SOP 18: Distress Protocols for Research on Sensitive Topics

The South African College of Applied Psychology Research Ethics Committee	
Title	SOP 18: Distress Protocols for Research on Sensitive Topics
SOP No.	SOP 18_SACAP REC_19.1
Date of approval	April 2022
Revision date	April 2024
Pages	8

1. COMPILATION AND AUTHORISATION

Action	Designated person	Date	Signature
Compiled for SACAP by	Dr Diana De Sousa	April 2022	
Checked by	REC Office	May 2022	K. J. Young
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Authorised by	Academic Dean	June 2022	J. Lotter

2. DOCUMENT HISTORY

Date	Version no	Reason for revision
April 2022	1	Development of document

3. ABBREVIATIONS AND DEFINITIONS

Abbreviation/ Term	Definition
CBPAR	Community-Based Participatory Action Research
Emotional distress	Anxiety, depression, embarrassment, or acute stress reactions as participants recall, re-examine, and reveal their experiences that arise over the course of the research
ID	Intellectual Disability (ID)
PTSD	Posttraumatic Stress Disorder (PTSD)
SACAP REC	The South African College of Applied Psychology Research Ethics Committee
Sensitive topics	Topics are considered sensitive if identification of participants would result in stigmatization, dissemination of findings could harm a social group, or the research challenges values that people hold sacred
SOP	Standard Operating Procedure/s

4. PURPOSE OF THE SOP

Professional organisations, regulatory bodies, and ethical review boards require that researchers identify and minimise emotional distress by developing distress protocols for research on sensitive topics.

The purpose of this SOP is to provide practical guidance to assist researchers conducting studies on sensitive topics, including traumatic or aversive events, to identify and respond to emotional distress, including grief, anger, fear, anxiety, depression, embarrassment, or acute stress reactions as human participants recall, re-examine, and reveal their experiences in response to remembered trauma that arises over the course of the research.

A distress protocol needs to be submitted to the SACAP REC with the ethics application if the research categorised as Low, Medium or High Risk poses psychological/emotional harm or distress to participants and/or the researcher. A distress protocol is a step-by-step document which details how the researcher will deal with any distress to participants and/or the researcher during and/or after the data collection process of potentially emotionally-charged topics in individuals with pre-existing medical or mental disorders, e.g. Posttraumatic Stress Disorder (PTSD), or depression, and thus might be at risk of significant distress that could cause harm. Even if there are ways to mitigate psychological/emotional harm or distress to participants, it must be it must be acknowledged that there is no exact equivalence that can be drawn between the risks that may be assumed by people with decisional capacities and those for whom these capacities are affected by their medical and/or mental illness and/or disability.

5. SCOPE

5.1. This SOP provides a framework for SACAP researchers (staff, academic associates, fellows, and students), non-SACAP researchers (visiting researchers and students), and the SACAP REC to engage in evaluating and addressing emotional distress in qualitative, quantitative, and CBPAR.

5.2. Screening and interviewing distress protocols that might serve as templates for those who research sensitive topics and seek to outline procedures for managing emotional distress in qualitative and CBPAR studies are provided for the protection of participants from emotional distress.

5.3. Distress protocol templates that can protect participants from emotional distress for use during the administration of survey research (e.g. checks on participant safety, formal scripts to screen for emotional distress, and post-survey assessments of being upset during the survey as well as continued distress afterwards) are provided in Annexure A of this SOP for researchers to select and adapt those most relevant for their specific study.

5.4. This SOP must be read in conjunction with SOP 17: Risk Assessment. A distress protocol should be submitted with the application form for ethical clearance for research involving participants submitted to the SACAP REC if the risk level of the study includes psychological/emotional harm or distress to participants and/or the researcher. Research studies are categorized as **Low, Medium, or High Risk**.

5.5. A **distress protoco**l is a step-by-step document that details how the researcher will deal with any distress to participants and/or the researcher during and/or after the data collection process. Information about applicable counselling/support/informational services should be given in full on the participant information sheet. These services must be free and accessible to participants.

5.6. It is the responsibility of the researcher, student researcher(s), and supervisor to consider specific counselling/support/informational needs of the community and/or participant

groups involved in the research project, concerning the risk level, topic, and research process of the study.

5.7. Information about applicable counselling/support/informational services should be provided in full on the participant information sheet. These services must be free and accessible to participants.

5.8. For **Medium/High-Risk studies**, a permission letter with the name and contact details of a particular person (at an organisation) who has agreed to provide support to participants if required should be submitted along with the ethics application to the SACAP REC. It is the responsibility of the researcher(s) to arrange with and inform this person of the nature and duration of the research project. It is also the responsibility of the researcher to make sure that the person is located near the participants. Making referrals to a generic support hotline like Lifeline or SADAG is not recommended in the instances of **Medium/High-Risk studies on sensitive topics.**

5.9. For **Low-Risk studies**, it may be appropriate to refer participants to general community-based or Non-Governmental Organisations (NGOs).

5.10. **When data collection is taking place remotely** (e.g. online or telephonically), the researcher needs to be highly sensitive and attentive to participant responses that might point to emotional distress, because body language may not be easily observable. Furthermore, the researcher might not be able to immediately intervene in the event that physically distress arises. Therefore, remote data collection activities may need to be considered very carefully and in-person data collection may be preferable for some studies. For instance, interviews with persons who may be suicidal, or with persons who have just lost a family member to COVID-19 should be carried out in-person instead of remotely so as to ensure that the research is able to deal with any distress to participants and/or the researcher during and/or after the data collection process.

5.11. Distress protocols for research with vulnerable populations, might require the content of communication, but also the method of communication on the part of the student researcher to be tailored to each individual participant depending on their cognitive and linguistic abilities. For example, the population of individuals with Intellectual Disabilities (ID) is complex and diverse, which means tailoring methods that are specific to each individual with regards to both ethical and practical guidelines, thus an interview approach instead of focus group is recommended. Further to this, some individuals with ID are unable to fully express their understanding of the study's purpose and data collection methods, which might be a traumatic experience. Moreover, the stipulation that if any evidence of discomfort is present the subject can withdraw does not necessarily protect individuals who are incapable of certain forms of expression and who may not be able to communicate their negative feelings or pain. Interviewers need to be flexible when conducting qualitative research with individuals with ID. Steps should be outlined when involving others who know the individual best, such as family members or caregivers, when assessing capacity to provide and obtaining informed consent, and monitoring for signs of psychological/emotional harm or distress to participants.

6. PROCESS OF EMOTIONAL RISK ASSESSMENT

6.1. Three broad principles of ethics of the Belmont Report Protection of Human Subjects of Biomedical form the foundation of distress protocols for research on sensitive topics. These three principles are autonomy, beneficence and non-maleficence, and justice.

6.2. **Autonomy** is the right to determine one's life course. Researchers honour the principle of autonomy by providing sufficient information regarding the risks and benefits of the research so that individuals may freely accept or decline participation.

6.3. **Beneficence** is the promotion of the welfare of individuals. This principle also includes non-maleficence, the mandate to do no harm. To ensure beneficence and non-maleficence, researchers are called upon to seek the greatest benefit for research participants while minimizing harm. **Non-maleficence** forms the cornerstone of minimising the risk of emotional distress. As such, the process of developing distress protocols necessitates considering the benefits of research on sensitive topics against the risks; the ethical principles of autonomy, justice, and non-maleficence; and the strengths, resiliency, and vulnerability of participants.

6.4. **Justice** is the ethical principle that requires researchers to equitably allocate the benefits and the burdens of research.

6.5. Constructing distress protocols, therefore, consists of exclusion criteria that promote the inclusiveness of participants who could safely participate in research, and excludes only participants at the highest level of psychical and/or psychological risk, currently experiencing acute distress at the time of the research, screening questions that involve participants in emotional risk assessment whenever possible, and minimally intrusive strategies to reduce the risk of harm.

7. REFERENCE DOCUMENTS

- Draucker, C.B., Martsolf, D.S., & Poole, C. (2009). Developing distress protocols for research on sensitive topics. *Archives of Psychiatric Nursing*, *23*(5), 343-350.
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- Labott, S., Fendrich, M., Feeny, N.C. & Johnson, T.P. (2016). Evaluating and addressing emotional risks in survey research. *Survey Practice*, *9*(1), doi: 10.29115/SP-2016-0006.
- Sims, J. & Waterfield, J. (2019). Focus group methodology: Some ethical challenges. *Quality & Quantity*, *53*, 3003–3022.

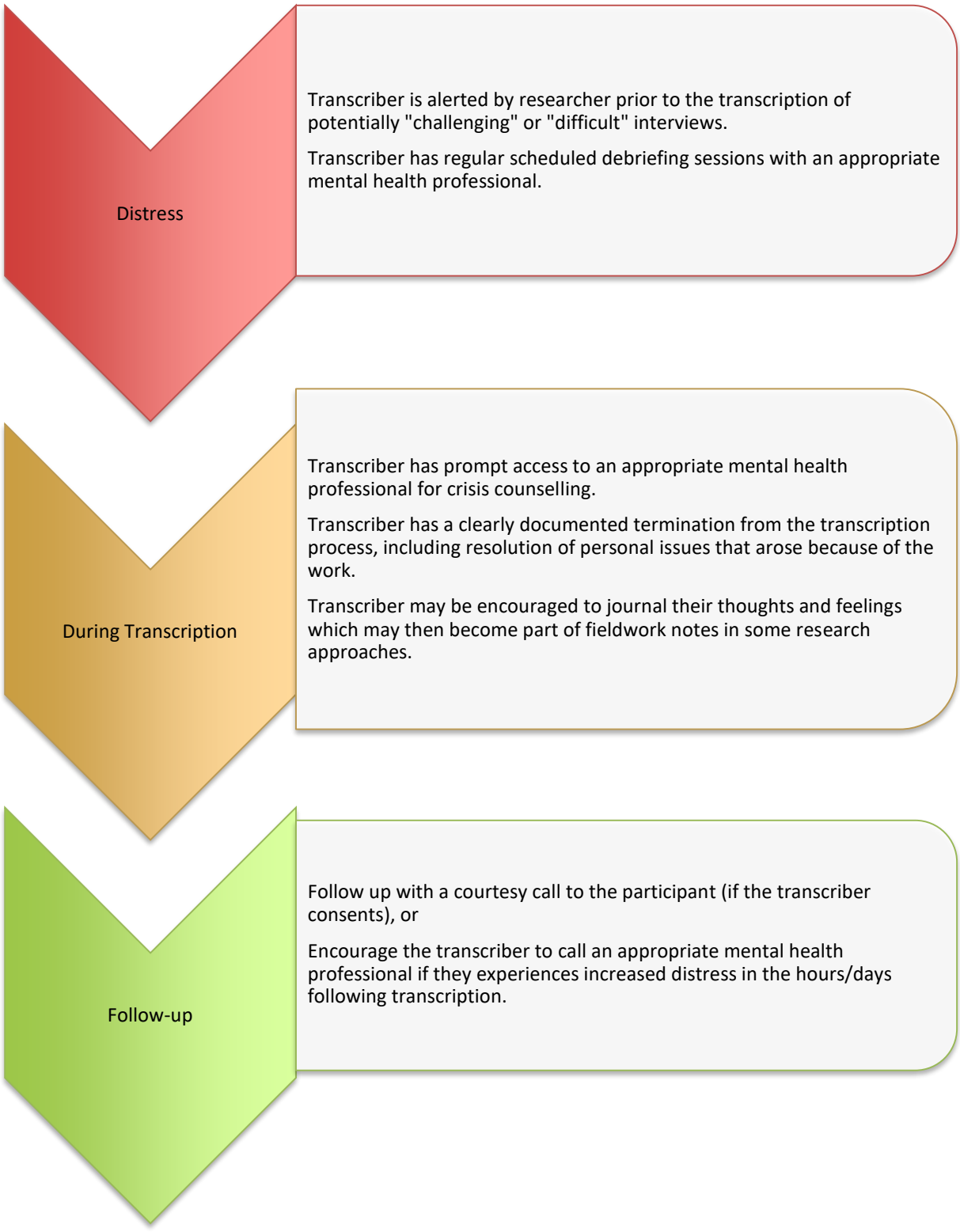
ANNEXURE A

Distress Protocol 1: Managing Emotional Distress in the Context of an Interview

Distress Protocol 2: Managing Emotional distress in the Context of a Focus Group

Pre-data Collection	The researcher(s) must carefully consider the potential physical and psychological impact of the research in terms of the human participant's description of life experiences. The researcher must consider the potential for emotional exhaustion.
Data Collection Stage	Ideally, there should be two people, a researcher and an observer, when facilitating a focus group, especially when sensitive topics are involved.
Distress	When a participant indicates during an interview that she/he is experiencing a high level of stress or emotional distress, OR Exhibits behaviour suggesting that the interview is too stressful, such as a trembling voice, crying or shaking, etc.
Response	Pause the Focus Group. Assess the psychological/emotional status of the participant by probing what her/his thoughts and feelings are?
Review	If the participant indicates that they feel able to continue with the focus group, resume with the focus group. If not proceed to stage response 2.
Response 2	If not, excuse the participant from participating and encourage the participant to contact the counselling service provider indicated on the information sheet if they experience increased distress in hours/days following the focus group.
Follow-up	Follow up with a courtesy call to the participant (if the participant consents). One distressed participant can lead to distress in other focus group participants. Consider group as a whole. Ask focus group members if they would like to continue the focus group or reschedule.
Debrief	At end of focus group, content summarised to participants, key issues around confidentiality and anonymity are reiterated. Potential sensitive and problematic issues raised during the focus group discussion should be clarified and contextualised. Participants can be invited to share their reactions. If not go to stage response 3.
Response 3	Reschedule the focus groups and encourage the participants to contact the counselling service provider indicated on the information sheet if anyone of them experience increased distress in hours/days following the focus group.

Distress Protocol 3: Managing Emotional Distress in the Context of Focus group /Interview Transcription



Distress Protocol 4: Evaluating and addressing emotional risks in survey research