

Dealing with Sensitive Research and the Professional/Researcher Dilemma; A Reflective Account on Men Living with Advanced Prostate Cancer

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Abstract

Background: There is developing literature that addresses the ethics and sensitivity of undertaking research with patients (and their family members) receiving palliative or end of life care, but there is little published guidance for a novice researcher and sparse evidence in this area that take account of culturally sensitive and resource-poor settings. Sensitive research can be emotionally challenging for researchers too.

Aim/ Method: This is a reflective account that draws upon research with men who have advanced prostate cancer and their family caregivers in a health resource-limited context

Findings: From a research standpoint, two sets of operational issues on challenging emotions and ethics were encountered. The first set of challenges involved the difficulty of researching in a poorly resourced country where many of the things that are taken for granted in the Western world is not the same for researchers. Patients and their caregivers have little access to palliative care, and family members provide most care at home. The second set of challenges entails having to navigate dual roles seamlessly as a nurse as well as a researcher-in-training. Dealing with the issue of double identity and interviewing while dealing with concerns about the care that the researcher observed could be dangerous to the participant's health.

Discussion: Although 'sensitive research' may provoke participants' emotional responses, and may put the researcher in a researcher/professional role conflict, it does have the potential for offering a therapeutic relationship. These included navigating issues of conducting interviews while also being asked for advice or identifying concerns about the care that were observed as potentially dangerous to the participant's health. Reaching out to participants about a research topic that carries cultural perceptions as a shameful and stigmatising disease is also challenging. Additionally, many aspects of fieldwork present additional considerations in resource-poor contexts. For example, travelling to and arranging fieldwork presents practical challenges, with poor transport and means of contacting participants.

Conclusion: This article presents insights into palliative care research in a cultural context where there are many challenges beyond those discussed and encountered in resource-rich contexts. Such a hazing role between nurse and researcher has repercussions for nurses who do qualitative research into sensitive topics that elicit a passionate, emotional response.

Introduction/background

There is developing literature that addresses the ethics and sensitivity of undertaking research with patients (and their family members) receiving palliative or end of life care (Casarett, 2015). However, there is little published guidance for a novice researcher and sparse evidence in this area that take account of culturally-sensitive and resource-poor settings. When discussing life-threatening conditions, researchers delve into areas where participants might become emotional or distressed. Sensitive research can be emotionally challenging for researchers too. Therefore, researchers need additional specific information to plan and execute interviews involving vulnerable people to minimise the emotional feeling of participants that may last even after the interview process. Sometimes the argument is that whether exploring this population is worthwhile (Jubb, 2002).

This study draws upon research with men who have advanced prostate cancer and their caregivers in Ghana. The use of semi-structured interviews allowed the researcher to explore their experiences of managing care at home and the challenges (and distress) that this presents. This article, therefore, addresses a sensitive and ethically challenging topic. The article will also discuss the doctoral student's experiences of researching while coming from a background of being a senior nurse in Ghana and the challenges this presents (of maintaining boundaries as a nurse and a researcher).

Access to practical knowledge on palliative care could improve the lives of about 100 million people globally (Stjernswärd, Foley, & Ferris, 2007) Research involving sensitive topics such as the end of life and palliative care is usually fraught with emotional issues and touches on painful experience (Seymour et al., 2005). In qualitative research, the researcher aims to get rich data by exploring further and more in-depth; however, they also have the duty of minimising the likelihood of causing emotional distress to vulnerable participants, be it the patient or the caregiver. Therefore, regardless of the level of the researcher in professional practice, there is the need to adequately plan the interview process to minimise, as far as practical, the distress that participants are likely to experience as they narrate and transverse their disease journey (Ashton, 2014; Dickson-Swift, James, Kippen, & Liamputtong, 2007; Mehta, Chan, & Cohen, 2014). Again, the researchers must also be mindful that they are in the field as such (researcher) and not professionals (nurse). The dilemmas thrown up by engaging in research in a sensitive, challenging areas and the potential for blurred boundaries between being a nurse and a nurse-researcher forms the basis of this reflective piece of work.

Research Ethics Committees and professional regulatory bodies do have a generalised guideline that direct and forewarn researchers, however; experience at the field while undertaking interviews present a unique situation (Casarett, Knebel, & Helmers, 2003). I believe that such reflections in the research report give additional flavour and context to the findings of the research. It can be a daunting arena for a novice researcher (or even an experienced researcher new to the field of palliative and end of life care and lack of guidance might deter some researchers (Benoot & Bilsen, 2016). There have also been debates that we should not be interviewing such a vulnerable population (Abernethy et al., 2014; de Raeve, 1994). Hence the aim to boost nurse researchers confident in venturing into studying into sensitive topic areas to broaden the evidence base in such specialty.

Methods

Reflective narrative of the experiences of interviewing men living with advanced prostate cancer and the family caregivers in a resource-poor context (Asselin, 2011).

Key Findings

This reflective narrative report two main operational issues on challenging emotions and ethics while interviewing the participants. The first set of challenges involved the difficulty of researching in a poorly resourced country where many of the things that are taken for granted in the Western world is not the same for researchers. Patients and their caregivers have little access to palliative care, and family members provide most care at home. Travelling to do fieldwork has several practical challenges of contacting participants,

talking about a complex and stigmatising disease, customs to follow -for example-following the death of a participant, having to attend funeral service to commiserate with the bereaved family.

The second set of challenges entails having to navigate dual roles seamlessly as a nurse as well as a researcher-in-training. Dealing with the issue of double identity and interviewing while dealing with concerns about the care that the researcher observed could be dangerous to the participant's health. These included navigating issues of conducting interviews while also being asked for advice or identifying concerns about the care that were observed as potentially dangerous to the participant's health. This researcher/professional role conflict could also raise emotional response for an early career researcher, and even some experienced researchers (Cite).

Reaching out to participants about a research topic that carries cultural perceptions as a shameful and stigmatising disease is also challenging. Additionally, many aspects of fieldwork present additional considerations in resource-poor contexts. For example, travelling to and arranging fieldwork presents practical challenges, with poor transport and means of contacting participants. This article presents insights into palliative care research in a cultural context where there are many challenges beyond those discussed and encountered in resource-rich contexts.

Researching Sensitive Issues; undertaking the study

The purpose of the study was to explore the experiences of patients with advanced prostate cancer and their caregivers and how they navigate their way through the care at home where there are very little or no support from health care professionals (Salifu, Almack & Caswell, 2021). Persons living with advanced prostate cancer being cared for at home (for the day-to-day care excluding technical procedures such as chemotherapy and radiotherapy) were recruited through a tertiary hospital in a resource-poor country, and they, in turn, gave permission for their primary family caregiver to be invited to participate in the study. The content of the research was explained to them at the time of recruitment and again reinforced before the interview to ensure that they fully understood and gave consent for the study.

Scholars have suggested the challenges of recruiting participants into studies that involve sensitive topics (Namageyo-Funa et al., 2014; Payne, Field, Rolls, Hawker, & Kerr, 2007) and that the anticipated numbers are not usually achieved (McPherson & Addington-Hall, 2004). One of the key reasons, aside from the bureaucratic research governance procedure that stifles the process, is the possible distress that the research causes to participants who might already be emotionally fragile. Dealing with frail patients presents additional challenges (Bramley, 2016) such as preventing and managing infection, handling the side effects of treatments, and the presence of other comorbidities.

Each participant was given the option of deciding where to be interviewed to allow him or her to be comfortable and in order not to cause undue distress in line with my ethical responsibility. While several were interviewed at a private room in the tertiary hospital as the time when they visited for an appointment, the majority of them had their interviews at home. Having practiced at a registered nurse and a counsellor for Tuberculosis patients, I have the experience of dealing with distressing situations; however, I was guided by my role at the field as a researcher but not as a nurse. I found Murray (2003)'s warning to nursing researchers

not become 'nurse therapists' at the field essential while at the same time not acting as professional with no sense of duty. Such a balance was difficult to handle while at the same time, remaining composed in order not to worsen participants' distress. Furthermore, the researcher was tactical during data collection in order not to unduly influence the responses that participants provided Ashton (2014).

Participants may be reticent to speak about sensitive issues such as impotence, advanced cancer, and dying as well as potentially stigmatising information that breaches on their dignity (Sailian et al, 2021). This feeling of being stigmatised is because, in Ghana, prostate cancer carries with its particular stigma; for example, men with prostate cancer been seen as having lived a licentious life (Salifu et al., 2019). To address these issues, participants participated in a follow-up interview that aimed at maximising the opportunity to capture further information. This repeat interview technique was preceded by a continuous reassurance of the strictest confidentiality, and this set the scene for the interview to proceed seamlessly and less nervous manner. Except for two individuals (one patient and one caregiver) who preferred not to be audio recorded, all the other participants allowed the audio recording, and this allowed me to focused on the conversation without having to make notes simultaneously. Those two who refused to be recorded did not state any specific reason, but I inferred from their conversation that they did so because of the stigma they perceived that came from prostate cancer being associated in Ghana with a licentious lifestyle. Researchers must, therefore, be mindful of the fact that some participants with sensitive issues might not be comfortable been recorded. What this means is that researchers should have a backup means such as pen and paper to take notes to note vital information, and this might take into account when the planning of the interview for such a population.

Preparation for and anticipation of issues that might arise

In qualitative studies, the inquirer plays a significant role in data collection and analysis or data generation (Creswell, 2012; Shenton, 2004) because we are part of the social world and could be influenced or be influenced by the study environment. Therefore, a greater sense of reflexivity on the part of myself as an investigator could be helpful. As recorded earlier in this thesis, I have been mindful of his professional background as a nurse as well as a teacher at a university. Reflexivity strengthens the quality and ensures the transparency of qualitative research (Marshall, Fraser, & Baker, 2010) Marshall and colleagues (2010) describe reflexivity as critical self-reflection throughout the study as it develops.

There are tendencies for academics to approach data analysis deductively (Mayan, 2009). However, using an inductive approach of analysis emerging themes in the study were developed from the data rather than from my personal, professional beliefs, assumptions, and experiences (Carter & Little, 2007; Charmaz, 2006; Miles & Huberman, 1994; Miles, Huberman, & Saldana, 2013). I, therefore, approached the data with an idea of capturing unexpected information as well (Charmaz, 2006). Frequent discussions with my supervisors assisted in this endeavour.

It is reported that our experiences add credibility to qualitative research (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

I have had the exposure to the use of qualitative research during my masters having had some training in Qualitative research methodologies from the University of Alberta, Edmonton, Canada as well as practical

experience interviewing people in a clinical setting.

During the interview, I kept a diary of my experiences and thoughts, which was useful to be reflexive. The writing of the diary and field notes also served as means to cope with some of the emotionally challenging aspects of dealing with sensitive and emotional issues of participants (Dickson-Swift et al., 2007; Rowling, 1999). The reflexive accounts and some debriefing with supervisors (second and third authors) relating to the period before, during, and after the data collection and analysis captures personal thoughts and experiences that might have influenced the research directly or indirectly.

I encountered three main ethical issues and learned many interesting things during the data collection processes: emotional responses, researcher/professional role conflict and the relevance of therapeutic self that has implication for nursing practice and education.

Discussion

1. Patients and caregivers' emotional responses

The first critical issue I experienced was my emotional responses to dealing with a sensitive aspect of the study (Rowling, 1999). Some participants were nervous as they chronicled their challenges in dealing with the care as well as how generally unhappy they were because of the shock of the diagnosis of a terminal illness. I was sometimes saddened by the plight of the patients and their caregivers as they narrated their experiences. When talking about issues of end of life care, a feeling of emotion and distress may be inevitable, and this research was not an exception (Ashton, 2014). The pain and the sentiments of the patients and their caregivers were powerful, such that I had to endeavour not to become emotional or let sadness overcome me (Valentine, 2007). Some family members expressed their emotions about how difficult it was to care and to witness a loved one dying (Morris, King, Turner, & Payne, 2015). The interviews brought up difficult emotions for both the participants (patients and family caregivers) and me. Discussing concerns about death was something that participants are often reticent engage with (Salifu et al., 2019); and this was particularly evident in my fieldwork given the Ghanaian cultural belief of not talking about when a person is sick or dying. Interviewing such a population can mean that the researcher is faced with the death of participants, which can be distressing (Casarett et al., 2003). In the Ghanaian culture, again this may be accentuated given that there are traditions I felt honour-bound to observe; calling to express condolences and attending a funeral. Venturing into palliative care research in a culturally sensitive topic, therefore, has its challenges of the researcher having to manage emotions and navigate through complex interpersonal and interprofessional dilemma (Broom et al., 2014).

Another area for reflection arose from interviewing professionals about their experiences of providing care. In Ghana, the limitations to the care health professionals can deliver out in the community is potentially distressing for them to reflect upon in an interview setting. Their compassion is evident, given how they went beyond the remit of their roles to provide care and resources to ensure the dignity of the patients (Sailian et al, 2021). For example, one health professional narrated how she used her car and money to fuel, buy some items and visit some person living with advanced prostate cancer (and other patients with other palliative care needs) at their homes. Others shared their experiences of having to support some patients at the hospital for

the patients to access treatment- such as chemotherapy, radiotherapy, surgery and the challenges that bring to the patient and their families (Salifu et al., 2021).

Additionally, I equally became aware of how vulnerable we as researchers (especially as an early career researcher in the field of palliative care) could be in dealing with sensitive and end of life issues (Payne et al., 2007; Seymour et al., 2005). This current study Corroborates with a recent study that claims that researching sensitive issues can be emotionally and psychologically demanding for researchers (Kumar & Cavallaro, 2018). Kumar and Cavallaro (2018) further highlighted four distinct areas of researchers' emotional experience in a research context: managing sensitive issues, researcher's prior personal experience, been engaged in traumatic experience during data collection, and unexpected that arises during fieldwork.

This finding, thus, has practice implication for novice and doctoral students, as well as experienced researchers, do who are who engages in research sensitive topics. Moreover, the frequent debriefing sessions I had with my supervisors in the form of supervision meetings and other correspondence provided helpful support in dealing with most of the difficulties. Speaking to my supervisors was necessary because they are experienced in this field and were able to offer both emotional and academic support. One other way that helped me to get rid of strong feelings was writing about the emotional challenges in field notes and my engagement with others about these issues.

2. Researcher/professional role conflict

Researcher and professional role conflict is one key areas that Institutional Review Boards could raise red flags for palliative care research (Abernethy et al., 2014). This research work made me appreciate the researcher/ professional boundary that I had only read of in textbooks and been cautioned about by my supervisors. During the fieldwork, I observed some practices of care by person living with advanced prostate cancer and their family caregivers, were, for example, potentially dangerous in terms of infection control and impacted on a patient's quality of life (Nursing and Midwifery Council, 2008). There is always the desire to intervene or provide intervention within the research context when a researcher observes some practices put patient participants at risk. At the home of Boat (See Table 1), I noted that his supra wound where his pubic catheter was inserted into the abdomen was becoming infected. After the interview, I asked Boat and his family caregivers about their method of wound care. I was informed that they use a flannel cloth to clean the wound, and after the wound cleaning, they washed and dry the flannel cloth on a window for reuse. I learned their supply of gauze, other wound dressing materials had run out, and they had not been able to get more due to partly to the cost and partly other reasons such as unavailability of wound dressing pack in nearby pharmacy shops. I felt duty-bound to explain to them the dangers of using an unsterile cloth to dress the wound, and how this could lead to infection of the wound, the peritoneum, and eventually sepsis (Emmons & Lachman, 2010). When I was told they have run out of their supply of gauze, I sought their permission to inform the Hospital about it and to urgently request for a new supply of sterile gauze for Boat's wound dressing. After this explanation, the family permitted me to inform the hospital about their situation. I further reassured them that, my decision to notify the hospital of this would not, in any way, affect their care they will seek at the hospital. Being a nurse researcher, thus, means having to navigate the complexities of dealing with

the dual role of a researcher and a professional and require one to do self-reflection consistently (Hewitt, 2007).

Table 1 Boat's* scenario

Age	78
Key Caregivers	Brother (Sabi) and Brother's wife (Safia)
Main concerns	He quickly forgets things (according to caregivers), difficulty in walking, a suprapubic catheter ^[1] in place, pain at the lower abdomen and legs, numbness of the legs, frequent urination.
Interview type: individual face to face	Interview 1: At home with Boat and Safia Interview 2: Home with Boat and Sabi, 8-weeks later
Palliative treatment	None
Work/Source of income	Unemployed/His support comes from his brother and nephews
Care needs	Some urine leaks through the catheter and sometimes through the accidental opening of the cork of the catheter. The patient is worried that due to his incontinence and his weakness affecting his independence and dignity as a man.

*All names are fictitious to protect the identity of the participants.

Another scenario was the case of Gyasi (See Table 2) who was using a wheelchair and had sores at the sacral area. The incident happened during the second interview at his residence. Gyasi had become lean and had developed bedsores because of infrequent change of position or turning in bed. He had also lost his appetite. I was again, caught between the professional /researcher dilemma. Since this development had a severe impact on Gyasi's quality of life, I felt the need to intervene before leaving the family after the interview. I educated the caregivers on the need to change Gyasi's position in the wheelchair and support it with soft pillows. I told them to turn him about four-hourly during the night to minimise further development of bedsores. I also educated them on the need to clean Gyasi properly after personal care since leaving the skin moist can also lead to skin breakdown.

Table 2: Gyasi's scenario (all names fictitious to ensure anonymity).

Age	64
Key Caregivers	Children (Otoo, Kwame, Agyei)
Main concerns	He is a wheelchair user, lost weight, with pressure sores.
Interviews: Dyad	Interview 1: At a private room at the hospital with his first son, Otoo Interview 2: At home, seven weeks five days later with Gyasi and his second son, Kwame.
Palliative treatment	Surgery and on chemotherapy
Work/Source of income	Retired/Pension and family income
Care needs	A wheelchair user with bed sores. Due to his special needs and significant mobility difficulty, he is always transported to the oncology unit by a private Ambulance service for his monthly appointment. He has had surgery done to remove his testes, and he is currently on chemotherapy. He wears an incontinent pad all the time and always requires the assistance of others for his care and movement. He is thankful to his children for the care they provide him on a rotation basis.

Other researchers such as (Colbourne & Sque, 2004), have also have reported on such researcher/professional role conflict while others, for example, (Jack, 2008)has outlined some guideline to assist this journey and when a researcher should intervene within the research setting. It is essential that as nurse researchers, we are deeply aware of the potential role conflicts and what to do in order not to obfuscate the aim of the study as a researcher. At the same time, it is the role of the researcher, ensuring patients' safety as expected from a nurse regardless of the context.

3. Therapeutic relationship

The purpose of qualitative interviews in providing some bonding between the researcher (Cartwright & Limandri, 1997) and participants can not be underestimated, especially in palliative care, where the show of compassion is an essential component (Hewitt, 2007; Murray, 2003). The kind of relationship and quality of data gathered could be influenced by the method (individual or dyad interviews) the researcher adopts in dealing with sensitive issues. Some participants described my visit to their homes as a 'show of love and concern'; they appreciated my presence in the field (participant's house). Participants having enough time (unlike in clinical settings) to express of their concerns provides cathartic relief as well as a sense of empowerment for participants (Hutchinson, Wilson, & Wilson, 1994; Moch & Gates, 2000).

Others also indicated that it allowed them to be relaxed in their homes and for me to see some of the things at first hand. For example, during both interviews, Stella, Ofori's wife, and caregiver were also glad that her husband's situation had necessitated a visit by someone they perceived to be a health care professional, albeit that I was there as a researcher. Stella observed that my visit as unique since no health personnel had visited them either for an interview or to offer support. She further indicated that she had been relieved by the opportunity to speak to me. In addition, this might have had more relevance to them, given the lack of

professional home care provided. Potentially there is a sense of abandonment or coping alone, and my presence could have alleviated this to an extent.

Murray (2003) suggests that nurse investigators are not 'nurse therapists' during fieldwork. While this should be the case, based findings from this current study, we argue that in as much as the nurse researcher boundary should be detached, the relationship that develops could inadvertently help patients and caregivers to live a more dignified life. The WHO public health model for palliative care identifies four key areas such as policy, drug availability, education, and implementation Stjersward (2007). This policy requires the integration of palliative care services into the national mainstream healthcare, providing accessible and supportive care to patients, including at home and involving others in the care. Since all of these are lacking in the Ghanaian context where the interview took place, I understood the appreciation expressed by patients and caregivers in having the opportunity to speak to a nurse (but in the capacity as a researcher.) I do agree that this issue of a therapeutic relationship is still contestable by others.

Furthermore, I have learned, while doing this study, the need for us to be very flexible in collecting qualitative data. Some participants were more comfortable with individual interviews where they could tell me about some sensitive and confidential issues that they did not want the other party to know. Most participants who had sensitive and confidential information preferred individual interviews with dyad interviews. This revelation points to the power of individual interviews providing an opportunity to share some 'sensitive' information that might not be revealed in other types of interviews such as focus group interviews.

Again, where dyad interviews were used, caregivers were careful using some words such as 'death' in order not to upset or demoralise persons living with advanced prostate cancer since discussing death in the presence of a seriously ill person in Ghana is regarded as approving his death (Zarhin, 2018). The use of dyad interviews in this study offered a significant methodological insight about how persons living with advanced prostate cancer and their family caregivers relate. Interviewing patients and their caregivers together provided very insightful data about the impact of prostate cancer on the family, and their shared experience of how they transverse their journey and the meaning and interpretation of such encounters (Taylor & de Vocht, 2011). The researcher 'hat' allowed me to gain privileged connections and insights into these patients' lives that would not have been accessible to me as a practitioner; such stories could help in developing policy for palliative and end of life care (Bingley, et al., 2008).

My fieldwork experience also brought me closer to the family unit as a whole than it would have been in a clinical setting (Benoot & Bilsen, 2016; Leslie & McAllister, 2002). Some participants occasionally called to tell me about their progress and of course some deterioration in their condition. In one instance, when the patient died, the family invited me to the funeral and insisted it was the wish of the patient too. His death happened about six weeks after the initial interview with Mike and his lovely caregivers.

Research on topics related to palliative and end of life care present significant emotional issues for both participants and the researcher. It requires skills to handle the interview in a sensitive manner and to ensure sources of additional support (for both participant and researcher) are to hand wherever possible. As a nurse researcher, additional issues arise in maintaining boundaries and addressing nurse-nurse researcher role

conflict. It also requires a unique skill of how to terminate with the participants, especially when such interpersonal relations have been built over a serial interview approach.

Nurses have a legal obligation to ensure a patient's safety and are likely to be in a state of dilemma while been a researcher and a nurse at the same time. Such a hazing role between nurse and researcher has repercussions nurses who do qualitative research into sensitive topics that elicit a passionate, emotional response. Therefore, nurse researchers should avoid the temptation of assuming that they might not need additional training in planning to conduct interviews involving vulnerable people, especially at the end of life.

Implication for practice

Authors conclude that participants who are interviewed by a well-prepared researcher will not only feel comfortable during the interactions but also be in a position to provide rich data that will facilitate a better understanding of participants' experiences (Patton, 2002). The personal contact I had with participants and interviewing them twice (repeat interview approach) afforded me the additional opportunity to better understand their experiences, perceptions, and their perspectives of living with prostate cancer.

Professional researchers, especially in the field of palliative and end of life care and novice researchers, are likely to be in a state of dilemma while been researching a resource-poor setting where professional home care is unavailable. This reflection highlights some issues of witnessing care that could affect the quality of life, and nurses have a legal responsibility to ensure the patient's safety (Duke & Bennett, 2010). Such a hazing role between nurse and researcher has repercussions for nurses who do qualitative research into sensitive topics that elicit a passionate and emotional response. Therefore, nurse researchers should have this in mind while planning to conduct interviews involving vulnerable people, especially at the end of life.

Conclusion

This article presents insights into palliative care research in a cultural context where there are many challenges beyond those discussed and encountered in resource-rich contexts. The narrative reflection also provides cognizance of what early career researchers could expect dealing with sensitive research in palliative and related disciplines. The hazing role between a clinician (nurse) and researcher has repercussions for nurses who do qualitative research into sensitive topics that elicit an emotional response. Awareness of this role conflict could lead to adequate preparation of researchers before conducting sensitive research. This reflection also calls for greater debate on the operational issues on challenging emotions and ethics when researching on a sensitive topic.

Dealing with the dilemma of double identity and interviewing while dealing with concerns about the care that the researcher observed could be dangerous to the participant's health could be traumatising to the researcher as well. Although 'sensitive research' may provoke participants' emotional responses, and may put the researcher in a researcher/professional role conflict, it does have the potential for offering a therapeutic relationship.

Declarations

Ethics to approval and consent to participate

This study received ethical approval from The University of Nottingham's Faculty of Medicine and Health Sciences research ethics committee (reference no. F12092016). Another ethics approval from study site (Ref no. CHRPE/AP/496/16). All participant gave consent for the study.

Consent for publication

Not applicable.

Availability of data and material

The datasets generated and/or analysed during the current study are available in the University of Nottingham PhD Thesis repository or could be available from the corresponding author on reasonable request.

Authors' Contributions

YS, KA, and GC made substantial contribution to the concept and design of this work in acquisition, analysis, and interpretation of data. YS conceived and drafted the article and KA and GC, research supervisors, revised it critically for important intellectual content. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

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Accordance

We can confirm that all methods were performed in accordance with the relevant guidelines and regulations.

References

1. Abernethy, A. P., Capell, W. H., Aziz, N. M., Ritchie, C., Prince-Paul, M., Bennett, R. E., & Kutner, J. S. (2014). Ethical conduct of palliative care research: enhancing communication between investigators and

- institutional review boards. *Journal of pain and symptom management*, 48(6), 1211-1221.
doi:10.1016/j.jpainsymman.2014.05.005
2. Asselin, M. E. (2011). Reflective narrative: A tool for learning through practice. *Journal for Nurses in Professional Development*, 27(1), 2-6.
 3. Ashton, S. (2014). Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nurse Researcher*, 22(1), 27-31. Retrieved from <http://ovidsp.tx.ovid.com/ovftpdfs/FPDDNCLBGANMFE00/fs046/ovft/live/gv023/00021768/00021768-201409000-00006.pdf>
 4. Benoot, C., & Bilsen, J. (2016). An auto-ethnographic study of the disembodied experience of a novice researcher doing qualitative cancer research. *Qualitative health research*, 26(4), 482-489.
 5. Bingley, A. F., Thomas, C., Brown, J., Reeve, J., & Payne, S. (2008). Developing narrative research in supportive and palliative care: the focus on illness narratives. *Palliative Medicine*, 22(5), 653-658.
 6. Bramley, L. (2016). *One day at a time: living with frailty: implications for the practice of advance care planning: a multiple case study*. University of Nottingham,
 7. Broom, A., Kirby, E., Good, P., Wootton, J., Yates, P., & Hardy, J. (2014). Negotiating Futility, Managing Emotions: Nursing the Transition to Palliative Care. *Qualitative health research*, 25(3), 299-309.
doi:10.1177/1049732314553123
 8. Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative health research*, 17(10), 1316-1328. Retrieved from <http://qhr.sagepub.com/content/17/10/1316.full.pdf>
 9. Cartwright, J., & Limandri, B. (1997). The challenge of multiple roles in the qualitative clinician researcher-participant client relationship. *Qualitative health research*, 7(2), 223-235.
 10. Casarett, D. J., Knebel, A., & Helmers, K. (2003). Ethical challenges of palliative care research. *J Pain Symptom Manage*, 25(4), S3-5. doi:10.1016/s0885-3924(03)00058-7
 11. Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis* (Introducing Qualitative Methods Series).
 12. Colbourne, L., & Sque, M. (2004). Split personalities: Role conflict between the nurse and the nurse researcher. *NT Research*, 9(4), 297-304.
 13. Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Sage.
 14. de Raeve, L. (1994). Ethical issues in palliative care research. *Palliative medicine*, 8(4), 298-305.
 15. Dickson-Swift, V., James, E., L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: what challenges do qualitative researchers face? *Qualitative research*, 7(3), 327-353.
doi:10.1177/1468794107078515
 16. Duke, S., & Bennett, H. (2010). A narrative review of the published ethical debates in palliative care research and an assessment of their adequacy to inform research governance. *Palliative Medicine*, 24(2), 111-126.
 17. Emmons, K. R., & Lachman, V. D. (2010). Palliative wound care: a concept analysis. *Journal of Wound Ostomy & Continence Nursing*, 37(6), 639-644.

18. Hewitt, J. (2007). Ethical components of researcher–researched relationships in qualitative interviewing. *Qualitative health research, 17*(8), 1149-1159.
19. Hutchinson, S. A., Wilson, M. E., & Wilson, H. S. (1994). Benefits of participating in research interviews. *Image: the Journal of Nursing Scholarship, 26*(2), 161-166.
20. Jack, S. (2008). Guidelines to support nurse-researchers reflect on role conflict in qualitative interviewing. *The Open Nursing Journal, 2*, 58.
21. Jubb, A. M. (2002). Palliative care research: trading ethics for an evidence base. *Journal of Medical Ethics, 28*(6), 342-346. doi:10.1136/jme.28.6.342
22. Kumar, S., & Cavallaro, L. (2018). Researcher self-care in emotionally demanding research: A proposed conceptual framework. *Qualitative health research, 28*(4), 648-658.
23. Leslie, H., & McAllister, M. (2002). The benefits of being a nurse in critical social research practice. *Qualitative health research, 12*(5), 700-712.
24. Marshall, J. E., Fraser, D. M., & Baker, P. N. (2010). Reflexivity: the experience of undertaking an ethnographic study to explore issues of consent to intrapartum procedures.
25. Mayan, M. J. (2009). *Essentials of qualitative inquiry*. Left Coast Press.
26. McPherson, C. J., & Addington-Hall, J. M. (2004). Evaluating palliative care: bereaved family members' evaluations of patients' pain, anxiety and depression. *Journal of pain and symptom management, 28*(2), 104-114.
27. Mehta, A., Chan, L. S., & Cohen, S. R. (2014). Flying blind: sources of distress for family caregivers of palliative cancer patients managing pain at home. *Journal of psychosocial oncology, 32*(1), 94-111.
28. Miles, M. B., & Huberman, A. M. (1994). Data management and analysis methods.
29. Miles, M. B., Huberman, A. M., & Saldana, J. (2013). *Qualitative data analysis: A methods sourcebook*. SAGE Publications, Incorporated.
30. Moch, S. D., & Gates, M. F. (2000). *The researcher experience in qualitative research*: Sage.
31. Morris, S. M., King, C., Turner, M., & Payne, S. (2015). Family carers providing support to a person dying in the home setting: A narrative literature review. *Palliative medicine, 29*(6), 487-495.
32. Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International journal of qualitative methods, 1*(2), 13-22.
33. Murray, B. L. (2003). Qualitative research interviews: therapeutic benefits for the participants. *Journal of Psychiatric and Mental Health Nursing, 10*(2), 233-236.
34. Namageyo-Funa, A., Rimando, M., Brace, A. M., Christiana, R. W., Fowles, T. L., Davis, T. L., . . . Sealy, D. (2014). Recruitment in Qualitative Public Health Research: Lessons Learned During Dissertation Sample Recruitment. *The qualitative report, 19*(4), 1-17. doi:
35. Nursing and Midwifery Council. (2008). The Code: Standards of conduct, performance and ethics for nurses and midwives. *NMC, London*.
36. Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work, 1*(3), 261-283.

37. Payne, S., Field, D., Rolls, L., Hawker, S., & Kerr, C. (2007). Case study research methods in end-of-life care: reflections on three studies. *Journal of Advanced Nursing*, 58(3), 236-245.
38. Rowling, L. (1999). Being in, being out, being with: Affect and the role of the qualitative researcher in loss and grief research. *Mortality*, 4(2), 167-181. doi:10.1080/713685968
39. Sailian, S.D., Salifu, Y., Saad, R. et al (2021). Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliat Care* 20, 112. <https://doi.org/10.1186/s12904-021-00791-6>
40. Salifu, Y., Almack, K., & Caswell, G. (2021). 'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative Medicine*, 35(1), 97–108. <https://doi.org/10.1177/0269216320951107>
41. Salifu Y, Almack K, Caswell G. (2019). Cultural responses to prostate cancer in ghana: masculinity and stigma. *BMJ Supportive & Palliative Care* 2019;9:A40.
42. Seymour, J., Payne, S., Reid, D., Sargeant, A., Skilbeck, J., & Smith, P. (2005). Ethical and methodological issues in palliative care studies: The experiences of a research group. *Journal of Research in Nursing*, 10(2), 169-188. doi:10.1177/174498710501000206
43. Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22(2), 63-75.
44. Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007). The public health strategy for palliative care. *Journal of pain and symptom management*, 33(5), 486-493. Retrieved from http://ac.els-cdn.com/S0885392407001224/1-s2.0-S0885392407001224-main.pdf?_tid=bf15ea5e-f82a-11e5-9fe2-00000aab0f26&acdnat=1459529998_abb8415cc55ff68075037ef173696653
45. Taylor, B., & de Vocht, H. (2011). Interviewing Separately or as Couples? Considerations of Authenticity of Method. *Qualitative health research*, 21(11), 1576-1587. doi:10.1177/1049732311415288
46. Valentine, C. (2007). Methodological reflections: Attending and tending to the role of the researcher in the construction of bereavement narratives. *Qualitative Social Work*, 6(2), 159-176.
47. Zarhin, D. (2018). Conducting Joint Interviews With Couples: Ethical and Methodological Challenges. *Qualitative health research*, 28(5), 844-854. doi:10.1177/1049732317749196