

# Ethical Issues in Qualitative Research

## Trauma Survivors Telling Their Stories for Research Purposes

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### 1 Introduction

Qualitative research with trauma survivors appears to be beneficial for those affected and forward-looking for effective prevention in the context of socio-political processes of recognising and coming to terms with trauma.<sup>1</sup> However, ethical deficits in the implementation of research projects remain (Radhika and Manual, 2018). This is due to research primarily not serving the goal of giving trauma survivors a voice and recognising their suffering, but rather interviewing them to address a wide range of scientific questions. Considering conflicting goals, the focus of the following paper lies within central questions of research ethics, based on the special opportunities and difficulties of trauma survivors who tell their stories (cf. more extensive Bobbert, 2024).

Psychological, sexual, criminal and terrorist violence, traumatic losses, threatening illnesses, accidents, natural and technical disasters, war, imprisonment, uprooting, fleeing or displacement are sudden or prolonged threatening, extremely frightening and hopeless events or assaults that often lead to psychological trauma, i.e. a wound. Traumatic

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events or stages of life often leave lifelong psychological and physical traces and are accompanied by varying degrees of impairment of quality and organisation of life.

### **1.1. Man-made trauma**

Trauma research distinguishes between accidental and man-made traumatic events because different effects occur. The scope of this article will lie primarily on the infliction of trauma for which people are responsible. Thereby, it focuses predominantly on man-made causes of trauma. The emphasis is on traumatising in Western industrialised countries in the post-war period that was imposed on people in family, institutional or state structures.

### **1.2. Concerns of trauma survivors**

Traumas that have happened need to be recognised. However, those affected must not be reduced to being victims. This is why today – as in the following – we often speak of survivors instead of victims. Through telling their stories, the victims can regain their subjectivity, because the unspeakable is conveyed to the world of others, because a connection to others can be re-established through speaking out. But the survivors also want to tell stories for others because they are seeking justice (Emcke, 2022, 98).

### **1.3. Specific vulnerability**

Trauma survivors are more or less alienated from their lives and hurt in body and soul as a result of the injustice they have suffered. It depends largely on the outsiders whether they can settle back into a “normal” understanding of life and world despite the injury they have suffered.

## **1.4. Trauma survivors as the subject of qualitative research**

In addition to hearings, round tables, commissioned expert reports and other forms of listening to and recording injustices that have occurred, research projects with trauma survivors are increasingly being carried out. In most cases, this is qualitative research conducted by the social sciences, medicine (especially psychosomatic and psychiatry), history or law (especially criminology). Victims of interpersonal violence are questioned about their experiences or asked to tell their stories in order to gain new insights: How could the abuse happen, what are the consequences for trauma survivors, what factors and structures need to be changed so that the injustice will not be repeated?

## **1.5. Additional protection for trauma survivors in qualitative research**

When people whose trust in the world has been shattered, whose vulnerability is accompanied by inner isolation and a loss of cognitive security, start to regain trust in others by telling them what has been done to them, all members of a society that has enabled such a civilisational rupture must ensure that they do not inflict any additional burdens on trauma survivors. Research must also fulfil this task.

## **2. Ethical reflection in the face of irresolvable conflicts of interest in research**

### **2.1. Codes of ethics for research involving human subjects**

In medicine, research involving human subjects has been regulated under professional law since 1963 by the Helsinki Declaration (World Medical Association, 2013) and, in Germany, because of the thalidomide scandal in 1964, in the revised Medical Products Act. In addition, most other countries in the world have legal regulations on medical research involving humans. Psychology, educational sciences and sub-disciplines such

as oral history can now also refer to ethical codes and committees (cf. critical on the quality of ethics committees Scherzinger and Bobbert, 2017).

However, codes of ethics for research in social sciences and history, which are adopted by professional societies, are usually quite general. Ethical indication of problems and reflections specifically oriented towards qualitative research with traumatised people are still a desideratum.

## 2.2. Specific codes of ethics for research with trauma survivors

In more recent studies on sexualised violence against minors and adults, more specific ethical recommendations have been developed, such as the 2015 Bonn Declaration of Ethics for Research on Sexual Violence in Educational Contexts (Poelchau et al., 2015). This declaration raises awareness of the particularities and challenges of research into sexualised violence against children and young people and recommends a procedure for disclosing and uncovering abuse. For the National Research Programme “Care and Coercion” of the Swiss National Science Foundation, the author of this article analysed the specific ethical issues and requirements in relation to the submitted projects. After a legal revision, minimal ethical requirements were submitted to all applicants for signature (Bobbert, 2018).

Overall, it can be observed that in the field of qualitative research with traumatised people, there are specific ethical problems that need to be addressed sensitively and in a solution-oriented manner.

## 2.3. Ethical reflection on research activities

Ethics as a theory of reflection that strives for generalisable ethical judgements must be distinguished from the moral convictions of individuals or the de facto moral consensus of a professional group, which can be for example reflected in a professional code of conduct (Bobbert, 2012). Ethics operates with general ethical norms that are relevant to research – first and foremost the right to protection of life and health

and the right to self-determination, which requires further specific differentiation depending on research question and study design. Although certain trade-offs between the protection of the test person and the potential benefits of research in the Declaration of Helsinki are certainly questionable, the critical interpretation and context-related continuation of its norms in medical ethics over the past 50 years has led to elaborate ethical problem issues and prioritisation. In this article, these will be made fertile for the field of research with trauma survivors.

### **3. Re-traumatisation as a risk and burden**

Research can pose special burdens and risks on trauma survivors who have been injured by other people. These result specifically from the experience of violence and the associated traumatisation (Maercker, 2019). The risk of re-traumatisation is discussed in the following, as trauma-informed research should integrate existing findings into its research design and the treatment of interviewees (Anderson et al., 2023; Campbell et al., 2019).

#### **3.1. Manifestations of post-traumatic stress disorder**

Studies on post-traumatic stress disorder (PTSD) reveal four clusters of symptoms: Intrusion, avoidance, negative cognitions and moods, and hyperarousal (cf. for the following Admundson, Stapleton et al., 2004; Naifeh et al., 2008; American Psychiatric Association, 2013, pp. 268–274; American Psychiatric Association, 2018, pp. 369–373).

##### **3.1.1. Symptom cluster intrusion**

While a person is experiencing a traumatising situation, too many different stimuli intrude that cannot be processed by the central nervous system. Therefore, unlike usual, the stimuli are not stored in the explicit memory, but remain in the implicit memory as incoherent, fragmentary perceptions (Ehlers et al., 2000; Ehlers, 2002). PTSD is accompanied by intrusions: these intrusions contain sensory impressions of the trauma

such as visual, acoustic or physical sensations and emotional reactions (Ehlers et al., 2004). They usually occur completely unexpectedly and are therefore experienced as uncontrollable. The memories are intrusive and very intense as “here-and-now”. They result in a feeling of current threat, as the sensory memories of the trauma are experienced without the individual realising that they arise from a past event (Ehlers et al., 2000; Ehlers, 2002).

### **3.1.2. Symptom cluster avoidance**

The avoidance symptom cluster involves avoiding feelings, thoughts, situations, people or places associated with the trauma. This often also applies to conversations about the traumatic event. The traumatic event may seem to have erased or is only remembered very vaguely. For the traumatised person, avoidance has a protective function that is intended to help prevent further threatening experiences. However, avoiding confrontations with the traumatic experience perpetuates the PTSD symptoms, as information is not processed correctly and therefore cannot be correctly integrated into the memory structure (Riggs et al., 2006).

### **3.1.3. Symptom cluster negative cognitions and moods**

The symptom cluster of negative cognitions and moods includes persistent and distorted cognitions and emotions such as blaming oneself or others, feeling alienated from others and having little interest in activities. The emotional state of traumatised people can vary greatly from person to person and sometimes changes frequently. Many of those traumatised no longer feel any intense emotions. This “flattening” is referred to as emotional numbness. However, it is also possible, that only intense negative emotions such as fear, anger, sadness, guilt and shame prevail.

### **3.1.4. Symptom cluster hyperarousal**

Anyone who has been through a traumatic situation may live in a constant state of increased alert, as if the danger still exists (Rabellino et al., 2015). This is because the sympathetic nervous system strengthens the organism in threatening situations and other stressful situations, e. g. by increasing muscle tone in the extremities or increasing the heart

rate for a fight and flight response. At the same time, the activity of systems that are less important right now, such as sexuality and digestion, is reduced (Wagner, 2015). Thus, the symptom cluster hyperarousal includes difficulties falling asleep and staying asleep, increased irritability and outbursts of anger as well as concentration difficulties. People with PTSD also report hypervigilance with heightened perception (increased vigilance) and increased nervousness.

### 3.1.5. Special characteristics of memory in PTSD

The four symptom clusters above are related to specific memory impairments in PTSD. Firstly, it should be noted that trauma survivors without PTSD are not affected by these specific memory impairments (Kleim et al., 2008; Moore et al. 2007). In people with PTSD, on the other hand, traumatic experiences can unintentionally “jump” back into the memory if they are reminded of them by certain cues (key stimuli). One can speak of re-traumatisation if the memories establish a connection between a current event and an initial trauma. It is the memory that consciously or unconsciously establishes relationships between the present and the past.

A particular characteristic of people with PTSD is an overgeneralised memory (Williams et al., 2007), which means that even when consciously and deliberately recalling non-traumatic memory content, only general memories can be recalled, but not specific ones. This makes it difficult or impossible for the person affected to visualise positive or resource-oriented autobiographical memories (Kleim et al., 2008; Moore et al., 2007).

Studies also show that in people with PTSD, trauma-associated content is closely linked to non-trauma-associated autobiographical content. This is particularly the case when the memories touch on specific emotional aspects such as personal involvement. So-called reference points are then formed (Berntsen, 2009), which lead to the unintentional, involuntary retrieval of non-trauma-associated memories triggering trauma-associated content and possibly leading to changes in affects (Böttche et al., 2014).

Thus, people with PTSD find it difficult or almost impossible to control traumatic memories. They also suffer from the difficulty of recalling these memories in a targeted and deliberate manner and verbalising them coherently (Bremner, 1999; Brewin, 2001, 2007; van der Kolk, 2003). The individual memory particles of a trauma are either not linked at all or only dysfunctionally linked, which prevents coherent intentional recall (Engelhard et al., 2008; Engelhard et al., 2003; Halligan et al., 2003). There is evidence that fragmentation/disorganisation is strongest with extremely threatening traumatic content, so-called hot spots (Ehlers et al., 2000).

The psychotraumatological phenomena described should not confuse our view of the “paradox of witnessing” (Emcke, 2022, p. 79): How can someone who has suffered the terrible event be able to give an uninvolved description? Someone who has been devalued and abused remains “ashamed”. Talking about one’s own abuse means making the humiliation “public” and possibly reliving the devaluation of the self. On the other hand, telling the story can lead out of isolation and forced intimacy with the perpetrators. Lost subjectivity can be regained by listening to and being recognised.

### 3.2. Prevalence of trauma and PTSD

In everyday language, many psychological stresses or difficult events are considered traumatising. In the current classification system DSM-5, the psychiatric statistical manual, trauma is defined as confrontation with actual or threatened death, serious injury or sexual violence (American Psychiatric Association 2013).

PTSD is the most common mental illness following the experience of trauma. According to studies from various countries, more than half of the general population have experienced trauma in their lifetime (Schock, 2016, p. 11). However, not everyone who has experienced trauma develops PTSD, but between 2 and 20 per cent, depending on the country and study. Women are more frequently affected by PTSD than men. In addition, the likelihood of suffering from PTSD depends on the type of violence: People who experience a man-made trauma have a

higher risk than those who are victims of a natural disaster or accident, for example. The highest risk of PTSD is after physical or sexual assault; regarding rape, the risk is around 50 per cent. One group particularly at risk of PTSD is refugees – especially victims of war and torture (Schock, 2017, p. 12).

Other risk factors for developing PTSD or suffering from it for a long time are young age, existing mental disorders such as anxiety disorders, depressive disorders or disorders of social behaviour. However, negative social factors that characterise the time after a trauma, e. g. an unstable family, lack of social recognition as a victim and the lack of recognition of the suffering experienced are also factors that make PTSD more likely.

PTSD consists of psychological, physical and interpersonal impairments. Chronic trauma-reactive symptoms often vary in intensity and extent. There is also a vulnerability to a renewed increase in symptoms in the event of new stress. For people who have experienced violence, re-traumatisation, i.e. the recurrence of intensification of PTSD symptoms, is a known risk.

#### 4. Ethical standards in research with trauma survivors

Research with trauma survivors, who are often particularly vulnerable due to their previous history, is characterised by three ethically relevant peculiarities:

- Trauma survivors usually have profound previous experiences of powerlessness, third party control and instrumentalisation.
- When trauma survivors talk about their experiences, they often expect that this will help them in the sense of “therapy” and that they will receive recognition and justice.
- Trauma survivors are at risk of further stress and harm.

In research with trauma survivors, these particularities must lead to corresponding ethical differentiations of the recognised research ethics standards and to concrete recommendations for their consideration.

But how can research adequately record and describe traumatisation without pathologising the victims and perpetuating their woundedness? How can it be methodically ensured that, on the one hand, the victims are not belittled by questioning their credibility and, on the other hand, that other sources and interpretations can be used? What must be guaranteed in the case of research so that people who have been victims of violence do not remain isolated and damaged because they feel misunderstood, because they again experience powerlessness instead of self-determination, because they again feel instrumentalised by others or because they are retraumatised – without having suspected it themselves?

In the following, the ethical norms of informed consent and non-harm in combination with the proportionality of benefits and risks established in medical research are used and applied to the treatment of trauma survivors by researchers and to the question of aftercare.

#### 4.1. Informed consent

Informed consent is recognised worldwide – above all through the Helsinki Declaration on research involving human subjects in medicine. This ethical standard – with the prerequisites of informed and voluntary consent – is also largely guaranteed by national legal regulations. Although informed consent is also cited in all ethical recommendations for research in the social sciences and history and is emphasised as a core norm by the Oral History Association (2018, p. 5), for example, there is far more to consider in research with trauma survivors than existing codices suggest.

Firstly, the concept of informed consent as it is outlined in medical ethics: The defining elements of informed consent are “information” and “understanding” (Faden et al., 1986). Comprehensive information should be related to the individual situation and ensure “sufficient understanding” with regard to opportunities and risks (Bobbert et al., 2014).

In the context of research with trauma survivors, this means: the asymmetry of knowledge and of role that exists between researchers as experts and laypersons should not be exploited, but rather minimised wherever possible. A high level of transparency with regard to

the planned procedure, an adequate understanding of the research question and the aim of the study, possible risks and impairments of the participants, and any benefits for the study participants themselves or only for others can be achieved by using language that is understandable to laypersons.

#### **4.1.1. The distinction between research and other forms of interaction**

Even if it goes without saying for the researchers, the differences between research and therapy, between standardised approach and communication geared towards an individual person must be clearly emphasised in any form of research with trauma survivors: Research follows a different objective than the goals of therapy, recognition, compensation reparation, etc., which are significant for trauma survivors. Research aims to gain knowledge about the extent of the event, about the framework conditions and relevant causal factors and interprets the events retrospectively or determines findings relevant for the future, for example for effective prevention. The primary aim of research – unlike court proceedings or a social reappraisal process – is not to attribute responsibility and determine and ascribe blame.

#### **4.1.2. Counteracting the “therapeutic misunderstanding” known from clinical research**

In addition, misunderstandings regarding individual benefits should be avoided by making the interests and expectations of both sides explicit. Medical research on humans is familiar with the so-called “therapeutic misunderstanding”, which consists of patients expecting healing from a research measure. Firstly, it must be made clear, that all benefit is potential. Secondly it is relevant, whether the potential benefit might be helpful for the patient, for a certain group of patients or only for future patients. In the latter case, it is therefore advisable to formulate in the patient information: “You yourself are unlikely to derive any individual benefit from participating in the study.” The purpose of the study is to develop a treatment for future patients.

#### **4.1.3. Preliminary communication about expectations of potential benefits from participation**

Trauma survivors are likely to have different expectations, ranging from therapy to recognition to justice. Researchers should clearly communicate their research interest and the potential benefits to participants (Scheidt et al., 2015) in order to counteract inflated individual expectations of their potential narrators. A recommended best practice, which did not relate to research but to hearings, aimed to align expectations, can be found in the questionnaires that Kavemann et al. (2019, 121–135) developed for trauma survivors who had registered for hearings of the Independent Commission. By listing the goals of the round table hearings, and by proposing goals of narrators, which could be answered in the affirmative or negative, potential narrators became clearer about what to expect. In research, for example, a similar questionnaire could help to ensure that the potentially differing expectations of those who wish to share their experiences are at least not ignored due to a lack of information.

#### **4.1.4. Recruitment of participants with a special focus on self-determination and voluntariness**

Another central element of informed consent is the condition of voluntariness: Since traumatised people are affected by previous experiences of powerlessness, third party control and instrumentalisation, special precautions must be taken to ensure that these experiences are not repeated by a research project.

The way in which participants should be recruited should therefore also be discussed from an ethical perspective. Researchers would like to recruit as many participants as possible in as short a time as possible and at a low organisational and financial cost. Since victims of violence are often stigmatised or feel shame themselves and because they have the right to choose between processing and suppressing their trauma, ways of identification and recruitment must be chosen in which those affected can control themselves whether and to what extent they reveal something of their life story. It may therefore be necessary to accept several stages of recruitment and numerous “opt-out” cases in order to en-

sure voluntariness. The research group led by psychologist Patricia Lannen, for example, developed a contact procedure involving two letters and then a telephone call before obtaining informed consent in order to prevent those close to the person being contacted from becoming aware of a previous orphanage stay and to enable the person concerned to have a voice in the contact process (Lannen et al., 2021, pp. 10–6).

The location, the people involved, the type and manner of the interview, the duration of the interview, the type of travelling and forms of compensation for expenses should be discussed at an early stage, as some trauma survivors may already have difficulties in this regard. Where the interview takes place – at home or in a formalised context that potential study participants may want to get to know beforehand – can be relevant.

#### **4.1.5 Confidentiality of personal data and information**

The confidential treatment of particularly sensitive personal data and compliance with the legal requirements of data protection and data security regarding data collection, storage, accessibility and destruction is self-evident for legal and ethical reasons. In addition, the rules of anonymisation must be observed when publishing research data.

For trauma survivors, who feel devalued and stigmatised by violence and abuse and paradoxically often feel shame, the confidential treatment and well-considered anonymisation of the narrative must not only be reliably guaranteed for the interpretation and publication process, but it also contributes to transparency and trust if the researchers explain the recording, encryption and storage process of the collected data in comprehensible manner.

#### **4.1.6. Transparency and respect for freedom in the conduct of discussions and interviews**

Overall, informed consent should not only refer to consent to participation. To comply with the norm in the course of research, it is important to always create transparency. Psychologist Angelika Treibel, who conducts research in criminology, expressed this in her recommendations for conducting victimological interviews in 2016: “The aspect of trans-

parency does not only refer to objectives and procedures that occur at the beginning of the interview. For example, it is helpful to explain things that you do as an interviewer, e.g. to explain why and for what purpose notes are taken, to comment on looking at the wristwatch. Questions and thoughts that arise for the interviewer during the course of the interview, as well as interruptions, can and should be made transparent. Being informed about processes means more transparency for the interviewees and less of a feeling of being at the mercy of others.” (Treibel, 2016, p. 162, own translation).

It is also important that the researcher convincingly communicates to the interviewee that they can always decline the researcher’s interventions and end their participation at any time without suffering any disadvantage. However, this presupposes that the interviewee is aware of the possible stresses and risks of the study, e. g. acute stress reactions or retraumatisation symptoms, and has learned to take care of him/herself.

#### **4.1.7. Structures to safeguard informed consent: preliminary training and ombudsperson**

The relevant aspects of the distinction between research and therapy and the knowledge of research methods and settings do not constitute general knowledge. Structured information on the prior education of potential study participants could create prior knowledge that “empowers” trauma survivors to reflect on the question of study participation and ask the individually relevant questions (Bobbert, 2019, pp. 160–161, 179–180). In this context, trauma-specific information could be provided on how those affected can take care of themselves (Liedl et al., 2018).

It would also strengthen potential study participants if they had access to an independent second opinion when it comes to making an informed decision on a study enquiry. The establishment of an independent ombudsperson for trial subjects, which provides scientifically competent assistance in reviewing the study documents handed out and discussing the advantages and disadvantages, in particular the burdens and risks, would therefore be a structural form of empowerment for trauma survivors. The basic equipment of such an ombudsperson’s office would

have to be financed by public funds. Under certain circumstances, voluntary work by researchers would be possible.

#### **4.1.8. Dealing with study results**

For reasons of transparency and self-determination, it must also be explained in advance whether and, if so, how the participants can inform themselves about the results of the study. In this regard, it must be explained to them that their story will be interpreted by outsiders without them generally being able to influence this – unless participatory research methods (Wansing, Schäfers and Köbsell, 2022) or certain forms of oral history are used. Werner Fuchs drew attention to the problem of research results that are “alienating” or objectifying for the interviewees as early as 1981 in the early German reference work on oral history by Niethammer: “Life paths and experiences of members of social groups who are not the intended recipients of the academic publication are recorded. This production of knowledge is not an expression of a need for information on the part of the people being analysed, a need for these groups to understand themselves in terms of possible solutions to their life problems.” (Fuchs, 1980, p. 335, own translation). In addition, many researchers in oral history, including Ronald J. Grele “do not want to refrain from checking sources, providing evidence and carefully weighing up individual testimonies” (Grele, 1980, p. 146, own translation). For methodological reasons as well as for reasons of research freedom, the handling of the results must be clarified and communicated in advance with regard to the interviewees.

#### **4.2. Ethical norm of non-harm with acceptance of only minor risks in connection with an expected research benefit**

The ethical norm of non-harm, or the requirement that no fundamental individual rights, above all the right to life and health and the right to self-determination, may be harmed, represents the second central norm of research ethics. However, in view of the risks and burdens associated with research, this norm is in tension with the potential benefit of research. In this respect, the norm of non-harm is “modulated” by the

corresponding risk-benefit assessment. However, the risk of burden or harm must be proportionate to the anticipated benefit of the research (as a potential therapeutic benefit for the subject, as a benefit for a specific group of affected persons or only as a future benefit). A study may only be conducted if the research design, based on the research question and methodology, indicates that a benefit, i.e. a relevant research result, can be expected that is in an acceptable proportion to the risks to the subject.

#### **4.2.1. Suboptimal research designs as a compromise**

In many cases in research with trauma survivors, unless it is therapy research, no definite individual benefit can be promised, although a study may happen to address one aspect of the diverse needs or motives of the respective interviewee. For this reason, most qualitative studies with trauma survivors represent “research for the benefit of others” (Bobbert 2012, pp. 727–723). Without the personal benefit of those who agree to be interviewed, the potential risks and damage must be minimised. This requires an anticipation of possible burdens and risks based on psychological and psychiatric expertise and the conception of a trauma-sensitive research design. This may also require compromises between optimal qualitative methodology and protective measures for the research participants.

#### **4.2.2. Safety precautions in the face of serious risks or persistent harm**

In medical research involving human subjects, no serious risks or lasting harm may be accepted. In this regard the Helsinki Declaration states: “Physicians may not be involved in a research study involving human subjects unless they are confident that the risks have been adequately assessed and can be satisfactorily managed” (World Medical Association, 2013, no 18). In addition: “Some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm. All vulnerable groups and individuals should receive specifically considered protection” (World Medical Association, 2013, no 19).

With regard to the risk of re-traumatisation, recognition and classification problems are already emerging due to the fact that the psychological diagnostic systems (ICD-10 and DSM-5) do not include the term re-traumatisation as a separate disorder, but only as an already diagnosed or newly diagnosed PTSD that is narrowly defined (American Psychiatric Association, 2013; Schmidt et al., 2015). Furthermore, it is almost impossible to reliably prevent the recurrence of trauma-related symptoms or re-traumatisation in trauma survivors, as the triggering stimuli cannot be identified in advance.

However, because the most serious consequences of study-related re-traumatisation can be suicidal tendencies or an actual suicide, but also other long-lasting stressful symptoms, it must be ensured in any case that trial participants can be referred to professional support and therapy facilities – without incurring any costs.

Regardless of the difficulties of prediction mentioned above, precautionary measures must be included in a study. The Declaration of Helsinki formulates this as follows: “All medical research involving human subjects must be preceded by careful assessment of predictable risks and burdens to the individuals and groups involved in the research in comparison with foreseeable benefits to them and to other individuals or groups affected by the condition under investigation” (World Medical Association, 2013, no 17).

#### **4.2.3. Preliminary planning: risk reduction through screening and inclusion and exclusion criteria**

For research with trauma survivors, risk-relevant information could be collected for the first time before including a person in a qualitative study, for example: Is the trauma survivor still suffering from trauma-related stress? How much time has passed since the experience to be described? What are the subject's motives: Does he or she want to tell the story out of inner distress? Particularly those who are recounting their traumatic experiences for the first time, or those for whom the trauma experience is still very recent, may show strong stress reactions due to the study that they themselves would not have expected. Those

who have not yet had any professional support may have less effective coping strategies.

Secondly, as in medical research, inclusion and exclusion criteria can be defined to protect subjects with health benefits. For example, trauma survivors with severe depressive phases or acute suicidal tendencies are heavily burdened or at risk. Researchers should not only be familiar with the symptoms of obvious and hidden depression and have learnt to inquire about possible suicidal thoughts. They could also use a psychological checklist in advance to at least recognise if there are signs of the most serious consequences of re-traumatisation, such as self-harm or suicide. Although suicide can hardly be predicted (Forkmann et al., 2016, p11), psychological screening tools and checklists can be used to identify suicidal thoughts, wishes or actions as well as the level of tension and stress experienced (Forkmann et al., 2016, pp. 37–61). Furthermore, a short psychological test to determine the stress level, which would be routinely presented at the beginning, would be conceivable under certain circumstances to protect the subject from the interview in the event of a high stress level. This is because a German review suggests that new stressful life events are more likely to influence the symptoms of PTSD than simply recounting or recalling a traumatic event (Schock, 2016, pp. 72–76).

Of course, the task of explaining the danger of those interested in the study and wanting to assess them in advance is not always easy to convey. Trauma survivors sometimes refuse to be reduced to a victim role or to be regarded as particularly vulnerable and emphasise their right to self-determination. If researchers wanted to avoid inclusion and exclusion criteria for this reason, structured communication with the trauma survivors interested in the interview would at least be necessary to clarify what support or help would be helpful in the event of distress.

#### **4.2.4. In the process: enquiring behaviour with a view to autonomy and self-protection**

In qualitative research designs, semi-structured interviews can be conducted, or follow-up questions can be asked for various purposes. However, in order to give the trauma survivors as much self-control as possible when telling their stories, open research designs should be chosen

in which the subject determines what they say and how they say it. It should also be anticipated from the outset in the study design that some subjects will not be able to provide a structured narrative.

If an interviewee suffers or has suffered from PTSD, different symptoms may occur unexpectedly.<sup>2</sup> In addition, memory may be blocked, distorted or unstructured and sometimes experiences or memories are not accessible or only accessible in a very generalised way. For an interview in a research context, this means that the narrative is imprecise, and the interviewer tends to ask for more precise details in order to be able to understand the situation described.

However, even if a narrative that is perhaps less productive for the study or obvious discrepancies normally motivate follow-up questions, there should be as little or only tentative interventions as possible. A maximally open method should be preferable out of respect for and to protect the interviewees.

Where and when questions are asked should not only be regulated in the interview guidelines but should also be carefully considered by the researchers during the interview for reasons of caution. Well-intentioned questions that are interested in clarification or that signalise doubts are interventions that pave or obstruct certain paths for the narrator. Whether certain events are dealt with in detail should depend less on the interviewer's questions than on the narrators themselves. It may be that traumatising events cannot be expressed. Jean Améry (2002) and Carolin Emcke (2022, pp 90–92) describe how “the first stroke” destroys trust in the world and is therefore particularly difficult to tell.

The researchers should also be always prepared and competent to address the interviewee about signs of stress and strain and to interrupt or terminate the interview if necessary. Specific termination criteria can also be defined in advance.

In the case of a more structured interview method, setting stop rules for interview questions can be a viable approach but requires the trauma

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2 However, those people who have suffered a trauma without developing post-traumatic stress disorder are not subject to the aforementioned difficulties in the narrative, but there are certainly also people with fluid transitions.

survivor to have good self-awareness and self-care skills. To not over-stress trauma survivors, the duration of the interview should be clearly limited and should generally not exceed 1.5 hours, as concentration and thus self-control and protective mechanisms will then diminish. Small breaks in between should be offered to allow self-perception and relaxation.

#### **4.2.5. Sharing tasks during the interview**

Ideally two people were responsible for the interview with shared tasks: One person conducts the interview, and another person with a therapeutic or supervisory background looks after the subject's well-being on the one hand and observes the interviewer on the other to intervene if necessary or to be available as a contact person after the interview. Such a division of roles is advisable in two respects: Firstly, two conflicting interests, namely the research interest and the ethical task of non-harming and caring for the trial participants, can be reliably recognised. Secondly, the question of aftercare can be specifically offered or coordinated for both the trauma survivor and the researcher.

### **4.3. Appreciation, transparency and mindfulness as attitudes of researchers**

Respect, appreciation and transparency are required from researchers when dealing with trauma survivors. Although these attitudes are rarely mentioned in codes of ethics and are rarely operationalised, they can be conveyed and implemented through specific knowledge, interview guidelines and communication training.

If researchers want to support those who expose themselves to their research project, it is important to at least not reinforce social abandonment or exclusion from society (Stauffer, 2015). The perpetrators are responsible for the injustice and the resulting loss of belonging to society for the victims. But many other people who did not listen, did not believe or met the victims with disinterest or aggression contribute to the continued isolation of trauma survivors. Trauma experts Andreas Maercker and Mareike Augsborg also emphasise that the opportunities for

disclosure and the social recognition experienced are of particular importance: “A lack of appreciation can contribute to the continued consequences of trauma, as studies and clinical experience have shown in various groups of traumatised people.” (Maercker and Augsburg, 2019, p. 40, own translation).

#### **4.3.1. Ethos of questioning to avoid further humiliation**

Therefore, the relationship or the way of interaction between the interviewee and the researcher is of particular relevance in research with trauma survivors, in contrast to other research on human subjects.

The reason and motives why trauma survivors tell their stories or decide to take part in a qualitative study may be very different (Emcke, 2022, p. 97). They may tell their stories out of anger at the perpetrators who went unpunished or escaped, out of distress because the burden of their experiences cannot be carried alone, out of fear of the story being repeated or out of concern for their descendants, out of aversion to the lies in their own family or out of a longing for justice. But telling and listening, talking to each other can be an attempt at a counter-strategy through which the survivors try to reassure themselves of their subjectivity.

Ideally, the interviewer makes him/herself available to a trauma survivor as a partner who listens in a focussed and attentive manner. They try to express appreciation towards the participant and recognise their suffering. Angelika Treibel writes in her recommendations for conducting victimological interviews in criminology: “An appreciative attitude should not be a specific feature of conducting a victim interview. However, it is particularly helpful and important in the context of victim interviews, as it will hardly be possible to engage in constructive communication if the attitude of the interviewer towards the victim is not characterised by respect and acceptance.” (Treibel, 2016, p. 161, own translation).

#### **4.3.2. Knowledge of the tendency towards epistemic injustice**

Appreciation and respect should go hand in hand with the knowledge of possible epistemic injustices (Fricker, 2023; Jackson, 2018; Lo, 2023;

Kavemann et al., 2022; Haslbeck, 2020; Künzel, 2005) and the competence to recognise trauma-related allusions, inconsistencies and distortions (Rosenthal, 2021; Emcke, 2022, pp. 30–45) and be considered accordingly when conducting a semi-structured interview, for example, or the subsequent interpretation (van der Linde, 2024). If, on the other hand, the testimonies of trauma survivors were only perceived in their function as evidence (in the sense of a legally verifiable truth) or as an insufficient source of knowledge, the ethical dimension of telling and listening would be disregarded and the interviewees would be instrumentalised as a source of knowledge and possibly even discredited.

#### **4.3.3. Training and research standardisation as professional prerequisites for researchers**

A perception of the participant's well-being during the interview does not come naturally but requires training. Since mechanisms of self-protection such as defence, distancing, wanting to explain and even unjustified accusations of guilt often occur as spontaneous reactions, self-awareness training is required in order to appropriately record reports from trauma survivors.

Appreciation, transparency, and recognition must be practiced. Person-centred interviewing according to Carl Rogers, for example, offers good foundations and forms of training. Overall, structured further training for interviewers, which emphasises the practice of these attitudes, should definitely be a standard part of research with traumatised people – especially for those disciplines that are not familiar with professional forms of face-to-face interviewing.

Research protocols and interview guidelines, which are intended to ensure a standardised procedure, could include assistance with regard to protection and appreciation. For example, a leaflet could be created for the interviewer with typical symptoms of strong stress reaction or re-traumatisation, or formulations of appreciation and the reaction to shared experiences of suffering could be considered in advance and recorded in a written form.

#### 4.3.4. Potential “benefit” for study participants

The narrative of trauma survivors in interviews, with the associated risks and burdens, must be accompanied by an ethos of questioning, listening and understanding. This is because, on the one hand, this approachability is a prerequisite for ensuring that trauma survivors are not inflicted with even more suffering through disrespect or instrumentalisation for other people’s purpose, and on the other hand, it can also represent a “benefit” for the subject.

It is desirable that the researchers succeed in perceiving the narrators in their double role, i.e. as the people they once were before they were pushed out of the world, and as the people they were made into through the experience of extreme disenfranchisement and violence. The philosopher Jill Stauffer emphasises the importance of intersubjective processes in the reappropriation and reassurance of one’s own biography: The narratives of those affected are also shaped by listening to third parties, their interest and resonance. If what they report is not supported, the narratives become questionable for those affected themselves.

#### 4.4. Follow-up: provision of protective structures and support in the event of stressful consequences

##### 4.4.1. Dealing with incidental findings

A separate ethical question in medical research on humans is how to deal with so-called incidental findings: Should the incidental finding of a dangerous aneurysm for example, be reported in a study using an imaging procedure? But incidental findings can also occur in interviews with trauma survivors:

In the event that trauma survivors are suspected of suffering from a mental disorder, such as post-traumatic stress disorder or depression, which has far gone untreated, this should be articulated and the person concerned should at least be shown a concrete treatment option – outside the institutional research context. The risk of extremely negative consequences such as re-traumatisation and suicide should also be discussed. It is true that diagnosis and treatment of mental illnesses,

unlike somatic illnesses, are less self-evident due to negative connotations. Nevertheless, researchers should be trained to carefully address secondary findings or suspected diagnoses in such a way that those affected do not feel patronised or pressured into treatment.

#### **4.4.2. Professional support for study-related negative consequences**

It is in the nature of the symptoms that trauma survivors may not face negative consequences just until they have completed a research interview, i.e. with a time delay. Not knowing your own boundaries or going beyond them and being caught up by one's own feelings later is also a phenomenon that many people are familiar with.

Qualitative research with trauma survivors requires that contact points are named that can be consulted promptly if psychological stress occurs after participation. Professional aftercare must not result in any costs for the participants. (Analogous to the insurance for subjects required by the German Drug and Devices Act, one could also consider insurance for injuries occurring to participants.)

Information about the forms of professional support for psychological problems in the follow-up should be provided at the beginning of the study.

In addition, it is also possible to set up a reporting centre to which study participants can complain. Similar to a reporting centre in institutions, such an office could also serve to improve qualitative study designs with regard to the respect and protection of trauma survivors in the future.

### **5. Well-being of researchers in the face of risk of secondary traumatisation**

Even though researchers should treat interview participants with consideration, respect and recognition, they must also maintain a certain professional distance. Prior training is certainly required for all researchers who are not familiar with clinical psychology, in order to

recognise transference phenomena and not to identify too strongly with the trauma survivors.

### 5.1. Phenomenon of secondary traumatisation

Furthermore, researchers themselves are still little considered as well as the danger of being “secondarily” or “indirectly” traumatised (Gebrande, 2021). On the one hand, when they get in contact with trauma survivors, they become witnesses in a society in which there can be no innocence of ignorance. On the other hand, this moral witnessing – a main motive or merely a side effect of their research – must not mask the risks and burdens that can accompany this area of research.

The phenomenon of secondary traumatisation is known from psychotherapy and social work (Maercker, 2019; McCann, 1990), but must be transferred to the specific context of research, which is not per se flanked by professional self-awareness and supervision processes. In addition, the current state of research in this area needs to be analysed in more detail: It is currently still a matter of debate whether there is a risk of “transmission” or whether secondarily traumatised persons have themselves been victims of violence. New studies need to be awaited here, because depending on the results, different pre- and aftercare measures may be necessary for the researchers themselves.

### 5.2. Phenomenon of guilt among the “unharmd”

In addition, the listeners or researchers may develop feelings of guilt due to their helplessness towards the affected subjects, because they react helplessly and inappropriately in the face of the subject’s difficulties. It must therefore also be clarified in more detail how researchers from the social sciences and humanities who have not already acquired skills in dealing with clinical disorders through their psychological or socio-educational careers can prepare themselves appropriately and how they can still take care of themselves afterwards (Christman et al., 2018). Professional supervision should always be available free of charge.

### 5.3. Communicating mutual expectations and opportunities

Overall, whether they like it or not, researchers are also witnesses who face difficulties in listening to and adequately absorbing the stories of trauma survivors. Their trust in other people and their world view will also change. In many cases, trauma survivors also legitimately hope for recognition and sympathy in a research setting. However, the interviewers cannot offer any form of support beyond the study. In an article on the trauma-sensitive design of interviews with migrants, social worker Sina Motzek-Öz argues that a “communication and negotiation process” with regard to the interview procedure and dealing with expectations protects both the interviewees and the researchers (Motzek-Öz, 2019).

### 5.4 Trauma-informed and trauma-sensitive training courses

Interviewers who are not therapeutically trained should receive training on trauma phenomena, practise trauma-sensitive attitudes as well as self-observation and self-care. Self-reflection-related skills may be foreign to the researchers, and therefore resistance is to be expected in such training courses. Nevertheless, it must be made clear that encounters with trauma survivors require special skills.

## 6. Outlook

At the moment, it is not ensured that researchers consistently reflect on their research with trauma survivors from an ethical perspective. The standards and distinctions presented do not claim to be exhaustive, but still need to be further developed for this area. An overview of the ethical issues was presented with numerous aspects to be considered and possible implementations, which of course depend heavily on the respective research design.

It is clear that more research is needed to clarify how trauma survivors experience a research project. The sociologist Barbara Kavemann, who made the feedback from interviewees part of a sociological study

with trauma survivors, is enlightening for German-speaking countries and for research relating to more recent reconciliation processes (Kavemann, 2019, pp. 136–149). In the English-speaking world, there have been studies on the reactions and consequences of research with trauma survivors for some time (Weare et al., 2022; Kirkner et al., 2019; Massey et al., 2013).

It is also evident that there is a need for trauma-informed research in which researchers from disciplines as diverse as history, social sciences, medicine and law acquire knowledge about traumatised people, think about and shape the research process with regard to voluntariness, disclosure and non-harm, and acquire skills in conducting interviews in a person-centred, appreciative and injury-sensitive manner. In the event of harm, they must also have professional support structures in place or have appropriate cooperation arrangements, through which the interviewees can be supported.

Up to now, qualitative research has mainly focussed on the victims who have been harmed, but rarely on those who, as eyewitnesses or bystanders, could tell of the justice that has occurred. From the point of research ethics alone, research settings that would expose fewer risks and burdens should be used, i.e. less vulnerable people should be included first if possible. Interviewing those indirectly involved or bystanders also represents a research desideratum in another respect – the processing of injustice experienced and future prevention.

Research with traumatised people must necessarily be flanked by a society in which the actual perpetrators, organisations, political decision-makers and state structures are held accountable. The injustice suffered must be recognised, needs-based support must be provided and the disadvantages suffered by those affected by the violence must be compensated for as far as possible (Kavemann et al., 2022). If victims are willing to talk about their experiences, there must be a willingness in society to listen and an appropriate response. Sexual, psychological and spiritual violence is not a misfortune, not a stroke of fate, but an injustice for which partly also people in the social environment and state institutions are responsible.

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