The Emotional Impact of Sensitive Topics: An Autoethnographic Account of an Ovarian Cancer Research

Dinah A. Tetteh
Arkansas State University - Main Campus, dtetteh@astate.edu

Follow this and additional works at: https://nsuworks.nova.edu/tqr

Part of the Health Communication Commons

Recommended APA Citation

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.
The Emotional Impact of Sensitive Topics: An Autoethnographic Account of an Ovarian Cancer Research

Abstract
Growing evidence suggests that qualitative research about sensitive topics is emotional work with varied unanticipated risks for researchers. This autoethnographic essay adds to the extant literature by discussing the complexities added when the research topic is sensitive, and the researcher has not personally experienced the topic under study. I reflect on and analyze epiphanies in my research with 28 ovarian cancer survivors in northwest Ohio and southern Michigan in the United States, including how I processed the death of some participants. I suggest that practicing active listening, reflexivity, and flexibility can help manage limitations of a research project of this nature; however, these strategies can complicate the emotional vulnerability of the researcher and further limit the research. Implications of the study include a need for researchers seeking to study ovarian cancer or other sensitive topics to proactively incorporate flexibility and reflexivity into every phase of the research process and avoid making decisions for participants. Additionally, this research suggests to healthcare practitioners to understand the varied influences on the ovarian cancer experience, including guilty feelings and fear of death or disease recurrence, and acknowledge these during counseling sessions and at follow-up visits to help validate women’s experiences and open avenues for support.

Keywords
active listening, emotions, flexibility, ovarian cancer, reflexivity, autoethnography

Creative Commons License

This work is licensed under a Creative Commons Attribution-Noncommercial-Share Alike 4.0 International License.

This article is available in The Qualitative Report: https://nsuworks.nova.edu/tqr/vol29/iss4/8
The Emotional Impact of Sensitive Topics: An Autoethnographic Account of an Ovarian Cancer Research

Dinah Tetteh
Department of Communication, Arkansas State University, USA

Growing evidence suggests that qualitative research about sensitive topics is emotional work with varied unanticipated risks for researchers. This autoethnographic essay adds to the extant literature by discussing the complexities added when the research topic is sensitive, and the researcher has not personally experienced the topic under study. I reflect on and analyze epiphanies in my research with 28 ovarian cancer survivors in northwest Ohio and southern Michigan in the United States, including how I processed the death of some participants. I suggest that practicing active listening, reflexivity, and flexibility can help manage limitations of a research project of this nature; however, these strategies can complicate the emotional vulnerability of the researcher and further limit the research. Implications of the study include a need for researchers seeking to study ovarian cancer or other sensitive topics to proactively incorporate flexibility and reflexivity into every phase of the research process and avoid making decisions for participants. Additionally, this research suggests to healthcare practitioners to understand the varied influences on the ovarian cancer experience, including guilty feelings and fear of death or disease recurrence, and acknowledge these during counseling sessions and at follow-up visits to help validate women’s experiences and open avenues for support.

Keywords: active listening, emotions, flexibility, ovarian cancer, reflexivity, autoethnography

Introduction

The emotional, ethical, and relational complexities of qualitative research have been well documented in the literature (Bloor et al., 2007; Ceballo, 2017; Ellis, 2007; Rager, 2005). Issues such as difficulties building rapport with research participants, feelings of guilt, anger, powerlessness, helplessness, and emotional exhaustion are common stressors researchers manage alongside delineating the intellectual contributions of their work (Ceballo, 2017; Dickson-Swift et al., 2007, 2009). Especially if the research topic is sensitive, the impact of these issues can be detrimental to the wellbeing of the researcher. The sensitive nature of the research topic and repeated exposure to participants’ stories through interviewing, coding, analysis, and presentation of findings can take emotional tolls on researchers that may manifest in various ways at different stages of the research project (Bowtell et al., 2013; Ceballo, 2017; Reed & Towers, 2021; Woodby et al., 2011).

Part of the emotional stress researchers experience comes from difficulties balancing “emotional safety” practices and actively listening to participants’ experiences (Woodby et al., 2011) and a sense of responsibility to properly use participants’ personal experiences (Ceballo, 2017). Additionally, emotional stresses can emanate from researchers’ inability to console distressed participants (Woodby et al., 2011), repay participants for their time and energy
(Johnson & Clarke, 2003), or reconcile contradictory feelings about how a researcher should feel, act, and respond and how she/he actually feels, acts, and responds (Darra, 2008). These emotional experiences can enhance understanding and empathy with research participants (Arditti et al., 2010) and can also represent data to be analyzed (Watts, 2008). The emotional experiences can authenticate the research process and outcomes as they enable co-creation of a shared “emotional space” and consequently a shared “narrative space” (Watts, 2008, p. 8).

Several scholars have shared their experiences about the messiness of doing qualitative research, importance of acknowledging the emotional impact of fieldwork on the researcher and research process, and a need for researchers to practice self-care and emotional safety (Bowtell et al., 2013; Ceballo, 2017; Ellis, 2007; Rager, 2005). The present autoethnographic essay adds to the extant scholarship by discussing the nuances added when the research topic is sensitive, and the researcher has not personally experienced the topic under study. I draw from tenets of autoethnography (Ellis et al., 2010; Ellis & Bochner, 2000, 2006) and analyze “epiphanies” from my experience researching ovarian cancer.

I begin my essay with background information about the research project and a reflection on how I processed the death of some research participants. I then use this story and other instances from the project to discuss the emotional impact of sensitive research on the researcher, how strategies such as active listening, reflexivity, and flexibility can be leveraged in instances where the topic is sensitive and the researcher has not personally experienced the topic, and how these strategies can complicate the emotional vulnerability of the researcher. My experience and the lessons learned will be useful to early career researchers who study sensitive topics and who may not have any personal experience of the topics they study.

Background

The research project on which this autoethnographic essay is based was for my Ph.D. dissertation¹, which was approved by the Institutional Review Board at Bowling Green State University in Bowling Green, Ohio, in the United States. Data for the project came from in-depth interviews and focus groups with 28 ovarian cancer patients/survivors in northwest Ohio and southern Michigan. Participants were between ages 23 and 84; six of whom were diagnosed at stages I and II each, 11 were diagnosed at stage III, three were diagnosed at stage IV, and two were unsure about the stage of the disease at diagnosis. At the time data were collected, six participants had recurrences and were in treatments and one person had terminal disease and had stopped treatments. Three participants had died by the time I finished the final write-up for the project, a period of about one and half years.

Recognizing how sensitive the research topic was, I followed proper procedure and training to minimize harm to participants, including attending sensitivity trainings, having regular meetings with my research supervisor, and following the institutional ethic board’s procedures. I also met with leaders of cancer support organizations in the local area to get their input about the research questions and best ways to approach the study. I volunteered for these organizations before beginning data collection and attended some of their programs, including an annual ovarian cancer walk and a survivors’ luncheon, to familiarize myself with the disease and build trust with these leaders. The ovarian cancer walk aimed to educate and create awareness about ovarian cancer. The event normally began in the morning with a group picture of ovarian cancer survivors, who, together with their families and friends, would take a walk along a route decorated with pictures of women who had survived the disease and those who had died. Participants, who all wore teal colored clothing and accessories, later converged on

¹See Tetteh (2016, 2017, 2018, 2022) and Tetteh and Akhther (2021) for publications related to the research project.
a venue for a presentation about ovarian cancer by medical experts and for raffle drawings. The survivors’ luncheon program also took place every year and it was meant to celebrate survivors by treating them to a three-course meal with musical performances.

As I explored ways to make the research rigorous and beneficial to participants (Tracy, 2010), I unwittingly underestimated the emotional impact the process could have on me, the researcher. Somehow, I did not think that suggestions for researchers to acknowledge and strategically manage their emotions during the research process could apply to me (see Blix & Wettergren, 2015). The researcher innocence I went into the project with was stripped away bit by bit with each participant I interviewed—an emotional experience that gradually heightened with the transcription of interviews, analysis, presentation of findings, and when I learned about the death of some participants.

Reflection on Death of Participants

When data collection ended, I sent emails to update participants on the project and to ask how they were doing. Some of them replied to my emails and others did not. With a disease such as ovarian cancer, it was difficult to predict what the problem was when participants did not reply to emails. My imagination ran wild, and I had a lot of “perhaps” to figure out what the problem could be: Perhaps they had recurrences and were preoccupied with treatments; perhaps they were too sick to communicate; or perhaps they had passed away. I tried not to think the worst. But during the interviews, two participants informed me the disease had recurred and they would be beginning treatments; so, I was worried when I did not hear back from them. I did not know anyone close to these participants to find out how they were doing. I truly wanted to know if all of them were fine, but I had no way of knowing.

I did a quick search on the Internet and found that two of the participants (Christie and Lyne) had passed away. Christie, who was 59 years old living with stage III ovarian cancer, died about a month earlier, which was about a year since our interview. Lyne, who was 60 years old and had terminal disease, died three months after the interview and I found out about her death nine months later. I found out about a third participant’s death (Nora) when her daughter replied to my emails to explain that her mom had passed away after the cancer came back aggressively. Nora was 59 years old and was diagnosed with stage II. I was grieved. I felt sad and powerless in my inability to stop ovarian cancer from claiming the lives of these women. I had sleepless nights when I saw their obituaries online, but at the time I did not know my sleeplessness was related to these events. To me, these women were not statistics; they were people whose voices I heard and whose faces I beheld; I knew these women. Their death hit home.

I recall my interviews with the deceased women. Christie had a worried look on her face when she told me her cancer had recurred and she would be beginning treatment. She sounded hopeful despite the grim situation and said she wanted her ovarian cancer experience to be one of hope because there were too many misconceptions about the disease in the public. I went back to the interview transcript and found this quote about Christie’s reflection on how a support group members’ death made her own mortality very real. She said:

A friend of mine died about a month ago; she was about my age. That makes you look at yourself and say, “I’m so blessed; I’m still here and I’m doing okay.” But it also makes you realize that “I don’t know, someday, it might be me.” So, you think both ways.

---

2 I used pseudonyms to protect participants’ identity.
Christie knew death was imminent, but she determined to make her story one of hope. How did she manage life and impending death so gracefully?

I also read the transcript of my interview with Lyne. Hearing her voice through the words on the computer screen made me wonder how she could be gone in just three months? Was she in pain toward the end of her life? I remember Lyne mentioned during our interview:

I don’t think about when I’m actually going to die; I only think about what I want when I die [funeral plans]. It scares me because I know ovarian cancer can be painful at the end but I’ve talked to hospice so we will get that involved at some point.

I was heartbroken reading these words; I cried. When Lyne spoke these words during the interview, I had not yet fully grasped the idea that she might die; I was hoping she would not die. So even though her health situation was distressing, I was not sad hearing her discuss her funeral plans but was rather amazed by how freely she talked about her impending death. I grew up in a culture where death is a taboo word and people do not openly talk about their own death; so, Lyne’s seeming acceptance of her impending death amazed me. But reading Lyne’s words after her death made me sad because her words were now real, and I also had difficulty reconciling the fact that the person whose voice I was hearing through the words on the computer screen was in fact dead and that she died only three months after our interview.

Lyne told me she had terminal disease when she contacted me to be interviewed. We rescheduled our interview three times because she was hospitalized for severe reaction to chemotherapy. When I finally interviewed her by phone, I wanted to cling to her, not wanting to let go for fear that I might not have the chance to talk to her again in this life. I could not express this fear to her because I knew it would not help the situation as Lyne herself was working hard to encourage her family. Her mother was taking anti-depressant medication and her father had not yet come to terms with her impending death; Lyne was their only child. I knew I had to make an effort to suppress my emotion—what Hochschild (1979) termed emotion work. Now, that fear was confirmed. I wanted to do more to keep Lyne alive; listening to her story was not enough. But what more could I have done? I was not sure. I felt powerless.

In the same vein, I wondered how Nora could be gone so soon? How did she feel during the last days of her life? When we met for the interview, she mentioned that she was afraid the disease would claim her life but said she had not expressed this fear to her children because she wanted to protect them. She said:

I don’t say too much in front of my children that “I’m scared” or “I’m going to die from this disease,” or “It is going to get me.” I don’t say those things to them because I don’t want much sadness in their world as much as possible. As a mother, you’re protecting until you’re gone. But I know I am not fooling them; I know that.

3 This was not a one-off comment made by Nora. The context for the comment was when I asked Nora how she talked about her cancer experience when it came up during conversations with friends and family and whether she openly shared all aspects of her experience. To support distressed participants during the interviews, I offered tissue papers when they needed some and offered to pause the interview so participants could recompose themselves. Also, I reminded participants to feel free to end the interview anytime they wanted to and to not answer questions they did not want to answer. Further, I read the informed consent to all participants before interviews and gave them copies of the consent form with information about free professional support services they could contact for help.
Although she did not disclose her fears to her children, Nora had trusted friends that she confided in. She noted, “there is only a handful of people I feel I can entirely open up to and tell how scared I am. It’s years of being with them; they are good friends.” Nora explained she was exhausted from going through treatments for three recurrences and from the “fear of death. It’s fear of what you’re going to go through between now and death.” So, to think that the disease in fact did claim her life was hard to imagine. I was sad.

On several occasions during the research project, I asked myself if my research would make any real impact in participants’ lives: Why did I choose a project with such huge emotional fallout? Why would I want to hear stories about cancer? Why didn’t I choose a livelier topic? Better still, why didn’t I choose a cancer with a better prognosis and high survival rate? But a part of me also reasoned, if nobody researched ovarian cancer, how would society get to know about women’s experiences? Is this not the aim of qualitative and feminist research?

Whenever questions such as the above came to mind, I would remind myself that I chose to study ovarian cancer but did not get to determine the nature of the disease or how it manifested in participants. I chose to research ovarian cancer because I wanted to learn about the disease to empower myself as a woman and to allow survivors to share their experiences to help break the silence and seeming invisibility around the disease (Holmes, 2006). I remember reading about the disease in one of my graduate classes and being shocked to learn that even though it is the deadliest gynecologic cancer, ovarian cancer has received limited research and funding attention, there is limited public knowledge about the disease, and there are few personal accounts of the disease—issues that have led to a disconnect between how the disease is experienced and public understanding and perceptions of it (Gubar, 2012; Holmes, 2006). Thus, I reminded myself that although my research might not make a direct or immediate impact in participants’ lives, it is meaningful.

Indeed, the women I interviewed were also curious to know why I decided to do a project on ovarian cancer. They wanted to know if I had a personal connection with the disease: “Did you have ovarian cancer?” “Does ovarian cancer run in your family?” They asked. In response, I explained that I had not personally experienced the disease but wanted to educate myself and the public about it. All participants agreed this was an important task. So, this common goal of educating about the disease connected me with participants. I bonded with participants not because of a common experience or background we shared but because of a common purpose, which was to educate about ovarian cancer.

In the sections below, I draw from the reflection above and other instances from my project to discuss the double-edged nature of strategies such as active listening, reflexivity, and flexibility in research scenarios where the topic is sensitive, and the researcher has not personally experienced the topic. On the one hand, these strategies can be leveraged to develop empathy with participants and manage limitations of the research while on the other hand, they can add to the emotional vulnerability of the researcher and further limit the research.

Active Listening

Active listening is a valuable strategy to employ when researching sensitive or difficult topics. Active listening can take different forms, including showing interest in interviewees’ stories and making them feel listened to (Louw et al., 2018). It can help participants develop “critical consciousness” about their experiences (Foss & Foss, 1994, p. 42) and can enhance empathic engagement in the research process (Atkins, 2015). It can be a gift the researcher gives distressed participants (Ellis, 2007); but can also constitute emotional labor (Emerald & Carpenter, 2015). Active listening is especially important when the researcher does not have a personal experience of the research topic because it can help him/her demonstrate affinity with
participants without coming across as “knowing” their experiences. In my project, I was careful to empathize with participants without presuming to know what they were going through. Before each interview, I would remind myself to be respectful and intentional in my listening because that was the least, I could do considering the health challenges participants were facing. I listened more than I talked during interviews; this was my way of making participants feel comfortable and assured that I cared deeply about their experiences.

However, I failed to realize that listening to participants’ stories about diagnosis, multiple bouts of treatments, aftereffects of treatments, and fear of (or actual) recurrences entailed more than just listening to ordinary stories. While active listening in and of itself is a valuable research strategy, it becomes a limitation when it is used to over-compensate for other seeming limitations the researcher brings to the research such as lack of personal experience with the topic. Particularly if the research topic is sensitive, actively listening to participants’ stories repeatedly can drain the researcher emotionally (Langer, 2016; McClelland, 2017) and result in emotional and physical symptoms such as nausea, migraines, exhaustion, and trauma (Coles & Mudaly, 2010; emerald & Carpenter, 2015). While I did not have any obvious physical symptoms from listening to participants’ stories, I was saddened by the stories. However, at the time I did not acknowledge sadness as my emotional reaction to those stories; I did not give myself time to consider that possibility. Benoot mentions how being an early career researcher played a role in her failure to recognize her feelings of anxiety as an appropriate emotional reaction to distressing stories from her research participants, consequently leading her to disguise that emotion (Benoot & Bilson, 2016).

Similarly, active listening can complicate the emotional vulnerability of the researcher when it is the primary means by which the researcher tries to earn participants’ trust. Developing a trusting relationship with research participants can occur in phases and it is important to enhancing trustworthiness of the research project and minimizing stress and discomfort for both researcher and participants during data collection (Boles, 2018; Pitts & Miller-Day, 2007). However, opportunities to develop rapport with participants before and after data collection—including frequent visits to the research site and multiple interviews with participants—may be limited in many research projects on sensitive topics such as ovarian cancer due to disease recurrences or hospitalizations. In such cases, the researcher may need to invest extra effort to earn the trust of participants during data collection by employing active listening strategies because that may be the only contact, she/he will have with participants. This can put a burden on the researcher to get it right during the limited time with participants. This was my experience where besides the initial emails or text exchanges with participants to schedule interviews and mail consent forms to them, I had not had any contact with them prior to data collection4. Thus, during the interviews, active listening became an important tool for me to connect with participants. It was emotionally exhausting trying to prove through listening intently that I cared about participants and their stories and even more exhausting to not know whether participants perceived my intent. This left some doubt about whether I was doing enough which, as I will discuss below, complicated feelings of inadequacy I experienced.

---

4 Not having met with participants prior to the interviews might have helped provide a neutral and safe environment for participants to share their experiences in honesty and detail. This is partly because participants might not feel a sense of responsibility to protect me from the burden of cancer when sharing their stories as they might feel toward their family and friends—a situation that can lead some cancer survivors to withhold certain details about their experiences from friends and family (Atkins, 2015). However, it could also have prevented them from sharing everything about their cancer experiences with me because they did not know me well to share some details with me. In her research, Boles (2018) did not observe any difference in richness of data collected from participants she had prior clinical relationships with and those she did not previously know.
Reflexivity

Reflexivity is another strategy researchers can employ to help manage the emotional impacts of researching sensitive topics. With its many variants, reflexivity includes the ongoing examination and acknowledgement of how the researcher’s positioning, background, assumptions, and subjectivity might influence the research process and product with the aim of improving trustworthiness of the research (Finlay, 2017). My positionality as a researcher included being younger than many of the participants, being an international student of African background, having no personal experience of (ovarian) cancer, and the only personal knowledge I had of death and dying was when my grandmother and aunt died in 1994 and 2008 respectively.

In researching sensitive topics, reflexivity can include actively reflecting on when and how to disclose to participants that the researcher does not have subjective knowledge of the topic and how such disclosure might impact quality of data collected and rapport with participants, or quickly learning and mirroring how participants want their stories to be received, or acknowledging the possible emotional impact of the research process and taking practical steps to ensure self-care. For example, in my project, I did not disclose that I had no personal experience of ovarian cancer unless participants specifically asked. But whenever I made such disclosure, I also told participants that I wanted to learn about the disease from their experiences. I noticed that this disclosure shaped how participants responded to me; many of them were detailed and explanatory in their narrations as they aimed to not only tell their stories but also teach me and help shape knowledge about the disease. Thus, such disclosure—or what Pezalla et al. (2012) would consider expression of researcher “naivety”—can give participants control over topics discussed during interviews, minimize power imbalances between researcher and participants, and lead to intersubjective knowledge production (Bell, 2014; Staller & Buch, 2014). Giving participants the upper hand in the research process can help acknowledge the “epistemic knowledge” they have about their experiences; it is important to let people who have specialized knowledge about a phenomenon because of their lived experiences articulate such knowledge (Collins, 1990). However, not readily disclosing that I had not experienced ovarian cancer might have posed a limitation to the study because it might have hindered reciprocal exchanges between participants and me. Thus, in the future, I would disclose such information without being asked, but would be mindful not to become the focus of the discussion.

Additionally, being reflexive meant I withheld any display of negative emotions such as sadness in the presence of participants as I learned they detested any negativity that could interfere with their sense of control over the disease. Some participants explained that they warned relational others not to cry as that could make them emotional as well; others also mentioned they did not want to be pitied. Thus, I learned and adjusted to how participants wanted their stories to be received and responded to—as stories of hope. However, my non-display of negative emotions during interviews might have come across as being insensitive to participants’ experiences which might have caused some of them to not share valuable moments of their experiences with me. My approach deviated from Rager’s (2005) observation that given the nature of participants’ experiences and the way they recounted those; it would have been “dishonest” (p. 425) on her part as a researcher not to respond emotionally to participants. In my case, however, I recognized that disguising my emotions was necessary to forge trust and respect with participants in the co-creation of knowledge about the topic. It was difficult for my facial expression to not reveal that I felt sorry for the woman who had five recurrences or the one who had learned of a recurrence and would be beginning treatment; but I learned to respect participants’ feelings and constantly stepped back and mirrored how they
wanted their stories to be received—a practice that further complicated the emotional impact of the research.

For instance, as I related above, when I interviewed the participant with terminal disease by phone, I did not want to end the interview out of fear that I might not have the chance to talk to her again in this life; but I could not express this fear to her or to anyone—it is one of those things that you do not openly admit in the culture I was raised in. How do I explain to someone that I was worried my research participant with terminal cancer might die and I wish there was a way I could prevent that from happening? I did not know how to have that discussion so I buried that fear and hoped she would not die. But she did die, and I was devastated when I found out.

Further, reflexivity can include acknowledging and taking steps to address possible emotional impacts of the research. But in some cases, no amount of reading about and reflecting on the possible emotional impact of a research project can adequately prepare the researcher for the impacts of their specific projects because research-related risk is fluid and dynamic (Coles & Mudaly, 2010; Sampson, 2019). In my case, the fatalities and disease recurrences I witnessed in participants were not exactly what I anticipated when I decided to undertake the research project. I know ovarian cancer can be difficult to discuss and research. It is the deadliest gynecologic cancer, and it is often diagnosed at advanced stages (i.e., stages III or IV). Advanced epithelial ovarian cancer has the lowest survival rate and high recurrence rate among all women’s cancers, and more than half of women diagnosed will die within five years (Torre et al., 2018). I was aware of these facts about the disease. However, I was still emotionally unprepared when I came face-to-face with these realities of the disease. I was not emotionally prepared to read the obituaries of some of my participants online. I was not emotionally prepared to hear that one person had severe reactions to chemotherapy, including pneumonia, bladder infection, mouth infection, and burnt hands, feet, and throat. I was not emotionally prepared to hear that the cancer had recurred five times in one woman, and she was still fighting and willing to share her story with me. The more I learned about the realities of participants’ experiences, the more unqualified I felt to engage with them—unqualified not in terms of academic preparation but in terms of limited life experiences that paled in comparison with participants’ experiences. As I discuss below, this feeling of inadequacy might have impacted the richness of data I collected and incisive data analysis.

As these examples show, reflexivity can potentially add to the emotional vulnerability of the researcher. For the researcher with no personal experience of the research topic, reflexivity can heighten awareness of her/his supposed limitations (e.g., lack of personal experience) and consequently lead to feelings of inadequacy. Constantly reflecting on your lack of personal experience with the research topic or of anything close to what participants have experienced—even though the practice is meant to help you develop empathy and thus improve the research process—can make you feel inadequate or unqualified to engage with participants about their experiences. This can, in turn, hinder your ability to ask probing questions during data collection which can ultimately undermine richness of data collected, and it can also impact the depth and critical eye with which you approach data analysis. Looking back, I could have probed some participants more on certain issues during the interviews, but I did not do so. Although allowing participants to lead discussions during data collection can help center their voices and ensure that they share aspects of their experiences they want highlighted, it can limit the research if this is driven by feelings of inadequacy on the part of the researcher. Especially for junior scholars who are more vulnerable to emotional impacts of research because of uncertain professional identity (Coles & Mudaly, 2010),

---

5 I did not go to therapy to talk about these issues.
feelings of inadequacy can manifest as imposter syndrome in other areas of their professional lives if these are not appropriately addressed.

I firmly believe that researchers should be adequately informed and knowledgeable about the topic they seek to study before entering the research field to collect data. However, researchers also must be aware that the lived realities of participants’ experiences may not align with knowledge gained about the topic from secondary sources. Thus, prior knowledge about the topic and appropriate training in research risk management may not adequately prepare them for—or shield them from—the emotional impact of the research. In my case, the preparations, and trainings I had prior to and during the project, including sensitivity trainings, regular meetings with my research supervisor, and regular communication with leaders of local cancer support organizations, helped equip me to successfully undertake the research project. But somehow, feelings of inadequacy crept in unawares when I encountered participants with more difficult cancer experiences—such as those living with recurrent or terminal disease or those who had severe reactions to treatments. However, I do not recall feeling inadequate in the moment of data collection; I was able to identify and name this feeling later as I reflected on the research process. In the moment of data collection, I was in awe of the strength and grace participants demonstrated and was grateful to them for choosing to share their stories with me.

Feeling inadequate before and after each data collection session can also add to the emotional vulnerability of the researcher by creating doubt about relevance of the research project. As noted above, I experienced doubts about the significance of my research on some occasions, and I coped with this feeling by determining to honor participants’ stories and amplify their voices in the research output. I am determined to highlight the reality of ovarian cancer in my writing, including the challenging times, positive moments, and resilience of participants.

Further, disguising or suppressing emotions, which is a way reflexivity can be expressed, can lead to depression and low self-esteem, among other outcomes (Gross & John, 2003). Suppressing emotions can provide emotional protection for the researcher in the short term but in the long term, it can lead to disembodied experiences and can hinder rapport building or create overidentification with participants, which can add to the emotional impact of the project (Benoot & Bilson, 2016). Thus, it is significant that if suppression of emotions is necessary during data collection, that the researcher finds an outlet (e.g., through therapy and formal or informal debriefing) to appropriately manage these emotions. Coles and Mudaly (2010) noted how formal debriefing sessions (instead of informal debriefing with family and friends) helped them as researchers to process their emotions and confront certain interview transcripts they were hesitant to work on.

In my research project, although participants and I were reciprocal in our exchanges by being kind, pleasant, and courteous to each other during the interviews, I refrained from showing sadness when some of them occasionally shed tears as they recounted difficult cancer experiences. I supported participants who cried by giving them tissue papers, offering to pause the interview so they could recompose themselves, and providing them with information about free professional support services they could contact. However, as previously stated, my failure to express sadness during the interviews could come across as being cold and insensitive to participants’ stories and might have impacted richness of data collected. This situation further complicated the emotional impact of the research because I cared about participants’ experiences and was touched by their health disclosures, but I just could not express this to them very well. I managed this tension by discussing participants’ stories with my spouse, writing about them in my fieldnotes, and later writing this article.
Flexibility

Flexibility is another strategy the researcher can use when researching sensitive topics. It is crucial to include diverse views and perspectives on a topic, acknowledging complexity of participants’ lived experiences, and adapting to unanticipated challenges (Boles & Daniels, 2019). Flexibility can take many forms, including making situated ethical decisions and/or modifying research site, strategies, questions, and timeline to accommodate unanticipated circumstances during the research process (Billo & Hiemstra, 2013; Boles & Daniels, 2019; CohenMiller et al., 2020; Guillemin & Gillam, 2004). For instance, CohenMiller et al. (2020) had to change their method of data collection to accommodate the needs of participants while Billo and Hiemstra (2013) had to modify the research site and method, daily research schedule, and even abandon the original research topic and questions as they encountered unexpected circumstances during data collection. Similarly, in her research on children with cancer, Boles (2018) consciously implemented and extended flexibility to participants during interviews; this included canceling or delaying research appointments due to unforeseen medical issues with participants, accommodating interruptions from hospital staff, scheduling mealtime and breaks into interviews so participants could rest if needed, and reminding participants of the option to reschedule interviews.

For my project, I had to reschedule my interview with the participant with terminal disease three times because she was sick and hospitalized. I also had to accommodate participants who, for unforeseen circumstances, called on the day of the focus groups to withdraw their participation. Further, I modified my interview guide in some instances depending on the health status of participants. For example, I did not ask the participant with terminal disease about her sexual health as I felt this issue was insignificant considering the possible death she was facing. In my view, putting the burden on this participant to reflect on her sexual health challenges would not be beneficial given her present state of health. Ellis (2007, p. 24) cautioned researchers against asking “too much of participants who may get little out of being part of their study.” Thus, I allowed this participant to be in control of the discussion and narrate aspects of her experience she wanted to share. She shared preparations she was making for her funeral and severe adverse reactions she had to chemotherapy. She was honest and detailed in her narration, and some of those details stayed on my mind for several days. During the interview, I could not immediately process how I felt about the experiences this participant was sharing although I knew her circumstance was distressing; I was not able to process my emotions and focus on her story at the same time. Thus, I kept my attention on the story she was sharing and was able to properly analyze my emotions afterward. Benoot had a similar reaction to participants’ stories where emotions she had suppressed during the interviews finally came out during the coding and transcribing phase when she was alone (Benoot & Bilson, 2016).

Additionally, I carefully considered participants’ health conditions when asking them to participate in focus groups. Procedure for data collection included in-depth interviews followed by focus groups. After each interview, I informed participants about the focus groups and later contacted those who had indicated interest. Out of 28 participants, 13 were able to participate in both the interviews and focus groups; those who did not participate in the focus groups either did not reply to my invitation (six participants), had scheduling conflicts (six participants), or were not invited by me because they had recurrences and were about to begin treatments (three participants). I did not invite participants in the latter category to the focus groups because I thought it was inappropriate to ask them in the first place, knowing their health conditions. This was a decision I made on a case-by-case basis, mirroring what scholars termed “ethically important moments” or “situated/situational ethics” where the researcher makes decisions regarding immediate ethical issues specific to a research situation (Guillemin
My decision also speaks to the concept of relational ethics (Ellis, 2007) where the researcher acts from “heart and mind” when relating to participants. Ovarian cancer treatments were grueling and demanded all of participants’ attention and energy; thus, it was important that I considered this and not make unnecessary demands on them.

However, my attempts to respect the time of participants who were about to begin treatments due to disease recurrences might have interfered with giving them the option to decide for themselves about participating in the focus groups, and this posed a limitation to the research. In the future when I am faced with a similar situation, I would contact these participants to make sure they were able and willing to participate in the focus groups, and I would reiterate to them that they could cancel or reschedule at any time. Also, I would allow these participants to indicate their preferred days and times for the focus groups and work around that schedule with the other participants. Although I conducted some of the focus groups via telephone conference call, I would also include video conference call as an option in the future to give participants varied opportunities to participate. When used as a follow-up to in-depth interviews, focus groups can provide valuable information on the research topic because the method places control over group interactions in the hands of participants and allows for a deeper understanding of the topic as participants interact with each other, comment on, and expand each other’s views (Kitzinger, 1995; Morgan, 1996). It also gives the researcher the opportunity to probe participants about unique perspectives on the topic. Because of these and other reasons, I would still use focus groups to collect data if I were to do the research again in the future; but I would seek ways to make it better and more inclusive.

Even though I did not know I would exclude some participants from the focus groups when I started the project, I did include some proactive strategies into the study design to allow participants to contact me at will following data collection. This included giving them my contact information and that of my research supervisor so they could contact us to discuss any issues related to their cancer experiences. I also asked participants if I could contact them after the interviews with follow-up questions, and I later reached out to two participants with follow-up questions. Another approach I used to manage limitations of the research was striving for data saturation. Saturation includes “building of rich data within the process of inquiry,” and it is characterized by data obtained from an adequate (i.e., large) and appropriate (i.e., knowledgeable) sample (Morse, 2015, p. 587). To ensure data saturation, my research included participants who were diagnosed at different stages of the disease and were from varied socioeconomic and educational backgrounds; participants also shared aspects of their experiences they felt comfortable sharing. Additionally, I involved leaders of local cancer support organizations throughout the research process. I met with these leaders prior to data collection to seek their inputs on the research questions, and regularly updated them on the progress of the project. Periodic meetings with these leaders helped me put the project into perspective and to realize that it was more than an academic engagement, but an invitation to help document important moments of participants’ cancer experiences.

Flexibility allows for creativity in the research process and can be used to the researcher’s advantage (Billo & Hiemstra, 2013). However, because it can lead to delays in completion of research projects, flexibility can sometimes be difficult to enact by junior scholars and those on the tenure-track for whom timely completion of research projects and dissemination of findings through peer-reviewed publications are necessary to secure employment in academia (Ballamingie & Johnson, 2011). It is also possible for rich perspectives on the topic to be lost when the researcher is unable to accommodate the flexibility and/or adjustments needed to include all potential participants in a study. This was the case for Patricia Ballamingie who encountered skeptical key informants but due to family obligations and constraints with time and funds, could not extend her stay at the research site to develop
trust with these individuals, and thus lost the opportunity to interview them (Ballamingie & Johnson, 2011).

Conclusion

Using my research project on ovarian cancer as an example, I discussed the emotional impacts sensitive topics can have on the researcher. I discussed active listening, reflexivity, and flexibility as strategies the researcher could use to manage limitations of a research whose topic she/he has not personally experienced. However, these strategies can also complicate the emotional vulnerability of the researcher and further limit the research. While there are many benefits to undertaking research on topics considered sensitive and/or under-studied, it is important that the emotional impact of the process and strategies meant to enhance the research are also acknowledged. This will ensure that the researcher is sensitized about and takes steps to balance the benefits as well as challenges of cornerstone qualitative research strategies. It will also provide insights for developing guidelines for training which, when routinely updated and followed, would reduce the “need for high levels of reflexivity and flexibility” in research projects (Bloor et al., 2007, p. 34).

Implications of this study for researchers, healthcare practitioners, and participants in future research include the following. First, for researchers seeking to study ovarian cancer or other sensitive topics, this research suggests a need to proactively incorporate flexibility and reflexivity into every phase of the research process, particularly during the data collection, analysis, and write-up phases because disease characteristics may interfere with the process. Researchers should also schedule breaks between interviews and throughout the project for emotional self-care and find appropriate outlets to manage emotional impacts of the research. Additionally, researchers should recognize that unpredictable disease progression (e.g., recurrences and hospitalizations) may hinder researcher-participant relationship building and find alternate means to continue to center participants’ voices, including involving key informants (e.g., leaders of local support organizations) as advocates for participants. Further, it is important for researchers to avoid making decisions for participants regardless of the severity of their disease symptoms. Researchers should give all participants equal opportunities to participate in all aspects of the research and let each participant decide what they are comfortable participating in.

Specifically for researchers seeking to study a topic they have not experienced; this research suggests that they study the topic and be knowledgeable about it but remember that the lived realities of participants present fundamental knowledge about the topic. This means that as researchers enter the research field, they must be flexible about their timelines and schedules, acknowledge that participants are experts of their experiences, and approach data collection with a mindset of a learner to allow participants’ experiences to foreground knowledge generated about the topic.

For healthcare practitioners, this study suggests that because aftereffects of ovarian cancer treatments can lead to psychological distress in survivors (Roland et al., 2013), it is imperative to work with each ovarian cancer patient/survivor to appropriately screen for distress, understand it, and develop a management plan. This is important because an appropriate intervention will not only enhance quality of life of survivors but also improve treatment outcomes (Pirl et al., 2012). Additionally, this research suggests to healthcare practitioners to strive to understand the varied influences on the ovarian cancer experience, including financial struggles and fear of death or disease recurrence, and acknowledge these during counseling sessions and at follow-up visits to help validate women’s experiences and open avenues for support.
Further, this research might benefit participants in research on sensitive topics by helping them understand how the researcher is impacted by the research as she/he processes events that happen before, during, and after data collection. This knowledge might help participants appreciate the emotional investments researchers make in helping bring visibility to participants’ life experiences and can help build trust and respect between participants and researchers. This research might also help potential participants better understand academic research and perhaps be more willing to participate.

Despite limitations of my research project and the fact that the findings cannot be generalized to other settings and situations, the research has helped shed light on the lived experience of ovarian cancer and provided important insights for future research and healthcare practice. The research has also enriched my life in important ways. First, it has enlightened me about the disease, helped me develop deep respect for survivors, and helped renew my commitment to continue researching ovarian cancer. I have also learned to process disease-related death more effectively. It still hurts to hear that ovarian cancer has claimed the life of a woman; but I now process the news differently and channel the sadness into helping create awareness about the disease. For instance, one ovarian cancer survivor I interviewed for a recent research project has died and prior to her death, I was able to share information about the disease she posted on her public social media page. I followed this participant on social media and knew she was ailing based on updates she posted; but it was still painful to read the post from her family announcing her death. I processed her death by taking a break from social media and encouraging friends to be knowledgeable about symptoms of the disease. This happened around the time that Canadian neuroscientist, Nadia Chaudhri also died of ovarian cancer (Williams, 2021); so, I shared Dr. Chaudhri’s story on my social media page and continue to periodically share relevant information about the disease to help generate awareness.

Additionally, I was inspired by how participants advocated for their health—some by consulting 11 different doctors before receiving a correct, albeit late, diagnosis, and how many of them reacted to news of the diagnosis. For example, after being misdiagnosed for several months, one participant said she cried when she received a correct diagnosis. She stated, “when [the doctor] told me I had cancer, I did not cry because I had cancer, I cried because I was right, and I knew something was wrong.” Another participant also said doctors were treating her as “a depressed hysterical woman” and was relieved when she finally received a diagnosis of ovarian cancer. She remarked, “When you do not feel good for so long and nobody can find anything and suddenly, they find something, you are like ‘hey, I am not crazy.’” These accounts have encouraged and taught me to be a better advocate for my health by speaking up more during doctor’s visits, thoroughly reading my medical reports, being up to date on my annual wellness exams, and proactively managing known medical conditions.

Similarly, it was eye-opening how participants seemed to have overlooked my supposed shortcomings as a researcher and invited me to share in their experiences with the disease. I was amazed by the strength and grace participants showed. Some were living with recurrent disease, others had just received news that the cancer had recurred, many continued to deal with aftereffects of treatments, and one person was living with terminal disease; yet they still made time to share their experiences with me whom they barely knew. Reflecting on this part of the project was humbling and made me deeply grateful to participants. But it also showed the level of trust participants had in leaders of the local support organizations—trust which participants extended to me. Leaders of the support organizations helped me recruit participants by sending notices about the study to people on their email lists and interested women contacted me to schedule interviews. So even though they did not know me very well, participants trusted me because they trusted leaders of the support organizations.
Another thing that stood out to me during the project was how some participants wanted to be called “warriors,” “thrivers,” and “fighters” instead of “survivors” because their experiences did not match general descriptions of a cancer survivor as someone who has been cured from cancer and embodies gratitude, heroism, and activism (Little et al., 2002). A few participants also mentioned feeling guilty for surviving ovarian cancer because other survivors had a worse disease experience than they did. Participants who harbored guilty feelings were mainly those who were diagnosed at early stages (i.e., stages I or II), had not experienced any recurrences, or had surgery but not chemotherapy or radiation treatment. It appeared these participants used normative views of ovarian cancer (e.g., late-stage diagnosis, grueling treatments, and recurrences) and of a cancer survivor to interpret their experiences, and when their experiences did not measure up to the supposed ideal, they felt guilty, believing they should have “suffered more” (Tetteh, 2022). This part of the research findings stood out to me because it showed that even though participants might be helping re-conceptualize the meaning of an ovarian cancer survivor by sharing their stories, many of them were still impacted by the standard narrative of ovarian cancer. This makes this research project important because it helps reveal that participants’ stories may not always be the “perfect” cancer stories society wants to hear, as they may be upsetting to some people and can challenge normative notions about ovarian cancer. But these stories are needed nonetheless because they can lead to advocacy, education, and awareness about the disease.

References


Bloor, M., Fincham, B., & Sampson, H. (2007). Qualiti (NCRM) commissioned enquiry into the risks to well being of researchers in qualitative research. QUALITI.


send a condolence card?” Promoting emotional safety in qualitative health research through reflexivity and ethical mindfulness. Qualitative Inquiry, 19(9), 652-663. https://doi.org/10.1177/1077800413500927


Reed, K., & Towers, L. (2021). Almost confessional: Managing emotions when research breaks your heart. *Sociological Research Online, 28*(1). [https://doi.org/10.1302/0/0013189X03400402](https://doi.org/10.1302/0/0013189X03400402)


**Author Note**

Dinah Tetteh, Ph.D., is Associate Professor of communication studies and James & Wanda Vaughn Endowed Professor in the College of Liberal Arts and Communication at Arkansas State University. Her research and teaching interests include health communication, women’s cancers, cancer survivorship, social support, and qualitative methodology. She is the author of *Communication Studies and Feminist Perspectives on Ovarian Cancer* (2018, Lexington Books). Her research has been published in journals such as *Feminist Media Studies, Cancer Investigation, Health Communication, Global Health Promotion, Qualitative Research in Medicine and Healthcare, Women’s Reproductive Health, Health Care for Women International, and Information Technologies & International Development*. Please direct correspondence to dtetteh@astate.edu

Copyright 2024: Dinah Tetteh and Nova Southeastern University.

**Article Citation**