FEATURE ARTICLE

Living with Chronic Pain in a Residential Aged Care Facility

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Abstract

The purpose of the overall study was to explore the lived experiences of older people with chronic unrelieved pain, who live in residential aged care facilities. This paper presents one of the main themes from the study which was conducted using a phenomenological study. This study was undertaken at three aged care facilities within the Hunter New England Area Health Service (HNEAHS).

Thirteen people aged 75 years and over, were interviewed for this study. The main outcome measures led to an understanding of what it is like for older people to live with chronic unrelieved pain in a residential aged care facility.

A key theme that emerged from this study was “Attending to life” comprising four sub-themes including “preserving oneself”, “feeling useful/useless”, “tending the body”, and “attending to spirituality”.

“Attending to life” shows how elderly people with chronic pain responded to the world of the residential aged care facility, in particular, how they immersed themselves in their “living present” whilst suffering with chronic unrelieved pain. An important feature of “attending to life” is that in order to stay actively engaged in the world, the participants busied themselves with acts of self-preservation and self-care.

The findings of this paper highlight the importance of self-identity in the nursing home setting and show how unrelieved pain mitigates this.

Key words: Older people, Nursing home, Chronic pain, Phenomenology.

INTRODUCTION

In aged care facilities worldwide the incidence of pain among the residents is very high (Herr, Bjoro, & Decker, 2006; Scherder, Oosterman, Swaab, Herr, Ooms, Ribbe, Sergeant, Pickering & Benedetti, 2005). In nursing homes in Australia (Madjar & Higgins, 1997; McLean & Higginbotham, 2002; Australian Pain Society [APS], 2005) and the United States of America (Ferrell, Ferrell & Osterweil, 1990; Ferrell, Ferrell & Rivera, 1995; Fox, Parminder & Jadad, 1999; Fries, Simon, Morris, Flodstrom & Bookstein, 2001; Parmelee, Smith & Katz, 1993; Shapiro, 1994; Sengstaken & King, 1993; Weiner, Peterson, Ladd, McConnell & Keefe, 1999) pain has been reported to be as high as 44 to 80 percent within the facilities surveyed. These studies show that the assessment and detection of pain is very poor, despite the monitoring and surveillance facilities are expected to provide.

Complications of chronic pain, such as depression, decreased socialisation, sleep disturbances and impaired mobility and cognitive function are worsened by the presence of pain and they increase health care utilisation and costs (Ferrell, 1995; Herr, Bjoro, & Decker, 2006).

The high prevalence of pain in older people, and its impact makes pain in this population a public health issue (Fox, Parminder & Jadad, 1999; Australian Pain Society, 2005). Indeed, it seems incongruous that while scientific research has uncovered many of the biochemical and neurobiological processes of pain, along with the development of sophisticated treatments for its control, many older people continue to live with unrelieved pain.

LIFE IN RESIDENTIAL CARE

In an Australian study, Nay (1993) explored the lived experience of nursing home life for 19 older residents. To begin, the participants felt they had no choice in the decision to relocate to the nursing home. Relocation heralded a sense of great loss as “everything went” including “home, possessions, friends, family, affection, pets, freedom, favoured locations and the environments, roles and lifestyles that were known and predictable” (Nay, 1993, p. 67). The move into the nursing home was an end to life previously known and cherished. Participants believed they were “just a number” (Tony, participant 2), and a “worthless burden” (Morrie, participant 10).

In another study about what it is like to live in a nursing home in Israel, Golander (1992) found that the major concerns of residents included how to achieve fast relief from discomfort in the face of continual discomfort, how to maintain a balanced relationship with staff, residents and family, how to retain a sense of independence and uniqueness in a state of dependence and collectiveness and, finally, how to make time pass in a meaningful way while acknowledging their own finitude (Golander, 1992, p. 196). Some social rituals, such as afternoon tea, were a welcome reminder of their capacity to participate in a normal flow of life.

These studies highlight the tensions that elderly people experience when relocating to a nursing home and living in this setting. A sense of great loss is experienced in relation to many significant aspects of their lives as they become institutionalised and subjected to rules, routines, and boundaries that characterise life in a nursing home. These studies also highlight the importance of self identity, social relationships, and meaningful pastimes. The idea that the nursing home is so unlike being at home is also a persistent feature of life in this setting.

METHODOLOGY

Merleau-Ponty’s (1945/1962) Phenomenology of Perception was used to guide explorations in the study and to address “What is it like for older people to live with chronic pain in a nursing home?” The reason for using phenomenology...
in this study was based on the desire to truly know and understand the nature of living with pain and to explore the impact pain has on the lives of older people. Phenomenology is a methodology that uncovers thoughts, understandings, feelings, and behaviours from the perspective of the person. It does not offer causal explanations or theories. Rather, it provides an account of the experience of being in the world of everyday life, of living in and through the world. Phenomenology values the perspective of the person. In the context of this study it values the perspective of the older person in pain and the meanings he or she attributes to the experience of pain.

The research method for this study centred on data from observations, field notes and in depth interviews with older people from three residential facilities in Hunter New England Health and was conducted over a period of nine months. Once approval for the study was obtained from the Hunter Area Research Ethics Committee and the Directors of the participating residential aged care facilities, information sessions about the purpose of the study were provided to nursing staff. Nursing Unit Managers approached eligible participants to determine their interest in the study. Included in the study were older people who had a history of chronic pain of at least three months’ duration and who had lived in the aged care facility for three months or more. All participants needed to be able to speak English, express their ideas in English, engage in a conversation and respond to questions.

Thirteen people, aged between 78 and 97 years, agreed to participate in a recorded interview about their experience of pain. Interviews were conducted in the privacy of their own room or other private area or space in the facility. While all participants had multiple sources of unrelied pain, some were ambulant and some were confined to bed or a wheelchair. During the first interview, the participants were asked questions that provided background data about their age, where they were born, what they did before they retired, whether they were married, whether they had family who visited, where they lived prior to entering the home, how long they had lived in the nursing home, and what their health was like when they were younger. This information helped to provide some background understanding to the identity of the person, who they were, their histories before they entered the aged care facility. In order to gain an understanding of what it was like to live with pain, participants were asked how it impacted on their lives and how they felt about their pain. They were also asked how they managed from day to day, and what it was like to live with pain in the nursing home.

Questioning followed a conversational style and followed the participant’s lead keeping in mind that the main purpose of the interview was to appreciate the lived experience of pain. A flexible approach was used whilst seeking enough detail and depth of conversation to allow for individual stories, variation and data that would allow for comparisons (May, 1989).

DATA ANALYSIS

Data analysis involved integrated processes of phenomenological reduction including turning to the phenomenon of concern, investigating the experience as it is lived, reflecting on the essential themes, writing and rewriting whilst balancing the research context by considering the parts and whole and maintaining an orientation to the phenomenon of concern (van Manen, 1990, 30–31).

After reading and re-reading the interview transcripts, a thematic description of each of the interviews was compiled. By reflecting upon the themes and comparing similarities and differences between the participants’ accounts common themes emerged. Taking each transcript, the phenomenological text was developed using Merleau-Ponty’s explication of “the body”. The text was “worked” (van Manen, 1990) with many months of writing and re-writing, the themes and sub themes being adjusted, corrected, modified, changed, and linked as they emerged more clearly out of the data.

TRUSTWORTHINESS

Throughout the research process rigour was maintained during each phase of the study. To this end, issues of trustworthiness outlined by Morse and Field (1995) were addressed. In addressing this concern the researcher endeavoured to accurately report the perspectives of the participants as clearly as possible. Conversations with the participants occurred over several weeks and sometimes months and they often meandered through reminiscences of participants’ pasts. The examples presented therefore, are edited versions of very long conversations, carefully pieced together in order to make a coherent whole for the reader of the participants’ stories. The researcher did not return to the participants with findings or interpretations since this seemed unnecessary and inappropriate given that participants often succumbed to episodes of ill health, which in some cases resulted in death. Findings were verified by ensuring the time spent in the field both interviewing and observing was sufficient to understand the lived experiences of the participants. In addition, where there were queries about what the older person was saying the researcher returned to their ideas as many times as needed in order to gain clarity of understanding. As Brink (1991) notes, it is the longitudinal nature of qualitative research and the use of multiple methods that enhance its validity and reliability.

FINDINGS

The main organising theme in this paper is described as “Attending to life”. As an aspect of existential pain “Attending to life” captures how a group of older people with chronic pain responded to the world of the aged care facility in which they lived. It shows how they embodied their pain and disability and how they immersed themselves in their lived present.

To attend to something in the world means that we direct or apply ourselves to it, and that we take care of it (Hoad, 1986). In illness, as well as the physical frailty that comes with advanced old age, the body becomes foregrounded and it is this unwanted consciousness of the body that alters how a person operates in relation to the world. “Attending to life” shows how the older people in this study responded to the world of the aged care facility. It illustrates how they embodied their pain and disability and how they immersed themselves in their living present.

“Preserving oneself” addresses the ways in which the participants cared for themselves in order to maintain their independence and their individuality and sense of self. “Feeling useful/useless” describes the paradox of living with constant pain and disability at the same time as preserving and safeguarding individuality. It captures how the participants wrestled with feelings of usefulness and uselessness as they commanded and/or desired their bodies to be “able” and to do things. “Tending the body” shows how the participants cared for and nurtured themselves so as to be able to participate in the life available to them. The last theme, “attending to spiritual life” depicts the ways in which some of the participants tended to their spiritual and religious needs while living with chronic pain.
Preserving oneself

To preserve is to “keep safe or free from harm or decay, to keep alive, or to maintain in its existing state” (Hughes, Michell & Ramson, 1992). Whatever the study participants did, they were committed to maintaining their independence in the face of debilitating and unrelieved pain and they were committed to retaining their identity and individuality. Their identity and individuality was unmistakable in the ways they cared for themselves and in the ways they attended to their lives.

In order to appreciate the need for the older residents to preserve their identity and individuality, one needs to realise how it contrasted with their previous life. Jennifer, for example, described her feelings, which she illustrated poignantly against the backdrop of her previous life. She said,

I am stranded. I led a very busy life out in the world. I was a telephone lifeline counsellor, I did meals on wheels and I was a Pink Lady [volunteer] for 14 years, so I was active. And I was President of the Research Foundation. That’s what I miss.

Mervin was a World War II veteran. He worked on jet fighters in war zones and many dangerous situations. He loved orchestral music, movies, and reading as the following shows.

I’ll tell you what I used to enjoy. To sit in the Town Hall and have a big orchestra and feel it, feel it. Not only see it, hear it, but FEEL it. Feel it go right to the heart of your body. I mean there is nothing better than a good movie and nobody wants to talk about the latest book. It worries me that I might be going mental I’ve seen the vegetation here. They are vegetables, the people here. Singing childish old songs.

As can be seen from this exemplar, the orchestra, the movies and reading broadened and enriched Mervin’s life. Without access to the things that mattered to him, that connected him to the world in a meaningful and passionate way, Mervin saw himself in danger of losing the very things that made him who he was, of losing himself.

Feeling useful/useless

Being able to use one’s body provides the opportunity to participate in life. Being able to do things for themselves, like the simple act of standing or sitting unaided, was an act of self-preservation and self-expression. It allowed participants the opportunity to engage the possibilities for expressing their uniqueness. It was also their way of attending to their life. Not being able to help themselves, not being able to do the things they wanted to do, to do the things they wanted to do, to express themselves and to feel human. The following field note illustrates Deslie’s pattern of self-care:

It’s 5.30pm. The evening meal is over. Deslie excuses herself from the table and shuffle, painfully and slowly, back to her room. She warms the wheat bags in the microwave oven for 3 minutes. She fluffs her pillows and orders them in her own particular way for comfort. She struggles unassisted onto the bed and carefully places wheat bags over the back of her neck and both knees. She throws a rug over her lower legs and turns on the television to her favourite evening program. At 8 o’clock she struggles off the bed, undresses and gets into her nightdress. Once under the bedclothes she continues to watch television until 10.30pm. She says, “At nighttime, I try to work to a pattern. I would say it is a pattern through the day too lovely. I think it is just the way I have been with me health”.

For Deslie, working to a pattern and keeping her painful joints warm coaxed her into a state of restfulness on most nights. Her rituals were uniquely orchestrated events that prepared her for calm that held the promise of a good night’s sleep. The latter helped her to cope with the pain the following day.

Pain and disability called upon the participants to carefully contemplate every movement; to anticipate the consequences of every activity and every event. For them habitual actions and behaviours that often characterise the uniqueness of individuals were reduced to movements aimed at keeping the pain at bay, keeping the body moving, and coping with pain.

Attending to spiritual life

“Attending to spiritual life” depicts the need to understand deeper meanings of life. In “attending to spiritual life” prayer was important for contemplating the meaning of life with pain, the future; it was how the participants expressed their fears.
The things that troubled Deslie could be discussed in prayer sensibly and without fear or favour. By “speaking to God” she was able to reconcile her feelings, doubts, fears, and concerns. The power of reconciliation and the belief that someone was helping provided her with comfort, hope, reassurance, and the strength to go on as the following shows.

I am a great believer in prayer and I talk to the Lord almighty. I tell Him all of my troubles and I ask Him for help [tears well in her eyes] and He has been very, very lovely to me [tears appear in her eyes]. God’s been good to me. I know He has helped me a lot along the way. It gives me a lot of hope and inspires me too. It is the only thing that keeps me going a bit. I thank Him and ask Him to help me with me [sic] pain.

**DISCUSSION**

To be able to use the body is to be able to do things for oneself, revealing our uniqueness and identity. For the participants of the study, being able to do things for themselves was in itself an act of self-preservation and self-expression. However, not being able to do things, in contrast to their limited ableness, left the participants with conflicting “feelings of usefulness and uselessness”. It was the body’s usefulness in contrast to the body’s uselessness, rather than the pain itself, that was paramount. Pain however, reduced their physical body to a “useless lump of flesh” (Mervin). Motivated by the need to express themselves, they often ignored pain in order to be “able”. The inability to do things for themselves emphasised their uselessness and their perceived worth to society and indeed themselves. Participants needed to be “able” in order to maintain the possibility of having a life, freedom, and independence.

In order to do things for themselves, in order to preserve their unique identity, the participants “tended to the body”. In taking care of themselves with routines and ritualised patterns of bodily care and attention, they coped with pain and attempted to safeguard their ways of expressing themselves. Their routines and rituals provided constancy to life; that they buried themselves in the tasks of self-care and attention meant they could also forget about their pain. Prayer, for some, helped them to understand the meaning of pain as a test of their faith in God.

**CONCLUSION**

Whilst the experience of pain is a universal human phenomenon, it is also uniquely personal. Its presence heralds suffering and profoundly impacts the life of the person in pain. Understanding what it is like for people to live with pain, and understanding the meanings people attribute to pain, are essential to being able to appreciate the nature of the experience. By understanding the lived experience of pain, professional health carers are better positioned to provide appropriate care, understanding and comfort to older people who live in nursing homes. Being cognisant of and sympathetic to the older person’s situation with pain, health professionals can find ways to act therapeutically, to provide effective counselling, support and advocacy (Benner & Wrubel, 1989; von Dietze & Orb, 2000).

That each of the participants in the study suffered multiple sources of chronic unrelieved pain impacted upon the quality of their everyday life and how they managed from day to day. The findings of this study emphasise the importance of allowing older people with chronic pain who live in residential aged care facilities the opportunity to “be” themselves and to be assisted to do as much as possible for themselves. However, in order for them to be able to reach their full potential for being themselves and having a life, their pain needs to be relieved.

The international research literature is unequivocal that pain in residential care often goes undetected and under treated. As yet, there has been little research aimed at explicating best practice in the management of pain in older people and yet there is research covering more than 30 years and documented understanding about pain and pain mechanisms. Instead there are situations that have the potential for people to be overlooked because of their age and their circumstances in residential care. Whilst there are many barriers to relieving pain (Seers, 2006), health professionals need to pay more attention to detecting pain in older people and ensuring that it is managed appropriately.

**References**


