The experiences of sepsis in people with a learning disability: a qualitative investigation

Article

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The experiences of sepsis in people with a learning disability; a qualitative investigation.

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The experiences of sepsis in people with a learning disability; a qualitative investigation.

Accessible Summary

- Sepsis is a very serious illness. It is a common cause of death in people with learning disabilities.
- We wanted to understand what it is like for people with a learning disability to have sepsis.
- We asked three people with a learning disability and five of their carers what it was like when they had sepsis. We asked about their health before sepsis, how their sepsis was treated and what health services could have done better.
- Carers often felt that people's mental health was worse after sepsis. They thought that even when people were physically better, their mood and behaviour was still affected.
- After sepsis, people were more worried about their physical health, and carers were careful to follow up on every health concern.

Key words: Learning Disability, Sepsis, Qualitative, Health

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Abstract

Sepsis is a common cause of death within the general population, and the third most common cause of death for people with a learning disability, suggesting an increased vulnerability or different trajectory within this population.

Despite this, there is currently no research into the direct lived experiences of people with a learning disability who develop and recover from sepsis.

Semi-structured interviews were conducted with 3 people with a learning disability (average age of 44.7, range of age 33 to 68) who experienced sepsis, and 5 carers (1 familial and 4 professional carers) (average age of 48.8, range of age 43 to 58) who had supported an individual with a learning disability whilst they had sepsis. Sepsis was caused by a range of physical health problems. Face to face semi structured interviews were conducted, transcribed and analysed using thematic analysis. Six main themes were identified: chronic and acute pre-existing health conditions; experiences within the hospital setting; physical recovery; mental recovery; returning to a normal life and the implications of sepsis. The findings highlighted some of the ongoing difficulties for people with intellectual disabilities in accessing timely healthcare provision and the ongoing mental health problems, even after physically recovering from sepsis. People with a learning disability have more comorbid health conditions which may compound the longer-term effects of sepsis. Future research should be conducted with people with learning disabilities about their experiences shortly after recovery from sepsis, to mitigate the effects of memory difficulties in recalling experiences.

Introduction

Sepsis

Sepsis is the systemic response to a complication of an infection (Bone, et al., 1992). It is a result of the body’s own inflammatory response which can lead to damage to, and failure of organs (Singer et al. 2016). When an infection is not treated swiftly there is an increased risk of sepsis occurring and causing organ damage and failure, ultimately leading to death. Sepsis can result from any type of infection, although it most commonly occurs following pneumonia and bloodstream infections (Mayo Clinic, 2018).

Sepsis is common with 1 in 5 deaths worldwide being caused by sepsis (IHME, 2020). Within the UK, 77,996 hospital admissions and 15,851 deaths were attributed to sepsis between 2016-2017 (Burki, 2018). The UK Sepsis Trust (2020) estimates 200,000 hospital admissions and 52,000 deaths from sepsis in the UK. The rise in numbers may be due to more accurate recording as awareness of sepsis increases (Burki, 2018).

One of the main barriers to the effective identification and treatment of sepsis, is that individual healthcare practitioners may fail to recognise when an infection becomes septic. Despite increased awareness of the condition meaning that screening for sepsis has increased in emergency healthcare settings (rising from 52 to 87 percent between 2015 and 2017; Burki, 2018), some practitioners still lack awareness of the presenting symptoms of sepsis. Early administration of antibiotics is critical in successfully treating sepsis, and reducing the risk of mortality (Seymour et al., 2017; Martel et al., 2020). Research suggest that difficulties remain with the timely diagnosis of sepsis, rather than the lack of effective medications and treatment once sepsis has been correctly identified (Burki, 2018; Kim & Park, 2019).

Long term sequelae

Over the past two decades Post Sepsis Syndrome (PSS) has been identified as a distinct entity with a number of defined symptoms (Mostel et al, 2020). These include a range of physical and psychological symptoms such as swollen limbs, reduced mobility, joint and muscle pains, insomnia, flashbacks, nightmares, hair loss and recurrent infections (often requiring re-hospitalisation), neurological problems, reduced ability to complete activities of daily living, and the acute exacerbation of pre-existing health conditions. Additional cognitive and psychological symptoms include panic attacks, anxiety, hypervigilance symptoms and cognitive impairments (Gallop, et al., 2015). Whilst around 50% of people whose sepsis is successfully treated in the acute phase will experience recovery, one sixth of these patients will experience severe, long-term complications of PSS. Indeed, even within those classified as recovered, some continued impairment in functioning was commonly reported (Mostel et al, 2020).

Cognitive impairment has been found following sepsis both in participants with no previous history of cognitive impairment, as well as those with pre-existing cognitive impairments such as dementia (Iwashyna, Ely, Smith, & Langa, 2010). However, there remains a lack of research into the long-term effects of sepsis, both within the general population and specifically within groups with pre-existing cognitive and physical impairments (e.g., dementia or learning disability) who seem to be affected more severely by sepsis.

Sepsis in people with learning disability

Since 2016, sepsis has been identified as the third most common cause of death for people with a learning disability, behind respiratory diseases and cancer (The Learning Disabilities Mortality Review, 2016). This report emphasises the urgent need for increased awareness, and better diagnosis of sepsis in people with a learning disability. There is currently little information about whether the experiences of people with a learning disability who develop sepsis differ from the general population. However, there are several factors which may indicate that people with a learning disability may have a different trajectory through sepsis, and that their experiences should be studied both separately from the general population, as well as within wider studies of sepsis and its treatment. Furthermore, people with a learning disability also have difficulties in communicating pain, as the standard method of assessing pain is through self-report (Beacroft & Dodd, 2011). This means their physical illnesses may be picked up less quickly, potentially impacting on treatment and prognosis around sepsis.

Within the general population, people with pre-existing health conditions may have different experiences from those who were healthy before developing sepsis (Gallop et al., 2015). People with a learning disability have higher rates of comorbid health conditions compared to the general population (Prasher & Janicki, 2008), suggesting an increased risk of infections such as pneumonia (Burki, 2018). These higher rates of physical health problems (Mencap, 2004) may increase their likelihood of getting sepsis and potentially impact their overall experience of sepsis.

People with a learning disability have greater rates of hospitalisation than the general population (Prasher and Janicki, 2008) and often receive unequal health care from professionals while in hospital (Mencap 2017). Case studies conducted by Mencap (2007) investigated the unequal health care that people with learning disabilities receive that can lead to preventable deaths. One case study Mencap (2007) described involves multiple re-admissions to hospitals and a lack of communication with family which led to this person developing sepsis which was fatal. Deficits in healthcare can arise from people with a learning disability being overlooked or misunderstood due to communication issues, or due to diagnostic overshadowing (whereby symptoms of illness are misattributed to the learning disability rather than as a separate issue in need of treatment) (LeDeR, 2018).

These issues can contribute to delayed or incorrect diagnoses, which is critical in sepsis due to the importance of early treatment and may contribute to the high mortality rate from sepsis in people with a learning disability.

Gallop et al (2015) conducted a qualitative study into the experiences of individuals without learning disability who had severe sepsis, and their caregivers. Themes around the lack of knowledge, around diagnosis and the continuing impact of sepsis, especially for patients with ongoing health complications, were identified. Participants found how, once discharged from hospital, accessing follow up support in the community was extremely difficult. It would seem likely that people with learning disabilities and their carers may also experience additional difficulties in accessing treatment, managing long term recovery, and coping with the physical and psychological consequences of sepsis.

A greater awareness of sepsis and equal health care in hospitals for people with learning disabilities could reduce the number of preventable deaths and deaths due to sepsis that are reported in the LeDeR (2018). One way to bring about this change is to conduct research highlighting the importance of improving identification of sepsis and the quality of care received in hospitals.

However, there is no research into this area at present. An increased understanding of the experience of sepsis, it’s treatment and recovery path in people with learning disabilities, will allow improved awareness and treatment in both acute healthcare settings, as well as mental health and rehabilitation settings. It may also facilitate the identification of those at highest risk of sepsis, and therefore access to prompt treatment.

Methods

Research question

What are the experiences of people with a learning disability who have had sepsis, and their carers, around symptoms and access to treatment (both immediately after diagnosis and in the longer term)?

Design

This study used a cross sectional qualitative design, conducting semi-structured interviews with individuals from two groups:

Group 1 – people with a learning disability who have experienced sepsis.

Group 2 – carers (family members or paid support workers) of people with a learning disability who have experienced sepsis.

Carers could be a paid carer or family member but must have had regular (at least monthly) face to face contact with the person both before and after admission to hospital for sepsis.

Methods

This study comprised of three stages. The first stage involved detailed consultation with a group of individuals with a learning disability who had not experienced sepsis. The involvement of Patient and Public Involvement (PPI) in the design of research materials is especially relevant for groups of people who may struggle with accessing research materials (UK Standards for Public Involvement, 2019). Four women with a mild learning disability, aged between 20 and 40 years, were identified through a local self-advocacy group. They worked with the researchers to develop the semi-structured interview schedule, and to ensure that the research was accessible and appropriate for participants with a learning disability. Feedback from this session was used to simplify the wording of some of the questions (e.g. replacing ‘recovery’ with ‘get better’).

The second stage involved the researcher identifying potential participants for the research and conducting separate meetings with each participant to explain the research, answer any questions and build rapport. This reduced participants’ anxiety before the interview.

The third stage involved the face to face interview with participants. Written, informed consent was obtained from each participant, and demographic information was collected. The semi structured interview was then conducted with each participant.

Participants

All participants were able to give informed consent to participate in the study.

Eight people (two men and six women) participated in the face to face interviews. Participants were either people with a learning disability who had experienced sepsis (Group 1) or those supporting for these individuals (Group 2).

The average age of participants was 52 years old, SD = 9.61. There were 6 participants who were of White British ethnicity and 2 participants that were of Black African ethnicity. All participants in Group 1 had a mild learning disability and had various causes of infection leading to sepsis including post-surgery, a sore on their leg, pneumonia and staphylococcus aureus infection (see Table 1). Participants have been given pseudonyms.

Table 1: *A Table showing the demographic information of participants.*

Name	Group 1 (Learning Disability) or 2 (Carers)	Ethnicity	Ages	Learning Disability or Carer	Living situation	Who cares for participants in Group 1 (Learning Disability)
Alex	1	White British	30-40	Person with a Learning Disability	Group Home	Mary, Kyle, Sarah
Kerry	1	White British	30-40	Person with a Learning Disability	Independently	No carers
Jas	1	White British	60-70	Person with a Learning Disability	Marital home	Dawn
Mary	2	African Black	40-50	Paid Carer	N/A	N/A
Kyle	2	African Black	40-50	Paid Carer	N/A	N/A
Sarah	2	White British	50-60	Paid Carer	N/A	N/A
Dawn	2	White British	40-50	Paid Carer	N/A	N/A
Sally	2	White British	50-60	Familial Carer	N/A	Cares for an individual with a Learning Disability that was unable to participate

*N/A Not applicable

Participants were recruited through local Community Teams for People with Learning Disabilities (CTPLDs) within the local NHS Foundation Trust. The project was approved by and registered with the NHS Trust Research Department (REF: 2018SE16).

There were three participants that had a mild learning disability that talked about their own experience of having sepsis (Alex, Kerry and Jas) and five carers (four paid carers and one familial carer). One participant with a learning disability (Kerry) participated without a designated carer. This was because Kerry lives independently without needing daily support. There were three paid carers (Mary, Kyle and Sarah) that spoke about their experience supporting Alex through having sepsis. One paid carer (Dawn) that spoke about her experience supporting Jas through having sepsis. One family carer (Sally) participated in the research, although her son was unable to participate as the level of their learning disability meant he was unable to give informed consent to the study.

There were two joint interviews that were conducted; Dawn and Jas were interviewed together, and Alex and Mary were interviewed together. Joint interviews were offered to reduce anxiety in the person with a learning disability. An advantage of joint interviews meant participants were more relaxed and able to speak freely. A disadvantage to joint interviews is that carers could speak for the person with a learning disability, and it would be difficult to separate the experiences of carer and person with a learning disability. When conducting the joint interviews both sets of interview questions were used (one for carer and one for the person with a leaning disability) this way both experiences were spoken about.

Development of the Interview Schedule

The semi-structured interview schedule was developed with input from members of the local CTPLDs, as well as covering areas identified by previous research in the literature. Additional areas identified from the PPI involvement, such as asking about the participant's experience travelling to hospital and their health before sepsis, were also included. Participants were asked about their experiences of receiving the diagnosis, the treatment for sepsis and the long term physical and psychological consequences of sepsis, all of which areas were identified by Gallop et al. (2015).

The interview consisted of open questions using simple language and a range of prompts to help facilitate discussion. Participants without a learning disability (Group 2) had a separate semi-structured interview schedule, which covered the same topics, but used more complex language.

Interviewers used their clinical judgement to manage any distress that arose during the interviews and to ensure that questions were appropriate to the participant's level of understanding.

Materials

Individual, face to face interviews were conducted by NG with each participant. Demographic data including age, gender, ethnicity, and level of learning disability was collected. Information about the cause of sepsis, length of hospital stay and comorbid physical health conditions was also collected.

Demographic data including age, gender, ethnicity and relationship to the person with sepsis was collected for each carer.

Interviews using a semi structured interview schedule asked about the level of support required by the person with a learning disability before and after sepsis. Other questions focused on the accessibility of emergency care services. Questions around treatment allowed for information about the cause of sepsis and the consistency of care received in hospital. Hospital stay and recovery were two main themes from Gallop et al. (2015) study, and therefore included in the semi structured interview. This allowed some comparison with Gallop et al.'s (2015) study around participant's experiences of being treated in hospital or and recovery trajectory due to pre-existing health problems.

Quality assurance in qualitative research

In order to ensure qualitative research has been carried out to a high standard, a number of key principles have been established; sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance (Yardley, 2008). One way of establishing whether these have been achieved is through a quality checklist specifically designed for qualitative research (Yardley, 2000; CASP, 2018). The Qualitative studies checklist (CASP, 2018) was used throughout the research, mainly during the design to ensure good quality research from the start when deciding on recruitment style and research question.

Sensitivity to the data and content was ensured by the following processes. Reflexivity is the process of reflecting on past experiences or preconceptions the researcher might have that could influence the study (Hesse-Biber, 2007). Processes employed to facilitate reflexivity including the use of a bracketing interview, maintaining a reflexive diary throughout the research process, and regular supervision. Supervision occurred with a Clinical Psychologist (OH) who is experienced in conducting qualitative research with people with learning disabilities. During the bracketing interview the main bias that was identified was the expectation that participants would have negative experiences in hospital, this was based off previous research by Mencap (2004). This bias was reflected upon and acknowledged throughout the research, especially during data analysis.

Procedure

Researchers liaised with Health care professionals (HCP) working within local CTPLDs and provided them with the study inclusion and exclusion criteria. Those HCPs with an eligible client approached the potential participant and provided them with verbal and written information about the study. Participants then gave consent to be contacted directly by the researcher via telephone or written communication to arrange a meeting. This meeting was to explain the research and answer any questions. Participants agreed to the interview at this stage, however, written informed consent was not obtained until the interview meeting to allow participants time to consider the research and withdraw if they wished. Another meeting was then arranged for the interview. In the interview meeting informed consent was obtained before the interview began.

Participants were provided with information about the research, appropriate to their level of comprehension, and in an appropriate format.

Interviews were conducted at the participant’s choice of venue by a researcher (NG) who was not involved in the person’s current or historical healthcare as this could have impacted the participant’s ability to provide honest feedback. Interviews were made accessible for people with a learning disability. Adaptations included using additional prompts, extra time to consider the question and presenting the questions in written format before and during the interview.

Before conducting the interview, participants were again provided with information about the research and reminded of their entitlement to withdraw, of their anonymity and confidentiality. Participants could withdraw their data up to two weeks after their interview. After two weeks their data was anonymised and combined with other participants' data for analysis. Interviews lasted between 30 and 135 minutes, mean time 50 minutes. Interviews were audio-recorded and transcribed verbatim.

Data analysis

Transcripts were anonymised and analysed using the thematic analysis procedure (Braun & Clark, 2006; Braun, et al., 2019). Thematic analysis is a method for identifying, analysing and reporting patterns or themes within the data. It is a recursive (rather than linear) process, involving six stages for the researcher: familiarising yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.

Half of the interviews were analysed by two researchers (NG & OH), who discussed and agreed how the codes of those interviews were grouped together into themes.

Confidentiality

Participants were informed that any identifying information would be removed in the write up of the research and that pseudonyms would be used to protect confidentiality. Participants were made aware of the limits of confidentiality. All participants gave consent for direct quotes to be included within the write up of the research.

Results

From the interviews with both groups of participants, six major themes were identified. These were: chronic and acute health conditions pre sepsis, experiences with the hospital setting, recovery/ changes since coming out of hospital, changes in mental health or changes in mood/ behaviour, returning to normal life after sepsis, implications of sepsis.

Within the major themes, subthemes emerged (see Table 2), which focus on different aspects of the overarching theme.

Table 2. Endorsement of Superordinate and Subordinate Themes

Superordinate Themes	Subordinate Themes	Alex	Kerry	Jas	Mary	Kyle	Sarah	Dawn	Sally	Total
1. Chronic and acute health conditions pre sepsis	Health before Sepsis			*	*		*	*	*	5
	Pre-existing contact with hospital	*	*	*		*	*	*	*	7
	Ongoing health problems	*	*	*	*	*	*	*	*	8
	Health leading up to hospital admission		*	*			*	*	*	5
2. Experiences within the Hospital setting	Care experience/ Time spent in hospital	*	*	*	*	*	*	*	*	8
	Treatment received for sepsis		*	*	*	*	*	*	*	7
	Diagnosis/ lack of diagnosis of sepsis			*	*			*	*	4
3. Recovery/ changes since coming out of hospital	Changes to care since coming out of hospital			*	*		*	*	*	5
	Length of recovery			*	*	*	*	*	*	6
4. Changes in mental health or changes in mood/ behaviour	Changes in mood post sepsis			*				*	*	3
	Changes in behaviour post sepsis		*		*	*				3
5. Returning to normal life after sepsis	Life after sepsis	*		*	*	*		*		5
	Resilience		*			*				2
6. Implications of sepsis	Impact on carers			*	*	*	*	*		5
	What does sepsis mean to them now		*			*		*	*	4

Theme 1: Chronic and acute health conditions pre sepsis

The first theme identified ‘chronic and acute health conditions pre sepsis’ illustrated that the participants people with a learning disability had multiple underlying health conditions and provided information about the participant’s health leading up to hospital admission for sepsis. All participants with a learning disability had identified physical and mental health problems, that were either historic or current at the time of developing sepsis. Sarah explained *‘This is the third time he’s been hospitalised’*. Sally stated *‘he’s had pneumonia twice’,* showing the predisposition this person with a learning disability had to infections and other illnesses.

As well as acquiring health conditions, people with learning disabilities often have congenital health problems. Sally described how the person she supports has had health conditions since birth *‘Addison’s disease’*. Jas explained *‘I’ve had diabetes’*, another long term health condition.

Participants described their health leading up to hospital admission and how their carers realised their health was deteriorating. Two participants collapsed or fell unconscious on the day that they were taken to hospital. Kerry describes this as *‘my eyes rolled into the back of my head and I lost consciousness erm then rushed into intensive care’*. Similarly, Sarah describes the events of the day while caring for someone that had sepsis, *‘I was here in the morning that he actually collapsed by the door’*. While the other participants did not collapse before admission to hospital, they described similar events of being rushed to hospital demonstrating this was an emergency. Jas explaining, *‘I went by ambulance’*, while Sally *‘called triple 1 they phone the ambulance’*. Some participants expressed that they did not realise the urgency of the situation until sepsis was explained to them, which is shown through them calling for medical advice before rushing to hospital.

Theme 2: The hospital setting

Within this theme participants described a range of different experiences of being in hospital; this theme highlights these inconsistencies. Two participants with a learning disability attended the same hospital and the other participant with a learning disability attended a different hospital.

Jas described herself as *'causing trouble for the [hospital] staff'* due to her poor mental health. Her carer adding that *she was in 'intensive care for about a month'* showing the severity of her sepsis. Dawn explains the frustrating journey Jas had to get treatment for sepsis as *'she was in and out of [physical health hospital] [mental health hospital] because there was mental health, physical health, it it was kept fleeting'* due to the doctors struggling to identify whether her physical or mental health needed prioritising. Dawn is describing how Jas was moved quickly between different hospitals, therefore, treatment and time in one hospital at a time was very '*fleeting*'.

Sally reported a frustrating lack of communication with the doctors *'one minute they're discharging us and then half an hour later they're saying no you're not going anywhere'*.

Conversely Alex was pleased with his hospital experience, *'I was happy'*. This was due to having his own nurse, *'a nurse look after me'*. His carers explained *'she [a nurse] only looked after you nobody else'*, so he had *'all the attention to himself'*.

One of Alex's carers described distressing symptoms of sepsis *'he was hallucinating'* and *'he was bedridden'*, which indicate how unwell he was.

Kerry also had a positive experience in hospital with the same high levels of individual support from hospital staff *'I was having 2 to 1 not 1 on 1 erm and erm she said actually we worked our socks off'*. Kerry explained that she had two nurses looking after her instead of one and had nurses and doctors working throughout the night because of the severity of her sepsis.

Theme 3: Recovery/ changes since hospital discharge

Participants talked about their physical recovery from sepsis. This theme includes treatment received in hospital and the process of physical recovery from sepsis. All participants were treated successfully with antibiotics *'The sepsis seemed to clear up with the antibiotics'*. The recovery time depended on various factors including initial infection site, severity of infection, and speed of treatment.

The time for physical recovery varied between participants. Sally explained the person she cared for recovered physically quite quickly once antibiotics were administered, *'two weeks he was then you could see the change in him'*. Whereas Mary described a much longer process *'it must have been a while maybe a couple of months'*. However, Dawn said, *'I would say at least a year it took her to get to get better'*, demonstrating the idiosyncratic process of recovery.

Theme 4: Changes in mental health or changes in mood/ behaviour

As well as changes to mental health that occurred when people were in the acute stages of sepsis, such as the hallucinations described by Alex's carer, participants discussed longer term changes in mental health and mood following sepsis. Most carers described the long-term impact *‘recovery wasn’t too bad apart from your mental wellbeing’* or *‘He’s not recovered fully mentally - physically he’s not done too bad’*. This suggests that whilst the physical symptoms of sepsis were treated and resolved relatively quickly, longer term sequela of mental health symptoms persisted.

Kyle described Alex’s change in mood as *‘frustration then he’s there screaming’*, behaviours he hadn’t shown before developing sepsis. Jas describes similar effects on her mood, *‘I get very moody, a terrible mood’*. Dawn went on to explain that the person she cared for was *‘left on some antibiotics for too long and it’s had err an effect on her’* which Dawn felt had a detrimental effect on her pre-existing Bi-Polar Disorder.

Theme 5: Returning to normal life after sepsis

The process of resuming their previous lifestyle after sepsis varied greatly for participants. Some participants were able to return to life before sepsis with almost no difficulty. Alex said *‘I do my wordsearch’* which is something that he would often do before having sepsis. Whereas Mary described some permanent changes, *‘you’re a lot more happier these days than before but every now and then he does, you do shout at me’*. Mary explained that the person she cares for has almost regained their previous, positive attitude to life, however some post-sepsis behavioural problems persisted. Sally explained that they have not been able to return to the life they had before sepsis as they are *‘constantly on guard is it if he’s ill again’*. Jas developed a coping strategy of praying while in hospital and continues to find comfort in faith *'I go to Church'*.

Theme 6: Implications of sepsis

This theme covers how sepsis has impacted on participants' lives. Two subthemes emerged: how participants feel about sepsis now and the lasting effects of sepsis that persist over time.

Most participants described on-going effects, both physical and mental as detailed in themes 3 and 4. Theme 3 explored the idea that participants recovery time varied from sepsis. However, some participants reported lasting effects. Kyle said that he cares for Alex differently, *'they [carers] check around his feet'* because this is where the infection started. Therefore, sepsis means carers are increasingly vigilant and note any change in health, however small. Jas also shows the impact on carers, *'even now here they will help with the shower'*. Jas explains that she needs help showering now whereas before sepsis she was able to shower independently.

Regarding the physical sequala, Dawn believes the person she cares for *'never got her strength back 100 percent'*. Similarly, Sarah said of the person she cares for *'his speech has deteriorated'* since having sepsis. The long-term physical effects of sepsis resulted in reduced independent living skills, which then impacted on the amount of personal care they required.

The second subtheme described how participants feel about sepsis now. Most participants lacked understanding about what sepsis was, and how their diagnosis was communicated to them. Sally didn't know the person she was caring for had sepsis until discharge. When reflecting on the diagnosis Sally said *'he could* *potentially die from it, I had no idea'*, which highlights the lack of knowledge around sepsis. Kyle emphasised, *'his health is always a priority to us'* which shows a vigilance around illness and preventing sepsis reoccurring.

Discussion

This study aimed to understand the impact of sepsis on people with a learning disability and their carers.

Sepsis is a serious illness, causing 11% of deaths in people with learning disabilities, although this figure is likely to be an underrepresentation due to poor reporting of causes of death (The LeDeR Report, 2019). This is the first study of the lived experience of people with learning disabilities who develop sepsis. Furthermore, some comparison to the experience of people in the general population with sepsis can be made (Gallop et al., 2015).

All participants experienced pre-existing health conditions prior to having sepsis, which is common amongst this population (Prasher & Janicki, 2008). Participants with pre-existing health conditions may experience more long-term effects of sepsis Gallop et al. (2015). The pre-existing health conditions experienced by participants in this study may have impacted the course of their recovery.

Gallop et al. (2015) found participants with pre-existing health conditions took longer to recover, and experienced persistent long-term effects of sepsis as well as having lasting effects after recovery. However, whilst some participants spent a month in intensive care and required a full year to recuperate, some participants recovered physically very quickly, despite underlying health conditions.

Participants described a range of experiences in hospital, both positive and negative, indicating inconsistency of care. A lack of clear communication both around the persons diagnosis, treatment and plan for discharge was also identified which is consistent with research investigating premature/avoidable deaths in people with a learning disability (Heslop et al., 2013; Government Ombudsman, 2009). This led to confusion and frustration in the carer and anxiety in the person with a learning disability. This inconsistency of hospital care is long-standing and has been highlighted by Mencap (2004; 2017) and the wider literature (Iacono & Davis, 2003). Mencap suggest that mainstream health services were not adequately adapted to support people with learning disabilities because of the presence of specialist community teams for people with a learning disability (CTPLD) services. Mainstream services delegate responsibility for people with learning disabilities to CTPLD services. Consequently, when people with a learning disability need to use mainstream services, such as emergency health needs, services are not experienced in treating or communicating with people with learning disabilities (Bradbury-Jones, Rattray, Jones & MacGillivray, 2013; Michael & Richardson, 2008).

Part of the inconsistency in mainstream hospital care received may be to do with the experience and confidence of healthcare professionals in working and communicating with people with a learning disability. Working with this client group is not a core part of training for many healthcare professionals.

This study identifies that the participants felt best cared for and supported with high levels of staffing. However, there is frequently confusion over where support should come from when a person with a learning disability is in hospital, especially for a long period of time (Tuffrey-Wijne et al., 2016). Nursing care is provided by hospital staff but additional support needs may require support from a person’s familiar support team, providing ‘in-reach’ to the person in hospital. This can be complicated by hospital admissions which are at a significant distance from a person’s home, and difficulties with transport links. To resolve the problem of who should provide support to people with a learning disability while they are in hospital, a joint team of hospital staff and support workers could be used. This team would provide the needed nursing care from hospital nurses and the presence of familiar support workers to help people with a learning disability feel calm and supported throughout their stay.

Carers described adapting their practice in supporting the person with a learning disability following sepsis. This included additional observations and monitoring of physical health, and increased responsiveness and readiness to respond when any symptoms of illness were identified. Gallop et al., (2015) highlighted this strain felt by carers and the lack of support once discharged from hospital. Although most participants in the current study required carers before sepsis, all participants described a loss of independence and needing additional support with daily activities to do activities after their illness. Such changes may reduce a person’s confidence and leave them feeling more vulnerable and dependent on others.

Results from this study suggest specific guidance around post sepsis care would be beneficial, particularly for people with a learning disability. The guidance could include information about the physical signs of sepsis for both carers and people with a learning disability, so they are prepared in case of a recurrence. Information about the potential anxiety and trauma of being in hospital and being at risk of dying or supporting someone through a life changing illness. Carers would then have the information to access additional support for both themselves and people with a learning disability.

One carer described their perception that the person they cared for was prescribed a course of antibiotics which lasted longer than needed and negatively impacted their mental health. Whilst the accuracy of this interpretation is impossible to ascertain, research has found that health professionals, including 90% of GPs find it difficult to accurately diagnose and treat people with a learning disability (Mencap, 2004). This may lead to misdiagnosis, incorrect treatments, and damaging side effects, as may have occurred for this person. This was also apparent when one participant was struggling to receive the correct care as hospitals were unsure on the prioritisation of the participants' mental and physical health, leading to the participant going back and forth between different hospitals to treat their different needs. This led to more anxiety in the person with a learning disability and severe physical health problems.

Most participants experienced a deterioration in their mental health after sepsis, which persevered for years. Whilst Gallop et al., (2015) found that participants had a different outlook on life and feared becoming ill again, the severe impact on mental health found in this study was not found in the general population. However, it can be difficult to distinguish between the mental health symptoms of sepsis and the trauma and anxiety caused from being very ill and needing lifesaving treatment. Understanding if it is a mental health symptom of sepsis or trauma can help psychologists to support people with a learning disability and carers post sepsis.

Further research is needed to explain why sepsis may have this significant, lasting effect on mental health in people with learning disabilities. Whilst individual interviews provide a useful way of exploring experiences, more complex methodologies such as conducting interviews longitudinally with participants, or incorporating other modalities such as collecting drawings or images created by participants or mapping out important relationships (Boden-Stuart, Larkin & Harrop, 2021), may increase the quality and richness of the data.

Strengths and limitations of the study

Given the sensitive topic of this research, a number of strategies were employed to reduce anxiety for participants. These included meeting the researcher beforehand to establish rapport and reassurance during the interview and emphasising that the interview can be stopped at any time without a reason.

The role of qualitative research methodology in people with learning disabilities has been queried for a range of reasons, including the difficulties experienced with communication and comprehension, and concerns that participants may be overly acquiescent, or prone to response bias. However, there is good evidence that qualitative research can be conducted with people with a learning disability (Rose, et al., 2019). To try to reduce potential bias participants were made aware that their care from the NHS Trust would not be affected by what was said in these interviews. Some participants spoke freely about negative hospital experiences.

Although recruitment was challenging, due to low numbers of people with a learning disability who met criteria for the study, the sample that was gathered had a broad range. Participants ranged in age, gender and cause of sepsis, which helps to capture a range of experiences. A limitation of the recruitment was trying to find participants that met our specific criteria for the study which could be reason to the lack of research in this area. Interestingly, one carer decided against participating as they felt they had insufficient knowledge of sepsis and received limited communication with hospital staff when they were supporting a person with a learning disability who had sepsis.

A range of techniques were employed to improve the credibility and rigour of this qualitative research. Half of the interviews (chosen at random) were analysed by two researchers independently (NG & OH), and the results compared. This process revealed a high level of agreement between researchers around the themes identified. The use of regular supervision, bracketing interviews, and reflexive diaries all contributed to the quality of the research (Yardley, 2000).

In line with much qualitative research using semi structured interviews, the topics for discussion had been identified before the interviews. This could be viewed as predetermining the themes found in the data. However, a number of themes emerged from the data that did not reference any questions, demonstrating that participants were able to talk about topics that they weren’t being asked about. The qualitative nature of the research means that people’s experiences are the focus of this paper, and therefore additional research into objective measures of sepsis and post sepsis recovery in people with learning disabilities, using quantitative methodologies would be welcomed.

Implications and directions for future work

Hospitals are working to improve accessibility for people with a learning disability through employing specialist liaison nurses to liaise between healthcare professionals and the person with a learning disability. Liaison nurses have specialist training around effective communication with people with a learning disability. Two participants had direct contact with the liaison nurse during their hospital stay and had one-to-one support provided by hospital staff. This level of staff support within hospital may explain the inconsistency in participants experiences of hospital, as those with one-to-one support generally had a positive experience while the other participants had negative experiences. Why the liaison nurse did not work with all participants is unclear. Future work could explore when liaison nurses are used and how to ensure their input for all people with a learning disability admitted into hospital. Also, the implications of providing a joint team of hospital nurses and familiar support workers to both provide support and care throughout the hospital stay.

This research suggests ways NHS Trusts could support clients, especially in the learning disability teams, pre- and post-sepsis. Highlighting the severity of sepsis can help to raise awareness of sepsis to others, including the risks of infection and how to respond when someone or themselves has an infection. Raising awareness of sepsis is key because not many people will know the first signs of sepsis. Previous research has shown how critical time is when an infection starts to become septic (Seymour et al., 2017). Therefore, easy read information can help to guide NHS Trusts, group homes, support workers and people with a learning disability to raise awareness of the first signs of sepsis in a person with a learning disability. In addition, health professionals should be made aware of the lasting effects (the decline in mental health and increase in challenging behaviour) that sepsis has on individuals with a learning disability. We suggest that any person with a learning disability who has been hospitalised with sepsis be referred to the CTPLD upon discharge from hospital. This would allow health professionals to provide extra support, for both physical and mental health, through the discharge process. This is extremely important, so a person's mental health can be monitored post sepsis.

Future research should consider recruiting participants that have recently had sepsis, perhaps within the last year. This would allow better recall of experiences in people who have memory difficulties, both due to a learning disability, and the cognitive effects of sepsis. Participants in this research experienced sepsis between four months and 10 years prior the interview. Due to difficulties with recruitment to this study, it was necessary to recruit participants that had sepsis many years ago. However, this allowed participants to reflect on how they felt sepsis had affected them over the years since treatment. Results indicated that even years after having sepsis there were still lasting effects on participants' mental health. Future research should consider why sepsis has a large impact on mental health within people with a learning disability and understand variations in the timing of recovery.

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