Appendix 1
Extended literature review

There is a world-wide demographic trend toward an ageing population [1]: in the UK, elderly people are the most rapidly-increasing population of pain sufferers and research is urgently needed into the special needs of elderly people in pain [2]. Despite the increase in the prevalence of chronic pain among older people, they are under-represented in multi-disciplinary pain clinics [3]. Chronic pain is generally defined as lasting more than three months [4]. The literature related to pain and coping suggests that elderly people use a more passive style of coping with life events [5], but Keefe and Williams [6] have noted that these differences may arise due to different life situations.

In an Australian study, Lansbury [7] noted that elderly people experience both physical and psychological barriers in managing chronic pain, including access to health care, lack of information, and fear of loss of control and independence. In addition, she noted that elderly people often had several medical disorders. In particular, she found that older people preferred to cope by using home remedies rather than professional ones, and that they would benefit from learning to ask for assistance.

Evidence that a majority of older people experience significant persistent pain has been cited by several authors [8, 9, 10 and 11]. However it is a misconception that pain is a normal part of ageing [12]. Chronic pain in older people has major implications for quality of life and care [13]. Pain is often under-treated in elderly patients due to several factors: patient fears, lack of education for health care professionals, and misconceptions that older people have a higher pain tolerance [14, 15, 16].

Davies and McVicar [17] note that pain, including that of older people, is under-treated in the UK, due to misconceptions of health professionals. The literature suggests that these misperceptions affect other parts of the world, as shown by Horgas and Pao-Feng [18 ] and Glajghen and Bookbinder [19] in the US, Kaasalainen et al [20 ] in Canada, Sloman et al [21 ] in Australia and Blomqvist and Hallberg [22, 23] in Sweden. Gibson and Helme [24] reviewed 11 pain prevalence studies and suggested a peak in the prevalence of pain by 65 and a decline in reported pain in ages 75-84 and 85-plus. This may mean that older people are more reluctant to report pain [25].

Gaston–Johansson et al [26 ] argue that in order to treat pain effectively there needs to be an analysis of the causes, a framework for understanding the pain and a protocol to assist health-care professionals in assessing and treating pain in older people. Effective management of chronic pain in older people poses a challenge to physicians, particularly because of the high incidence of co-morbidities. [27, 28]. Older people have special needs for effective management of pain, and this is gradually being recognised [29]. Assessment of pain should form part of all assessments of elderly people [30].

Many older patients with chronic pain have clinically-significant depressive symptoms and low self-reported quality of life scores [31]. Gold and Roberto [32]
noted that the literature on chronic pain does not pay enough attention to the issues and concerns of older people suffering chronic pain, and suggest that research should examine psychosocial variables as causes and consequences of chronic pain in later life.

It has been shown that attitudes and beliefs of older people can have an effect on how pain is perceived and managed. The pain experience of older people may be related to their history of accumulated life experience [33]. Health professionals may not assess pain correctly because they may not believe people when they report it, or may think it is exaggerated and not document it correctly [34, 35, 36]. Shahady [37] suggested that 50% of older patients have beliefs that inhibit diagnosis and effective management of pain. Similarly, it has been noted [38] that optimal management of pain in older people should take account of the beliefs of the patient. Otherwise such beliefs can interfere with the patient’s willingness to acknowledge pain and to provide full information about the pain they experience. Examples include beliefs about the aging process itself, and about the potential consequences of treatment, such as addiction. In some cases, health professionals may need to allay a belief that pain represents punishment for some past behaviour. Davis and Srivastava [39] noted that barriers to pain management in the elderly include a sense of fatalism, denial, the desire to be “the good patient” and geographical and financial factors.

Chronic pain may have an effect of the family unit and particularly have negative effects on a partner of a person suffering chronic pain [40]. Social disintegration and disruption of family life has been noted [41], and role change within the family may occur [40]. It has also been shown that both sufferers and their spouses demonstrate psychological distress [42].

It is reported that elderly people are less likely to seek information about their illness, or to control their medical treatment [43]. Elderly people, it has been suggested, do not use so many cognitive coping mechanisms as younger people because they do not like psychological services. One suggestion has been that older people do not use these coping strategies because they are less reliant than young people on internally-mediated strategies [44]. In Lansbury’s study, [7] elderly people in pain preferred their own versions of medical treatments and used informal cognitive strategies such as distraction in the form of social activities – e.g. playing bowls, visiting neighbours, listening to music, prayer and using humour. The respondents in Lansbury’s study did not like professional forms of treatments, such as medication, physiotherapy and exercise. Dill et al [45] reported similar findings. Meisenhelder and Chandler [46] have noted the importance of faith associated with positive mental health in older people.

References


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Appendix 2
Research methodology and analysis

Using qualitative research
The aim in qualitative research is to present data in such a way that the informants speak for themselves [47]. Unlike in quantitative methods, one does not begin with a theory and sets out to test it. Rather, one begins with an area of study - in this case the effect of pain on the lives of older people - and the information relevant to the area is
allowed to emerge. A number of authors have suggested that the use of qualitative methods can highlight the subjective experience of pain [48, 49, 50]. A grounded theory approach stresses the importance of context in which people function: it is more structured than other types of qualitative research [51]. The main aim of grounded theory is to generate relevant concepts from the data collected.

**Data collection**

Features of grounded theory are that the researchers explore the ideas and perceptions of the participants and immerse themselves in the setting under study [52], the theory is not predetermined, the researcher and the researched are equals as human beings and finally, that data and analysis interact. The last point means that analysis commences as the researcher collects the information. Working propositions are then formulated, modified in subsequent data collection. When seeking information from new participants, ideas that previously emerged are taken into account so that data and analysis interact at each stage. [53]. In Grounded Theory, as developed by Strauss and Corbin [47], the theory is discovered, developed and provisionally verified through the systematic data collection and analysis of data pertaining to that phenomenon. This continual intermeshing of data collection and analysis bears directly on how data collection is brought to a close [54].

Because of this, it is difficult to predict the tempo of emerging information and the length of time the project will take. This style of research uses ‘constant comparison’ [47], with each section of data compared for similarities, differences and connections. Themes and categories are identified as the data are collected, coded and categorised, and from this major themes and constructs are formed. Data collected from initial interviews are used as cues to develop ideas in further interviews. The data which emerge provides direction for further questioning, which is termed theoretical sampling. From this theoretical sampling relevant categories are developed and refined. An example of this in the present study was a participant alluding to the importance of ‘looking nice’ and the researcher taking this cue to find out how this was accomplished by later participants. This category resulted in the identification of a major theme - ‘looking good and feeling good’.

An *aide mémoire* was developed in the present study, to assist the researcher to focus on areas of interest in case the participant ‘dried up’. It consisted of some key words such as ‘daily activities’, ‘transport’, ‘family activities’ ‘physical limitations’ and ‘support’. It was used minimally in the present study, because most participants had much to say about their own story of managing their pain. The first prompts in the first interview were to do with the effect on the participant’s life of chronic pain, the support the participant had, and how she coped. Most of her concerns were to do with her negative experiences in hospital and dealing with the medical profession. The issue of communicating with health professionals frequently arose throughout the interviews and will be the basis of a further publication.

**Analysis**

One turning point occurred at the 11th interview where great emphasis was placed on using aids to increase mobility. Other turning points were interview no.19, ‘looking good and feeling good’ and at interview no. 21, where importance of prayer was emphasised. Hints of relationship issues and irritability appeared early on, but became more emphasised with married couples later on. This increased openness and ease
with which respondents discussed these issues may have been to do with the accumulated experience of the researcher at listening to such disclosures.

Some biases may have been introduced when spouses or carers were present. This was noted particularly on one occasion when a daughter who was a carer contributed to the discussion (following the interview of her Mother) and contradicted some of what her Mother had said. For the most part, when partners were present, there was congruence of opinions usually with the interviewee seeking affirmation from the partner re the ‘truthfulness’ of a particular issue or statement or the partner finishing a sentence. For example, interviewee 59: “I would say it is essential because” Partner: “if you’re not careful you grow apart”. There were frequent occasions where a spouse would interject and augment a response. For example, interviewee 60: “we do a lot of charity work”. Spouse: “I think not as much as we’d like to”.

**Emergence of themes**
All the coding was carried out by hand by the lead researcher in collaboration with one of the other authors. All the transcriptions were read by three people and each category highlighted by colour coding. Discussion took place but there were no discrepancies between the interpretations of the different coders. The themes that subsequently emerged were agreed by the first and third author. Other themes emerged which are not included in the present publication. These included relationship and communication issues, both personal and with health professionals and the health system. It is anticipated that these themes may form the basis of a further publication. Because of the large number in the sample it is not practical to include all the findings in the present report.

**Validity**
Validity and reliability have different meanings in qualitative and quantitative research. ‘Credibility’ and ‘authenticity’ in qualitative research correspond to internal validity, i.e. that the participants themselves recognise the meaning they give to their experience and the ‘truth’ of the findings in their own social context. To carry out a ‘member-check’ [55]: a telephone call to each participant ascertained their response to a written interview summary of the main points covered in the interview. Care was taken to include in the summary at least one ‘positive’ item mentioned by the respondent. The summary to the respondents included only information from that individual and not the overall findings.

Member checks can help to enhance the credibility of the findings. Ashworth [56] noted that member checks are not necessarily evidence of the trustworthiness of the research because participants may not wish to disagree with the researcher. In the present study participants were given the opportunity to change or clarify information. Four participants chose to do so. Other researchers also reviewed the data for meaning. External validity is concerned with generalisability. Although the findings of a small study cannot easily be generalised to the whole population of older people in pain, they do have typicality and the ideas could be applied to other similar situations.

**References**
Appendix 3
Ethical Issues

Recruitment
Patients were recruited through two pain management clinics in the South East of England. Patients over the age of 60 were invited to take part in the study by the consulting doctor, who gave them an invitation to participate together with an information sheet and a slip to return in a stamped addressed envelope to the researcher if they wished to be involved in the study. Written informed consent was obtained from each participant prior to the interview. Patients were included in the study if they were over 60 years of age, had experienced pain for three months or longer, were attending a Pain Clinic and had no current diagnosis of malignant disease. GPs were sent a letter inviting a response if they considered that a patient should not be involved. All audio-tapes were coded and kept secure.

Talking about pain
An additional ethical issue is about talking to people about their pain. This could cause distress. In a discussion prior to the interview, it was stressed to each participant that the interview could be interrupted or stopped at any time if they so wished.
two occasions the audio-tape was paused at the researcher’s initiative, but in both cases the respondent was emphatic that they wished to continue. On both these occasions, a resource for counselling was suggested to the participant following the interview. Almost all the participants expressed gratitude that they had been listened to. The effects of the interviews were not evaluated, but there is evidence that this kind of interview can be therapeutic and may help respondents to find new purpose and meaning in their lives [57, 58].


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