

Experiences and self-management of chronic pain

By Claire Budge and Melanie Taylor

Introduction

In this article on chronic pain, we use the 2018 (year three) data from *Talking about Health*, a longitudinal study of people with long-term conditions (LTCs) in the MidCentral region.¹ The aims of this article are to:

- explore the prevalence of pain and co-morbidities in our sample
- see who is consulted for pain management
- describe the location of pain and circumstances in which it is experienced
- see how having pain relates to ratings of health and quality of life and self-care challenges of sleeping and anxiety/depression
- see how self-management of pain relates to ratings of health and quality of life and self-care challenges of sleeping and anxiety/depression
- share some of the advice participants offered

Measurement

Chronic pain is persistent or long-term pain that lasts for more than three months.² Pain as an LTC was self-identified by study participants on the initial consent form. In the study, general health (GH: single item with response

poor/fair/good/very good/excellent), physical health (PH: four-item scale) and mental health (MH: 4 item scale) were measured using the PROMIS Global SF.³ The effect of LTC/s on quality of life was measured with a single question, rated on a scale from 0 (no effect) to 10 (very large effect). A list of self-care challenges was provided and respondents were asked to tick each one that applied to them and to add extra ones as required. Pain self-management was measured with a single question asking how well people considered themselves to be managing their pain at home overall on a scale from 0 (not at all well) to 10 (extremely well).

In the second of a series of professional education articles based on the results of the *Talking about Health* study, the authors look at chronic pain, how it can be better managed, and how it relates to health and quality of life.

Results

Prevalence and comorbidity

Of the 370 participants remaining in the study by year three, 234 (63.2 per cent) had chronic pain, and of these, 147 (62.8 per cent) had arthritis, 90 (38.5 per cent) had another type of pain and 35 (15.0 per cent) had both. The presence of other LTCs for those experiencing chronic pain was high; eg 58.5 per cent also had hypertension, 44 per cent had diabetes, 35 per cent had a respiratory condition, 23.9 per cent had depression or anxiety related to having an LTC, 17.9 per cent had memory issues and 16.7 per



cent had angina. Over half the people with pain (58.1 per cent) had two to four other LTCs.

Pain management consultations

Twenty participants (9.2 per cent) indicated they had not consulted any health professionals about pain in the previous year. The number of people consulted ranged from zero to nine, the average being 1.8 (mode/most common=1). The individuals consulted are displayed in Table 1 (right). Therefore, with the exception of the 20 per cent of people consulting physiotherapists, the small numbers of people seeing a practitioner outside their general practice team suggests that pain is generally being managed within general practice. Only a small group received input from pain specialists. Participants were asked if they had a plan, agreed by a doctor or nurse, to manage their ongoing pain. About a third (35 per cent) said they had, almost half (47.7 per cent) did not and 17.3 per cent were unsure.

Pain locations and experiences

The location of the pain experienced is presented in Table 2 (N=215) on p22. The percentages add to more than 100, as most people indicated they had pain in more than one location. The number of pain locations ranged from one to 11 (M=3.9, mode=3). The most common pain sites were lower back, knee, shoulders and hip.

Pain is experienced most often at night, when walking and when going up and down stairs.

To explore the times at which people experienced pain, we included the pain items from the Nottingham Health Profile,⁴ which requires respondents to answer "yes" or "no" to whether or not they are currently experiencing pain during the times/activities listed. The results are presented in Figure 1 (see p33).

Pain is experienced most often at night, when walking and when going up and down stairs – all of which affected approximately two-thirds of the pain participants. A third said they experienced constant pain, a fifth indicated that their pain was unbearable and 30

(14.9 per cent) said it was both constant and unbearable. Looking at these people more closely, there were more women than men and ages ranged from 40s to 85-plus years. All but one had consulted a practitioner about their pain in the

previous year. The number of people consulted ranged from one to nine (M=2.5), and included pain specialist doctors (n=4), pain specialist nurses (n=5) and a neurologist (n=1). Only 11 of the 30 indicated they had a pain

Table 1. Number (per cent) of people indicating they had consulted specific health professionals regarding their pain

Practitioner	N (%)
General practitioner	186 (85.7)
Practice nurse	57 (26.3)
Physiotherapist	46 (21.2)
PHO-based LTC nurse	33 (15.2)
Massage therapist	13 (6.0)
Chiropractor	12 (5.5)
Osteopath	10 (4.6)
Specialist pain doctor	10 (4.6)
Specialist pain nurse	9 (4.1)
Acupuncturist	4 (1.8)
Orthopaedic surgeon	3 (1.4)
Rheumatologist	2 (0.9)
Nurse practitioner	2 (0.9)
Neurologist, Ora Kinetics clinic, podiatrist, urologist, Wellington Hospital, occupational therapist, hospital, kidney specialist, oncology, lymphoedema practitioner, orthotics, vocational therapist	1 (0.5)

Table 2. Location of chronic pain

Location	N (%)
Hip	95 (44.2)
Knee	113 (52.6)
Lower back	152 (70.7)
Upper back	39 (18.1)
Shoulders	98 (45.6)
Elbows	27 (12.6)
Wrists/hands	97 (45.1)
Ankles/feet	83 (38.6)
Internal	28 (13.0)
Head	24 (11.2)
Neck	88 (40.9)

plan, 10 did not and nine were unsure.

To convert responses into a score, predetermined weights were assigned to the “yes” responses. These were then added together to generate a scale where 0 represents good and 100 represents poor health. The mean score was 44.0 and the standard deviation was 28.4. Moderate-strength Pearson’s correlations (which measure the strength of the association between two variables) were found between the Nottingham pain scores and GH ($r=-.39$), effect of LTCs on quality of life (QoL) ($r=-.42$), PH ($r=-.58$) and MH ($r=-.30$). This suggested that the more circumstances under which pain is experienced, the

poorer the health status reported and the greater the negative impact LTCs have on quality of life.

Pain in relation to health and quality of life

To examine the way having ongoing pain relates to self-reported health and quality of life, we compared those with pain to those without (see Figure 2, p33).

Here we see that, on average, people with pain reported poorer general, physical and mental health, and indicated that their LTCs have more of an impact on their QoL than people without pain. With respect to self-care challenges faced, we found that more of those with pain than without pain reported sleeping to be a challenge (51.7 per cent compared with 29.4 per cent) and more with pain than without pain reported anxiety/depression to be a challenge (30.3 per cent compared with 14.7 per cent).

‘Use distraction therapy like reading a book, or watching a TV programme you enjoy.’

‘Get all the help you can from everywhere, including using equipment.’

‘Try to retain a normal lifestyle, ie outings, meetings, sport and exercise.’

ADVICE FROM STUDY PARTICIPANTS

‘Use hot water bottle on back when sitting – relieves pain well.’

‘Each morning when you wake, take a deep breath and remind yourself this is a marathon, not a sprint.’

‘Try to exercise each day, but know your limits.’

‘Talking to others with similar issues helps.’



‘Take somebody to appointments with you – husband, partner, friend or relative – especially when you are in a lot of pain. They can do your talking for you.’

‘Make sure you get your medications ahead of time so you are not stressed about running out.’

‘Learn to listen to your body and don’t force overdoing as it will take much more time to recover.’

Key points

- CHRONIC pain was experienced by more than half the participants.
- PEOPLE with pain had poorer health and indicated that their LTCs had a greater impact on their quality of life than people without pain.
- PAIN was most commonly experienced in the lower back, knee, shoulders and hip.
- A third said they were in constant pain and a fifth said their pain was unbearable
- THE more circumstances in which people experienced pain, the poorer their self-rated health.
- SLEEP and anxiety/depression were bigger problems for people with pain than for those without pain.
- PEOPLE with pain who experienced sleep disturbance and/or anxiety and depression related to their LTCs managed their pain less well than others.
- PEOPLE who felt they were managing their pain well reported better health and rated their LTCs as having less impact on their quality of life.
- MOST people with pain did not have a pain plan or were unsure if they had one.

Pain self-management in relation to health and quality of life

Ratings of pain self-management ranged from 0 to 10 ($M=6.9$, $mode=8$). Again, moderate strength correlations with GH ($r=-.39$), effect of LTCs on QoL ($r=.42$), PH ($r=-.58$) and MH ($r=-.30$) were found. This suggested that people who perceived themselves to be managing their pain well had better health and considered their LTCs to be having less effect on their QoL than those managing less well. People who indicated that sleep was a challenge rated themselves as managing their pain less well than those who did not ($M=6.4$ compared with $M=7.3$). The same applied to those indicating anxiety/depression was a challenge ($M=6.3$) compared to those who did not ($M=7.1$).

Advice to others

Finally, we asked our participants what piece of advice they could provide to others and some examples are provided on page 32.

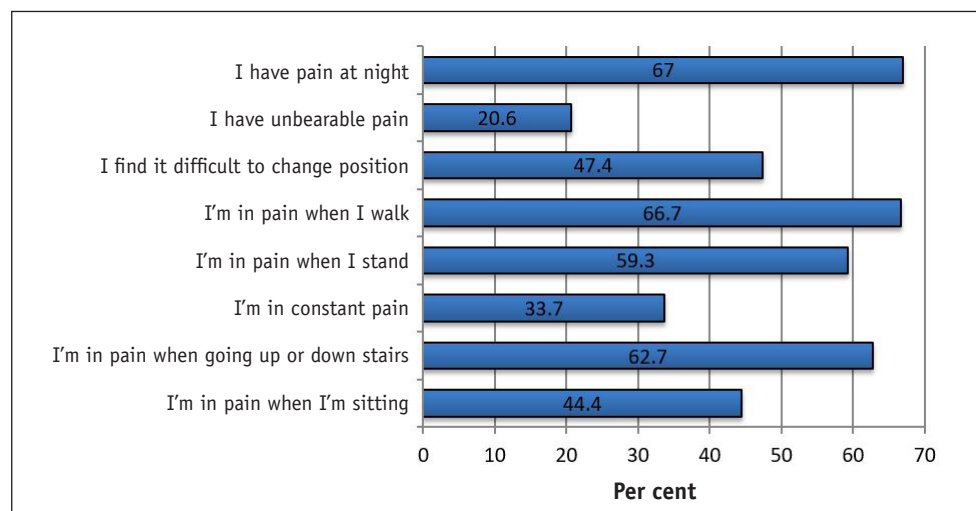


Figure 1. Per cent of 'yes' responses to the Nottingham Health Profile pain questions

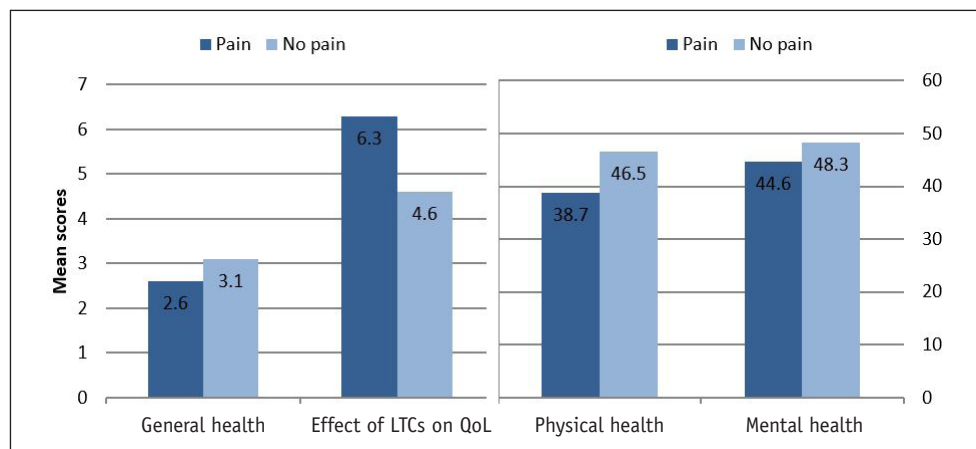


Figure 2. Mean score comparisons for people with and without chronic pain on measures of self-reported health and impact of conditions on quality of life

Practice points

- Think about what your primary care practice could do in the waiting area to encourage people to share their pain concerns. Is managing pain included in the brochures or posters on display? Is it on health TV or part of a questionnaire?
- Develop a pain plan in partnership with the client to enable them to identify goals and know what to do on bad days. Make sure they have a hard copy so they can refer to it at home to guide their self-management.
- Use a “what matters most” approach in the consultation to enable people to share their concerns about ongoing pain.
- Many people have benefited from attending the Stanford Chronic Disease Self-Management Programme. This six-week programme is available across most of New Zealand, and covers how to improve self-management knowledge, skills and confidence in general. Pain and managing the symptom cycle are key components. Some regions offer a chronic pain version of this programme.
- The Health Navigator site has very good information, resources and videos for managing chronic pain. Get to know it, so you can advise clients on how to use the site.
- Learn more about providing good self-management support from the self-management support tool kit (www.sms Toolkit.nz).
- As many of the participants had arthritis, contact with Arthritis New Zealand may benefit them. They can ring 0800-663-463 for education and advice.
- A mobility action programme (MAP) is available in many areas; in Manawatu it is called the hip and knee mobility action plan. This is a community-based intervention for people with hip or knee osteoarthritis and/or lower back pain, focusing on learning long-term self-management.
- Some regions have dedicated services for chronic pain. Find out if there is a care pathway and what the referral criteria is in your region.

Discussion

From these results, we can see that chronic, or ongoing pain, was a major problem for many of our study participants, and its presence was associated with poorer ratings of health and LTCs having a larger impact on quality of life.

Chronic pain affects a much larger proportion of people than many practitioners realise. The latest New Zealand Health Survey found that one in five adults experience chronic pain.⁵ Pain is a common co-morbidity for people with more generally acknowledged LTCs such as diabetes, and cardiac and respiratory conditions,⁶ but is not always discussed during primary-care consultations. This can be because not all practitioners feel competent in managing pain. Or it may be because people themselves don't bring it up, as they assume that it is something they “just have to put

up with” as a normal part of ageing, or they don't like the idea of taking pain medication.

However, pain, especially in combination with sleep problems and depression as is often the case, can be extremely debilitating. As such, it warrants exploration during consultations, even if it is not broached spontaneously by the

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patient. The emphasis today is on patient self-management and for this, good self-management support – including recommendations of good websites and resources to use – is important. A good approach to providing self-management support for people living with pain is the

strategy wheel devised by United States psychologists Richard Wanlass and Debra Fishman.⁷

Likewise, the need for regular review and follow-up is vital, and referral to other skilled practitioners, including the community pharmacist, may improve the management of people's chronic pain. •

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