

Pressure ulcers: home-based nursing

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This pilot study focused on the lived experiences of seven older people receiving nursing care in their home for a pressure ulcer. This care was provided by home nurses working in Melbourne, the capital city of an Australian state, Victoria. The primary aim was to gain initial understandings of how the pressure ulcer experience may be unique to a home setting so that relevant further research of this topic could be planned. Another aim was to provide tentative knowledge for empathetic and effective nursing care of such clients. Hermeneutic phenomenology was the method applied as this helps to unfold the possible meaning of human experience.

Background

A pressure ulcer is 'any lesion caused by unrelieved pressure resulting in damage of the skin and underlying tissue' (Australian Wound Management Association, 2001, p.1). Pressure ulcers may occur in both health-care facility and home settings. Prevention and management of these chronic wounds for which some older people are prone, is a traditional focus of nursing care. Providing pressure ulcer care for people in hospitals is costly, exacerbated by high risk of infection and extended length of stay (Elliot, 2001), and in many cases, if possible it is preferable to treat the pressure ulcer in the home setting.

The prevalence of pressure ulceration in acute and sub-acute health sectors in Victoria, Australia, is reported to be 17.6% (Victorian Quality Council, 2006). Less is known about prevalence in community settings although in just one metropolitan home nursing service in Victoria, 930 clients received care of a pressure ulcer during a 12-month period (Kapp and Nunn, 2005). Having a pressure ulcer was

recorded as the primary cause of death for 31 Australians in 2008 (Australian Bureau of Statistics, 2010).

The nursing care of people with pressure ulcers across the life span and in a range of settings has been researched but seldom researched is the experience of receiving that care when living at home. A pertinent phenomenology conducted in the UK by Hopkins et al (2006) interpreted three themes for this experience: pain, restricted life and coping. Sub-themes of pain were constant presence, keeping still, equipment pain and treatment pain. The subthemes for restricted life were impact on self, impact on others and consequences. Ways of accepting the situation and comparing self with others were the two sub-themes for coping. Otherwise it is known that pressure ulcers generally can cause pain, limit physical functioning, reduce engagement with activities of daily living, plus have a negative effect on wellbeing and quality of life (Pasero and Krasner, 1995; Rintala, 1995; Maynard, 1996; Franks and Moffat, 1999; Neil and Munjas, 2000). Evidence for best practice regarding home-based care of pressure ulcers requires useful programmes of relevant research. With this care in the community increasing, further research leading to greater understanding of the experience of older people at home with pressure ulcers becomes vital for enhancing holistic care and improving client outcomes.

Methods

To discern both commonalities and uniqueness of this human experience, hermeneutic phenomenology methods as recommended by van Manen (1990) were selected. This qualitative research approach explores questions about life and experience pertinent to health issues that can be researched to usefully inform nursing practice (Benner, 1984; Annells, 1999; Koch, 1999; Krasner, 2001).

Ethics

Before commencing the research, approval was gained from the relevant institutional ethics committee. Therefore, ethical research standards set by the Australian National Health and Medical Research Council were met, which are congruent with ethics guidelines established by the Declaration of Helsinki.

Participants

Seven participants (4 men and 3 women) aged 65 years and older (mean = 73 years), and who were not cognitively impaired, were recruited ethically. Three participants were

ABSTRACT

Older people living in the community may develop pressure ulcers that require home-based nursing care. This qualitative research pilot study conducted in Australia illuminated four themes unique to this experience. Firstly distinctive aspects of pressure ulcer pain were discerned, secondly restrictions of the home environment were identified, thirdly challenges associated with multi-disciplinary care in the community were recognized, and lastly a positive experience was facilitated by home visiting nurses. This study adds new insights on a topic that can inform best practice home-based nursing care and planning of further research.

KEY WORDS

Pressure ulcers ♦ Nurses ♦ Home care ♦ Older people

married, three were single and one was widowed; therefore, four were living alone. At the time of participation, all were receiving home-based nursing care for a pressure ulcer. People who did not speak English well were excluded from participation as interpreting services were too expensive for this, a non-funded study. For a pilot qualitative study, a smallish sample size is acceptable and data saturation is not required – also, for hermeneutic phenomenology, richness of data from articulate participants is considered most important and sample size needs neither to be large nor representative (Whitehead and Annells, 2007). Rich descriptions are a fertile source for interpreting relevant themes; quality of themes indicate adequacy of sample size (Byrne, 2001).

Data collection

At-home, individual, conversational, unstructured, in-depth interviews averaging 50 minutes duration were conducted by the same researcher. Interviews began with the question, ‘Tell me what it is like having a pressure ulcer and to be living at home?’ Probes were also used such as ‘How do you feel about that?’ or ‘Can you tell me more about that?’ Probes encouraged further discussion and deeper exploration of the topic. All interviews were audio-taped and then transcribed verbatim by the researcher who conducted the interviews. The need for second interviews to clarify or extend data was considered during initial analysis of data but these were not necessary.

Data analysis

A thematic analysis process suggested by van Manen (1990) guided interpretation of data (text). Thematic analysis constructs the meaning of the lived experience through interpreting themes embodied in text (van Manen, 1990). The process required consideration of the whole text (transcripts of interviews), selective reflection on parts of the text, and a detailed approach of line-by-line review of text. This provided an initial micro- and then macro-level analysis. After setting aside the results of this analysis for a period of time, the text was returned to several times for further consideration and interpretation. This involved returning to the ‘whole’ and stepping away from the ‘parts’ that had previously been interpreted. Re-interpretation led to only minor changes of provisional themes.

Results

Four themes were found to be particularly relevant to the older person’s experience of home-based nursing care of a pressure ulcer; these themes present the most unique aspects of the experience. Some data quotes (non-identifying participant codes indicated) are offered to illuminate and illustrate these themes, and also to provide part of an audit trail regarding interpretation.

To live with discomfort

Participants spoke about the soreness and pain they experienced with their pressure ulcer. This varied in intensity,

characteristics, frequency and significance. They indicated that the ‘discomfort’ was most significant early in the wound episode:

‘That one there prickles a couple of times but it doesn’t get back to throbbing like it used to.’ (P2)

‘Well, it was – it was literally hell because when they first came out, they were sore...really hell, so ah, I wouldn’t wish it on anyone else.’ (P6)

Providing care in the home meant that opportunities to address management of discomfort were limited. One participant spoke of pain experienced in bed at night, a time when home nurses do not usually visit. This pain was considered to be unavoidable, perhaps because immediate help was not available. The same participant spoke of the discomfort experienced when sleeping in their usual bed. This too demonstrates the risk of a missed opportunity as someone’s own bed is less accessible than the bed provided to a patient in a health-care facility. Consequently, pain-managing devices and strategies may not be so easily implemented. Personal problem-solving might be necessary:

‘It’s very painful at night if you’re in bed and sliding your ankles around. If they’re padded, they don’t slide on anything. It’s the only way you can stop the irritation or the pressure. If you go to sleep, the pressure will come, the ankle will hurt, you’ll turn over to get away from it and then you’re on the other one.’ (P2)

Living at home also meant that participants were engaging in many normal activities and they spoke of discomfort that occurred in response to day-to-day contact to the ulcer site:

‘You’ve got to be constantly aware that you don’t bump it... that means opening and closing refrigerators, bathrooms, anything at all like that you can bang; you can belt the top off it.’ (P2)

Although participants tried to manage their activities at home to minimize pain, when the nurses visited the home to dress the wound, control over this was lost to some degree and the resulting experience was very unpleasant:

‘...someone sloshes it with cold saline...after it was very painful still.’ (P7)

Participants also indicated that while the pressure ulcer had caused some discomfort, this was not necessarily the greatest concern to them. They spoke of discomfort arising from other health conditions that added complexity to self-management. Living at home and in the community was found to exacerbate those other conditions:

'Ah no, not at all – not for the heel wounds. Sometimes when I had a lot of walking to do, my hip got cranky... I took pain killers for that.' (P6)

To live with differing interests

Living with a pressure ulcer at home required involvement from more than one community-based health professional and for some participants this meant health-care providers with different commitments to the care of the pressure ulcer and differing priorities for treatment. On occasion, this interest did not relate directly to the pressure ulcer:

'When I went to see the orthopedic surgeon, he didn't even ask to have a look at the feet [site of the pressure ulcer acquired during hip surgery]. Ah, he said um, you know, why have I come', and I said, "About the feet", and he said, "What about the hip?" and I said, "The hip hasn't given me any trouble at all." So that was OK. That's as far as we went.' (P3)

The multidisciplinary health professionals spoken about by these participants were not answerable to a common employing body. Therefore, the need to communicate was less and on account of being in the community, the ability to readily communicate would not occur as it might in a health-care facility. It was clear that this divergent interdisciplinary interest could cause frustration for the older person:

'When I saw the podiatrist, or when they saw me, they zeroed in on this heel...but then the physiotherapist got into the act...from then on it was a battle. They got into hots [heated discussion] about what who was doing and who was right...I wanted the heel fixed.' (P1)

To live with restrictions

Living with a pressure ulcer at home meant that adaptation may be required to accommodate physical restrictions imposed by the wound. These restrictions may change over time, as explained by one participant:

'At first trying to walk was hard because I'd spent so much time in bed.'

Later, once bed rest was no longer required:

'My joints ached. I think that's from sitting too much.'

More recently:

'Yes, I still can't walk very far um, because of the wound still being open.' (P5)

For some the ability to maintain their usual domestic role was constrained:

'I could see things around the house that needed doing...and ah, I couldn't even help with the dishes

or anything like that...I think they are [important] to most women, to keep the house clean.' (P5)

'I'm not much use around the house...it's all fallen on her [wife] now, even carrying the heavy shopping.' (P1)

Frequently mentioned was not only being unable to do things around the house but also how getting things done was such a slow process:

'I wish I could do the things I used to do and I'm so slow at doing things you know. It's a bit frustrating at times.' (P3)

For some participants, living with the pressure ulcer meant being confined to home, particularly early in the episode of home care when these physical restrictions prohibited getting out:

'Um, I can't get out. Last week was the first time I was able to get into my car.' (P1)

However, restriction was sometimes related to the constraints of receiving home care, and it was not always only the client who was inconvenienced:

'I've got to be up, in my shower and back on my bed by the time that the nurses come...If they come late, I'm hanging out waiting. If they come early, then they have to wait.' (P7)

Although some were completely home bound by the pressure ulcer experience ('you can't go anywhere.' [P2]), others frustratingly could do so only if assisted by family or friends:

'One of my nieces is coming to pick me up and take me there, and sometimes I think, "I just wish I could get in a taxi and go."' (P3)

'I've had to impose on other people to drive me to meetings. At one stage of the game...they had to carry me upstairs to the meeting room.' (P1)

To place trust and have faith in the nurse

It was apparent that all participants trusted the home nurses and had faith in their wound management skills:

'I mean, I just feel I was lucky to um, you know, be in good hands, I guess.' (P7)

Furthermore, the opportunity to receive this nursing care in the home was highly valued. For one participant, an event early in the care episode cemented his feelings about his home care:

'So anyway, they didn't do much about it except put a few bandages on at the rehab and then when I came

home, I got the attention from [nurses] and that gave me, what shall I say, ah – attention and relief.’ (P6)

The development of this trust and faith seemed strengthened by ongoing interaction between participants and the nurses. Conversation was the key, and in the ambience of the home, this built the relationship between patient and nurse:

‘... but all of them will sit and talk to you, you know, they don’t rush in and rush out...and of course we converse while they’re doing the dressing and um, then they sit and fill in their report, talk to you, you know.’ (P5)

‘She was one you could really talk to and you sort of knew you could rely on what she said.’ (P5)

Getting things moving and getting results cemented the faith:

‘But when [nurse] arrived, it was full steam ahead. She worked very hard on getting the answers about it and she produced an occupational therapist (OT), who is actually probably the only OT I’ve met who’s actually done anything practical.’ (P7)

Participants especially mentioned that interactions over time with the nurses visiting their homes, which could be over many weeks or months, gave opportunity to develop

hope for the healing of the ulcer:

‘Yes, yes. I feel they must be getting better if they’re only coming twice a week. I’m hoping they’ll come and say they’ll come once a week.’ (P3)

‘The nurse took one look at it and said, “I’ll have them healed in 12 months.”’ (P2)

Discussion

Four themes were interpreted that offer new and unique perspectives on the experience of the older person living at home receiving nursing care of a pressure ulcer: to live with discomfort, to live with differing interests, to live with restrictions and to place trust and faith in the nurse.

In this study, some similar and different elements were found to what already is known about the sensory emotional experience of pressure-related tissue damage. Similar to Langemo et al (2000), Neil and Munjas (2000), Beitz and Goldberg (2005) and Rastinehad (2006), participants in this study also used a range of descriptors to describe their experience: ‘stinging’, ‘burning’, ‘aching’ and ‘stabbing’. However, new insights are added as this experience was considered less significant than had been elsewhere reported. Hopkins et al (2006) interpreted ‘endless pain’ as the most salient finding, Langemo et al (2000) interpreted pressure ulcer pain as extreme, and Fox (2002) suggested

pain to be the most dominant factor of pressure ulcer experience. In this study, however, it was more a 'discomfort' and an experience that waned over time.

It is possible that participants in this study experienced less pain or that pain was better managed. It is also possible that discomfort was less a concern because it had reduced over time. As participants were at home trying to engage in their routines and usual activities, this may have provided some distraction that would not be possible in other care settings.

Therefore, home nursing attention to pressure ulcer pain may be more effective, and have the potential to resolve discomfort more quickly, if prioritized very early in the wounding episode. Timely assessment and recommendation of non-pharmacological interventions should be a major focus on admission to a home nursing service. As shown in this study, the person's home environment can be a stimulus for this experience. Home nurses are in a unique position as, when providing wound care, they have frequent contact with the person and can assist to adapt the home environment to avoid discomfort. It is also important that discomfort and pain are comprehensively and repeatedly explored so as to prevent likelihood of the person considering the experience as unavoidable.

It was disappointing to find that for several participants the pressure ulcer was not seen as a priority by the other care providers and yet it was clear that the presence of the ulcer was most restrictive to participants' home lives and, therefore, their convalescence. It is also disappointing that within the multi-disciplinary team, communication may be lacking. In this study it was shown for one participant in particular that treatment happened 'to' them, not 'with' them. The resulting impact in both these situations can be that priorities are concluded without engaging the person at the centre of the experience. For older people in the home environment, goal setting and participation in self-care is necessary as maintaining independence is paramount during this life stage. This theme 'living with differing interests' alerts the opportunity for home nurses to facilitate multi-disciplinary care that is congruently client focused and embedded in an enablement framework of health and wellbeing.

The theme 'to live with restrictions' reflected the impact of the pressure ulcer experience on the person's ability to be able to do the things they wanted to do, and what they usually did do. Physical restrictions were paramount, causing day-to-day activities to be very slow. This could also make participants home-bound sometimes, resulting in frustration and the need to inconvenience others to be able to get out and about.

Restrictions on mobility and activity have elsewhere been shown to have a significant impact on living at home (Chase et al, 2000; Neil and Munjas, 2000; Johnstone, 2003; Ribu and Wahl, 2004; Hopkins et al, 2006). Balancing concurrent goals of healing the ulcer and enabling participation in usual roles and activities, should be considered. Beitz and Goldberg (2005) and Langemo et al (2000) suggest that social isolation risk should be assessed among people with chronic wounds and the findings of this study further support this opinion. Home nurses are well placed to identify ways to resolve

restrictions such as identified by the participants of this study. They are also well placed to monitor the changing needs of the person and adapt strategies throughout the care episode. To do so successfully, home nurses need be informed of community services that may assist with reducing barriers to restrictions experienced at home. Additionally, knowledge of activities outside the home and ways to access them, which are acceptable to the person, will reduce the impact of the restrictions experienced.

The positive impact by skilled nurses on the experience of having a chronic wound while living at home, has been previously noted by Douglas (2001), Haram and Dagfinn (2003), Hopkins (2004), and Beitz and Goldberg (2005). That trust and faith in nurses was engendered in this setting, often in absence of attention from others, is an important finding of this pilot study. It is a privilege to provide nursing care in a person's home; therefore, nurses should from the beginning of care provision, foster a positive and trusting relationship. This study suggests that it can be the home nurse who directs the management of the pressure ulcer and, therefore, may be looked to for guidance and support. In addition, the potential to perceive home nurses as a resource for hope and optimism demonstrates the valuable role of this health-care provider in this particular context. This is not dissimilar to the findings of Hyde et al (1999) who identified that people with pressure ulcers whose nurses had facilitated effective coping strategies, were more likely to express hope for the future.

Recommendations

Below are the recommendations the authors garnered from the study:

- ♦ That home nurses are attuned to the potential negative impact of a pressure ulcer on the ability of older people to live at home in a manner acceptable to them, and intervene appropriately where necessary and possible to ameliorate this impact
- ♦ That education for home nurses include not only pressure ulcer prevention and management, but also the need for attunement to factors specific to this particular client group and care setting to maximize potential to provide care that improves the client's health and wellbeing
- ♦ That further research is conducted on: the experience of pressure ulceration for older people in other community care contexts; the perspective of home nurses providing this care; specific themes interpreted from this pilot study and production of evidence for best practice regarding these themes.

Limitations

As a pilot study using methods that lead to interpretations not necessarily generalizable to other care environments, nor necessarily reflective of every experience of the phenomenon, all results are tentative and require further research. However, results may be useful to guide assessment of experiences of the phenomenon in other contexts, nationally and internationally.

Conclusion

The findings of this pilot study suggest that the discomfort experienced by older people from their pressure ulcer was less problematic than accommodating the restrictions associated with the ulcer at home. A multi-disciplinary and negotiated approach, which includes the patient's preferences, has potential to facilitate better patient-focused outcomes. The role of the home nurse in the care of older people living at home with pressure ulcers may be remarkable – as their role affords them the opportunity to assess and intervene early, promote collaboration and focus and generate hope for healing and wellbeing.

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