

A Case Study Characterizing the Impacts of Engaging with Patient Advisory Councils on Long-Term Recovery for Sepsis Survivors and their Families.

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Background

SEPSIS IMPACT

- Life-threatening condition with global significance.
- Survivors face long-term disability and psychological sequelae. (Prescott, 2017)



FAMILY IMPACT

- Caregivers and family members can experience ongoing psychological and emotional distress, including PTSD.
- Often considered patient partners in sepsis care.



NECESSITY OF UNDERSTANDING

- Unique and persistent challenges for sepsis survivors and their families.
- Essential to comprehend factors influencing long-term recovery.

Methodology

SYSTEMATIC REVIEW (UPDATE)

- Identify tools/frameworks for evaluating patient and family partner engagement
- Inform survey questions, interview guide, and data analysis

MIXED-METHOD STUDY

- Quantitative survey to gather baseline data
- In-depth interviews to explore experiences in depth
- Sequential approach: survey informs interview topics

Systematic Review

REVIEW BY BOIVIN ET AL. (2018)

- Identified 27 tools for evaluating patient and public engagement in research and health decision-making.
- Most tools aimed to enhance engagement but lacked scientific rigor and patient input in their design and reporting.

NEED FOR AN UPDATE

- Rapid growth of patient engagement in health contexts, driven by initiatives like SPOR.
- Warrants an updated systematic review.

Data Collection

SURVEY

- Quantitative data on patient engagement experiences
- Quantitative results guide interview content
- Allows for broader insights

IN-DEPTH INTERVIEWS

- Qualitative data on personal experiences
- Explores nuances and emotions
- Provides a deeper understanding

Integrated Knowledge Translation

- Collaborative approach involving patients, researchers, and clinicians
- Ongoing patient engagement beyond the study team
- Centers patient-identified research priorities
- Enhances relevance and impact of the research



While sepsis can affect individuals across the spectrum, it disproportionately impacts those who face systemic barriers to healthcare access. We will aim to recruit a representative sample of participants, including equal representation of gender. Given the disproportionately distributed burden of caregiving and other family-based responsibilities, we will also conduct additional analyses, stratified by gender, to identify any potential differences in engaging with patient advisory councils across genders.

Implications

CLINICAL PRACTICE

- Informing patient-centered care approaches
- Enhancing survivor outcomes

RESEARCH

- Improving research quality through patient insights
- Driving patient-centered research priorities

Expected Outcomes & Future Directions

- Rich insights into sepsis survivors' and families' engagement experiences
- Understanding of the impact of engagement on long-term recovery
- Identification of areas for improvement in patient advisory councils
- Dissemination of findings to healthcare providers, researchers, and policymakers
- Potential refinement of patient engagement strategies

Further exploration of patient engagement's role in other medical contexts



What are the impacts of engaging with patient advisory councils on long-term recovery for sepsis survivors and their families?

AIM #1

Conduct a scoping review to identify a framework for evaluating patient partner engagement in patient advisory councils.

AIM #2

Explore the experiences of patient partners engaging with patient advisory councils using a mixed-methods approach, and characterize the impact on patients' long-term recovery.