

List of amendments to second revision (20 October 2015) of Rowan, Moffatt and Olden with links to referee's comments

Content changes

Page 3 (Comment A1): The aim of the article has been rewritten in the abstract.

Page 5 (Comment A2): The content on Husserl's approach has been expanded, and a new reference (Moran 2000) added.

Page 8 (Comment A3): New text, quotation and reference (Genomics England 2015) added about withdrawal of consent.

Pages 8 and elsewhere (Comment A4): A more recent reference (Noland 2012) replaces Lee 1993; earlier editions of texts on research methodology have also been replaced with more recent ones:

- Polit and Beck 2014
- Maxwell 2012
- Holloway and Wheeler 2010

Page 9 (Comment A5): Reference to legislation (Data Protection Act 1998) added.

Page 13 (Comment A6): Singular.

Page 15 (Comment A7): "Main researcher" is used because the paper has as co-authors the supervisors of the original thesis. This particular topic was suggested by one co-author, who also helped with the paper and its revisions.

Page 15 (Comment A8): The point about some terminally-ill patients being happy to participate in research has been addressed – an Australian example (Terry et al 2006) has been added.

Page 15 (Comment A9): The referee's point about influencing care decisions has been added.

Page 16 (Comment A10): Reference to the study on schizophrenia removed.

Page 16 (Comment A11): Reference to observational studies removed.

Page 17/18 (Comment A12): The section on limitations has been rewritten.

Page 18 (Comment A13): Removed the new information from the conclusion and inserted it in the discussion.

Page 18 (Comment A14): The sentence has been rephrased as per the reviewer's comment.

The references have also been tidied up, bringing authors' names in full conformity with the journal's style.

List of amendments to first revision

Content changes

- Removed: “*No studies on this specific subject (the lived experiences of patients with cancer suffering from fungating/cancerous wounds) were found*”. Although this statement referred to when the research proposal was presented to the University. While research was in live phase and during the writing up, a number of publications on the subject emerged.
- Page 4: expanded on exclusion and inclusion criteria and consent
- Page 5: rephrased statement about doctors.
- Page 7: stated language proficiency
- Page 4 and 5: added information on the approval process in the UK
- Pages 6: more information on how it relates to people with malignant
- Page 7: added information on patient that has been withdrawn although information was present in the table.
- Pages 8: more on transcribing and the transcriber
- Pages 9 and 10: table information corrected, made less specific
- Pages 10 - 15: Alexander paper and other similar papers included in the discussion
- Pages 14 and 15: recent articles added on Italian mentality towards psychology and telling patients the truth.
- Page 15-16: changed conclusions. Very good point. Thank you

Abstract

Background: Researching the experiences of terminally ill patients with disfiguring wounds is likely to be a challenge anywhere, and this investigation came face-to-face with different attitudes on the part of both patients and nurses and doctors in England (the South-East) and Italy (Tuscany). **Aim:** To highlight the complexity of researching sensitive subjects and the difficulties encountered from the perspective of the researcher(s). **Methods:** Fourteen patients were interviewed. In England access was relatively straightforward, with nurses linked to the hospice doing most of the recruitment. Access was more difficult in Italy, with some doctors expressing opposition. **Discussion:** How ethical is it to treat dying patients as subjects for research? How does research of this kind vary from one culture to another? **Conclusions:** Interviewees can find it therapeutic to talk about their experiences to a sympathetic listener — although the listening does pose a considerable strain on the researcher.

Key words:

Death and dying

Cancer patients

Malignant fungating wounds

Researching

Researching the lived experiences of cancer patients with malignant fungating wounds

Fungating wounds refer to a category of wounds that resemble in their shape a fungus or a cauliflower. They have a proliferating shape. The structure can extend beyond the skin surface and become extensive in size. Not all malignant wounds correspond to this description; some start as an ulcerated area, becoming a crater – and if expanding they can form a sinus or a fistula or have a multitude of different shapes and sizes. These wounds become worse during terminal stages of illness (Grocott 2007; Lo et al 2008). Malignant skin lesion as a term refers to wounds created due to the progress of cancer. Malignant wounds in advanced stages of cancer are considered ‘‘non-healable’’. The goals of care are palliative (Maida et al 2008). There is no known reason why these wounds occur in some cancer patients and not in others.

Malignant fungating wounds may continue to grow throughout the life of the patient. Malignancy is an uncontrolled disease and the dressings currently available are not always capable of controlling these circumstances (Lo et al 2008; Probst et al 2013).

Aim

This paper aims to highlight the complexity of researching sensitive subjects and the difficulties encountered from the perspective of the researcher(s). It is drawn from a study (Rowan Wertzberger, 2014) that attempted to know and understand the lived experience of terminally ill cancer patients with complex and disfiguring wounds.

Methods

The main concern of phenomenological research is what people experience with regard to the phenomenon and the meaning they give to that experience (Polit and Beck, 2014). The subject of terminally ill patients with fungating wounds is complex. It includes a variety of

associated subjects, such as disfigurement, chronic illness, pain, difficulties in coping, poor quality of life, and death. Phenomenology as used for the purpose of research is concerned with a specific, usually complex, phenomenon that is singled out for the purpose of the investigation. The conceptual framework for the research question and the qualitative methodology were decided once the literature research was carried out.

It seemed relevant to give space to patients' voices, in a manner untainted by assumptions, to describe the phenomenon in the way it is presented and lived by the patients in an attempt to understand the whole experience with which patients are faced. This exploratory qualitative study adopted the approach of Edmund Husserl, who envisaged a way to explore a phenomena not limited by prejudice or tradition. This whole process involves a number of stages: bracketing, reduction, intuition and description. Husserl wanted to explore experience in a pure manner, one not tainted by assumption (Moran 2000).

Characteristics of patients studied

The health care professionals treating the patients in the UK and in Italy (where the main researcher is based) were asked to identify appropriate subjects:

- Patients with cancer, suffering from either a primary or a secondary oncological wound.
- Patients in the palliative phase of their illness, and therefore toward the end of their life. Patients in this phase were selected because it was believed that they could provide information on their journey through their disease.
- Patients above eighteen years of age, with no diagnosed mental disorder, and willing to be interviewed according to the health care professionals, who knew the patients well.

An information sheet was prepared with answers to questions such as:

- What is the purpose of the study?
- Why have I been chosen?
- What will happen to me if I take part?
- What do I have to do?
- What are the possible disadvantages and risks of taking part?
- What will happen when the research study comes to an end?
- What if something goes wrong?
- Will my taking part in this study be kept confidential?
- What will happen to the results of the research study?
- Who is organising and funding the research?
- Who has reviewed the study?

The research took place at a hospice and its community region in South-East England and at a university hospital and its community region in Tuscany, Italy. The intention was to explore cultural differences, with respect to the phenomena, in two groups of patients in these countries.

Ethics and the negotiation of access

In the UK the hospice board of directors and research nurse evaluated the study proposal and agreed for the research to be conducted in the hospice. The research was then submitted for approval to the South-East England NHS region Ethical Committee. The main researcher appeared before the ethical committee to answer questions. Members included people from various walks of life, including a priest. The hospice nurses and community nurses linked to the hospice did most of the recruitment. The patients were asked if they wanted to take part in the research and if they did they were provided with information and a consent form. On each visit the researcher made to the UK, the referral nurse for the study made efforts to find patients who would be eligible, so that the researcher could use the visit to interview at least one more patient.

Issues about access to patients were raised in Italy. The main researcher approached a university hospital in Tuscany, to be informed by one consultant that this study appeared unnecessary, because patients at this stage were solely concerned with death. The head of

department of a second hospital agreed that the research could be carried out, although another doctor was strongly opposed. The version of the proposal approved by the main researcher's university was translated from English to Italian and given to the team. A follow-up meeting was arranged. At this meeting, some doctors expressed doubts as to the researcher's background and skills in interviewing cancer patients. They were worried that their patients might be upset, especially since the proposal stated that "providing support to the patients after the interviews will be discussed with the corresponding doctors". In addition to this, questions were raised about the main researcher's fitness for the task due to her research protocol stating that she would also avail of counselling should the need arise (her university had requested this). Obviously health care professionals wish to protect patients and families, and some are more cautious than others.

After a month, the head of department at the hospital in Tuscany gave agreement and assigned a clinical psychologist to work with the main researcher. Once ethical approval had been obtained, Italian participants could be accessed through the department of oncology. There were no hospice facilities in Tuscany at the time the interviews were conducted, and the hospital provides the community services to these patients. They were treated at home, which meant that the interviews were carried out either at home or in the hospital.

It took almost a year to get access to patients in Italy and another six to eight months to get ethical approval. In Italy the ethical approval was processed electronically and no meeting with the ethical committee took place. In Italy the head of the oncology department and the ethical committee requested a chart flow of a scenario prior to the interviews to ensure that the researcher was well prepared and able to face difficulties. The research proposal and patient information sheet were requested in the UK and during the meeting with the ethical committee questions were asked regarding the type of question the researcher was going to ask.

The interview process

At the start of the interview patients were asked again if they still agreed to it and if they needed any further explanation. It is standard practice in research that participants can withdraw consent at any stage without explanation or penalty. For example the 100,000 Genomes Project points out that “if a participant changes their mind ... and wishes to withdraw from the Project, then they don’t have to give a reason and they will continue to receive the highest standard of healthcare that is normally available” (Genomics England, 2015).

Listening was important in order to establish a supportive and trusting atmosphere. The intention was to ensure an open conversation in which the topics under investigation could be discussed (Ritchie and Lewis, 2009). Sometimes it involved asking if the participant wanted to share their lowest moments. Sensitive questions were not always asked in a direct manner, but when the patient was open and direct questions seemed accessible, this was done. Sensitive topics for research can be defined according to the category of people investigated, or by topic. Noland (2012) defines sensitive topics as those topics that people may feel difficulties discussing either because they are taboo topics or generally topics that reside in the private spheres of our lives. Any research that poses some kind of threat to those who are involved is considered sensitive, both for the investigators and the researched

Also at times cancer and death came up naturally in the conversation. Pleschberger et al (2011) report that in some cultures talking about death is more acceptable, for example in the Netherlands and Belgium. In the UK this does not seem to be the case, so there the subject was approached very carefully at the end of the interview. The approach employed was flexible, but it usually started with simple questions aimed at building a trusting relationship, for example: “Could you please tell me a bit about yourself?” This allowed the patients to say what they wanted. Participants were eager to help. Once trust was established

they opened up. Like cancer and death, sexual abuse is considered to be a sensitive topic, touching one's most inner being, and McCosker (1995) reports in her study that abused women were relieved to be able to talk about their experiences. Disclosure can be cathartic, and an interview can be healing (Gale, 1992). Walker (2007) discusses the importance of monitoring for signs of distress. Participant well-being was always given priority. Walker also recommends that if follow-up support should be required, the participant should know about sources of help. In one case an interviewee started crying within the first five minutes. He was asked if he wanted to interrupt the interview, which he did. He was given the option to talk to somebody about what he was going through, but he refused. The nurse was informed. The patient was withdrawn from the study.

Each patient was interviewed once, and the interviews were tape-recorded. Interviews lasted 40 to 90 minutes. Patients' silences and movements were recorded in the research diary. Each interview was identified by date and a serial number so that the patient's identity could be protected – it is worth pointing out that according to UK legislation “sensitive personal data” includes information about the “physical or mental health or condition” of the data subject (Data Protection Act 1998, chapter 29, part 1, section 2). After each interview, the tapes were transcribed, with space for coding. Although the main researcher is fluent in both English and Italian, she arranged for the interviews carried out in Italy to be translated into English by a professional translator. The translations were true to the patients' words; they conveyed the meaning and nuances of the Italian language correctly. Lane (1996) points out that although transcribers are often silent they can be affected emotionally and psychologically by the content of the research. The transcriber of this study did not report emotional difficulties regarding the content of the interviews. Steinar (1996) describes the importance of the transcriber in the transformation of the data from oral to written and the challenge of capturing the essence as well as the technical quality of the interview.

The interviewees

There were ten interviewees in the UK group, but only eight could be included in the analysis. There were seven interviewees in the Italian group, with six included in the analysis (see table below for country of origin, diagnosis and personal data). Twelve of the fourteen analysed were female and two male. Ages ranged from 40 to 85.

Interviewees	Country	Diagnosis and personal data
#1	UK	40-year-old female. Interviewed in the hospice. Diagnosed six years earlier with squamous cell CA. Pain in RT gluteus. Rhabdomyosarcoma, a wound the size of a football, present in the sacral area. Married, no children.
#2	UK - Not included in the analysis	Not possible to transcribe: background noise and poor recording quality.
#3	UK	60-year-old female with cancer of the breast. Interviewed at home, just released from hospice. Widow with 3 grown-up daughters.
#4	Italy	59-year-old female. Interviewed in the hospital. Diagnosis of skin lymphoma, mycosis fungoides. Ulcer on left hip and gluteus extending to the abdomen. Living with husband, has adult sons.
#5	Italy	69-year-old male. Interviewed in the out-patient clinic. Diagnosed two years earlier with melanoma with skin metastasis. Doctor by profession. Married and has two sons.

#6	UK	75-year-old female. Interviewed in the hospice. Cancer of right breast. Fungating wound on right breast. Divorced, one son.
#7	Italy	81-year-old female. Interviewed at home, diagnosed with breast cancer five years earlier. No surgery, only chemotherapy. Suffered from heart disease. Fungating wound of the breast present for three years. Married, with grown children.
#8	Italy - Not included in the analysis	Maxillo-facial cancer. Interviewed at home. Family intervened in a protective manner during the interview. Although patient wanted to talk, family silenced him. Impossible to carry out a proper interview.
#9	UK	76-year-old male. Interviewed in the hospice. Diagnosis: mycosis fungoides. Wounds on the scalp and various parts of the body, disfigured face. Married, with sons and grandsons.
#10	UK	42-year-old female. Interviewed at home. Bilateral advanced carcinoma of the breasts with bone metastasis. Fungating wounds on both breasts. Found unconscious on the street. Husband abandoned her when she became sick.
#11	UK - Not included in the analysis	Broke into tears within five minutes of the start, and preferred not to be interviewed. Took place in the hospice.

#12	UK	77-year-old female. Interviewed at home. Diagnosis of cancer of the left breast eighteen months earlier. Fungating wound. Widow, daughter lives in another country.
#13	UK	75-year-old female. Interviewed in the hospice. Primary colon cancer, colostomy present. Liver metastasis present. Hysterectomy five years earlier. Fungating wound on the thigh area and an arterial ulcer.
#14	Italy	70-year-old female. Interviewed at home. Right mastectomy. Fungating wound. Lives with husband and two sons, one of whom is disabled.
#15	UK	85-year-old female. Interviewed in the hospice. Cancer of the rectum invading the pelvic wall. Fungating wound on left thigh.
#16	Italy	81-year-old female. Interviewed at home. Cancer of the vulva. Wound of the vulva. Patient lives at home with husband, has a married daughter who comes to help.
#17	Italy	65-year-old female. Interviewed at home. Lymphoma with tumour extending to the right axilla. Amputation of right arm due to the cancer and open wound. Tended not to finish her sentences. Living with husband, has a daughter and grandchildren.

Emotional issues associated with conducting research on terminally-ill patients

Johnson and Macleod Clarke's (2003) study of individuals conducting research on cancer,

HIV/AIDS, or death and dying describes their difficulties at witnessing suffering and not being able to reciprocate. Some of the cancer researchers started to worry about whether they too might have cancer after listening to the stories of others. The same thought occurred to the main researcher of this paper all through the researching and writing of the thesis from which it is drawn. The interviewing was emotionally difficult. Here are extracts from the research notes:

First year: Once I started to interview patients I found myself facing two kinds of difficulties. The first was my uncertainty as to whether I was carrying out a good interview.... The second difficulty is more complex. At a certain point I encountered an emotional resistance to carrying on with the interviews. They came to a halt. I started counselling. The themes that are coming out in counselling are: my fear of cancer.

A year later into the research: I am indexing Interview n.10. It is a difficult one. I stopped after a while. At night I dreamt that I had a lymph node in my thigh. I was looking for help. I was telling the director of nursing. She asked me teasingly if I had decided to experience the research first-hand.

Two years into the research: I have had a few sessions of counselling. In each of them the interview I was indexing came up. The last two are the most difficult. I look at each page to see how many are left. Interview n.17 – her right arm has been amputated. I had pain in my right shoulder arm and breast during all the session. The fear of cancer, of having it, the horror of what the patient has experienced (as I imagine it) is present.

Writing the thesis: The magnitude of death.... I experienced paralysing fear. In a fish bowl with no water, feeling apart from the world around me.

Acknowledging the effect it had on the main researcher allowed her to bracket it, and the bracketing allowed her to be aware of her preconceptions and reactions. In her study of women who had been raped, Campbell (2002) refers to the impact of such research on the researcher. She recommends that researchers ask why a particular interview affects them in the way it does, so that they may learn from it. These interviews may have an empathic element or potential for transformation for us. Quinn (2003) carried out a qualitative study exploring nurses' experience of supporting patients in their search for meaning while living with cancer. The nurses in Quinn's study reported that witnessing suffering and supporting cancer patients affected them and that they themselves needed support. Similar results are reported by Alexander (2010). Alexander's study is the first to simultaneously look at the experience of the patients, at the nurses who care for them and at the families/caregivers. The impact on the carers was marked by the fact that they were left with very intense memories of the wound. Memories that remained imprinted and surfaced easily in their daily life. In their study, Peterson et al (2010) state that witnessing the suffering of patients is one of the biggest sources of stress for nurses: those who worked with dying patients coped in two ways, by drawing on internal and external resources. Internal resources meant that the nurses had to re-evaluate their relation to death. Maintaining professional distance helped as well. The external resources where nurses found support were religion and perhaps surprisingly the patients and their families. As the main author of this paper had a one-time only contact with patients, this kind of support was not relevant. However, re-evaluating one's relationship to death, suffering and disfigurement was a way of coping with the many emotions. Johnson and Macleod Clarke (2003) actually question whether new researchers should be undertaking research on sensitive topics on their own, suggesting that the first time should be with a senior researcher.

According to Dickson-Swift et al (2009) sensitive topics should prompt us to reflect on our own responses while doing the research. Is it possible to avoid being touched by so much suffering? They recommend that researchers ask themselves why they have chosen a specific topic. Is it because it resonates with something inside us? For this main researcher it was certainly an attempt to make sense of illness, suffering, and ultimately death.

The researcher herself could have been one of these health care professionals with a “paternalistic” approach to cancer patients. This study is possibly an attempt on her part to overcome this. It is not possible to predict the impact that research content may have on a researcher, and it is not possible to stop researchers being affected by content when exploring sensitive topics.

Discussion

Is it ethically appropriate to conduct research on terminally ill patients? Is it the same as another research topic or should it be placed in a different category? De Raeve (1996) challenges the right to carry out research on vulnerable people. He questions our motives in doing research on the dying. Is it because of our own fears? On the other hand all twenty-two patients interviewed by Terry et al (2006, p. 406) in a hospice in Australia wanted to participate for reasons of “altruism, enhancement of a sense of personal value, the assertion of persisting autonomy and the value they placed on a commitment by doctors to optimising care by research”.

The main researcher admits that curiosity about cancer, disfigurement and suffering motivated her to carry out the work. But there were other motivations also, for example the wish to help others. One could argue that the dying have a right to participate in research just like everyone else. In Dickson-Swift et al (2006), a large number of the researchers found that their participants mentioned that the interviews had a therapeutic value, as they found

they had an opportunity to tell their story. Holloway and Wheeler (2010) state that interviews can be therapeutic, although their purpose is not therapy.

Gysels et al (2008) noted that at times ethical committees base their decisions on suppositions of vulnerability of these patients and lack real evidence upon which to make their decisions. More research and knowledge on dying patients may help ethical committees with making decisions as well as influence care decisions. They conducted their qualitative research using semi-structured interviews on 104 participants. The results showed that both the patients and carers reported positive feedback regarding the interviews. The authors advocate a more inclusive approach towards studies on dying patients and recommend that ethical committees should keep in view the positive effects and not only the risks.

In the present study no questions were asked about the interview itself, but some of the interviewees did mention that it made them feel better, for example Interviewee 14 (p.15 of transcript):

“I like to speak to people ... like yourself ... when it is not just useless and meaningless chatter or gossip or inquisitiveness, but when we talk about things that give me pleasure to talk about. And this gives me pleasure and I speak about it willingly. When Doctor X told me about you and told me that it was up to me and she had nothing to do with it; she asked me [laughs], she told me that you just wanted to do an interview, and since it is something that should be talked about and isn't talked about....”

Some of the Italian health care professionals encountered were suspicious about the main researcher's fitness for the job once they learned that she herself might avail of psychological support and counselling during the study. The doctor who was against the research stated that the protocol needed to be rewritten, that the main researcher was a *voyeur*.

In her study of patients' experience with fungating wounds, Alexander (2010) describes her difficulties in recruiting patients and caregivers. The health care professionals decided not to refer patients to her. Patients were not informed of the study and thus could not make their own decision. Alexander reports that the professionals were afraid that patients would be upset by the interviews and therefore thought they would protect them by denying them the chance to decide independently whether to participate or not. The taboo of death, and of talking about it, is not exclusive to patients. It affects health care professionals as well.

Some of the difficulties encountered in accessing Italian patients could be explained by the fact that communication in Italy regarding the subject of terminal illness is enveloped in secrecy, relying on the patients "knowing and not knowing". Non-disclosure is also used where prognosis is good and the cancer is curable. In Italy, health professionals and families believe that telling the truth about a terminal illness corresponds to "leaving one without hope". Gordon (1994) describes the ethics of ambiguity and concealment around cancer in Italian society: doctors commonly use euphemisms to cloud the subject, "protecting" their patients from the truth. Surbone, Ritossa and Spagnolo (2004) found partial disclosure and non-disclosure still present. According to Locatelli et al (2013, p.1112), while more open disclosure of the truth to cancer patients is being reported in countries such as Italy, it was one of those countries known for a "paternalistic vision of the patient-doctor relationship" and a "protective role to family ties with regard to the sick person". As this research was conducted in Italy, these dynamics have been taken into account and in the consent form and information sheet the word "cancer" was not used. Instead, it was referred to as "chronic illness".

Findings

Findings are to be reported in another paper, but they include the experience of patients of their wounds and the role of dressings in improving quality of life and the cultural difference between the patients in Italy and in England.

Limitations

Researchers bring both strengths and weaknesses with them to their work: as Maxwell (2012) points out it is impossible to separate the researcher from the research. Accessing and interviewing very ill and vulnerable patients proved challenging for the neophyte main researcher, one moreover who was conducting the investigation on a part-time basis. The recruitment pace was slow: around three patients per year.

Conclusions

This paper has attempted to highlight the complexity of researching a sensitive subject. The difficulties relate not only to the research subject, but also to the researcher's background. This means that it is not possible to generalise or to predict the impact the interview would have on the participant. Neither can the interviewees predict or be aware of how the interviews will affect them beforehand, at least not always. However there can be an opportunity for growth and transformation for both participants and researchers. Positive aspects include providing a voice for a vulnerable group of people. Talking about their experience can help patients counteract the loneliness experienced by people with terminal cancer. It is difficult to estimate and evaluate how the interviews affected the participants in the current study. Upon reflection, some may have consented because they felt it was a way to express gratitude to the health care professionals, but as it transpired they found the experience therapeutic.

In the current study, some difficulties were highlighted relating to conducting research on terminally ill cancer patients and in gaining access to such patients. Such difficulties often reflect unresolved issues around death and cancer on the part of health care professionals. Being close to a dying person can be an enriching experience, it can challenge one to come to terms with one's own fears and emotions, but the difficulties that accompany it cannot be denied.

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