PATIENT PERSPECTIVES

Older people’s experiences of cancer pain: a qualitative study


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 in 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 life.

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.

Keywords

cancer, older people, pain, palliative care, patient perspectives, qualitative research

CANCER IS mainly a disease of older people, and pain is often associated with cancer. Pain in older people interferes 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 (International Association for the Study of Pain 2017). Cancer pain is complicated. It may include acute and chronic pain at different times because of the cancer itself or, more often, its 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 disease (Deandrea et al 2014). The physical causes of cancer pain are varied due to the many different disease types, tumour sites, surgical procedures, chemotherapy and radiotherapy (DeSantis et al 2014).

Often, 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 the 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 is likely to be older people 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 healthcare needs requiring the combined input of geriatric and palliative care services. In the absence of understanding the nature and extent of the problem, pain management 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 healthcare needs of older people are complex and challenging, as those with cancer are more likely to become frail and vulnerable (Mohile et al 2009). For those aged over 60 and diagnosed with cancer, the co-morbidities of ageing add to an already complicated picture.
This increasingly aged population presents a significant demographic challenge for society and healthcare provision, as old age is correlated with increasing illness and inequalities of healthcare provision (Allmark et al 2010). Older people are proportionately the greatest users of healthcare services in the UK (NHS Digital 2010). Given the predicted demographic changes and their anticipated effects on healthcare 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 2009). 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, as it suggests, putting the needs of the person first and ensuring that they are an equal partner in their 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). They were recruited from three hospices in a northern region of the UK in 2013 and 2014. Those who identified themselves as experiencing pain were approached by members of the multidisciplinary team 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 healthcare (Buckley et al 2014).

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), 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.

**Ethical considerations**
The necessary NHS research ethics 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 in accordance with 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.
- Denial of pain.

**TABLE 1. Characteristics of the study participants**

<table>
<thead>
<tr>
<th>Name* and age</th>
<th>Ethel, 82</th>
<th>Robert, 68</th>
<th>John, 67</th>
<th>Eric, 72</th>
<th>Fred, 83</th>
<th>Dougie, 84</th>
<th>Ernest, 72</th>
<th>Bob, 68</th>
<th>Hilda, 88</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer diagnosis</td>
<td>Breast</td>
<td>Liver</td>
<td>Prostate</td>
<td>Prostate and bone</td>
<td>Prostate</td>
<td>Bowel</td>
<td>Myeloma</td>
<td>Myeloma</td>
<td>Stomach</td>
</tr>
</tbody>
</table>

*Pseudonyms have been used
One of the participants, Bob, was 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 it, 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: ‘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. They appeared to say that their cancer’s status was not as significant or problematic as others might imply. John said: ‘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 and 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 about pain and losing independence was presented by most. Hilda disliked not being able to get out when she felt ill but was emphatic that she was in control of her 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 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 an 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 dependence 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 after his cancer diagnosis.

Bob had lost his identity as the ‘breadwinner’ 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 dislike of 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 analgesia effective, hence her reluctance to take it. It 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 said he was ‘suffering with all the losses’ and his awful symptoms, including pain. He desired to once more be the tough soldier that he had been.

The reticence to use the word ‘pain’ in the interviews perhaps reflected the diminished power which participants chose to give to the cancer.

Discussion
Important limitations of this study include the lack of generalisability and the possibility of bias in the interpretation of the data. This study did not 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 cancer and its treatment. Solicited daily health diaries have been found to be effective with older people with other healthcare 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, 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 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 participants’ accounts appear to reflect the disruptive nature of cancer in a life story. Bury (1982) coined 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 (Banning 2008, Henriques et al 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 et al (2009) noted that people with cancer may be reluctant to declare worsening pain as they fear it means a worsening prognosis. All participants in this study either denied or belittled their pain experience and some chose to describe or disguise their pain by using metaphors.

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, rather than general assumptions about the needs of older people or the needs of people with cancer.

Implications for practice
» Self-reporting 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 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 nurses about whether to correct this.
» When caring for older people in receipt of specialist palliative care, priorities should be directed by the expressed needs of the older people themselves, rather than 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.
Listening empathetically, to engage with the older person as a person first rather than ‘old’, may be challenging. If professionals acknowledge some people’s self-identification as being old this can deflect attention from the distress of the cancer diagnosis and help the person with cancer to stay in control. However, 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 research 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 to facilitate person-centred care, it would seem appropriate to explore other methods of collecting contemporaneous data. Subsequent quantitative research might help to identify the extent to which themes arising from this study are representative of the wider population of older people with cancer pain.

References


