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An Auto-Ethnographic Study of the Disembodied Experience of a Novice Researcher Doing Qualitative Cancer Research

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Charlotte Benoot¹ and Johan Bilsen¹

Abstract

Qualitative health researchers who explore individuals' experiences of illness are exposed to an emotionally demanding work environment. After doing 49 interviews with cancer patients living alone, I was confronted with serious emotional distress that kept me from my work for almost 6 months. Because there is a need for discussion within academia about the emotional risks encountered by researchers, I used auto-ethnography to explore what I call the "three disembodied experiences" I encountered during the research: disembodiment linked with suppression of emotions, disembodiment linked with distal traumatization, and disembodiment linked with overidentification with the participant. I illustrate these concepts with personal stories of doing research with cancer patients living alone. I conclude that writing down experiences of doing qualitative research in an embodied and reflexive way holds two advantages: It can protect the researcher and enhance the quality of research.

Keywords

empathy; emotions; emotion work; embodiment; bodily experiences; burnout; cancer; reflexivity; qualitative; auto-ethnography; Belgium

Introduction

Qualitative researchers who explore individuals' experiences of illness, death, and dying are exposed to an emotionally stressful work environment (Dickson-Swift, James, Kippen, & Liamputtong, 2008). As a qualitative researcher myself, I (CB) was appointed in 2011 to conduct a research project on the lived experiences of people with cancer who are living alone (Benoot, Bilsen, Grypdonck, & Deschepper, 2014; Benoot, Deschepper, Saelaert, Grypdonck, & Bilsen 2015). After 2 years, having conducted and analyzed 49 interviews among this population, I was confronted with serious emotional distress that kept me from my work for almost 6 months.

I still enjoy and value my job as a qualitative researcher, but after this period of sick leave, I started to explore the dynamics that drove me toward these serious mental health problems. I searched for literature on researchers' distress, wondering whether others had been confronted with similar experiences. To my surprise, I found a lot of literature that confirmed my experiences: In the last 10 years, there has been an explosion in reported challenges for qualitative researchers doing sensitive research (Dickson-Swift, James, Kippen, & Liamputtong, 2007).

Encouraged by this mass of literature, I decided to present my story at a congress for qualitative researchers (Benoot, Bilsen, Grypdonck, & Deschepper, 2014). The reaction to this oral presentation and the resonance it generated were overwhelming. As a consequence, I felt that it was my duty to tell my story, which is one of an inexperienced novice researcher doing qualitative cancer research. I emphasize the fact of being a young investigator, as I believe that my age and life experience influenced how I experienced difficult issues during the research process (Johnson & Clarke, 2003). Some authors claim that novice researchers are particularly vulnerable to the emotional challenges of sensitive topic research (Woodby, Williams, Wittich, & Burgio, 2011). Nutov and Hazzan (2011) state that neophyte researchers are unprepared for dealing with the emotions involved and that they need specific

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attention and guidance in the form of supervision. Some authors even pose the question of whether it is ethically appropriate for novice researchers to undertake research into sensitive issues, such as illness and death (Johnson & Clarke, 2003). With this article, however, I do not want to claim that novice researchers are more or less vulnerable, but that there are some particular aspects of being new to the field that can contribute to specific personal and professional challenges.

As I plunged deeper and deeper into the literature of emotional challenges/distress, while trying to find an appropriate way to write down my experiences, I discovered the methodology of auto-ethnography, and I was wildly enthusiastic about the approach it offered. It not only changed my perspective on and epistemological background to doing research. Above all, it helped me to understand my own situation by putting it into a broader, cultural perspective. Auto-ethnography pursues the ultimate goal of a cultural understanding of highly personal experiences of the researcher. In my case, my personal struggles reflected the dynamics of the academic discourse about rational, objective science and the dichotomous basis of Western thinking that is connected to the fundamental dualism of mind and body (Holland, 2007).

In this article, I will unfold these experiences through auto-ethnography. This auto-ethnography will eventually lead to some recommendations and insights into embodied knowledge and reflexivity, which I will argue are both methods to improve the way we do qualitative research, and to improve self-care for the author/researcher.

Method

Auto-ethnography—especially the evocative or emotional ethnography (Ellis, 1999)—has recently become a popular form of qualitative research. Auto-ethnography makes the researchers' own experiences the focus of the research. The self is the source of the data, in the form of writing down the day-to-day concrete details of life—a process which is called “zooming in” (Chang, 2008, p. 125). Yet, the self is not examined in isolation but with reference to the socio-cultural backdrops against which one's life is lived (Taylor, 2013): This involves a process of “zooming out” which enables you to see how your own case is related to others, and how your case is connected to its context (Chang, 2008, p. 129). Auto-ethnography is thus more than autobiographical writing and has a theoretical framework which comes from a body of relevant literature. Auto-ethnography should be ethnographical in its methodological orientation, cultural in its interpretive orientation, and autobiographical in its content orientation (Chang, 2008). In short, an auto-ethnography should consist of three axes: the story (auto), the culture (ethno), and the method (graphy).

Experiences/Auto

The way of storytelling is akin to the novel or biography and thus fractures the boundaries that normally separate social science from literature (Ellis & Bochner, 2000). To write down my experience, I paid attention to my own physical feelings, thoughts, and emotions, writing them down in the form of a story. All of these stories were written down retrospectively by recalling emotional scenes and self-observation, because of the absence of reflexive notes during the research project. I am well aware of the limitations of this way of recalling experiences. As Chang (2008, p. 5) says,

memory is both a friend and foe of auto-ethnographers. Whereas it allows researchers to tap into the wealth of data to which no one else has access, memory selects, shapes, limits, and distorts. Memory fades as time goes, blurring the vitality of details.

However, as Ellis (1999) argues, narrative is always a story about the past, always written from a particular point of view at a particular point in time. Every story is thus partial and situated. Indeed, one advantage of writing retrospectively about experience is that the researcher is less involved, which makes it easier to get outside it to analyze from a cultural perspective (Ellis & Bochner, 2000).

Culture/Ethno

An auto-ethnography has the potential to link the micro with the macro (Boyle & Parry, 2007). It connects aspects of the everyday with broader social and cultural practices. In this auto-ethnography, I will work with the constructs of emotional labor and disembodiment to frame my own experiences and to make the tacit aspects of the academic organization more visible (Boyle & Parry, 2007). Emotional labor is the display of organizationally desired emotions (Hochschild, 2003; Zapf, 2002). Disembodiment is a concept derived from the embodiment theory. Embodiment, as a summary term for the bodily aspects of human subjectivity, emerged as a central term in the French phenomenological tradition (Csordas, 1999). Embodiment is an existential condition, a bodily being-in-the-world, in which the body is seen as the subjective source or intersubjective ground of experience. Disembodiment, then, means the “disappearance” of a body as it was previously experienced as taken for granted (Merleau-Ponty, Johnson, & Smith, 1993). Disembodiment entails not so much a change in body image (although that may eventually take place) but a distinct physical distancing from one's own body (Morse & Mitcham, 1998).

Writing/Graphy

By writing in the form of a coherent and structured article, the two elements of the auto and the ethno are brought together in a coherent reflection. I make sense of the whole by combining the general and the private. I try to answer the question of “why”: “Why does the self perceive, think, behave, and evaluate the way it does and how does the self relate to others in thoughts and actions?” (Chang, 2008, p. 9).

Ethics

I am aware that auto-ethnography includes information about others, who are, by association, recognizable, even if their names have been changed. Indeed, through my stories and my reflection, I might make critical points about the academic institution in general and more specifically about my own research group and supervisors. Therefore, this article has been constructively revised and discussed with my current supervisor, and full consent was obtained from all members of the research project team that coached me during this study.

Also we requested and received ethical committee approval (Ethical Committee of the Academic Hospital of the Vrije Universiteit Brussel) for writing this article. We maintained the privacy and confidentiality of the participants.

Auto-Ethnographic Study of a Disembodied Experience of a Novice Researcher

As auto-ethnography must at least provide some autobiographical information, I will first give some specific information about the author and the research project mentioned here. I am a 29-year-old woman with a master’s degree in sexology and social sciences. I started my academic career 4 years ago, when I applied for the position of junior researcher in a 2-year project exploring the experiences of living alone while having cancer. This meant that I did 49 interviews with 32 cancer patients in their home environment. I also transcribed, coded, and analyzed all 49 interviews with the support of a research team. Before I started this research project, at the age of 25 years old, I had never met a cancer patient in my life. I also had never been confronted with illness and death in my family and inner circle.

It was only after 2 years, when the research project was almost finished, that I realized the psychological side effects of doing this research. I was confronted with what I called different disembodied experiences (see definition above). I will structure my auto-ethnography under three different disembodied experiences I encountered during the research: disembodiment linked with the suppression

of emotions, disembodiment linked with distal traumatization, and disembodiment linked with overidentification with the participant.

Disembodiment Linked With Suppression of Emotions

When I was applying for the job, my supervisor warned me that doing interviews with sick people could be tough, asking me: “are you a resilient person who can manage this? Because it is not going to be entirely rosy.” Because of his question, I suddenly remembered an incident during my childhood, where I fainted during a speech by a person who had been invited to our school to talk about her experiences with multiple sclerosis, because I was so upset about the story. Of course, I did not tell my supervisor about this incident; it happened more than 10 years ago and was of no relevance, or so I thought. I responded instead that I am a stable person who is resilient and can handle such a situation calmly—the kind of appropriate answer people give usually when they get such a questions during a job application.

In this story, it can be seen that I immediately adapted my authentic emotions to those that I thought were appropriate in the work environment (called emotional labor; see earlier Zapf, 2002). I thought that to be able to do this research, I had to be stoical. From that moment on, I was the resilient researcher who had no issues with interviewing people about illness, suffering, and death. We can call this a disembodied experience because I displayed observable emotional and bodily reactions that were congruent with the expectations of my work environment, but incongruent with my normal emotional and bodily reactions (Hochschild, 2003).

I never talked about the emotional challenges of doing this research with the members of my research project team. Instead, the first meetings with my supervisor and the other team members focused mainly on how to construct an interview guide and how to elicit the required information from the patient. Moreover, before I started with my interviewing process, I read a lot of books and manuals on how to interview participants. On the basis of what was in those books, I started building up an interview questionnaire; I also learned the techniques of probing, redirecting, paraphrasing and so on. After reading these books, and after having revised my interview guide, we decided as a team I was ready to go into the field. I, however, felt anxious about starting fieldwork and meeting the first cancer patient in my life. The idea of meeting a patient with cancer, living alone, immediately resonated with me in a vivid way. However, I suppressed the anxiety I had before the start of the interview. I felt as if my interview guide was a weapon against the anxiety, as was my status as an academic researcher.

Academic discourse follows the dichotomy in Western philosophy of the fundamental dualism of mind/body,

where reason and emotions are posed antithetically (Holland, 2007; Jaggard, 1989). So I classified my anxiety as an irrelevant feeling impeding the smooth course of events. The emphasis of my supervisors on the interview guide and the manuals as guidance affirms the idea that knowledge can best be achieved linked with rational, distanced, and unemotional means (Malacrida, 2007). Moreover, the suppression of my own authentic emotion, which was contact anxiety at that moment, also stemmed from my perception of my role as a researcher. Rogers-Dillon (2005) mentions that the structural position of novice researchers makes them very vulnerable when they work in qualitative research teams, as they struggle to establish a professional identity and have little power in the research. The hierarchy of a project group meant that the feeling of anxiety I had before the onset of the interview left me with a concern that I was particularly weak, rather than relating my anxiety to events that are raised by the nature and characteristics of the research I was doing (Johnson & Clarke, 2003). The fact that I was an inexperienced researcher contributed the fact that I did not recognize that these emotional reactions were a part of the professional work of a qualitative researcher (Beale, Cole, Hillege, McMaster, & Nagy, 2004).

My first interview was with a woman with breast cancer who had been living alone for about 20 years. We sat together on a big sofa in the living room. When I asked her how she became a widow, she started to sob hard. She told me the devastating story of her husband, who committed suicide; while she was telling me this, she stood up, and walked to the kitchen door. "Here," she said, "this is where he hanged himself, from the hook of this door! And as I have to lie down in the sofa all the time, my gaze is constantly directed towards that door. Even after 20 years, I can't bear the view." Although she was in tears while she told me this disturbing story, I did not have the impression it affected me very much at that moment. Instead, I was trying to figure out my next question, in order to distract the woman towards another topic in the interview guide. I did this with success and the woman regained her composure. I remembered that I felt very relieved as I closed the door behind me. It felt a bit like I could finally exhale after holding my breath for 2 hours. In my opinion, surviving the interview without being emotionally devastated myself or without upsetting the patient was a big achievement. So when my friends and family, who knew me as a very emotional person, asked me "how are you managing such sad stories, isn't it really upsetting?" I actually answered—sincerely—that I was doing particularly well and that the stories were not affecting me in the way I thought they would.

As novice researchers are taught that the research process is orderly and logically structured, they typically focus on the cognitively articulated aspects of the interview and not on their own and their participants' emotions (Ezzy,

2010). As a consequence, they are unaware of the role of emotions in shaping their behavior. What I was experiencing at that moment was—although I was not aware of it—an emotional response to a distressing situation, which Johnson and Clarke (2003) call "desensitization": It means that you become estranged from your feelings. The ideal of being a rational and autonomous person led me to depersonalize the patient, turning her into a "research subject" (Ezzy, 2010). However, this suppression of feelings can be a counterproductive strategy that brings the topic to be suppressed to the fore in the long term (Candel & Merckelbach, 2003).

By focusing mostly on the procedures and techniques of interviewing: I neglected the fact that interviewing is more than just words. Interviewing is an embodied experience (Ezzy, 2010). Neglecting this, I maintained an illusory distance between myself and the participants. My conduct in the interviews was thus a disembodied performance. I was intentionally avoiding emotionally distressing situations, thereby not only disguising what was happening but also failing to establish a rapport with a lot of my participants.

Disembodiment Linked With "Distal Traumatization"

Likewise during the coding process, I encountered unforeseen difficult situations. "Life is like a children's shirt: short and shitty" was a quote from a woman with terminal throat cancer. Over and over again I was shocked as I had to re-hear, and then re-read this sentence full of desperate cynicism about what her life had been and still was. I could not handle comments like that. Certainly, it was meaningful to my investigation. But what could I do with it? How could I take a step back from so much suffering? Every time I tried to do that it felt as though I were betraying her sincerity.

I also had this feeling of powerlessness with Patrick, a man who was going to die soon. In his interview, he was struggling very hard to satisfy his basic need for ordinary comforts. His stubborn and artistic character made him refuse any financial help or other kinds of support. When I coded his story, I felt very rebellious. Questions in my head were popping up like: "What am I doing here? Couldn't I spend my time better by giving the man a hot meal or some heating during this cold winter?" I was shocked by my own failure to comfort this man. I could not get him out of my mind, so after a month, I googled him. Noticing that he had already died, it was even harder for me to continue coding his story.

Coding the interview of Martha, on the other hand, made me feel very guilty. Our research team was wondering whether or not living alone led to particularly distressing experiences. We found evidence of this in the interview with Martha. Martha was a very depressed person, completely isolated, with no visible informal caregivers around her. For these reasons, she doubted that her life had any meaning and was

thinking about having euthanasia. Consequently, there was some confirmation of expectations in the research team because we had finally collected a story about a negative experience of living alone. At the same time, I felt guilty about my own contentment in what we found. How could we be happy about the sad situation the woman was in?

Thus, there was confusion between handling the interview professionally and containing my emotions after multiple interviews and at the stage when I started to transcribe and code. The qualitative handbooks that were guiding me through my analysis process gave me a very different message to that in the handbooks about the interviewing procedure. Here, the message was that while analyzing the data, a qualitative researcher has to “assume the posture of indwelling” (Maykut & Morehouse, 1994, p. 25). I was told to “be at one with the persons under investigation, walking a mile in the other person’s shoes, or understanding the person’s point of view from an empathic rather than a sympathetic position” (Maykut & Morehouse, 1994, p. 25). The act of coding and transcribing made me relive the emotions I suppressed while conducting an interview, without the necessity of controlling them. This was because I was alone at that time, which gave me more freedom to express my feelings, and also because I had had more time to take the story in. Moreover, the repeated listening, replaying, and typing intensified the emotional responses to sensitive materials (Woodby et al., 2011).

The coding activity had also some disembodied qualities (Malacrida, 2007) because of taking the stories of these patients out of context by abstracting them and making judgments about their personal experiences. This disembodiment brought feelings of powerlessness and guilt, because of the physical absence of the participant and the inability to have a reciprocal interaction at that time. As a consequence, the stories of the patients took on a life on their own. I call this experience an experience of “social” disembodiment, or a feeling of estrangement from the real world, from which I felt my findings and abstractions were so far removed. It is a process similar to what calls “distal traumatisation,” which is a vicarious victimization that happens when there is no longer any direct contact with the distressing event (Gilbert, 2001). This feeling of “social” disembodiment was also paired with an “ethical hangover” (Lofland & Lofland, 1995), which is a feeling of guilt and unease over what is viewed as a betrayal of the participants under study.

Disembodiment Because of Overidentification With the Participant

Some participants could penetrate the armour I was wearing. One of these patients was a young woman around 35 years

old: her name was Carla and she had advanced breast cancer. As I sat in front of her, there was a sudden resonance between us that somehow shocked me. We had done the same studies; we had the same kind of sense of humour, a similar outlook on the world. Because I easily felt at home with her, it was the first time I started to realise that cancer could happen to me as well. However, I recovered quickly, thinking to myself, “Maybe she’s young, but she is at least 10 years older than me.” Then she started telling the story of how her cancer affected her for the first time—10 years ago—when she was 25 years old. I shivered, and immediately countered this feeling of anxiety with the thought “well, at least there must be something genetic at work here, so I’m safe.” Then she unconsciously countered this presumption, saying that she was the only one in her family who ever had been confronted with a cancer diagnosis. Again I shivered, and this time it was hard to control. I began to panic: “So this could really happen at my age, in my life?” I pulled myself together again with the idea that I, at least, have a supportive husband who would comfort me during the treatment. Later in the interview I discovered that her husband left after 2 years because he could not bear the cancer process anymore.

After doing a lot of interviews, close to the end of the data collection, the boundaries between my life and the patients’ life were blurring. As a consequence, I started to internalize the bodily complaints my patients had, which means that I often literally could feel the pain symptoms or nausea from the patient I was interviewing at that time. Another consequence was that the fear of getting cancer myself grew with every interview I took.

Because I am a young researcher, illness, death, and dying had not been among my experiences of daily life. However, my encounter with patients who were dying started to shake this false predictability, this inauthentic way of being in the world. Slowly, with the growing number interviews I did, I became absorbed with the idea of being healthy one day, and then suddenly becoming someone who was seriously ill. My false sense of the world’s predictability was now working in the opposite direction: Doing 49 in-depth interviews in a relatively short time with cancer patients, having never met one before, made me suddenly drop the idea that cancer could not happen to me. I realized that life itself was a life-threatening event. This fear of getting cancer was strengthened by the current “culture of health” and the discourse of prevention, which makes people start to worry even when feeling well: They are the “worried well” (Devisch, 2013)

The meeting with the 35-year-old woman with breast cancer was the first experience I was fully conscious of finding distressing, leading to a lot of existential questions. However, it was not during the initial interview process that I started to become distressed. The distressing experiences came only after I had done most of the interviews. This is what other researchers have called the

notion of cumulative distress (Johnson & Clarke, 2003; Woodby, Williams, Wittich, & Burgio, 2003), because of a repeated exposure to distressing interviews.

This overidentification with participants' plights has been especially described in the case of younger researchers and has been named in the literature as "research student syndrome" (Malacrida, 2007), analogous with medical student syndrome, or "compassion stress" (Pickett, Brennan, Greenberg, Licht, & Worrell, 1994). It means that novice researchers see themselves at risk of similar life events as those of their participants, and experience physical and emotional responses that parallel those of participants, because of a loss of emotional separation. Other authors call this "secondary victimization" (Gilbert, 2001), or the phenomenon of "counter-transference" (Halbrook & Ginsberg, 1996), which is the subconscious transfer of patients' experiences to the researcher (Wray, Markovic, & Manderson, 2007). For example, in a study of rape victims, nurse researchers who did the case reviews reported responses such as anger, dreams, and fear of physical injury parallel to those reported in the literature on rape victims (Alexander et al., 1989, cited in Beale et al., 2004).

Emotional and Embodied Reflexivity: A Win–Win Situation for the Researcher and the Research

This article makes clear that researchers have to take into account that their work is characterized by embodied interactions (Malacrida, 2007).

Also, emotions are embodied experiences (Denzin, 1996). These ideas challenge academic discourse, where researchers define their bodies as essentially irrelevant to the production of knowledge (Denzin, 1996). It challenges the idea that 'facts' come out of our heads, and 'fictions' out of our bodies (Ellingson, 2006). This article, however, implicates that the primary way of learning is through the body, as Merleau-Ponty, Johnson, & Smith (1993) also suggested.

Researchers should thus systematically reflect on the emotional as well as the embodied performance of the research process.

The advantage of embodied reflexivity can be twofold. First of all, it protects the researcher. This article has shown that emotional labor, consisting of hiding or suppressing emotions to meet environmental expectations, can be helpful to protect emotional stability in the short term, but it can also result in disembodied experiences such as self-estrangement, distal traumatization, and overidentification in the long term, as described above. This article, however—as an example of embodied reflexivity—was written only after completion of the research process and after a period of emotional distress,

and could thus not serve as "evidence" for prevention of researcher distress. Writing down experiences in an embodied, reflexive way, however, helped me to recover and to resume my function as qualitative researcher.

The second advantage of embodied reflexivity is that it can enhance the quality of the research. The fact that research work is not merely intellectual labor but also emotional labor, and embodied knowledge is reflected in various studies (e.g., Coffey, 1999; Gilbert, 2001). Instead of ignoring this emotional labor, we should be conscious of it and develop this emotional work and embodied knowledge, so that we can use it as a means for enriching the data gathering and analysis processes (Nutov & Hazzan, 2011). It is through such introspective, emotional self-awareness that qualitative researchers can develop more open and attentive interviewing practices in which the interview is framed as communion rather than conquest (Ezzy, 2010). Indeed, some authors have already argued that the field of qualitative health research could benefit significantly from embodied reflexivity (Ellingson, 2006). Gilbert (2001) suggests, "It is not the avoidance of emotions that necessarily provides for high quality research. Rather, it is an awareness and intelligent use of our emotions that benefits the research process" (p. 11).

Implications for Practice

Implementing embodied reflexivity in practice first of all implies that we have to rethink the nature of qualitative research methods (Ezzy, 2010). Ellis (1999) describes this need to change the way we perform qualitative research by saying that we have "to include the heart" in writing down our qualitative results. It is no coincidence that we say "heart" to refer to a body part as well as an emotion: We have to write in an embodied way, or Ellingson (2006) calls it, in "the language of the body".

More specifically, specific support and training should be given to early career researchers to cultivate emotional reflexivity and physical awareness, thereby teaching them the appropriate skills which can prevent distressing situations. This can be done, for example, by arrangements in the form of a peer support program that brings together a range of researchers involved in some form of researcher support (Dickson-Swift et al., 2007). Furthermore, strategies like intervision, debriefing, counseling, and the development of ethical protocols focusing on both physical and emotional safety are recommended.

Also, emotional and embodied reactions—from the interviewer and the interviewee—should be used as data in the analysis. More specifically, using methods based on clinical supervision, for example, when a researcher risks to mistake their own concerns for those of the

participants they analyze, can lead to a deeper level of understanding in a research context (Midgley, 2006).

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