

**Older people's experiences of cancer pain : a qualitative study nursing older people**

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## Abstract

**Aim:** To consider how the older person constructs the experience of cancer pain and how this is informed by expectations and experiences.

**Method:** Nine older people with cancer were asked to keep diaries and subsequently interviewed about their experiences of living with cancer and pain.

**Findings:** Five themes were identified, 'better to be old than to be dying with cancer', 'maintaining control and independence', 'loss of identity-adapting and grieving for a former self', 'dislike of analgesia' and 'denial of pain'. The themes give a perspective on the embodied meaning of 'pain' in daily lives.

**Conclusion:** Clinical pain assessment alone, without listening to people's pain stories, does not always identify pain or problems with daily living. Appreciation of the individuality of the lived experience of cancer can advance our understanding of pain and end of life care

**Key words:**

Older people, pain, cancer, palliative care, patient perspectives,

Cancer is mainly a disease of older people and pain is frequently associated with cancer. Pain in older people is known to interfere with function and quality of life (Abdulla et al 2013); but the extent and nature of pain in older people with cancer is largely uncharted (IASP 2008). Cancer pain is complicated because it may include both acute and chronic pain at different times as a consequence of the cancer itself or, more frequently, the treatment (National Council for Hospice and Specialist Palliative Care Services 2003).

## Literature review

An estimated 30% of patients receiving treatment for cancer experience pain, increasing to 90% in those with advanced cancer (Deandrea et al 2014). The physical causes of cancer pain are varied because of the many different cancer types, sites of tumour, surgical procedures, chemotherapy and radiotherapy (DeSantis et al 2014). Frequently, pain is accompanied by fatigue, nausea and restricted mobility (Barbera et al 2010). There is also evidence that pain management in cancer care can affect quality of life and quality of dying (Mori et al 2012, Holland et al 2013).

The effects of living with cancer pain in later life are mostly unexplored and the most reliable source of information on the experience of living with cancer pain is likely to be the older person themselves (Mohile et al 2009, Dunham et al 2013). Cancer incidence globally continues to increase; in developed countries this has been attributed at least in part to enhanced screening (Siegel et al 2015). Cancer is primarily a disease of older people and incidence increases greatly with age (Ferlay

et al 2013). Older people with cancer are likely to have more complex health care needs requiring the combined input of geriatric and palliative care services. In the absence of understanding the nature and extent of the problem, management of pain may present a major issue for older people with cancer and their healthcare providers.

The World Health Organization (2011) articulated the need to improve understanding and awareness of pain in older people as part of palliative care. The health care needs of older people are complex and challenging as older people with cancer are more likely to become frail and vulnerable (Mohile et al 2009). For those diagnosed with cancer aged over 60 years the co-morbidities of ageing add to an already complicated picture. This increasingly aged population presents a significant demographic challenge for society and health care provision, as old age is correlated with both increasing illness and inequalities of health care provision (Allmark et al 2010). Older people are proportionately the greatest users of health care services in the UK (HES 2010). Given the predicted demographic changes and their anticipated effects on health care provision, it is important to understand the needs of older people with cancer pain.

## Aim

The aim of this study was to consider how the older person constructs the experience of cancer pain and how this is informed by expectations and experiences.

## Method

An interpretative approach, informed by the tenets of interpretative phenomenological analysis (IPA), was used to consider the unique personal experience of living with disease (Smith et al 1999). Understanding the experience of pain may be considered as more than the measurement of pain and may be expressed in the concepts of person-centred and holistic care (Matthias et al 2010,). Person-centred care is what it suggests, putting the needs of the person first and ensuring that they are an equal partner in their health care (McCormack and McCance 2006). IPA, because of its focus on the unique individual experience was considered an appropriate approach to consider the individual older person's expressed needs..

The participants were nine older people with a diagnosis of cancer and in receipt of community based specialist palliative care services (table 1). These were purposively recruited from three hospices in one Northern Region in the UK in 2013 and 2014. Those who identified themselves as experiencing pain were approached by members of the multidisciplinary team (MDT) supporting their care.

Participants were invited to complete a two week 'page a day' diary about their experience of living with pain. History and diary keeping are acknowledged aspects of narrative research methods, of which this research was a type, with older people accessing health care (Buckley et al 2013).

Subsequent interviews, informed by the diaries, were intended to be open and non-directive except for the general focus of living with cancer and pain. All interviews were digitally recorded and transcribed verbatim.

The diary and interview, with each participant, were considered and analysed individually using the stages of IPA (Smith et al 2009: 83) drawing on the original words and phrases used by the participant. Rigour was established through the detailed and iterative processes of analysis following the stages of IPA. To further validate theme development, members of the consumer research panel, who supported the development of the study, independently read several of the anonymised transcripts.

Table 1

name & age	Ethel 82	Robert 68	John 67	Eric 72	Fred 83	Dougie 84	Ernest 72	Bob 68	Hilda 88
cancer diagnosis	breast	liver	prostate	prostate & bone cancer	prostate	bowel	myeloma	myeloma	stomach

## Ethical Considerations

The necessary NHS research ethics (NHS REC 12/YH/0476) and local governance approvals were obtained for the study. All participants were asked to give their formal consent to participation and given pseudonyms to preserve anonymity.

Participation was voluntary with the right to withdraw at any stage in the study. Data

were stored in a secured computer facility and archived as per the University's data protection policy.

## Findings

Five overarching themes were identified in the study: 'better to be old than to be dying with cancer', 'maintaining control and independence', 'loss of identity-adapting and grieving for a former self', 'dislike of analgesia' and 'denial of pain'.

### Better to be old than to be dying with cancer

A significant and important finding of this study was that the participants appeared to prefer to present themselves as old rather than be regarded as people with cancer. Having something other than the cancer to focus on appeared to be preferable to acknowledging cancer as the cause of their symptoms and physical limitation.

Bob was quite clear that his age was a significant factor in explaining why he did not feel too good 'Well yeah, I've slowed down a lot, I've had to slow down because the body won't take it. It wouldn't take it anyway, not at my age. You think it will, your mind says get on but your body won't take it, so I've had to cut my cloth a little bit and I'm not happy about it.'

Being old was used to rationalise some of the pain and problems. Descriptions included noting the 'wear and tear' of having lived a long full life as described by Ethel ' I've not got arthritis as I know to but maybe I have in my legs and that but you

see I used to do a lot of (things) for people, I used to do a lot of papering, decorating. ...I am paying for that now.' Fred added this 'As I say, the body is just getting worn out'.

The participants conveyed a sense of needing to be in control of a situation where age was expected but cancer and its debilitating consequences were not. The participants in this study seemed to say that their cancer's status was not as significant or problematic as others might imply; John noted that 'My body's telling me stop, and I did. I'd always listen to my body, what it tells me...'

#### Maintaining control and independence

All participants noted the importance of maintaining control of their lives to keep their independent status and this was reflected in accounts of daily activities. For some this meant embracing new challenges as exemplified by Ernest 'Oh it's absolutely changed my life that... shopping online this week.'

The participants expressed pride in the way they managed with minimal support. This was confirmed in accounts of a variety of mundane daily activities and chores as depicted by Ethel. 'To get in I pull a chair forward and sit on the chair. I manage to get in, in that way. You just...it compels me to be that little bit more independent. Somebody would do it for me but I like to you know you just... it makes me feel better to do it for myself.'



Ernest needed to stay physically and mentally active, he had prepared his home to support this '...I've got a lot of puzzle books in my bedroom... I've got an exercise bike what I bought with rowing things on it...'

A mix of pragmatism and fear towards pain and losing independence was presented by most. Hilda did not like not being able to get out when she felt ill but, was emphatic that she was in control over her own life and that decisions should not be made about her. '...I can yes, I can decide for myself, so they're supposed to talk to me first, not to (other family members).'

Loss of identity-adapting and grieving for a former self

Most participants were showing what they had lost of their former selves. Hilda conveyed a former self that that she had been strong and independent; she used her memories of dreadful war experiences to contrast with her current experience of living with cancer. Hilda's former strength was evident in her depiction of a very independent life; but, she now described herself as weak and as 'a very poorly woman' and contrasted this with her strong desire to maintain some quality of life.

The army had been an important factor in the lives of the men because of National Service. Fred and Ernest had been career soldiers; they projected experiences of force, implied stamina, strength and toughness in their personalities. Fred personified this stereotype; he had been a runner and especially fit 'When I'd finished work, before I had my dinner, I'd go out and probably run about four or five miles to have a bit of training.'

John was aggrieved at his current dependency on others and his limited mobility. He recounted tales of the former self which he had lost. John was sad at the loss of past

years, the loss of work as a miner, the passing of his children's childhood, his widowhood, the loss of one of his children and a grandchild, and the loss of control over his future following his cancer diagnosis. Bob had lost his identity as the 'bread winner' and he was still enjoying working at the time of diagnosis. He resented his new identity as retired husband and chauffeur for his wife.

### Dislike of analgesia

All the participants disliked analgesia and they had a complicated relationship with the taking of analgesia. For some the dislike of analgesia was hard to extract from a general issue with taking medication. Analgesia was described as causing unwelcome side effects, demonstrating weakness or something to keep for only the worst possible pain.

The contempt for analgesia is depicted in Ethel's account; she was concerned that if she took it too frequently it would not be as effective 'if she really was in pain'. She also did not find them very effective, hence her reluctance to take them. They also made her 'feel really ill'. Robert did not like his analgesia; he could not eat when he took any of the stronger tablets, because they made him nauseous.

### Denial of pain

Pain was denied in several ways. The language used was individual to the person; discomfort, ache and other less commonly used words were used to describe pain. Hilda talked of 'plenty trouble' as a substitute for pain, Dougie used the term 'hurt'

and Ethel talked of 'having a bad day' when she experienced pain. Use of the word 'pain' was problematic for some of the participants. Eric mentioned pain in his diary but face to face at the interview he would only talk of 'discomfort'. 'I've written down all the aches and pains I get, but I don't think any of them will be to do with cancer'

Robert similarly preferred the term 'discomfort' rather than saying he was in pain:

'...the only discomfort I have is from being diabetic and having kidney failure'

The concept of suffering was exemplified by Ernest who expressed that he was 'suffering with all the losses...' and his awful symptoms, including pain, he desired to be again the tough soldier that he had been. The reticence to express the word 'pain' in the interviews perhaps reflected the diminished power which they chose to give to the cancer.

## Discussion

Important limitations to this study include the lack of generalisability and possibility of bias in the interpretation of the data. This study failed to demonstrate the benefits of using the diary-interview as a method with older people with cancer. Diaries were accepted by the participants but largely not used as intended, mainly because of neurological effects on manual dexterity and fatigue associated with the cancers and their treatment. Solicited daily health diaries have been found to be very effective with older people with other health care problems (Milligan et al 2005, Miche et al 2014), future research participants could be offered alternative media to record their daily thoughts and experiences.

Novel to this study is the apparent coping strategy of blaming old age rather than presenting oneself as having incurable cancer. The participants preferred to describe their old age as the problem, they overtly presented this, and yet as the conversations progressed it became clear that the cancer was a major cause of their problems. The participants described the different effects, of being old, in the context of living with cancer and pain yet there is no detailed exploration of these or similar accounts identified in current research. However, it has been suggested that there may be benefits, to the older person, of self-stereotyping as old (Levy 2009, Miche et al 2014). The older people interviewed for this study may have been presenting an internalised ageism, a preferred identity, to fulfil the stereotype which they perceived was expected of them.

Maintaining control and independence was another concern for each participant. This reflects wider research evidence, that pain can impede independence (Kroenke et al 2010, Rustøen et al 2013, Deandrea et al 2014). Control and independence are associated with an individual's physical ability to perform tasks and cancer has been noted to have a significant effect on independence (McCormack and McCance 2006, Macmillan Cancer Support 2012).

Understanding the importance of identity from the perspective of the person with cancer may enable greater empathy with feelings of loss and grief for a former self (Yamada and Decety 2009). The accounts of the participants appear to reflect the disruptive nature of cancer in a person's life-story. Bury (1982) established the

phrase 'biographical disruption' to conceptualise the way people experience the upheaval of serious illness.

The dislike and possible fear of analgesia should be understood alongside general accounts of disliking taking any medication. Studies have similarly reported that older people are reluctant takers of medication (Henriques et 2012, Sengstock et al 2012). The participants in this study did not want to take multiple medications, with some fearing they might lose control.

Denial of pain could be associated with fear of progression of the cancer. Breivik noted that people with can be reluctant to declare worsening pain as they feared this meant a worsening prognosis (Breivik et al 2009). All participants in this study either denied or belittled their pain experience and some chose to describe or disguise their pain by reference to metaphor.

#### Implications for practice

- The self- report of being old may be preferable to identifying as living or dying with cancer
- For the older people in this study, control, independence and the prevention of dependence were factors in their expression of their lived experience of cancer pain
- Independence and the prevention of dependence are major factors to consider in the expression of the experience of cancer pain
- When older people attribute cancer symptoms to old age an ethical issue arises for the nurse concerning whether to correct this

- When caring for older people in receipt of specialist palliative care, the priorities of care should be directed by the needs of the older people themselves as voiced by them and heeded in preference to general assumptions about the needs of older people or the needs of people with cancer.
- Contemporaneous and innovative methods of gathering information about the effects of cancer pain on the individual should be developed if care is to be individualised.

## Conclusion

This study explored the subjective phenomenon of nine older people's experience of cancer pain. Despite the differences between participants, this study has illustrated the importance of allowing older people to express their concerns and needs. When caring for older people in receipt of specialist palliative care, the priorities of care should be directed by the needs of the older people themselves as voiced by them and heeded in preference to general assumptions about the needs of older people or the needs of people with cancer. Listening empathetically, to engage with the older person as person first rather than 'old', may be challenging. For professionals to acknowledge some people's self-identification as being old may be a useful and supportive coping strategy which can deflect attention from the distress of the cancer diagnosis and helps the person with cancer to stay in control. This raises an ethical issue about what is said, and what should be said by professionals, to people living and coping with their own experiences of cancer in their daily lives.

Further qualitative study is needed to replicate this study in different older populations to consider how older people from different backgrounds, cultures and ethnicities experience cancer pain. Given the challenges experienced in accessing this population's experiences, and in order to facilitate person centred care, it would seem appropriate to explore other methods of collecting contemporaneous data. Subsequent quantitative study may help to identify the extent to which themes arising from this study are representative of the wider population of older people with cancer pain.

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