

## LITERATURE REVIEW

# Pain Management Programmes for Non-English- Speaking Black and Minority Ethnic Groups with Long-Term or Chronic Pain

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### Abstract

Increasing ethnic diversity in the UK means that there is a growing need for National Health Service care to be delivered to non-English-speaking patients. The aims of the present systematic review were to: (1) better understand the outcomes of chronic pain management programmes (PMPs) for ethnic minority and non-English speaking patients and (2) explore the perspectives on and experiences of chronic pain for these groups. A systematic review identified 26 papers meeting the inclusion criteria; no papers reported on the outcomes of PMPs delivered in the UK. Of the papers obtained, four reported on PMPs conducted outside the UK; eight reported on ethnic differences in patients seeking support from pain management services in America; and the remaining papers included literature reviews, an experimental pain study, a collaborative enquiry, and a survey of patient and clinician ratings of pain. The findings indicate a lack of research into UK-based pain management for ethnic minorities and non-English-speaking patients. The literature suggests that effective PMPs must be tailored to meet cultural experiences of pain and beliefs about pain management. There is a need for further research to explore these cultural beliefs in non-English-speaking groups in the UK. Culturally sensitive evaluations of interpreted PMPs with long-term follow-up are needed to assess the effectiveness of current provision.

### Keywords

Chronic pain; pain management; ethnicity; culture

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## Introduction

Experiencing chronic or long-term pain has negative implications for quality of life and has been shown to impact

on a number of factors, including physical and mental health and the ability to work (Breivik et al., 2006). Multidisciplinary pain management programmes (PMPs), commonly incorporating cognitive behavioural therapy (CBT), have been used effectively to improve health-related outcomes, including pain intensity, for people with chronic pain (Hoffman et al., 2007). In addition, CBT pain management interventions have been shown to improve mood, reduce disability and reduce catastrophic thinking when compared with waiting list controls (Williams et al., 2012). The British Pain Society recommends multidisciplinary PMPs for chronic pain management in the UK (British Pain Society, 2013). However, this type of intervention has been traditionally developed for and evaluated with white, Western, English-speaking individuals, and little is known about PMP effectiveness for other cultural and ethnic groups. Ethnic diversity in the UK is growing; the 2011 census of England and Wales revealed that 7.7% of the population reported a language other than English as their first language, 1.3% could not speak English well and a further 0.3% could not speak English at all. Certain areas of the UK, including London and Birmingham, have higher levels of people unable to speak English well or at all (4.1% and 2%, respectively) (Office for National Statistics, 2013). This changing population demographic means that there is a growing need for the use of interpreters in National Health Service (NHS) care. One community healthcare NHS trust pain service in the UK has been delivering PMPs for a number of years and has found that delivering standard PMPs to non-English speaking minority ethnic groups via the use of interpreters can be problematic. Their experience suggests that attendance can be limited due to family and religious reasons, with attendees often reporting back to their general practitioner (GP) with pain symptoms within 12–18 months of the PMP. There are also concerns about whether the Western definition of self

management, traditionally used in PMPs, is or can be understood by ethnic minority groups (personal communication, 2014).

The present literature review was conducted to provide further information on the outcomes of PMPs for ethnic groups which represent minority populations within the UK. Enhanced knowledge of this evidence base will aid the tailoring of PMPs better to suit the needs of non-English-speaking people with chronic pain, improve pain-related outcomes and reduce the number of patients returning to their GPs with pain related concerns following PMP completion.

## Method

### Search strategy

A systematic review of the databases Web of Science, CINAHL, OVID, PsycArticles and PubMed was conducted between January and February 2014. Search terms were derived using the CHIP (context, how, issues, populations; Shaw, 2010) tool, which aids the generation of key terms relating to the context, methods (how), issues and populations used in research studies. Search terms included: pain, chronic pain, pain management, interventions, Asian, Somalia, Arabic, African American, ethnic difference and ethnicity. In addition, reference lists of all relevant papers were searched manually for studies meeting the inclusion criteria. No date restrictions were applied for the literature search.

### Inclusion criteria

Inclusion criteria were kept purposefully broad in order not to exclude any papers which may have been able to contribute to an improved understanding of PMPs for these groups. Criteria were: (1) Papers had to report on participants who would represent a minority ethnic group in the UK; (2) Papers had to include either a report of outcome measures of participants who had completed a PMP or information relevant to the experiences of individuals presenting for treatment for chronic pain.

### Search results

A flowchart of the search results can be seen in Figure 1.

The initial searches yielded 2,237 papers. Duplicates were excluded and titles were read for relevance, resulting in 53 potential papers. The abstracts of these papers were reviewed and a further 28 papers were deemed irrelevant and rejected (see Figure 1 for details).

Full texts were sought for the remaining 25 papers and 16 met the inclusion criteria (three of these could not be obtained: Bates and Edwards, 1992; Gor et al., 2009; Ogala-Echejoh and Schofield, 2010). Reference lists of the 13 obtainable papers were reviewed and 12 papers were included in the review (one could not be obtained: Kodiath and Kodiath, 1992). A final Google Scholar search found one further paper, resulting in a total of 26 papers. Of the papers obtained, four reported on the results of PMPs and eight reported on ethnic differences in individuals seeking pain management services. The remaining papers included literature reviews (n = 11), an experimental pain study, a collaborative enquiry study focused on cultural attitudes to communication and the interpretation of pain, and a survey of patient and clinician ratings of pain comparing black and non-black patients in America.

## Findings

### Evaluations of multidisciplinary PMPs

Four examples of multidisciplinary PMPs for individuals who would represent minority ethnic groups in the UK were identified; one was delivered in Hong Kong (Man et al., 2007), one in America (Merry et al., 2011), one in Japan (Kitahara et al., 2006) and one in Malaysia (Cardosa et al., 2012). No papers were identified evaluating PMPs delivered in the UK. Summaries for these papers can be seen in Table 1.

### Participant samples

Participants were recruited through referral to healthcare services (two pain management services and two hospitals). The mean age ranged from 40.2 to 55, with a slight majority female in three studies and male in one study (Merry et al., 2011). A range of ethnic groups were included in the programmes: white American, African-American, Malay, Chinese, Indian, Japanese and people from Hong Kong. Three studies described the sites of

pain reported by participants, with the majority reporting back pain. Other pain sources included: head, neck, legs, chest and multiple pain sites. One study did not provide information about pain locations (Kitahara et al., 2006).

#### Intervention delivery

Three of the interventions were based on a group therapy model and one used individual one-to-one therapy (Kitahara et al., 2006). All interventions involved multiple sessions over a number of weeks; however, a number of approaches to the length of sessions were used, ranging from 30 minutes to full days. All interventions were delivered by multidisciplinary teams and professions involved included: pain specialists, physiotherapists, clinical psychologists, pain nurses, psychiatrists, surgeons, occupational therapists and medical social workers.

#### Intervention content

All interventions included education about pain, action planning/goal setting activities and graded exercise. Two referred explicitly to the use of CBT (Kitahara et al., 2006; Merry et al., 2011); however, all appeared to use cognitive behavioural techniques (reconceptualization of pain, identifying and challenging unhelpful cognitions, relaxation etc). One reported encouraging participants to withdraw from the use of medication (Cardosa et al., 2012) and two described including medication management information (Cardosa et al., 2012; Merry et al., 2011). One included training in communication and coping strategies (Man et al., 2007) and another included inter-disciplinary meetings to discuss the progress of individual participants where necessary (Kitahara et al., 2006). The content of the interventions tended to follow a set programme delivered consistently to all participants. However, one intervention tailored the exercise, long- and short-term goals and medication management aspects of the PMP according to the individuals' physical condition, social situation and medication intake (Kitahara et al., 2006). The individually delivered rather than group therapy nature of this intervention enabled tailoring such as this to be easily included. Most interventions finished following the delivery of scheduled sessions, however, one reported including reviews at one, six and 12 months in which participants were encouraged to keep up with the management strategies covered on the course (Man et al., 2007). Another described including family members during one of the sessions; the purpose of this was for family members to act as support for the participant in continuing self-management following the end of the PMP (Cardosa et al., 2012). The majority of interventions were delivered in the participant's own language; however, one delivered some sessions in English to non-English-speaking participants, with intervention content interpreted by local staff (Cardosa et al., 2012).

#### Intervention outcomes

A range of outcome measures, generally using prevalidated questionnaires, were used (see Table 1 for further details) and all studies reported positive outcomes for patients with either reduced levels of disability or increased levels of activities of daily living immediately following the intervention. Other positive outcomes included: increases in pain self-efficacy (Cardosa et al., 2012; Man et al., 2007), improvements in employment (Kitahara et al., 2006; Man et al., 2007), reductions in pain ratings or increased pain relief (Cardosa et al., 2012; Kitahara et al., 2006; Man et al., 2007), reductions in depression and anxiety (Cardosa et al., 2012; Merry et al., 2011), improvements in physical abilities (Kitahara et al., 2006), reduced use of pain medication (Kitahara et al., 2006) and significant improvements in pain catastrophizing (Cardosa et al., 2012). In one study, positive long-term outcomes were reported for physical abilities and levels of pain catastrophizing at both six and 12 months (Man et al., 2007); however, most interventions did not report long-term follow-up. Only one study compared participant outcomes across ethnic groups and reported that, while black and white Americans alike experienced improvements in depression levels and pain interference following the PMP, only white participants reported a reduction in pain severity (Merry et al., 2011).

#### Studies comparing the characteristics of ethnic groups presenting for pain management or undergoing pain management treatment

Eight studies compared the characteristics of different ethnic groups either already undergoing PMPs or presenting for pain management services (a summary of these papers can be seen in Table 2). All of these studies were conducted in America, where there is no universal system of healthcare coverage, and, while some federally funded programmes exist (i.e. Medicare and Medicaid), it is generally down to individuals to obtain health insurance. Therefore, learning from these studies should only be applied with caution to the free-at-the-point-of-access NHS care provided in the UK.

## Participants

The majority of the papers included comparisons of white and black Americans (Baker and Green, 2005; Green et al., 2003a, 2004; McCracken et al., 2001; Ndao-Brumblay and Green, 2005; Riley et al., 2002). However, some other ethnic groups were compared, including: Hispanic (Bates et al., 1993; Edwards et al., 2005), Irish, Italian, French-Canadian and Polish (Bates et al., 1993).

## Age and gender

Participants in all the comparison studies were aged over 18 years, with means ranging from 36 to 53. There was one exception in which younger and older participants were compared, and a mean age of 63 for the older white American participants was reported (Baker and Green, 2005). Gender balance tended to be evenly split, with a 50/50 or 60/40 distribution; however, one study included a 100% female sample (Ndao-Brumblay and Green, 2005).

## Measures

A wide range of measures were used, with most studies including a measure of pain intensity. Other aspects of the pain experience were also recorded including: physical and psychological symptoms of pain, impact on life, impact on daily activities, pain disability, overt pain behaviour, the degree of social reinforcement of pain behaviour, reduction in family-related responsibilities, the impact of rest and avoidance activities on pain, coping strategies, anxiety, depression, locus of control, and emotional distress.

## Study findings

Several studies reported greater pain intensity in black American participants (McCracken et al., 2001; Ndao-Brumblay and Green, 2005). However, when comparison groups were matched in relation to age, pain location, gender, education level, work status and pain duration, these differences were not reported, suggesting that ethnic differences in pain and distress may be explained by differences in factors other than ethnic group (Edwards et al., 2005). Regardless of ethnicity, greater distress was associated with greater pain severity, greater pain affect and more disability (Edwards et al., 2005).

There were ethnic group differences reported in both attitudes towards and behavioural and psychological responses to pain (Bates et al., 1993). For example, black patients have been reported to differ in pain beliefs (Green et al., 2003a, 2004), report more avoidance, fearful thinking, anxiety and physical symptom complaints (McCracken et al., 2001) and show the strongest link between emotional distress and pain behaviour (Riley et al., 2002) than white patients. In addition, black women have been reported to experience greater levels of psychosocial distress due to pain and more functional impairment (Ndao-Brumblay and Green, 2005). These variations in the experience of pain may be partly explained by the differences in approaches to coping evident in the studies reviewed. For example, the use of praying and hoping as a coping technique is positively related to disability and increased distress in some ethnic groups, and this type of coping may be particularly important for some individuals (Edwards et al., 2005). In addition, the tendency to catastrophize as shown to predict elevated distress and higher levels of affective pain in pain clinic participants, suggesting that working to improve mood and reduce catastrophizing may be an important element for helping individuals to manage their pain (Edwards et al., 2005). The extent to which people with chronic pain attribute control of their pain to internal and external factors was also reported to be related to pain intensity, with participants with a more external locus of control perceiving pain to be of higher intensity (Bates et al., 1993). There are two possible explanations for this relationship: high-intensity pain may result in a belief that a person is unable to control their pain, or beliefs about the inability to control pain may influence pain perception; more research is needed to establish causality in this relationship. Despite this, the locus of control in relation to pain was reported to vary by ethnic group in participants living in America, with Italian, French-Canadian, Irish and Polish participants reporting a higher internal locus of control and Hispanic participants reporting a higher external locus of control, suggesting that ethnic background, including socialization and experiences of being a group member, may influence the locus of control style (Bates et al., 1993).

Overall, the studies illustrated that the differences reported between ethnic groups seeking pain management services are likely to be explained by variables other than ethnic label. This is supported by the within-group differences reported (Baker and Green, 2005; Bates et al., 1993; Edwards et al., 2005), and evidence that,

when other variables were accounted for, there were no differences in pain and distress (Edwards et al., 2005). Therefore, more attention needs to be paid to other issues, including an individual's history, culture, age, socioeconomic status, family environment and coping styles, in order to explain individual differences in reported pain intensity, impact of pain and levels of distress. Findings from the other research into the chronic pain experiences of different ethnic groups

### Ethnic differences in pain experience

Clinical and laboratory studies have reported ethnic differences in pain perception, with more pain response generally reported by African-American, Hispanic, American-Indian, Alaskan native, Chinese, Indian and Asian-American participants (e.g. Campbell and Edwards, 2012; Edwards et al., 2005; Green et al., 2003b). This finding has been confirmed across multiple experimental pain stimulus modalities (Campbell et al., 2005) and some evidence suggests that these differences may be due to enhanced physiological pain sensitivity and specific neurobiological processes (Campbell and Edwards, 2012). There is also evidence of significant disagreements between ethnic minority individuals and healthcare professionals (HCPs) in relation to pain level ratings, even when HCPs have access to patients' reports of pain intensity (Staton et al., 2007). This is particularly the case for black individuals who may be at risk of under-treatment of pain in primary care settings (Staton et al., 2007).

The majority of research to date has been conducted in American populations, and other ethnic groups have been under-researched in relation to chronic pain. Therefore, the application of existing research to the UK cultural context is unclear. In particular, very little research has looked at Asian experiences of pain and pain management. One review by Njobvu et al. (1999) suggested that, with regard to pain symptoms, Asian patients in the UK tend to visit GPs more than white European populations but are less likely to attend emergency departments, choosing only to attend these services on referral from their GP. In addition, the review suggested that, compared with white British individuals Asian individuals experience higher levels of pain and lower pain tolerance, Asian women report experiencing more musculoskeletal conditions and Asian people are more likely to express pain somatically (presentation of bodily symptoms). However, as discussed earlier, these differences may be explained by factors other than ethnicity itself (age, socioeconomic status etc).

### Ethnic differences in coping with pain

It has been found that individuals with strong non-Western ethnic identities do not attribute the same meaning to pain or exhibit the same response to pain as those assimilated to dominant Western cultures (Bates et al., 1993). Biological, social and psychological mechanisms have all been reported to play a role in these observed ethnic differences in pain response (Edwards et al., 2001). One important social mechanism is culture; cultural beliefs about the meaning of pain can influence pain management decisions; for example, a person who believes that by enduring pain they will be given more merit in life after death will manage pain differently to someone who does not believe in the existence of an afterlife (Narayan, 2010).

There are cross-cultural differences in both the meaning ascribed to pain and the coping styles employed, suggesting that pain behaviours may be culturally dependent (Callister, 2003; Green et al., 2003b). In addition, certain ethnic groups have been suggested to rely more heavily on specific types of pain management strategy; for example, evidence suggests that African-American patients are more likely to use passive coping (Campbell and Edwards, 2012), praying and hoping (Edwards et al., 2005), and religious coping strategies (Edwards et al., 2001). The coping style used by a patient may moderate the relationship between ethnicity and pain, with those using passive 'catastrophizing' strategies more likely to experience negative outcomes (Campbell et al 2005; Edwards et al., 2005).

### Religious coping

Religion can play a key role in the experience of and response to pain, and religious coping has been found to be particularly important among some ethnic minority groups in America. For example, the use of praying as a coping strategy has been related to negative outcomes, including greater pain severity, higher levels of affective pain and greater disability (Edwards et al., 2005). While the directional relationship here is unclear, the association reported is important and should be taken into account when developing pain management services.

Koenig (2003, cited in Unruh) has proposed four common misconceptions about pain management held by individuals with strong religious views: 1) reluctance or refusal to take pain medication owing to fears about addictions; 2) beliefs that pain should only be dealt with in spiritual terms (i.e. the use of medication is not allowed as it would be relying on something other than God); 3) beliefs that pain should not be relieved because the experience of pain may result in spiritual growth; 4) experiences of persistent pain being regarded as a sign that faith is not strong enough or a punishment by God. If the pain management approach promoted is at odds with religious views, then acceptance of these strategies may not occur (Unruh, 2007). To address this issue, an open discussion of religious and spiritual beliefs with individuals with chronic pain is needed and, rather than ignoring or challenging beliefs, they should be incorporated into PMPs. Unruh (2007) suggested that one way to achieve this is to show patients that, by managing their pain, they will be able better to serve others as part of their spiritual commitments.

### The need for culturally sensitive pain Management.

A number of authors have stressed the need for culturally sensitive pain assessment and management. The acknowledgement of cultural difference in the pain experience by HCPs is central to this (Callister, 2003; Davidhizar and Giger, 2004). Currently, there is a danger that cultural differences between the HCP and the patient may lead to an under- or over-treatment of pain (e.g. Edwards et al., 2005), resulting from a lack of understanding in the patient-provider relationship and pain-management decisions based on stereotypical assumptions (Callister, 2003).

Cultural background can determine how pain experience is communicated to others, with some ethnic groups being more likely to verbalize pain and others more likely to take a more stoic approach. One study with HCPs illustrated that cultural views about pain experience and causes can exist alongside medical ones and that it is cultural views that are likely to dominate the pain experience in terms of the response to pain and its management, even for the HCPs themselves (Lovering, 2006). It is important to be aware of individuals' cultural frames of reference and how these might influence pain management decisions. Many cultures hold non-Western beliefs about how to manage pain, and these should be explored and acknowledged within PMPs. Respecting these cultural norms will promote a feeling in PMP attendees of being valued and therefore enhance compliance (Narayan, 2010). In addition, the placebo effect illustrates that what we think works, often does work and therefore engaging in these non-harmful cultural practices is likely to be beneficial for pain management when the patient believes they will work (Narayan, 2010).

Davidhizar and Giger (2004) proposed a number of strategies for increasing cultural sensitivity in pain management: the use of culturally relevant pain assessment tools; appreciation of differences in affective pain response (such as stoicism or emotive responses); sensitivity to variation in communication style between different cultures; a recognition that the communication of pain is not acceptable in some cultures; appreciation of the differences in the meaning of pain to different groups; and using the knowledge of biological variations in pain when assisting specific individuals. Similarly, Weissman et al. (2004) suggested five requirements of professionals offering culturally competent care: 1) awareness of their own cultural and family values; 2) awareness of their personal biases and assumptions about people with different values than theirs; 3) awareness and acceptance of cultural differences between themselves and individual patients; 4) capability of understanding the dynamics of this difference; 5) ability to adapt to diversity.

Different cultural groups use different cognitive frameworks (e.g. definition of words) in order to conceptualize and describe their pain (Narayan, 2010); this may help to explain the differences in reports of intensity between patients and HCPs, especially if individuals come from different cultural groups. This is important for PMPs as ethnic minority patients may not have had the same level of management in terms of medication from GPs as non-minority patients, therefore resulting in disparities in the outcomes of PMPs and a higher likelihood of a return to GPs at a later stage for modifications to pain medications.

### Discussion

The present review has highlighted that PMPs with individuals from a number of different cultural groups can be successful and can improve health outcomes. However, without follow-up it is impossible to say whether PMPs can be effective in the long term. For example, Merry et al. (2011) reported changes in behaviour (i.e.

reduced interference in daily life) for black Americans without changes in cognition (i.e. perceived severity of pain) and, in line with cognitive behavioural theory, it may be expected that this type of change may not be maintained in the long term owing to the lack of change in underlying cognition. Only two of the programmes reviewed included follow-up (Cardosa et al., 2012; Man et al., 2007) and, while these data go some way to suggest that PMPs can be effective in the long term, this type of research design needs to be adopted across all intervention valuation studies in order to strengthen the evidence base. PMPs need to include full training for staff to ensure that information is provided consistently. One study ensured this by including a two-day refresher course in cognitive behavioural techniques prior to delivering the intervention (Cardosa et al., 2012); another included training, peer observation by the delivery team, and an intervention manual to encourage reinforcement of all aspects of the PMP by all team members (Man et al., 2007). Another asked staff to ensure consistency by encouraging systematic reinforcement of achievements (through praise) and avoiding reinforcing pain behaviours (Kitahara et al., 2006).

Cognitive behavioural approaches were used within all of the interventions; however, some of the studies acknowledged that this model of behaviour change has been mainly developed and evaluated within Western populations. Two interventions included steps to modify the PMP in line with cultural beliefs. Cardosa et al. (2012) included elements of local religious practices within deep-breathing exercises and challenged the concept of 'total surrender to God' and fate beliefs by using the religious teachings of 'self-responsibility' or 'self-effort' consistent with self management approaches. Kitahara et al. (2006) did not involve family in the PMP as this currently occurs only in psychiatric care in Japan and the authors did not want participants or family members to think that pain was a psychiatric illness and experience stigma. From these studies, it is clear that successful PMPs should develop central concepts of pain management in a way that complements the language, culture, attitudes and concepts of the targeted group.

In order to be successful PMPs need to acknowledge ethnic and cultural differences in pain perceptions and experiences. There is a need for cultural sensitivity which takes into account individuals' expressions of pain, religion and language (Briggs, 2008). This is particularly important when working with recent immigrants and first-generation decedents of immigrants as these individuals are likely to maintain strong ethnic ties (Bates et al., 1993). Despite this, caution must be used to avoid unhelpful stereotyping; within-ethnic group variations in experience must not be ignored (Bates et al., 1993). Cultural cognitive frameworks (such as language) play a huge role in the understanding of pain and how it should be managed. Often, those delivering PMPs have a different frame of reference to those participating.

Language differences are usually addressed by the provision of an interpreter; however, it is also important that interpreters are familiar with the aims and outcomes of the PMP to ensure that interpreting does not lead to information being misunderstood (Narayan, 2010). One solution here may be the use of expert patients who have been part of the PMP and have made beneficial changes to their pain management techniques as a result. These individuals would understand the programme, understand the cultural frames of reference of the participants and be able to translate information in a way that is aligned with the PMP aims and understood by the participants. Generally, there has been a lack of research into pain management for ethnic minorities within the UK. There is a need for further research to explore the cultural beliefs about pain and perceptions of pain management in ethnic minority groups in the UK in order to inform PMPs. In addition, full evaluations of PMPs for ethnic minority groups should be a priority in order to assess the effectiveness of current provision. However, the evaluation of PMPs is challenging and there is a need for language- and culturally specific tools to be used (Briggs, 2008; Davidhizar and Giger, 2004). In addition, research has traditionally focused on the ethnicity of the individual with chronic pain and the relationship between this and pain outcomes. Some researchers have stressed the likely interaction between participant and HCP ethnicity and pain outcomes and argued for more exploration of the impact of providers' race and ethnicity on pain outcomes in future research studies (Edwards et al., 2001).

In conclusion, the literature reviewed highlighted four key recommendations for the development of PMPs for non-English-speaking individuals with chronic or long-term pain: (1) Delivery of PMPs should take into account the cultural, spiritual and religious beliefs of patients in relation to the experiences and causes of pain and how this can be managed. These issues need to be researched in the target population, recognized and discussed with participants, and, where relevant, incorporated into the content of PMPs; (2) In order to ensure long-term success, PMP participants need to be engaged in follow-up assessment of their progress in order to discuss

challenges and remind them of the teaching delivered as part of the PMP; (3) Teams delivering PMPs (including interpreters, where required) should be fully educated about all aspects of the programme in order consistently to reinforce positive behaviour change and intervene when harmful detrimental behaviours are exhibited by participants;(4) Evaluation tools chosen for PMPs need to be culturally sensitive. For example, in multicultural groups, the use of visual analogue scales could be used to assess changes in beliefs and behaviours in a way that reduces the risk of miscommunication.

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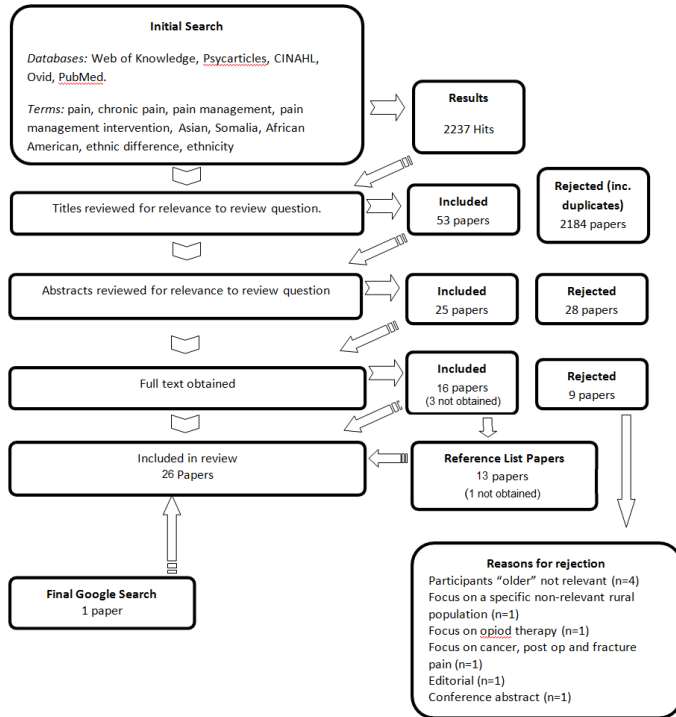
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Figure 1: Search Flow Chart



## APPENDIX 1: TABLE OF INTERVENTION STUDIES

| Study        |                            | Cardosa et al., 2012   | Merry et al., (2011)   | Kitahara, Kojima, Ohmura (2006)   | Man et al., (2007)  |
|--------------|----------------------------|--|--|---|---|
| Location     |                            | Malaysia   | America  | Japan   | Hong Kong   |
| Participants | Recruitment                | Majority Ambulatory patients in hospital<br><br>N=70/102 (70%)   | Patients attending a multi-disciplinary pain treatment programme<br><br>N=155 (no information about non-participators)                 | Patients referred to pain clinic (n=74 completed after 25 drop outs)<br><br>N=74/99 (74%)                         | Patients at a Hong Kong hospital<br><br>N= 45/49 (92%)  |
|              | Mean age, gender ethnicity | Mean Age:42.87 (Range not reported, SD 9.87)<br><br>M:36%<br>F:64%<br><br>Malay (37%)<br>Chinese (13%)<br>Indian (50%)               | Mean Age: 40.2 (range 21-56)<br><br>M:61%<br>F: 49%<br><br>White (82%)<br>African-American (18%)                                       | Mean Age: 55 (range 14-86)<br><br>M: 48%<br>F: 62%<br><br>No ethnicity information- reported as Japanese patients | Mean age: 42 (range 23-57)<br><br>M: 33%<br>F: 67%<br><br>No ethnicity information  |
|              | Pain                       | Persistent pain >3months<br><br>Pain sites:<br>Head (6%)<br>Neck/ upper limb (21%)<br>Back/ lower limb (54%)<br>>two pain sites (3%) | Pain persistent for a number of years<br><br>Pain sites:<br>Low back (60%)<br>Head (14%)<br>Leg (11%)<br>Upper limb (11%)<br>Neck (5%) | Previous non-successful therapy for non-cancer pain<br><br>Pain sites:<br>No information given                    | Median duration of pain: 46 months<br><br>Pain sites:<br>Back (56%)<br>Limbs (22%)<br>Neck (6%)<br>Chest (4%)<br>Multiple sites (4%)<br>Others (4%) |

| Intervention | Length and delivery type | 10 days over 2 weeks<br><br>Group therapy | 4 week programme (approx.)<br><br>Group therapy (4-8 participants) | 30 minute sessions every 1-3 weeks on 8-12 occasions<br><br>Individual therapy with one care provider | 14 full days (9:00-16:30) of structured outpatient sessions over a 6 week period.<br><br>Group therapy. |
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|  | <p>Content</p> | <ul style="list-style-type: none"> <li>-Some sessions delivered in English with translation by local staff</li> <li>-Team meetings to discuss patients issues and difficulties including understanding of the content and concepts of the programme</li> <li>-Family members encouraged to attend for at least 1 day- enlisted to support self-management approach post-programme</li> <li>-Emphasised: re-conceptualisation of the pain (as chronic but not harmful), education about pain, goal setting, applied relaxation and desensitisation training, training in identifying and challenging unhelpful cognitions (beliefs, thought processes), practising effective problem-solving and pain management strategies (e.g. activity pacing, daily planning), programmed exercise and systematic encouragement of activities to limit avoidance behaviours and to regain confidence in functioning despite pain.</li> <li>- Medication withdrawal encouraged.</li> </ul> | <ul style="list-style-type: none"> <li>-Informational sessions covering; psychological and behavioural components of pain, cognitive-behavioural group therapy, medication management.</li> <li>-Exercise sessions of increasing intensity</li> </ul> | <ul style="list-style-type: none"> <li>- Interdisciplinary conferences with other specialists for individual patients if required</li> <li>-Based on the biopsychosocial model targeting 5 components;</li> <li>Education: about specific diagnosis, background of diagnosis, diagnosis-specific treatment strategies, differences between chronic and acute pain, the influence of disuse, importance of physical activity and necessary and unnecessary medication.</li> <li>Exercise: stretching, strengthening upper limbs with weights, strengthening lower limbs with squats and walking. Increased on a quota system as patient progresses.</li> <li>Long-term and short-term goal setting: longer term (i.e. back to work, admission to college), short term (i.e. increase walking distance, going out daily shopping).</li> <li>Medication management</li> <li>Cognitive and behavioural techniques: reframing, relaxation techniques, breathing techniques, positive imagining. Focus on reduction of fear associated with musculoskeletal pain.</li> <li>-Education and cognitive and behavioural techniques were the same for all patients.</li> <li>-Exercise, long and short term goals and medication management were tailored according to individual physical condition, social situation, and medication intake.</li> <li>-Staff systematically praise and reinforce achievements and avoided reinforcing pain behaviours.</li> <li>Staff systematically praise and reinforce achievements and avoided reinforcing pain behaviours.</li> </ul> | <p>Out-patient sessions including:</p> <ul style="list-style-type: none"> <li>-Pain education</li> <li>-Training in communication skills and coping strategies (cognitive reconceptualization of pain, goal and action planning, activity pacing, thought challenging exercises, desensitisation, relaxation techniques)</li> <li>-graded physical exercises and functional activities training</li> </ul> <p>Review at 1, 6 and 12 months where patients were encouraged to keep up with the pain management strategies learnt on the course.</p> |
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|          | Delivered by | pain specialist, physiotherapist, clinical psychologist, psychiatrist, pain nurse   | Clinical psychologist, physical therapists  | <p>Psychosocial aspects delivered by trained anaesthesiologist (due to lack of clinical psychologists in Japan)</p> <p>Interdisciplinary conferences with other specialists (e.g. psychiatrist, surgeon, physical therapist, medical social worker) for individual patients if required</p>   | Pain nurses, pain specialist, clinical psychologist, physiotherapist, occupational therapist, medical social worker.  |
| Outcomes |              | <p>Pre-post intervention self-report data collection (1 month and 1 year follow up)</p> <p>Significant improvements at 1 month and 1 year follow up in:</p> <ul style="list-style-type: none"> <li>-Numerical pain rating (0-10 scale)</li> <li>-Disability (Roland and Morris Disability Questionnaire)</li> <li>-Depression, anxiety and stress (Depression Anxiety and Stress Scale)</li> <li>-Pain Self-efficacy questionnaire</li> <li>-Coping and catastrophising (Pain-related self statements)</li> </ul> | <p>Pre-post intervention self-report data collection</p> <p>Significant improvements for all patients in:</p> <ul style="list-style-type: none"> <li>-depression scores (Beck depression inventory)</li> <li>-Pain-interference (Multidimensional pain inventory)</li> </ul> <p>Significant improvements for white patients only in:</p> <ul style="list-style-type: none"> <li>-Pain severity (Multidimensional pain inventory)</li> </ul> | <p>Pre-post intervention self-report data collection</p> <p>Improvements in</p> <ul style="list-style-type: none"> <li>-Pain relief (6-point verbal pain relief score)</li> <li>-use of pain medications (reduction in use for 75% of patients)</li> <li>-Enjoyment of travelling/shopping, sleep disturbance, interference in activities of daily living (activities of daily living questionnaire)</li> <li>-walking ability and ambulatory distance</li> <li>-Employment levels</li> </ul> | <p>Pre-post intervention self-report data collection (6 and 12 month follow up)</p> <p>Significant improvements in:</p> <ul style="list-style-type: none"> <li>-Catastrophizing from baseline to 6 and 12 months (Pain Catastrophizing Scale)</li> <li>-Efficacy from baseline to 1 month (Pateint Self Efficacy Questionnaire)</li> <li>-satisfaction and performance from baseline to 1, 6 and 12 months (Canadian Occupational Performance Measure)</li> <li>-Functional tolerances from baseline to 1, 6 and 12 months (duration sitting and standing)</li> <li>-physical and role emotional health related quality of life at 6 and 12 months (Medical Outcome Survey Short Form 35)</li> <li>-Work status (from 4-22% in work)</li> </ul> |

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| <p>Learning Points</p> |  | <ul style="list-style-type: none"> <li>- Programme staff given a 2 day refresher course in cognitive behavioural methods</li> <li>-Local cultural beliefs were addressed in applying the intervention. Religious practices (i.e. meditation) incorporated into deep breathing exercises/ concept of 'total surrender to god' and fate beliefs challenged by religious teachings of 'self-responsibility- or 'self-effort' consistent with self-management.</li> </ul> | <p>Significant improvements in depression for African American patients despite no reduction in severity of pain (approaching significance).</p> <p>-Change in behaviour for some patients but not in cognitions (i.e. perceptions of pain severity). May not be maintained long term due to lack of change in underlying cognitions</p> | <p>Three cultural modifications made (compared to western programmes).</p> <ul style="list-style-type: none"> <li>-Vocational counselling not included (new idea in Japan and no resources are available to support this)</li> <li>-Family not involved in treatment (currently only occurs in psychiatric care in Japan and did not want to stigmatize patients or family members into thinking pain was a psychiatric illness)</li> <li>-Medication management focuses on all medications taken by the patient (not just those for pain) to improve side effects and reduce pain.</li> </ul> | <ul style="list-style-type: none"> <li>-need to encourage patients to continue using the strategies after the programme ends (i.e. through a maintenance plan)</li> <li>-All staff members need to be consistent to avoid confusing patients and reinforce all aspects of the programme (a manual created to aid this)</li> </ul> |
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APPENDIX 2: TABLE OF PAPERS REVIEWING DIFFERENCES BETWEEN ETHNIC GROUPS ATTENDING FOR OR RECEIVING PAIN MANAGEMENT SERVICES

| Study                | Aim  | Country | Groups compared                   | Demographics   | Measures  | Results  | Conclusions  |
|----------------------|--|---------|-----------------------------------|--|---|--|--|
| Baker & Green (2005) | Examine specific within-race-group differences across age groups | America | -Black American, - White American | -Younger group <49 years<br>-Black (n=361); Mean age: 36.7<br>M: 30%, F: 70%<br>-White (n=3392); Mean age: 46.6<br>M: 40%, F:60%<br><br>-Older group >50 years<br>-Black (n=164); Mean age: 60<br>M: 41%, F: 59%<br>-White (n=1906); Mean age: 63<br>M: 40%, F:60% | - <i>Pain intensity</i> : McGill Pain Questionnaire<br>- <i>Pain disability</i> : Pain Disability Index (amount of interference a patient has with normal role functioning due to pain)<br>- <i>Pain related suffering, coping and control</i> : 3 single items<br>- <i>Depression</i> : Beck Depression Inventory<br>- <i>Post-traumatic stress</i> : Post-Traumatic Chronic Pain Test<br>- <i>Physical comorbidities</i> : Checklist<br>- <i>Problems with sleep</i> : 4 items<br>- <i>Specific social behaviours</i> : single items (i.e. alcohol) | -Younger black Americans reported more pain intensity and depressive symptoms than older black Americans<br>-Older black Americans reported better ability to cope with pain than younger black Americans. | -Considerable within-group variation in pain intensity and depressive symptoms<br>-Variability may result from differences in levels of coping skills.<br>-Older adults may have acclimated to higher pain thresholds therefore having lower expectations about physical abilities |



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| <p>Bates, Edwards and Anderson (1993)</p> | <p>Explore cultural differences in perception of chronic pain intensity and if sociodemographic, psychological and medical variables serve as predictors of intra-ethnic group variation in pain intensity</p> | <p>America</p> | <p>-American -<br/>-Hispanic<br/>-Irish<br/>-Italian<br/>-French-Canadian<br/>-Polish</p> | <p>-American (n=100)<br/>Mean age: 43.5<br/>M: 50%, F:50%<br/>-Hispanic (n=44)<br/>Mean age: 41.1<br/>M: 66%, F:34%<br/>-Irish (n=60)<br/>Mean age: 46.1<br/>M: 58%, F:42%<br/>-Italian (n=50)<br/>Mean age: 46.5<br/>M: 56%, F:44%<br/>-French Canadian (n=90)<br/>Mean age: 44.2<br/>M: 47%, F:53%<br/>-Polish (n=28)<br/>Mean age: 46.6<br/>M: 50%, F:50%</p> | <p><i>-Cultural and sociodemographic backgrounds and pain experiences and Locus of control:</i> Ethnicity and pain survey<br/><i>-Medical variables:</i> previous surgeries, previous treatments, current medication, diagnosis<br/><i>-Pain intensity:</i> McGill Pain Questionnaire (sensory and affective pain experience), Pain Control Centre Questionnaire (reported pain intensity at its worst, usual and least), Pain rating scale (0-10)</p> | <p>-Older patients reported lower pain intensity (MPQ)<br/>-Significant relationship between locus of control and ethnic identity<br/>- external locus of control reported higher pain intensity (measured by MPQ)<br/>-22% of variation in pain intensity was explained by age, ethnicity and locus of control (age did not remain significant as a predictor when controlling for ethnicity and locus of control)<br/>-Intra-ethnic differences in pain intensity were associated with heritage consistency and locus of control</p> | <p>-There are ethnic group differences in attitudes towards and behavioural and psychological responses to chronic pain.<br/>-attention to cultural differences in pain perceptions and experiences are essential if treatment programmes are to be successful. Particularly when working with recent immigrants, first generation descendants of immigrants, or patients who maintain strong ethnic ties.</p> |
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| <p>Edwards, Moric, Buvanendran &amp; Ivankovich (2005)</p> | <p>Evaluate group differences in coping, distress, and pain related variables when matched on: sex, pain location, age, education, work status, pain duration</p> | <p>America</p> | <p>-African-American<br/>-Hispanic<br/>-White</p> | <p>-African American (n=97)<br/>Mean age: 46.3<br/>M: 53%, F:47%<br/>-Hispanic (n=97)<br/>Mean age: 45.1<br/>M: 53%, F:47%<br/>-White (n=97)<br/>Mean age: 45.1<br/>M: 53%, F:47%</p> | <p><i>-Pain experience:</i> Multidimensional Pain Inventory (severity, impact on life, impact on daily activities)<br/><i>Pain intensity:</i> McGill Pain Questionnaire, Visual analogue scale (10cm)<br/><i>-Pain symptoms:</i> Brief symptom inventory (psychological symptomology, Global Severity Index)<br/><i>-Coping:</i> Coping strategies questionnaire (cognitive and behavioural strategies, active coping, passive coping)<br/><i>-Depression:</i> Beck depression inventory</p> | <p>-African Americans and Hispanics scored higher on praying and hoping coping subscales<br/>-Greater distress is associated with greater pain severity, greater pain affect, and more disability in all groups<br/>-Greater pain severity is associated with higher distress and more physical disability in all groups<br/>-White participants only showed significant positive relationship between affective pain and active coping<br/>-Prayer/hoping as a coping strategy was positively related to disability (and more distress only in African Americans)<br/>-Catastrophizing was a significant predictor of elevated distress and a moderate predictor of higher affective pain<br/>-Catastrophizing was related to greater pain severity only among African American and white patients</p> | <p>-No ethnic variation in distress or pain were found suggesting that these differences are a result of other variables than ethnicity<br/>-Religious coping may be particularly important among individuals from ethnic minorities<br/>-Greater use of praying and hoping as a coping strategy was generally related to greater pain severity, higher levels of affective pain, and predicted greater disability (in all groups)<br/>-Differences in coping styles may play some role in initiating and maintaining group differences in the experience of pain.<br/>-Ameliorating negative mood and reducing catastrophizing may be important across ethnic groups.</p> |
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| Green, Baker, Sato, Washington & Smith (2003) | Examine the influence of race on initial presentation at a multi-disciplinary pain centre   | America | -White American<br>-Black American | <p>White Americans (N=3316)<br/>Mean age: 36<br/>M: 40%, F:60%</p> <p>Black Americans (N=353)<br/>Mean age: 37<br/>M: 30%, F: 70%</p>   | <p><i>Pain intensity:</i> McGill Pain Questionnaire<br/><i>Pain disability:</i> Pain Disability Index (<math>\alpha=0.848</math>)<br/>Pain related suffering, coping and control: 3 single items<br/><i>Depression:</i> Beck Depression Inventory<br/><i>Post-traumatic stress:</i> Post-Traumatic Chronic Pain Test<br/><i>Physical co morbidities:</i> Checklist<br/><i>Problems with sleep:</i> 4 items<br/><i>Specific social behaviours:</i> single items (i.e. alcohol)</p> | <p>-Black Americans were significantly older, more likely to be male, and had significantly lower household income<br/>-Black Americans reported significantly more pain, suffering, disability, depressive symptoms, irritability, anxiety and significantly less control<br/>-No significant differences in coping ability even after controlling for pain severity</p>   | -There are differences in psychological functioning, pain characteristics, pain disability, and some co-morbidity between black and white Americans presenting for pain assessment. |
| Green, Baker & Ndao-Brumblay, (2004)          | Explore healthcare utilisation, sources of healthcare, access to pain treatment, attitudes and perceptions regarding pain management, and referral patterns | America | -White American<br>-Black American | <p>-Black Americans (n=150)<br/>Mean age: 47<br/>M: 32%, F: 68%</p> <p>-White Americans (n=136)<br/>Mean age: 53<br/>M: 32%, F: 68%</p> | <p>4 page 50-item questionnaire developed by the authors.</p> <p>Subscales included:<br/>-<i>Healthcare utilisation</i> (13 items)<br/>-<i>Financial and physical access</i> (5 items)<br/>- <i>attitudes and perceptions regarding pain management and regarding healthcare access</i> (13 items)</p>  | <p>-Black participants were significantly younger, lower income employment and education<br/>-Black patients significantly more likely to have visited another pain centre previously<br/>-Black women were more likely to agree that ethnicity/culture affected access to pain treatment<br/>-Black men were significantly more likely to agree that ethnicity/culture affected ability to control pain<br/>-Women were more likely to believe that gender affected health care access</p> | -Clear differences in health care experiences between black and white Americans   |

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| <p>McCraken, Matthews, Tang and Cuba (2001)</p> | <p>Compare the chronic pain experiences of patients presenting for chronic pain treatment</p> | <p>America</p> | <p>-White American<br/>-Black American</p> | <p>-Black Americans (n=57)<br/>Mean age: 47.3<br/>M: 27%, F: 73%</p> <p>-White Americans (n=207)<br/>Mean age: 46.6<br/>M: 46%, F: 64%</p> | <p>-Pain: 0-10 pain rating scale<br/>-Depression: Beck Depression Inventory<br/>-Physical symptoms associated with emotional distress: Modified somatic perception questionnaire<br/>-Pain anxiety – Pain anxiety symptoms scale (cognitive anxiety response, escape and avoidance, fearful thinking, psychological anxiety)<br/>-Illness impact on daily activities – Sickness impact profile</p> | <p>-no difference between groups for sex, pain location, previous surgeries, medical diagnosis, pain medications, receipt of wage replacement, involvement in litigation<br/>-Black patients reported higher pain, more avoidance, more fearful thinking, more anxiety, more physical symptom complaints, more physical, psychosocial and overall disability.<br/>-controlling for pain rating avoidance, fearful thinking, anxiety, physical symptom complaints remained significant<br/>-no difference between groups for depression, cognitive or physiological symptoms of anxiety or pain related physician visits.</p> | <p>-There are differences in adjustment to chronic pain between black and white patients seeking care<br/>-Black patients may suffer more severe symptoms before seeking treatment<br/>-Greater fear and avoidance may result in difference more negative perceptions of pain experience or differences in social circumstances, beliefs about pain, beliefs about self-management may produce differences in pain related avoidance, fear, physical symptoms.</p> |
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| <p>Ndao-Brumblay &amp; Green, (2005)</p> | <p>Identify racial differences in the chronic pain experience of women with chronic pain</p> | <p>America</p> | <p>-White American<br/>-Black American</p> | <p>White American (n=1192)<br/>Mean age: 43<br/>M: 0%, F: 100%</p> <p>Black American (n=104)<br/>Mean age: 41<br/>M: 0%, F: 100%</p> | <p>-<i>Pain intensity</i>: McGill Pain Questionnaire<br/>-<i>Disability</i>: Pain Disability Index<br/>-<i>Pain related suffering, coping and control</i>: 3 single items<br/>-<i>Depression</i>: Beck Depression Inventory<br/>-<i>Post Traumatic Stress</i>: Post-Traumatic Chronic Pain Test<br/>-<i>Physical co morbidities</i><br/>-<i>Problems with sleep</i></p> | <p>-Black women reported higher pain severity score and higher sensory pain and miscellaneous pain ratings.<br/>-Black women reported more disability due to pain and more pain interference with functioning<br/>-Black women reported more psychosocial distress due to pain<br/>-Black women reported more functional impairment which could be attributed to difference in coping.<br/>-higher depression levels in black women are mediated by disability, pain severity and affective distress.</p> | <p>-Poorer outcomes for black women are explained by the presence of psychological and physical factors<br/>-Managing the physical symptoms of black women early could reduce the racial differences in mental health conditions for chronic pain patients.</p> |
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| <p>Riley et al (2002)</p> | <p>Explore the pain experience and pain stages of patients with chronic pain</p> | <p>America</p> | <p>-White American<br/>-Black American</p> | <p>White American (n=1084)<br/>Mean age: 45.8<br/>M: 44%, F: 66%</p> <p>Black American (n=473)<br/>Mean age: 43.7<br/>M: 35%, F: 65%</p> | <p><i>-Pain intensity, pain unpleasantness, depression, anxiety, frustration, anger, fear: Visual analogue scales</i><br/><i>-Pain experience: Psychosocial Pain Inventory pain behaviour subscales (extent of overt pain behaviour manifested by the patient at home, degree of social reinforcement for illness behaviour, reduction in family related responsibilities, impact of rest and avoidance activity on pain)</i></p> | <p>-African Americans reported significantly higher levels of pain unpleasantness, emotional response to pain (depression, anxiety, anger and fear), and pain behaviour<br/>-No group differences were found for pain intensity</p> | <p>-African American patients showed the strongest link between emotions and pain behaviour. They also show greater levels of emotional suffering in response to similar levels of pain intensity.<br/>-perception of pain is less influenced by psychosocial factors than pain unpleasantness</p> |
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