



Trauma-Informed Research Ethics

A literature review

About the authors

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Introduction

In 2021 Centric embarked on a project to look at why communities in Lambeth, Southwark and Lewisham were becoming increasingly sceptical of healthcare services and medical institutions. Two of the primary insights from that project were: people had been through traumatic experiences while in healthcare settings – which impacted their trust in health services, and also black women had distrust and cynicism of healthcare services as a result of poor maternal health experiences.

It was evident that there was distrust in healthcare institutions, systems and services indicative of the the **current crisis of epistemic trust** (Goldenberg, 2021) facing public health reflective of the wider societal trend of distrust of government (Hardin, 2004: 4), politics (Claude and Hawkes, 2020), science and media (Birkhead et al., 2022: 269; Warner and Lightfoot, 2014: 452; Stoto et al., 1996: 11).

In previous papers we have looked at both trauma-informed practice and trauma-informed digital design. This piece however will explore trauma-informed ethics for research, and if there are any ethical codes for trauma-informed research beyond respect for the individual; non-maleficence (i.e. 'do no harm'); beneficence; justice and informed consent. In such a framework, trauma-informed ethics could include active signposting for participants, embedded reflection for researchers, continuous learning, advocacy and deeper consideration of positionalities and boundaries.



Ethical Issues When Working with Trauma

A research process may cause anxiety, especially for those who have had experiences of abuse, violence and adversity. Without taking due care of these factors, communities and individuals will be less likely to participate in research as they may feel harmed. Edelman (2022) for instance emphasises that when those undergoing adversity are unable to participate in health and social care research, this then has a knock-on effect on designing preventative health interventions.

Matos et al. (2023) also note that there is 'community research fatigue', as they found in their research project with Syrian refugees in Portugal, hence there are key ethical considerations when conducting research with people who have experienced trauma.

Firstly, it is useful for researchers to be able to identify helpful approaches rather than harmful treatment. Next, is being able to assess for self-harm or suicidal ideation. Utilising accurate diagnosis and assessment tools' practice within national legal frameworks (Rosenbaum et al., 2006) which includes when to break confidentiality, reporting (to a designated safeguarding lead), signposting, safeguarding etc.

These were systems put in place since 2019 when Centric Community Research was initially incubated.

Ethical principles such as 'Do No Harm', in a trauma-informed context will include avoiding processes that could cause triggers, and hence being aware of any potential triggers and a researcher avoiding anything which would cause retraumatisation.



Why is Being Trauma-Informed Useful When Engaging Communities in Research?

Co-producing knowledge is appropriate for intervention development aimed at specific communities or populations which are prone to particular health conditions. Edelman (2022) notes that a trauma-informed and intersectional approach can ensure that both health inequalities are not reinforced, and that seldom-heard groups can influence research design.

Like other commentators, Edelman also notes that in recent years, research co-production has gained more traction as co-producing knowledge via partnerships between communities and academia becomes more commonplace. Therefore, based on our experiences in community research, a trauma-informed approach for sensitive research (Campbell et al., 2019):

- Understands the significance and impact of trauma and hence researchers should be prepared to listen to these narratives.
- Signposts and identifies resources to support any recovery.
- Extols empowerment of participants who have experienced traumatic events.
- Places control and choice in the hands of participants, which extends to data sharing.
- Upholds equitable relationships to avoid power imbalances and highlights participant rights when recruiting for a research project.
- Seeks to facilitate safe, open, transparent spaces where data collection is more respectful.
- Aims to reduce retraumatisation and hence steers clear of intrusive trigger questions and processes. Thus, data protection is outlined from the outset.
- Employs a culturally competent approach and so graded language is utilised which is clear.
- Allows for extended participant recruitment, as sensitive research topics may require time and delay if prospective participants have been recently traumatised.



Edelman (2022) proposed a framework which merged trauma-informed approaches and resilience, and hence developed the 'TRIRPP' model. Herein, trauma is positioned as part of the adversity context in which resilience may emerge.

A key assumption of TRIRPP is that the research context itself can exacerbate or present new adversities such that "an individual's needs for special protections in the research context depend...on the particular features of the research protect and environment in which it is taking place" (Levine et al., 2004: 47).

Approaching Research Projects with Trauma-Informed Ethics

Study participation from ‘tame populations’ who have little say and may even feel coerced into participating in a project, can merely serve to perpetuate unequal findings and thereby poor interventions. Centering trauma-informed ethics aims to improve engagement by recognising trauma, its signs, symptoms and preventing retraumatisation.

If careful consideration is not made, a research project may re-traumatise those with trauma or face chronic adversities. Trauma and resilience informed research principles and practice therefore invites the researcher to think more deeply about the context and processes via which participant recruitment, data collection and dissemination are conducted. Research interviews may lead to participants who have experienced trauma to relive those events, and this can cause feelings of anger, shame, fear etc. (Seedat et al., 2004; 262). Research interviews therefore that elicit traumatic memories can worsen psychological distress.



Experiences in Research for People Who Have Experienced Trauma

There are potential risks associated with research participation for people who have experienced trauma. A few studies have found an association between participation-related distress reactions and those with more severe PTSD symptoms or higher levels of depression (Legerski and Bunnell, 2010: 431).

Although often difficult to access them (Miralles et al., 2022; Buchanan and Denyer, 2015), many participants in trauma-related research report positive feelings about their experiences of participation. Participants report benefitting from the opportunities to discuss their challenges or experiences in a non-judgemental manner and without fear or condemnation (Seedat et al., 2004: 262). Participants who have had traumatic experiences also report feelings of recognition and validation by being able to share their stories and narratives in a manner that could help others. The discussion of past negative experiences is unlikely to be the same as retraumatisation (Legerski and Bunnell, 2010: 431).

Matos et al. (2023) explored narrative accounts of traumatic experiences, and they found that although follow-up protocols were often time-consuming and emotionally draining, participants reported feeling thankful, reassured of the purpose of their contribution and empowered “as they reclaimed control over their life story and, as some shared, found purpose in their suffering”.

Matos et al. (2023) also note that only a few participants involved in trauma research have reported retraumatisation and that most survivors of trauma find value in contributing to knowledge creation that can help others. And “where narrative methods are used, participation can offer an empowering opportunity for individuals to regain control over their life stories and promote agency and healing.”



How Can Researchers Better Incorporate Trauma-Informed Ethics in Research?

Twenty years ago, Seedat et al. (2004: 265) noted that participants must be informed at the start of interviews that they can refuse to answer any questions they may not want to and that they can terminate the interview at any time.

This has been utilised at the outset for any interviews which Centric Community Research have conducted over the last four years. Hence, trauma and violence-informed interviews allow participants to:

- skip questions.
- end the interview early.
- take breaks and then return when appropriate.
- have a support person with them.

While the researcher must:

- ensure participant confidentiality and safety.
- check to end conversation if interview is interrupted.
- use coded language.
- offer compensation that arouses less suspicion.
- offer resource sheets (participant info sheet).
- identifying support services.

There may be instances for instance when a researcher is concerned about a participant's safety. Loud noises being heard in the background, followed by silence, or there may be a prior abuse history, or there could be an abrupt interruption of the conversation. All of this indicates that risk must be assessed along with effective responsive action.



Community Researcher Wellbeing as a Pivotal Component of Trauma-Informed Research Ethics

Institutional Review Boards and Ethics Committees largely provide bog standard advice and often give scant attention to support systems for those conducting research with survivors of trauma, abuse and violence, or research in volatile contexts. Institutional bodies and academic institutions however are not necessarily well-placed when it comes to their gatekeeping of vulnerable participants (Burgess-Proctor, 2015: 125) and are hesitant to accept research proposals which explore sensitive and traumatic events even when no ethical violations are likely (Legerski and Bunnell, 2010: 430). Ethics committees therefore may offer unreasonable and unrealistic safeguards that merely serve to disenfranchise vulnerable participants, such as refugees for instance, thereby reinforcing oppression, silence and paternalism. Matos et al. (2023) note that “strict compliance with fixed ethical principles may set unrealistic expectations and place undue burden on researchers”.

Conducting research in traumatising environments involves intense and upsetting encounters of injustice and suffering, which may leave the researcher feeling guilty and exhausted (Miralles et al., 2022). Researchers may need to make ‘in the moment’ ethical deliberations regarding listening to difficult stories of abuse, the wellbeing of participants and the integrity of the research project. As a result, there must be time for reflection and debriefing of their experiences to develop their judgement, skill and practice. Given the nature of research with participants who have been through such experiences this can lead to secondary traumatic stress for researchers. This is also known as ‘compassion fatigue’ and also ‘vicarious trauma’, the latter being a term coined by Pearlman and Saakvitne (1995) and refers to secondary exposure to trauma content on direct service providers, including clinicians, therapists and humanitarian workers (Matos et al., 2023). In this way, trauma workers may display symptoms that mirror those of the client.

Vicarious trauma among researchers can occur while conducting research on trauma-related subjects. Researchers may be at risk because they are limited to researching and analyzing without offering direct assistance or allowing space for further reflection with a team or supervisor.



Circumstances that can contribute to vicarious trauma among researchers:

- the level of which a researcher engages with the narratives and issues they listen to and imbibe.
- continued listening of narratives of abuse and violence, yet unable to intervene while in such a detached data collector role.
- a researcher's sense of their own safety and security while gathering data in unknown locations and when speaking to those involved in crimes or violence.

Indicators of vicarious trauma among researchers: feeling powerless; not wanting to engage in researching topic; anxiety and depression; loss of empathy and numbness. Research managers and supervisors can mitigate vicarious trauma as follows:

- Allowing for breaks from traumatic material
- Taking a 'mental health day off' (Matos et al., 2023).
- Encouraging self-care among researchers, via exercise, massage therapy, sauna, entertainment etc.
- Providing reflective practice and supervision session; developing policies and procedures related to caring for the research team, i.e. maximum number of interviews to conduct per day etc.
- informing prospective researchers as to the content of upcoming research projects and potential issues if this will be difficult for researchers to conduct.



Cultural Humility in Trauma-Informed Ethics

Trauma-informed frameworks can also merge with conceptual perspectives such as cultural humility. Cultural humility refers to “a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals.” (Foronda et al., 2015; 213). Cultural humility when imbibed by researchers empowers the agency of participants in a research project. This also allows for true co-creation of knowledge as participants can be more freely involved to the process and uncover insights which would otherwise be below the radar. The key principles of cultural humility are: institutional accountability; changing power imbalances; critical self-reflection and life-long learning.



Trauma-Informed Engagement Solutions

A ‘third space’ where deep exchanges between researchers and participants occur based on reflections on their similarities and differences and then develop authentic connections. Serrano et al. (2023) note that such reciprocal exchanges do not sit easy with researchers (Knox and Hill, 2003) yet they can be relevant for marginalised groups who have experienced trauma and for whom relational space is key for mitigating potential harm.

The challenges of establishing these relationships and building relational equity with communities who are usually distrustful or have experienced trauma will be discussed in a forthcoming piece.

Conclusion

Researchers and participants cannot necessarily know beforehand what level of distress will lead to an adverse reaction from a participant. The determination of consent must be recognised as an ongoing process subject to renegotiation and withdrawal at any time – this was something that Centric Community Research have implemented since its initial incubation in 2019. Researchers may face these challenges: creating emotional spaces for the empowerment of participants experiencing distress; navigating unexpected disclosures that are potentially harmful or illegal, and respecting cultural norms within communities.

A researcher can assume a support role by assessing wellbeing, checking if participant wants to continue, follow participant's lead; assess risk and consider safety. In this way, researchers can protect participants from unexpected distress and empower participants to have increased control over what they disclose.

While things for research supervisors to consider for community researchers in particular are:

- **positionality and self-awareness.**
- **reflection sessions.**
- **support systems.**
- **current life experiences.**
- **coping strategies and self-care.**
- **personal history of trauma or past exposure to traumatic events.**



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