

The Experience of Sepsis amongst People with Learning Disabilities and those who care for them

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Introduction



My name is Anne. I am a nurse and a student researcher at the University of Hertfordshire.

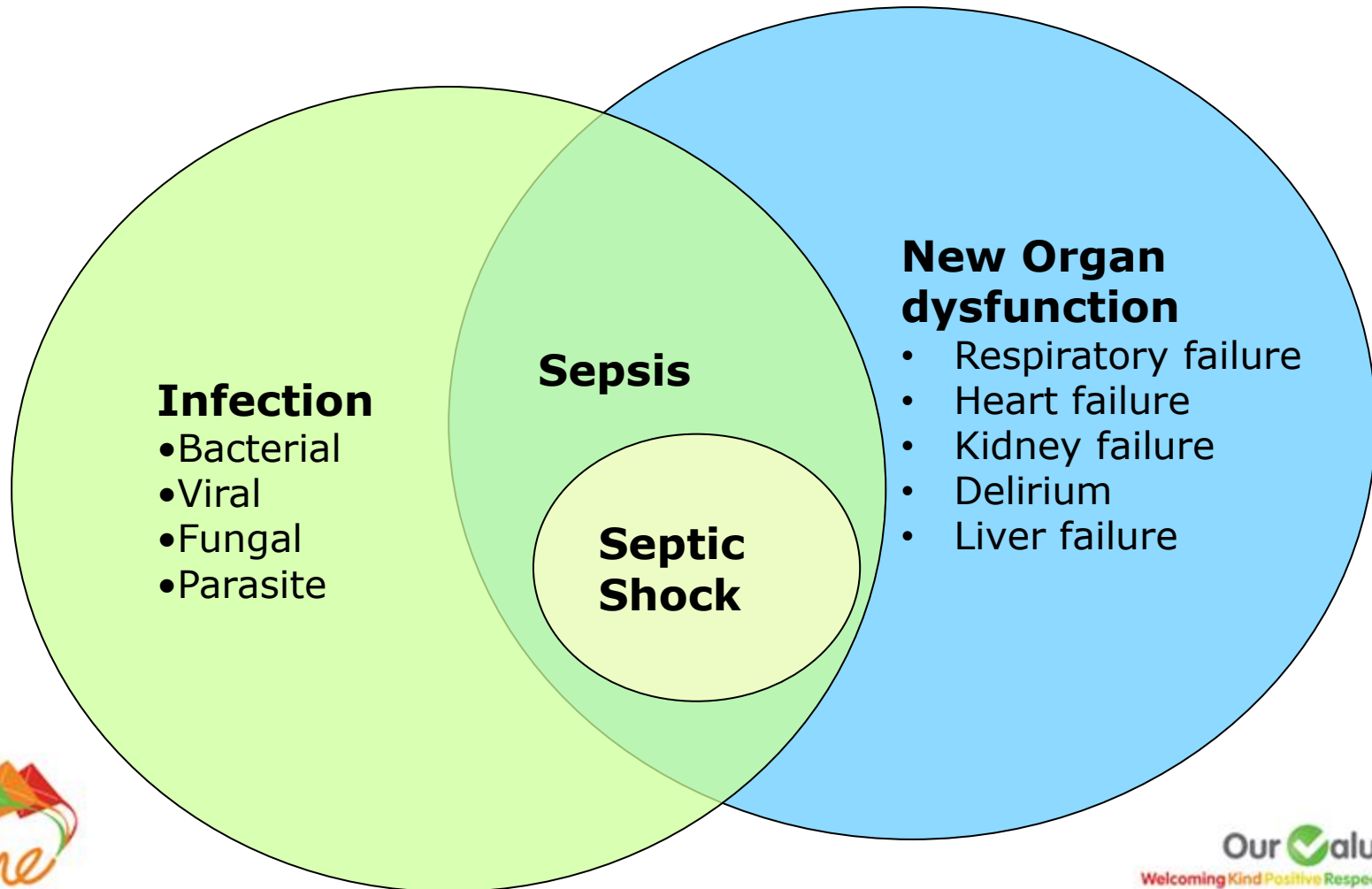


I want to find out what it is like having a serious infection or sepsis.



I want to listen to people's stories of becoming unwell, being ill and getting better.

What is Sepsis?



Sepsis Recognition and Diagnosis

- No test to confirm or rule out sepsis
- Experts disagree how to identify patients with sepsis outside of the intensive care unit (Kopczynska et al., 2018, Churpek et al., 2017).
- Diagnosis relies on bedside clinical decision-making
 - Decision that inflammatory response and subsequent organ dysfunction have most likely been triggered by infection.
- Lack of consistent diagnosis of sepsis leads to unclear documentation, which in turn affects the records of the burden of this condition (Hex et al., 2017).



Sepsis Research

- Large multicentre trial of sepsis treatment bundles, n=4329
- Increased compliance with bundles
- *“Compliance with early resuscitation elements during the first 3 hours after emergency department admission caused ineligibility, through lower subsequent severity of illness, for these later bundle elements”*(Miller, Dong et al. 2013)
- Mortality reduced from 21.2% (2004) to 8.7% (2010)
- Led to Sepsis Six – evidence base contentious



Investment in Sepsis Service Developments

- *Delay in recognition, poor documentation and failure to mention the word 'sepsis'. Clinical care could have been greatly improved.* 'Just Say Sepsis' NCEPOD (2015)
- Sepsis CQUIN 2016-2019;
- WHA adopted a resolution to improve prevention, diagnosis & management of sepsis worldwide by 2020
(World Health Assembly / WHO 2017)
- Coding changes 2018 & 2019
- NHS Long Term Plan 2019
- [Sepsis Insights \(sos-insights.co.uk\)](https://www.sos-insights.co.uk)



Vague Early Symptoms of Sepsis

- Image of the sick person
- Vasodilation; perfusion, relative hypotension – look well
- May feel awful:
 - how this is expressed & perceived will depend on function and knowledge of baseline
 - Infection as a cause of pain: pain behaviour
 - New confusion; delirium,
- Beware diagnostic overshadowing: all behaviour is communication



Recognising & Responding to Infections & Sepsis

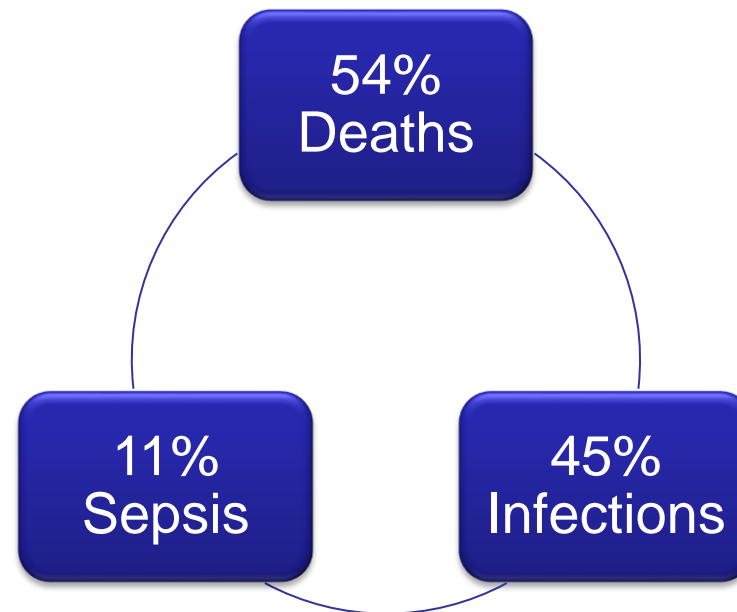
- Death by Indifference Mencap 2007
- The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) found delays and issues with diagnosis and/or treatment contributed to the premature death of people with learning disabilities (Heslop et al. 2013)
- The Learning Disability Mortality Review found that sepsis was more likely to be the cause of death amongst people with Learning Disabilities who had experienced gaps in their care thought to have led to their death (LEDER, 2018)



Learning Disability Mortality Review 2017

Table 3.5: Most common conditions identified as causes of death anywhere on Part 1 of MCCD

| Most frequent causes of death | No. | % |
|--|-----|-----|
| Pneumonia – unspecified | 140 | 24 |
| Aspiration pneumonia | 96 | 17 |
| Sepsis | 66 | 11 |
| Dementia | 34 | 6 |
| Epilepsy | 28 | 5 |
| Down syndrome | 25 | 4 |
| Cardiac arrest | 24 | 4 |
| Respiratory infection | 22 | 4 |
| Total (where cause of death is reported at notification) | 576 | n/a |



Literature Review

Systematic
search

Broad search
terms

Conducted in
2019 publications
until 31/12/18
with no earlier
time limit applied

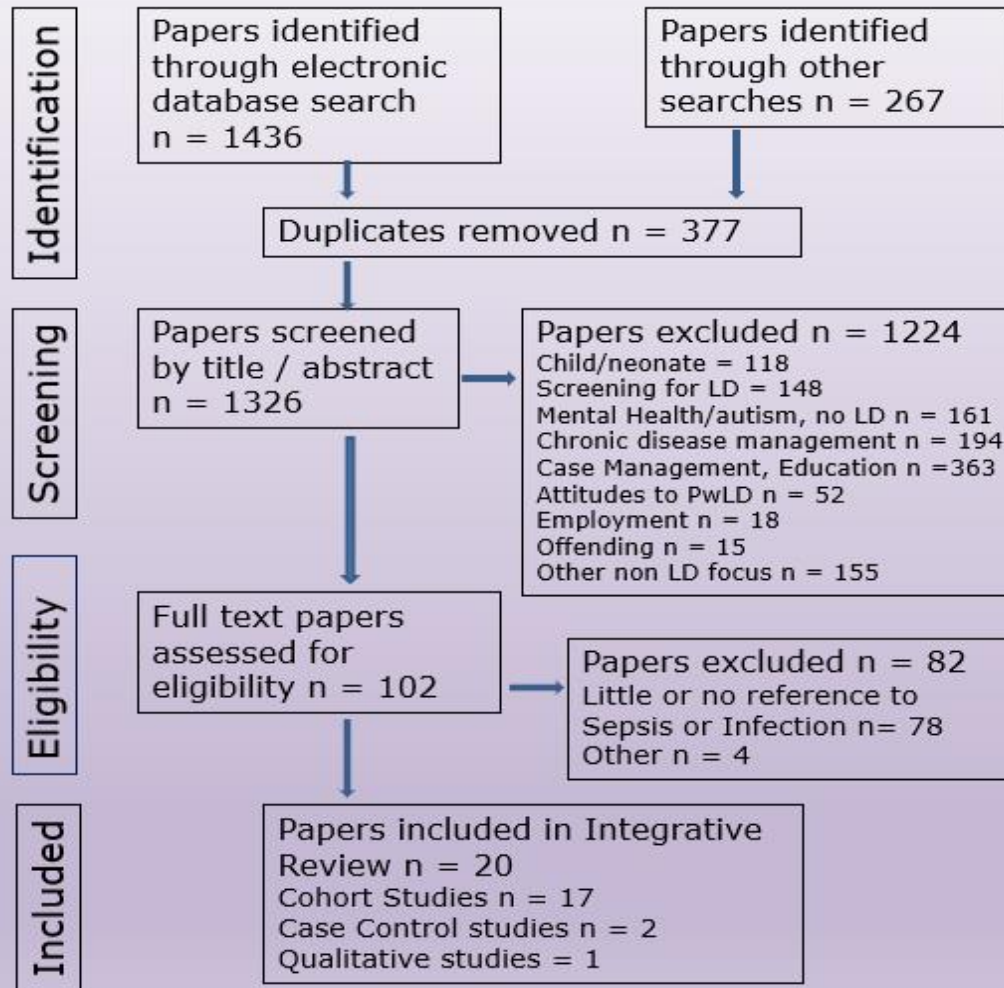
POPULATION: LEARNING DISORDERS; LEARNING DISABILITIES; INTELLECTUAL DISABILITIES; MENTAL RETARDATION; SPECIAL NEEDS; DOWN'S SYNDROME; TRISOMY 21

ISSUE & CONTEXT COMBINED: SEPSIS; SEPTIC; INFECTION; PNEUMONIA; PYELONEPHRITIS; 'UTI'; CELLULITIS; PATIENT CARE; HOSPITAL; ACUTE CARE; EMERGENCY CARE; PRIMARY CARE; PREHOSPITAL; 'GP', 'GENERAL PRACTICE'; DOCTOR; AMBULANCE; PARAMEDIC; SECONDARY CARE

OUTCOME: ATTITUDES; EXPERIENCE; PERCEPTION; VIEWS; 'PATIENT PERSPECTIVE'; 'PATIENT EXPERIENCE'



PRISMA



Findings

- People with Intellectual Disabilities are more likely to be admitted to hospital with infections and sepsis than people without Intellectual Disabilities
- People with Intellectual Disabilities are likely to stay in hospital longer than people without Intellectual Disabilities
- Residential Care workers are responsible for recognising health needs including deterioration with infection, without medical training



Findings

- Respiratory diseases including pneumonia and aspiration pneumonia are the leading causes of death amongst people with intellectual disabilities worldwide
- These are the most common triggers for sepsis, but sepsis is rarely mentioned in the literature
- Bacteraemia, organ failure and critical care admission are mentioned, all of which indicate probable sepsis
- Where it is mentioned, diagnosis with Sepsis was associated with higher mortality



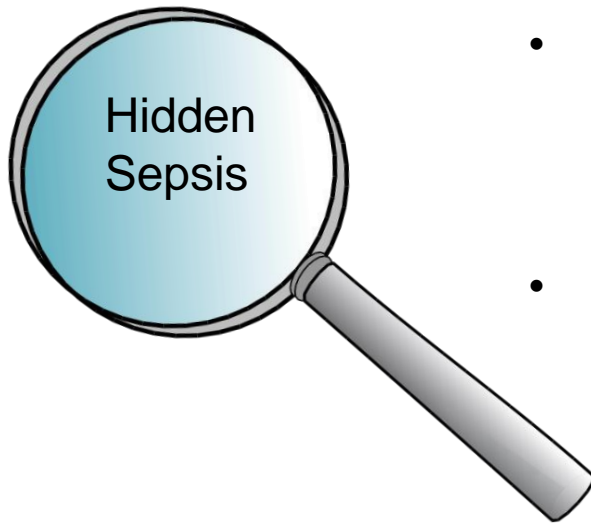
Conclusion



- Infections identified as leading causes of hospitalisation & death amongst people with learning disabilities are also those which are the most common triggers for sepsis:
- pneumonia,
- urinary tract infection
- cellulitis.

Gaps

- There was no literature found to describe the experience of infections and sepsis amongst people with Intellectual Disabilities who survive
- There was no literature found to describe the experience of informal or professional carers of people with intellectual disabilities who develop sepsis and survive
- There was no literature found to describe whether people with intellectual disabilities are receiving prompt sepsis care
- There was no literature found to describe the response to sepsis care amongst people with intellectual disabilities
- A recent review of the NIHR portfolio revealed that there are no studies focused on pneumonia and sepsis which include people with learning disabilities (Spaul, Hudson et al. 2020)



Research Question

- What is the experience of sepsis amongst people with learning disabilities and those who care for them?
- A qualitative study to explore and explain the sequence of events & intensity of illness from the person with intellectual disabilities becoming unwell with infection, through diagnosis and treatment in hospital for sepsis, to recovery.



Methodological Approach

- Qualitative approach,
 - drawing on constructivist grounded theory to explore a subject that is under researched yet common in the researcher's clinical practice as a sepsis nurse
 - The constructivist grounded theory approach sets out with an open mind to discover or generate theory
 - theory generated will be grounded in the data collected rather than testing preconceived hypotheses
- Triangulating experience from multiple perspectives



Ethics

- IRAS project ID 261521
- Mental Capacity and Informed Consent
- Confidentiality
- Risks of Coercion and Power imbalance
- Risk of causing worry or distress
- Camberwell St Giles REC
- Supportive – minor amendments imminent



Prospective Recruitment

- Stage 1
- Recruitment of People with Learning Disabilities
- Via Health Liaison Team in Hertfordshire
- Carers and Care Workers via participants
- Stage 2
- Carers and Care Workers
- Health Care Professionals





Research Participants Required

University of Hertfordshire **UH**

Nursing and Medical staff with experience of caring for people with Sepsis and Learning Disabilities

Are you willing to be interviewed about your experience of caring for a patient with learning disabilities who had sepsis?

People with learning disabilities and carers will also be interviewed about their experience of sepsis.

Gift voucher offered for participation.



Interviews will be conducted by Anne Hunt. These may be carried out face to face, by telephone or by Skype. You will not be asked for any identifiable patient information.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study we will save some of the data in case we need to check it.

We will make sure no-one can work out who you are from the reports we write. The information sheet tells you more about this.

The Experience of Sepsis amongst People with Learning Disabilities and those who care for them: a qualitative, exploratory study

If you would like to take part please contact

Anne Hunt, Deputy Director of Nursing HPFT & Doctoral Student

UH Tel: 07812 650577 anne.hunt1@nhs.net

IRAS Project ID 261521 Date 06/08/2022 V3

Sepsis Prevention

- People with learning disabilities are five times more likely to be admitted to hospital with a chest or urine infection than someone in the general population
- If a person with Learning Disabilities is unwell, always think
- *Is there an infection?*
- *Could this be Sepsis?*



Early stages of sepsis

- Flu
- Tummy upset
- Chest infection
- Call NHS 111 and say you are worried about Sepsis
- **#SaySepsis**



Practicalities: don't assume

- Can they take (antibiotic) tablets? *Just ask*
- Swallowing – size, crush, suspension
 - Can they keep them down?
 - Vomiting
- Has the patient understood?
- What to do if...
- AKI: *Think Kidneys!*
 - Sick Day Rules (Medication)



Danger signs need urgent attention

- S Slurred speech or confusion
- E Extreme shivering or muscle pain
- P Passing no urine (in a day)
- S Severe breathlessness
- I It feels like I am going to die
- S Skin mottled or discoloured
- Call 999 #SaySepsis



Don't assume Health Professionals will be looking for sepsis

- Tell them what you have noticed
- Listen to their observations / assessment but challenge if they are making assumptions
- Ask
 - *Could this be sepsis?*
 - *Will you check him/her for sepsis?*
 - *Can you explain how you have ruled sepsis out?*



Recovery from Sepsis

- Can take weeks, months, occasionally years
- Physical
 - Fatigue and/or trouble sleeping; difficulty concentrating
 - Hair loss, brittle nails; itchy & dry skin
 - New allergies or food intolerances
 - Joint pains, headaches, migraine
 - Recurrent infections
- Psychological
 - Flashbacks, PTSD



Post Sepsis Syndrome

- Around 40% of survivors of sepsis suffer at least one of a range of lasting symptoms
- Physical
 - Hair loss, allergies & intolerances, chronic pain and fatigue
- Cognitive
 - Brain fog, concentration
- Psychological
 - Fear, anxiety, PTSD





The Purple All Stars

<https://www.youtube.com/watch?v=Sw0nfCJ7Ftc&t=1s>



Thank You for listening

- Happy to take questions
- Anne.hunt1@nhs.net
- @huntanne

