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# Living with persistent pain: experiences of older people receiving home care

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**Living with persistent pain: experiences of older people receiving home care**

**Background.** Although the topic of pain among older people has received increasing interest, little is still known about how pain is experienced or handled by those who no longer manage independently but depend on professionals for help with daily living. Developing pain management for older people requires such knowledge.

**Aim.** To explore sense of self, sense of pain, daily living with pain, sense of others and ways of handling pain in older people with persistent pain.

**Methods.** Interviews with 90 older people receiving home care from nursing auxiliaries in their own homes or in sheltered accommodation were collected from January to June 2000. A typology of older people in persistent pain was developed. Activities for handling pain were examined using content analysis.

**Findings.** Respondents' experiences of themselves and their pain varied. Two groups of older people, considered as 'competent and proud' and 'confident and serene', expressed satisfaction in spite of pain, while the groups 'misunderstood and disappointed' and 'resigned and sad' expressed dissatisfaction. The most common strategies used were medication, rest, mobility, distracting activities and talking about pain. Respondents chose strategies by balancing the advantages of the activities against the disadvantages these brought for their daily living.

**Conclusion.** This study indicates that characteristics of the older people, such as their way of experiencing themselves, how pain affects their daily life and how they perceive effects and side-effects of pain management are areas that need to be identified when staff assess pain and plan pain management. Caring for older people in pain could be improved by listening to and believing their complaints, evaluating effects and side-effects from medications and nonpharmacological pain management and by emphasising the importance of common everyday activities such as mobility and distraction to relieve pain.

**Keywords:** typology, content analysis, pain, pain management, older people, nursing

## Background

Although prevalence and correlation statistics bring understanding about the magnitude of the problem of pain among older people, such studies tell us little about how pain is experienced by them, how it affects their daily lives or how they handle the pain. In particular this concerns those with great impairments. Research has shown that pain is a common problem among older people in general and in particular among those who live in some kind of sheltered accommodation (Ferrell *et al.* 1990, Parmelee *et al.* 1993, Sengstaken & King 1993, Blomqvist & Hallberg 1999, Won *et al.* 1999, Blomqvist & Hallberg 2001). The trend in Sweden, however, is that older people to a greater extent remain living in their own homes and that sheltered accommodation is offered to those with the most serious impairments or greatest psychosocial needs (Swedish Institute 1999). Both in ordinary and in sheltered accommodation, publicly provided help with household chores or personal care is offered.

Studies of pain prevalence among those who live in their own homes show rates between 60% and 85%. Grimby *et al.* (1999), in a study of 1558 people over 75 years, reported musculoskeletal pain in 62%, Brochet *et al.* (1998) ( $n = 741$  over 65 years) reported some pain during the last year in 71.5% and persistent pain in 33%, and Mobily *et al.* (1994) found that 85% ( $n = 3097$ , >65 years) had experienced some pain during the last year. Above all, pain seems to be located in the extremities, joints and back. Results from correlation studies have shown that pain may affect everyday activities such as mobility and sleep (Ferrell *et al.* 1990, Mobily *et al.* 1994, Ross & Crook 1998) and ability to participate in hobbies and recreation (Ferrell *et al.* 1990, Mobily *et al.* 1994). Mood, feelings of having control over life and life satisfaction are other parts of life that may be affected by the pain (Beekman *et al.* 1995, Turk *et al.* 1996, Ross & Crook 1998).

A few studies have focused on the people's own beliefs and perceptions of living with pain. Yates *et al.* (1995) used focus-group interviews with people ( $n = 42$ , 35 women and 7 men, >65 years) in long-term residential care and found a resignation to pain. They perceived methods for managing pain to be of limited value and avoided complaining of pain due to a reluctance to bother others or feelings that staff were busy or unwilling to relieve pain. Carson & Mitchell (1998) studied how people experienced persistent pain ( $n = 17$ , 10 women and 7 men, 55–93 years). Respondents described alternating between expressing pain and showing an unaffected appearance in spite of pain. They fluctuated between withdrawing and engaging in activities and described

how they decided to carry on some activities and give up others.

In nursing literature, older people in pain are often described as viewing pain as an inevitable effect of the normal ageing process (Herr & Mobily 1991, Yates *et al.* 1995). In a recent study ( $n = 50$ , >60 years) of older people living in their own homes, Ross *et al.* (2001) found that some respondents viewed it as a symptom of illness which should therefore not be accepted. The authors hypothesised that older people's decisions about pain management might differ depending on how they view their pain.

Previous research indicates that older people who live independently handle the pain mainly by self-administered strategies such as distraction and rest (Davis & Atwood 1996, Hopman-Rock *et al.* 1998, Lansbury 2000, Ross *et al.* 2001), while medication may be avoided due to its disadvantages (Lansbury 2000, Ross *et al.* 2001). Whether this finding also applies to older people who need assistance from staff in daily living is uncertain. It seems that studies about how older people in persistent pain experience their situation and what they do to handle pain are scarce. Such knowledge is needed as a basis for developing pain management to older people.

## The study

### Aim

To investigate how older people in persistent pain and needing assistance from staff perceived themselves, the pain and significant others, and what they did to handle their pain.

### Methods

#### *Sample and procedure*

The study was carried out in a municipality in southern Sweden with about 60 000 inhabitants of whom 10% were over 75 years of age. For this study a sample of people over 75 years in persistent pain was recruited with the intention of representing those living in ordinary homes and special accommodation in inner city, suburban and rural parts of the municipality. Inclusion criteria were being 75 years and over, being in persistent pain (defined as pain more or less daily for more than 3 months), receiving help from staff, and being able to participate in an interview. Staff in the areas identified which people could be interviewed ( $n = 313$ ), and gave them a letter in which they were asked if they were in persistent pain and were willing to participate in an interview. After one reminder 89 people (28%) had replied that they were not in pain, 94 (30%) were in pain and willing to participate, 39 (12%) were in pain but did not consent and 91 (29%) did not

**Table 1** Characteristics of respondents ( $n = 90$ )

	<i>n</i>	%
Sex		
Women	66	73
Men	24	27
Living area		
Inner city/suburban	55	61
Urban	35	39
Dwelling		
Own home	64	71
Sheltered accommodation	26	29
Help with IADL		
Daily	61	68
Less often than daily	29	32
Help with PADL		
Daily	27	30
Less often than daily	63	70

PADL = Personal activities of daily living; IADL = instrumental activities of daily living.

respond. Four respondents were excluded due to difficulty in talking about their daily living with pain. The mean age of the participating 90 people was 85 years (SD 6.0); 61 (68%) received daily help from staff while 29 (32%) received help less often than daily (Table 1).

In order to allow comparison between the groups, care providers collected demographic and functional status data for those who did not consent or respond. This was done using a system of code numbers and without revealing these people's identity to the researchers. Analysis (Kruskal–Wallis test) showed no significant differences concerning gender ( $P = 0.2$ ), age ( $P = 0.9$ ), living area ( $P = 0.1$ ), kind of dwelling ( $P = 0.2$ ), personal activities of daily living (PADL) ( $P = 0.2$ ) or instrumental activities of daily living (IADL) ( $P = 0.9$ ) between nonrespondents, those who did not consent and study participants.

### *Ethics*

In the introductory letter, respondents were informed about the study, that participation was voluntarily and that they were free to terminate the interview at any time. They were phoned and asked to choose a time and place for the interview. The Ethics Committee of Lund University approved the study (no. LU 544-99).

### *Data collection: interviews and assessments*

Data were collected in a personal interview that lasted 45–90 minutes and included open and structured questions. Respondents were invited to tell their story of how the pain had started and developed. In order to obtain concrete descriptions, they were asked to re-think and talk about a

particular and ordinary day with pain. They were also asked to say what activities they had performed in order to handle their pain. Open questions were followed by structured questions about activities to manage pain from the Pain Management Inventory (PMI) (Davis & Atwood 1996) and questions about their perceptions of how significant others viewed and reacted to their pain.

The PMI was designed to provide a clinical tool to identify what methods patients with arthritis use to manage pain and how helpful they perceive the methods to be (Davis & Atwood 1996). Individual items cover the areas of prescribed medication, over-the-counter medication, rest, exercise, bracing or splinting the affected part, bio-feedback, massage, hot bath/shower, heat, cold, transcutaneous electrical nerve stimulation (TENS), distraction, talking to someone who understands, relaxation, reducing stress and participation in support groups. Items are presented in the format: 'Have you during the previous week used relaxation to relieve the pain?'. Davis et Atwood found all but one item to be content valid. In their test-retest of individual items, satisfactory levels of agreement were reported. For the present study, several changes were made: the item 'using bio-feedback' was removed, 'bracing or splinting the affected part' was changed to 'used brace, splint or bandage' and the item 'drinking alcohol' was added, giving an index of 16 possible methods for managing pain. Changes were motivated by results from a proceeding pilot study to test the instruments. Interviewees' 'self-talk' while answering the structured questions were tape-recorded and treated as interview data.

All interviews were performed in respondents' own homes and in five cases a close relative or nursing auxiliary was present. Nine respondents did not want their interviews to be tape-recorded. In these cases written notes were taken, noting respondents' own words and expressions. Notes were re-read to respondents for confirmation that statements had been properly apprehended. The first author performed all but three interviews, which were performed by another Registered Nurse. Interviews were transcribed verbatim.

### *Data analysis*

The researchers' preunderstanding is an issue that has received much attention in methodological textbooks about qualitative research (Benner 1994, Dahlberg *et al.* 2001). Authors highlight the risk of researchers reading in their preconceptions when analysing the texts (Benner 1994). We had a preunderstanding of older people's experiences of living with persistent pain, mainly gained from reading scientific literature and from experiences as nurses working in care settings for physically or mentally ill older people.

The impression from interviews and a first perusal of the texts was that the stories differed and so we decided to explore these differences by constructing a typology. A typology has been described as a theoretical construction where types are used to describe some empirical tendency (Frank 1995). Weber (1949, p. 90) argues for the use of ideal types by stating: 'The ideal typical concept will help to develop our skill in imputation in research. It is not a hypothesis but offers guidance for the construction of hypotheses. It is not a description of reality but it aims to give unambiguous means of expression to such a description.' In order to construct the typology, the text was analysed in several steps.

We each independently read through a sample ( $n = 21$ ) of interviews focusing on what respondents spoke about concerning their views of themselves, their pain and significant others. Discussions resulted in a number of preliminary types. Further discussions revealed overlapping types, so it was decided to proceed with the analysis.

The sample was increased with another 25 interviews. The second reading gave the impression that interviews differed according to how respondents spoke about their experiences. After further readings and discussions we agreed that some texts expressed satisfaction and others dissatisfaction and that the texts were either intense or subdued. A four-field matrix of satisfaction–dissatisfaction and intense–subdued texts was constructed (Figure 1). All interviews were then read with the following questions in mind: 'Does this particular text express satisfaction or dissatisfaction?' and 'Is the text intense or subdued?'

A manifest content analysis (Berg 1998), that is line-by-line examination of the text, was performed for each interview. This focused on respondents' views of themselves as people in persistent pain, their descriptions of the pain, the impact pain had on their daily lives and on their views of significant others in relation to their pain. The characteristic features of each type were identified and types were labelled according to how respondents viewed themselves.

	Intense	Subdued
Satisfaction	COMPETENT AND PROUD	CONFIDENT AND SERENE
Dissatisfaction	MISUNDERSTOOD AND DISAPPOINTED	RESIGNED AND SAD

**Figure 1** A typology of older persons' experiences of having persistent pain as expressed in the texts.

As a final step, an analysis of activities used to handle pain was performed using a manifest content analysis (Berg 1998). The first author and a research assistant studied a sample of interviews and jointly decided on the coding process. All text concerning people's ways of handling pain was identified, coded and put into categories with similar content. Within each category, the meaning of the activity and its side-effects were searched for. The research assistant performed the main part of the coding. The Non-numerical Unstructured Data Indexing, Searching, and Theorizing software (NVivo) was used for the analysis. Numerical data were described using nonparametric statistics.

## Findings

Pain was above all located in the legs and back (Table 2) and the duration of the most troublesome pain was eight years (q1–q3; 3–20 years). Respondents spoke more about how the pain had started and its impact on daily life than about the pain itself. Four ways of viewing oneself as a person in persistent pain were identified: Competent and proud, Confident and serene, Misunderstood and disappointed and Resigned and sad (Figure 1).

### Competent and proud

#### *Sense of self*

People of this type ( $n = 18$ , 20%) viewed themselves as competent. They felt proud about how they managed daily life in spite of the pain, and about having a cheerful temperament and not complaining unnecessarily. The stories were characterised by statements about abilities and efforts rather than about pain and failures. They expressed unwillingness to be a bother and tried to maintain reciprocity by not demanding help from family or staff and/or by helping others who were worse off (Table 3).

**Table 2** Pain location/s ( $n = 90$ )

	Pain location		Most troublesome pain	
	<i>n</i>	%	<i>n</i>	%
Leg/s	73	84	31	36
Back	58	67	22	25
Arm/s	41	47	9	10
Chest	23	26	6	7
Stomach	21	24	2	2
Head	15	17	0	0
Other	7	8	3	3
Multiple locations/ whole body			11	13

**Table 3** Quotations from respondents demonstrating the typology**Competent and proud**

It is difficult to define, but it's clear, as I say, that it comes back if I'm not lying level, or more exactly, I move in my sleep, for I always have to make sure that the right leg, it steers the left one, so that when I'm lying I lie with the right leg over and then with the left leg over so that there's a cross up here at the thigh and it sometimes happens you move in your sleep, and then it's released in the form of pain, but that, well, it's like what it said in our spelling book, that practice makes perfect, and it's the same if you've had constant trouble with pain, you learn to accept it, but it's still there. (No. 6, man 83 years)

I wake at six and open the window and doors, no matter how cold it is, and switch off the radiator and do a few movements in the doorway, just because I'm afraid of cramp. It attacks my legs sometimes, and then massage gymnastics helps. I do that for 10 minutes. Then I close the door and switch the heat on again. I do that every morning, and twice a week I wash off my body in the evening, Tuesdays and Fridays. You have to stay in shape. (No. 28, man 92 years)

**Confident and serene**

But I was lucky, I was at the chiroprapist's. When I got there in the lift and he could see that I found it hard to walk, he helped me. Sometimes you're lucky. I sat for half an hour waiting for the lift, but then they all came. Sometimes you're lucky, thank goodness. (No. 85, woman 83 years)

My neighbour is the closest person to me, I would say. When we meet we don't talk about my pain, we don't talk about that. He's mourning for his wife, so I let him talk about his pain. I choose to stay in the border zone (No. 37, woman 95 years).

**Misunderstood and disappointed**

The home help, they're supposed to come and make breakfast. But they're late and I'm in such pain in the morning and take strong medicine, I usually do, sometimes it's difficult, but I get up and try to make a little porridge. When they come they usually make some coffee and I have breakfast. I try to cook, but I get so tired that I haven't got the strength to eat. I have trouble with my stomach, have had all my life. And I've had trouble with my back, several fractured vertebrae. It's an occupational injury, I've worked in the hospital and lifted a lot of people...When I got home I was off for just 1 month instead of two and it persisted and it never went away after that. (No. 46, woman 86 years)

I think, that bloody doctor, it's cramp for God's sake, have you no cure for it, I said to him. No....It's the same thing he said about that dizziness, without examining me or anything, just – it's a vein that's gone in the brain, a vein. As if he knew that just by looking at me. I thought, all doctors are rubbish, I've never had any benefit from any doctor, they can't do anything when I come, it's funny. I must have some unusual diseases that they can't handle, they just guess, but it doesn't matter, it's all right. (No. 25, man 99 years)

**Resigned and sad**

I've done my bit. I've had to work and toil like hell, it was fun, it was much more fun in those days at least, when I was young and had my health, then everything went well. Now it's the same every week, it's nothing special. Neither better nor worse. It's the same, it can't get better, only worse. If I had some painkillers so that I didn't have the pains, but I can't get that. I've had two different kinds, but they don't help, they're all just as bad. (No. 31, man 90 years)

I fell and the walking frame came with me. Had to call for an ambulance. They operated, I was in plaster for 6 weeks and then four more weeks. Then I'd been still for so long that I got pains in my knees and my back. The knees and the back have got worse. They have to help me out of bed and out of the wheelchair. 'You're just wearing me out.' I think I'm a nuisance, I can sit down and cry about it. In the past I helped everyone else. (No. 79, woman 95 years)

***Sense of pain***

When people described their pain they used words like pain, hurt or stiff. The cause of the pain was described as a consequence of having 'worked hard' or as an accident. The pain was viewed as a threat to their self-image as an independent person and they tried to hide the pain. They explained their unwillingness to complain in terms of 'proud' or 'vain', and hiding pain was described as an 'instinct of self-preservation'.

***Impact of pain on daily living***

These people had the lowest help need. By allowing activities to take time and adjusting them to the present state,

respondents could handle much of their daily living. As pain impaired mobility, it hindered them from doing things they liked, such as needlework, visiting friends, travelling and sleeping. Being dependent on home care staff due to pain brought a longing for an independent life: 'That's what I miss, though, you don't have the freedom. I haven't got the freedom to lie as long as I want. That's what I miss.'

***Sense of significant others***

The view of other people was mainly positive. Respondents expressed unwillingness to put a strain on others and were aware that other people could not offer them support as they

had not been told about the pain: 'When they ask, I tell them it's all right'.

### **Confident and serene**

#### *Sense of self*

People belonging to this type ( $n = 25$ , 28%) seemed satisfied in spite of the pain. Although they often needed help with both personal and instrumental activities in their daily living, they did not hesitate to ask relatives or staff for help. These people said that they felt appreciated and showed appreciation to those who helped them (Table 3).

#### *Sense of pain*

The pain was described as hurting or aching, adding expressions such as 'just a little' or 'not so bad'. Diseases, accidents or hard work were viewed as causing the pain. In spite of problems with pain, they felt it could have been worse. The positive view was reached, for instance, by comparing oneself with those who were worse off or with periods in their previous lives when pain had been more severe: 'It is almost impossible for me to find the right position in bed – I haven't the strength to lift myself a centimetre. It hurts, but not as much as before'.

#### *Impact of pain on daily living*

Help needs were high, with 9 out of 25 people receiving daily help from professionals. Pain was described as impairing mobility, which in turn hindered them from performing basic activities such as getting dressed. Sleep was also often affected. Some people described their impaired abilities as distressing, while others focused on their capacities.

#### *Sense of significant others*

People expressed a positive image of others, and felt concerned about their families as well as the staff. They expressed confidence in family and staff. Observations that staff came without always being asked made them feel cared for. They were sure that in times of need they would get the help they required. Most spoke with warmth about one person with whom they had a close relationship. Usually this was a close relative such as the husband, wife or child, but close relationships with staff were also described. The relationship could also be to 'our heavenly Father'.

### **Misunderstood and disappointed**

#### *Sense of self*

People ( $n = 18$ , 20%) felt disappointed and unfairly treated with respect to pain. They spoke about occasions when they

had been misunderstood, badly treated, received no or faulty medical therapy for the pain. They felt that older people in general were discriminated against by health care services, and such experiences brought irritation or worry about the future (Table 3).

#### *Sense of pain*

When people of this type described their pain, they used intensifiers such as 'terrible pain' or 'it is hopeless beyond description', as well as metaphors such as 'it feels like being in an ant-hill' or 'twinges and throbs'. Accidents, diseases or malpractice were considered to have caused the pain. Although people spoke about not feeling old, they called their pain 'infirmity' or 'old man's disease'.

#### *Pain impact on daily living*

Only two out of 19 people received daily help from professionals. They described how they managed most aspects of daily living in spite of feeling that they were entitled to get assistance from society. The pain made them tired and forced them to take frequent rests, and was perceived as an obstacle to visiting friends or participating in social activities. Problems with transportation and feelings of being unable to take part in the same way as previously were considered barriers.

#### *Sense of significant others*

People felt that their families or care staff did not pay enough attention to their pain problems and wished that staff would ask about their pain. They gave examples of how people among their acquaintances had not believed their complaints and gave several examples of when they had had to implore others in order to get their rights.

### **Resigned and sad**

#### *Sense of self*

People belonging to this type ( $n = 28$ , 31%) were characterised by resignation to pain and feeling sad. They expressed loneliness, worry and tiredness and spoke about their previous life with longing. Statements like 'incurable', 'there is no point' or 'when you're in pain, you're in pain' expressed resignation. Often the pain restricted them and made them feel as if they were a bother to others (Table 3).

#### *Sense of pain*

Pain was described as hurting, aching, a feeling of cold or as if a body part was 'sleeping'. Accidents, hard working as well as neurological diseases were often viewed as causing the pain. In their stories, they expressed a longing for lost abilities

and feelings that pain restricted them from living the life they desired.

#### *Pain impact on daily living*

Twelve out of 28 people received daily help from professionals. They described their daily living by statements such as 'unable to do anything', and spoke about areas such as housework, social interaction or going out for a walk. Being dependent on others to perform activities reduced the pleasure and their failures made them resigned. Often pain was described as disturbing their sleep, by waking them up in the middle of the night or early in the mornings.

#### *Sense of significant others*

People felt that others did not understand how bad the pain was. Although they tried not to bother care staff or their families, they believed they were viewed as an encumbrance. They felt that talking about pain was meaningless as other people could not comprehend: 'It's not worth talking, they don't understand anyway.'

### **Strategies for handling pain**

The analysis identified 13 activities for managing pain. When respondents chose activities they judged them as: Effective, Effective but involving side-effects, Uncertain effect but harmless. Statements about effect were lacking for three activities: waiting for the pain to go ( $n = 23$ , 26%), contacting a health care provider ( $n = 12$ , 13%), and special foods or herbal remedies ( $n = 5$ , 6%).

#### *Activities perceived as effective*

*Mobility* ( $n = 59$ , 66%). Going out for a walk, performing solitary exercise, everyday housework, physiotherapy and changing position were categorised as mobility activities. Mobility was necessary to not becoming stiff, and was particularly important in the mornings after a night of lying still.

#### *Activities perceived as effective but involving side-effects*

*Medication* ( $n = 77$ , 86%). Not only analgesics but also drug treatment of anal pain, gastric acid secretion diseases, osteoporosis, gout and Parkinson's disease, as well as antidepressives, sedatives or sleeping pills, were used to relieve pain. Side-effects were common.

*Rest* ( $n = 60$ , 67%). Rest was often perceived as a prerequisite to managing daily living. Some respondents spoke about how they often had to break off an activity to rest. Although rest brought relief, stiffness was considered a side-effect.

*Communication concerning pain* ( $n = 49$ , 54%). Talking about pain meant telling others about it or complaining. Although talking about pain could bring relief and reduce strain, a majority considered it ineffective. Fear of being perceived as a whiner or a risk of not feeling understood were considered as side-effects.

*Splint, brace or bandage* ( $n = 28$ , 31%). Support stockings, corsets, splints, neck collars and orthopaedic shoes were used to protect joints and thereby relieve pain. Respondents emphasised side-effects such as discomfort, dependency on others to put on the brace, and restricted ability to perform daily activities when it prevented them from bending down.

*Mobility devices* ( $n = 27$ , 30%). Mobility aids such as wheeled walkers or sticks were perceived as relieving as well as preventing pain. Immobility brought stiffness and pain, and the aid was considered indispensable if they were to move. A fear that the walker would be stolen or destroyed made people dependent on others to bring it indoors.

*Avoiding painful activities* ( $n = 18$ , 20%). Some respondents decided to refrain from activities they desired, such as performing household chores or eating particular foods, to prevent pain. If their desires exceeded the fear of feeling pain, they decided to do what they longed for and 'took the punishment' of having pain afterwards.

#### *Activities with uncertain effect but perceived as harmless*

*Distraction* ( $n = 61$ , 68%). Distracting activities included reading, watching television, doing needlework or cooking, meditation or praying, travelling, meeting friends and attending activities run by an occupational therapy auxiliary. If the activity was to be perceived as effective it had to be attractive or interesting. Although distraction was not always effective, it was perceived harmless.

*Heat, hot bath/shower* ( $n = 34$ , 38%). Bathing or showering, blankets, warm clothes or heating pads were heaters. Heat was mainly used when the pain was located in the musculoskeletal system or stomach, but was also considered a way to prevent chest pain due to angina.

*Massage* ( $n = 26$ , 29%). Massage was above all used as a self-care activity when respondents rubbed the hurting part of the body. Massage was used after strenuous activities or when waking up at night. Although most respondents spoke about massage as a method that helped, some pointed out that at least it was not harmful.



### *Presence of activities to handle pain*

Medication, distraction, rest and mobility were the four most commonly described activities in the whole group, while foods/herbal remedies, contacting health care staff and avoiding painful activities were seldom spoken about. The presence of activities used to handle the pain was similar in the four types.

## **Discussion**

A major finding of this study was that being old and living in persistent pain was not inevitably considered as an obstacle to experiencing one's life as satisfactory. Within the study were two types of people, the 'confident and serene' and the 'competent and proud', who expressed satisfaction and described themselves and their significant others in a positive way. This finding could be interpreted in at least two ways. First, it could be viewed as a manifestation of 'social desirability'. Previous studies of people in pain or illness who depend on staff have shown how patients strive to please them. For example, Fagerhaugh and Strauss (1977) and Strandberg (2002) described how people who were dependent on care staff put great effort into becoming 'good patients' by praising the staff, not complaining or asking for help in a proper manner. A second way to interpret findings is as an expression of true satisfaction. In this study there were people who seemed to attain satisfaction by keeping silent about pain and not complaining unnecessarily. Others felt appreciated and satisfied in spite of being dependent on family and staff, and their worries were instead directed against significant others. Studies have shown that older people may assess their health as good in spite of having pain (Grimby *et al.* 1999, Hillerås 2000). Development theories (Peck 1956, Erikson 1980) suggest that older people may reappraise which areas of life are important. Peck (1956) described the phenomenon of bodily transcendence among older people as if the body, illness or pain is perceived as less important for their existence.

Findings that people can experience satisfaction in spite of suffering from persistent pain have implications for planning nursing care. Nurses may play a vital role in understanding how individuals experience and value their daily living with persistent pain and plan interventions accordingly. Although further research is needed to understand how to act, it seems reasonable to suggest that professionals should use their competence to identify older people in pain, to confirm them in their ability to handle the pain, and to inform them about what methods of managing pain are available.

For other people, being old and living with persistent pain meant dissatisfaction. Those classified as 'misunderstood and disappointed' and 'resigned and sad' expressed emotional

distress and distrust in significant others. This finding resembles what Ruth and Öberg (1996), in a study of older people's views, called 'the bitter life'. These authors state that 'life for these suffering ones did not turn the way they wished, often because of illness, both physical and mental...the world at large is seen as hard, unfair or even mean, and personal suffering is caused by forces out of control' (p. 173). In our study, not only the pain itself but also reactions from family or staff contributed to dissatisfaction when participants felt that significant others refused to listen to or did not believe their complaints. Feelings that significant others viewed them as a bother brought still more suffering. Findings from studies about satisfaction/dissatisfaction with care (Lövgren *et al.* 1996, Sherwood *et al.* 2000) show great similarity to the results of the present study. Lövgren described how patients' desires to talk about problems were not met and how this brought suffering. Sherwood *et al.* in a large study about satisfaction with pain management, reported that patients viewed affirmation from staff as satisfactory, while being disregarded brought dissatisfaction. Authors in the field of 'suffering from care' seem to agree that sufferers need confirmation, and should be allowed to show anger and be freed from demands to be patient or gentle (Sundin *et al.* 2000, Norberg & Zingmark 2002). The findings of our study imply that a multidimensional treatment of pain could be achieved by identifying and treating both pain and depression and by acknowledging older people's experiences of pain as true.

The consequences the pain had for respondents' daily living seemed to be a greater problem for them than the pain itself. All spoke about pain as restricting their lives, although what parts of life were restricted differed. That the consequences pain had for daily life were considered a greater problem than the pain itself was reflected in respondents' reporting how they handled the pain. Rest was often described as a prerequisite for managing daily living, and mobility was considered a necessity to reduce stiffness and thereby relieve pain. Respondents decided whether to use a brace or mobility device by balancing its pain-relieving effects against its disadvantages for their ability to perform daily activities or live an independent life. Peolsson (2001) reports how people (21–56 years) with chronic pain described that everyday duties became 'projects' and that their pain experience existed in a context of everyday activities. Our study implies that characteristics of how pain restricts the person's daily life and how these restrictions are appraised and handled are areas that must be included in nurses' assessments.

Our study, which included very old people depending on care staff, showed that respondents handled their pain mainly by self-care activities. Their ways of handling it, by medication, distraction, rest and mobility, showed great similarities

to how younger and less dependent older people handle persistent pain (Davis & Atwood 1996, Hopman-Rock *et al.* 1998, Lansbury 2000, Ross *et al.* 2001). Previous research indicates that people choose how to handle pain by noting the desirable and undesirable outcomes of different activities (Lansbury 2000, Ross *et al.* 2001). In particular this has been described in relation to medications and exercise. However, undesirable outcomes were attributed to other activities such as talking about pain, resting, using a brace, handling mobility devices and avoiding painful activities. As with medication, it seems important to consider what disadvantages different activities might have, to inform people about them and do whatever is possible to remove barriers.

### Validity

In qualitative research procedures to assure trustworthiness are recommended (Guba 1981). To reduce the risk of subjectivity, we performed the analysis independently and the second author did not enter the study until the analysis phase. To make the research process visible to the reader, quotations from study participants have been given. Benner (1994) highlights a need for researchers to challenge their own preunderstandings and suggests that the validity of the analysis could be questioned if the researcher does not see something unexpected. One of the main findings of our study, that about half of respondents did not consider pain to be a great problem, was unexpected and this may strengthen its trustworthiness.

### Limitations

The questions of sample size and dropouts and what significance these could have for the transferability of the findings should be considered. The sample size was large. As the area of interest was fairly unknown, the study was designed with the aim of performing a quantification of the inductively developed categories and relating these to ways of handling the pain. Although the combination of qualitative and quantitative data is sometimes questioned, Sandelowski (2000) described that mixed-method could be used to clarify, explain or more fully elaborate the results of analysis. Although external dropout was large, an analysis of external dropouts showed no difference concerning age, gender, living conditions or functional status, which strengthens transferability.

### Conclusion and clinical implications

Being old and in persistent pain is a highly subjective experience. The way these people view themselves, their

pain and significant others differs, and so staff need to understand how individuals experience and appraise their situation. The findings of this study could serve as a guide for such identification and constitute a basis for individually planned interventions to manage pain. Although pain cannot always be cured, it can always be relieved. To relieve pain, staff need to acknowledge people's experiences, listen to and believe their complaints about pain, emphasise the importance of ordinary everyday activities for handling pain and acknowledge side-effects from pain management activities.

Although the study highlighted the situation for older people, those with the greatest cognitive and/or communicative impairments were not included. To understand their experiences of pain and pain management requires another kind of approach. One way could be to plan and implement care built on the same principles as those preferred by less impaired older people, and to evaluate the effects of interventions by a systematic observation of behaviours.

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