



A Qualitative Investigation of Patients' and Caregivers' Experiences of Severe Sepsis*

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Objectives: To explore and describe the subjective experiences and long-term impact of severe sepsis on survivors of severe sepsis and their informal caregivers (e.g., spouse or family member) through qualitative research methods.

Design: A qualitative exploratory study using semi-structured interviews with survivors of severe sepsis and their informal caregivers in the United Kingdom and United States. Participants also completed a demographic background form and sites provided medical history details. Transcripts were analyzed using a thematic analysis approach.

Setting: Patients were recruited from a large National Health Service hospital in the United Kingdom and a level 1 trauma center hospital in

the United States. Caregivers were recruited through eligible patients. Interviews were conducted either face to face in participant's homes or another convenient location or over the telephone.

Patients: Patients who were 18 years old or older and had experienced an episode of severe sepsis in the previous 12 months were recruited by clinical staff in each hospital. Caregivers were family members or friends who had provided informal care for the patient after their episode of severe sepsis.

Interventions: None.

Measurements and Main Results: Thirty-nine interviews were conducted with 22 patients and 17 informal caregivers (of these 28 were conducted face-to-face and 11 by telephone). Five main themes were identified in the qualitative analysis: awareness and knowledge of severe sepsis; experience of hospitalization, ongoing impact of severe sepsis; impact on caregivers; and support after severe sepsis. Experiences varied depending on the patients' health prior to the severe sepsis, with the worst affected reporting lasting impacts on multiple aspects of their life.

Conclusions: The study extends what was understood about severe sepsis from the patients' and caregivers' perspectives from the previous limited literature. Caregivers as well as patients reported enduring impact. The study also identified problems of lack of awareness of diagnosis and understanding of severe sepsis by patients and caregivers and difficulties accessing appropriate healthcare providers and ancillary services after discharge from hospital. (*Crit Care Med* 2015; 43:296–307)

Key Words: caregivers; health-related quality of life; interviews; patients; qualitative research; severe sepsis

*See also p. 479.

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Severe sepsis is a life-threatening condition, defined by the presence of acute organ dysfunction secondary to infection (1, 2), with treatment normally requiring admission to an ICU (3). Previous research has been criticized for focusing only on short-term survival in severe sepsis (4), more recent research has identified that those surviving severe sepsis face long-term physical and psychological sequelae including cognitive impairment, functional disability (5, 6), critical illness muscle weakness (5, 7), delirium (8), dyspnea, and fatigue associated with residual organ dysfunction (9). Many patients

will experience “postintensive care syndrome,” which includes new or worsening function in cognition, mental health, or physical function (10). Many severe sepsis survivors demonstrate a marked deterioration in health-related quality of life (HRQL) from time of admission to ICU, with only gradual and incomplete improvement at 3–12 months postdischarge (5, 11), decrements continuing to be recorded at 5-year postdischarge (12), and HRQL rarely returning to preadmission levels (13). The majority of survivors are unable to return to work due to these impairments (14), with resulting loss of income placing additional economic burden on the survivor and their families.

Severe sepsis survivors require a considerable amount of care, especially on discharge from hospital. There is limited evidence of the impact of severe sepsis survival on caregivers; a previous study of caregivers of ICU survivors, which included a proportion of patients with severe sepsis, found that more than 70% of caregivers spent over 40 hours per week in the caring role (15), and reported burden, such as feeling that their life would be different if they did not have to care for someone, missing out on life because of having to care for someone, and wanting to escape from their situation as a caregiver.

Previous research has provided some evidence of the impact severe sepsis has for survivors and caregivers; there is a lack of experiential evidence to provide more detailed understanding although studies that reported more generally on critical illness survival were identified (16, 17). The potential of qualitative research to gain further insight in severe sepsis has been acknowledged (15). This study aimed to further develop understanding of the impact of severe sepsis on patients and their informal caregivers through qualitative research with survivors of sepsis and their informal caregivers from the United States and United Kingdom.

MATERIALS AND METHODS

Study Design

Qualitative research methods were used to explore HRQL in survivors of severe sepsis and the impact on informal caregivers in the United States and United Kingdom. Data were collected by semi-structured interview with severe sepsis survivors and their caregivers. Patients and caregivers were interviewed in order to develop a broader understanding of the impact of severe sepsis. The study was conducted in the United Kingdom and United States to allow for a comparison of the experience of severe sepsis between the countries. The study was approved by Schulman Associates IRB (<http://www.sairb.com>) (United Kingdom), the Independent Investigational Review Board (<http://www.iirb.com>, United States), and the University of Alabama at Birmingham (UAB) Hospital Institutional Review Board (United States). Written informed consent was taken prior to data collection.

Patients were recruited through St Thomas’ hospital (United Kingdom) and the University of Alabama at Birmingham Hospital (United States). St Thomas’ hospital is a large NHS hospital in London, United Kingdom, which is a part of Guy’s

& St Thomas’ NHS Foundation Trust. The hospital provides a full range of services for local residents as well as specialist services for patients from across London, South East, and further afield. UAB hospital is a level 1 trauma center hospital located in Birmingham, Alabama, United States, that provides a complete range of primary and specialty care services. It is the major tertiary care center in Alabama, serving approximately 35,000 patients annually. Clinical ICU staff at each site reviewed patient records postdischarge to identify patients at least 18 years old who had experienced a severe sepsis episode (defined as presence of infection, systemic inflammatory response syndrome, and at least one organ failure) in the previous 12 months and had been cared for in the ICU. This definition was based on published criteria (1, 2) and clinical review by specialists at participating sites. Recruiting patients who had experienced severe sepsis up to 12 months ago allowed the long-term impacts to be captured. The following patients were excluded: lack of local language fluency, traumatic brain injury, preexisting cognitive disorder, moribund status, and currently participating in a clinical trial for severe sepsis. The exclusion criteria were designed to ensure that those recruited would be able to engage in the interview. Caregivers were recruited through eligible patients. Each recruiting site aimed for diversity in terms of patients’ age and the number of organ failures experienced.

Data Collection

Interviews were conducted by experienced qualitative researchers following semi-structured patient or caregiver interview guides. Where possible, interviews were conducted face to face, telephone interviews took place if was more convenient for the participant. Interviews lasted up to 1 hour and were audiorecorded and transcribed verbatim for analysis. Although questions were asked initially about “severe sepsis,” interviewers then adapted their questions to refer to terminology used by the participants, for example, their type of infection (e.g., pneumonia and blood poisoning) or their time in hospital or ICU. Patients provided sociodemographic data on a structured form and completed two validated general health questionnaires, the EQ-5D (18) and the Hospital Anxiety and Depression Scale (HADS) (19). EQ-5D utility scores range from 0 (representing dead) to 1 (representing full health) (18). HADS scores greater than or equal to 8 are considered suggestive of anxiety or depressive disorders (20). A medical history form was completed by site staff from patient’s hospital records (Appendix, Supplemental Digital Content 1, <http://links.lww.com/CCM/B51>).

Analysis

Qualitative analysis was conducted on the interview transcripts using thematic analysis (21), which uses inductive and deductive coding to identify, analyze, and report patterns (themes) across a dataset. Four researchers were involved in the analysis (K.H.G., C.E.P.K., A.N., L.V.); the lead analyst (K.H.G.) worked through each transcript (assisted by qualitative analysis software Atlas.ti v5.5) to code aspects that may form the bases of

repeated patterns (themes), coding and potential themes were then discussed in analytic meetings.

A small number of patients who reported being generally healthy before the onset of sepsis without prior experience of serious illness offered the clearest picture of the experience and impact of severe sepsis. Data for this subsample of patients (and their caregivers) were analyzed first to aid interpretation of experiences and impacts discussed by those who experienced severe sepsis in more complex illness contexts and who may be less able to describe experiences and impacts of severe sepsis.

As part of the qualitative analysis process, the adequacy of the data was considered, in particular whether saturation had been achieved within the interviews conducted (22). A saturation table (23) showed that no new codes were identified in the last four interviews, and codes that were added toward the end of the coding process were subthemes providing additional detail and definition of existing theme content. This combined with a collective judgment by the analysis team during coding review that there was sufficient depth in the analysis supports a conclusion that at least a certain level of thematic saturation was achieved within the interview sample. However, with such variation in experiences reported in the context of a condition where so little has previously been explored from a patient or carer perspective, a firm conclusion of achievement of saturation was hard to confirm.

RESULTS

Participants

Thirty-nine interviews were conducted: 22 patients (United Kingdom, 13; United States, 9) and 17 informal caregivers of these patients (United Kingdom, 10; United States, 7). The majority of interviews were conducted face-to-face (17 out of 22 patient interviews and 11 out of 17 caregiver interviews were conducted face-to-face). Background information for participants are presented in **Tables 1** and **2** (patients) (caregivers), and clinical details are presented in **Table 3** (patients). Participants in the United Kingdom and the United States were of similar age on average; fewer male patients were interviewed in the United States than the United Kingdom; all U.S. patients had chronic health problems, and on average, U.S. patients reported worse HRQL (EQ-5D utility) as well as higher levels of anxiety and depression. Mean Acute Physiology and Chronic Health Evaluation (APACHE) II and Sequential Organ Failure Assessment (SOFA) scores recorded on the first day in ICU were higher in the U.S. patient sample, indicating on average comparatively greater severity, risk of death, and organ dysfunction in U.S. participants than participating U.K. patients. However, the U.K. patients were treated longer in ICU and stayed considerably longer in hospital after leaving ICU care.

Participant Experiences

Patients' health before experiencing severe sepsis varied widely, including some patients who were relatively healthy before suddenly developing severe sepsis, patients with significant preexisting health problems, and/or patients originally

admitted to hospital for major surgery who then developed severe sepsis. This was reflected in the wide variation in experiences reported, with those who had previously been healthy less likely to be experiencing significant ongoing impairments. The context within which severe sepsis was experienced was more of an indication of ongoing impacts than clinical markers of severity such as the number of organ failures or APACHE and SOFA scores.

Five main themes were identified in the qualitative analysis of participant experiences: awareness and knowledge of severe sepsis; experience of hospitalization; ongoing impact of severe sepsis; impact on caregivers; and support after severe sepsis. These themes are summarized below, with illustrative quotations provided in **Tables 4–8**.

Awareness and Knowledge of Severe Sepsis

The level of awareness of severe sepsis as a diagnosis the patient had received varied greatly among patients and caregivers, as did the level of understanding of severe sepsis. Several patients and caregivers (USP03; USC02; UKP02; UKC02; UKP05; UKC05; USP07; USP09; UKP06) were even unaware that they had been given a diagnosis of severe sepsis until being invited to take part in the research which caused difficulties with attributing their experiences to severe sepsis specifically. Some were vaguely aware that the term "sepsis" had been used at some point but did not actively seek further information at the time (USP01; UKC05; UKP17; UKP06). One patient (UKP04) had not been told about the diagnosis by their caregiver as they did not want to scare them. In general, there was a lack of understanding of severe sepsis. Two U.K. caregivers (UKC04; UKC03a) mentioned that all they knew about sepsis previously was that it could be fatal; therefore were shocked by the diagnosis. A small number of participants reported that they sought further information about severe sepsis (USP04; UKC04; USC05).

Although patients may not have been aware of their severe sepsis diagnosis or known what it was, all were aware that their illness had been life threatening. Caregivers discussed being told about the patient's chance of survival, and being warned that they may not survive, and some caregivers and patients recalled friends and family being called to the hospital to see them for the last time (USC06; UKP17).

Experience of Hospitalization

Recollections of waking up in intensive care varied greatly. Some described it as feeling as though they were having a bad or weird dream, or feeling like they were in "slow motion" (UKP17), others reported "drifting in and out" of consciousness (UKP03) or not knowing where they were or why they were in hospital. Other participants commented that they had missed days of their life as they did not remember anything of that time. Several patients reported experiencing strange dreams, hallucinations, and/or paranoia when they regained consciousness (UKP04; UKP07; UKP08; USP07). For caregivers, these experiences caused distress and concerns about possible lasting brain damage or personality changes.

TABLE 1. Sociodemographic Characteristics (Patient Reported)

Participant Characteristic	United Kingdom (n = 13)	United States (n = 9)	Overall (n = 22)
Age at interview			
Mean (SD)	56 (17.31)	57 (11.18)	56.01 (15.12)
Range	25–79	38–75	25–79
Gender (%)			
Male	6 (46.2)	2 (22.2)	8 (36.4)
Female	7 (53.8)	7 (77.8)	14 (63.6)
Education (%)			
Did not complete high school/left school with no qualifications	3 (23.1)	1 (11.1)	4 (18.2)
High school/left school with qualifications	2 (15.4)	5 (55.6)	7 (31.8)
Some college/further qualifications	2 (15.4)	1 (11.1)	3 (13.6)
University level	6 (46.2)	2 (22.2)	8 (36.4)
Ethnic background (%)			
White	10 (76.9)	5 (55.6)	15 (68.2)
Black/Black Caribbean	1 (7.7)	4 (44.4)	5 (22.7)
Asian	1 (7.7)	0 (0.0)	1 (4.5)
Nepalese	1 (7.7)	0 (0.0)	1 (4.5)
Main activity (%)			
Employed full-time	1 (7.7)	1 (11.1)	2 (9.1)
Employed part-time	2 (15.4)	0 (0.0)	2 (9.1)
Retired	5 (38.5)	1 (11.1)	6 (27.3)
Looking after home	1 (7.7)	0 (0.0)	1 (4.5)
Temporarily unable to work	2 (15.4)	1 (11.1)	3 (13.6)
Permanently unable to work	2 (15.4)	6 (66.7)	8 (36.4)
Relationship status (%)			
Married	6 (46.2)	2 (22.2)	8 (36.4)
Partnership	2 (15.4)	0 (0.0)	2 (9.1)
Single	2 (15.4)	5 (55.6)	7 (31.8)
Divorced	2 (15.4)	1 (11.1)	3 (13.6)
Widowed	1 (7.7)	1 (11.1)	2 (9.1)
Chronic health problems (%)			
Yes	10 (76.9)	9 (100.0)	19 (86.4)
No	3 (23.1)	0 (0.0)	3 (13.6)
Living situation (%)			
Prior to sepsis: Home	13 (100.0)	9 (100.0)	22 (100)
At time of interview			
Home	12 (92.3)	6 (66.7)	18 (81.8)
With relatives	0 (0.0)	3 (33.3)	3 (13.6)
Other	1 (7.7)	0 (0.0)	1 (4.5)
EQ-5D utility			
Mean (SD)	0.57 (0.41)	0.40 (0.27)	0.49 (0.36)
Hospital Anxiety and Depression Scale (SD)			
Anxiety mean	7.38 (4.73)	9.56 (3.20)	8.27 (4.31)
Depression mean	7.38 (5.24)	8.33 (3.43)	7.77 (4.61)

TABLE 2. Sociodemographic Characteristics (Caregiver Reported)

Participant Characteristic	United Kingdom (n = 10)	United States (n = 7)	Overall (n = 17)
Age at interview			
Mean (SD)	58 (14.10)	58 (12.90)	57.74 (13.62)
Range	36–80	32–76	32–80
Gender (%)			
Male	6 (60.0)	2 (28.6)	8 (47.1)
Female	4 (40.0)	5 (71.4)	9 (52.9)
Education (%)			
Did not complete high school/left school with no qualifications	5 (50.0)	3 (42.9)	8 (47.1)
High school/left school with qualifications	1 (10.0)	2 (28.6)	3 (17.6)
Some college/further qualifications	0 (0.0)	1 (14.3)	1 (5.9)
University level	4 (40.0)	1 (14.3)	5 (29.4)
Ethnic background (%)			
White	8 (80.0)	4 (57.1)	12 (70.6)
Black/Black Caribbean	1 (10.0)	3 (42.9)	4 (23.5)
Nepalese	1 (10.0)	0 (0.0)	1 (5.9)
Main activity (%)			
Employed full-time	2 (20.0)	0 (0.0)	2 (11.8)
Employed part-time	2 (20.0)	1 (14.3)	3 (17.6)
Retired	3 (30.0)	3 (42.9)	6 (35.3)
Looking after home	2 (20.0)	3 (42.9)	5 (29.4)
Student	1 (10.0)	0 (0.0)	1 (5.9)
Relationship status (%)			
Married	8 (80.0)	5 (71.4)	13 (76.5)
Partnership	2 (20.0)	0 (0.0)	2 (11.8)
Single	0 (0.0)	1 (14.3)	1 (5.9)
Widowed	0 (0.0)	1 (14.3)	1 (5.9)
Relationship to patient (%)			
Spouse/partner	8 (80.0)	1 (14.3)	9 (52.9)
Parent	2 (20.0)	1 (14.3)	3 (17.6)
Child	0 (0.0)	2 (28.6)	2 (11.8)
Sibling	0 (0.0)	1 (14.3)	1 (5.9)
Aunt	0 (0.0)	1 (14.3)	1 (5.9)
Partner's mother	0 (0.0)	1 (14.3)	1 (5.9)
Chronic health problems (%)			
Yes	2 (20.0)	4 (57.1)	6 (35.3)
No	8 (80.0)	3 (42.9)	11 (64.7)
EQ-5D utility			
Mean (SD)	0.90 (0.12)	0.72 (0.15)	0.82 (0.16)
Hospital Anxiety and Depression Scale (SD)			
Anxiety mean	5.11 (3.20)	9.00 (3.89)	7.35 (4.07)
Depression mean	3.11 (4.61)	7.00 (5.07)	4.59 (5.11)

TABLE 3. Severe Sepsis Patients: Clinical Details (From Medical Records at Treating Hospital Sites)

Participant Clinical Characteristic	United Kingdom (n = 13)	United States (n = 9)	Overall (n = 22)
No. of organ dysfunctions (%)			
1	3 (23.1)	3 (33.3)	6 (27.3)
2	4 (30.8)	1 (11.1)	5 (22.7)
3	4 (30.8)	3 (33.3)	7 (31.8)
4	2 (15.4)	2 (22.2)	4 (18.2)
Residual organ dysfunction (%)			
Yes	4 (30.8)	5 (55.6)	9 (40.9)
No	6 (46.2)	4 (44.4)	10 (45.5)
Missing	3 (23.1)	0 (0.0)	3 (13.6)
Acute Physiology and Chronic Health Evaluation II score ^a			
Mean (SD)	19.15 (5.76)	27.22 (10.02)	22.45 (8.74)
Range	10–29	12–46	10–46
Sequential Organ Failure Assessment score ^b (day 1 in ICU)			
Mean (SD)	7.92 (3.67)	9.89 (4.79)	8.73 (4.28)
Range	3–12	2–18	2–18
Location of infection ^c (%)			
Pulmonary	9 (69.2)	6 (66.7)	15 (68.2)
Urinary tract	0 (0.0)	1 (11.1)	1 (4.5)
Abdominal compartment	3 (23.1)	0 (0.0)	3 (13.6)
Vascular infections	3 (23.1)	0 (0.0)	3 (13.6)
Other ^d	1 (7.7)	0 (0.0)	1 (4.5)
Not applicable or unknown	0 (0.0)	2 (22.2)	2 (9.1)
Infecting agent (%)			
Gram-negative organisms ^e	8 (61.5)	3 (33.3)	11 (0)
Gram-positive organisms ^f	0 (0.0)	3 (33.3)	3 (13.6)
Disseminated fungal infections ^g	1 (7.7)	1 (11.1)	2 (9.1)
H1N1 influenza A	2 (15.4)	0 (0.0)	2 (9.1)
None isolated/unknown	2 (15.4)	3 (33.3)	5 (22.7)
Length of hospital stay			
No. of days in ICU			
Mean (SD)	9.54 (5.30)	7.78 (7.51)	8.82 (6.36)
Range	3–19	1–27	1–27
No. of other hospitalized days			
Mean (SD)	34.31 (29.66)	10.56 (9.27)	24.59 (26.29)
Range	3–91	2–30	2–91
Primary admitting service (%)			
Medicine	10 (76.9)	9 (100.0)	19 (86.4)
Surgery	3 (23.1)	0 (0)	3 (13.6)

(Continued)

TABLE 3. (Continued). Severe Sepsis Patients: Clinical Details (From Medical Records at Treating Hospital Sites)

	United Kingdom (n = 13)	United States (n = 9)	Overall (n = 22)
ICU admission source (%)			
Emergency department	5 (38.5)	7 (77.8)	12 (54.5)
Transfer from outside hospital	2 (15.4)	2 (22.2)	4 (18.2)
Hospital ward	6 (46.2)	0 (0.0)	6 (27.3)
Time since discharge (mo) at time of interview ^b			
Mean (SD)		6.99 (2.35)	
Range		4–11	
Discharge disposition (%)			
Home independent	6 (46.2)	2 (22.2)	8 (36.4)
Home with paid care	0 (0.0)	3 (33.3)	3 (13.6)
Rehabilitation facility	2 (15.4)	1 (11.1)	3 (13.6)
Home other (unsure of level of support)	5 (38.5)	3 (33.3)	8 (36.4)

^aAn ICU scoring system applied within 24 hr of a patient's admission to an ICU. The score is based on several measurements and can range from 0 to 71. Higher scores indicate greater severity and increased risk of death.

^bAn ICU scoring system to determine the extent of a person's organ function or rate of failure. Sequential Organ Failure Assessment (SOFA) is based on an assessment of six organs. SOFA can range from 0 to 24, with a higher score indicating more organ dysfunction.

^cSome participants had infection in multiple locations.

^dBlood.

^e*Escherichia coli*, *Pseudomonas aeruginosa*, *Klebsiella*, *Proteus mirabilis*, *Enterobacter aerogenes* in blood, and *Neisseria meningitidis*.

^f*Streptococcus viridans*, *Streptococcus pneumoniae*, and *Enterococcus cloacae*.

^gFungal histoplasmosis and *Candida albicans*.

^hData not available for U.K. patients (ethics approval restrictions).

TABLE 4. Awareness and Knowledge of Severe Sepsis

Awareness and Knowledge of Severe Sepsis	Example Quotations
Some patients and caregivers were unaware of the severe sepsis diagnosis	"Well, since I never knew I had it and was never given any discussion about what causes it, how—what the symptoms are, what the cures are, I—impossible for me to answer that." (USP03; age 75; male; 1 organ dysfunction) ^a
Vaguely aware but did not actively seek further information	"No, I think—well, until you said, I didn't even realise they classed it—the PCP as being sepsis but I do remember them thinking that you were in sepsis prior to deciding that you'd got a breathing problem (...) the knowledge as a carer or as a next of kin when they're in Intensive Care, it's a bad enough time as it is but, (...) sometimes things are moving faster than you realise, and really understanding what's going on." (UKC05; age 38; male; patient's partner)
Family did not tell patient about severe sepsis diagnosis	"nobody actually came and told me I had sepsis. (...) And I think even [partner's name] didn't want to tell me because he didn't want to make me afraid. (...) So the truth is I don't really know." (UKP04; age 60; female; 2 organ dysfunctions)
Aware sepsis can be fatal	"And then later on it was sepsis that was said, so that's why I knew I didn't know much about that except that you could die from it, you know, and so it was kind of shocking" (UKC04; age 60; male; patient's partner)
Lack of understanding of severe sepsis	"I'm not quite sure what the sepsis (...) So after they gave me a piece of paper with a long list of things they said was wrong with me. I remember asking [boyfriend's name], you know, 'What's this?' and he said he didn't know either, but there was so much going on and they could have told it then and we didn't recognize it." (USP01; age 38; female; 3 organ dysfunctions)
Chance of survival	"And then my daughter called me and told me that he'd called all the family in, that they weren't giving her no chance." (USC06; female; age 76; patient's mother)

^aParticipant ID codes indicate whether the participant is from the United Kingdom or the United States and whether it is a patient ("P") or a caregiver ("C"), caregivers have the same number as the patient they cared for, for example, UKC01 was a caregiver for UKP01. Where two caregivers were interviewed for one patient, they were given the same number and distinguished with an additional "a" or "b." Additional information (age, gender, number of organ dysfunctions for patients, and relationship to patient for caregivers) is provided with each illustrative quotation.

TABLE 5. Experience of Hospitalization

Experience of Hospitalization	Example Quotations
Patients missed days while they were unconscious	"it's like you missed 30 days of your life. I woke up and my cousin's little girls were bigger and [name] had graduated from Elementary (...) to Junior High (...) so you just missed out on stuff." (USP01; age 38; female; 3 organ dysfunctions)
Patient experience of hallucinations when waking up in intensive care	"I was hallucinating a lot and I had this feeling that I was being abducted by the aliens and I was taken in a spacecraft to another planet. And all the time I was thinking now that I've been taken to a different planet, I have to find a way to escape from there, so, I was plotting ways to get out of the planet" (UKP08; age 61; male; 4 organ dysfunctions)
Caregivers' experience when patient is hallucinating	"having been married 30 years you can tell (...) he looked at me rather coldly on the first few occasions once he was conscious again and I just knew there wasn't something quite right. And it transpires that he thought that I too was an alien and that I've done my homework and knew a lot about the family, and on one occasion he said to me, 'Oh, you're not my (caregiver's name), you're an impostor,' (...) I was so, so upset because you're so desperate for your loved one to survive and be okay, (...) I was very frightened for a couple of days that he might've incurred some brain damage." (UKC08; age 58; female; patient's wife)
Frightening and worrying time for caregivers	"I mean, I was just—you know, like I said, she means everything to me, you know, it was just—not only a worry, it was just heartbreaking to see her that way" (USC08; age 55; male; patient's husband)
Hearing other families receive bad news about a patient	"for a split second it took me, if I was in their shoes, and I didn't want to be there." (UKC01; age 56; female; patient's mother)

TABLE 6. Ongoing Impact of Severe Sepsis

Ongoing Impact of Severe Sepsis	Example Quotations
Ongoing impairments causing problems with self-care	"I think when I got up I could barely bathe myself, first of all. My daughter helped me to bathe myself because I think I mostly stayed in the bed." (USP07; age 42; female; 3 organ dysfunctions)
Feeling like a burden to family members or friends	"I mean, my dad's 64, my mum's 61, they've only just retired, but if I need—like the commode during the day or where the pores are leaking fluid on my legs, I have to get them to come down, hoist me up, change the pad, hoist me back down, so it's putting a lot of strain on them because they're tied now to me. They can't go and plan a day out unless me husband's off." (UKP03; age 42; female; 3 organ dysfunctions)
Loss of independence	"My life has changed in every aspect because I can—I no longer can rely on myself. I have to rely on others and that's the biggest thing in the world. (...) It makes me feel bad, really bad." (USP02; age 63; female; 1 organ dysfunction)
Emotional impact: fear of sepsis recurrence	"I do get panic attacks like, you know, when I'm driving I feel, oh, I'm going to get this sepsis again and what am I—what can I do if I do and that's—invariably that affects my thinking and worries about things, but it suddenly—a few minutes later it goes away." (UKP08; age 61; male; 4 organ dysfunctions)

TABLE 7. Impact on Caregivers

Impact on Caregivers	Example Quotations
Coping with complex medication regimes	"Well, it's the amount of medication he had to take, I think. I think mealtime was quite—I wouldn't use the word stressful, but needed to be on time. You need to take the medication on time and with food, and that sort of stuff, so I think my day was centred around him." (UKC01; age 56; female; patient's mother)
Days revolve around the patient's needs	"It's just like having a newborn baby. You've just got to get - all her wants and needs I have to take care of, (...) I've got to fix her meals, you know, I have to give her a bath. If she's got to go to the bathroom or take a shower and get dressed, you know, and I have to, you know, like everything basically a woman normally does, is not supposed to do but, you know, normally does, you know, is left up to me now, you know, from cooking, cleaning, the washing, you know?" (USC08; age 55; male; patient's husband)
Emotional impact on caregivers	"Well, it kind of—I'm kind of glad she's here, but then some days I be so tired or some days, you know, I'm doing I just—sometimes I just wish somebody else would come and get her and take her off my hands... Every day I feel guilty about saying that because it's my mom, you know what I mean?" (USC05; age 52; female; patient's daughter)

TABLE 8. Support After Severe Sepsis

Support After Severe Sepsis	Example Quotations
Lack of information about severe sepsis and what to expect during recovery	"They didn't tell me. They didn't warn me what to look for. They didn't warn me of what. They didn't even tell me nothing about sepsis. (...) And I don't think that's right. I think—I had to hear it this a-way, now I mean, I got to go and do research and to me I would feel better if a Doctor had sat me down and her and talked to us about it" (USC02; age 65; female; patient's sister)
Difficulties accessing follow-up treatment after discharge	"we've had a battle with the District Nurses who should be here every day, only wanting to come every other day because of their costs, time and workload, etc., so it's just—it's not smooth sailing, is it?" (UKC05; age 38; male; patient's partner)

Although patients had little or no memory of their time in intensive care, caregivers recalled this as a frightening and worrying time. Improvements and deteriorations in the patient's health were described as an "emotional rollercoaster" by one caregiver (USC05). Seeing the patient dependent on life support in intensive care was often particularly distressing, or "heartbreaking" (USC08) for caregivers, who described patients as being "hardly recognizable" (UKC08).

While patients were sedated at this time, caregivers were very active. Most of the caregivers reported visiting the patient in hospital every day or ensuring that someone was visiting the patient every day. In addition, caregivers were also communicating regularly with other family members and friends about the patient's condition. Caregivers reported talking to the patient in the hope that they could hear them and spending a lot of time in the waiting room in between visiting hours. The shared waiting room was described by one caregiver as a "community of people with the same cause" (UKC01), as each family would ask about the other patients. Three of the caregivers were in the waiting room when other families received bad news about patient's who died, which made them imagine themselves in that situation (UKC01; UKC08; UKC05).

Several patients were hospitalized for some time after regaining consciousness. Patients reported being "wired up" with drips and tubes (UKP17) and wanting to have the tubes taken out. Several patients reported difficulties with eating or talking at this time, due to having a tube down their throat, and a lack of coordination. Several patients also had considerable mobility difficulties at this time as they had become weak due to being inactive while hospitalized, and some were unable to roll over or sit up in bed without assistance.

Ongoing Impact of Severe Sepsis

Although the level of impact varied greatly, with improvement in some aspects over time, many patients reported lasting impacts of their severe sepsis episode in terms of sensory (UKP08; UKP17) or cognitive impairments (USP02; UKP17; USP01; UKP03; UKP04), physical appearance (USP01; UKP03; USP07; UKC02, reporting impact on UKP02), ongoing symptoms from complications (e.g. blood clots; UKP08; USP03; UKP17; USP08; UKP03; UKP05), and medication side effects (UKP08; USC02, reporting side effect experienced by USP02; UKC02, reporting side effect experienced by UKP02; USP03; UKP01; UKP03; UKP04; USP07). Some patients reported significant ongoing mobility impairments due to

muscle weakness, with two patients (UKP03; UKP14) who had been independently mobile prior to severe sepsis still unable to stand for long and unable to walk at all at the time of the interview. For many patients, these impairments meant they had difficulties with self-care during their recovery, particularly the period of time soon after discharge from hospital.

During recovery, activities such as cooking, gardening, household chores, driving, shopping, social activities, and working, which the patients did regularly before developing severe sepsis, were limited by the patient's lack of mobility or strength or lack of confidence. A number of patients who had been independent prior to having severe sepsis had become completely dependent on others (UKP05; UKP13; USP09; USP02; UKP03; UKP14), for others the impact on independence was short term. Some patients described feeling like they were a burden to family members or friends who now had to care for them. Patients described feeling helpless, embarrassed, and angry about their loss of independence. Participants with significant ongoing impairments to their usual activities, mobility, or independence were patients who experienced severe sepsis along with other chronic conditions or after an operation for an existing condition.

Patients also reported other emotional impacts, in particular a fear that the severe sepsis might come back; in one case so much so that the participant kept a bag packed in case she has to return to hospital (USP06). Similarly, some patients reported now feeling scared about undergoing further medical tests, which would not have worried them before developing severe sepsis (UKP08; USP01). Others expressed concern that they may cause themselves to get ill again if they do too much activity (UKP08; USP07), attributing the cause of the sepsis to their prior over active lifestyles. Another strategy described was a heightened awareness and avoidance of infections to prevent recurrence. The fear of severe sepsis recurrence was a particular issue for patients who had previously felt healthy. For some, the experience of severe sepsis had changed their outlook on life, their lifestyle and personality in both negative and positive ways. For example, one participant (UKP08) who had felt healthy prior to sepsis reported now feeling very vulnerable and had lost confidence, whereas another participant (UKP01) had become more focused on making the most of his future.

Impact on Caregivers

The time of greatest impact on caregivers' usual activities was when the patient was discharged from hospital and at the start

of their recovery and caregivers assisted with patients' self-care and complex medication regimes. However, several caregivers reported that even at the time of the interview, their days revolved around the patient's needs, in some cases caregivers were unable to leave the patient on their own, which further restricted their usual activities, work, freedom, and independence. This was a particular burden to male partners or husbands of patients, who had to take on domestic roles which they had not been previously used to.

The reduced freedom and burden of caregiving along with distress related to the patient's condition had a lasting emotional impact on caregivers. Caregivers also reported feelings of frustration, guilt, anxiety, and stress related to their role as a caregiver.

Support After Severe Sepsis

Although most patients and caregivers were satisfied with the medical care they received while in hospital, participants reported a general lack of information about severe sepsis and what to expect during recovery and that the hospital should provide this information.

Many patients and caregivers reported difficulties accessing follow-up community treatment, such as physiotherapy once discharged home or that the level of support and care available at that time was inadequate. This was reported by patients and caregivers in both the United Kingdom and United States; however, accessing follow-up support and care was more of a challenge for U.K. patients and caregivers who had received inpatient care a long way from their home. Caregivers of these patients (UKC03a; UKC03b; UKC05; UKC07) had faced additional challenges, costs, and disruption to their lives while the patient was being treated far away in hospital.

DISCUSSION

This study aimed to further develop understanding of the impact of severe sepsis through conducting in-depth interviews with survivors of sepsis and their informal caregivers. The analysis identified five main themes: awareness and knowledge of severe sepsis; experience of hospitalization; ongoing impact of severe sepsis; impact on caregivers; and support after severe sepsis.

The sample consisted of patients who had experienced severe sepsis in a wide variety of contexts, including some who considered themselves to have been reasonably healthy prior to developing severe sepsis; while these individuals may have included less severe cases, their experience appeared to be particularly shocking for them and they feared the recurrence of severe sepsis. The group of patients with significant preexisting health problems and/or recovering from major surgery included those with most significant ongoing mobility problems and knock on limitations to their ability to look after themselves, performance of other usual activities, and independence.

Interviews were conducted in more than one country, allowing commonalities of experience to be identified across different healthcare systems. Descriptive sample information

suggests that patients interviewed in the United States may have been comparatively more severe cases than those interviewed in the United Kingdom and that they received shorter ICU and inpatient care (based on APACHE II scores); however, while the U.S. sample included many patients with significant ongoing impacts of severe sepsis, so did the U.K. sample and there was little evidence of systematic differences in experiences of patients and caregivers between the two countries nor of any straightforward relationships between severity, amount of hospital care, and lasting impact.

In this study, there was a widespread lack of awareness and understanding of severe sepsis among patients and caregivers. Several patients and caregivers were unaware of the diagnosis of severe sepsis. This is perhaps unsurprising during the critical ICU treatment period when survival is likely to have been a greater concern and patients and caregivers may be unable to process such information. However, in many cases, the lack of information does not appear to have been addressed at any later stage, with some who sought additional information finding little of any use.

A number of findings from this study reflect those reported in previous severe sepsis and critical illness research, including lasting cognitive impairment, functional disability, and muscle weakness (5–7, 9, 12, 17). Distressing flashbacks, panic attacks, hypervigilance to symptoms, anxiety about medical tests, and worsening physical and cognitive functioning are in line with “postintensive care syndrome” previously reported for severe sepsis patients (10) and the lasting effects of negative memories of time spent in ICU found by the previous qualitative studies conducted with survivors of a critical illness (16, 17).

In addition, this study provides explanatory detail to previously identified impairment in patient HRQL (11), in particular providing explanation of impact on physical, social, and role functioning. At the same time, the results of this study broaden our understanding of the lasting HRQL impact of severe sepsis for patients to include body image, confidence, anxiety, and independence.

The caregivers interviewed for this study seem very different from the sample surveyed by Foster and Chaboyer (15), who were predominantly middle-aged female spouses of ICU survivors. Caregivers in the current study also reported developmental burden, although few explicitly expressed a wish to escape from their situation, preferring it to the alternative of the patient not having survived or having been worse affected. In addition, the caregivers interviewed here report significant emotional burden as well as the social restrictions that result from their loss of freedom. In line with previous studies (24, 25), male caregivers interviewed in the current study reported specific negative effects of adopting a caregiving role, in this case related to the male spouse taking on new domestic responsibilities that had previously been fulfilled by their female spouse.

Lack of knowledge of the diagnosis and understanding of severe sepsis by survivors and their caregivers has not previously been reported by published research. However, more general lack of public awareness of sepsis was reported by

an international survey conducted by the Surviving Sepsis Campaign (26), which found that only 19% (United States) and 14% (United Kingdom) of those polled had heard of the term “sepsis,” with very low awareness of the number of people that die from sepsis in each country each day. Given this level of public awareness, it is unsurprising that patients and caregivers were unfamiliar with the term (severe) sepsis when used by healthcare professionals, particularly without additional explanation. However, it is surprising that awareness and understanding among those affected by severe sepsis remained so poor long after diagnosis. This finding reflects the broader issue that severe sepsis does not get enough medical attention and resources. It is also worth noting that the Surviving Sepsis campaign (2, 26) and existing clinical and drug development efforts understandably focus primarily on increasing survival. However, the current study highlights ongoing impacts, needs, and burden of care among survivors of severe sepsis and those around them. Post-ICU there is a disconnection in terms of provision of community-based care and support for postsepsis survivors who continue to face long-term challenges as a result of their severe sepsis experience. Further education of community-based medical staff may also have a beneficial role to play here, as would dedicated resources for more structured long-term follow-up post-ICU and handover to community-based healthcare support. A particular strength of this study was the use of qualitative methods to gain in-depth and detailed insights of the experience of severe sepsis, short-term and lasting impacts. By capturing both the patient and caregiver perspectives, particularly where these are related, interviews provided a fuller account and qualitative analysis developed a broader understanding of how the experience affected individuals involved.

However, when interpreting the results of this study the following limitations should be acknowledged. Patients and caregivers were recruited from a single site in each country. This means that experiences may be dependent on the treatment available and quality of care at these specific sites and may not be representative of experiences of severe sepsis survivors at other U.S. and U.K. sites. The variation in the length of time since the episode of severe sepsis and discharge from hospital may have caused some of the variation in experience reported. The limited clinical data available to describe the patient sample limits interpretation of the impact time post episode/discharge may have had on experiences, although all participants had experienced an episode of severe sepsis within the prior 12 months. The differing interview methodologies should also be considered, while most interviews were conducted face-to-face, some were conducted by telephone which may have affected the data collected. It was felt that caregivers in particular were able to speak more openly over the telephone away from the patient than they may have done if they were interviewed with the patient also present. Furthermore, due to the lack of awareness of severe sepsis and the many comorbidities experienced, it was difficult for some participants to attribute their experiences to severe sepsis specifically. However, as detailed in the *Materials and Methods* section, the interviews

with participants who were relatively healthy prior to the onset of severe sepsis were analyzed first in order to aid interpretation of the remaining interviews.

CONCLUSIONS

This qualitative study goes beyond previous severe sepsis research to provide insight into patient and caregivers' experience of onset, treatment, recovery, and lasting effects of this critical illness. Experiences varied depending on the illness context in which the severe sepsis was experienced with the worst affected patients reporting lasting patient impacts in terms of mobility, sensory, and/or cognitive impairments, negative changes to physical appearance along with other complications and medication issues, and limitations to self-care and usual activities. Caregivers as well as patients reported enduring loss of independence and emotional, work, and financial impacts. The study also identified problems of lack of awareness of the diagnosis of and understanding of severe sepsis by patients and caregivers and difficulties accessing sufficient follow-up community healthcare after discharge from hospital.

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