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Patient stories of living with a pressure ulcer

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Patient stories of living with a pressure ulcer

Aim. This paper reports the findings of a pilot study exploring the experience of older people living with pressure ulcers.

Background. Pressure ulcers are known to be a significant health burden, but little is known of the impact on the quality of life of the sufferer. They mainly affect older people, and this is a neglected group in previous studies of this topic.

Methods. A Heideggerian phenomenological approach was used and patients were recruited if they were over 65 years of age and had a grade 3 or 4 pressure ulcer that had been present for more than a month. Patients were recruited from multiple centres but the data were analysed centrally. The study took place in 2003–2004.

Findings. Analysis of the transcripts revealed three main themes, all with associated subthemes: pressure ulcers produce endless pain; pressure ulcers produce a restricted life; coping with a pressure ulcer. The endless pain theme had four subthemes: constant presence, keeping still, equipment pain and treatment pain. Some patients found that keeping still reduced their pain. Several patients also reported that pain was exacerbated by their pressure relieving equipment and at dressing change. There were three subthemes for the restricted life theme: impact on self, impact on others and consequences. Patients found that the pressure ulcer restricted their activities and had an impact on their families. In addition, for some, the restrictions delayed their rehabilitation. To cope with their pressure ulcers, patients developed ways of accepting their situation or comparing themselves with others.

Conclusions. Although a pilot, this study has produced a wealth of data that demonstrates the impact of pressure ulcers on people. While a larger study is

required to obtain a European perspective, it is still reasonable to conclude that the issues of pain and restrictions should be considered in the development of pressure ulcer treatment and prevention guidelines.

Keywords: chronic illness, interviews, nursing, pain, phenomenology, pressure ulcers, quality of life

Introduction

This paper is a report of the findings of a phenomenological study that explored the experience of living with a pressure ulcer. The study was a pilot study to test the feasibility of undertaking a wider European study. It was undertaken in four centres in two European countries and was funded by the European Pressure Ulcer Advisory Panel (EPUAP). In this paper, we describe the findings of the pilot study, which explored quality of life (QoL) issues in a group of older people with pressure ulcers, and discuss the implications for clinical practice.

Background

A pressure ulcer can be described as acute, localized damage to the skin and tissue resulting from disruption of the blood supply to the area, usually caused by pressure, shear or friction, or a combination of any of these (EPUAP 1998). Pressure ulcers are a common clinical problem, affecting about 10% of acute hospital patients in the United Kingdom (UK) (O'Dea 1999). Although pressure ulcers can occur in people of all ages, they are most commonly found in older people. [Whittington et al. \(2000\)](#) surveyed 17,560 acute patients and found an incidence rate of 7%; of these 73% were over 65 years in age. A pilot survey undertaken by the EPUAP, which included 5947 patients located in Belgium, Italy, Portugal, Sweden and the UK, found an overall prevalence of 18.1%, although there was some variation between countries (Clark et al. 2002). Prevention and treatment of pressure ulcers generally consist of frequent change of position, regular skin inspections, skin care, the use of specialized pressure relieving equipment and also the treatment of malnutrition and incontinence ([Walsh & Bennett 2004](#)).

Quality of life

Quality of life has been defined as physical, mental and spiritual well-being that interacts with cultural and economic factors (Marks et al. 2000). Research has shown that health and illness differ in societies and between different socio-

economic groups (Townsend et al. 1988, [Wilkinson 1996](#)). Health as a concept is complex, and meanings of health cannot be understood without taking account of the environments in which we live out our lives (Bernard 2000). If 'health' is socially constructed then perspectives will vary, changing with age and circumstances. Bernard (2000, p. 7) found that older people tend to view health in 'functional terms, emphasizing the importance of resilience and of being able to cope, rather than fitness'.

Self-assessment of health is not easy to measure objectively but it is related to a person's perception of their life's quality. In the presence of physical disability or frailty, [Siddell \(1995\)](#) found that a minority of older people persists in defining themselves as in good health despite contradictory evidence. Hence, external assessors cannot classify others as ill or healthy without a proper grasp of how these terms are conceptualized, understood or experienced (Bernard 2000). Older people may draw on a more holistic account of health, one that is related to life satisfaction or self-esteem ([Siddell 1995](#)), or a subjective estimation of their present mood and happiness, for which they alone are the authority ([Downie et al. 1996](#)). In addition to age, disability has been shown to alter a person's perspective. [Weitzenkamp et al. \(2000\)](#) found that disabled people altered many of the criteria that serve as yardsticks against which they measured QoL. This ensured that, despite suffering loss and unmet needs, they found a good QoL. It is thus more helpful to see health in the older adult as a continuum, embracing many other factors, not merely the absence of disease.

This brief introduction to what QoL and health may mean to a person shows the complexities inherent in the definitions we often take for granted. [Price \(1996, p. 140\)](#), in her discussion of health-related QoL measurement tools, found that they 'represent a multidimensional construct that includes the psychological, physical and social domains' – yet how these are linked remains unclear. If older or disabled people have different yardsticks by which they measure their QoL and health, then exploration of these should produce rich and surprising data.

Phenomenology has been employed to explore pressure ulcers ([Langemo et al. 2000](#), [Fox 2002](#)) revealing concerns about loss of independence, pain, wound exudate, body

image and social isolation. While the results of studies testified to the impact of pressure ulcers on the participants' lives, the oldest participant was 64 years. [Whittington *et al.* \(2000\)](#) found that the majority of people with pressure ulcers were over the age of 65 years, thus our understanding of the impact of pressure ulcers on this group is limited. [Langemo *et al.* \(2000\)](#) also included patients with spinal cord injury and the authors discussed the difficulty of separating the impact of spinal cord injury from the impact of the pressure ulcer.

The study

Aim

The aim of this pilot study was to explore lived experience of older patients with pressure ulcers.

Methodology

A Heideggerian phenomenological approach was used, with single interviews. The data were collected in 2003–2004.

Participants

Eight patients were recruited during 2003–2004 using purposive sampling. The inclusion criteria were that participants must be over the age of 65 years, have a pressure ulcer that was grade 3 or 4 (EPUAP grading) for longer than 1 month, and be able to give informed consent. Patients were excluded if they had spinal cord injury, a criterion suggested by [Langemo *et al.* \(2000\)](#).

Method

The eight participants were interviewed at four centres using multiple data collectors. Three study centres were in the UK but one was in Belgium, so there was the additional concern of translation.

Unstructured interviews were employed to explore patients' view of their world and experience. This method assumes that there is a link between this and their beliefs, that what the participant says has some significance for them ([Smith 1995](#)). In the hermeneutic phenomenological tradition, the aim is to elicit narrative data through which the participants interpret the meaning of their lives (Kahn 2000). It is essential that the interviewer is able to make sense of people's experiences and that their stories are not disrupted. To prevent the former and any contamination of their discourse, [Jasper \(1994\)](#) suggests that researchers require very specific interview skills.

Translation

The research group recognized that using multiple data collectors, with translation for two accounts, threatened the validity of the study. To control this, a rigorous approach was taken: this included training for the researchers in the theoretical framework, the unstructured interview technique and use of probing, and the analytical approach chosen. In a phenomenological study, the findings need to present the essence of the phenomenon. When placing translation in this context, it is possible that patients' stories could be compromised or contaminated. Translation is in itself an interpretive process; there are different dialects and colloquialisms contributing to meaning, thereby increasing the potential for miscommunication ([Esposito 2001](#)). To minimize this, the interviews conducted in Flemish were transcribed in the source language, translated verbatim by professional translators and then verified by the local researcher.

Ethical considerations

Approval for the study was obtained through the appropriate health service research ethics committees. Participants were given written and oral information about the study, confidentiality and withdrawal to ensure consent was informed. They were observed during the interviews for signs of distress, and reassured that participation and discussion was confidential and would not affect their care.

Data analysis

Analysis was undertaken centrally. Interpretative phenomenological analysis (IPA), as described by [Smith *et al.* \(1999\)](#), was used to analyse the rich data obtained, enabling the identification of themes and connections and the exploration of patterns and tensions. Following central analysis, the individual researchers verified themes from the texts. The research group then undertook further analysis to establish the implications and relevance of the analysis for nursing knowledge and understanding.

Findings

A description of the participants is given in Table 1. Three main themes with associated subthemes were identified from the eight transcripts (see Table 2), all of which had an undercurrent of a sense of powerlessness and a 'never ending story':

- pressure ulcers cause endless pain;
- pressure ulcers produce a restricted life;
- coping with a pressure ulcer.

Table 1 Patient details

Pseudonym	Gender and age	Place of care	Duration of ulcer	Position and grade of pressure ulcer	Pressure relieving equipment
Betty	Female, 67 years	Home, UK	10 years	Lower thigh, grade 3	Alternating air mattress + pressure relieving cushion
David	Male, 67 years	Home, UK	2 years	Ankle, grade 3	Pressure relieving cushion
Joan	Female, 68 years	Hospital, UK	4 months	Buttocks, grade 4	Alternating air mattress and cushion
Theresa	Female, 76 years	Hospital, UK	3 months	Sacrum, grade 4	Alternating air mattress
John	Male, 80 years	Home, UK	2 months	Heel, grade 4	Heel device
Bob	Male, 77 years	Home, UK	> 10 years	Buttock, grade 3	Alternating air mattress and cushion
Denise	Female, 76 years	Nursing home, Belgium	1 year	Ankle, grade 3	Sheepskin
Maria	Female, 101 years	Nursing home, Belgium	8 months	Buttock, grade 3	Water mattress

Table 2 Findings: themes and subthemes

Theme	Subtheme
Endless pain	Constant presence Keeping still Equipment pain Treatment pain
Restricted life	Impact on self Impact on others Consequences
Coping with a pressure ulcer	Comparison Acceptance

Pseudonyms are used to identify patients in the following quotations.

Endless pain

Pain was a *constant presence* and was described in a graphical manner by all except David. As John said, it was enough to make ‘a grown man cry’. Pain was an ever-present feature for this group and various descriptors were used throughout the transcripts to describe the shock and severity: ‘constant’, ‘suffering’, ‘splitting’, ‘limping’. Analgesia was not always effective: ‘they give me pain killers and sleeping tablets but I wake up with it’ (Theresa). John also described how ‘you put a bit of weight on your heel and (it) feels as though it’s burst open’. It caused him to feel as though he could only ‘creep around’ and there was awareness that this was preventing rehabilitation from his hip replacement operation causing additional concerns. Some participants found that the severity of the pain was not recognized by their doctors or that the analgesia prescribed did not successfully reduce their pain. Several had developed strategies that reduced their pain. ‘Keeping out of the way’ was an option for John. Two participants found that repositioning

sometimes reduced their pain. Unfortunately for them and others, the more general response to the pain was *keeping still*. Pain had a significant effect on mobility with participants fearing to move; simply put, the pain was bad but moving made it worse. Principally their strategy to reduce or prevent pain was not to move:

Maria: I don’t dare move because everything then gets worse. I lie very still.

John: I don’t move it. As soon as I do it’ll jump and start all over again.

Joan: ... holes in both sides of my bottom ... I could not move in bed or nothing. It was ever so sore.

Importantly, there was awareness that movement and repositioning should help but in reality it did not. Maria said, ‘When I am sitting in my chair like now, then that also hurts and if I move a little it hurts even more, so I sit very still in the chair, but still, still it hurts’. This appeared to give a sense of control over the pain. However, John also commented that this control was lost when he slept, because he could not always hold his position. The pain prevented movement and made treatment or handling by their carers an additionally painful experience.

Despite most participants receiving appropriate pressure relieving equipment, several described the painful effects of equipment. Again the descriptors used to depict the alternating pressure mattresses were graphical: the mattress cells were ‘lumps’ (Joan) or ‘rods’ (Theresa), sticking into their backs or aggravating their pain. Bob said, ‘As it comes up, the pressure is on the sore, you really do feel it’.

The interviewees had knowledge of the varieties of equipment and of what was actually useful for them. Denise was aware that pillows were not practical for they either flattened or moved. John was given a water-filled glove for his sore heel (against hospital guidelines) which he recognized as

useless for his situation: 'Of course, as soon as you move, it falls away and you have had it!' Maria's carers had tried the 30° tilt but it felt unsafe and had not been helpful. Several patients were aware that their reduced mobility was not a useful feature and would probably have consequences ['staying longer in my chair than I should do' (Betty)], giving an acknowledgement of their understanding of the importance of repositioning.

In addition, the local wound *treatment* was found to either increase or diminish the pain. For some, the decrease in pain at dressing change was evidence of healing. For others, the pain was ever-present despite evidence of healing. As Theresa described, 'When they clean it, it is like a needle scraping my nails. It is very painful'.

There were many different treatments employed, often with the carers finding it difficult to find an effective treatment. Nurses tried to give reassurance but were not always believed: 'They say it is getting better but I wonder if it is' (Denise).

A restricted life

Pain had a significant impact on participants' lives, restricting them in many ways. This impact was sometimes difficult to quantify because it was in addition to comorbidities such as arthritis. However, it was clear that the restrictions of the pressure ulcer had an *impact on self* for most of the participants. The event of a pressure ulcer was in itself shocking. When a carer reported that the size of the sore was not as big as some, Denise's response was, 'It is a wound and I am not used to it'. Sometimes participants felt useless and compared themselves with how they were before, often making themselves miserable: 'Miserable sod I was. I would not speak to no one. I would not let them touch me or nothing' (Joan). They described feelings of worry, depression, being burdensome, inadequacy and a sense of powerlessness: 'Obviously, when this situation develops, you cannot see the end of the road' (Betty). John compared his present activity with his past activity: 'That's what gets to me more than anything. I can't do, can't do sod all', and he went on to describe his younger life as a soldier and youth worker. There was a sense of worthlessness as John continued: 'This limping about is so painful, I'm happier when I am sitting out of the way... where I used to be so active'. Several people talked about the impact of wound odour, either real or imagined. As Bob described, 'That was the worst part, the smell. It always seemed to be worse when anybody was here but it wasn't, it was in my mind'.

The restrictions had a significant impact on their social lives and general activities. Thus there was great awareness that these restrictions in turn had a significant *impact on others*. Primarily, the participants were anxious about their

spouses, sibling(s) or children and the inherent burden that their restrictions put on them, causing the family additional worry: 'He [spouse] has been a worried man' (Theresa). They were aware that their restricted lives brought new restrictions to others. Again the feeling of being useless to their partner was evident: 'I can't go with her now, even if I did, I wouldn't be any good' (John). Others were acutely aware of the extra workload for their spouse or child, producing additional concerns: 'She was the one who did all the work and all the worry' (Bob). For Maria, it meant agreeing to use certain equipment to please her daughter. Several noted that their lives would have been worse without all the support and work of their families. For David, the added workload for the District Nurses was a concern.

The new restrictions on their lives brought by the pressure ulcer had additional *consequences or implications*. Extended hospital stays and restrictions placed on rehabilitation were a consequence of their pressure ulcers. The unexpected event of the pressure ulcer had complicated their lives and produced other problems. As John said, 'Unfortunately, because of the heel, I've been unable to exercise that leg and I suppose that is getting to me too'.

Betty commented that fear of infection restricted her activity: 'I do not wish to circulate any germs [or] wish to get any back'. Betty also knew that healing was possible with complete bed rest and had discussed this with her consultant but 'we both know that is not very practical'. However, her discourse revealed the tension between what she wanted and what she felt she had to do in order to effect healing; she 'has got to do something about it', yet there was a fear of making her other problems worse or restricting her life further.

The nurses' visit restricted participants' lives and reduced their ability to remain involved in their social activities. Betty said: 'Although the nurses are very good and try and come at a certain time, the whole of my morning is completely disrupted until they are gone, then I have the rest of the day to myself'.

David also described social restrictions owing to the wheelchair and his perception that he was stared at: 'They look at you like you are a freak. I am human just like them but they are lucky'.

Coping with the pressure ulcer

Coping with this event and the consequences for their lives predominantly focused on *comparison*. They compared themselves with others, self and the knowledge that it could be much worse. The participants knew that they were not the only ones with pressure ulcers, 'I am not alone in that'

(Denise), and they questioned why they should have a different experience, 'there are other people worse off than me' (David). Indeed, for Maria and Denise, their nurse or carer also made comparisons, stating that their ulcers were not as large as some they had seen. Several participants also commented that, despite the pain from the wound, this was not the worst health experience they had had: 'Those are problems. The wound is nothing in comparison' (Denise). Thus they knew that their lives could be much worse, with one participant commenting, 'It would be worse if my tongue stopped working!' (Maria).

These comparisons often led participants to an *acceptance* of their situation with an air of fatalism through their discussion: 'With me, I say what will be will be' (Bob) or 'Well, that's how it is, I suppose – the pain in the heel, you put up with it' (John). Acceptance also went hand in hand with trying to play their part: 'They help me and I have got to try and help them' (Theresa) or 'I know I have to be careful' (Joan).

Talking about it did not change the situation, but positive thinking was necessary to help them through. As Betty said, 'You are very conscious of it when it is hurting and you think you have worked through an ulcerated area before, so you just try and get on with your normal life'. Several people tended to underplay the enormity of the impact of the pressure ulcer.

Discussion

The theme of endless pain was the most salient and surprising finding for us, despite its powerful presence in literature surrounding the lived experience of leg ulceration ([Walshe 1995](#), [Chase et al. 1997](#), [Krasner 1998](#)). The stories described in those studies provided undeniable and shocking revelations about the intensity of pain and the subsequent impact on, and meaning of, their lives.

Importantly, there were two elements to the pain experience: one was the magnitude of the pain and the second was that the pain stopped them moving away from the stimulus. On reflection, we believed that before the study we would have considered pain to be significant for those with ulcers over the heels or the ankle but less so over the sacrum or buttocks. This assumption was certainly not borne out in this study and the participants eloquently described their pain and its subsequent impact. Yet, as clinicians, we had to question our surprise at these findings, although it is also well recognized that there is a lack of routine use of pain assessment tools and provision of analgesia ([Dallam et al. 1995](#), [Szor & Bourguignon 1999](#)). The pain for these participants was not necessarily continuous but the cycle of

pain was endless; they did not move as they knew that movement would cause more pain. This finding was highly significant. Fear of moving was not expected and conflicts with the nurse's aim of frequent repositioning. Indeed, there is robust evidence for the need for regular repositioning in the prevention and management of pressure ulcers ([Clark 1998](#), [National Institute for Clinical Excellence 2003](#), [Defloor et al. 2005](#)). Yet this pain led the participants to describe a feeling of hopelessness and this is mirrored in other studies discussing chronic pain ([Krasner 1998](#), [Hopkins 2004a](#)). Thus, as part of the group discussion, we questioned our previously held assumptions and how these assumptions came about; we were surprised that we had not appreciated the significant pain that many experienced. This caused reflection and the acknowledgement that this new understanding would be a major influence on our own practice and assessment as well as in the educational programmes we provide.

The impact of the alternating pressure air mattress (APAM) on participants' pain was considerable and once again described in alarming terms. While it was our understanding that some patients may dislike the sensation of being on an APAM, the finding that this actually increased pain for some was disturbing. In the literature on pressure relieving equipment provision (for example [Vanderwee et al. 2005](#)), the patients' experience or comfort issues are either not discussed or only briefly alluded to.

In the UK, pressure relieving equipment is often provided through a contract with a single commercial company, which restricts the choice of equipment to the product range of that company. If, on questioning the patient, the equipment supplied is reported to cause pain or discomfort, then a different product may be needed and additional funding will be required. Although quality of care is the primary consideration, this may cause a financial dilemma for the practitioner and healthcare organization. An outcome for one participant was that the researcher could not ignore his story about discomfort, and obtained a low air loss mattress for him at additional cost to the healthcare provider. However, because of financial restrictions, this will not always be possible, leaving clinicians with an ethical dilemma. Unfortunately, improving patient comfort and experience will not lead to cost reduction or containment.

The restrictions that the pressure ulcers brought to participants' lives reflected the findings of [Langemo et al. \(2000\)](#) and again echoed themes from the leg ulcer literature ([Ebbeskog & Ekman 2001](#), [Hopkins 2004b](#)). Restricted life can be linked to the concept of biographical disruption proposed by [Bury \(1982\)](#). The participants'

stories reveal the shock of having a pressure ulcer, the pain and subsequent change its presence brings to their lives. Their narratives reveal the meaning of this pain and interpretation identifies the essence of this phenomenon. Unrelieved pain has an impact on how they see themselves (Charmaz 1983) and their interaction with their families. It produces a disliked dependence on others. Some of the participants described the comparison with their former lives but this also goes hand in hand with acceptance of their situation. This acceptance reveals that biographical disruption and crisis is not the whole story. Sanders *et al.* (2002) and Pound *et al.* (1998) found that, in the older adult, these crises are part and parcel of their life experiences and actually serve to reinforce aspects of their biographies. The participants in our study all had comorbidities, the most common being significant arthritis, which already served to restrict their lives. For this reason, age, their life experiences and health to date possibly further mediated the impact of restriction.

Participants described their worries about their families, the impact of the ulcer on the families and their sense of gratitude towards them. Based on the findings from a study on carers by Baharestani (1994), they were right to be worried: pressure ulcers do have an enormous impact on spouses. However, in comparison, one concern that was not raised in this study, but was an issue for Baharestani's North American cohort, was the anxiety about finances and paying for treatment and equipment. Other studies exploring issues for patients in relation to their partners also found this essence of a 'sense of indebtedness' towards the carer (White & Grenyer 1999).

Coping with the pressure ulcer can be linked to the theoretical concepts of coping expounded by Folkman *et al.* (1986) who explicate coping into behavioural and emotion-focused coping. Behavioural coping can be seen in the way some participants attempted to control their pain through a deliberate lack of movement even when they knew this was not good for them, but they perceived it to be the lesser of two evils. Emotion-focused coping centred on acceptance (what will be will be) or comparison (it could be worse), and these themes resonate in the literature on living with chronic wounds (Neil & Munjas 2000).

From the consistent stories, it appears that our concerns about translation and the potential for inaccurate data were not sustained. Twinn (1997) contends that, in phenomenological research, the use of translation must be seriously questioned. However, common themes across the transcripts support the methodology chosen and the integral training of the researchers to promote consistency and thus validity for the study.

Study limitations

Recruiting study participants proved surprisingly difficult. As experienced clinicians in this field, we were aware that a cohort of patients with pressure ulcers was likely to be ill or less likely to be able to give consent. However, obtaining only two patients from each centre took several months. The reasons for this were:

- The age limitation.
- Comorbidity was a major issue and clearly revealed how pressure ulcers are a consequence of other conditions.
- Some invited patients had undue anxiety about whether they would be saying the 'right thing', thereby preventing agreement to participate.
- All the researchers were clinicians working in areas where there were effective pressure ulcer prevention programmes; thus there appeared to be a reduced pool of suitable patients.

In Belgium, plastic surgery to repair pressure ulcers is often considered for this group, which also reduced the number of potential patients. Despite excluding those with spinal cord injury, we also discovered that participants had difficulty in separating their experience of a pressure ulcer from comorbidity issues; as previously mentioned, this problem was identified by Langemo *et al.* (2000) in their study with spinal cord-injured patients. However, it became apparent that, whatever the concurrent illness or the underlying cause of the pressure ulcer, the issues were the same: the experience of living with a pressure ulcer was formed in chronic or debilitating illness experience and thus the phenomena could not easily be distinguished. This is in sharp contrast to many of the QoL papers describing the experience of people with leg ulceration. This finding underscores the evidence that pressure ulcers do not occur in isolation but are a consequence of a debilitating illness.

Implications for nursing research and practice

This study was undertaken as a pilot study with the intention of testing the study methodology before planning a larger European study. Several implications for a future study were identified:

- Site of the interview. If we were to compare the experiences then there is a suggestion from the transcripts that the two participants who were still in hospital had less to say about the impact on their lives. If the aim of the study was to look at the lived experience, then it may be pertinent to exclude those still in hospital. However, the pain they described was still new and fresh in their minds. Thus, a consensus of opinion would be required.

What is already known about this topic

- Pressure ulcers are an extensive problem affecting mainly older people.
- Grade 3 and 4 pressure ulcers take a considerable time to heal and so can disrupt sufferers' lives.
- Pressure ulcers have been shown to have an impact on the lives of younger people, especially those with spinal cord injury.

What this paper adds

- Understanding about the impact of pressure ulcers on the lives of older people.
- Revelation about the pain suffered by older people with pressure ulcers and how the use of pressure relieving devices may increase their pain.
- Awareness of the coping mechanisms developed by older patients with pressure ulcers.
- Insight into the impact of pressure ulcers on patients' lives.

- The requirement to follow the original study design which included central and group analysis.
- That social network is very important and we would recommend that the next study looks at different parts of Europe, north, south and east, as social networks are likely to be different across Europe and thus patient experience elsewhere could contradict our findings.

The practitioners' knowledge and resources can limit the offer of holistic care. Thus, it is hoped that the stories that are presented in our paper will guide practitioners to interact in new ways with their patients. Ultimately, it is anticipated that future treatment guidelines will take this aspect of care into consideration.

Conclusions

A successful exploration of both the method and methodology was achieved, confirming its suitability for use in a larger study. In addition, some of the findings of the analysis were not anticipated; in particular, the issue of pain in general and the coping strategies developed by patients raise concerns for patient care. Although this was a pilot study, the findings require the attention of healthcare professionals to patient assessment and practice as they challenge assumptions and current management.

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Author contributions

AH and CD were responsible for the study conception and design and drafting of the manuscript. AH, CD, SB, TD and FW performed the data collection and data analysis. CD obtained funding. SB, TD and FW made critical revisions to the paper.

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