of the time aspect for inclusion in the study was that it should not be too close to the sepsis episode, to minimize discomfort, but not too distant either in order for the participant to easier relate their experience to the actual sepsis episode and not to what had happened in general. The reason for the age limit of 65 years is that studies [20, 45], have shown that sepsis survivors over 65 years have a very high tendency to get residual symptoms after surviving sepsis, for example they tend to need help with activities of daily living (ADL), they can rarely move home again after been discharged from the hospital and those who work are less likely to return to their work place. Another limitation of this study could be that the participants were recruited from the same closed web forum: the "Sepsis forum", where all sepsis survivors are willing to share their story. They could therefore be considered as a selected group of outspoken people who dared to share their experience and to make their voice heard, and not as representatives for all sepsis survivors. However, the benefit with this sampling method is that more and more persons can be included, within a certain timeframe, until enough material was obtained.

5. Conclusions

Sepsis has a huge impact on all aspects of life, both physical and mental. Many suffer from persistent residual symptoms of varying degrees and varying extent to which they have to adapt. The sepsis survivors need information about what to expect during and after the hospital stay and it has to be individually adjusted depending on what state they are in. Therefore, a multidisciplinary team around them are needed for decisions about care, rehabilitation, review of the sepsis episode and follow-up. Further research needs to be done to understand the impact of PTSD and what sepsis survivors may need, regardless of intensive care or not, to be able to return to a life as normal as possible

Declarations

Ethics approval and consent to participate

Ethical approval was obtained (2019-00001) by The Swedish Ethical Review Authority. All participants signed a consent to participate before each interview.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on request.

Competing interests

The authors declare that they have no competing interests" in this section.

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Authors' contributions

SA collected, analyzed and interpreted the data and wrote the manuscript. AKL was an initiator of the study, collected data and wrote the manuscript. LL wrote and had intellectual input in the manuscript. AL was an initiator of the study, help collecting data and wrote the manuscript.

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Figures

Figure 1

Model over categories