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Sepsis impacts and opportunities for health service improvement: a qualitative study

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Preface

The Australian Commission on Safety and Quality in Health Care (the Commission) has commenced a program of work to improve early recognition, treatment and outcomes for patients with sepsis in Australia. In consultation with internal and external stakeholders, the Commission has identified a series of actions that will be implemented over 2020–22.

The program of work to improve outcomes in patients with sepsis in Australia includes:

- Performing an [epidemiological analysis](#) of national inpatient sepsis data.
- Conducting a retrospective medical record review of sepsis patient clinical documentation to examine aspects of sepsis recognition, management and clinical coding.
- Conducting a [literature review](#) of trigger tools that promote the early detection of sepsis symptoms.
- Developing [materials](#) relevant to the National Safety and Quality Health Service (NSQHS) Standards (2nd edition) to ensure health service organisations demonstrate the use of evidence-based practice in the early detection, treatment and monitoring of sepsis.
- Revising the [Antimicrobial Stewardship Clinical Care Standard](#) with regard to the role that prompt treatment with intravenous antibiotics in patients with suspected severe infection.
- Developing a dedicated [Sepsis Clinical Care Standard](#).
- Partnering with the Australian Government, states and territories and the George Institute for Global Health to lead a multi-modal [public awareness campaign](#).
- Publishing [a report](#) scoping the need to establish a coordinated approach for improving sepsis services, to address the high rates of disease recurrence and associated morbidity and disability.

Background

Sepsis is a time-critical medical emergency requiring prompt recognition and rapid clinical management to reduce the risk of severe morbidity and death. An estimated 55,000 Australians suffer from sepsis annually and more than 8,700 people will lose their lives to the condition each year.¹ For those who survive, sepsis can impact physical, cognitive and mental health, in addition to burdening families and carers as patients experience ongoing health complications in the months and years after illness.

This qualitative study was prepared by Dr Kelly Shaw of KP Health on behalf of the Commission and describes the lived experiences of sepsis survivors, their families and carers, and those who have lost a family member to sepsis.

The report follows a [literature review](#) undertaken by KP Health, recommending the Commission undertake further research to identify effective strategies that improve survival, quality of life and cognitive and physical function in people who have survived sepsis.

Aim

The study engaged 39 participants through semi-structured interviews to explore their experiences of sepsis in the acute care setting and following discharge into community and primary health care settings. Two main themes emerged from this work – delivering planned,

recovery focussed post-sepsis care; and supporting consumer actions to improve sepsis outcomes.

Findings

The main findings from the study include participants views that:

- The health system focus is on acute hospital care of sepsis, and that post-discharge care needs are not well planned for or addressed.
- There should be better information about sepsis and its health impacts, and a structured, rehabilitation-oriented approach to post-sepsis care that includes peer support.
- Gaps in clinician knowledge about sepsis that need to be addressed.
- People experiencing bereavement from sepsis have distinctive care needs that should be addressed by health services.
- Peers and peer-support programs have an important role in supporting people after sepsis loss.

Recommendations and next steps for the Commission

Based on wide stakeholder consultation and the findings presented in this report, the following recommendations are proposed as potential actions to support improvement in post sepsis care:

- Consider developing and evaluating a post-sepsis model of care for survivors and a post-sepsis model of bereavement support after sepsis loss.
- Work closely with consumers to identify and further develop resources that meet people's information needs.
- Include information and resources to consumers as an important part of clinical management of sepsis in the national Sepsis Clinical Care Standard.
- Include information about post-acute sepsis impacts in the national Sepsis Clinical Care Standard.
- Consider mechanisms for delivering GP education on sepsis, post-sepsis impacts and comprehensive care for sepsis patients. In children, this education may also extend to other specialist disciplines, for example paediatricians.
- Consult with consumers to prioritise other clinician groups in whom knowledge gaps should be addressed.
- Support further investment by health systems to better include consumers in leadership roles that provide more than just advice.

Sepsis impacts and opportunities for health service improvement: a qualitative study



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Abstract

Background

There is a paucity of evidence regarding interventions to improve recovery after sepsis and to reduce ongoing morbidity. This qualitative research project expands the evidence base by exploring the lived experience of people who have experienced sepsis and describes health system improvements that are needed to improve post-sepsis care.

Methods

Semi-structured interviews were conducted with people who had received care for sepsis, their families and their carers. Interviews were content transcribed and illustrative quotations were recorded. Content analysis of the interview transcripts was performed independently by two researchers. NVivo software was used to characterise themes against the research questions.

Results

Thirty-nine participants, representing the experiences of twenty-seven patients (eighteen adult and nine paediatric) completed an interview. From participants views, two main themes emerged – delivering planned, recovery focussed post-sepsis care; and supporting consumer actions to improve sepsis outcomes.

People can experience cognitive, physical and mental health issues after their sepsis diagnosis. They report the health system focus is on acute hospital care of sepsis and that post-discharge care needs are not well planned for or addressed. Participants want better information about sepsis and its health impacts and describe a need for a structured, rehabilitation-oriented approach to post-sepsis care that includes peer support. They identified gaps in clinician knowledge about sepsis that need to be addressed.

Participants see themselves as agents for change in improving post-sepsis outcomes. They want to contribute to increasing public awareness about sepsis, improving parental awareness, providing better information to people in acute care, supporting clinician education and skills development and strengthening peer support. People experiencing bereavement from sepsis have distinctive care needs that should be addressed by health services. Peers have an important role in supporting people after sepsis loss.

Conclusions

The ongoing care needs of people after sepsis are varied. Post-sepsis models of care need to be developed and evaluated that address gaps in care for people experiencing sepsis, including people experiencing sepsis bereavement. Models of care should provide patient education about sepsis and its health impacts. People with ongoing health problems after sepsis need periodic comprehensive assessment of their ongoing care needs; goal-oriented multidisciplinary management; and peer support. Consumer organisations are an important health system asset that, if resourced and supported, could contribute to health service improvements for sepsis.

Background to this project

The Australian Commission on Safety and Quality in Health Care (the Commission), together with The George Institute for Global Health (TGI) was appointed by the Australian Government Department of Health (the Department) to lead and co-ordinate the [National Sepsis Program](#) body of work.

In June 2020, the Commission engaged KP Health to undertake a [literature review](#) to describe the evidence regarding the burden of disease associated with sepsis in the Australian population, the impacts of sepsis on people who experience the illness, and evidence for interventions to improve outcomes after sepsis.²

The literature review demonstrated approximately half of all patients who survive a hospitalisation for sepsis do not achieve a complete or near complete recovery at two years after discharge. People may experience physical, cognitive and / or mental health problems after sepsis. The longer-term impacts of sepsis on the patient are usually, but not always, positively correlated with the severity of the sepsis episode. There are significant gaps in the evidence about outcomes associated with sepsis in paediatric patients and how to improve them as most studies have been conducted in adult survivors.

People are frequently re-hospitalised after their initial hospitalisation for sepsis. The mean rate of re-hospitalisation at 30 days is 21.4% (95% CI 17.6–25.4%). Rates of re-hospitalisation increase over time, from 9.3% (95% CI 8.3–10.3%) at 7 days to 39.0% (95% CI 22.0–59.4%) at one year after hospital discharge. Infection is the most common reason for re-hospitalisation.³

The health-related quality of life) of people who have experienced sepsis generally improves over time. However, some patients are left with residual physical function deficits that interfere with health-related quality of life and are susceptible to further infections.

Post-Sepsis Syndrome describes a group of physical, cognitive and mental health problems that people may experience following sepsis. Post sepsis syndrome can affect people of any age and can impact all three areas of the person's health. Most people with post sepsis syndrome will recover within 18 months, whereas other survivors including children and those with existing health complications may take considerably longer to recover and some survivors never resume their pre-sepsis state of health.

There is very little evidence of formal interventions to improve mortality, morbidity and quality-of-life in patients after sepsis as few studies have been conducted to identify interventions that successfully improve quality of life or function. Available evidence from one meta-analysis examining 43 studies suggested the mean one-year post-sepsis mortality rate is 16.1% (95% CI 14.1%, 18.1%) ($I^2 = 98.9\%$; $p < 0.001$).⁴

Furthermore, sepsis survivors, their families and caregivers require information about a patient's diagnosis, prognosis and follow-up care needs. Some patients also require additional assistance navigating the health system after sepsis as a result of ongoing

health complications.² Beyond that, little is currently known, nor widely demonstrated, about how to support people after sepsis.

This project

In view of the lack of evidence regarding interventions to improve recovery after discharge and to reduce ongoing morbidity, an examination of people who have experienced sepsis was undertaken.

This qualitative research project expands the evidence base by describing the following:

- How sepsis affects people, their families and carers.
- What supports people need from health services to address sepsis impacts.
- What health system improvements are needed to improve sepsis outcomes.

Research Design and Methodology

Research Design

In-depth interviews were conducted with consumers with lived experience of sepsis. In-depth interviewing is a qualitative technique involving intensive one-on-one interviews with study participants. This approach provides detailed information about an individual's beliefs and behaviours. The authors explored consumers' perceptions of the care they received from health professionals, gaps in care and priorities for improved delivery of health services after sepsis.

Sample

The Australian Sepsis Network (ASN) employed criterion sampling, a form of purposive sampling, to invite consumers who met either of the following criteria to participate in the project:

- Recipient of sepsis-related health services within the Australian health system
- Families and / or their carers of people who have received sepsis-related Australian health services.

Criterion sampling is useful for identifying participants who meet predetermined criteria of importance, thus ensuring quality of the data collected and the veracity of data saturation. Consumers were recruited via telephone, e-mails and letters. All participants provided verbal, informed consent prior to participation.

Data Collection

A semi-structured interview guide was developed and approved by the Commission and the ASN prior to interviews commencing (see Appendix 1). A public health physician who is an experienced interviewer asked consumers broad, open-ended questions about their sepsis experience and opportunities to improve post-sepsis care.

Interviews were conducted via video conference as a global pandemic of COVID-19 had been declared and people who have previously experienced sepsis have an increased susceptibility to infection¹. Interviews were 45 to 60 minutes in duration. Interviews were conducted between May and June 2021.

The interviewer content transcribed interviews and recorded illustrative quotations to capture key points and observations from the interviews. The interviewer used directive probes to elicit additional information and clarify questions. Names and identifiers were removed to protect consumer confidentiality.

Two criteria were used to evaluate the sampling: adequacy and appropriateness.

¹ The European Society of Intensive Care Medicine (ESICM). The Global Sepsis Alliance (GSA). & The Society of Critical Care Medicine (SCCM). Reducing the global burden of sepsis: a positive legacy for the COVID-19 pandemic? *Intensive Care Med* 47, 733–736 (2021). <https://doi.org/10.1007/s00134-021-06409-y>

- Adequacy addressed the volume of the data, or, in other words, whether adequate data supported the emergent insights.
- Appropriateness addressed the quality of the data, or, in other words, whether the data provided the descriptive and interpretive depth required to clearly delineate themes.

Using these criteria, data were collected until saturation was reached, that is until no new information was generated from the interviews (redundancy).

Data Analysis

Content analysis of the interview transcripts was performed independently by the project team – a public health physician and a social scientist. NVivo software (QSR International, released March 2020) was used to develop codes, using the research questions as guides, to characterise the overarching themes.

Qualitative software such as NVivo helps researchers categorise, sort, and arrange data so that large amounts of data are organised and easily retrieved.

Results

Participant characteristics

Thirty-nine consumers representing the experiences of 27 patients participated in semi-structured interviews (*Table 1*). There were 24 participants whose experience related to adult sepsis (18 adult patients and 6 carers of adult patients). There were 15 participants whose experience related to paediatric sepsis (parents and family members of nine affected paediatric patients). All patients had been hospitalised for sepsis during their sepsis experience.

Table 1: Participant characteristics

Patient characteristic	Percentage (%)
Age group of patients (N=27)	
<ul style="list-style-type: none"> <18 years 	33%
<ul style="list-style-type: none"> 18-50 years 	54%
<ul style="list-style-type: none"> >50 years 	13%
Female patients	63%
Male patients	37%
Received hospital care	100%
Received care in an Intensive Care Unit (ICU)	68%
Received sepsis care in rural or remote area	15%
Family members of person who did not survive their sepsis hospitalisation	15%
Described experiences associated with sepsis-related limb amputations	28%

Consumers from all Australian states and territories participated in the project.

Emergent themes

Through thematic analysis, two main themes emerged from consumers' descriptions of their experiences:

- Delivering planned, recovery-focussed post-sepsis care.
- Supporting consumer actions to improve sepsis outcomes.

Transcript exemplars indicating identification number and sex are included with quotations (e.g. carer of female, 40-49).

Theme 1: Delivering planned, recovery-focussed post-sepsis care

1.1 The focus of the health system is acute hospital care for sepsis

According to participants, the current health system priorities in sepsis care are:

- Hospital-based sepsis diagnosis, resuscitation and medical stabilisation.
- Treating the underlying cause(s) of the infection (e.g., respiratory infection).
- Managing acute complications of sepsis (e.g., organ failure, compromised peripheral circulation).

From a consumer perspective, the focus of the health system’s efforts is saving the person’s life and destroying the micro-organisms responsible for the sepsis. Although timely access to comprehensive acute sepsis care is also a priority for consumers, so is accessing high quality post-acute sepsis care.

“Treated the infection. Given antibiotics. Put on life support. Once infection treated was discharged. Didn’t know if I was supposed to still be unwell” (Male, 30-39).

“Went through emergency. Got antibiotics. Went to ICU. Had surgery. Talked about surgery recovery, not about sepsis or getting better after sepsis. Didn’t find out I had sepsis until after I got out of hospital” (Female, 30-39, amputee).

1.2 The health system focus needs to broaden to include post-acute sepsis care

Many participants in this study described ongoing health issues at the end of the acute phase of sepsis care. They described cognitive, physical and mental health effects that, in some cases, lasted years after the acute sepsis episode. The most reported issues were changes in cognition, fatigue, effects on mental health, other physical effects, and ongoing pain.

Table 2: Ongoing effects of sepsis reported by survivors of sepsis and their carers

Cognitive	Physical health	Mental health
Memory loss	Amputations	Anxiety
Poor working memory	Fatigue	Depression
“Brain fog”	Insomnia	Nightmares
Word-finding difficulty	Increased susceptibility to infection	Post-traumatic stress disorder (PTSD)
Poor concentration	Weight loss	
	Hair loss	
	Gait disturbance	
	Poor dentition	
	Muscle / joint pain	
	Loss of sexual function	

Cognitive	Physical health	Mental health
	<p>Changes to vision / hearing</p> <p>Disturbed bladder / bowel function</p>	

1.3 Communication, discharge planning and post-discharge care

Participants received very little information about sepsis whilst in hospital. In some cases, participants were not informed of their sepsis diagnosis. Post-discharge care specific to sepsis was generally not discussed or planned for ([Table 3](#)).

Table 3: Discussing and planning for sepsis-specific care after discharge

Issue identified	Illustrative quotes
Post-acute health issues associated with sepsis not discussed with participant	<p><i>Nobody told me he had sepsis. Told he would make a full recovery. He didn't. I didn't know what was going on. (Carer of male, 0-9)</i></p> <p><i>Nobody explained she had sepsis or what to expect afterwards. Was told I would return to normal within a few weeks. (Female, 10-19)</i></p>
Prognosis not communicated	<p><i>Not told infection can make you sick for months – expected to just get better and was told would be right by the medical staff. (Male, 60-69)</i></p> <p><i>No help to get memory back. Not sure if it would ever come back – nobody discussed prognosis. (Male, 60-69)</i></p>
Inadequate discharge preparation	<p><i>No discharge preparation. No advice about what to do after discharge. No paperwork. (Female, 20-29)</i></p> <p><i>Patient information poor. Discharged without instructions except for my amputations. (Female, 30-39, amputee)</i></p>
No comprehensive assessment of needs prior to discharge	<p><i>No assessment and planning. Googled what was wrong and what can be done about it. (Female, 40-49)</i></p> <p><i>Not even given iron supplement even though was told he was anaemic. (Carer of male, 0-9)</i></p>
Insufficient post-discharge support	<p><i>At discharge it was stressful. Was sent home on IV antibiotics with pump. Didn't know what to do. (Female, 10-19).</i></p> <p><i>Discharge was completely disorganised. Sent an OT home to look at the house. Other than that, no follow-up except limb rehab. (Female, 40-49, amputee)</i></p>
Insufficient specialist follow-up	<p><i>No post-discharge follow-up organised with the hospital. No follow-up bloods or x-ray. Told would feel very tired. No other symptoms discussed. (Female, 40-49)</i></p>

Issue identified	Illustrative quotes
	<p><i>No follow-up after infection. Saw infectious diseases physician in hospital but not after discharge. Wasn't warned about C-diff (Clostridium difficile). Didn't know what to do when got severe diarrhoea. Lost lots of weight. Couldn't eat lots of foods. (Carer of female, 40-49)</i></p>
<p>Insufficient access to specialist advice after discharge</p>	<p><i>No consistent advice about self-management (vaccinations needed after sepsis, antimicrobial prophylaxis) (Female, 10-19)</i></p> <p><i>Not told what to do if she got sick again. No advice about taking antibiotics / vaccinations after sepsis. (Carer of female, 40-49)</i></p>

"You had a bug, the bug is treated, you are OK now". (Male, 30-39)

"Sepsis isn't a long term thing. Once the infection is treated the sepsis is fixed" (Male, 40-49)

1.4 Clinician awareness and acceptance of post-acute sepsis impacts

Participants felt that doctors were either unaware of the long-term impacts of sepsis or were unwilling to accept that ongoing health issues can be associated with a sepsis diagnosis. Participants also voiced that their ongoing health issues appeared to be inconsistent with the expectations of treating clinicians, who instead conveyed to them a message of sepsis recovery.

Lack of knowledge:

"Doctors haven't heard of post-sepsis effects. Treat you like you are making it up." (Female, 20-29)

"Doctors don't know what to do if I have symptoms after sepsis or complications." (Female, 40-49)

Lack of acceptance of ongoing health issues:

"Doctors didn't listen, didn't believe the patient." (Carer of female, 40-49)

"Concerns dismissed by GP. "You're young and you'll bounce back." Didn't seem to believe me." (Female, 40-49)

1.5 A rehabilitation-oriented approach for post-acute sepsis care

Participants described needing care for their ongoing health issues. This care involved:

- Many actions
- Delivered by many people
- From different organisations
- Over a prolonged period
- Covering a wide range of professional activities.

Embedding a structured, rehabilitative approach to the health system’s management of sepsis is a priority for consumers. The overarching goal is to rehabilitate the patient and to support the patient, their family and caregivers, to minimise the long-term impacts of sepsis and improve function and wellbeing.

The key features of a structured approach described by participants are:

1. Comprehensively assessing the patient for cognitive, physical and mental health impacts of sepsis.
2. Formulating a comprehensive plan of management with a focus on patient goals and addressing the care and support needs of the patient and their families and caregivers.
3. Regularly re-assessing cognitive function, physical health and mental health and re-formulating goals of care as care needs change over time.

Consumers require ongoing support from both peers and health professionals.

Peer support

Peer support is an essential component of a structured approach to post-acute sepsis care. Participants generally wanted access to people who had similar experiences after surviving sepsis or losing a family member.

Table 4: Peer support needs identified by participants

Support need	Illustrative quotes
Parental bereavement support	<p><i>“Struggled to find anybody who was a bereaved parent. Started looking for other bereaved parents online.”</i> (Bereaved parent of female, 10-19)</p> <p><i>“Wanted to talk to other parents. Wanted to reach out to parents on the news. Didn’t want parents who hadn’t lost their child, or parents from cancer support groups”</i> (Bereaved parent of male, 10-19)</p>
Peer support from Australian peers	<p><i>“Found UK / US sepsis support organisations. Couldn’t find anything in Australia.”</i> (Female, 60-69)</p> <p><i>“Joined some overseas sepsis groups. Would have been better if they were local. Would have been good to meet up”</i> (Female, 40-49)</p>
Peers with ‘like’ experiences	<p><i>“No links to other people who had same experience. Had to find on the internet.”</i> (Male, 60-69)</p> <p><i>“Need to connect to other people going through the same”</i> (Female, 40-49, amputee)</p>
Formal peer support organisations	<p><i>“No efforts to link patients to peers. No foundation to find peer support.”</i> (Female, 30-39, Amputee)</p> <p><i>“Need structured group that people can tap into. Need to know it is legitimate”</i> (Male, 30-39)</p>

Participants emphasised that peers providing support need to be “true” peers – sharing similarities in their sepsis experience. Local community peers were valued, in order to receive and share local knowledge, but online forums were also valued for their ability to foster connections with people with very similar experiences, regardless of geography.

Some participants cited examples of structured peer support that met their needs, including the “ASN Life after Sepsis” peer support group list and the Queensland Peer Mentor Program currently under development by the Queensland Paediatric Sepsis Program. Consumers who were familiar with these were not directed to these sources of peer support by health professionals – they found sources of peer support through the internet after hospital discharge.

Coordinated health professional support

A broad range of health professionals may be required to deliver care in the post-acute phase as the impacts of sepsis on the individual vary widely (*Table 5*).

Survivors of sepsis and their carers were asked what members of a health team would ideally be available to them for care after sepsis. Almost all participants mentioned a GP (with one specifying that the GP should be appropriately knowledgeable about sepsis and post-sepsis care). Participants also identified different medical specialties, allied health and nursing disciplines they require ongoing access to, together with access to various disability support, home care, employment and social support organisations.

Table 5: Post-sepsis healthcare disciplines identified by participants

Clinical discipline	N
GP	24
Psychologist or psychiatrist or counsellor (inc. specific for sexuality and relationships, and for grief)	21
Physiotherapist or exercise physiologist	21
Other medical specialists (incl. pain specialist, neurologist, surgeon, infectious diseases physician, paediatrician, rheumatologist, rehabilitation specialist)	20
Nurse (incl. specialised in wound care, stomal therapist)	16
Dietitian or nutritionist	13
Social worker	11
Social and system assistance (inc. NDIS navigator, home care and support, financial assistance)	11
Occupational therapy	10
Rehabilitation service	10

Post-acute sepsis care planning should commence early in the discharge planning process from hospital. Patients should also be provided with information and resources about the health impacts that may be experienced after sepsis, including how to seek care for these should they arise. The transition of care back to the community needs to

be facilitated through appropriate referral, handover and associated documentation on the patient's sepsis condition and be considerate to ongoing management needs.

“Need patient education whilst in hospital and after discharge. Need information about psychologist, dietitian, GP with knowledge about sepsis. Need peer support. Need advice about what to do if symptoms recur. Need self-management “action plan”. Need advice about health insurance, work health and safety advice. Need advice on immunisation and antibiotic prophylaxis pre-procedure.” (Male, 40-49)

“Should be a complete model of care for people after they leave hospital – include mental health care needs, physical therapies, patient education and self-management support. Should be information about recovery from sepsis – what to expect, what to do if you get after-effects, who can help you.” (Female, 60-69)

Consumers expect access to health services delivered by informed health professionals with knowledge of post-sepsis impacts and how to manage them. Health professional education in post-acute sepsis impacts and their management is a priority.

“Should have information to send to the GP at discharge because GPs don't know about after-effects of sepsis.” (Female, 40-49)

“Doctors have poor knowledge of sepsis. Should be some communication with the doctor to tell them about it when discharged.” (Male, 30-39)

For some consumers, the hospital environment is associated with a traumatic experience of sepsis. Alternative settings of care may be preferred by consumers. Telehealth may extend the reach of health service supports beyond urban areas and may minimise distress to consumers.

Phobia about doctors and hospitals. Not going back to the hospital where treated.” (Female, 20-29)

“After-care booked for the hospital but couldn't get out of bed for 3 months so no treatment.” (Female, 40-49)

Theme 2: Supporting consumer actions to improve sepsis outcomes

Participants in this study want to contribute to improving sepsis outcomes. They believe consumers will be instrumental in improving health service delivery for sepsis in key areas (*Table 6*):

- Increasing public awareness about sepsis
- Increasing parental awareness
- Improving communication with patients in acute care
- Supporting clinician education and skills development
- Strengthening peer support.

Table 6: Consumer actions to improve health service delivery

Improvement area	Actions	Illustrative quotes
Increasing public awareness about sepsis	Contribute to the education of the public about the signs and symptoms of sepsis.	<p><i>People with experiences can help inform the community. Community members need information about the signs of sepsis so they can raise concerns with clinicians. (Female, 40-49, amputee)</i></p> <p><i>“Very difficult to prevent sepsis. Need a consumer group who do awareness raising of medical profession and the community to identify it (sepsis) and do the right thing to respond to it”. (Female, 40-49, amputee)</i></p>
Increasing parental awareness	Provide parents with education and marketing materials about normal versus abnormal course of infection in children, when to be concerned and how to respond to a child that is not following a normal course of illness.	<p><i>Parents should be told about sepsis. Consumer groups can design fridge magnets and posters and booklets for parents to tell people “Antibiotics don’t kill all the bugs, all the time. This is what to look out for” (Bereaved parent of male, 0-9)</i></p> <p><i>“Parents don’t have the language to raise concerns. If you don’t know it’s sepsis, how can you talk about it? Need to help other parents know how to raise concerns” (Bereaved parent of female, 10-19)</i></p>
Improving communication with patients in acute care	Improve communication for people with sepsis, their	<i>Discharged without being told I had sepsis. Had to</i>

Improvement area	Actions	Illustrative quotes
	<p>families and caregivers about sepsis, its ongoing health impacts and how to access health care to address these.</p>	<p><i>look up symptoms on the internet to find out it was sepsis. People who have had sepsis could design a good website for other people with sepsis. We've been through it (Male, 30-39).</i></p> <p><i>Should be told about sepsis at the time. Had breast cancer. Cancer had good pamphlets and a website and online groups to talk to other people with breast cancer. For sepsis there is nothing. (Female, 40-49)</i></p>
<p>Supporting clinician education and skills development</p>	<p>Improve clinician knowledge about post-acute sepsis health impacts (cognitive, physical health and mental health).</p> <p>Embed comprehensive patient assessment and goals-based multidisciplinary management in patient care pathways accessible to clinicians.</p>	<p><i>We need to educate doctors about health problems after sepsis. (Male 60-69)</i></p> <p><i>Doctors find it difficult to communicate what sepsis is in layman's terms. We need to work on our messaging and train up in communicating it. (Male, 30-39)</i></p>
<p>Strengthening peer support</p>	<p>Formalise peer support systems, resource these and promote them to clinicians and consumers.</p>	<p><i>Support groups / peer support is needed. Clinicians don't know about what is available. People who have had sepsis can support others but need to support them too as stressful. (Female, 10-19)</i></p> <p><i>Support group that is sepsis specific and links you to your peers. (Female, 40-49, amputee)</i></p>

2.1 Supporting consumers who help other consumers

Some participants noted that the ability to contribute by supporting others going through similar experiences helped them make sense of their own experiences and channel their grief. Others cautioned against over-burdening and re-traumatising peer mentors and emphasised the need for comprehensive support for those contributing as peers.

People need the opportunity to contribute – needs to be a centralised, organised body to support people. (Bereaved parent of female, 10-19)

Peer mentorship is taxing. You need to be able to dip in and out of being a support because; it is personally taxing. (NHS sepsis trust experience) Asked patients to tell their

story. They didn't realise patients were still ill and still vulnerable and would get sick afterwards. Better to do it online and do it in their own time. Needs to be paid and supported. (Female, 40-49)

2.2 Supporting people experiencing bereavement

Some people do not survive their sepsis. Most bereaved participants in this study were parents of a child who died from sepsis.

Some bereaved participants had been referred to peer support for families who had lost a child from other diagnoses (particularly cancer and other chronic illnesses). They reported the bereavement experience from sepsis is different and that being offered peer support with other families who had experienced sepsis loss is preferred.

"The only available support was for parents of SIDS (Sudden Infant Death Syndrome). Sepsis feels very different and it didn't work well." (Bereaved parent of male, 0-9)

"I was sent to a children's cancer group. I didn't relate. You need to talk to other people who this had happened to. It needs to be sepsis-specific." (Bereaved parent of male, 10-19)

Parents and other family members and people in the family's network may need access to ongoing support.

"Siblings should be offered support over a long period of time. Siblings can be very young when it happens." (Bereaved parent of male, 0-9)

"The family may need support at different times in their lives. You need support for friends and family members who are trying to support the bereaved family." (Bereaved parent of male, 10-19)

Discussion

The peer-reviewed literature indicates approximately one half of all patients experience significant symptoms two years after discharge. Other patients are at increased risk of premature mortality and ongoing health problems associated with their.⁵

This qualitative study interviewed 39 participants representing the experiences of 27 patients with a previous diagnosis of sepsis. Survivors of sepsis described ongoing cognitive, physical health and mental health impacts associated with their sepsis. These had varying impacts on the person's physical, social and family function, and on their education, employment and income.

The literature shows people who survive sepsis are at increased risk of subsequent premature mortality, recurrent infection, impaired cognitive and / or physical function and reduced quality of life.⁶⁻⁹ One in five people will be re-admitted to hospital within 30 days of hospital discharge after sepsis.³

Despite this well documented post-sepsis disease burden, participants in this study were largely not informed by health care providers about the complications of sepsis during their hospitalisation, at discharge or after they were discharged. They described difficulties finding information about sepsis itself, the health problems associated with sepsis and how they could address complications they were experiencing. Participants found information themselves. They reported clinicians they sought help from appeared unaware of the complications of sepsis and experienced a lack of acceptance by clinicians that sepsis can have long-term health impacts.

Few published studies have explored interventions to improve recovery after hospital discharge and to reduce ongoing morbidity after sepsis.¹⁰ Participants in this study described a health service system that is focussed on acute care for sepsis but not comprehensive, planned post-acute sepsis care.

Participants described the need for a structured, rehabilitation-oriented approach to the health system's management of post-acute sepsis, the key features of which should be:

1. Comprehensively assessing the patient for cognitive, physical health and mental health impacts of sepsis.
2. Formulating a comprehensive plan of management with a focus on patient goals and addressing the care and support needs of the patient and their families and caregivers.
3. Regularly re-assessing cognitive function, physical health and mental health and re-formulating goals of care as care needs change over time.
4. Ensuring access to support services for bereaved family members and carers where necessary.

Although the features of this approach are straightforward, the multidisciplinary care needs of patients are not. Specialised skills may be required to support cognitive assessment; specialist management across physical, cognitive and mental health domains; goal setting that is rehabilitation focussed, measurable and achievable; and coordination of care by knowledgeable, skilled health professionals.

The rehabilitative approach described by participants does not appear to have been extensively assessed in the peer-reviewed literature. A comprehensive review of the literature undertaken as part of the [National Sepsis Program](#) body of work identified one systematic review of rehabilitation interventions to improve recovery in patients with sepsis.¹¹ The systematic review authors, only identified two randomised controlled clinical trials of rehabilitation interventions, both conducted in ICUs. No trials of community rehabilitation were identified.¹¹ Another low-quality review reported results from observational data from a study of 30,000 sepsis survivors that showed that referral to rehabilitation services within 90 days of hospital discharge was associated with lower risk of 10-year mortality compared with controls, and a small pilot RCT of a post-ICU rehabilitation program that improved cognitive and functional outcomes for survivors of sepsis.⁵

Consumer organisations are an important health system asset. They can protect high standards of care in health services, contribute to consumer and clinician education, raise community awareness and support patients, families and caregivers.^{12, 13} They need to be appropriately resourced and supported in their role in order to be effective.¹³

Participants in this study see themselves as important agents for improvement in sepsis outcomes. As people who have experienced sepsis firsthand, they possess unique knowledge which could be harnessed to raise public awareness about sepsis, improve communication with patients in acute care, support consumer, parental and clinician education, and improve peer support. Participants also report consumers have a central role in providing bereavement support. Participants want to be empowered by the health system and governments to deliver this support, in order to improve outcomes for people who have experienced sepsis.

Conclusion and Recommendations

People can experience cognitive, physical and mental health issues after their sepsis diagnosis. The rehabilitative approach to post-sepsis care described by participants has not been documented or evaluated in the literature. People who experience bereavement from sepsis have distinctive care and support needs that are not currently addressed. Care needs at discharge and throughout the rehabilitation and support process also need to be targeted to different cohorts; both in adults and paediatric patients.

People experiencing sepsis are not well informed by health care providers about the complications of sepsis during their hospitalisation, at discharge or after discharge. They described difficulties finding information about sepsis itself, the health problems associated with sepsis and how they can find help to address complications they are experiencing. People want better information about sepsis and its health impacts.

There are gaps in clinician knowledge about sepsis that need to be addressed. A broad range of clinicians were identified where sepsis knowledge gaps exist. Some clinicians are unaware of the long-term impacts of sepsis or are unwilling to accept that ongoing health issues can be associated with a sepsis diagnosis. Although knowledge gaps were described across a broad range of medical, nursing and allied health specialties, general practitioners were identified by participants as involved in ongoing care for most people after sepsis and were viewed as a clinician education priority.

Participants see themselves as agents for change in improving post-sepsis outcomes. They want to contribute to increasing public awareness about sepsis, improving parental awareness, providing better information to people in acute care, supporting clinician education and skills development and strengthening peer support.

Based on findings from participants views, KP Health puts forward the following recommendations for future action to support improvement to post-sepsis care:

Recommendations

- 1. To develop and evaluate post-sepsis models of care for survivors** that includes:
 - Comprehensive assessment of cognitive, physical health and mental health impacts of sepsis
 - Care planning, which commences early in the discharge planning process during acute patient care, in accordance with the patient's goals and wishes
 - Addressing the care and support needs of a patient's families and caregivers
 - Regularly re-assessment and re-formulation of goals of care as patient care needs change over time
 - Improved referral, handover and documentation between health professionals on the patient's sepsis condition and ongoing management needs.

2. **To develop and evaluate post-sepsis models of bereavement support after sepsis loss** that:
 - Recognises the bereavement care needs of parents, siblings and other people can change over time
 - Includes options for peer support.

3. **To work with consumers to identify and further develop resources that meet people's information needs**

4. **To include the provision of information and resources to consumers as an important part of clinical management of sepsis in the national Sepsis Clinical Care Standard**

5. **To increase delivery of GP education on sepsis, post-sepsis impacts and comprehensive care for sepsis patients.** In children, this education may also extend to other specialist disciplines, for example paediatricians.

6. **To include post-acute sepsis impacts in the national Sepsis Clinical Care Standard**

7. **To work with consumers to prioritise other clinician groups in whom knowledge gaps should be addressed**

8. **Support further investment by health systems to better include consumers in leadership roles that provide more than just advice.**

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Appendix 1: Interview Questions

- **Please tell me about your sepsis experience**

Patient prompts (what happened / what was done / what should have been done):

- Experience of becoming unwell, obtaining a diagnosis and receiving acute treatment.
- Time of discharge.
- Post-discharge / follow-up.
- Difficulties articulating concerns with health professionals

How has sepsis affected you / the person you care for?

What critical illness supports do you have / need?

- **Please tell me about your experiences of the health system for people who have had sepsis:**

What works well?

What does not work well?

What are the priorities for improvement? How should these be improved?

What (if any) are the challenges navigating the health system?

What about patient education?

What about communication between clinicians?

What about moving between different parts of the health system?

Issues with fragmented care / gaps in holistic management?

Ideally, what members of the health team would be available to you for care after sepsis? What are their roles?

- **Specific prompts (carer):**

What care needs does the person you care for have?

What care do you provide?

What care is provided by other people?

How did you go about getting this care? Any issues?

What are the gaps in care and support services for people who have survived sepsis?

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