

- ation: differences between geriatric and intensive-care patients. *J Hosp Infect* 1997; 36: 209–22.
22. Blanc DS, Pittet D, Ruef C *et al.* Epidemiology of methicillin-resistant *Staphylococcus aureus*: results of a nation-wide survey in Switzerland. *Swiss Med Weekly* 2002; 132: 223–9.
23. Harbarth S, Pittet D. Control of nosocomial methicillin-resistant *Staphylococcus aureus*: where shall we send our hospital director next time? *Infect Control Hosp Epidemiol* 2003; 24: 314–6.
24. Giret P, Roblot F, Poupet JY *et al.* Study of methicillin-resistant *Staphylococcus aureus* colonization among intermediate-care facility patients. *Rev Med Interne* 2001; 22: 715–22.
25. Morrison L, Stolarek I. Does MRSA affect patient outcomes in the elderly? A retrospective pilot study. *J Hosp Infect* 2000; 45: 169–71.
26. Westerman M, Bennett RG. Colonization of skilled-care facility residents with antimicrobial-resistant pathogens. *J Am Geriatr Soc* 2001; 49: 1735–7.
27. Nicolaes L, Buntinx F, Banuro F, Lesaffre E, Heyman J. Consequences of MRSA carriage in nursing home residents. *Epidemiol Infect* 1999; 122: 235–9.
28. Jaqua-Stewart MJ, Tjaden J, Humphreys DW *et al.* Reduction in methicillin-resistant *Staphylococcus aureus* infection rate in a nursing home by aggressive containment strategies. *S D J Med* 1999; 52: 241–7.
29. Minary-Dohen P, Bailly P, Bertrand X, Talon D. Methicillin-resistant *Staphylococcus aureus* (MRSA) in rehabilitation and chronic-care-facilities: what is the best strategy? *BMC Geriatr* 2003; 3: 5.
30. Francois P, Renzi G, Pittet D *et al.* A novel multiplex real-time PCR assay for rapid typing of major staphylococcal cassette chromosome mec elements. *J Clin Microbiol* 2004; 42: 3309–12.

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Chronic pain as perceived by older people: a qualitative study

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Abstract

Background: the practical issues confronting older people who suffer chronic pain may not be tackled in a pain clinic setting and little is known of their strategies for coping. They seem to have little or no information on how to improve the quality of their lives or on resources available to them.

Aim: the aim of this study was to ascertain from older people the practical, physical and psychosocial limitations they faced because of chronic pain, and the strategies they used to deal with them.

Method: a qualitative approach to generating data was chosen using a Grounded Theory approach and unstructured interviews. Sixty-three people ranging from 60 to 87 years of age participated in the study. Audio-tapes were transcribed verbatim. The material was coded and collapsed into themes.

Results: two main themes emerged: (i) the desire for independence and control; and (ii) adaptation to a life with chronic pain. The valuing of independence is in line with previous findings. With only three exceptions none of the participants were certain how or where to get help with practical issues and so they lived in fear of loss of their independence. Several sub-categories formed the theme of adaptation. These were acceptance and non-acceptance, pacing oneself, helping other people, the use of prayer and 'looking good and feeling good'. When independence and control is effective, older people may adapt better to chronic pain.

Conclusion: understanding chronic pain sufferers from their own perspective may have important clinical implications. The interview data informed the development of a booklet designed to meet the needs of older patients with chronic pain.

Keywords: *older people, chronic pain, independence, adaptation, qualitative research, elderly*

Background

One-third of older people suffer chronic pain [1] and many suffer chronic pain severe enough to interfere with their normal functioning, most commonly from arthritis and the neuralgias [2, 3]. There is evidence that many older people do not receive adequate pain management [2, 4] and that the practical issues confronting them may not be tackled in a pain clinic setting. Little is known of older people's strategies for coping with chronic pain [5]. Because pain is a subjective experience, obtaining relief may not be planned with certainty and it is known that it can severely undermine quality of life, especially in older people where the link between illness and depression may be stronger [6]. Though pain that interferes with life is not a normal part of ageing [2], older people themselves may regard it in this way. They may have little or no information on how to improve the quality of their lives, or on resources available to them. They may lack the social support of close family [7] and suffer disproportionately from major stresses such as bereavement, loss of home or job, and failing health [8]. While there is a worldwide literature on chronic pain and its effects generally, the issue of chronic pain and older people is less well published. Little has stemmed from the UK and certainly few studies have examined the social impact of chronic pain, though Roy [9] has done so in a Canadian context. For an extended review of the literature please see Appendix 1 in the supplementary data on the journal website (www.ageing.oxfordjournals.org).

The overall aim of this study was to ascertain from older people the practical, physical and psychosocial limitations they faced because of chronic pain, and the strategies they used to deal with them.

Method

Data collection

A qualitative approach to generating data was chosen, using a Grounded Theory approach and unstructured interviews [10]. This approach was employed in the present study because qualitative methods focus on people's everyday life, experience and perceptions [11].

Sample size

Sixty-three people, 42 female and 21 male, were interviewed by the first author for approximately one hour, in their own home setting. Twenty-eight carers/spouses also joined in at the wishes of the respondents. The interviews were audio-taped. The sample size in Grounded Theory is not determined before the research starts but goes on to 'saturation'. Sampling continues until completeness [12] and until the

researcher is satisfied that no new ideas are emerging. In the present study, starting with a small sample, the concepts of importance were followed up until no new ideas were generated. Saturation was reached at $n=60$. The final three interviews were conducted because they had been scheduled.

Data analysis

Initial questions about the effect of pain provided ideas which guided further questioning, and the interviews became progressively more focused on particular issues. Following a Grounded Theory approach to data collection [13, 14], emerging theoretical ideas and concepts were thus rooted directly in the data. Each section of data was compared with incoming data. Data collection and analysis interacted, continuing until saturation was reached and no new ideas emerged.

The audio-tapes were transcribed verbatim following each interview and checked for accuracy. The material was read through several times and then coded by the lead researcher and by an independent expert in qualitative research. The codes were further collapsed into themes, allowing construction of an exploratory theoretical framework. A similar approach had been used previously when studying back pain patients' experiences [15, 16].

For further information about the method, analysis, validity and reliability, the use of an aide mémoire and key changes that occurred as the interviews progressed, please see Appendix 2 in the supplementary data on the journal website.

Ethical issues

The study was subject to ethical review and approval through the NHS Local Research Ethics Committee. Participation was voluntary and based on informed consent, with confidentiality and anonymity assured. For further information on participation and additional ethical issues, please see Appendix 3 in the supplementary data on the journal website.

Results

Two main themes emerged, concerned with: (i) the desire for independence and control; and (ii) adaptation to a life with chronic pain.

The sub-categories for the first theme included the use of aids and adaptations to the home and garden. Several sub-categories formed the second theme. These were acceptance and non-acceptance, pacing oneself, helping other people, the use of prayer and 'looking good and feeling good'.

The themes are highlighted by direct quotations from participants (all names given are pseudonyms).

Independence and control

The desire for independence featured strongly: 'I've always been an independent person, and still like to be' though alongside some acceptance of the loss of mobility and agility. There was a strong reliance on technical help. All participants had made alterations or adaptations to their home (and some in their garden) to accommodate their loss of mobility. Many had worked out ways to distract themselves from pain.

Mr and Mrs R had moved to a bungalow because Mrs R could no longer manage the stairs and the garden in their former house. She described him as her 'main aid'. He had built waist-high troughs in the new garden so she could continue her favourite pastime.

Peggy, aged 87, lived alone. She was unable to walk. 'I have invested in an electric buggy, and it is a godsend... but choosing a supermarket where you can park the buggy is important'. Another participant commented '...once a week, I have a scooter out. It's called shop-mobility... I book a scooter and it's ready for me, and I have it out for about 3 hours, and that is wonderful because I am mobile, I'm on my own, I'm independent...'

A plethora of practical aids were used, whether procured via Social Services or from local care shops. By far the most common was the walking stick—not only used for aiding mobility. One lady (aged 87) said: 'A stick—the most useful thing I've got... If you're in the supermarket and you want something which is on a higher shelf and it's un-gettable, then you put your stick with the crook upwards and pull the thing off the shelf... it might fall on the floor but you hope not... You get experienced, you see...'

Adapting to a life with pain

Part of acceptance was learning to live with what could be done. 'I just accept the pain and get on with life'. Marjorie was in her 60s and had led a very active life, but had to give up her work because of the pain '...it's no good you know, fussing over what you can't do... so you learn to live with what you can't do and cope with what you can... otherwise I think you make a rod for your own back'. She was saving for a three-wheeled scooter so that she could get about more.

Non-acceptance of pain, on the other hand, often presented a challenge in dealing with the system—fighting the idea of having pain and trying every way possible way to obtain relief: 'pressing the system and try everything you can... it gets to the stage where you're not going to give in'.

Many respondents talked about 'pacing'. 'One thing I've learnt is to pace myself, always think about the next day—because that is when the suffering is going to be, very often' (Ann, 74). Paul, 60, had given up work because of pain. He said '...we'll just be walking around and I turn and say "that's it, I'm not going any further", and we just sit down and have a cup of tea'. Elaine, in her 60s, would sometimes go with her grandchildren to the cinema: 'I usually take a flask of tea or coffee... I've anticipated that I'm going anyway, so I get myself into a pain control mode, so if I know I'm gonna be in the cinema two hours and it starts at 7.30 p.m., I will have made sure I've had a tablet at 4.30 and 6.30.'

Most respondents had found ways of helping other people. Many talked about others being worse off than themselves, while others simply regarded helping as part of life. Some were modest about the help they provided, while others were more specific. Phoebe, aged 82, said she liked to help people in the church 'poor old things you know'. She invited them to her home for coffee and gave them little presents. Mary, a former health professional who lived alone, suffered chronic pain as a result of a traffic accident. 'Helping others makes you feel better, if there is somebody else you can support.' Andy, 83, had been a professional entertainer all his life, and still liked to perform for charity. Daisy, 77, was a retired nurse who now volunteered in an arthritis clinic said 'it gets you out... it adds to the quality of (your) life'. Like other retired health professionals, she saw a good way both to benefit a cause and to meet other people.

Several participants involved themselves in committee work, either to do with their sheltered accommodation or with volunteer agencies. A few played host to students from abroad. Where this occurred, male participants noted how chronic pain had changed their role from 'family provider' to 'provider of family'. Dan, a former steel constructor, had had three hip operations and suffered from neuropathic pain. He saw his role in life as 'looking after the students... I don't let my illness—I suppose you can call it—my pain—my feelings, I don't show them to them'.

Prayer was frequently seen as a source of comfort, not necessarily as a way toward removing the pain, or 'a way of coping but not as healing'. Some saw it as a way of relieving loneliness—'You feel as though you've got someone to talk to'. Several reported praying at home alone because churches were difficult to get to or not comfortable. Where people did go to a church, it was often to seek company. However, one participant went to church three times a week to pray, and described her faith as being the most important element in her life: 'I get a lot from the church... inner strength... I couldn't cope without it'. While some sought solace, others prayed 'in desperation'. One respondent reported that he prayed and 'swore at the same time...'

'Looking good and feeling good' emphasised that having pain was no reason to neglect appearances. As Peggy A, aged 76, put it: 'People stop me in the street and say when I've got me makeup on, "oh you do look well Mrs A"... if I don't wear makeup they say "you don't look at all well Mrs A" and I don't like that, so I'd rather put a bit of makeup on...'

Dora aged 78 lived alone. She said: 'I've got someone coming in to do my eyebrows, nails and hair... I would like my family... to think of me as someone... who tried to keep her appearance up as opposed to someone who's a very old Granny'.

The need to look 'normal' was especially strong for the women, but male respondents also reported dislike of other people seeing them in pain, perhaps reflecting fear of stigma: '...I don't show it to other people because they shun you' and 'I'm not going to let them know the amount of pain I am in or how distressed I am about it'.

Thus the analysis of the data revealed the emergence of two main themes: the ‘desire for independence and control’; and ‘adaptation to a life’ with chronic pain. A link was identified between these two themes. Therefore it could be hypothesised that when independence and control is effective, older people may adapt better to chronic pain. This seemed to be the overarching theory grounded directly in the data. By implication the converse could apply [17].

Discussion

The valuing of independence is in line with previous findings [4, 16]. Several participants had to struggle to maintain independence because of financial constraints. Their frustration highlighted the inadequacies of a social system which theoretically recognises the importance of ‘older people having independence’ but either fails to provide the financial aid for them to do so and/or takes a very long time to assess their needs. It has been previously noted that older people could help themselves more if they had the opportunity to be more assertive [4]. With only three exceptions (all retired nurses) none of the participants were certain how or where to get help with practical issues and so they lived in fear of loss of their independence.

Ridson *et al.* [18] suggest that further work should be carried out to understand adaptation to chronic pain. There were some clues from our participants. They were resourceful in seeking distraction from their pain. However, several gave the impression of having under-reported pain—a tendency amongst older people noted by Weiner [19], while Helme *et al.* [3] argue that their pain should be acknowledged, and treated whether they complain of it or not [4]. Furthermore, many appeared to accept the pain as part of ageing [20]. Harkins [21] points out that pain is not a normal part of ageing but that there is a social expectation that it is.

Possibly, acceptance of pain is a first step in adaptation—changing one’s life in order to function in the environment, while giving up attempts to control it [18]. Most individuals in our sample did exactly that, in several instances having moved house. Many referred to ‘pacing’ because they had heard it from their pain clinic doctor. This term has crept into the literature on chronic pain in recent years [22]. However, it could mean anything, e.g. from doing a little housework each day to doing none at all.

Despite adaptation and pacing, viewing other people as worse off than oneself was commonly expressed. Previous researchers have noted such ‘downward comparisons’ as promoting a sense of well-being [16]. Here, however, there were indications that helping other people was instrumental in distraction from pain, and that it was this that contributed to well-being. Well-being was also seen as resulting from community activities, with participation in religious worship often providing social contact. Prayer and belief in God helped several participants, but it seemed that people who had experienced tragedy held less religious beliefs. Praying featured both as a way of seeking consolation and as part of a belief that God would intervene. Bearon and Koenig [23] also reported the tendency to believe that good health is a gift from God.

Koenig [24] further asserts that acceptance involves turning pain that cannot be relieved over to God. Only one participant indicated that this was her spiritual attitude.

Lansbury [5] noted a preference amongst elderly people for self-administered strategies. One day-to-day strategy was clearly ‘trying to look good’, possibly to avoid being stigmatised [25]. Several of the female respondents had gone to some trouble to enhance their appearance on the day of interview. This was a self-management strategy alongside the fact that a ‘visitor’ (the interviewer) was taking an interest in their lives and their pain.

Despite trying to maintain a social life, several participants indicated that they felt socially cut off, confirming previously reported barriers to social engagement [5], including lack of knowledge about social groups or lack of transport to attend them. Social activity includes activity with family, where chronic pain had had obvious effects. For example, many respondents were fearful of alienating their children because of inability to baby-sit grandchildren. Family dynamics obviously played an important part in many participants’ lives. This was not explored in the present study, but it was noteworthy that no explanations about the nature of chronic pain had been offered to spouses, carers or extended families.

On the whole, knowing a cause of pain did not appear to be a major concern. This might be because the majority of respondents tended to be more accepting of chronic pain and of their treatment than younger people. It may also have been to do with previous life experiences, such as having lived through World War II in several instances.

Conclusions

All participants appeared pleased to talk about how they coped with chronic pain. Some commented on the usefulness of ‘just talking’. As previously found [5], such studies can give participants their first opportunity to talk frankly about their pain, its consequences and their concerns and strategies. This in itself may be a useful therapeutic intervention for older people. The advent of the ‘expert patient’ programme may well be of benefit here.

Older people may be more vulnerable than their younger counterparts due to their life circumstances, but they are just as entitled to have their views acknowledged and their well-being considered. Understanding chronic pain sufferers from their own perspective may have important clinical implications [15, 26]. Health care professionals should gain increased understanding of the needs of older people in relation to chronic pain. Primary care groups should seek to improve provision for referral of older patients to sources of help such as support groups and occupational therapy services.

Outcome for participants

A daytime meeting with participants was convened to provide feedback and sharing of ideas. The interview data informed the development of a booklet (*Pain in Later Years: Practical Ideas to Help You Cope*) designed to meet the needs of older patients with chronic pain [27]. The authors are

grateful to The Halley Stewart Trust for a grant to enable its production. The booklet is the subject of a further academic publication, and is available from the first author.

Key points

- Little is known of older people's strategies for coping with chronic pain.
 - The aim of this study was to ascertain from older people the practical, physical and psychosocial limitations they faced because of chronic pain, and the strategies they used to deal with them.
 - A qualitative approach was employed in the study because qualitative methods focus on people's everyday life, experience and perceptions.
 - Older people who suffer from chronic pain adapt to a life with chronic pain while valuing independence and control.
 - Understanding chronic pain sufferers from their own perspective may have important clinical implications.
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References

1. Cousins M. Pain Relief as a Human Right. Webcast, Global Day against Pain. 11th October 2004.
2. Gagliese L, Melzack R. Chronic pain in elderly people. *Pain* 1997; 70: 3–14.
3. Helme RD, Katz B, Gibson S, Corran T. Can psychometric tools be used to analyse pain in a geriatric population? *Clin Exp Neurol* 1989; 26: 113–17.
4. Helme RD, Gibson SJ. Pain in the Elderly. In Jensen TS, Turner JA, Wiesenfeld-Hallin Z, eds. *Proceedings of the 8th World Congress on Pain. Progress in Pain Research and Management*, 1997; Vol. 8. Seattle: IASP Press.
5. Lansbury G. Chronic pain management: a qualitative study of elderly people's preferred coping strategies and barriers to management. *Disabil Rehabil* 2002; 22: 2–14.
6. Turk DC, Okiko O, Schraff L. Chronic pain and depression: role of perceived impact and perceived control in different age cohorts. *Pain* 1995; 61: 93–8.
7. Fe-Bornstein M. Chronic pain in the elderly: an overview. *Clin Geriatr* 2002; 10: 17–19.
8. Hofland SL. Elder beliefs: blocks to pain management. *J Gerontol Nurs* 1992; 18: 19–23.
9. Roy R. *The Social Context of the Chronic Pain Sufferer*. Toronto: University of Toronto Press, 1992.
10. Holloway I, Wheeler S. *Qualitative Research for Nurses*. 2nd edition. Oxford: Blackwell Science, 2002.
11. Hammersley M, Atkinson P. *Ethnography: Principles and Practice*. 2nd edition. London: Tavistock, 1995.
12. Rubin HR, Rubin IS. *Qualitative Interviewing*. Thousand Oaks CA: Sage, 1995.
13. Glaser BG, Strauss AL. *The discovery of Grounded Theory: strategies for qualitative research*. New York: Aldine Publishing Company, 1967.
14. Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd edition. Thousand Oaks CA: Sage, 1998.
15. Walker J, Holloway I, Sofaer, B. In the system: the lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain* 1999; 80: 621–8.
16. Osborne M, Smith JA. The personal experience of chronic benign lower back pain: an interpretative phenomenological analysis. *Br J Health Psychol* 1998; 3: 65–83.
17. Walker J. *Control and the Psychology of Health*. Buckingham: Open University Press, 2001.
18. Ridson A, Eccleston C, Crombez G, McCracken L. How can we learn to live with pain? A Q-methodological analysis of the diverse understandings of acceptance of chronic pain. *Soc Sci Med* 2003; 56: 375–86.
19. Weiner DK. Improving pain management for older adults: an urgent agenda for the educator, investigator and practitioner. *Pain* 2002; 97: 1–4.
20. Gibson SJ, Katz B, Corran TC, Farrell M, Helme RD. Pain in older persons. *Disabil Rehabil* 1994; 16: 127–39.
21. Harkins SW. Pain in the elderly. In Dubner R, Gebhart GR, Bond MR eds. *Proceedings of the Vth World Congress on Pain*. Amsterdam: Elsevier Science, 1988, pp. 355–67.
22. Severn AM. Therapy—psychological. In Grady KM, Severn AM, Eldridge PR eds. *Key Topics in Chronic Pain*, 2nd edition. Oxford: BIOS Scientific Publishers Limited, 2002, pp. 195–7.
23. Bearon LB, Koenig HG. Religious cognitions and the use of prayer in health and illness. *Gerontologist* 1990; 30: 249–53.
24. Koenig HG. *Chronic Pain. Biomedical and Spiritual Approaches*. New York, London, Oxford: The Haworth Pastoral Press, 2003.
25. Asbring P, Närvänen A. Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qual Health Res* 2002; 12: 148–60.
26. Gullacksen A, Lidbeck J. The life adjustment process in chronic pain: psychosocial assessment and clinical implications. *Pain Res Manag* 2004; 9: 145–53.
27. Sofaer B. (ed) *Pain in Later Years—Practical Ideas to Help You Cope*. Clinical Research Centre for Health Professions. University of Brighton, 2004.

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