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A hidden problem: pain in older people

A QUALITATIVE STUDY

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1 Executive Summary

1.1 Background

Chronic pain is both a common experience and a serious problem in later life, but one which has been relatively neglected by policy makers and service planners. Although there is a good deal of research on the subject, it shows some obvious gaps and suggests the need for further investigation. In particular, a fuller understanding of pain management in care homes from the perspective of the residents themselves has rarely been attempted and yet has the potential to improve the quality of life of those living in such settings. This is the first major UK investigation to examine directly and in detail the chronic pain experiences of care home residents.

1.2 Study aims and methods

The aim of the research was to improve our understanding of how chronic pain is perceived and responded to in care homes in England by exploring the views and experiences of *residents* from nursing homes in different parts of the country. Research questions focused on:

- residents' assessment of their own pain
- how residents' pain is usually managed or treated
- their own role in its management
- and whether they think anything can be done to improve its management.

The study was a mixed method – but largely qualitative - investigation involving in-depth interviews and interviewer-administered questionnaires. Seventy seven residents were interviewed in twenty four care homes in 4 parts of the country. A mixture of larger and smaller homes in both the private and voluntary sector was selected in urban, suburban and rural areas. All had nursing home status. The majority of respondents (77%) were female and the average age was 82.5 years.

1.3 Findings

Residents' assessment of their own pain
The research demonstrated a widespread stoicism in the face of the high prevalence of chronic pain amongst those interviewed. Most residents experienced constant or frequent, moderate to severe pain, usually as a result of long-term conditions such as arthritis, osteoporosis and stroke. The effects of pain were wide-ranging, limiting mobility, increasing reluctance to take part in communal activities and depressing mood. Nevertheless, very few residents envisaged an alternative to this situation. Pain was generally accepted as an inevitable consequence of ageing.

The management and treatment of pain
All but one resident took medication to relieve pain and this was the most frequently mentioned effective form of pain relief. However, over a third of residents had

experienced side effects and many saw medicines as a necessary evil. From the evidence provided by our interviewees, it seems that the management of medicines was heavily reliant on drugs like Paracetamol and Cocodamol, seldom tailored to the individual and occasionally subject to shortages and delay. Residents rarely saw their GP and less than half said that care home staff asked them about their pain. There were several references to physiotherapy, but the availability of other alternatives to medication was generally quite limited and often had cost implications. Opportunities to reduce discomfort, for example, bathing and showering, were dependent on staff time. Although special beds, mattresses and other appliances did alleviate pain, the use of some care home equipment actively caused it, particularly hoists.

Residents' role in managing their own pain
There were a number of ways in which residents attempted to relieve their pain, some more successful than others. Many did gentle exercises, either in their own room or as part of a structured activity. Lying down or resting also helped when the pain was particularly severe. Some residents found that doing things they enjoyed such as reading, watching television, listening to music or drawing helped to take their mind off the pain, if only temporarily. Care home staff supported these activities to a certain extent, but it seemed that more could be done to explore different options.

Improving the management of chronic pain
Less than a quarter of residents felt that anything more could be done to relieve their pain. Very few residents had been given the opportunity (or sought the opportunity) to discuss other ways of managing their pain with either their GP or the nursing staff in the care home. There was very little awareness of other services available and the overwhelming acceptance of pain as inevitable meant that few showed any real interest in challenging the pain management regime of the care home.

1.4 Conclusions

- Chronic pain is widespread amongst the residents of care homes. This leads both staff and residents to accept pain as an inevitable consequence of growing old.
- The effects of chronic pain significantly reduce residents' quality of life, limiting their mobility, restricting their social life, causing depression, irritability and tiredness.
- The management of pain in care homes is heavily dependent upon basic pain relief medication, dispensed on a routine rather than an individualised basis.
- Although seen as the most effective form of pain relief by many residents, medication is often viewed with suspicion and taken reluctantly.
- Residents rarely see their GPs and appear to take little part in any reviews of their medication.
- The high level of stoicism amongst residents means that they often suffer in silence, yet care home staff are failing to ask residents about their pain.
- There is a general failure to explore or offer alternative pain relief solutions and more could be done to support residents' own efforts to relieve pain.
- Whilst specialist appliances and facilities can help to alleviate pain, the use of some equipment, particularly hoists, can exacerbate discomfort.
- Activities which can alleviate pain or offer comfort are often dependent on staff time.

2 Introduction

2.1 Background

Chronic pain is both a common experience and a serious problem in later life, but one which has been relatively neglected by policy makers and service planners. For example, none of the eight standards in the NSF for Older People (Department of Health, 2001) specifically addresses pain; in fact the subject is only included in the NSF directly as it relates to (a) care of the dying, and (b) pain management whilst in acute hospital. This ignores the problem of 'living with' as opposed to 'dying with' pain, as well as chronic pain at home or in a long-stay residence.

Although there is a good deal of research on the subject of pain in later life, it shows some obvious gaps and suggests the need for further investigation as far as chronic pain in older people is concerned, both into the needs of the sufferers and into the means of prevention, alleviation and treatment of pain. In particular, a fuller understanding of pain management, as perceived and practised by residents of care homes has the potential to benefit older people and therefore to improve their quality of life.

More than half a million older people aged 65 or over now live in care homes (SCIE, 2004). Eyers and Byran (2006) note the increasing dependency of older people moving into care homes. The provision of continuing care for older people in Britain has increasingly shifted from hospital to the community, and nursing homes play a growing part in providing support for older people with complex health and social care needs.

2.2 Research aims and objectives

The overall aim of the research was to help improve the management of chronic pain among older people who live in nursing homes by improving our understanding of how such pain is perceived and responded to in such settings in England. This is the first major UK investigation to examine directly and in detail the chronic pain experiences of care home residents.

The research objectives were to examine older residents' own perceptions of pain and how it is handled by investigating:

- residents' assessment of their own pain
- how residents' pain is usually managed or treated
- their own role in its management
- and whether they think anything can be done to improve its management.

The project obtained the views and experiences of residents from twenty-four nursing homes in four parts of the country.

2.3 Research questions and themes

We used the areas identified as research objectives to develop research questions and themes for discussion with residents:

- residents' assessment of their own pain

whether the resident had pain, when they last had it, how long it lasted and how often they experienced it; or whether it is continual; what the pain felt like, where it was felt, what they think caused it, what brings it on or precipitates it; what the effects of the pain are; whether it affects how they feel or what they can do; what their general attitudes to pain are, whether they believe it is inevitable as they get older and whether it is something that can be successfully managed.

- how residents' pain is usually managed or treated

what, if anything, they usually do, or have done to them, to prevent, alleviate or cure the pain; whether treatment is routine or varies; how often they have the treatment; who does what to help alleviate the pain; whether the staff help; if nothing is done, why not; whether the measures taken work; what works best; why they think that.

- their own role in its management

whether they take an active role in pain management; what else they have tried; whether they have thought of trying anything else; what they think other residents do.

- and whether they think anything can be done to improve its management

what they think is the best thing to do about pain; whether they have heard of other kinds of treatment; whether there is anything else they would like to try.

In addition, we sought background information on the characteristics of the residents interviewed: age, sex, marital status, any children, frequency of visitors; length of residence; reported general health; cognitive and emotional well-being; any limiting long-standing illnesses or disabilities.

3 Previous research on pain

There are particular reasons for paying attention to the treatment of chronic pain among older people living in care homes. Its prevalence is high, as one would expect given that many conditions of later life can involve pain, for example, arthritis, osteoporosis, and vascular disease. Many of these conditions also contribute to disability. A systematic review of the international literature by Fox et al (1999) suggests that between 49% and 83% of nursing and long-term care home residents have chronic pain, and that prevalence increases with age (Jakobsson et al, 2003). In a recent UK study, 37% of nursing home residents were found to be experiencing chronic non-malignant pain (and 2% experiencing chronic malignant pain such as that caused by cancer) (Allcock, McGarry & Elkan, 2002) while US researchers have found one-quarter to one-third of nursing home residents to have moderate to severe pain on a daily basis (Gaston-Johansson, Johansson & Johansson, 1996; Teno, Weitzen, Wetle & Mor, 2001). Teno et al (2004) found that a small proportion of, mainly younger, residents (3.7%) had daily pain that was at one or more times excruciating in the previous week.

A study of nursing home residents in rural Australia found that pain among residents was under-diagnosed and under-treated (McLean & Higginbotham, 2002). The researchers concluded that there was insufficient dialogue with residents about pain and that a substantial number of residents had inadequate or irregular pain relief. In the US, Hutt et al (2006) found that fewer than half of residents with predictably recurrent pain were prescribed scheduled pain medication. According to Melding (2002) 'too many older people have "as required" medication, which is the least effective method to attain adequate blood levels of analgesic'. She concludes 'chronic pain is unnecessary'.

One reason for under-diagnosis and under-reporting may be that pain may be seen by both elderly residents and staff as a normal part of old age (Allcock et al, 2002). An Australian study showed older care home residents are resigned to pain, ambivalent about treatment and reluctant to express their pain (Yates et al, 1995). Leventhal and Prohaska (1986) in America found that older people tend to minimise their own pain and may stoically suffer in silence, reluctant to be "a bother". The acceptance of pain as normal makes it hard to assess, and therefore treat. A further barrier to diagnosis and effective treatment are fears among both older people and professionals about the toxicity of drugs and addiction (McCaffery & Beebe, 1994). Higgins et al (2004) reviewing the literature note research evidence that older people may also under-report because they fear further tests and treatments related to their ill-health; a belief that they may not be taken seriously when they report pain; that they do not understand the possible consequences of untreated pain; or have no expectation that their pain can be relieved.

In addition, US research indicates that staff may lack training, be too busy or simply fail to ask residents about pain (Sengstaken & King, 1993). Similarly, studies in the UK by Allcock et al (2002) and Mozley et al (2004) note the lack of in-service training for nursing and care staff. There are also concerns in both the UK and the US about the lack of formalised and regular assessment of pain (Sengstaken & King, 1993; Allcock et al, 2002).

A report in 2006 by the Commission for Social Care Inspection (CSCI, 2006) found nearly half of all care and nursing homes were failing to meet minimum standards in medicines management. Key areas of weakness included: the wrong medication being given to residents; poor recording of medicines received and administered; medicines being inappropriately handled by unqualified staff; and medicines being stored inappropriately. Researchers have found that more than two-thirds of care homes (nursing) have no written policy on pain management for residents and do not employ a standardised tool for assessing pain (Allcock, McGarry & Elkan, 2002). A large and complex study by Mozley et al (2004) in the UK found high rates of prescription medication and polypharmacy in care homes with more than half of residents on four or more drugs.

It has also been found that older people who believe pain control is a matter of chance are more likely to be depressed and have more pain (Gibson & Helme, 2000). The consequences of chronic pain in older people are serious, including depression, poor concentration, fatigue and memory impairment (Seers, 2006). Not only does depression appear to be more prevalent among older people who are in pain (Williamson & Schulz, 1992) but it also appears to heighten the suffering of those in pain (Parmelee, 1997). This difficulty is compounded by the high levels of cognitive impairment in care homes (Frampton, 2003; Ferrell, 1995). Research shows that people with cognitive impairment in care homes may be prescribed lower levels of medication than those who are not cognitively impaired (Kaasalainen et al, 1998) and that there is a mismatch between staff and patient assessments of levels of pain among such residents (Weiner, 1999).

Undiagnosed and untreated pain impacts not only on the psychological state of older people but may also lead to immobility, decreased functional ability, disturbed sleep, decreased social activities, increased isolation and loss of appetite (Gaston-Johansson et al, 1999). Thus it can affect residents' overall quality of life and their ability to participate fully in the activities of daily living. Higgins et al (2004) in a small qualitative study of nursing home residents in Australia found that 'pain was rarely spoken about. Its existence was smothered in silence or words that veiled its presence'.

Although there are various coping strategies and approaches to the management of pain, there are very few evaluated interventions (Fox et al, 1999). Research suggests that giving patients an active role in pain management is both preferred and beneficial (Ersek et al, 2003; Lansbury, 2000; McDonald et al, 2001), and that multi-disciplinary or multi-method approaches are effective (Baier et al, 2004; Gibson et al, 1996).

The perception of pain and how we experience it may be affected, according to Larson et al (1994) by a range of factors including: attitudes, beliefs, coping ability, age, gender, cognitive capacity, ethnocultural factors, religion, health status and disease. Treatments may address pain at the level of sensation, emotion or cognition, though most would address all three levels. As well as pharmacological treatments, attempts may be made to alleviate pain through: exercise or other physical approaches such as relaxation, massage or nerve stimulation; psychological approaches such as hypnosis or cognitive behavioural training; diversionary therapy such as music or other activities; and diet. However non-pharmacological approaches are often absent (Higgins et al, 2004) and opportunities for keeping occupied are limited in the main (Mozley et al, 2004). Perhaps – as Seers (2006) states – the key to successful management of pain is to use a variety of techniques and to persist with them. Allcock et al (2002) consider that the limited use of non-pharmacological techniques in nursing homes indicates that there is potential for improving both the assessment and management of pain in nursing homes.

4 Methods and sample

4.1 Sample and recruitment

The study was a mixed method investigation involving face-to-face interviews with nursing home residents. Some of the research questions were explored through a questionnaire using standard questions, but with mostly open-ended responses. However, for some of the topics a more in-depth approach was used because these are complex issues which are revealed more fully in qualitative interviews. This allowed the research participants to talk at length and in their own words about the experience of living with pain and how they cope with or handle it. Consequently, we selected a sub-sample of participants for longer interviews.

A large-scale survey was considered inappropriate and impractical because of the frailty of the participants; the difficulty of gaining agreement from care home proprietors, of contacting residents, and of obtaining a sufficiently high response rate; and because the research timetable was limited. However, since some robust findings about pain management in care homes were needed, we set out to achieve a relatively large number of qualitative interviews.

We conducted 77 interviews in twenty-four nursing homes for older people in England. This was a sufficient number to enable the main parameters which distinguish between such homes to be covered. A mixture of larger and smaller homes was selected, some well-established and some more recently set up, in urban, suburban and rural areas. All those selected had nursing home status. Most nursing homes are in the private sector (some owned by very large companies, others by individuals); the voluntary sector also owns and runs some homes; but there are now very few statutory sector homes. We used the Registered Nursing Homes Association database as our sampling frame for the selection of nursing homes. As there is a difference between areas in how many homes are registered with them, in some areas this had to be supplemented by searching local databases for the names of nursing homes. The characteristics of the care homes visited are provided in Table 1.

Within each home we sought to obtain four interviews, one of these involving a longer, more in-depth discussion, as well as the questionnaire items. It was originally envisaged that participants would be randomly selected within each home, by using random numbers within alphabetical lists of all residents. However once exclusion criteria were applied (severe cognitive impairment, serious acute physical illness, psychotic illness or severe depression), we were frequently obliged to interview all those remaining to reach our target number. All the residents who were interviewed spoke English.

The interviews were tape-recorded with the permission of those involved and transcribed. Qualitative analysis, using N-Vivo software, was carried out on the transcripts, and the standardised questions were analysed using SPSS software.

Table 1 – Nursing home location, size and provider

HOME	LOCATION	PLACES REGISTERED	PROVIDER
1	East Sussex	40	Voluntary
2	East Sussex	36	Voluntary
3	East Sussex	40	Private (individual)
4	East Sussex	25	Private (company)
5	East Sussex	34	Private (individual)
6	East Sussex	40	Voluntary
7	West Yorks	31	Private (company)
8	West Yorks	41	Private (company)
9	West Yorks	34	Private (individual)
10	West Yorks	44	Private (individual)
11	West Yorks	129	Private (company)
12	West Yorks	25	Private (individual)
13	West Yorks	51	Private (company)
14	Oxfordshire	50	Voluntary
15	Oxfordshire	15	Private (company)
16	Oxfordshire	30	Private (individual)
17	Oxfordshire	26	Private (individual)
18	Oxfordshire	30	Private (individual)
19	Oxfordshire	65	Private (company)
20	West Midlands	40	Private (company)
21	West Midlands	46	Private (company)
22	West Midlands	50	Private (company)
23	West Midlands	59	Voluntary
24	West Midlands	54	Private (company)

4.2 Data collection

Obtaining ethics committee approval, identifying suitable nursing homes with a sufficiently high number of residents able and willing to participate in the research, and negotiating access to the selected nursing homes presented a challenge and added to the time involved in data collection. A preliminary visit to all homes was carried out to discuss the purpose of the research, possible interviewees, and organise consent. Data collection was carried out between September and December 2006.

June – September	Selection of sample of Homes Preparation & submission of REC application Further literature review and design of topic guide and questionnaire
September – January	Pilot interviews in one Home Refinement of topic guide and questionnaire Main fieldwork
January – February	Transcription of tapes Analysis of data Writing up main findings

Two researchers were involved in conducting the interviews and compared progress and emerging findings on a weekly basis.

4.3 Characteristics of respondents

The majority of those interviewed were women (77%), reflecting the typical composition of nursing homes in terms of gender (Department of Health, 2002). Thirty-nine per cent of residents were aged between 75 and 84, and 43% were aged 85 or above. The average age was 82.5 years.

Two-thirds (66%) of respondents had been widowed, 17 per cent had never been married, nine per cent were married (some with their spouses in the same home) and eight per cent were divorced or separated. Nearly three-quarters (74%) of interviewees had children, (although not all still living) and nearly three-quarters (74%) of those with children had one or more children near enough to visit.

Many of the respondents were very frail: four out of five (79%) could not walk at all without help; 89 per cent could not bath or shower without help; and 55 per cent could not get in or out of bed without help. Eighty-two per cent of respondents had a long-term illness or disability (matching the levels reported in the Health Survey for England (Department of Health, 2002). In spite of high levels of disability and frailty among those interviewed, 62 per cent said that their health was good or better than good. Only one in eight (12%) of respondents said that their health was poor and 27 per cent that their health was fair.

4.4 Data analysis

Of course the analysis had to be largely qualitative as numbers are too small - despite the representativeness of the sample - for statistical analysis or generalization. It must also be borne in mind that the study focused solely on residents and their own experiences of pain. The qualitative data were analysed using a framework analysis (Ritchie & Spencer 1994). In contrast to the grounded theory approach, framework analysis was developed in the context of applied policy research. It is often used in health related research to provide specific information usually in a short time scale. In this project, the themes identified in the research proposal, and explored in the questionnaire and topic guide provided the initial 'nodes' for grouping the data. Additional 'nodes' were identified emerging from discussion between the researchers and a review of a sample of transcripts.

Respondents are identified in the text by their age and gender.

5 The views of care home residents

5.1 Residents' assessment of their own pain

Location and frequency of pain
Nearly 90 per cent of the interviewees said that they had experienced aches or pains in the last two or three months. Eighty-five per cent of those experiencing aches or pains said that they were *often* troubled by aches or pains. The most widely cited areas of pain were the legs (including knees), followed by back, arms and shoulders (see Table 2). Many respondents experienced pain in a number of locations around the body, often joint pain related to arthritis.

Table 2 – Location and frequency of pain

Location of pain	Frequency % (No. in brackets)
Legs (calves & knees)	62% (48)
Back	44% (34)
Arms & shoulders	36% (28)
Hands	29% (22)
Feet	27% (21)
Chest/abdomen	26% (20)
Head	21% (16)
Hips	18% (14)
Ankles	5% (4)
Other	12% (9)

Well I think I get aches and pains all over the place I suppose.
83 year-old female

In the great majority of cases (74%), the interviewees had been experiencing pain for over a year, while 15 per cent had been suffering for a few months, and eight per cent for a few weeks. Some had a long history of chronic pain, going back over several decades.

I have them all the time and have done for 28 years or more.
82 year-old female

The majority of those interviewed experienced pain intermittently (61%), nearly two in five experienced constant pain. However, for some people it varied, worsening from time to time.

In the night I can have terrible pains but it doesn't last that long, it just goes, it's like a stab and a couple of minutes, later it's gone.
79 year-old female

Severity of pain
Most respondents responding to the question described their pain as either severe (38%) or moderate (33%) most of the time. However, some thought that their pain was masked by the medication they were on: without pain-killers, they felt that their pain would have been much worse. Eight per cent described their pain as excruciating.

For some residents, their experience of pain was greatest in the morning when joints had stiffened up, and as the effects of the previous night's painkillers and sleeping pills wore off; for others, it was during the night that their pain was at its worst. Some of the most extreme discomfort was caused by phantom pain.

> *The other pains are nothing compared to the phantom pain. It is difficult to explain that to me the worst pain that I have is phantom pain because with the ordinary pain when you are asleep… you do get some respite from it then, but with the phantom pains, it is day and night and it is really bad.*
>
> 76 year-old female

The severity of pain clearly varied – often at different times of the day and night, and in some cases, according to the weather, worsening during damp, wet weather.

Description of pain
The most frequent description of pain was as a dull ache (55%), followed by a stabbing or sharp pain (17%), and a throbbing pain (3%). A quarter described their pain in another way. In a number of cases, the experience of pain ranged across these descriptions, varying from the sharp and severe, to the more moderate dull ache. Several residents struggled to find a way to convey the exact nature of the pain.

> *It's a screaming pain.* 72 year-old female

> *It's an evil trap…..It's going to let you off for a little while, but then it'll jump on you.*
>
> 87 year-old female

Medical conditions causing pain
More than four out of five respondents (82%) said that they had a long-standing illness or disability. The most frequently mentioned was arthritis (36%), but osteoporosis, Parkinson's disease, stroke, multiple sclerosis, and diabetes were also cited. Pain was often associated with these conditions and for those who mentioned a long-standing illness, the great majority (90%) said that it limited their activities in some way.

> *It's arthritis and I get it in my hands, my elbows, shoulders, knees and my ankles, generally. It's always worse in the morning and then during the day it gradually lessens so by the time bed comes, I'm almost free of pain and then during the night it comes back again.*
>
> 76 year-old male

In addition to these long-term illnesses there was a wide range of other conditions that caused pain including falls, amputation, ulcers, bed sores, infections and bowel problems – even anxiety in the case of one man who had regular headaches.

The ulcers cleared up, but then I've got a blood infection .....I've had the wounds nurse from the hospital comes regularly....they sting when they've just been dressed ....and if anyone puts their hand on the bandaged part of my leg when they're doing anything for me, I'll go potty.
83 year-old female

Actions causing pain
For those respondents who suffered from some form of musculo-skeletal condition, pain was usually exacerbated by movement or conversely, lack of movement.

I ache when I try to move about. 72 year-old female

That's why I don't like really sitting in one position too long.
87 year-old female

Getting in and out of bed was problematic for several respondents (31%). This could be associated with joints stiffening up overnight, and the use of hoists. A few residents had developed their own ways around this in order to limit the discomfort caused.

I mean I now have a technique where I probably roll over to one side first, rest a few minutes and then come a little further up and rest a few minutes and eventually without undue pain I'm out of bed.
89 year-old female

Sitting (22%), walking (14%) and using the bathroom (14%) were also highlighted as times when pain occurs. However, others failed to identify any particular activity that triggered it.

5.2 Effect of pain

Effect on mood
The effect of pain on how people were feeling was most frequently to make them miserable or depressed (38%). One in four (25%) interviewees said that it made them feel tired, or irritable, and others used a variety of expressions to describe how they felt from 'fed up', 'grumpy' and 'frightened' to 'lousy', 'worn out' and 'annoyed'. A small number admitted to suicidal thoughts.

It makes you wish you were dead, you wish you were and you think I wish it would happen soon. The older you get the damn worse it is.
79 year-old female

But there was also a remarkable stoicism amongst some respondents who were keen to emphasise that they did not let it affect them.

I try not to be miserable, I try to be happy go lucky, I've always been like that.
89 year-old female

Several residents discussed the unhappiness caused by the lack of mobility and loss of independence associated with chronic pain.

I don't like asking people to do things I have always done it myself. I get a little irritated. Not depressed, irritated.

86 year-old female

Effect on sleep and appetite

Over half the residents had sleep problems attributable to pain (59%), although for others insomnia was a problem in itself. As a result, several people spoke about taking sleeping tablets.

But every night time I'm very upset, I'll cry quite a lot in the night where it's so bad, the pain's awful….I don't go to sleep before half past eleven or twelve o'clock….I'm awake by one.

95 year-old female

Pain affected some people's appetite (28%), but many residents said that they ate very little anyway. Some put this down to a lack of exercise, being confined to their rooms for large parts of the day.

I know I don't eat as much in here as you would if you were out…because you're not getting out, you're not able to walk and exercise, you see.

84 year-old female

Effect on mobility

Lack of mobility was a major issue for many residents and this was associated with pain by seventy-four per cent of interviewees. It was very clearly one of the main causes of distress, restricting activities and reducing independence.

I like to try and walk, but then sometimes I'm in pain and I don't walk as much as I would like to.

79 year-old male

A few people were able to get out – either with relatives or on trips organised by the home. However, even this could be problematic.

When I was out this Monday it was very painful when I was sitting in the car. I suppose it is because it is a harder back than the cushions that I have in this chair.

76 year-old female

Effect on participation in communal activities

Pain did not restrict all the respondents' ability to engage in communal activities. However just under half of the residents (46%) felt that it did increase their reluctance to take part.

When the pain is there I just want to sit, I don't want to do anything or talk to anybody.

72 year-old female

A few people were concerned that their discomfort might actually spoil other people's enjoyment.

I did try it once and I thought not again….because of the backache….I can't sit too long… and I'm shuffling and shifting about, and there's people around me and all that, well it spoils their fun.

87 year-old female

Activities avoided

Nearly half of those interviewed (48%) said that they avoided doing things because of the pain they caused, but for a number of residents, activities were not so much avoided, as no longer possible. Those in wheelchairs were severely restricted in their ability to go out and those with arthritis were not able to do things requiring manual dexterity.

I crocheted for years and years…and I've done baby christening layettes and all that, and now I can't do it….I can't, I've been struggling, one afternoon, all afternoon…I've got the pin in my hand and I know how to do that, but it's to try and keep the wool around that middle finger…

87 year-old female

Residents were aware of these limitations and adapted their routines accordingly.

If I write for, try and write for too long…it makes my arm, my hand and my arm ache so I can't do much at a time, you see.

84 year-old female

However, others felt determined that the pain was not going to limit what they could do.

Oh no, I've made myself walk a bit this afternoon because… I had to get the girl to bring me a chair by the door to sit for a while, but no I don't believe in giving in…

89 year-old female

In one or two cases residents implied that it was not pain that restricted their activities but care home staff.

I would love to go out and walk…..they said I can't.

75 year-old female

5.3 Residents' attitude to pain

There were few respondents who did not adopt a "grin and bear it" attitude to the pain they experienced and some interviewees were reluctant to describe the discomfort they experienced as 'pain'. When asked whether they agreed with the statement: *"As you get old, you just have to put up with some aches and pains"*, 82% agreed. This indicates the difficulty which concerned professionals may face when seeking to identify and treat chronic pain among older people in eliciting information to enable appropriate diagnosis and treatment.

Well you put up with it, don't you, I would have thought. I don't suffer an awful lot of pain…. I don't want to make a fuss about it, it's not that bad.

85 year-old female

I'm afraid I haven't said much to them about it… I'm afraid I hate being a nuisance.

89 year-old female

The fact that pain was a constant factor for many meant that they had learned to live with it and 61% of respondents agreed with the statement that *"Those who complain the most are often the people who suffer least"*. Indeed one resident thought that to dwell too much on her pain might make it worse.

I think you get used to it in a way. You try and ignore it don't you? You can make it worse if you think about it too much.

83 year-old female

For people who had lost much of their independence, dealing with chronic pain in their own way was a sign that they still managed an element of control over their lives. Some spoke of it as a battle that had to be fought, indicative of their strength of character.

I think you should deal with things yourself. If you have got a pain, put up with it.

86 year-old female

Well I fight off the pain. 88 year-old female

Most residents saw pain as an inevitable part of growing old and did not expect to ever be totally free of it.

What can't be cured has to be endured. 75 year-old female

I expected to have some side-effects with my age, you know, I wasn't surprised to get it, but some people seem to make such a lot of fuss about it. But it's natural, it's, you know, one has to accept it, it's one of those things.

83 year-old female

One resident made a distinction between pain associated with a specific illness and the general aches and pains that she believed often accompanied old age.

I don't think anyone should have to put up with pain that is unnecessary but when you get old you can have aches and pains.

72 year-old female

Only a very few respondents thought that their pain could be investigated and treated successfully.

What aches and pains you get you can have looked into. I mean you don't have to put up with them.

83 year-old female

Given the level of stoicism expressed by most residents, it is perhaps not so surprising that despite the prevalence of long term conditions and chronic pain, many described themselves as being in reasonably good health.

I think it's very good, you have to take into account that I am 94 so I think you can say very good.

94 year-old female

Discussion with other residents

It seemed very unusual for respondents to discuss their pain with other residents and in a few cases this seemed to be a matter of care home protocol.

It's not the rule actually….because I made a mistake asking how somebody was, and they said oh you mustn't ask how… and it seems very rude to me not to ask somebody how their health is.

86 year-old female

But there was a more general problem in homes where the majority of residents had some degree of cognitive impairment.

The lady who used to be in this room, we became very good friends and she died 23rd of September and …….she had a lot of things wrong with her and you know she'd got a pain there or a pain there or whatever …….we really got on well, but there are very few of them that one can have a conversation with.

72 year-old female

This same resident also talked about the difficulty of trying to explain what it was like to experience a certain kind of pain to someone who did not have it.

Somebody who doesn't have arthritis hasn't got a hope in hell of trying to understand what you're talking about.

72 year-old female

Another resident commented on the importance of keeping each others spirits up.

We each try to keep the other jolly by not saying how bad we are.

86 year-old female

This contrasted with the only resident who thought people were too ready to discuss their aches and pains if given the opportunity.

I think the less one thinks about them the better, particularly in a place like this where everyone would take the whole meal time telling you how wretched they feel or whatever.

86 year-old female

5.4 Pain management: medication

All but one of those interviewed said that they took medication to relieve their pain. About one third (35%) mentioned Paracetamol, and 13 per cent said that they took Cocodamol. Residents also referred to steroids, Tramadol, Sulfasalazine, Gaviscon, Demerol and Gabapentin, and three interviewees said that they were on morphine. In many cases, however, where respondents were taking a lot of medication for long term conditions, sleep problems, constipation and other reasons as well as pain, they could

not name the drugs and simply referred to the amount of tablets and how regularly they were taken.

> *I take two pain killing tablets, and there's two more I take in the mornings but what they are I don't know… and there's the one I take after, oh no, once a week on a Monday, on Monday morning before I have my breakfast.*
> 90 year-old male

> *I take a bucket of tablets a day.* 83 year-old female

Side effects of medication
Over one third (36%) of those interviewed said that they had suffered side effects ranging from mild symptoms to delusions. In some cases this had led to a change of medication or a reduction in dose. The most common side effects were drowsiness and constipation, although nausea and a sore mouth were also mentioned.

> *I did try one about two months or six weeks ago which was supposed to be a new one, Tetra something, I'm not quite sure of the name but it made me sick, I felt sick down in the dining room so the doctor said well drop it off.*
> 90 year-old female

> *I was on eight a day but I found that that was the cause of acute constipation. But five a day, I'm quite happy.*
> 95 year-old male

In a few cases respondents had to balance the side effects against the pain.

> *I've been on a stronger one which was better, but I was so dopey and sleepy all the time that it was, I didn't like it.*
> 86 year-old female

Residents at one home felt that they were experiencing side effects even though care home staff thought it unlikely.

> *And there's a red pill they like to give you, and I'm not awfully fond of it…it always tends to make me feel sick…and they say it can't do, and I said have you taken it? They said no. So I said well how do you know that it doesn't make you feel sick?*
> 89 year-old female

Self-medication
In a few cases residents appeared to be able to regulate their own pain control by taking medication as and when they need it.

> *No I keep my own, I do my own medication. I don't know if there's anybody else who does in this place, I don't think so.*
> 72 year-old female

But in the vast majority of cases residents were not permitted to self-medicate and did not keep pain killers in their rooms. They relied upon the regular drug rounds at the care home, although most were able to request additional relief if required. It seemed, however, that such requests could only be authorised by qualified nursing staff.

If any painkillers I ask the, what I call the poisons nurse. There's one Sister who is doing all of that and they'll ask her for me, and she's got a list of the time they had the last ones. I mean I know myself, you know, that I'm alright, but she checks.

83 year-old female

Attitudes towards medication

Despite the overwhelming use of pharmacological solutions to chronic pain, there was a real reluctance to take medication amongst many respondents. Some of this stemmed from long-held beliefs and a general suspicion of drugs, but there was also a fear of dependence, unpleasant side effects and reduced effectiveness if over-used. A majority (71%) of interviewees agreed with the statement that *"People shouldn't be too dependent on pills and medicines."*

I don't take them unnecessarily because I believe that if you take things regularly then when you do have a severe pain you would be used to the tablets, wouldn't you?

76 year-old female

I think you grow up with this idea you are not to have too many pills….You were brought up like that I suppose.

75 year-old female

The wide-spread stoicism of residents meant that to accept pain relief was almost to admit defeat for some respondents.

I must admit that I don't like taking them regularly….because I think well because all my life I have just mastered anything.

86 year-old female

Perhaps most worrying was the comment made by one resident who did not appreciate that he was entitled to request anything to relieve his pain.

I've never felt that I was in a position to ask for help with pain relief, but the girls give me, as I say, two Paracetamol four times a day, I'm reasonably happy with it.

63 year old male

This was somewhat contrary to the 88% of respondents who agreed with the statement that *"It is our right to have whatever medical treatment is available."*

Effectiveness of medication

Although many residents disliked taking drugs, they did seem to accept them as a necessary evil and medication was by far the most frequently mentioned effective method of relieving pain (41%) and 78% of respondents agreed with the statement that *"Nowadays, with modern medicines most kinds of pain can be relieved".* Nearly one in five (19%) could not say or felt that they did not know what was the most effective pain relief method.

Dr S recommended Gabapentin? I think that is the correct name. They have helped…..that is why it is so wonderful to come in here and to think that someone at last is doing something about it. 76 year-old female

You pray for the medicine trolley to come round.
75 year-old female

However, a few issues were raised in connection with the management and administration of medication. Two residents spoke of their care homes actually running out of supplies.

Yes, but they've run out at the moment…the nursing homes do things like this… and when I said excuse me, I'm supposed to be taking painkillers. 'Oh the chemist didn't come today, something happened.'
76 year-old female

But the cough medicine has run out. 88 year-old female

One of these residents was also concerned about the way she was expected to take her medication.

I'll tell you what really concerns me though, is that you're supposed to take these tablets with food…. we don't always take them with food.
76 year-old female

Whilst another commented that time pressures on staff meant she did not always get her medication at the right time.

Well if they're too busy, it can't be helped, there's other people besides me here, you don't always get your tablets on time.
89 year-old female

5.5 Pain management: alternatives to medication

Exercise and physiotherapy
Residents mentioned a number of activities and measures that contributed to the reduction of pain. Most frequently mentioned was exercise in some form – either personal efforts (44%), supervised (22%) or physiotherapy-led (16%). Physiotherapy and supervised exercises were offered in several homes but not all. Residents had mixed opinions on how useful it was and it was usually seen as helping general health and fitness rather than alleviating pain.

I wouldn't say they control the pain, but they enable me to move.
89 year-old female

Waste of time. I'm not being rude.
87 year-old female

Where physiotherapy was not available it sometimes appeared to be a question of cost.

Now this is one of the things, pretty well everything here on the medication side is no charge…but I believe physiotherapy is, I believe that was in the instruction, I've never had any need to follow it up, but I'm pretty sure I've read that that is the responsibility of the… inmate, as I call them.
95 year-old male

Many respondents preferred to do exercises in the privacy of their own rooms and at their own pace – even if they were originally shown how to do them by a physiotherapist.

> *I do exercises in bed in the morning when nobody's about. One of the physios at* [hospital] *taught me a few whilst I was there.*
>
> 87 year-old female

A number of interviewees expressed an interest in more help with supervised exercise and advice on exercises.

> *I had some sometime ago but I don't know, actually I wouldn't mind some more.*
>
> 83 year-old female

Bath/shower

Thirty-six per cent of respondents spoke about the comfort they derived from taking a shower or having a bath. Sadly, because this was dependent on staffing it seemed that this was not available to residents more than once or twice a week in many homes.

> *And it's a hydro bath, you know, it's got the, like the spa…and that is lovely. Oh I have, well when they've got time, but every week I have one normally, and a shower in between.*
>
> 71 year-old female

Distraction

Distraction techniques, such as reading, listening to music, watching the television, drawing, writing poetry and quizzes helped some residents to take their mind off the pain they were experiencing. Indeed fifteen per cent of interviewees found some kind of diversion the most effective form of pain relief.

> *'Well I do my best to have my concentration away from the pain and I think really that's one of the best things, and I'm fortunate enough to still have a moderate brain that wasn't as good as it was, so I'm always listening either to the wireless or to the tapes which I get from Caliber. And I think that's one of the ways of getting over moderate pain (laughs), to concentrate on other things.'*
>
> 86 year-old female

One resident complained about the lack of organised activities to take his mind of the pain.

> *When you do get a headache, you know, you've got nothing else to do, and it's there throbbing away and you can't take your mind off of it….that's the only problem I've got with these places, it's just there's nothing to do.*
>
> 58 year-old male

Resting

Forty-one per cent of residents talked about the beneficial effects of lying or sitting down for a while to ease the pain.

I very often have to lie on the bed and I feel better off for about five or ten minutes.
79 year-old male

If the tablets don't work very well I usually ask them to put me in bed so they put me in bed and the pain seems to go off when I've been lying down.
80 year-old male

But this was not an option for everyone. Residents with back pain, for example, explained that lying down could exacerbate the pain whilst a few residents gave the impression that it was actively discouraged by care home staff.

Matron doesn't like you lying down, you know. 91 year-old male

Sitting for any length of time could also be uncomfortable.

When I sit down my bottom hurts, all the time, even now as I sit.
76 year-old female

Heat
Keeping warm was an important factor for several residents although heat treatment as such was only mentioned by eight interviewees. Others had either never tried it or felt it would not be helpful, particularly if the care home was already somewhat overheated.

I've got an electric pad, you know, that I used in the winter when the bed's cold... the warmth helps.
83 year-old female

Staff also appeared to prohibit the use of hot water bottles in many homes on health and safety grounds.

Alternative therapies
Only eight residents mentioned alternative therapies, although a few others had tried acupuncture and massage before they moved into a care home. In one home, reflexology was provided by a member of the nursing staff on a private basis when she was off duty.

I did some massage for a bit, it didn't seem to do an awful lot of good and so that was stopped and right now I'm trying a course of reflexology and it's very soothing and it's very nice.
86 year-old female

A few residents expressed an interest in finding out more about such therapies.

I've got a friend that does yoga, so I'm going to see if she'll come in and talk to me about relaxing.
71 year-old female

I know of nobody who has acupuncture or is taken there or has an acupuncturist that comes here, so it's easier just to do nothing. Also they're very short of staff so I couldn't go on my own, so I don't know how to go to these places.
86 year-old female

But as with physiotherapy, the cost implications deterred many residents whilst others were quite sceptical about the benefits.

> *I haven't got that kind of money….you have to pay for things like that.*
> 87 year-old female

> *If I can be frank…..I have no patience with it.*
> 86 year-old female

Other ways to relieve pain
Occasionally respondents mentioned the role of chiropody in relieving discomfort or, in one case, causing it.

> *I do wish the chiropodist would come every six instead of every eight weeks, because my toes are quite sore.*
> 89 year-old female

> *The left bunion has been very painful for 6 weeks now since the chiropodist came.*
> 76 year-old female

A few residents massaged themselves, using topical anti-inflammatory gels or creams. Sometimes just rubbing a foot or knee appeared to bring a brief relief from the pain. Another resident felt that cod liver oil helped to relieve the effects of arthritis.

> *I'm just sat here all the time, but I keep having to stroke this like this, and go like this* [rubbing knee/leg]
> 95 year-old female

> *I do take cod liver oil, and that helps a lot that do. I rely on that, I think that helps my arthritis. I have one tablet a day, cod liver oil.*
> 98 year-old female

Others had their own relaxation methods which seemed to ease their discomfort and one resident had briefly experienced an alternative to prescribed medication.

> *Just learning to relax which isn't that easy at times either … my husband had cancer and we used to get these CD's, stress and relaxation which are really very, very good… and I usually put that on and listen to it you know, so you have to sit up and lay down, learn how to stretch and relax your muscles.*
> 72 year-old female

> *I normally have a Scotch before I go to bed….It relaxes me, kind of thing.*
> 71 year-old female

In just over a third of cases (34%), residents felt that the alternatives proved very effective, and for over a third (38%), they were fairly effective. But for 28 per cent, these other options either worked not very well or not at all. Where a respondent did nothing else to try to control their pain, a couple said that nothing works, and three said they felt at their age that they just had to put up with it.

I'm just stuck with this, it won't go away. It's there permanently so you just put up with it.

83 year-old female

5.6 Pain management: the role of health professionals and care home staff

Only a quarter (25%) of those interviewed said that a nurse or doctor had ever talked to them about how to keep their pain from getting worse; and a smaller proportion (15%) said that a doctor or nurse had talked to them about how their pain could be treated.

The role of the GP

In most homes residents seemed to see their doctor infrequently and only if they specifically requested to see him/her or were very ill.

He's a funny man, our doctor……he doesn't seem to like seeing people.

89 year-old female

Even when requested, it did not always appear to be easy to see a doctor.

And one often asks can I see the doctor for some reason or another, and they say well we'll put your name down, and you don't hear any more.

79 year-old male

In several cases, it seemed to be the practice nurse who visited the home rather than the doctor.

One resident's comments seemed typical of many. The nurses had told her that her doctor wanted to gradually take her off the morphine she was taking, but she had played no part in this decision and seemed happy to leave it to him.

I've only seen this doctor once since I've been here…but apparently he's telling the nurses to try and wean me off of it if they can wean me off of the morphine…he wouldn't say what it was all about, you know….and the nurses tell me I've got to try and get off the morphine if I can, he doesn't want me on it.

95 year-old female

Even when residents did see their GP, they often felt that there wasn't the time or the opportunity to discuss pain management.

I don't understand if there's anything that can help me…I wish, I would do if she had time…If she would propose something….but there doesn't seem any time to talk.

86 year-old female

Most of the discussion about medication and pain management appeared to take place between the GP and the qualified nursing staff in the home. Residents were seldom involved.

Well I suppose I saw him about a month ago, three weeks ago, and that's the first time I've actually seen him since he's been in here….because the manageress sort of collects all the data, and then she sees him in her room and she's just putting the facts in front of him.

83 year-old female

There were cases when respondents spoke more positively of their relationship with their GP.

I had to change the doctor but I have been well satisfied with him, he has been very considerate and caring and I couldn't believe it when they suggested something for the phantom pain.....He said if I found that they didn't work that there were other things that they could suggest which I thought was very good.

76 year-old female

But amongst many respondents there seemed to be a widespread acceptance that the treatment they were receiving was all that was available and that nothing more could be done. In this situation it did not seem to matter whether they saw their doctor regularly or not.

No I don't bother to see them, it's not worth it. I mean there's nothing… there's nothing really that they can do.

83 year-old female

Even when residents left the home to see a specialist it seems that they were often reluctant to raise the issue of pain management as in this case when an interviewee had visited the local eye hospital.

Well they were talking and I'm not the sort to interrupt their talking.

88 year-old female

The role of the nursing home staff

If, as it appears, the doctors rely upon information from the nursing staff about the pain experienced by individual residents, then it would seem important that nurses asked about pain and that residents felt able to tell them about any changes. Some residents spoke highly of the care they received in this respect.

They always ask you if you're alright, if there's anything wrong you know.

83 year-old female

However, not many residents enjoyed such a level of attention. Less than half (43%) of respondents said that care home staff ever asked them about their aches and pains. The shortage of qualified nursing staff and the time pressures on care assistants were major problems.

Well you have to tell them really you know if you've anything wrong.

79 year-old female

Well really there is one nurse, she hasn't… I mean I'm not grumbling because there's so many of us here…No, they really wouldn't have time to listen.

86 year-old female

Just as residents did not want to bother the doctor, in many cases they also seemed reluctant to bother the nursing staff in the home. In other cases, they simply felt there was little they could do other than dispense the appropriate medication and keep them comfortable.

> *All they can do is make you as comfortable as possible.*
> 79 year-old female

> *They can't do anything but give me my tablets.*
> 81 year-old female

One resident preferred it to be left up to her to ask when she needed help with pain relief.

> *Oh the staff here are marvellous, I mean they don't so much ask, they watch you and then say 'Do you want…' or 'Would you like some help?' but they respect us and leave us, credit us with the intelligence to ask when we can't cope.*
> 89 year-old female

For most respondents (69%), care home staff did play a part in helping with alternatives to medication, about half without being asked. But in some homes, it seemed that unless it was part of a medication regime, for example, applying an anti-inflammatory gel or cream, staff only helped in a limited way when they had the time.

> *I do understand the staff are very understaffed, so many people don't come, but they haven't got time.*
> 86 year-old female

One resident gave the clear impression that pressures on staff time meant they were unwilling to offer other options.

> *The only one that I had any help from was a TENS machine, but I had to stop using that because I couldn't put it on for myself. That was for my back when the vertebrae collapsed…. and I don't think they want to be bothered here.*
> 82 year-old female

General views on care home staff varied tremendously, sometimes even within the same home.

> *Some are better than others and that's it…..there's a certain few that are really very, very good and you can tell that they're… you know they're different from the rest, so I mean you have to be thankful for those people.*
> 79 year-old female

> *They're excellent staff, I mean I know as I say I've worked in places like this and half the time the staff never took any notice of you at all but these do, they're always there if you need them and the night staff as well.*
> 83 year-old female

5.7 Pain management: awareness of other services

Only fifteen per cent of interviewees claimed any awareness of other services that might help with pain relief. A few residents were receiving or had received treatment for long term conditions in hospital units outside the care home, but whether much benefit had been gained from these experiences seemed questionable.

> *I do attend the rheumatology clinic regularly….I have mentioned my shoulder blade, but I said I thought it was because I had been doing too many crosswords.*
>
> 76 year-old female

> *I've been to a nerve specialist at Bournemouth and he said there's nothing, nothing that can be done.*
>
> 90 year-old female

5.8 Contributory factors

Care home facilities
It was clear that a range of additional factors had an impact on residents' well-being and comfort. In several cases residents spoke about the pain relieving effects of specialist equipment and appliances.

> *I mean this bed has made a big difference, because it's, you know it's like a different bed and of course this mattress is quite different … it's really marvellous because I mean you can adjust it to what you want… but this mattress has made a heck of a difference, otherwise I should think I would be… I'd probably have a lot more aches than what I have.*
>
> 79 year-old female

But in a number of cases, pain and discomfort were actually caused by appliances and equipment used in the care home, particularly hoists.

> *They tried to use the hoist but I don't want it, with my shoulders being painful it hurts me, so they manage without that.*
>
> 95 year-old female

> *It's painful to go in the hoist really, it hurts, well it's the angle you have to get in, it hurts me under the arms and the belt that goes around goes right around my boobs, you know.*
>
> 83 year-old female

Communication with the outside world: visits, phone calls
In most cases, respondents depended upon communication with the outside world for social interaction yet nearly one in five interviewees (19%) could not use the telephone without help and several had no telephone in their room. However, seventy-eight per cent of those interviewed had visits from family or friends once a week or more: in a few instances, they had daily visits. Nineteen per cent had visits from family or friends once a month or less frequently.

One resident explained the importance of having a regular visitor when care home staff changed so often.

> *I also pay for a milkman's wife who's become my good friend and she comes to me twice a week for a hour or so and reads my things and writes my letters and does my shopping for me ….it's really what a blind person needs because as kind as all these various people are, each new lot doesn't know where everything is and I'm inclined to forget it anyway so it's a problem, so she really is a great asset.*
>
> 86 year-old female

Others spoke of the support they received from relatives and friends with regard to medicines information and pain control.

> *I'm lucky that I've got a good daughter, she's very good, yes… she makes sure that I've got my tablets and everything.*
>
> 89 year-old female

> *I'll often ask my son to have a look on the internet and see what there is about such and such a thing or find out about something.*
>
> 72 year-old female

But there were residents whose friends were no longer able to visit or who were anxious not to be seen as a burden on relatives.

> *I don't really want them to visit me... I didn't want him* [son] *to see me with Parkinson's.*
>
> 81 year-old female

Loss of mobility

Mobility problems were not always associated with pain. Many of the respondents were very frail: four out of five (79%) could not walk at all without help; 89 per cent could not bath or shower without help; and 55 per cent could not get in or out of bed without help.

> *I can't do anything for myself. I can't wash myself or dress myself.*
>
> 76 year-old female

Whilst some residents seemed to have accepted this situation, for others the loss of dignity was almost unbearable.

> *What absolutely terrifies me is that jolly soon I won't be able to tend to myself on the loo so I'm making arrangements of what I can do so that I don't have to ring for people because I just dread, dread, dread that indignity.*
>
> 86 year-old female

A few people never got dressed.

> *Over a year I haven't had my clothes on.* 97 year-old female

Poor mobility was also connected to unsteadiness and a fear of falling. Many residents had suffered falls – either prior to living in their care home or whilst in the home.

This last fortnight I seem to be falling all the time, and I bashed my knee two or three times, what caused it I don't know, I just went.
89 year-old female

Loss of independence
For many residents the loss of independence associated with living in a care home caused significant unhappiness which may have compounded their general discomfort.

And they say to me 'Come on Jean', but sometimes I'm nearly in tears…. I said I can't make you understand. 'Well what do you want to say?' I said well, you see, I've been so used to being on my own, I've been so independent, you see. …I nursed my father, I nursed my husband. And I said I can't come to terms with having to be looked after myself.
84 year-old female

5.9 Improvements in pain management

Despite the high incidence of chronic pain amongst the residents interviewed, less than a quarter (23%) thought that anything more could be done to alleviate it and there was relatively little criticism of the way in which their pain was managed.

Well nobody has ever suggested anything and I can't think of anything.
82 year-old female

There's nothing else they can do, you see. 95 year-old female

Only a few interviewees demonstrated any interest in exploring other ways to manage their pain or gaining a better understanding of its causes.

Well I think we should all you know be interested in trying to stop pain or at least show us a better way of managing it, do you know what I mean?
72 year-old female

Where respondents did think more could be done, it was mainly by care home staff or others.

Our findings confirm and extend the findings of previous research on pain in care homes, for example, in terms of the stoicism of residents contributing to the under-diagnosis and under-treatment of chronic pain.

6 Conclusion and recommendations

- Chronic pain is widespread amongst the residents of care homes. Often associated with long-term conditions, it can become such a constant factor that there is a danger that both care home staff and older people themselves accept it as an inevitable consequence of the ageing process.

- Pain causes depression and irritability among many residents, disturbing their sleep, restricting mobility and limiting their ability to take part in communal activities. In a few cases, residents had suicidal thoughts.

- Residents rarely see their GPs and offer little evidence that pain is regularly assessed or that medication is regularly reviewed. Discussions about pain management appear to take place between nursing staff and GPs, and rarely involve the residents themselves.

- There is a heavy reliance upon the regular administration of basic painkillers, such as Paracetamol. Although medication is believed to be the most effective kind of pain relief, it is also clear that in most cases it is only partially effective.

- Alongside analgesics, a significant minority of residents found that other activities could alleviate their pain or provide comfort, for example, through exercise, heat treatment or a bath. Unfortunately, some of these activities are dependent on staff time and their availability is often restricted.

- The suspicion with which many residents view medication means that it is often seen as a necessary evil, but there are few attempts to think more imaginatively about pain relief or to give it in the most effective ways. There is a general absence of non-pharmacological approaches to pain control. In most homes this may be due to financial issues. If not offered as part of the care home regime, additional or alternative treatments have cost implications for residents and most can simply not afford them.

- Certain care home practices actually appear to contribute to the pain experienced by residents, particularly the use of hoists.

- The presence of pain compounded by attendant loss of mobility is a major cause of depression and isolation amongst care home residents who are not cognitively impaired, but have little opportunity for social interaction.

- There is a need for a more pro-active approach to the management and treatment of pain by health care and nursing home staff, alongside guidance, advice and support for residents' own efforts to alleviate chronic pain.

- Many of these results parallel findings from a study of carer's experiences by YouGov for the Patients Association (2006) for example, in terms of the effects of

chronic pain on sufferers and the heavy reliance on medication as opposed to other approaches.

7 References

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Appendix I – Topic guide for care home residents

Introduction

We are conducting some research on behalf of the Patients' Association. We are trying to find out whether care home residents like yourself often experience pain and how that pain is relieved. By getting a better understanding of how pain is experienced and treated, we are hoping to help improve the management of chronic pain among people who live in care homes.

1. Do you have any kind of aches or pains?

Probes:
- *Is it there all the time?*
- *How often do you get it?*
- *How long does it last?*

2. Do you think your pain is worse/less/about the same as that experienced by other residents in the home?

Probes:
- *Do you discuss pain with the other residents?*
- *What does everyone feel about it – part of growing old?*

Thinking about the last time you had pain:

2. What do you think caused the pain?

Probes:
- *Did anything in particular bring on the pain (eg weather, movement,)*
- *Is it part of a long standing condition?*

3. What did the pain feel like?

Probes:
- *Dull ache*
- *Stabbing pain*
- *Mild, moderate, severe*

4. Where did you get the pain?

Probes:
- *All over*
- *Specific parts of the body*

5. Did you try to relieve the pain yourself? If so, how?

Probes:
- *Rest*
- *Exercise*
- *Own pain-killers*
- *Heat*
- *Other*

6. Did you ask someone in the care home to help alleviate the pain?

If yes –

Probes:
- *Who did you ask?*
- *What happened?*

If no –

Probes:
- *Did you feel that staff are too busy to help?*
- *Did you feel that staff are not qualified to help?*
- *Were you afraid of being seen as a complainer if you ask for pain relief?*
- *Were you afraid you may have to have further tests and investigations?*
- *Do you prefer your own methods?*
- *Did you think you just have to put up with it?*

Thinking more generally about your pain:

7. Do the care home staff ever ask you about pain?

Probes:
- *When, how often?*
- *Is pain relief provided regularly/routinely or just when you ask for it?*
- *Is it always the same or a variety of treatments? (ask for details)*

8. Do you ever see your GP about your pain?

Probes:
- *Regularly or on request?*

9. What do you think about taking medication for your pain?

Probes:
- *Do you experience any side effects? (ask for details)*
- *Do you worry about becoming too dependent on certain drugs?*

10. What do you find is the most the effective way of relieving your pain?

Probes:

- *Why do you think that works best?*

11. Have you heard of any other kinds of treatment for pain?

Probes:

- *Have you ever been offered any alternative therapies etc?*
- *Is there anything else you would like to try?*

12. When you have pain, how does it affect you?

Probes:

- *Does it make you feel tired?*
- *Does it make you feel depressed?*
- *Does it limit what you can do?*
- *Does it disturb your sleep?*
- *Does it affect your appetite?*

13. Do you feel your pain is getting worse/better/about the same since you've been in the care home?

14. Do you take an active part in deciding how best to relieve your pain or is it decided for you by care home staff/GP/other?

Probes:

- *If not, why not?*
- *Do you prefer to leave it to health professionals?*
- *Are you given different treatment options?*

15. Do you think you get enough information about the causes of your pain or the different ways to relieve your pain?

Probes:

- *Who provides the information? Health professionals, care assistants, other residents, visitors?*
- *Do you ever look for information yourself?*

16. Characteristics:

- Age
- Sex
- Marital status
- Children
- Frequency of visitors
- Length of residence
- General health
- Long-standing illnesses or disabilities

Appendix II – Questionnaire for care home residents

QUESTIONNAIRE ON ACHES AND PAINS FOR RESIDENTS OF CARE HOMES

We are interested in any aches or pains you may have and how you deal with them. There are no right or wrong answers. Please take your time. Let me know if you get tired of talking and we will stop.

Q1 Have you had any aches or pains or hurts in the last two or three months?

(1) Yes
(2) No
(3) Can't remember/don't know

Q2 Are you often troubled with aches or pains or hurts?

(1) Yes
(2) No
(3) Can't remember/don't know

Q3 In the last two - three months have you had any ache, pain or hurt in your:

Interviewer tick all that apply

(1) Back
(2) Head (including eyes, ears, mouth, teeth, face)
(3) Hands
(4) Arms/shoulders
(5) Chest/abdomen
(6) Hips
(7) Legs (eg calves or knees)
(8) Feet

IF NO TO ALL, THANK AND TERMINATE INTERVIEW

Q4 **a)** How bad is the pain in your [site of pain first mentioned] most of the time?

(1) Mild/uncomfortable
(2) Moderate
(3) Severe
(4) Excruciating/as bad as you can imagine

b) For about how long do you think you have had it?

(1) A few weeks
(2) A few months
(3) More than a year
(4) Don't know/can't remember

c) When you get the pain how long does it usually last?

(1) All the time
(2) Off and on/intermittent

d) How would you describe the pain?

(1) A dull ache
(2) A stabbing pain
(3) A throbbing pain
(4) Other: PROBE details

e) How does it make you feel?

Interviewer tick all that apply
(1) Miserable/depressed
(2) Tired
(3) Grumpy/irritable
(4) Other: PROBE details

f) When does the pain occur?

Interviewer tick all that apply
(1) Getting out of bed
(2) Using the bathroom
(3) Walking
(4) Sitting
(5) Other: PROBE details

g) When you've got that pain in your [……] does it affect:

Interviewer tick all that apply
(1) Your sleeping
(2) Your eating
(3) Your concentration
(4) Your mobility
(5) Going out
(6) Taking part in activities in the communal lounge
(7) Other: PROBE details

h) Do you avoid doing things because of the pain they cause?

(1) Yes: PROBE details
(2) No

CONTINUING WITH FIRST PAIN MENTIONED IN Q 4

Q5 **a)** Thinking about the aches or pain you have in your [……], do you take any pills/syrup/injections or other medicine to help control that pain?

(1) Yes (PROBE details)
(2) No

b) (IF MEDICATION TAKEN) Do you suffer any side effects?

(1) Yes (PROBE details)
(2) No

c) (IF MEDICATION NOT TAKEN) Why do you not take medication for your pain?

Interviewer tick all that apply
(1) No medication has been prescribed for my pain
(2) My doctor has prescribed medication but I worry about the side effects
(3) I find it difficult to remember to take my medication
(4) I prefer other remedies

Q6 **a)** (Apart from what you've already mentioned) do you do any of the following when you get that pain in your [……..]?

Interviewer tick all that apply and probe fully for details
(1) Lie or sit down for a bit
(2) Have a bath
(3) Heat and cold treatments
(4) Patches
(5) TENS
(6) Take exercise/move about
(7) Get physiotherapy
(8) Supervised exercise programme
(9) Alternative therapies (eg meditation, massage, reflexology, acupuncture)

(10) Have a drink
(11) Eat something. (PROBE what?)
(12) Smoke a cigarette, cigar or pipe
(13) Other
(14) Don't know/can't remember)

b) (IF ANY REMEDY MENTIONED) Do staff members here help with this?

(1) Yes, without asking
(2) Yes, but only when I ask them
(3) No
(4) Don't know/can't remember

c) (IF ANY REMEDY MENTIONED) How well does this help to control your pain?

(1) Very well
(2) Fairly well
(3) Not very well
(4) Not at all.

f) (IF NO REMEDY MENTIONED) Why don't you do anything about your pain?

(1) Nothing works
(2) At my age, I just have to put up with it
(3) Other reason: PROBE details

CONTINUING WITH PAIN MENTIONED IN Q 4

Q7 **a)** Again thinking about the aches or pain in your [……] has any doctor or nurse ever talked to you about how to keep your pain from getting worse?

(1) Yes
(2) No
(3) Can't remember/don't know

b) Has any doctor or nurse talked to you about how the pain in your [……..] could be treated?

(1) Yes
(2) No
(3) Can't remember/don't know

REPEAT Q4-7 FOR OTHER PAIN SITES MENTIONED AT Q3

Q8 Thinking more generally about pain, do care home staff ever ask you about your aches and pains?

(1) Yes
(2) No
(3) Don't know/can't remember

Q9 Thinking about all your aches and pains, what do you find is the most effective way of relieving your pain? PROBE details

Q10 Do you think anything else could be done to help relieve the pain?

(1) Yes: PROBE details
(2) No
(3) Don't know

Q11 [IF YES] Who do you think could be doing more to help relieve the pain?

(1) Yourself
(2) Care home staff
(3) Other: PROBE details

Q12 Do you know of any other services that might help with your pain?

(1) Yes PROBE details
(2) No

Before we finish, just a few more questions about you and your general health.

Q13 We need to understand what difficulties people may have with various activities because of a health or physical problem. Please can you tell me whether you have any difficulty doing the following without help from someone else:

a) Walking across a room without a stick or frame

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

b) Walking across a room with a stick or frame

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

c) Dressing, including putting on shoes or socks

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

d) Bathing or showering

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

e) Eating, such as cutting up food

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

f) Getting in or out of bed

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

g) Using the lavatory

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

h) Making telephone calls

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

i) Taking medication (pills)

(1) Can't do at all without help
(2) Can do with difficulty
(3) Can do easily

Q14 Would you say your health is generally

(1) Excellent
(2) Very good
(3) Good
(4) Fair
(5) Poor

Q15 **a)** Do you have any long-standing illness, disability or infirmity? (By long-standing I mean anything that has troubled you over a period of time or is likely to affect you over a period of time?)

(1) Yes
(2) No
(3) Can't remember/don't know

b) IF YES: do these/this illness(es) or disability(ies) limit your activities in any way?

(1) Yes: PROBE details
(2) No

Q16 Some people say that as they get older their memory becomes less good than it used to be. How are you at remembering things about family and friends, (eg what they do, their birthdays, their names and addresses?)

(1) Very good

(2) Good
(3) Fairly good
(4) Fair/not that good
(5) Poor.

Q17 Are you:

(1) Single
(2) Married/in long term partnership
(3) Widowed
(4) Divorced/separated?

Q18 Do you have any children?

(1) Yes
(2) No

Q19 IF YES: Are any of them living near enough to visit you?

(1) Yes
(2) No

Q20 Do they visit you? IF YES, about how often do you have a visit from one of your children?

(1) Once a week or more frequently
(2) 2 or 3 times a month
(3) Once a month
(4) Once every 2 or 3 months
(5) Less often

Q21 What is you date of birth?

Q22 INTERVIEWER TO RECORD
Male/female

Q23 Can you tell me if you agree or disagree with the following things that people sometimes say:

a) "A*s you get old you just have to put up with some aches and pains"*

(1) Agree strongly
(2) Agree
(3) Not sure or bit of both
(4) Disagree
(5) Strongly disagree

b) "*Nowadays, with modern medicines most kinds of pain can be relieved"*

(1) Agree strongly
(2) Agree

(3) Not sure or bit of both
(4) Disagree
(5) Strongly disagree

c) *"Those who complain the most are often the people who suffer least"*

(1) Agree strongly
(2) Agree
(3) Not sure or bit of both
(4) Disagree
(5) Strongly disagree

d) "*People shouldn't be too dependent on pills and medicines"*

(1) Agree strongly
(2) Agree
(3) Not sure or bit of both
(4) Disagree
(5) Strongly disagree

e) "*It is our right to have whatever medical treatment is available"*

(1) Agree strongly
(2) Agree
(3) Not sure or bit of both
(4) Disagree
(5) Strongly disagree

Q24 Before we finish is there anything else you would like to tell me about?

Or anything else you'd like to ask me? ……

THANK AND END INTERVIEW

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