Living with chronic pain: the patient's perspective
McHugh, Gretl, MSc, BNurs, RHV, RGN; Thoms, Gavin, MBChB, MSc, FRCA, MFPHM, DCH. Nursing Standard 15.52 (Sep 12-Sep 18, 2001): 33-7.

Abstract (summary)
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A sample of 245 patients with chronic pain, who attended specialist pain services in 11 UK hospitals, were interviewed using a structured questionnaire. Patients' ages ranged between 23 and 86 years (median 51 years), and the duration of pain ranged between six months and 57 years (median five years).

Patients reported that pain had had a profound effect on their lives, restricting daily living and leisure activities. 33 per cent (81) were classified as medically disabled. Patients' perceptions and attitudes to the management of chronic pain varied. Their main concern was that, although they wanted a specific diagnosis, they were often not given a reason for their chronic pain.

Pain management requires a significant amount of input by health professionals. Patients wanted advice on the best techniques to help them cope with chronic pain. Most patients had previously tried many different pain treatments to obtain short-term pain relief. One third of patients had waited up to four months for their initial pain assessment at the pain service. Once referred to specialist pain services, patients were satisfied with their care. Almost half (47 per cent, 115) of the interviewees reported that their pain had improved. As chronic pain has a profound effect on patients' lives, it is important that early diagnosis, treatment and referral to appropriate specialists is given high priority. This study has raised the awareness and understanding of an important, but often misunderstood area.

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Conclusion Pain management requires a significant amount of input by health professionals. Patients wanted advice on the best techniques to help them cope with chronic pain. Most patients had previously tried many different pain treatments to obtain short-term pain relief. One third of patients had waited up to four months for their initial pain assessment at the pain service. Once referred to specialist pain services, patients were satisfied with their care. Almost half (47 per cent, 115) of the interviewees reported that their pain had improved. As chronic pain has a profound effect on patients' lives, it is important that early diagnosis, treatment and referral to appropriate specialists is given high priority. This study has raised the awareness and understanding of an important, but often misunderstood area.

Key words
* Pain and pain management
* Patients: attitudes and perceptions
These key words are based on the subject headings from the British Nursing Index. This article has been subject to double-blind review.

**CHRONIC PAIN** has a profound effect on patients' lives and can cause a great deal of distress and disability. Pain is defined as: '...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (IASP 1986). The term 'chronic pain' implies pain that persists after the point at which healing would be expected to be complete, or in disease processes in which healing does not occur. It usually refers to pain that persists for longer than three months. There is little epidemiological research on the prevalence of chronic pain. It has been estimated that 7 per cent of the population experience chronic pain at any one time (Bowsher et al 1991), while an earlier study estimated that 7 per cent of people might have chronic pain (Crook et al 1984). A more recent survey of 3,605 people with chronic pain in the community showed that 46.5 per cent of those surveyed reported chronic pain (Elliott et al 1999).

Research has provided in-depth accounts, of individual experiences: of living with persistent pain. Feelings of isolation are a common experience (Carson and Mitchell 1998, Rose 1994, Walker et al 1999), as well as having an effect on their family relationship, such as distancing themselves from family and emotional distress (Smith and Friedemann 1999). Persistent pain that becomes chronic can have a devastating and profound effect on the lives of individuals and their families. Individuals often have to make major lifestyle changes to cope with persistent pain, with many being unable to continue working or undertake leisure activities. Chronic pain often results in days being lost from work (Bowsher et al 1991).

**Chronic pain** is distressing for patients and their families, is costly to the NHS and effective management often requires substantial medical and nursing time. Dependency on health and social care is great and yet there is often no improvement in the person's pain (Cook and Hassencamp 2000, Walker et al 1999). The subjective nature of pain makes it difficult to evaluate interventions and professional preferences lead to the use of a wide range of treatments in chronic pain management.

Much chronic pain is not recognised and, therefore, remains untreated (Fishman and Carr 1992). The majority of patients presenting with chronic pain are cared for in general practice, with some requiring specialist services (SOHD and SHSAC 1994). Specialist services in the UK are referred to as 'pain clinics' or 'pain services'. They provide treatments and services for patients with chronic pain, such as lower back pain and neuropathic pain. These services are staffed by consultants in pain management (who are usually anaesthetists), other medical consultants, specialist nurses, clinical psychologists, physiotherapists, occupational therapists and pharmacists. Once patients have been referred to pain clinics, there is often a long wait for specialist treatments (Walker et al 1999).

**Study**

A survey of patients attending specialised pain services or pain clinics in 11 randomly selected hospitals throughout the UK was carried out during 1997, as part of a large national study reviewing pain services and standards of pain management for the Clinical Standards Advisory Group (CSAG 2000). The aim of the survey was to:

* Identify the characteristics of patients attending pain services.
* Investigate what services and treatments patients experienced before referral to a specialist service.
* Establish waiting times and mode of referral.
* Examine patients' satisfaction with the management of chronic pain.

**Method**

Ethical approval was obtained for each of the study sites before commencing the study. Patients were recruited during a five-month data collection period in 1997. The study sites were randomly selected. Sequential patients were approached until a predetermined number of patients had been recruited. Patients were asked whether they would be willing to participate in the study; written consent was obtained and an information sheet was given. Piloting of the questionnaire was undertaken in two pilot sites and small amendments were made to the data collection tool.

To increase reliability, researchers were trained in the use of the questionnaires before undertaking the interviews and information collected from the patient's medical records, confirmed diagnoses, treatments and length of time attending pain services. The use of categorical scales and pre-coded questions and the piloting of the questionnaire enhanced validity. Quality control procedures were also put in place and a selection of the interviews were tape recorded to ensure accuracy of data recording among interviewers. Questionnaires were checked for missing data and obvious errors and returned to the Interviewers for clarification. Face-to-face interviews were carried out in quiet locations in the pain clinics. A trained researcher interviewed the patients, using a structured questionnaire and the interview lasted about 20 minutes. Issues covered in the questionnaire are summarised in Box 1. During the interview, patients were invited to discuss the effect of living with chronic pain and one of the case studies is described in Box 2.

**Results**

A total of 257 patients were approached for interview; 12 refused to be interviewed, and the remaining 245 were included in the study. The majority (64 per cent, 158) of patients had attended the pain service previously. The remaining 36 per cent (87) of patients were attending the pain service for the first time. New attendees to the pain service were unable to comment on certain aspects of the questionnaire, for example, those focusing on experiences of
the pain service.

Characteristics of patients attending chronic pain services The age of patients interviewed ranged from 23 to 86 years. Figure 1 provides a breakdown of the range of ages of patients who were interviewed for the survey. The median age was 51 years. Many (68 per cent, 167) of the patients interviewed for the survey were less than 60 years of age. More than half (62 per cent, 151) of the participants were women. The majority (97 per cent, 237) of patients interviewed were white; 3 per cent (n = 8) were of Asian (Indian subcontinent), Oriental or African Caribbean origin.

During interview, the participants reported having pain for many years; the median duration of pain was five years. Twenty three per cent (n = 56) of those interviewed had experienced pain for a year or less, while 8 per cent (n = 20) of patients had pain for 20 years or more. Pain was reported to be constant for 72 per cent (176) of patients. Many (55 per cent, 134) patients surveyed for this study had given up work because of chronic pain. Eighty patients (33 per cent) identified themselves as being medically disabled. Figure 2 provides details of the employment status of the study sample.

The vast majority (91 per cent, 223) of patients interviewed reported that chronic pain had prevented them from doing everyday tasks at home. Patients also reported that pain inhibited their ability to walk or sit for long periods.

Reasons for pain In this study, back pain was the most frequent reason given by patients (34 per cent, 83) for chronic pain. Nerve damage is often associated with, or caused by, a number of conditions, for example, disc compression, viral infection, diabetes or cancer infiltration. This type of pain is termed neuropathic (or neurogenic) pain and is often very distressing - 16 per cent of patients had this condition (n=39). Other types of pain were lower limb pain (16 per cent, 39), neck and shoulder pain (11 per cent, 27) and complex regional pain syndrome (5 percent, 12).

Services and treatments Before attending pain services, patients had tried or had been referred to a range of services, and experienced different treatments for chronic pain (Table 1).

The most frequent technique, apart from medication, was physiotherapy (63 per cent, 155). However, the precise type of physiotherapy received, or whether the physiotherapist had a special interest in painful conditions, was not identified. Additional treatments available on attending the pain service included: nerve blocks; pain management programmes; epidurals; and spinal cord stimulation.

Referral to pain services Most patients interviewed had been referred either by the GP (49 per cent, 120) or by a hospital consultant in another specialty (44 per cent, 108). A minority of patients (3 per cent, 7) had requested referral to a pain clinic. However, the majority of patients (65 per cent, 159) had no previous knowledge of the existence of pain clinics.

The case story illustrates the profound impact that pain has on the patient's life and the importance of early referral and proper management of individuals with chronic pain. Like Mary, a third of the patients interviewed said that they felt they were not believed about the severity of their pain.

Patients often waited years before being referred to a specialist pain service. In this survey, patients reported waiting times that ranged from being seen immediately to having a two-year wait. Median waiting time was 13 weeks. Thirty three per cent (80) of patients reported having to wait more than four months for an initial assessment at the pain service.

Patients' perceptions of, and attitudes to, the management of chronic pain were variable. Patients' main concern was that they were often not given a reason for the pain and wanted a specific diagnosis. It was noteworthy that more than one third of patients interviewed (35 per cent, 86) had not been given a reason for the pain before attending the pain service.

Patients also wanted reassurance about how best to manage chronic pain. Having an expert who could instruct them in what they could or could not do to manage their pain was viewed as highly beneficial. Patients generally wanted advice on the best techniques to help them cope and deal with the pain. Any short-term improvement in the patients' chronic pain symptoms was felt to be of great benefit.

Patient satisfaction with the pain service The 158 patients who had attended a pain service previously were asked how their pain compared with the pain they had on first attending the pain service. Almost half the patients (47 per cent, 75) reported that their pain had improved (Table 2). The length of time patients attended the pain service was examined to see if those patients who had attended for longer felt that their pain had improved. Patients who rated their pain as being worse since attending the pain service had been attending the clinic longer for pain treatments.

Patients were asked to rate how the pain service managed their pain. Sixty seven per cent of the interviewees (n=164) were able to express an opinion. Most were satisfied (72 per cent, 118) with pain services; only a small percentage (5 per cent, 9) were dissatisfied, and the remaining patients (23 per cent, 37) were indifferent about the care they had received from the pain service. Most patients (85 per cent, 208) reported being acknowledged by reception within a few minutes of arriving at the pain clinic and they were seen within 30 minutes of their appointment time. A total of 164 patients (67 per cent) did not receive any information in advance about treatments offered by the pain services. The majority of participants (81 per cent, 198) did not receive any information (either written or verbal) about facilities or services provided by the pain clinic they attended. Many patients expressed feelings of isolation. Only 3 (1 per cent) patients attended a support group for chronic pain.

Discussion and conclusions
Living with chronic pain: the patient’s perspective - ProQuest

Chronic pain has a considerable effect on the patient’s life and causes much distress and discomfort. One third of patients interviewed identified themselves as being medically disabled. Chronic pain is associated with disability (Watson 1997). A patient’s ability to work is often affected by chronic pain, including the ability to carry out normal household tasks or leisure activities. The majority (91 per cent, 222) of patients surveyed had their daily living and leisure activities restricted because of pain. Pain was responsible for an inability to walk or sit for any length of time. A survey of disabled adults by the Social Policy Research Unit reported similar results (SPRU 1991). Chronic pain has been reported to be more common among women (Bowsher et al 1991, Crook et al 1984). This was also the case in this study where 62 per cent (151) of the interviews were conducted with women.

Many patients with chronic pain tried a number of different treatments and services to get pain relief. In an earlier study on chronic pain, many of the patients surveyed had used both conventional and complementary health services (James and Large 1992). The survey also found that patients spent a considerable amount of their own money on pain management (James and Large 1992). Although patients were asked about the usefulness of the treatments and services received, this study did not focus on this aspect. However, two recent publications have investigated this, McQuay et al (1997) conducted a systematic review of the effectiveness of outpatient services for chronic pain control, treatments and services, and the evidence base for pain relief treatments has also been examined (McQuay and Moore 1998).

Waiting times for patients to be seen by an appropriate specialist were identified as being long, and patients felt that the wait was often intolerable. One third of patients had to wait more than four months for an initial assessment at the pain clinic. The report by the Scottish Office and Health Department and Scottish Health Service Advisory Council (1994) found that waiting times in some Scottish pain services were as high as 20 weeks, with nine weeks being the median.

Where information was provided on treatments, facilities, or services provided by the pain service, it was of a high standard. In one hospital, patients were sent information before attending for treatment, thereby making them more aware of the procedures. This information was perceived as informative and was welcomed by patients. However, only a small minority of the patients (19 per cent, 47) received information about the facilities and services provided by the pain clinic. Similarly, in a study of adults with chronic lower back pain, Walker et al (1999) found that communication was poor and there was little co-ordination or continuity of care in their management.

For patients with chronic pain, a service that can assist them with pain management is extremely valuable. The survey found that patients, benefited by attending a pain clinic. Patients often reported that if the treatment provided only short-term pain relief, it was still worth having. Almost half the patients felt that their pain had improved since first attending the pain service. Patients were generally satisfied with pain services. It is difficult to assess patient satisfaction using a structured questionnaire and additional research methods are often required. The questionnaire used in this survey was limited in its interpretation.

Patients’ reaction to chronic pain is often influenced by their understanding of the cause. Ignorance of the explanation of symptoms often increases anxiety and pain-related behaviour. The fear of not knowing what is causing the pain; fear of not being given an appropriate diagnosis; and fear of not being believed were issues of great concern for patients. Other studies have focussed more extensively on patients’ experiences of living with Chronic pain (Carson and Mitchell 1998, Seers and Friedli 1996). Seers and Friedli (1996) found that the issue of being believed was crucial to patients and this was highlighted in this study.

Other issues that emerged from the patient interviews included the need for assurance and confirmation of how best to manage their pain. As illustrated by the case story, once an individual has been referred to the appropriate specialist service, even though there is no cure for his or her pain, being taught coping strategies and proper management was valued highly. Patients generally sought advice on the best techniques to help them cope with chronic pain. It is important that health professionals give patients adequate knowledge and information about their pain, causation, outlook, and strategies for treatment or other management.

As chronic pain has a profound effect on patients’ lives, it is important that early diagnosis, treatment and referral to appropriate specialists is given a priority. Early intervention with certain chronic pain conditions can lead to improved success with treatment (Bowsher 1993). Using a multidisciplinary approach is viewed as the most appropriate and best way to manage patients with chronic pain (SOHD and SHSAC 1994, Watson 1997). A multidisciplinary approach to the care and management of such patients is valuable because the complex and multifaceted nature of chronic pain conditions calls for the skills and expertise of a range of health professionals. The survey clearly demonstrates that patients with chronic pain try a variety of treatments and endure considerable pain. The study has raised the awareness and understanding of an important, but often misunderstood area.

Sidebar

Sidebar
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Sidebar
Implications for practice

* Chronic pain has a considerable effect on an individual’s life

* Patients need reassurance and guidance on how to manage their pain
* There needs to be an increased awareness of the provision of specialist pain services
* There is great potential to improve chronic pain management

A multidisciplinary approach is required to management of patients with chronic pain

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Author Affiliation

Greti McHugh MSc, Bnurs(Hons), RHV, RGN, is Research Fellow, School of Nursing, Midwifery and Health Visiting, University of Manchester. Gavin Thorns MBChB, MSc, FRCA, MFPHM, DCH, is Consultant Anaesthetist, Evaluation and Audit Unit, Department of Anaesthesia, Manchester Royal Infirmary. Email: gretl.mchugh@man.ac.uk

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MeSH Activities of Daily Living, Adult, Aged, Aged, 80 & over, Chronic Disease, Female, Humans, Leisure Activities, Male, Middle Aged, Nursing Methodology Research, Pain -- diagnosis, Pain -- etiology, Pain Measurement, Patient Education as Topic, Quality of Life, Questionnaires, Referral & Consultation, Self Care -- methods, Adaptation, Psychological (major), Attitude to Health (major), Pain -- prevention & control (major), Pain -- psychology (major), Self Care -- psychology (major)

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