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Neglected bodily senses in women living with vertebral fracture: a focus group study

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Abstract

Objective

Older women are at particular risk of osteoporosis. Among women with osteoporosis, fractures of the vertebra (vertebral fracture) are common, hard to detect and associated with risk of further fracture. Identifying vertebral fracture in a timely manner allows instigation of preventive measures to reduce the risk of further fracture. Although detection of vertebral fracture requires spinal radiograph, many women do not receive referral. To begin development of a screening tool to identify women in need of referral we undertook a qualitative study to characterise women's experiences of vertebral fracture, using Eccleston's 'Ten Neglected Bodily Senses'.

Methods

Four qualitative focus groups were conducted with women who had been diagnosed with vertebral fracture (n=19, age 60-91 years). Data were audio-recorded, transcribed and analysed thematically using the 'Ten Neglected Bodily Senses'.

Results

Women's experiences of vertebral fractures related to seven senses: pain, movement, fatigue, balance, pressure, appetite and breathing. Pain was the dominant sense and all participants explained how pain increased with activity, reaching a crescendo, and described strategies to minimise this disruption. Most participants had become physically shorter making some feel "squashed", putting pressure on other body parts. Some described appetite loss or sense of restricted breathing. Participants experienced a sense of being 'pulled' forwards, impacting on balance and exacerbating fear of falling.

Conclusion

The study found senses that have not been previously described in the experiences of women with vertebral fracture. These will be used to inform the design of a new screening tool for use in primary care.

Key words: vertebral fracture, osteoporosis, qualitative research, pain, and screening

Key Messages

1. Using qualitative methods we characterised experiences of vertebral fracture to contribute to a screening tool
2. Unique symptoms of vertebral fracture identified were pain that built with activity and loss of appetite
3. Symptoms of vertebral fracture included balance, downwards pressure in women with spinal shortening and breathing

Introduction

Older women are at particular risk of osteoporosis, which is associated with fracture. Vertebral fractures are the most common type of osteoporosis-related fracture, with around 1.4 million people affected worldwide[1]. Vertebral fracture involves the collapsing of a vertebra in the spine: in a process of 'compression'. These types of fracture often happen in the mid to lower back, and people may experience multiple fractures. Unlike other osteoporotic fractures such as hip fracture, 75% are associated with everyday activities such as bending forwards and lifting objects[2]. Incidence of vertebral fracture increases with age and it is estimated that around 5–10% of women of 50–69 years of age are living with these fractures, this rises to over 30% in those of 80 years and older[3].

Vertebral fractures can have profound impact on wellbeing. Such fractures can lead to reduced mobility, difficulty participating in everyday activities and emotional challenges such as fear of dependency[4, 5]. People with vertebral fractures are at high risk of subsequent fractures such as hip fracture. Identifying individuals at risk of further fracture in a timely manner provides an opportunity to intervene with therapies to reduce the likelihood of further fractures: bone protection therapies can reduce the likelihood of subsequent fracture by 30–50%[6]. However, women who present at primary care with symptoms—such as back pain—that might indicate vertebral fracture are not always referred for further investigation, which would necessitate spinal radiograph for accurate diagnosis. As a result, more than two-thirds remain undiagnosed[7].

In our previous work we have used the McGill Pain Questionnaire[9] to investigate whether characteristics of back pain in women with vertebral fractures are different from those in women with no vertebral fractures. A case-control study of 64 women with back pain and vertebral fractures and 113 controls with back pain and degenerative spinal disease provided evidence of some unique features of back pain associated with vertebral fractures: pain with sudden onset, crushing pain, pain that improves on lying down and pain that does not spread down the legs[8]. This early evidence highlights the potential to use women's own descriptions of vertebral fracture to inform development of a tool to identify women who may benefit from further clinical investigation.

A large body of work has explored the value of self-report questionnaires, in general and in relation to pain. As pain is a subjective experience then self-report is acknowledged as the best way to capture its intensity, severity and quality[10]. However, ensuring that self-reporting accurately reflects experience is key. Previous work has explored the appropriateness and completeness of self-report for people with pain, for instance among young people[11]. Although well validated measures such as the McGill Pain Questionnaire, the Brief Pain Inventory and similar scales were developed on the basis of thorough background, testing and validation work[9, 12], there remains scope to develop measures that are condition-specific.

Exploration of people's experiences of bodily senses is well established in the social and behavioural sciences, which provide ways of conceptualising the body during illness. This includes understanding that our bodies are environmentally situated and how our senses interact with our thoughts, feelings and behaviours[13]. This is known as the experience of 'embodiment'. Psychology has often centred its attention on the five main senses: sight, sound, smell, taste and touch. Recent work by Eccleston suggests the primacy of these senses has led to a lack of attention to what he terms the 'Ten Neglected Bodily Senses'. These include pain, balance, movement, pressure, breathing, fatigue, pain, itch, temperature, appetite and expulsion[14]. Eccleston's schema provides a new way to understand the experience of people who are living with challenges to their health. The qualitative study described in this article explored bodily senses in women living with vertebral fractures. We used Eccleston's 'Ten Neglected Bodily Senses' as a schema to inform analysis and interpretation. This qualitative work forms part of the wider Vfrac study which aims to produce and evaluate a clinical tool to screen older women with back pain for vertebral fractures in primary care. The future clinical tool will be a simple binary assessment of (1) yes—this person needs a spinal radiograph, or (2) no radiograph needed. To achieve this, the qualitative research is part of a wider package of questionnaire development that will reflect the findings from the study described in this article along with existing validated measures such as the McGill Pain questionnaire[9], Pain DETECT[15], and known risk factors for vertebral fracture including age, smoking and use of corticosteroids.

In this way, this qualitative work will contribute to a simple checklist ready for testing within the NHS.

Methods

Identification of participants

To identify potential participants, ethical approval was obtained for a study team rheumatologist to search spinal radiographs performed in the previous three months from the NHS digital radiological archives in a large hospital in the United Kingdom. 1150 images were reviewed and 200 women over 50 with vertebral fractures were identified women. All 200 women were sent study information packs that included an invitation letter, study information booklet and a reply slip. Although 52 agreed to take part, only 24 were aware they had a vertebral fracture and were therefore eligible to participate. Ethical approval was provided by the North of Scotland Research Ethics Service (Reference number 16/NS/0110). Written informed consent was provided by all participants before the focus groups, this included consent for publication and sharing of anonymised information

Data collection

Four focus groups were conducted with women who had been diagnosed with vertebral fracture, with four to five women in each group. This method was selected since it enabled participants to discuss and clarify their ideas and experiences[16]. Each focus group took approximately 90 minutes. Nineteen of the 24 women eligible to participate were available to take part, and we stopped recruitment at this point as data saturation had been achieved such that no new insights were identified[17]. Focus groups included women of all ages and those with single and multiple fractures.

A 'topic guide' was used to guide discussions, including participants' experiences of diagnosis, pain, other bodily sensations and social and emotional impacts. The topic guide was used flexibly to facilitate discussion, with probing used to enable follow-up on women's experiences[18]. Similarities and differences between participants' views were explored to ensure we captured a range of experiences.

Focus groups were facilitated by an experienced qualitative researcher, with an assistant present. Focus groups were conducted in a quiet private room within a research unit. Participants were provided with refreshments and transport costs were reimbursed.

Data analysis

Focus groups were audio-recorded, transcribed, anonymised and imported into NVivo 11 data management software. An inductive thematic analysis was conducted: transcribed data were initially coded using NVivo by the researcher (SD) and independently on paper by another member of the research team (RGH)[19]. Coding was discussed and refined, and the research team explored the relationship between existing literature about pain and the coded data. Coded data were transposed onto Eccleston's 'Ten Neglected Bodily Senses'[14]. This meant that we were able to identify any themes that did not fit within the framework, so that data were not 'forced' into predefined constructs. In this way, our inductive approach was complemented by the use of existing theory, providing structure for descriptive accounts and interpretation[20].

Results

Nineteen women participated in four focus groups, with four to five women in each group. Mean age was 78 years and range was 60–91 years (Table 1). All identifying features have been removed to ensure anonymity.

The bodily experiences reported by participants living with vertebral fractures were understood using seven of Eccleston's 'Ten Neglected Bodily Senses': pain, movement, fatigue, balance, pressure, appetite and breathing[14]. We found that a further three of the 'Ten Neglected Bodily Senses'—itch, temperature and expulsion—were not included in the women's descriptions of vertebral fracture. Bodily senses do not occur in isolation and participants described the interrelationships between them. See Table 2 for illustrative quotes relating to these sensations.

Pain

Pain was the dominant bodily sensation that participants described when talking about their vertebral fractures, although experiences varied. Some focused on the pain that they experienced as an acute episode at the time of fracture, although others experienced a lower level of pain over a longer period of time. Acute pain at fracture was sudden and described as 'agony', 'excruciating', 'intense' and the quality of the pain 'sharp' and 'stinging' and was also continuous. Emotionally, this pain was shocking and intensely disruptive. Duration of this intense pain varied from around a week to up to two months. Some participants described their pain as localised whilst others stated it was more widely spread.

Acute episodes subsided into a lower-level chronic pain over an extended period of time that all participants experienced, including those who could not identify when the fracture occurred. Chronic pain tended to be described as a 'dull ache', 'grinding' or 'gnawing' pain. For others, it was more of an 'intense discomfort' or 'niggle'. For a smaller number, pain maintained a sharper quality or was characterised as a burning sensation. Pain could be 'persistent' or intermittent, which was more often experienced by younger participants. Severe pain could be entirely absorbing or a 'distraction' from meaningful activity.

Site of pain could be localised to a region of the back or generalised to a wider area such as lateral waist, ribs or arms. A smaller number reported that they felt their pain moved down their legs although they were uncertain whether this was caused by their fractures. Participants who were living with multiple vertebral fractures did not feel that experiencing additional fractures influenced the quality of their pain, although one described how having multiple fractures meant the pain could 'flit about'.

Movement

There was a strong relationship between movement or activity and pain. For those experiencing acute pain at the point of fracture, pain could be 'immobilising'. One participant described how she felt as though she had been 'shot in the back' and subsequently fell down the stairs. Pain was a barrier to movements such as stretching, lifting or pushing which limited women's ability to perform everyday tasks such as getting dressed.

All participants described how pain built with activity, reaching a 'crescendo' or 'peak'. Movements that contributed to this were walking, standing, leaning and associated activities including gardening, cooking, cleaning and getting dressed. Washing the dishes, which involved standing and leaning forwards for an extended period of time, was frequently mentioned. Duration of time to reach this 'peak' varied. For some, it was 'a few minutes' whilst for others, particularly younger participants, it was an accumulation over hours. Pain could also accumulate during an active day.

Pain placed limitations on what participants were able to achieve at home and at work. A desire to remain active when experiencing pain was often a source of frustration and one participant described it as a 'battle'. There was a perceived tension between remaining active and 'doing too much' which exacerbated the pain. In order to alleviate pain during activity, participants rested by lying down, sitting or 'reclining', before resuming the task. Many participants, particularly those who were older, spent time prioritising their activity, balancing what was feasible with what they wanted to do. These strategies helped to mediate the disruption to their daily lives.

Several participants expressed a sensation that they were constantly being 'tugged' and 'pulled over' and one described how she felt her body 'wants to curl up into a ball'. Some attributed this to the curvature of the spine and 'stooping' which characterise vertebral fractures. A loss of control over posture and movement was a source of anxiety. On account of this, a number of participants expressed a desire to elongate their bodies, 'stretch', 'lean back' which made them 'feel better'. Participants made concerted efforts to adopt these positions, even when it was painful.

Fatigue

Participants in one of the focus groups discussed the relationship between activity and fatigue which some explained was the result of the pain 'taking it out of you'. As with pain, fatigue could build up during a shorter period of activity or during an active day. Living with pain could also make it more difficult to sleep, contributing to feelings of tiredness. As with pain, feelings of fatigue placed limitations on activity.

Balance

There was a feeling amongst some participants that the damage to their spine had affected their 'core strength', which impacted on their ability to balance. These challenges meant that participants found it difficult to manoeuvre. For instance, some reported that they struggled to stand from a bending or sitting position. Feelings of instability were heightened by a fear of falling as a result of sustaining a previous fracture. To manage this, participants exercised increased vigilance over their bodies by changing their behaviours and making postural adjustments. However, fear of falling also led to avoidance behaviour that impacted on their engagement with everyday life. Feelings of being 'tilted' or 'tugged' forwards contributed to this.

Pressure

Multiple vertebral fractures left many participants physically shorter. Several expressed distress that they were 'sinking' and this seemed to be associated with a sense of loss as participants contrasted their current bodies with their former selves. A smaller number of participants explained how they felt 'squashed' or experienced a downwards pressure on their bodies. One woman thought that the truncation of her spine was putting pressure on other parts of her body, giving her a 'squashed stomach feeling' and making her ribs feel like an 'over-packed suitcase'.

Participants discussed feelings of heaviness and lightness. Some reported that living with a vertebral fracture made parts of their bodies such as their arms feel heavy and cumbersome which was related to feelings of fatigue. For instance, one participant reported that she felt as though she no longer had enough strength in her spine to support her head and had to rest it 'every now and again'.

Appetite

A number of participants described how their appetite or ability to eat had changed since their fracture. Some explained they became full more easily because they could not 'fit it in', whilst others were unsure of the cause or related appetite changes to pain. One described this change as a 'lack of interest' in food. Changes in appetite had led to pronounced weight-loss in some participants which contributed to a sense of diminishment and related

to the senses of pressure and fatigue. This was a source of profound distress and one described the wider impact of this change on their family, who expressed concern.

Breathing

A small number of participants described how multiple fractures restricted their breathing. One explanation was that the experience of intense pain left them breathless. Others thought that the ‘concertina-ing’ of the spine or feeling of being ‘pulled over’ which they described, restricted the movement of the chest and meant they could not inhale as deeply as before. As in the other senses, this was often linked to pain.

Interrelationship between the senses

Across all seven senses participants described interactions between the senses. Pain was particularly important and dominated women’s experiences of fracture. The relationship between pain and movement was marked, with participants describing how pain built up during activity and movements, in a crescendo-like manner. Interestingly, there were also clear relationships across other senses, for instance with pressure related to fatigue and appetite. In the experiences of all senses there was evidence of the impact of vertebral fracture on emotional wellbeing and on how people thought about their everyday lives and their behaviours in the face of pain and limitations. Figure 1 shows how participants described the relationships between the senses, in an illustrative manner.

Discussion

This study characterised the experiences of women living with vertebral fracture in relation to their experiences of their bodies. We found that experiences of fracture reflected seven of Eccleston’s ‘Ten Neglected Bodily Senses’: pain, movement, fatigue, balance, pressure, appetite and breathing. The other three senses—itch, temperature and expulsion—were not contained in the data. Findings also highlighted the interrelationship between the senses, and the ways in which women adapted their behaviours.

The study builds on previous work that had identified some features of back pain that are associated with vertebral fractures: sudden onset of pain, crushing pain and pain relieved by lying down[8]. Previous research has also suggested that women with vertebral fractures

have a reduced quality of life and that activities such as walking, reaching and preparing meals are affected[21, 22] and that this is mainly due to a reduction in physical functioning [23]. Our study shows that problems with movement are related to other senses such as pressure and pain, and that women try to adapt their activities to cope with these challenges.

Some of the 'clinical features' of vertebral fracture are already known, but our study identifies the emotional impact of these as well as some new features. For instance, height loss is a recognised clinical feature described by people with vertebral fractures[24], along with increased forward flexion of the thoracic spine[25, 26]. Furthermore, previous research has suggested that increased forward flexion can make it more difficult for people to breathe easily, particularly on exertion[27]. Both height loss and forward flexion were described as sensations that impacted on their daily lives, such as being vigilant regarding their movements. Although a loss of height, particularly at the trunk, is a known clinical feature of vertebral fracture[28], the sensation of this as 'pressure' is a novel finding. Similarly, the relationship between vertebral fracture and loss of appetite or inability to eat is new, and may be of value in screening and in design of whole person care for people with vertebral fracture. Finally, of particular note were women's experiences of a crescendo of pain that impacts markedly on daily life.

Next steps for the research are use of the findings to contribute to development of a self-report questionnaire that will be administered as part of the Vfrac study to help identify clinical risk factors predictive of the presence of vertebral fractures[29].

Qualitative research methods enabled us to explore and describe women's own descriptions of experience[30]. Social epidemiology has started to place society and bodies at the heart of patterning and health and there is a growing interest in the intersection between diagnosis, assessment and the embodied experiences of people living with health conditions[31]. Focused examples include an understanding of the impact of fractures on everyday life[4, 5]. We used inductive analysis followed by an abductive approach comprising allocation of coded material to Eccleston's 'Ten Neglected Bodily Senses'. A challenge in using any theoretical framework is that data may be forced into predefined

constructs[20]. We found that seven of the 'Ten Neglected Bodily Senses' accounted well for the data and provided an appropriate framework within which to make sense of the material. Our work may highlight the value of using the lens of Eccleston's 'Ten Neglected Bodily Senses' to develop an appreciation of the lived experience of disease.

One limitation of our study in identifying symptoms of potential value as part of a screening tool for undetected fracture is that we only included women who had already been informed that they had a vertebral fracture (24 of 52). This was because we did not think it ethically appropriate to include women who had not been informed in the absence of an appropriate clinical conversation. As such, it is unclear if similar symptoms occur in women who have a fracture but no diagnosis yet. Once the tool has been developed, we will be able to assess the transferability of these findings. In addition we will be able to analyse the prevalence of these descriptions in women with and without vertebral fractures. The study only included women aged 60 years and over who were able to speak and read English and who were drawn from a single hospital. This means that it is possible that their experiences may not represent the experiences of all women living with these fractures. For instance, all participants self-identified as white British which may limit the transferability of findings since the way that bodily senses are expressed and understood varies between languages and cultures[32]. We are also aware that findings may not represent other population groups, including men and younger people[33]. However, we were confident that the study achieved data saturation[17] and that as such the findings are robust and represent the experiences of the included population.

Conclusions

Older women's experiences of vertebral fracture comprise pain, movement, fatigue, balance, pressure, appetite and breathing. This means that these seven senses could provide domains for the development of a screening tool. The results of this qualitative study will therefore be combined with findings from quantitative analyses, and investigated in a wider sample of women than those studied here, in order to develop a tool to help healthcare professionals identify which older women presenting with lower back pain who may have experienced a vertebral fracture.

Figure Legend

Figure 1 Participants' descriptions of the interrelationship between the senses

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