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Rowan Robinson and Johanna E Maree

Abstract

Background: Most people with cancer experience pain caused by the disease and treatment. **Aims:** To describe the experience of cancer pain of South African patients. **Methods:** A qualitative descriptive design was used; 20 (n=20) participants were purposively selected and in-depth interviews were conducted. Inductive content analysis was used to analyse the data. **Findings:** Two themes and five subthemes were identified. The themes were pain as a unique multi-dimensional experience, and that the unmet needs of the patient can influence their experience of pain. **Conclusion:** The participants experienced total pain. Emotional pain, enhanced by loneliness and unmet information needs was experienced, and this was felt by participants as the worst kind of pain. Pain was mediated by means of medication that did not work well for all, support, compassionate care and hope that God would cure them and take the pain away. **Recommendation:** A person-centred approach to pain management is needed, especially in diverse countries, such as South Africa, to better understand the complexity and influence of culture, language and education on the pain experience and to guide individual pain management.

Key words: cancer pain ● total pain ● unique and multi-dimensional experience

Similar to the rest of the world, cancer is a serious public health problem in South Africa with nearly 110 000 people newly diagnosed with cancer in 2020 and 51 000 dying from cancer in the same year. Cancer of the breast, cervix and colon/rectum are the most common cancers in women, while prostate, lung and colorectal cancer are the most common in men (International Agency for Research on Cancer (IASP), 2021).

Pain is a common problem for patients with cancer as 55% of patients receiving anti-cancer treatments and 66% of patients living with advanced, metastatic or terminal disease will experience pain (World Health Organization, 2019). Pain can also be a presenting symptom of cancer as pain is often experienced when seeking health care or being diagnosed with cancer (Bingo et al, 2020; Maree et al, 2020). Unfortunately, South African patients often present with advanced disease due to a variety of factors, including a lack of knowledge about cancer, poverty and inefficiency of the healthcare system (Potgieter and Maree, 2018; Chitha et al, 2022).

Pain is described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage (Twycross, 2003; IASP, 2020) and can only be described by the person experiencing it. Pain is a psychosomatic phenomenon modulated by mood and morale, as well as what pain means to the patient (Twycross, 2003; Tadman et al, 2019). Total pain consists of four domains: physical pain that can be associated with impaired mobility, psychological pain related to factors, such as anger, fear, despair and hopelessness, social pain related to the various losses the patient experiences and feelings of abandonment and isolation, and spiritual pain associated with a loss of sense of purpose and questioning the meaning and purpose of life (Twycross, 2003; Franklin and Lovell, 2019).

As pain is experienced differently by each person experiencing it, cultural beliefs may influence how people respond to pain, express pain and interpret its meaning (Brant, 2017). This emphasises the need for a person-centred approach to pain management (Brant, 2017) to better understand the complexities of the unique pain experience. Beck (2000) highlighted the importance of the relationship between healthcare providers and patients and the need for effective communication that is particularly relevant in South Africa with its diverse cultures and 11 official languages (Alexander, 2023).

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This study was part of a greater multi-phased study aimed at the development of a patient informed pain assessment instrument. This manuscript reports on the second phase of the study and focused on the following research question: how do cancer patients, admitted to an acute cancer care setting experience their pain? Knowing how patients' experience their pain allows nurses to develop person-centred non-pharmacological interventions and advocate for pain medication that will be acceptable to these patients.

Methodology

The study

This study used a qualitative descriptive design (Sandelowski, 2000) to present a descriptive summary of pain experiences from the patient's viewpoint as it occurs in their everyday life.

The setting

The setting was the medical oncology clinic and wards of an academic hospital in Johannesburg. The hospital forms part of the public healthcare system, has 1088 beds, and offers both inpatient and outpatient speciality services. The hospital receives referrals from hospitals in its catchment areas from within the province, but it is also a referral centre for specialist services needed by neighbouring provinces (Gauteng Provincial Government, 2018). Specialist services include haematology and oncology and treatment and care is provided free of cost to the majority of patients (Travelground, 2018).

Population, sampling and recruitment

The population consisted of all patients receiving cancer treatment at the study setting. Purposive sampling (Sandelowski, 2000) was used to select information rich participants. After obtaining ethical clearance from the University (M170495) and permission from the hospital, the first author approached the patients waiting for a scheduled appointment at the clinic and those admitted to the oncology ward and invited them to participate in the study. To be included in the study, patients had to be 18 years and older, diagnosed with cancer, able to understand basic English and have a history of pain.

The study was explained to them, and all received an information leaflet, which was discussed and read out loud. A total of 22 patients were recruited and 20 participated in the study after informed consent was obtained in writing. Of the two patients who did not participate, one patient was called to see the doctor and did not return to the waiting room, and the second patient admitted that she only wanted to participate if it meant that she would see a doctor sooner.

Data collection and management

In-depth interviews were conducted in English by the first author after demographic data were collected. A multi-lingual faculty member who specialised in mental health, was present to reduce any language barriers (Beck, 2000), enabling participants to express themselves in their language of choice when they could not express themselves clearly in English. One opening question: please tell me what it is like for you to live with pain? was asked, with probing and prompting questions added to elicit a deeper understanding of responses.

The interviews were conducted in a private consulting room from April 2018 to July 2018 and lasted on average 25 minutes each. Two of the participants became emotionally distressed, and although a distress protocol was developed, they declined referral and preferred to be assisted by the researcher and faculty member.

Data management and analysis

Demographic data were entered onto an Excel spreadsheet. The audio-tape recordings were given a number and were transcribed verbatim; the names of the participants were replaced with pseudonyms. The data was analysed manually and used an inductive content analysis method (Elo and Kyngäs, 2008). The transcribed interviews were re-read several times to become completely familiar with the data. Coding was done by underlining interesting words and phrases in the transcribed scripts. Words and phrases were transferred to coding sheets and similar ideas were grouped together in subthemes. The subthemes were grouped into themes and higher order headings were allocated to the themes. Both authors were involved in the data analyses and met regularly to reflect on how the researcher's privileges, culture and life experiences could influence the findings of the study (Malterud, 2001; Pillow, 2003).

Enhancing rigour

The criteria of Lincoln and Guba described by Shenton (2004) was used to enhance the rigor throughout the study. Credibility was enhanced by using well-established research methods and subjecting the proposal to peer review. Probes and prompting questions were used to gather comprehensive data and member checks to enhance the accuracy of the data. Both authors were familiar with the research setting and

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regular meetings were held to discuss the study progress and developing ideas. Transferability was enhanced by providing a detailed description of the phenomenon under study, and the study setting allowed comparisons to be made while purposive sampling helped us to select information rich participants. Dependability was enhanced by repeated coding by the first author. This was then reviewed by the second author to discuss findings and compare results. Lastly, confirmability was confirmed through audit trails and reflexivity.

Findings

The participants consisted of 20 patients (n=20) between the ages 20 to 76 years, with an average age of 52.2 years (SD±14.62). The majority were female (11 of 20) and Zulu was the language spoken by the highest number (7 of 20). The majority of the participants had solid tumours (14 of 20), while the rest suffered from one of the haematological malignancies. Most had received a combination of surgical and chemotherapy treatments (13 of 20) (*Table 1*).

A total of 618 codes were identified in step one and in the second step, similar ideas were grouped into five subthemes and two higher order themes (*Table 2*).

Due to the distance to the hospital, the first author collected the data in three interview periods. The data were analysed at the end of each period. Theoretical saturation of information was achieved after the eighteenth interview, as no new themes or subthemes were identified.

Table 1. General inFemaleorMaleation about the patients (n=20)

PseudonyMale	Age	Gender	Home language	Diagnosis
Peter	37	Male	Zulu	Multiple myeloma
Mary	67	Female	Northern Sotho	Breast cancer and multiple myeloma
James	76	Male	Xhosa	Oesophageal cancer
John	51	Male	Arikaans	Melanoma
Martha	62	Female	Zulu	Breast cancer
Magdalene	52	Female	Tswana	Breast cancer
Joanna	36	Female	Not stated	Colon cancer
Andrew	59	Male	Zulu	Multiple myeloma
Susanna	62	Female	Not stated	Acute myeloid leukaemia and breast cancer
Salome	73	Female	Arikaans	Breast cancer
Prisca	71	Female	Tswana	Breast cancer
Junia	30	Female	Southern Sotho	Breast cancer
Julia	51	Female	Arikaans	Breast cancer
Ammeia	45	Female	Zulu	Breast cancer
Philip	51	Male	Zulu	Chronic myeloid leukaeia
Perpetua	45	Female	Xhosa	Colon cancer
Bartholomew	47	Male	Zulu	Lymphoma
Thaddeus	48	Male	Not stated	Multiple myeloma
Thomas	20	Male	Zulu	Sarcoma
Mathew	61	Male	Ndebele	Lymphoma

Table 2. Themes and subthemes arising from the data

Theme	Subtheme
Pain as a unique multi-dimensional experience	• The physical experience of cancer and its treatments • The emotional burden of having a feared disease • Factors relieving pain
The unmet needs of the patient influencing the experience of pain	• The need for information and communication • The need for compassionate care and support

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Subtheme 1: The physical experience of cancer and its treatments

The participants experienced different types of pain and the intensity of the different pains also varied. Joanna explained:

'The heavy pain … feel like a deep breath, the sharp pain bites you. Narrow pain like something you can feel it far [away] but it's still coming, something slowly coming. That pain is a different pain.'

Andrew added:

'Today, that pain, sometimes, it just keeps quiet. It's not talking ...'

Cancer treatments were also identified as being a source pain. The participants were divided as to whether chemotherapy made their pain better or worse. Perpetua said:

'This chemo thing was not meant for human beings. Maybe it was meant for lions. Even if I survive this cancer, this chemo will kill me.'

Magdalene added:

'It's the devil. It is the devil alive.'

In contrast, Junia said:

'Though chemo is painful, at least it helps with lots of pains in the body… rather give me the chemo, because my pain is not going away.'

The many side-effects participants experienced after chemotherapy also caused pain. Fatigue and gastro-intestinal disturbances seemed to cause the most distress. Julia explained:

'My life is just about lying down and pain.'

Ammia said:

'When I get home I vomit: that was the worst pain …'

Subtheme 2: The emotional and spiritual pain

The participants agreed that the emotional pain they experienced was worse than the physical pain. Peter said:

'Outside is fine, but inside is not fine.'

John added:

'It's not just a physical pain, it's a mental pain as well, you know. It can bring you into a struggle …'

The participants experienced various losses that caused severe emotional pain. Junia explained:

'I woke up … to … another torture. No breast, only one … 2 weeks after [starting chemotherapy] they terminated the baby … Even today, when I think of that loss, it's huge for me…'

Thomas added:

'It [cancer] has changed my life a lot. I used to talk with my mum and have fun with my mum, but now we just sit …'

Stigma added to the participants' emotional pain. Mary explained:

'They spread some words around. Look at her —she is sick, she is going to die.'

Philip added:

'[Colleagues] thought that maybe if I sit next to them the disease will spread to them.'

Andrew said:

'Some of them say it [is] witchcraft.'

While Thaddeus added:

'For us, black people, the sickness that the one with cancer [has] is not completely their own, most of the people think somebody had given him muti [traditional medicine]. Several participants isolated themselves to stop the rumours and perceptions spread in the community, however, the loneliness they experienced caused severe emotional pain.'

Julia said:

'The loneliness—I think that this is the most painful.'

The participants also experienced spiritual pain. Perpetua said:

'The pain is in your soul; it's not in your body. I was never suicidal, I was just wishing to go to sleep and never wake up …'

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Joanna added:

'You feel like nobody wants you because everything changed.'

Subtheme 3: Factors relieving pain

The participants agreed that the analgesia they took relieved their physical pain, but some did not experience relief every time they took the medication. Mary said:

'The pain is still going on, but the pills numb it.'

Some of the participants found the pain medication quite confusing. Peter said:

'It confuses us when you get a lot of tablets, because they do not work the same. So when I am there in my house I mix it myself, so I know which one is stronger than the other one.'

Some participants saved their pain medication for when they experience severe pain, while others did not receive enough tablets to last for a month, and therefore had to use it very sparingly. Mary said:

'If I overdo it now, then when the worst pain comes, this pill won't be working for me.'

Andrew added:

'I only get 10 tables per month … [I take them] when it is too much … I don't want to finish them.'

Faith and hope helped the participants to cope with their pain. They hoped that they would be cured, and believed that God would intervene and take their pain away. John explained:

'The Lord taught me to give my burdens and pain to him. So that makes it easier for me to carry you know. Not giving up.'

Andrew agreed:

'One day I will be healed. That hope.'

Theme 2: The unmet needs of the patient

Subtheme 1: The need for information and communication

Unmet information needs and inadequate communication added to the participant's emotional pain, causing fear, insecurity and a lack of trust in the healthcare system. Some patients did not know what the cancer was, and feared that it could spread to their families. Others needed more information about their disease and treatment. Peter said:

'I want to know … can the cancer … affect my family, or not?'

Philip explained:

'At what stage, you always ask yourself, is the disease? Is it at a later stage or a beginning stage, or in the middle stage?'

Some of the participants believed they were misdiagnosed, and also received incorrect information about the symptoms they presented with. Junia stated:

'We get wrong information, we are misled at the very same hospitals that we go to …'

Magdalene recalled:

'[My breast] was bleeding from the nipple. The doctors kept giving me medication, and said there's no need to run to the clinic … it will go away.'

Communication with the medical team was also a problem as the doctors were perceived as busy, and used language that the participants did not necessarily understand. Susanna said:

'The doctors are so busy and you cannot even ask them anything.'

Thaddeus added:

'Yes, they gave me medicine, but I don't understand the language of the doctors that gave that medication …'

Subtheme 2: the need for compassionate care and support

The distress of being away from home, being lonely, under supported and frightened, negatively influenced how the participants experienced their pain. Compassionate and empathetic care eased the pain. John said:

'There are some nurses we have conversations with full of compassion and understanding that cuts you open, and it's OK. You can see from experience that they care more than just doing their job.'

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John said:

> **'They feel with me. They understand my confusion and my pain and try to help … this helps me coping with it … even though I know the medicine they are going to give me is not really going to relieve the pain.'**

In contrast, John said:

> **'It's a job, and you do it … you want to get it finished because you want to go home. Or get to the next [patient].'**

Being supported by family, friends and healthcare professionals helped the participants to cope with pain. However, not all the participants had a good support system. Junia said:

> **'If my journey that time had great doctors, the great support system, my journey would have been different because I would not have cried so much, I wouldn't have so many sleepless nights at home.'**

Discussion

The study provided evidence that the participants experienced pain as unique, multi-dimensional and very complicated. The participants' pain changed from day to day, and they experienced different types of pain at varying intensities, in different parts of their bodies; and total pain was present.

Physical pain was experienced as a consequence of the disease and treatments, however, many participants experienced chemotherapy as being the most painful medical intervention. The side effects of this treatment were also described as painful.

The emotional pain the participants experienced far outweighed their physical pain. It appears that the experience of pain and the patient's ability to cope with that pain was also influenced by the patient's emotional wellbeing that, according to Brant (2017), could be negatively influenced by states of loneliness, fear and vulnerability. The stigma of a cancer diagnosis should also be considered as potentially playing a role in a patient's perception of their pain (Wallace et al, 2018; Nakash et al, 2019).

Participants described different experiences of pain relief, and gave confusing accounts of the analgesia that they had received. The same trend was reported by Kaila and Maree (2018) when investigating pain in South African women living with cervical cancer. However, the pharmacological treatment recommendations for cancer pain management are well-described in the literature (Ripamonti et al, 2012; Fallon et al, 2018) with several references to the WHO's stepladder approach to pain treatment remaining the gold standard for comparison. While it cannot be said with certainty that the WHO guidelines were not followed for patients included in this study, it is evident that there were compliancy and adherence issues, and that participants might not have received adequate information about their analgesia.

The need for quality information and improved communication about the disease and its treatment was also identified. Language and medical jargon were identified as barriers which have also been described by Butow and Sharpe (2013). The problems created by 11 official languages and cultural issues could have played a role.

According to Davidhizar and Giger (2004) and Miyashita (2018), information about the disease of cancer, the various treatment options and anticipated side-effects of these treatments should not only be discussed at a level that the patient can understand, but also discussed in the language of their choice, so that subtle variations in translation or interpretation can be avoided. Participants in the present study suggested that this information should be given in a therapeutic manner that is not hurried, giving time to explore options and to ensure that concepts are understood. Ongoing education and counselling

Short reports

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at all levels and at all stages of the disease are needed for patients and their family members.

To do this effectively, it appears that healthcare practitioners also need training in cancer pain management, and on how to use opportunities to educate patients and how to deliver bad news in a simple and more compassionate way. According to Maree (2010), nurses who spend the most time with cancer patients, should study cancer pain and its management to better fulfil their role in patient care.

Most of the participants experienced a need for compassionate care. Trzeciak and Massarelli (2019) describe compassion as being an emotional response when seeing pain and suffering in others and a genuine desire to assist. Compassionate care appears to have a positive impact on how patients experience their pain. Participants who had received a gentle word or a soft touch were still in pain, but appeared to endure their pain better than the participants who had been spoken to harshly, or felt that they were not cared for or respected.

This research aligns with findings from studies conducted beyond South Africa, emphasising the unique and multi-dimensional nature of cancer pain experienced by individuals diagnosed or living with cancer. The potential association between pain, stigma and quality of life underscores the need for individualised assessment of total pain (Nakash et al, 2019). Importantly, this study calls for further investigations within the South African context to deepen our understanding of this complex cancer pain experience.

Limitations

Qualitative description is not theory driven and can be seen as lacking the rigour of other qualitative designs (Doyle et al, 2020). In addition, this study was conducted in one academic hospital that is not representative of all hospitals and care settings providing cancer care. Lastly, no qualitative study provides the only truth as the data can be interpreted in various manners.

Conclusion

The participants experienced total pain. The physical pain consisted of different types of pain at the same time, with each different pain varying in intensity. Emotional pain was enhanced by loneliness and unmet information needs, while emotional pain was experienced as the worst kind of pain. Pain was mediated by means of medication that did not work well for all, support, compassionate care and hope that God would cure them and take the pain away. *IJPN*

Statement of interest: *None*

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CPD reflective questions

- Describe the concept of total pain
- How can compassionate care influence the patient experience of cancer pain?
- What information should be given to patients as part of the management of their cancer pain?

Key points

- Cancer pain is unique, multi-dimensional and complicated
- Patients diagnosed with cancer experience total pain and emotional pain can outweigh physical pain
- There is a need for quality information and improved communication about the cancer and its treatments
- Nurses, who spend most of their time with patients, should study cancer pain and its management to better fulfil their role in person-centred care

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