

Research Question

How do clinicians perceive communicating with team members about patients in states of disordered consciousness (DoC)?

Background

- Patients with DoC following TBI present unique challenges for clinicians
 - Unable to verbally communicate needs
 - Uncertainty about prognosis
 - Limited indicators of meaningful change [1]
- Families of patient's with DoC perceive patient to be more conscious than the clinicians [2]
- Communication and collaboration that include the caregiver perspective is central to providing **person-centered care (PCC)** [3]

Study Design

- Qualitative, exploratory design
- Narrative interviewing methodology [4]

Methods

- 11 rehabilitation clinicians working in post-acute rehabilitation settings with experience treating adults with DOC following severe TBI.
 - Participants include: Occupational, Physical, Speech, & Recreational Therapists, Nursing, Psychology, Physicians, & Case Managers.
- Thematic analysis is iterative, ongoing coding develops and adjusts the themes (NVivo 11 Plus)
 - Cases of disagreement: team members discuss and re-code until consensus is reached.

Conceptual Framework

- Systems perspective [3, 5]
- Thematic & constant comparative data tools to organize and analyze the data. [4, 6, 7]

Analysis

- Thematic and Comparative methods [6]
- Line by line** open coding
 - Examples** of codes: 'collaborating with staff', 'creating rapport', 'discrepancy in interpretation', 'refusing admission', 'family tells clinician things'
- Open codes developed into axial codes (i.e. categories) that share a characteristic, pattern, feeling
 - Axial** codes explicitly describes the open codes
 - Examples** of axial codes: 'Interpretations of Patient Responses', 'Patient becomes more aware', 'Factors Influencing the Patient's Recovery', 'Communication between multi-disciplinary team members', 'Challenging Conversations with Family'.
- Axial codes help generate a theme.
- Themes** are abstractions that capture codes into a meaningful whole.
 - Examples of themes: 'clinical reasoning in the midst of uncertainty', 'clinical decision making as a trial and error process', and 'lack of clarity with clinical assessments'.
 - Uncertainty exists when describing patients' behaviors and recovery process during communication with team members

Uncertainty as a Key Feature of this Clinical Work

- The theme of uncertainty was recurrent in the interview data:
 - Describing patients' behaviors
 - Reporting patient recovery process
 - Communicating with team members & insurance organizations
 - Planning for discharge
 - Supporting families
- Uncertainty encompasses the everyday experience of these rehabilitation clinicians
- Influences how a clinicians works with this population to deliver healthcare services
- We use a systems approach to capture this theme due to its ubiquitous nature.

Theme: Uncertainty exists when describing patients' behaviors and recovery process during communication with team members

Rehabilitation clinicians and families express frustration with not knowing what health insurance will cover which impacts decision-making.

Clinicians describe the challenge of capturing change to meet the needs of the medical model. Uncertainty arises with discharge planning and selecting the next level of care.

Clinicians discuss specific clinical programs focused on disorders of consciousness that are available at their facility.

Clinicians express how wide variations in training for this population influence care and are uncertain about other clinician's interpretations of behaviors.

Clinicians describe that they expect inconsistency but look for the patient show consistency. Clinicians try interventions with the patient to see what works.

Clinicians perceive the need to work with the family. The family knows about the patients interest, but clinicians are cautious when discussing patient behaviors.

Clinicians perceive the patient's behaviors with uncertainty. Clinicians express how they talk to the patient as if they understand what is being said.

External Influences
Health insurance, Economy, Politics

Health Care System
Medical Model, Lack of care for chronic conditions, care pathways

Organizational Culture
Mission, Values, Resource Structure, Hierarchy vs. Heterarchy

Rehabilitation Culture
Cross-disciplinary team members, relationships between & within disciplines, formal & informal communication

Clinicians
Individual training, philosophy, beliefs, worldview

Family
Pre-injury relationship with patient & hope for recovery

Person with Disorders of Consciousness
Etiology, personality, medical history

"These patients tend to have lots of frustrating **roadblocks** and we didn't know how long his coverage would last...there were just a lot of **frustrating dynamics** there in terms of not being able to get straight answers to create a easy plan for the family..."

"[The families know] in our program, they are there for a limited amount of time. ...if you don't make change then you are not going to continue here."

"[Clinicians at another facility] said he was attempting to verbalize in the **previous notes** only when I went in he had that mouth movement that to an **untrained eye** I think would be misconstrued..."

"maybe something is just off today. **Fluctuation is the norm.** We don't expect consistent performance"

"[This family was] **unrealistic.** They were like 'nope he's coming home. We're going to get a ceiling track and he's going to be walking with us.' That was the **hardest as a team** to address with the family..."

"he wasn't able to verbally communicate. He would acknowledge the presence of other people...and would light up when people came into the room"

Discussion

Theme of Uncertainty

- Fluctuation** of behavior is common for this patient population.
- Clinicians are **uncertain** about interpreting patient behaviors; they express **frustration** with communicating uncertainty to families and other team members.
- Clinical assessments and their interpretations **do not provide clarity** on prognosis or diagnosis (~40% misdiagnosed) [8]
- The figure shows the multiple factors that can influence clinician communication within this healthcare delivery system

Future Directions

- New themes will emerge as more data are coded.
- Theme of uncertainty in health will facilitate future clinical trainings on effective communication to facilitate better patient outcomes
- Currently interviewing caregivers to understand their perceptions of this issue (communication).

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References

- Mallinson T, Pape T, Guernon A. (2016). Responsiveness, Minimal Detectable Change, Minimally Clinically Important Differences for the Disorders of Consciousness Scale. *Journal of Head Trauma Rehabilitation*, 31(4); E43-E51.
- Moretta, P., et al., *Caregivers' opinion about level of awareness in patients with disorders of consciousness.* Conference: 11th World Congress on Brain Injury of the International Brain Injury Association, Netherlands, 2016. *Brain Injury*, 30(5-6); p. 579-580.
- Papadimitriou C, Cott C. Client-centred practices and work in inpatient rehabilitation teams: Results from four case studies. *Disability and Rehabilitation: An International, Multidisciplinary Journal*. 2015;37(13):1135-1143.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, 5(1), 80-92.
- Sturmberg JP, Martin CM. *Handbook of Systems and Complexity in Health*. New York, NY: Springer, 2013.
- Saldana J. *The Coding Manual for Qualitative Researchers*. Third ed. Los Angeles, CA: SAGE; 2016.
- Glaser, B. G. (1965). The constant comparative method of qualitative analysis. *Social problems*, 12(4), 436-445.
- Cruse D, Chennu S, Chatelle C, et al. Bedside detection of awareness in the vegetative state: a cohort study. *Lancet (London, England)*. 2011;378(9809):2088-2094.