

Navigating the role of clinician-researcher: Insights from a Constructivist Grounded Theory study in traumatic brain injury

Stephen Kivunja, PhD Candidate^{1,2}, Julie Pryor^{1,3}, Clinical Associate Professor,
Jo River, Associate Professor^{1,4}, Janice Gullick Associate Professor¹

1. Susan Wakil School of Nursing and Midwifery, the University of Sydney, 2. Department of Neuroscience, Westmead Hospital NSW. 3. Royal Rehab NSW, 4. Faculty of Health, University of Technology



Abstract

Using the case of traumatic brain injury, this paper explores 1) challenges to academic and ethical integrity when in the role of clinician-researcher, and 2) potential strategies to enhance ethical qualitative research involving people with possible physical and/or emotional trauma and temporary or permanent cognitive disruption. When undertaking qualitative research with patients, families, and/or health professionals, a researcher's clinical background may stimulate insightful and relevant research questions, interviews, and/or field observations of care to inform meaningful and translatable practice improvements. However, there may be tension between clinician versus researcher values, and these priorities affect what the clinician sees and interprets in the field. A clinician's ingrained values and professional socialisation can make it difficult to hold their professional assumptions about various phenomena at bay. The principles of human research merit and integrity, justice, beneficence, and respect, along with methodological clarity, can provide a rigorous foundation for discussion of ethical research in traumatic brain injury.

This paper discusses challenges and strategies through: 1) examining clinical assumptions; 2) determining capacity for consent; 3) considering dependent or unequal power relationships; 4) determining the scope for field observations; 5) responding to unprofessional practice; 6) discriminating between research interviews and clinical conversations; and 7) critically reflecting on research data. Implications for clinical research are evident: seeing past one's own construct of understanding is challenging for clinician-researchers aiming to illuminate both patient and family experiences of care, and nuanced clinical skills. Careful ethical and methodological planning can protect participants while illuminating elements of specialist practice.

Keywords: Nurses, brain injury, clinician, researcher, ethics, grounded theory

Introduction

Care of people with traumatic brain injury (TBI) is complex and challenging as, depending on the severity of the head injury, TBI patients may struggle with injury-related outcomes such as physical disabilities, cognitive impairment, emotional, psychiatric, and behavioural changes, as well as social isolation (Diaz-Arrastia et al., 2017; Gould et al., 2019; Salas et al., 2018). Neuroscience nurses may, therefore, provide care to patients with reduced self-awareness and capacity to understand or follow instructions, a heightened propensity for distress, anger, and risky or challenging behaviours, and relational conflict. People with TBI may struggle to find new ways of managing activities of daily living or

to reconstruct personal identity in the face of often multiple personal losses, disability, and invisibility (Oyesanya et al., 2018; Stenberg et al., 2022). To provide quality patient care that addresses these unique challenges to recovery, neuroscience nurses increasingly seek to engage in research to understand how TBI care can be shaped in ways that improve clinical practice, systems of care and patient outcomes (Smith et al., 2018).

Questions or comments about this article should be directed to Stephen Kivunja

Email address: stephen.kivunja@sydney.edu.au

DOI: 10.21307/ajon-2021-008

Copyright © 2021ANNA

However, this specialist knowledge can also present both ethical and methodological challenges.

These include: 1) assumptions stemming from extensive clinical knowledge that may constrain critical openness toward new understandings during data collection and analysis; 2) determining capacity for consent; 3) recruiting people in dependent or unequal relationships; 4) what should (or should not) contribute to field observation data; 5) responding to unprofessional practice; 6) discriminating between research interviews and a clinical conversation; and 7) critically reflecting on research data in ways that allows for innovation (versus generating solutions only from one's current therapeutic repertoire). The systematic application of ethical and methodological strategies may help to manage the tension between the clinician-researcher's pre-existing knowledge and assumptions and the phenomenon being studied so that new understandings are enhanced by subjectivity, rather than being skewed by bias.

This paper explores ways of managing these challenges through careful ethical and methodological design. A study of social processes that promote and preserve personhood for people receiving rehabilitation care is used as a vehicle for this discussion. Reflexivity is an important basis for examining the clinician-researcher role. The primary researcher (SK) is a Clinical Nurse Specialist (CNS) in an acute neuroscience ward at a major tertiary teaching hospital, caring for people with a range of neurological conditions including TBI. Such care extends to the support of family members, providing updates, support and education about ongoing care and treatment. This doctoral research project arose from the clinician-researcher's curiosity about the lived experience of TBI and its intersection with nursing care.

Background

The multi-centre research study that provides context for this discussion paper uses Constructivist Grounded Theory (CGT) (Charmaz, 2014). Human Research Ethics Committee approval was received (Ref:2019/ETH13511) to investigate the social processes that promote and preserve personhood in TBI nursing care across three brain injury inpatient rehabilitation units in Sydney, Australia. Participants are people with TBI, family members, and nurses working in TBI inpatient rehabilitation care settings. The data collection involves either single or longitudinal one-to-one semi-structured interviews

with all participant groups, and field observations of nursing care. Data collection and data analysis occur concurrently where data coding is undertaken using the constant comparative method, a central component of CGT (Charmaz, 2014). The study addresses a gap in our understanding about giving and receiving care for TBI identified in an earlier integrative review that informed the design of this study (Kivunja et al, 2018).

Aim

The aim of this paper is to explore 1) challenges to academic and ethical integrity when in the role of clinician-researcher, and 2) potential strategies to enhance ethical qualitative research design involving people with possible physical and/or emotional trauma and temporary or permanent cognitive disruption using the case of TBI.

Methods

Framework for the discussion

In Australia, the guiding ethical framework is the "National Statement on Ethical Conduct in Human Research" from the National Health and Medical Research Council (NHMRC, 2018a). It provides guidelines for the ethical design, conduct and dissemination of results of human research. The National Statement builds upon the Declaration of Helsinki (World Medical Association, 2018) and stipulates four principles that guide ethical conduct of research: research merit and integrity, justice, beneficence, and respect (NHMRC, 2018a). These principles, along with ethical considerations specific to particular participant groups (for example, people in dependant or unequal relationships, and people with cognitive impairment), and methodological processes aligned to CGT were useful in identifying, examining, and developing strategies to facilitate navigation of the clinician-researcher role.

Discussion of challenges and strategies

There were seven challenges encountered in designing and implementing this research, and the following discussion is inclusive of research design strategies.

Challenge 1: Examining assumptions stemming from extensive clinical knowledge

The clinician-researcher (SK) is both an experienced neuroscience nurse and a doctoral researcher, with prior theoretical and clinical knowledge. He has a Masters degree in neu-

rosience nursing and has published an integrative literature review on the experiences of receiving and giving care in TBI settings (Authors blinded, 2018). His clinical experience within this field spans over ten years and equips him with a bank of clinical experiences that are related to the research topic. To a certain extent, these clinical experiences were a major challenge to the role of researcher. For example, they had potential to influence how the interview questions for people with TBI were phrased, what terminologies were chosen for participant information statements and patient and family interviews, what aspects of nursing care were chosen to observe during field data collection, and how the observed patient-nurse interactions were interpreted and reported. He navigated this challenge using the following three strategies:

Strategy 1.1 - Building ethical knowledge:

As a novice, the clinician-researcher familiarised himself with the National Statement on Ethical Conduct in Human Research (NHMRC, 2018a), the Australian Code for Responsible Conduct of Research (NHMRC, 2018b) and Good Research Practice (GRP) by attending specific GRP training, and Emotional-First Aid training.

Strategy 1.2 - Clarifying the philosophical stance:

An early determination of the chosen philosophical stance secured the assumptions under which data were to be viewed (Charmaz, 2014; Weaver & Olson, 2005). A detailed documentation of the choice of paradigm (constructivist), ontology (the multiple nature of reality), epistemology (the subjective nature of knowledge), and methodology (CGT) (Charmaz, 2014) was compiled. These choices clarify that the aim is to construct a theory that will explain a social process, that there are multiple realities reflecting multiple truths for participants, and that this knowledge is co-constructed according to apriori social understandings. Communicating these elements is fundamental to the conception and conduct of a robust study (Howes, 2017; Guba & Lincoln, 1994) and provides a solid foundation for a rigorous constructivist grounded theory investigation (Charmaz, 2014).

Strategy 1.3 - Being open minded and reflexive:

Charmaz (2014) advises that a researcher using CGT should approach their study, not as a blank slate, but as a knowledge-laden individual with an open mind. The clinician-researcher's values, priorities and positions can affect what they see and interpret in the field, and nurses' in-

grained values and intensive professional socialisation can make it difficult to hold their professional assumptions about phenomena at bay (Charmaz, 2014; Hay-Smith et al., 2016). Seeking an open mind can assist nurse-researchers in examining and alleviating such embedded philosophies or practices (Berthelsen & Hølge-Hazelton, 2017; English et al., 2022). Another strategy to maintain an open mind is working within a team with varied clinical backgrounds. Approaching analysis as a team allows team members to challenge assumptions about the data with analysis becoming more insightful due to these multiple perspectives.

To put this doctrine into practice, the clinician-researcher applied a reflexive approach, documenting an early reflexive statement as the basis for a research decision trail, or reflexive journal (Berger, 2015; Koch, 1994). This evidence documents the initial potential influences and biases arising from experiences as a nurse working in an acute neuroscience ward, and associated disciplinary idiosyncrasies (Hay-Smith et al., 2016). It also records any research related decision-making that resulted in a change in process or an emerging ethical issue (Davis, 2020; Mortari, 2015). Examples of reflective journal entries include ethical and method-related changes resulting from the SARS-CoV-2 (COVID-19) pandemic, including changes in study scope, and safe access to participants. The journal was, for example, a useful and readily accessible resource to inform the process for an interview with a participant deemed a close contact of a person with suspected COVID-19. The reflexive journal remains a dynamic document that captures the various approaches to participant recruitment, interviews, field observations, data analysis, coding, developing categories and interpretations as the study progresses. A position of reflexivity is aligned with CGT methodology to facilitate a transparent and open discussion of how a researcher is situated, relative to their data and participants (Charmaz, 2014; Davis, 2020; McGhee et al., 2007; Peddle, 2021) and is considered a criterion for rigour in qualitative reporting generally (Tong et al., 2007).

Challenge 2: Determining capacity for consent

The clinician-researcher works in a taken-for-granted way in their clinical role with vulnerable patients. They develop methods to communicate, determining preferences and including families, with a focus on safe care and recovery from an acute injury. However,

the approach required to addressing the vulnerabilities of these people as research participants required a different lens. Some of the potential patient participants would have cognitive impairment (Gorgoraptis et al., 2019; Haarbauer-Krupa et al., 2021). This required an ethical process for informed consent, given that participants were at the rehabilitation phase of care, and the dynamics of the study settings were unknown to the research team. As a measure of respect for participants, the clinician-researcher had to re-examine his clinical assumptions about cognitive impairment as a barrier to participation in scholarly activities. The strategies employed to address this challenge are as follows:

Strategy 2.1 - Redefining capacity for consent:

Considering the ethical principle of justice, the National Statement principles hold that people with cognitive impairment are entitled to be included as participants in research studies that are of benefit to them (NHMRC, 2018a). An assessment form, 'Guide to determining capacity for consent and suitability of participation' (Supplementary file 1), was developed and used for this purpose. The tool enabled identification of candidates who may be cognitively impaired but could express their wishes about things that affect them in their day-to-day life, including things they do not want to do, could participate in a simple conversation about recent events and were less likely to be distressed if a researcher sat at their bedside observing their care, or asked questions about events that led to their TBI. In line with the principle of research merit and integrity (NHMRC, 2018a; Section 4.5.1), the clinician-researcher deliberated on how the capacity for patient participation would be addressed from the perspective of a researcher, rather than that of a nurse clinician. Participant information statements clarified that consent could be withdrawn at any time and refusal to participate was respected and would not impact researcher or clinician relationships (NHMRC, 2018a; Sections 4.5.9 and 4.5.11). Ongoing consent was further confirmed during interviews: a handheld 'Stop sign' that could be raised by the participant to stop the interview or field observation was created in the understanding that it may be easy to assent to elements of participation, but harder to withdraw that consent during data collection.

Strategy 2.2 - Witnessing the consent process:

Beneficence refers to the benefits of research outweighing the risks, but cognitive impairment may hinder a person's decisions about their own best interests (Xu et

al., 2020). Consent for participation in the study was sought from participants individually (NHMRC, 2018a; Section 4.5.5), but due to issues of cognitive impairment in people with TBI, the research team determined a need for a designated patient advocate, who was external to the research team and acting in line with the patient's best interests. An advocate was considered a person with the capacity to understand the merits, risks and procedures of the research, who was independent of the research team and, where possible, knew the participant and was familiar with their condition (NHMRC, 2018a; Section 4.5.8). They may be, for example, a family member, or a clinical staff member involved in their care. In this study, the advocate, with reference to the 'Guide to determining capacity for consent and suitability of participation' (Supplementary file 1), signed the consent form (under the patient's signature) to confirm that they also had considered the potential harms arising from the patient's participation and that the patient understood enough about their participation to make a decision in their best interest.

Challenge 3: Considering dependent or unequal relationships

Navigating the role of clinician-researcher required critical examination and management of unequal relationships or perceived coercion to participate. Unequal relationships were foreseen firstly between patients and the clinician-researcher (Franco & Yang, 2021; Mauthner, 2019), who had extensive TBI nursing experience and advanced training in research, in a world where clinical knowledge is often privileged over other ways of knowing (Foucault, 1980; Eide & Kahn, 2008). Clinical knowledge is a form of 'biopower' which aligns behaviour as either normal or deviant, creating pressure for patients to conform to normative social behaviours, which may include perceived pressure to take part in research (Foucault, 1980). This power imbalance can be intensified for people with TBI who may present with a degree of cognitive impairment (Bashir, 2020; Gorgoraptis et al., 2019; Oyesanya et al. 2019; Stålnacke et al., 2019). A second form of potential power imbalance was between local senior nurse clinicians who assisted with nurse participant screening, nurse unit managers who supported the research, and potential nurse and patient participants. Nurses represent a form of power in brain injury settings, as depending on the nature of the facility and the stage of the person's recovery, they may organise almost every element of the person's day and operationalise

restrictive approaches to care. The strategies used to navigate unequal relationships are as follows:

Strategy 3.1 - Collaboration with local stakeholders: Several meetings between the research team and local senior nurses who were key contacts at each site clarified key aspects of the study to promote voluntary participation. The clinician-researcher collaborated with site senior nurses who disseminated recruitment flyers and identified potential participants (Kraft et al., 2020a). These senior nurses, who were not in supervisory roles, explained the purpose and activities related to the research. The clinician-researcher then spoke to potential participants about the study and provided them with written participant information statements. Participants were given as much time as they wished to consider participation and the clinician-researcher then returned at a negotiated date to finalise consent. The recruitment and timing of consent was negotiated with specific nurse clinicians at each site to secure the most convenient time for potential participants, and to minimise disruption to unit workflow (NHMRC, 2018a; Section 4.5.6). Only people with no previous relationship to the clinician-researcher, either professional or personal, were recruited. Purposive sampling was initially used to recruit the most suitable participants to provide data that would help answer the research questions, then as lines of inquiry emerged from the data, theoretical sampling was used to target participants who could address important parts of the developing theory, or to revisit and reinterview existing participants (Fletcher, 2019).

Strategy 3.2 - Communicating research merit and integrity (NHMRC, 2018a; Section 4.3.3): A supervisory team with expertise in CGT methodology, rehabilitation nursing and care of vulnerable populations supported development of a sound research protocol. Researcher qualifications and academic roles were listed on participant information statements. Letters of invitation to patient and family participants were signed by the Nurse Unit Manager, communicating the clinical oversight of the study by local healthcare professionals with the best interest of patients at heart. Letters inviting nurse participants were signed by the principal university research supervisor supporting an arm's length approach (Chiang et al., 2001), independent of hierarchical hospital structures.

Strategy 3.3 - Simplifying participant information: A simplified participant infor-

mation statement was designed for patient participants with possible cognitive impairment, and for patients and families, interview questions were phrased using lay terms (for example, the term 'head injury' instead of 'traumatic brain injury' or 'TBI').

Challenge 4: Determining the scope for field observation data

Another challenge for the clinician-researcher was deciding what constituted data in field observations; what to observe and what to omit for methodological, ethical and privacy reasons. One fundamental property of grounded theory is the doctrine that all is data (Glaser & Strauss, 1967); everything encountered in the field has potential to contribute data. However, early observations demonstrated a tendency to only see clinical issues that underpinned clinician practice, and privacy implications presented further constraints.

Strategy 4.1 - Developing a field observation tool: A 'Framework for field observations' was developed to allow for a structured approach to gathering observable data in the field (Lapid et al., 2021). These included the observable care needs of patients, emotional needs, things patients could either do or needed help with, how patients communicated their needs to family and nurses, how nurses communicated with patients, and what nurses/families did to support personhood. The participant information sheet noted that observations would not include personal care such as showering or toileting. Participants could request the clinician-researcher to leave if they did not wish something to be observed, and all participants had the choice to participate in interviews only.

Challenge 5: Responding to unprofessional practice

A potential ethical challenge was responding to any observed unprofessional nursing practice during field observations. This might include unsafe clinical practice, non-adherence to policies and procedures, imminent medication errors or lack of consideration for patients or family members. Although not yet encountered, the following strategies are in place:

Strategy 5.1 - Following mandatory reporting guidelines: Mandatory notification guidelines for healthcare professionals in relation to unprofessional practice that endangers the health, safety, and wellbeing of patients are stipulated by the Australian

Health Practitioner Regulation Agency (AHPRA, 2020). One benefit of being a clinician-researcher is that they can interrupt poor and potentially dangerous practice. In recognising both notifiable behaviour, but also unprofessional practice that would not meet the threshold for mandatory notification, the following statement was included in the nurse participant information sheet:

"If during an observation, the researcher notes an imminent safety issue such as a likely fall or medication error, he would raise this immediately with you so you could respond to the safety issue yourself. If the researcher observes something that constitutes "Notifiable behaviour... (e.g., intoxication, sexual misconduct, or significant departure from accepted professional standards that has placed the public at risk)" he would seek advice before making any notification. Behaviour that is unprofessional in some way but not unsafe would be considered part of the confidential research data. In all cases, the researcher would aim to manage the situation in a respectful and just way"

Challenge 6: Discriminating between a research interview and a clinical conversation

A challenge for the clinician-researcher in the interview phase was to recognise how a qualitative research interview differs in purpose and structure from a clinically focused conversation with a patient. This required careful construction of an interview guide, and careful consideration of choice of terminologies, the location and duration of interviews, and how to manage moments of distress (DeJonckheere et al., 2019; DiCiccio-Bloom & Crabtree, 2006; Josselson, 2013). The following strategies addressed this challenge:

Strategy 6.1 – Drawing on prior knowledge, clinical experience and consumer engagement: The initial interview guide was informed by the clinician-researcher's clinical expertise in TBI, findings of the team's integrative review and feedback from consumer engagement (a patient and spouse with lived experience of TBI). Consumer input was valuable for incorporating TBI consumer-related concepts into the interview guide (Australian Clinical Trials Alliance, 2018; Brett et al., 2014; Kraft et al., 2020b; Miller et al., 2017) and drew attention to clinical jargon in interview and recruitment documents. Acknowledging respect for participants' intrinsic value (NHMRC, 2018a), inter-

view questions explored participants' beliefs, customs, and cultural heritage.

Strategy 6.2 - Performing pilot interviews:

Two pilot interview sessions with neuroscience nurse colleagues were conducted using the draft interview guide and these verbatim transcripts were critiqued by members of the research team. Pilot interviews with peers give insight into clarity of questions, language, and active listening skills prior to commencing data collection (McGrath et al., 2019). They can sensitise the interviewer to effective use of prompts, following up on key topics, and pausing to allow participants space to consider their thoughts and answers. Reflection of content and feelings helped to check for understanding and communicate active listening. In CGT, interview guides evolve according to the researcher's developing theoretical sensitivity, as they follow emerging lines of inquiry from previous interviews (Charmaz, 2014; Colon et al., 2015). Interview guides are continuously reviewed and updated so that emerging lines of inquiry inform theoretical sampling (subsequent participants are sought to explore specific emergent issues for examination) (Charmaz, 2014).

Strategy 6.3 - Being mindful of interview duration:

TBI can impact a person's capacity for concentration (Stålnacke et al., 2019). Though the anticipated duration was 30-60 minutes, there was provision for pausing, stopping, and rescheduling interviews where needed. The clinician-researcher's experience made him attuned to subtle patient cues of tiredness or inattention. Interview schedules were negotiated and planned for periods when patients were less likely to be tired, such as before exercises, physiotherapy or energetic recreational activities (NHMRC 2018a; Section 4.4.5; Sigstad et al., 2014).

Strategy 6.4 - Preparing to manage distress:

Given the potential for discomfort or distress during interviews that involve recollection of traumatic events (NHMRC, 2018a; Section 4.5.2; Sander et al., 2013) a 'Participant Distress Protocol' was developed (Supplementary file 2) to guide actions in response to either a self-limiting or extended period of distress.

Challenge 7 - Critically reflecting on research data

A final challenge for the clinician-researcher was to critically reflect on research data, using the lens of a researcher rather than that

of a nurse clinician. The following strategies helped to overcome this challenge:

Strategy 7.1 - Memoing: Memo writing is a key strategy in CGT; it prompts and supports researchers to construct codes and categories earlier in the research process to support the abstraction of novel theoretical ideas (Charmaz, 2014). Memos can be documented in the reflexive journal (Bowen, 2009; Charmaz, 2014).

Strategy 7.2 - Analysing data in a team environment: The clinician-researcher regularly engaged with the research supervisors through collaborative analysis and team dialogue. This enabled refinement of codes and critical feedback on the developing categories. When early codes were interpreted through the nurse-clinician eyes, the supervisors continually challenged this narrow perspective, to encourage routine critical questioning of clinician assumptions, so as to remain open and theoretically sensitive to the unfolding theory (Berger, 2015; Charmaz, 2014; Glaser, 1978). This researcher triangulation brings multiple perspectives to data analysis, which is a strength in qualitative research.

Conclusion

Neuroscience nurses who function in the role of clinician-researcher can face several ethical and methodological challenges. Use of the National Statement on Ethical Conduct in Human Research helps to embed the values and principles of ethical conduct: respect for human beings, research merit and integrity, justice and beneficence to develop research practices underpinned by trust, accountability and ethical equality (NHMRC, 2018a). In the study discussed here, ethical considerations specific to patients with TBI, their family members and/or nurses who care for them included people in unequal or dependent relationships, and people with cognitive impairment. Elements of CGT, such as openness, reflexivity and memoing supported the clinician-researcher to challenge previous clinical assumptions and move from concrete clinical thinking to abstraction of novel theoretical ideas.

Acknowledgements

We would like to acknowledge the Westmead Charitable Trust Nursing and Midwifery Career Development Scheme for the research grant that is supporting the primary study.

The authors report no conflict of interest related to this manuscript

References

- Australian Clinical Trials Alliance (ACTA). (2018). Consumer involvement and engagement toolkit. <https://involvementtoolkit.clinicaltrialsalliance.org.au/>
- Australian Health Practitioners Regulation Agency (AHPRA). (2020). Guidelines: mandatory notifications about registered health practitioners. Retrieved January 19, 2022 from <https://www.ahpra.gov.au/Notifications/mandatorynotifications/Mandatory-notifications.aspx>
- Bashir, N. (2020). The qualitative researcher: the flip side of the research encounter with vulnerable people. *Qualitative Research*, 20(5), 667- 683. <https://doi.org/10.1177/1468794119884805>
- Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234. <https://doi.org/10.1177/1468794112468475>
- Berthelsen, C. B., & Hølge-Hazelton, B. (2018). Caught between a rock and a hard place: An intrinsic single case study of nurse researchers' experiences of the presence of a nursing research culture in clinical practice. *Journal of Clinical Nursing*, 27(7-8), 1572-1580. <https://doi.org/10.1111/jocn.14209>
- Bowen, G.A. (2009). Supporting a grounded theory with an audit trail: an illustration. *International Journal of Social Research Methodology*, 12(4), 305-316. <https://doi.org/10.1080/13645570802156196>
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations*, 17(5), 637-650. <https://doi.org/10.1111/j.1369-7625.2012.00795.x>
- Chiang, V. C., Keatinge, D., & Williams, A. K. (2001). Challenges of recruiting a vulnerable population in a grounded theory study. *Nursing & Health Sciences*, 3(4), 205-211. <https://doi.org/10.1046/j.1442-2018.2001.00090.x>
- Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: Sage.
- Conlon, C., Carney, G., Timonen, V., & Scharf, T. (2015). "Emergent reconstruction" in grounded theory: learning from team

- based interview research. *Qualitative Research*, 15(1), 39–56. <https://doi.org/10.1177/1468794113495038>
- Davis, D. (2020). Presenting research reflexivity in your PhD thesis. *Nurse Researcher*, 28(3), 37–43. <https://doi.org/10.7748/nr.2020.e1644>
- DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, 7(2), e000057–e000057. <https://doi.org/10.1136/fmch-2018-000057>
- Diaz-Arrastia, R., Dreier, J. P., Duhaime, A.-C., Ercole, A., Giacino, J., Laureys, S., ... Parizel, P. M. (2017). Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *Lancet Neurology*, 16(12), 987–1048. [https://doi.org/10.1016/S1474-4422\(17\)30371-X](https://doi.org/10.1016/S1474-4422(17)30371-X)
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314–321. <https://doi.org/10.1111/j.1365-2929.2006.02418.x>
- Eide, P., & Kahn, D. (2008). Ethical issues in the qualitative researcher-participant relationship. *Nursing Ethics*, 15(2), 199–207. <https://doi.org/10.1177/0969733007086018>
- English, W., Gott, M., & Robinson, J. (2022). Being reflexive in research and clinical practice: a practical example. *Nurse Researcher*, 30(2), 30–35. <https://doi.org/10.7748/nr.2022.e1833>
- Fletcher, J. R. (2019). Negotiating tensions between methodology and procedural ethics. *Journal of Gerontological Social Work*, 62(4), 384–391. <https://doi.org/10.1080/01634372.2018.1564718>
- Foucault, M. (1980). *Power/Knowledge: Selected Interviews and Other Writings 1972–1977*. Colin Gordon, ed. Brighton: Harvester
- Franco, P., & Yang, Y. N. (2021). Exiting fieldwork “with grace”: reflections on the unintended consequences of participant observation and researcher-participant relationships. *Qualitative Market Research*, 24(3), 358–374. <https://doi.org/10.1108/QMR-07-2020-0094>
- Gorgoraptis, N., Zaw-Linn, J., Feeney, C., Tenorio-Jimenez, C., Niemi, M., Malik, A., ... Sharp, D. J. (2019). Cognitive impairment and health-related quality of life following traumatic brain injury. *Neuro Rehabilitation*, 44(3), 321–331. <https://doi.org/10.3233/NRE-182618>
- Glaser, B. G. (1978). *Theoretical sensitivity: advances in the methodology of grounded theory*. Mill Valley, California: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory; strategies for qualitative research*. Chicago: Aldine Pub. Co.
- Gould, Hicks, A. J., Hopwood, M., Kenardy, J., Krivonos, I., Warren, N., & Ponsford, J. L. (2019). The lived experience of behaviours of concern: A qualitative study of men with traumatic brain injury. *Neuropsychological Rehabilitation*, 29(3), 376–394. <https://doi.org/10.1080/09602011.2017.1307767>
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). London, England: Sage.
- Gullick, J. (2017). Participant observation: A method to evaluate a nursing research community of practice. *SAGE Research Method Cases*. <http://dx.doi.org/10.4135/9781473997875>
- Haarbauer-Krupa, J., Pugh, M. J., Prager, E. M., Harmon, N., Wolfe, J., & Yaffe, K. (2021). Epidemiology of Chronic Effects of Traumatic Brain Injury. *Journal of Neurotrauma*, 38(23), 3235–3247. <https://doi.org/10.1089/neu.2021.0062>
- Hay-Smith, E. J. C., Brown, M., Anderson, L., & Treharne, G. J. (2016). Once a clinician, always a clinician: a systematic review to develop a typology of clinician-researcher dual-role experiences in health research with patient-participants. *BMC medical research methodology*, 16(1), 95–95. doi:10.1186/s12874-016-0203-6
- Howes, L.M. (2017). Developing the methodology for an applied, interdisciplinary research project: documenting the journey toward philosophical clarity. *Journal of Mixed Methods Research*, 11(4), 450–468. <https://doi.org/10.1177/1558689815622018>
- Josselson, R. (2013). *Interviewing for Qualitative Inquiry: A Relational Approach* (1st ed.). New York: Guilford Publications.
- Authors Blinded (2018). *Journal of Clinical Nursing*

- Kivunja, S., River, J., & Gullick, J. (2018). Experiences of giving and receiving care in traumatic brain injury: An integrative review. *Journal of Clinical Nursing*, 27 (7-8), pp 1304-1328. <https://doi.org/10.1111/jocn.14283>
- Koch, T. (1994). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 19(5), 976-986. <https://doi.org/10.1111/j.1365-2648.1994.tb01177.x>
- Kraft, S. A., Duenas, D. M., Lewis, H., & Shah, S. K. (2020a). Bridging the researcher-participant gap: A research agenda to build effective research relationships. *American Journal of Bioethics*, 20(5), 31-33. <https://doi.org/10.1080/15265161.2020.1745936>
- Kraft, S. A., Rothwell, E., Shah, S. K., Duenas, D. M., Lewis, H., Muessig, K., ... Wilfond, B. S. (2020b). Demonstrating "respect for persons" in clinical research: findings from qualitative interviews with diverse genomics research participants. *Journal of Medical Ethics*, 47(12), e8-e8. <https://doi.org/10.1136/medethics-2020-106440>
- Lapid, M. I., Clarke, B. L., Ho, J. B., Ouellette, Y., Armbrust, T. L., & Wright, R. S. (2021). Research involving participants with impaired consent capacity. *Mayo Clinic Proceedings*, 96(11), 2806-2822. <https://doi.org/10.1016/j.mayocp.2021.04.029>
- Mauthner, N. S. (2019). Toward a posthumanist ethics of qualitative research in a big data era. *The American Behavioral Scientist*, 63(6), 669-698. <https://doi.org/10.1177/0002764218792701>
- McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60(3), 334-342. <https://doi.org/10.1111/j.1365-2648.2007.04436.x>
- McGrath, C., Palmgren, P. J., & Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews. *Medical Teacher*, 41(9), 1002-1006. <https://doi.org/10.1080/0142159X.2018.1497149>
- Miller, C. L., Mott, K., Cousins, M., Miller, S., Johnson, A., Lawson, T., & Wesselingh, S. (2017). Integrating consumer engagement in health and medical research - an Australian framework. *Health Research Policy and Systems*, 15(1), 9-9. <https://doi.org/10.1186/s12961-017-0171-2>
- Mortari. (2015). Reflectivity in Research Practice: An overview of different perspectives. *International Journal of Qualitative Methods*, 14(5), 160940691561804. <https://doi.org/10.1177/1609406915618045>
- National Health and Medical Research Council (2018b). The Australian Code for the Responsible Conduct of Research 2018. Retrieved from <https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018#block-views-block-file-attachments-content-block-1>
- National Health and Medical Research Council (2018a). The National Statement on Ethical Conduct in Human Research (2007). Retrieved from https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#toc__95
- Oyesanya, T. O., & Thomas, M. A. (2019). Strategies nurses use when caring for patients with moderate to severe traumatic brain injury who have cognitive impairments. *Journal of Clinical Nursing*, 28(21-22), 4098-4109. <https://doi.org/10.1111/jocn.14958>
- Peddle, M. (2021). Maintaining reflexivity in qualitative nursing research. *Nursing Open*. <https://doi.org/10.1002/nop2.999>
- Salas, C. E., Casassus, M., Rowlands, L., Pimm, S., & Flanagan, D. A. J. (2018). "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychological Rehabilitation*, 28(7), 1161-1178. <https://doi.org/10.1080/09602011.2016.1247730>
- Sander, A. M., Maestas, K. L., Clark, A. N., & Havins, W. N. (2013). Predictors of emotional distress in family caregivers of persons with traumatic brain injury: A systematic review. *Brain Impairment*, 14(1), 113-129. <https://doi.org/10.1017/BrImp.2013.12>
- Sigstad, H. M. H. (2014). Characteristic interviews, different strategies: Methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities. *Journal of Intellectual Disabilities*, 18(2), 188-202. <https://doi.org/10.1177/1744629514523159>
- Stenberg, M., Stålnacke, B.-M., & Saveman, B.-I. (2022). Family experiences up to seven years after a severe traumatic brain injury-family interviews. *Disability and Rehabilitation*, 44(4), 608-616. <https://doi.org/10.1080/09638288.2020.1774668>
- Smith, S., Gullick, J., Ballard, J., & Perry, L. (2018). Clinician researcher career pathway

for registered nurses and midwives: a proposal. *International Journal of Nursing Practice*, 24(3), e12640–n/a. <https://doi.org/10.1111/ijn.12640>

Stålnacke, B.-M., Saveman, B.-I., & Stenberg, M. (2019). Long-term follow-up of disability, cognitive, and emotional impairments after severe traumatic brain injury. *Behavioural Neurology*, 2019, 9216931–9216937. <https://doi.org/10.1155/2019/9216931>

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>

Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, 53(4), 459–469. <https://doi.org/10.1111/j.1365-2648.2006.03740.x>

Webster, J., Taylor, A., & Balchin, R. (2015). Traumatic brain injury, the hidden pandemic: A focused response to family and patient experiences and needs. *South African Medical Journal*, 105, 195 - 198. <https://doi.org/10.7196/SAMJ.9014>

World Medical Association (WMA). (2018). WMA Declaration of Helsinki -ethical principles for medical research involving human subjects. <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>

Xu, A., Baysari, M. T., Stocker, S. L., Leow, L. J., Day, R. O., & Carland, J. E. (2020). Researchers' views on, and experiences with, the requirement to obtain informed consent in research involving human participants: a qualitative study. *BMC Medical Ethics*, 21(1), 2808–2822. <https://doi.org/10.1186/s12910-020-00538-7>

ORCIDs

Stephen Kivunja: <https://orcid.org/0000-0002-0088-9239>

Clinical Associate Professor Julie Pryor: <https://orcid.org/0000-0003-4907-8530>

Associate Professor Jo River: <https://orcid.org/0000-0002-5270-4013>

Associate Professor Janice Gullick: <https://orcid.org/0000-0002-9878-5533>



10-11 November 2022
ANNA Conference

'Diving into Neuroscience Nursing – Just Keep Swimming'

Supplementary file 1

Guide to determining capacity for consent and suitability for participation

Title of the research:

Social processes that promote and preserve personhood in traumatic brain injury nursing care

Participation in field observations of care with proxy consent

- Is this person likely to be easily distressed if a researcher is sitting in proximity to the bed space observing their care?

Participation in field observations and / or interviews (patient consent)

- Is this person likely to be easily distressed if a researcher is sitting in proximity to the bed space observing their care?
- Is this person likely to be easily distressed if a researcher asks them questions about their injury and nursing care?
- Can this person express their wishes about things that affect them in their day-to-day life? E.g., things they don't want to do
- Can this person conduct a simple conversation about recent events in their life?

Supplementary file 2

PARTICIPANT DISTRESS PROTOCOL**RESEARCH PROJECT**

Social processes that promote and preserve personhood in TBI Nursing Care

A guide for management in the case of a participant's emotional distress during or after the interview.

1. It is recognised that research participants discussing emotive topics in in-depth interviews may become emotionally distressed. In such instances the following management will occur.

Scenario	Action
The participant has a short, self-limiting period of emotion in response to a difficult topic	<ol style="list-style-type: none"> 1. Pause the interview 2. Ask the participant if they would like to take a break or stop the interview completely 3. If the participant expresses a wish to continue the interview and is able to do so without undue distress, allow them to do so 4. If the participant wishes to stop the interview, ask if they would like to continue the interview at a later time or date or withdraw from the study. 5. At the end of the interview, explore the five elements of psychological first-aid (safety, calm, connectedness, self/group - efficacy and hope) 6. Offer to refer them to the counselling support programme at the site Hospital.
The participant has an extended period of emotional distress.	<ol style="list-style-type: none"> 1. Stop the interview 2. Ask if they would like you to call a support person 3. Stay with the participant until they are calm. 4. Explore the five elements of psychological first-aid (safety, calm, connectedness, self/group -efficacy and hope) 5. Refer them, with their permission, to the 'Employee Assistance Program (staff participants) or to the social worker or psychologist for the TBI Unit (patient and family participants). 6. In the case of a patient participant, significant distress will trigger immediate cessation of the interview or observation. We will thank the participant for their time and will destroy any data collected and withdraw the participant from the study. 7. Call the next day to check on their well being 8. Offer them the option to withdraw from the study. 9. Report to the ethics committee as an adverse event.