

SOP 18: Distress Protocols for Research on Sensitive Topics

The	The South African College of Applied Psychology Research Ethics Committee		
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1. COMPILATION AND AUTHORISATION

Action	Designated person	Date	Signature
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2. DOCUMENT HISTORY

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April 2022	1	Development of document

3. ABBREVIATIONS AND DEFINITIONS

Abbreviation/ Term	Definition	
CBPAR	Community-Based Participatory Action Research Anxiety, depression, embarrassment, or acute stress reactions as participants recall, reexamine, and reveal their experiences that arise over the course of the research Intellectual Disability (ID)	
Emotional distress		
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 protocol** 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

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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.
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ANNEXURE A

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

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.

Stop the interview

Stage 1 Response Assess the psychological/emotional status of the participant by probing what her/his thoughts and feelings are.

Tell me what thoughts you are having. Tell me what you are feeling right now. Do you feel you are able to go on about your day? Do you feel safe?

Review

If the participant indicates that they feel able to continue, resume the interview. If participant is unable to carry on, go to stage response 2.

Stage 2 Response Arrange to reschedule an appointment to continue with the interview and encourage the participant to contact the counselling service provider indicated on the participant information sheet if they experience increased distress in hours/days following the interview.

Follow-up

Follow up with a courtesy call to the participant (if the participant consents).

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

Transcriber is alerted by researcher prior to the transcription of potentially "challenging" or "difficult" interviews.

Transcriber has regular scheduled debriefing sessions with an appropriate mental health professional.

During Transcription

Transcriber has prompt access to an appropriate mental health professional for crisis counselling.

Transcriber has a clearly documented termination from the transcription process, including resolution of personal issues that arose because of the work.

Transcriber may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches.

Follow-up

Follow up with a courtesy call to the participant (if the transcriber consents), or

Encourage the transcriber to call an appropriate mental health professional if they experiences increased distress in the hours/days following transcription.

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

Consent Process Informing participants of potential risks so that they can choose not to participate. Potential risks need to be described using information about the specific survey content. E.g. a survey about reactions to the death of a loved one is likely to be significantly more distressing (and therefore associated with greater emotional risk) for someone who is depressed or who has recently lost a loved one, than for someone who has not had these experiences. Letting potential respondents know that if they choose to participate now, they can also choose to skip questions or to stop participating later.

Identify strong emotional reactions, e.g. observed while doing a telephone survey (e.g. crying, sniffling, and vocal changes).

Participants can be asked if they are okay, if they would like to take a short break, if they would like to reschedule the remainder of the interview for later, or if they need counselling.

Develop safety scripts to assess a participants' emotional distress and then take appropriate action. For example, if a participant made a comment about suicide, the researcher needs to inform the participant that a mental health professional will provide a follow up call/appointment with the them immediately (If this procedure is used, it is important to make respondents aware during the consent process that confidentially could be breaches in certain instances).

During Data Collection

If the participant is not acutely suicidal, then they should be asked if he or she wanted to continue with the survey, reschedule to complete it at a later time, or stop completely.

At the end of the survey the participant asked if they wanted a mental health professional to follow up with them, if they wanted to contact their own mental health professional, and/or if the participant wants a list of community resources for support sent to him or her. Participant needs to consent to follow-up interventions to not violate the principle of autonomy.

Review

Ask post-survey questions about the experience of being upset during the survey as well as continued distress afterward. In addition, offer participants a call from a counsellor, a hotline number, or information about nearby counselling services.

Post survey