

# Learning from people with chronic pain: messages for primary care practitioners

Claire Budge PhD;<sup>1</sup> Jenny Carryer RN, PhD, FCNA (NZ) MNZM;<sup>2</sup> Julie Boddy RN, PhD<sup>2</sup>

<sup>1</sup>MidCentral District Health Board, Palmerston North, New Zealand

<sup>2</sup>School of Health and Social Services, Massey University, Palmerston North

## ABSTRACT

**INTRODUCTION:** A large number of people live with chronic, non-malignant pain, which impacts on their work, social activity and quality of life. For many people pain appears to be inadequately treated and controlled, in part due to a reluctance to take appropriate medication. The aim of this study was to learn more about people's experience of pain in the context of long-term illness, in order to inform primary health care practice.

**METHODS:** Twenty people previously identified from a survey about chronic illness care were interviewed about their pain-related experiences. Interviews were taped and transcribed and a thematic analysis was carried out to identify the key themes relating to practitioners' support of people with chronic pain.

**FINDINGS:** Three main themes, which were common to all authors' analyses and are considered most relevant to practice, are presented and discussed. These themes were labelled 'medication concerns', which encompasses side-effects, reluctance to take pills and pain medication as a choice; 'coping with pain', including acceptance, pacing yourself and non-pharmaceutical pain relief; and 'seeking help for pain', which included negative and positive experiences and lack of care continuity.

**CONCLUSION:** Pain limited how participants lived, yet many were reluctant to take pain relief as prescribed, if at all. They found other ways of coping, and accepted their pain. Messages for practitioners include the importance of asking people about their pain, listening and acknowledging the reality of pain and its effect on daily life and providing education, reassurance and support for taking pain medication.

**KEYWORDS:** Chronic disease; medication adherence; pain; primary health care; quality of life

## Introduction

Living with pain is a reality for a significant proportion of the population. The latest New Zealand Health Survey found that one in six of the respondents experienced chronic pain<sup>1</sup> and a similar prevalence has been reported in Australia.<sup>2</sup> In a New Zealand study of people with chronic illness,<sup>3</sup> a third indicated that they had chronic pain which, given their age, was comparable to national statistics.<sup>1,4</sup> Previous researchers have also observed that pain appears to be under-treated<sup>1,5</sup> and a recent European review found primary care practitioners often unable to provide effective pain control.<sup>6</sup> It is generally understood that unrelieved pain has serious and long-lasting

psychological and physiological consequences. It is associated with fear, anxiety and sleep problems<sup>7</sup> and can affect social functioning including work, and relationships with friends and family.<sup>8</sup> Wells, McCaffery and Pasero state that pain 'robs people of their lives' and suggest that the inability to escape from pain can create a sense of helplessness, and may result in reluctance to seek medical care for other health problems if pain has been inadequately controlled.<sup>9</sup> After reviewing studies of attitudes and beliefs about the treatment of pain, McCaffery and Ferrell concluded: 'In general, the public tends to endorse and value a "grin and bear it" approach to pain, an avoidance of the use of pain medication, and a reliance on "natural" methods of pain relief.'<sup>10</sup>

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## CORRESPONDENCE TO:

**Claire Budge**  
Millbank, 33 Old Mill  
Road, RD3, Motueka,  
New Zealand  
clairebudge@gmail.com

The current study was designed to explore in more depth the experiences of an existing NZ study cohort living with long-term conditions who had already identified that pain was a significant problem.

## Methods

### Procedure

Ethical approval for this study was granted by the Massey University Human Ethics Committee. Information sheets and study invitations were sent to 50 participants from the earlier chronic illness study<sup>3,11</sup> who had indicated they were experiencing chronic pain and responded positively to at least six of the eight pain items from the Nottingham Health Profile.<sup>12,13</sup> If they consented to an interview about their experience of living with pain they returned a post-paid envelope. Twenty-three indicated they were interested and 20 interviews were conducted (three were not available at suitable times for the scheduled data collection period). All three authors were involved in the interviewing; 10 interviews being conducted by CB, 6 by JB and 4 by JC. The format was semi-structured with participants being asked to talk about the onset and ongoing experience of living with pain; its impact on their life; experiences of seeking help with pain; medication experiences and views; and what they thought would help with their pain. Interviews lasted from 30 to 90 minutes and were taped, with permission, and later transcribed by CB. On completion of the study a feedback and thank you letter was sent to all participants. The set of interview transcriptions were analysed separately by the three authors who read them, categorised descriptions and comments into sets according to content and identified the representative themes expressed in each set.<sup>14</sup> Each author listed these themes and presented them independently to the other two authors. The lists of themes were compared and three, some with subthemes, were found to be consistent across all authors.

### Sample description

Seventeen of the 20 interviewees were women and participants' ages ranged from 54 to 92 years ( $M=69.7$ ). The majority were New Zealand European (17), two were Maori and one Maori/

## WHAT GAP THIS FILLS

**What we already know:** Chronic pain is a prevalent problem in New Zealand and around the world. Despite many pain sufferers being treated for other chronic conditions, pain seems to be underdetected and undertreated.

**What this study adds:** Discussions with people living with chronic pain as a component of other long-term conditions suggest that they view pain differently from other chronic conditions, with medication for its relief being taken less seriously and with greater reluctance. People feel that health practitioners ignore or are unable to do anything about pain, but they would benefit from assessment and appropriate support and treatment especially if they are to meet any lifestyle goals for their long-term conditions.

Table 1. Frequency of responses to the Nottingham Health Profile pain questions

Item	Frequency	Percentage
I have pain at night	19	95
I have unbearable pain	11	55
I find it difficult to change position	20	100
I'm in pain when I walk	19	95
I'm in pain when I stand	20	100
I'm in constant pain	14	70
I'm in pain when going up and down stairs	19	95
I'm in pain when sitting	18	90

Chinese. Income levels were low, with 15 participants living on less than NZ\$20,000 per annum. Although three participants had pain as the only chronic condition, all others had additional diagnoses including diabetes, respiratory and cardiac conditions, depression and osteoporosis. Pain experienced was mostly back pain with pain originating from a range of sources including falls (7), polio (2), other spinal problems (2), arthritis (4), diabetes (1), and a work injury (1). Two were unsure about the underlying reason for the pain. Fourteen people acknowledged they experienced pain all the time, with levels ranging from 3 to 9 on a 0 (no pain) to 10 (worst imaginable pain) point scale. However, regardless of whether the pain was constant, all interviewees said that the pain tended to be worse some days than others, rising to 7–10 on the same 10-point scale. One wanted to give her episodic pain a score of 12. Reasons for fluctuation were not always apparent. Responses to the Nottingham Health Profile pain questions are presented in Table 1. Of these 20 participants, 6 had said yes to all eight items, 7 to seven and 7 to six of the items.

## Findings

Three themes considered relevant to practice were identified in the interviews. These were labelled 'medication concerns', 'coping with pain', and 'seeking help for pain'. The themes and sub-themes are described in the following sections along with interview extracts to exemplify them.

### Medication concerns

One of the most prevalent and complex themes was associated with pain medication, which for many participants extended to a discussion of taking medication in general. There was a general view expressed that taking pills for pain relief was somehow bad, but for varying reasons. These reasons are represented by a series of subthemes, one concerning people not wanting to take pain medications due to the associated side effects:

If you take heavy medication it makes you sleepy and you feel like a zombie walking around. I think I'd rather have the pain. (P16)

Four participants used the term 'zombie' to describe the side effects of taking pain relief. There was also concern about the long-term effects of taking pills. One person said, 'I'm scared of getting hooked on morphine' (P10) and another said:

You know you're taking this for this and that for that and something to stop your organs getting damaged with it and I got very overwhelmed. (P9)

This and other quotes also alluded to the sheer number of pills people needed to take as a result of having pain in addition to other chronic conditions. As one woman said:

I take about 20 a day and I say 'if you give me any more (pills) I'm going to rattle'. (P16)

The polypharmacy aspect was expressed too:

I sometimes feel as if I'm on too much medication you know? I wonder if I really absolutely need all of it because I really feel that my system's become immune to tablets, I've had so many, that it's not taking any new ones and you know really, ideally I feel like I need to be detoxed. (P9)

Another theme linked to medication concerns was the notion that medication for pain was somehow less important than that prescribed for other chronic conditions. Just as pain appeared to be viewed differently to conditions such as diabetes or asthma in that it was something to be 'put up with' and often not talked about, pain medication was also seen differently to other medications in that it was considered optional or to be taken variably. This often resulted in people being undermedicated for their pain:

I am most probably not treating it as effectively as I should do but I try I still take two a day every day. I take more if I need to but otherwise I take one in the morning and one at night and if it's bad I'll take two at night so that I'll settle a bit more but apart from that I don't take them all day no, no. I don't because maybe I'm old fashioned or something but I don't like the idea of taking huge numbers of pills. (P9)

Some people were worried that the pain might get worse and if they take pain relief now there will be nothing left 'when I really need it':

I keep it (pain relief) for emergencies. My doctor tends to say 'well the emergency's here, don't keep it for emergencies'. (P13)

For several it was clear that taking pills did not sit comfortably with their self-concept, with comments being made about how 'once upon a time I'd never take a pill and now I take about 20 a day' (P16) and 'I've hardly had a tablet in my life until recently' (P5). Another person said she wasn't 'a chemical person'. (P12)

Overall, pain medication seemed to be something to be avoided, and perhaps even feared with people choosing not to take a therapeutic dose but then being disappointed with its effectiveness. Concerns about side effects and that the pain might progress requiring stronger medication in the future if pills were taken now added to their general reluctance.

### Coping with pain

Whether people were taking pain medication or not, they needed to find ways to cope with daily pain and 'pacing yourself' was one way of coping.

For some, pain required moderation 'It doesn't stop me doing things it just reduces the amount of time I can do those things for' (P12), but for others pain was seriously limiting what could be achieved and just getting through the day required careful planning and active avoidance of exercise. This makes for an uneasy balance between conserving energy and the desirable lifestyle interventions considered beneficial to living with a long-term condition. Pain-related loss of sleep can also be seen as counterproductive to coping with ongoing pain.

Acceptance of pain was another theme which again enabled people to cope and possibly allow them to avoid medication if they were reluctant to take it. Pain was described as being 'just part of my life' (P14) and 'I've got used to it now, it's like something you just deal with every day I suppose' (P6). These comments show that acceptance of pain meant for many that the pain had become part of who they were. Given the general reluctance to take medication, it is not surprising that the people we talked to had discovered non-pharmaceutical methods for coping with their pain. Having a good chair was considered very important, one woman spent days and nights in her recliner and several others sat in them all day. Heat, either from the shower, electric blanket, hot water bottle or a heat pad was also mentioned frequently:

Heat does at times, I put, I quite often heat the wheat bag up in the microwave and cuddle that or put it around my back. (P7)

Other helpful things recorded were massage/physiotherapy, going to bed and listening to music. One woman said:

I go and put a DVD on and if I put the music on it takes my mind off it a little bit. (P8)

### Seeking help for pain

A number of people had not sought help for their pain and described themselves as 'independent' or 'pig-headed'. Others said they had asked once and been 'knocked back' or given something they found ineffective or that didn't suit them and had not asked again. One had been offered help and had refused it saying:

She (nurse) was going to send somebody to talk to me and I said 'that's no good' so I'm my own worst enemy. (P7)

The majority of participants described various encounters with a range of health professionals, some being good while others were not so good.

It was clearly felt that doctors and nurses don't have the time to hear about or deal with ongoing pain.

You're sort of allocated a certain amount of time when you go to the doctors and you sort of say the things that have to be said (about other conditions). (P14)

There was also a sense that GPs were not really interested in people with pain, perhaps because they don't know what to do or have given up:

I just think the GP gets sick of trying, he doesn't know what to do with me... my doctor used to tell me I was his favourite patient but he hasn't been telling me that lately, he's sick of me. (P10)

A number of people didn't see the point in talking to a doctor about their pain as the only outcome would be another prescription and, as the existing pills weren't working, they didn't want more:

I keep telling my GP and the last thing she did was sent me to a neurologist at the hospital and he, all he did was increase my pain medication. (P11)

Oh he (GP) puts me on another painkiller that doesn't work. (P1)

Nurses were described as 'good' and 'lovely' but also as not having the power to help much, for example:

When I talk to the nurse about the pain she just makes notes on the computer. Well she doesn't have the authority to change medication or anything. I guess she speaks to the doctor about it. (P16)

Four of the participants were concerned that doctors felt they were faking their pain, one saying:

I think the doctors have got to be a lot more understanding of it. A lot of doctors don't understand it. You go along and tell the doctors you've got a bad

back and they think automatically 'oh he's just having us on'. (P17)

Another said:

They kind of look at you sideways as if like, mm, you need psychiatric help rather than physical. (P6)

The need to be listened to was great:

They don't listen to you, nobody listens and you think oh well and then you just go on doing things. (P18).

Lack of continuity of care added to people's stress and impacted on help-seeking behaviours. If a different person is seen every time they go to a clinic, they spend a lot of time and energy going over the same history to bring the GP 'up to speed' and then may receive less than optimum treatment. This leads to frustration and a lack of trust.

If you go down you see someone totally new that doesn't know anything about you and last time he said 'oh well I'll give you some painkillers', Panadol with codeine, then you don't see that doctor again 'cos he's gone. (P2)

Although some participants made it clear that they were not prepared to broach the subject of pain with a health practitioner, many had struggled with a range of different professionals and few were satisfied with their present treatment situation. Concerns that doctors don't listen, care or know what to do were raised and people felt they needed to fight for things to change. Many lacked the energy or finances to push for better support.

## Discussion

This qualitative study was initiated by findings from the earlier survey of people living with chronic illness indicating that chronic pain is widespread amongst this population. The majority of the people interviewed had other long-term conditions for which they were receiving care from primary health care practitioners. Despite this, they were all living, or struggling, with debilitating levels of undertreated pain. It appears that medication concerns are one of the key reasons and that this is exacerbated in the context of long-term conditions because medication use is already heavy. The general preference was for not taking medication for pain relief, although many people were reliant on it to be able to function.

Although most participants were accepting medication for other conditions, they appeared to consider pain medication as optional. Many were consequently taking too little and/or irregular pain medication and not getting optimum relief. This behaviour was also identified by Sale et al. who found that people with osteoarthritis were generally adherent to other medications, but purposely did not take pain medication, or took it in a lower dose or frequency than prescribed.<sup>15</sup> Similarly, Breivik et al. reported that half their sample would rather take medication for illness than for pain.<sup>5</sup>

We also found evidence of concerns about addiction to medication, particularly morphine, and about side effects. The main problem was the 'zombie' effect of taking pain medication, although other instances of medication intolerance were also discussed. Two-thirds of Breivik et al.'s respondents worried about medication side effects and 40% feared addiction.<sup>5</sup> Similarly, as reported by Torma, McCaffrey and Pasero's 1999 clinical manual on pain notes some patients' expectations that pain cannot be relieved and that this, together with fears about addiction and medication side effects, make a significant contribution to pain being undertreated.<sup>16</sup>

Molton et al. note that a number of studies have found older adults are less bothered by living with chronic pain than younger adults.<sup>17</sup> One of the theories for this is that pain is somehow considered to be more normal or expected as one ages.<sup>17</sup> Our study supports this notion as participants clearly felt that experiencing pain was part of the ageing process and something to be got on with, many commenting that there were others worse off. In general there was an acceptance of pain accompanied by an acknowledgement of the need to pace yourself<sup>18</sup> in order to accept the limitations of pain and achieve at least some of the things you would like to without the payback of it becoming unmanageable.

The experience of seeking help from primary health care practitioners was clearly mixed. Some participants described positive, supportive relationships with GPs but they were in the minority. A number of people felt their doctors had 'given up' and didn't know what to do with them, yet did not report referrals to pain clinics. Continuity



of care was an issue with people feeling reluctant to make an appointment with yet another doctor who didn't know their history, and who was unlikely to do anything beyond writing another prescription. Consultations with nurses were conspicuous by their absence with the few participants who did describe them indicating that nurses lacked the authority to act on pain-related matters. This supports Tollefson, Usher and Foster's finding that the chronic pain sufferers they interviewed denied receiving support from nurses.<sup>19</sup> They describe it as unfortunate as nurses are well placed to contribute to managing people with chronic pain, particularly in rural areas.

There was concern expressed that doctors thought people were faking the pain, yet self-report is the single most reliable indicator of pain intensity.<sup>20</sup> It appears that many people are choosing not to take pain medication, or else take a non-therapeutic dose, based on inaccurate beliefs about addiction and the long-term effects of pain medication. Education and reassurance about these can be part of the health professional's role in supporting people with chronic pain. Our participants discussed non-pharmaceutical approaches to dealing with pain, including physiotherapy, heat pads, showers, suitable beds and chairs, music and helpful gadgets. Information about these and referrals where possible would complement the support provided by primary health care practitioners.

### Strengths and weaknesses

While the number of people interviewed was quite small, they were reasonably varied in terms of age, rural/urban location and functional abilities. We would have liked to include more men in the study, but were reliant on volunteers. Although everybody's experience was clearly different, there was sufficient similarity in what participants said to be reassured that the data reflected common experiences and feelings.

### Conclusion

An important message to take from this study is that people view chronic pain differently from other chronic conditions, and they also believe that other people, including friends, family and health professionals do as well. Pain is viewed

as an 'add on', something to be put up with and not moaned about—just part of daily life. This framing of pain, in combination with a reluctance to take pills for pain relief and a lack of belief that anything could or would be done if they did seek help, perhaps explains why people living with chronic pain are not well treated. Also, while it can be positive for the individual to find ways of coping with pain by lowering expectations and limiting daily activities, this type of self-management may provide an excuse for not seeking professional help. A better outcome may be achieved by appropriate medication and support from practitioners being balanced with self-management techniques in a collaborative approach to pain management. For most of the people interviewed, pain was seriously limiting and was defining just what their daily life could consist of, narrowing horizons and removing pos-

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sibilities. As Thomas said, 'their Lebenswelt (life world) was shrunken and their freedom greatly restricted'.<sup>21</sup> Miles, Curran, Pearce and Allan suggest the basic problem challenging people with chronic pain is one of constraint, with changes to body, activity and identity constraining a normal life.<sup>22</sup> Anything that can be done to address the loss associated with living in pain would greatly benefit individuals and their families.

There are clear messages emerging from this study which reinforce the need for practitioners to enable people to discuss pain as well as their other conditions. If time is taken to acknowledge people's pain and its effect on their lives, they will feel better supported and may be more open to treatment options. In addition, considerable reassurance and information is clearly needed about the benefits of effective pain control and the relative safety of analgesia. Pharmacological review may also offer potential for reducing the numbers of drugs being taken. Improved pain control may also enable patients to better self-manage their other conditions.

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## COMPETING INTERESTS

None declared.