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The violence of bereavement from the research psychologist's perspective

Chemrouk Yasmine, PhD. SuLiSoM, Strasbourg University, France; Delphine Peyrat-Apicella, Lecturer, UTRPP, Paris North Sorbonne, France; Rozenn Le-Berre, Lecturer, ETHICS, Catholic University of Lille, France; Livia Sani, PhD. SuLiSoM, Strasbourg University, France; Marie-Frédérique Bacqué, Professor, SuLiSoM, Strasbourg University, France.

Abstract

This clinical vignette stems from French research into sedative practices and their influence on bereavement in spouses of cancer patients. We worked with hospital departments to recruit participants. They were offered a questionnaire and were invited to a research interview. This led us to explore the various issues that palliative care providers may face, including their relationship with the patient's loved ones, questions about bereavement, and how best to support the bereaved. Feelings of bereavement are difficult to put into words, and there is often concern that talking about it may increase the suffering of the person concerned. The question we raise in this case study is whether fears about talking about bereavement come from the bereaved person or from the caregiver. In other words, for whom is talking about bereavement more painful? This point relates to two ethical challenges in our study: first, we seek to better understand the relationship between spouses of cancer patients and health care providers, starting with how to narrate the experience of grief. The second question relates to the ethics of research and specifically the possibility of including patients and family members in the research process.

Introduction

Mrs G is 44 years old. She was married for 20 years and had two children aged 11 and 16. During our research interview, which took place three months after her husband's death, Mrs G recounted the history of her marriage and the birth of her children, and then talked about her husband's personality. She then described in detail the months of her husband's illness with metastatic kidney cancer. These themes corresponded to our pre-announced interview guide, and at no point did we need to follow up or redirect Mrs G's discourse. The interview was fluid and unfolded like a story which had already been thought out and elaborated. The narrative did not appear to require any support other than a neutral, benevolent presence. It seemed to us that this space to speak, which was offered within the framework of the research, proved to be truly beneficial for this woman, who seemed to feel the need to recount her painful experience. This interest in narrative is a way to explore the various functions of narrative, as Paul Ricoeur asks with the concept of "narrative identity" (1992).

The course of the interview

The interview took place by videoconference, a few days after the Christmas holidays. Prior to this point, we had only exchanged e-mails. The interview lasted three hours, without interruption. The duration of this interview is unconventional and at the same time not surprising in this context. The particularity of a research interview, unlike a psychotherapeutic session, is underscored by its unique temporality. Typically, these encounters are single, or at least clearly spaced apart from subsequent ones. During these interviews, the researcher delves into the participant's history, creating an environment in which all that is pertinent must be articulated and carefully absorbed in this unique and meaningful encounter. Our interventions were very occasional and mostly non-verbal. Mrs G was at home, on her own in a room, and her children were present in the house. At the start of the interview, Mrs G went into detail about the history and facts of their relationship as a couple, in particular the difficulties she and her husband had

encountered in having children, and how this ordeal – in her opinion – had brought them closer together. She said, “We had a normal, simple family life, but I liked it so much, this simple, normal family life”.

She went on to talk about the prodromal stages of the disease, saying she hadn't thought about cancer, despite her husband's symptoms. She stated, “I'm a very observant person, and I didn't see, well, I did see that he was sleeping a lot, that he'd lost weight.” We later came to understand her guilt. Indeed, Mrs G believes that what she calls a form of “denial” led to a delay in treatment, and thus to a diagnosis of incurability when the disease was first discovered. She said, “I wish I had a magic wand to go back to August 2021 and tell him ‘you urgently need to go to the doctor, you're going to have kidney cancer, you need to have your kidney removed right away’ [...] I don't have this magic wand, I didn't see, I saw that he was sleeping a lot, I didn't understand that it was cancer.” The progression of the disease was therefore very rapid. Mrs G's incessant flow of words seems to illustrate this lightning-fast, ineluctable progression. Nonetheless, her discourse corresponds to an elaborate, chronologically organised logorrhoea, in which she addresses concrete facts as well as her emotions, feelings, and questions. By the operation of creating a story (from beginning to end), we can assume that Mrs G puts her experience in order and creates a story that she can pass on. Is this a way of operating the form of catharsis referred to by Ricoeur (1992), according to Aristotle's *Poetics* (2006)?

Mrs G's discourse revealed the violence of her experience. The illness may have seemed very brief, but its stigma changed both her husband's physical appearance and his personality. She repeated many times how she no longer recognised him. The interview was interspersed with restrained sobs and occasional tears, and we also saw flashes of intense anger. Anger at the disease, of course, but also at the people around her who don't understand her situation, and who sometimes act clumsily, throwing her “widow” situation back in her face. “I still have a lot of anger,” she says, “I can't say otherwise, I'm still angry”. Importantly, emotions are still present in the spouse's experience through her narrative. Emotion, in this case, is a way of processing relatable thought.

The purpose of the interview and the narrative process

If we had approached Mrs G's interview with a clinician's hat on, the framework would have been different. Our posture, as well as the timing of the exchange would have been completely different. In our role as researchers, Mrs G was able to tell her story without any time constraints, and the interview was free of the need to fulfil a therapeutic function. The narrative process seemed to bring her together and soothe her, and in picking up the pieces of her recent history and continuing to make connections, it encouraged further elaboration. At the end of the interview, Mrs G's sobs gave way to smiles, humour, a little cynicism, and light words. A new, lighter form of spontaneity emerged. Towards the end of the interview, we intervened more often, the atmosphere changed in colour and tone, and it began to resemble more an exchange than a monologue. We can assume that this process (from monologue to dialogue) may be a way of exploring how to build a real partnership with patients and family members in research. In a way, this kind of process paved the way for the formation of a kind of research team, between the spouse and us as researchers, thus reducing asymmetry.

After the interview, we were exhausted. We felt that we had been supporting Mrs G's words with our silent presence, and this reinforced our perception of the violence of her experience. We felt we had “suffered” the violence, and had to absorb it, despite our active position as researchers. Ultimately, we took on the role Mrs G gave us during the interview: that of a receptacle for her suffering. Mrs G had been under the care of a psychologist since the death of her husband, however, research offered a totally different context. This was the first time she had been given the space to tell her story, to express herself without interruption and, consequently, without a feeling of fragmentation. We hypothesise that this

opportunity to recount her story without hindrance enabled her to move in the direction of psychological reassembly.

The transcription process

We transcribed the interview in the weeks that followed. This stage was also marked by an echo of violence. Re-hearing Mrs G sob and break down in tears at times, was difficult for us. As a result, we felt the need to take breaks from this exercise, which was very tiring. At times it appeared that the transcription process was proving to be more difficult than the interview itself, as if we were confronting the intensity of the emotions by replaying them. Transcription requires that attention be paid to every word, and each passage must be listened to several times, in order to record the speech as accurately as possible.

Once the transcription was complete, we felt a pressing need to discuss this clinical vignette with our fellow researchers. Sharing Mrs G's story and our subjective experience was necessary and salutary. We felt the need to share everything she had confided, everything she had "deposited" with us through her speech. The idea of writing an article came to us following these discussions, and it was as if we felt that by sharing the violence we had experienced, this could help us to metabolise it, make sense of it, and give it new resonance.

Discussion: vicarious trauma?

Mrs G's experience can be described as traumatic. The brutality and rapidity of the illness, followed by her husband's death and the circumstances surrounding it, naturally had a devastating effect on her. We experienced the violence that Mrs G felt, and this upset us, both during the interview and in the aftermath, leading us to question the nature of vicarious trauma in this relationship. The concept of vicarious trauma has been widely discussed in psychological literature. Vicarious trauma is understood here as the "contagiousness" of the traumatic event and its emotional impact upon the person to whom the event is being narrated. Vicarious trauma differs from other related concepts such as compassion fatigue and secondary traumatic stress. Initially, vicarious trauma referred specifically to the traumatic experiences of therapists working with survivors (McCann & Pearlman, 1990). Later, the definition was extended to a wider group of people, including all those who help survivors or traumatised people (Saakvitne *et al.*, 2000). Here, we hypothesise that, through the context of the research interview (as we have described it), a traumatic event in Mrs G's life became contagious, yet the interview simultaneously allowed for a kind of metabolisation of the traumatic load. We can hypothesize that this traumatic burden has been extended to health care workers and psychologists, after death, during bereavement support, but also during the end of life, as anticipation. Therefore, one of the questions the study asks is how health care teams deal with grief through their discourses and practices, such as sedation practices.

The risk of compassion fatigue could also be mentioned here. Repeated confrontation with suffering and death can generate this phenomenon in professionals. Compassion fatigue corresponds to an emotional load that is accompanied by a reduction in professional performance, an increase in errors, and a deterioration in relationships with colleagues (Schwam, 1998). Professionals may experience psychological and physical exhaustion, apathy, feelings of powerlessness, frustration, and even the desire to change profession (Leon, Altholz, & Dziegielewski, 1999).

This epistemological statement closes with questions of clinical ethics or ethics of care, especially in Carol Gilligan's work (1982). While considering our experience of this singular research interview experience, we began to wonder about the impact of these fears which exist around engaging with the bereaved. Would proposing a space to talk about bereavement put the professional in difficulty even though the bereaved person might find the interaction soothing? In other words, could the fear of

vicariousness among professionals in the field of psychological care be at the root of resistance towards providing a space for discussion?

Our hypothesis is that this is a psychological both an ethical issue: how do we do better? As a crucial question for ethics, this focus on emotions (of patients, family members and professionals) is a challenging issue to question the ultimate finality of the research which is to open perspectives on grieving experience.

Conclusion

As psychologists working in cancer and palliative care departments, we have accompanied many patients' loved ones through the grieving process. Although some situations have been tiring, they have not had quite the same "tone" as this one. In other situations, the feeling of "experiencing" violence, of intensely receiving it, was not as significant. In this case, it was as if the violence experienced by Mrs G was transmitted to us and we experienced it in the same way. Adopting the position of researchers and needing to transcribe the interview probably contributed towards this experience, but the difficulties we encountered led us to question the experience of caregivers who are faced with this type of narration. In our work, we frequently note reservations expressed by teams when it comes to reconnecting with loved ones after the death of a patient. They often speak of their fears that engaging with the patient's loved ones could reactivate their suffering, and that such attention could prove deleterious. It seems to us that greater attention needs to be paid to staff training in this regard (Bacqué *et al.* 2023).

Ethics

The research protocol, which complied with Helsinki guidelines, was approved by the ethics committee of the University of Strasbourg (Unistra/CER/2021-42).

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