

MidCentral District Health Board, in partnership with THINK Hauora, recently completed a three-year longitudinal study of people with long-term conditions (LTCs) known as *Talking about Health*. This article – the first in a series of professional development pieces drawn from this research – provides background to the study and explores participants' self-care challenges.

# Talking about Health:

## Study overview and self-care challenges experienced by people with long-term conditions

By Melanie Taylor and Claire Budge

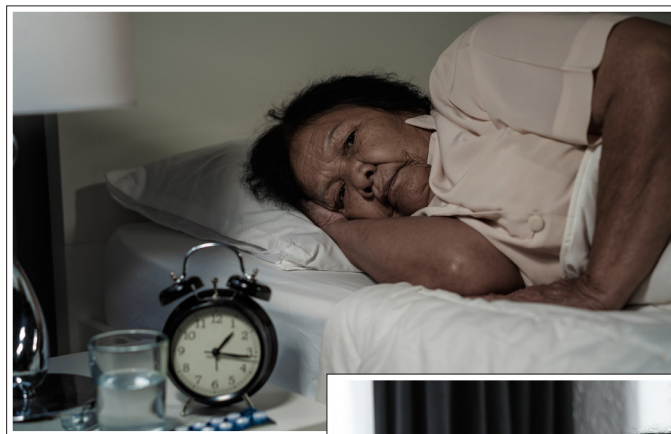
### Talking about Health

**T**alking about Health is a three-year longitudinal study recently completed by MidCentral District Health Board, in partnership with THINK Hauora (formerly the Central PHO). In the study, we explored the patient experience of living with one or more long-term conditions (LTCs), and the care provided within the general practice setting to support their LTC management.

After obtaining approval for the study from the Health & Disability Ethics Committee (HDEC) (ref 16/NTA/32), we sent out invitation letters, information sheets and consent forms to all people aged 18 or over in the MidCentral region who had had a comprehensive health assessment completed in primary care during the previous three (Māori and Pacific) or two (other ethnicities) years (N=2730).

In 2016, those who agreed to take part were sent the first of three annual questionnaires by post, or a link to an online version, according to their preference. The questionnaire covered measures of health, healthy behaviours, experiences with doctors and nurses in general practice, patient activation, care planning/goal support and demographics. Some participants were subsequently invited to participate in face-to-face interviews.

The 569 study participants were predominantly New Zealand or other



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European (82 per cent), 15 per cent were Māori and less than 1 per cent were Pacific. Just over half the sample was female (56 per cent) and the majority (62 per cent) were aged between 65 and 84 years. Around a third (31 per cent) of the participants were living alone at

home and 17 per cent indicated they had insufficient income to meet their daily needs.

The number of LTCs each participant was dealing with ranged from one to 11 (Mean/average=3.3), with only 13 per cent reporting having a single condition.

**Table 1. Number (per cent) of non-Māori (n=318) and Māori (n=36) participants reporting specific self-care challenges and main self-care challenges**

Challenge	N (%) Indicating it is a challenge		N (%) Indicating it is a main challenge	
	Non-Māori	Māori	Non-Māori	Māori
Home/garden maintenance	173 (54.4)	14 (38.9)	55 (17.3)	4 (11.1)
Sleeping	146 (45.9)	18 (50.0)	34 (10.7)	5 (13.9)
Mobility	145 (45.6)	13 (36.1)	60 (18.9)	4 (11.1)
Pain	135 (42.5)	18 (50.0)	47 (14.8)	4 (11.1)
Exercise	133 (41.8)	19 (52.8)	31 (9.7)	5 (13.9)
Housework	114 (35.8)	12 (33.3)	25 (7.9)	3 (8.3)
Being overweight	107 (33.6)	15 (41.7)	37 (11.6)	7 (19.4)
Anxiety/depression	78 (24.5)	13 (36.1)	20 (6.3)	4 (11.1)
Lack of money	70 (22.0)	15 (41.7)	21 (6.6)	6 (16.7)
Breathing	78 (24.5)	6 (16.7)	26 (8.2)	4 (11.1)
Healthy eating	54 (17.0)	13 (36.1)	8 (2.5)	3 (8.3)
Communication with health professionals	45 (14.2)	7 (19.4)	6 (1.9)	3 (8.3)
Social isolation	36 (11.3)	8 (22.2)	4 (1.3)	5 (13.9)
Friends or family/whānau/fanau not understanding	31 (9.7)	7 (19.4)	3 (0.9)	3 (8.3)
Health monitoring	30 (9.4)	6 (16.7)	4 (1.3)	1 (2.8)
Taking medication	28 (8.8)	6 (16.7)	3 (0.9)	1 (2.8)
Not smoking	17 (5.3)	9 (25.0)	5 (1.6)	2 (5.6)

The most frequent conditions reported were chronic pain (61 per cent), hypertension (54 per cent), diabetes (50 per cent) and a respiratory condition (35 per cent). It was notable that 24 per cent of Māori and 18 per cent of non-Māori indicated they experienced depression/anxiety related to having an LTC. Most participants rated their health as good (43.7 per cent), while approximately 20 per cent rated their health as very good or excellent and 36 per cent as poor or fair.

### SELF-CARE CHALLENGES

A question about self-care challenges was added to the final questionnaire in 2018, as we realised from earlier responses that people were struggling with managing a range of social, environmental and health issues. We provided a list of possible issues and asked participants to indicate:

(a) which they found to be a challenge in caring for themselves, and  
(b) which they found to be the *main* challenge or challenges. They could tick as many as they liked and could add extra ones. By year three, there were 376 participants remaining (10 per cent Māori, 59 per cent female) and 354 answered the question. Their responses are provided in Table 1 (see p21).

The self-care challenges most commonly experienced by Māori were somewhat different from those experienced by non-Māori. For Māori, the four most frequently expressed self-care challenges were pain, sleeping, being overweight and lack of money, whereas for non-Māori the top four were home and garden maintenance, sleeping, mobility and pain. Other notable differences were that more Māori than non-Māori found healthy eating, not smoking, taking medication, social isolation and whānau not understanding to be challenging. More non-Māori than Māori identified breathing to be a challenge. When asked to choose the *biggest* or *main* challenge, the most frequent responses for Māori were being overweight, lack of money, sleeping, exercise and social isolation. For non-Māori, the *main* or *biggest* challenges were mobility, home and garden maintenance, pain,

being overweight and sleeping.

The number of self-care challenges faced ranged from none to 17 (M=4.6). More challenges were specified by: Māori (M=5.6) than non-Māori (M=4.5); women (M=4.9) than men (M=4.1); those who lived alone (M=5.1) than those who lived with others (M=4.3); and those with insufficient or just enough income (M=5.5) compared to those with enough or more than enough income (M=3.7). The number of main challenges identified ranged from none to 13.

For Māori, the additional self-care challenges added were (number of responses in brackets): transport (2);

transport was included as a main challenge by Māori respondents, and travel, hearing, caring for others, motivation, access to services and toileting were listed as main challenges by non-Māori.

### DISCUSSION

The self-care challenges identified by this group of predominantly older people with LTCs were interesting for a number of reasons. Firstly, basic aspects of daily life – sleep, mobility, exercise and pain – were found to be highly challenging, and we are unsure if these challenges are discussed and interpreted as “client

need” during routine appointments. It was notable that 19 per cent of non-Māori and 14 per cent of Māori indicated they had problems communicating with health professionals and this may inhibit open discussion about their needs.

Our study found pain was quite prevalent in this sample, so it is not surprising that 43 per cent indicated it was a challenge. This suggests people’s pain is being inadequately managed, and this is a discussion worth having in a primary-care consultation. In a recent study, primary-care patients were surveyed before a GP consultation about the symptoms they intended to discuss. Consultations were videotaped and in 23 per cent of them, symptoms remained undisclosed.

Those least likely to be discussed were sleep problems/tiredness and joint pain.<sup>1</sup> Health monitoring and taking medications are some of the other potential challenges that are likely to be addressed in consultations. As they were less commonly described as challenging in our study, perhaps these areas of self-care are being better supported in primary care.

A second interesting finding is that a

### Key points

- THE average number of self-care challenges expressed was 4.6.
- OVERALL, more self-care challenges were faced by Māori, women, people who lived alone and those with lower incomes.
- THE pattern of self-care challenges was different for Māori than non-Māori.
- THE main or biggest challenges for non-Māori were identified as: mobility, home and garden maintenance, pain, being overweight and sleeping. For Māori, being overweight was first, followed by having enough money, sleep, exercise and social isolation.
- HEALTHY eating, not smoking, taking medication, social isolation and whānau not understanding affected more Māori than non-Māori.

learning new technology, shopping, volunteering and transport (1). Transport was listed as a main challenge by two people. For non-Māori they were: eyesight (3); caring for others (3); deafness (2); transport (2); access to health services, adjusting to false teeth, collecting firewood, ageing, fatigue, lack of motivation, self-care, fear of heart attack, undressing and toileting (1).

Out of the self-generated challenges,

## Practice points

- ASK people about their self-care challenges and encourage them to talk about the emotional and psycho-social impacts of living with LTCs. A holistic assessment should identify people's ongoing needs and enable practitioners to partner with them to meet these needs. This may involve referring people: for a support needs assessment; to a secondary care service or community organisation; or to an occupational therapist or physiotherapist to review their mobility. The goal is for them to live well, stay well and get well in the community – the future outlined in the New Zealand Health Strategy.<sup>4</sup>
  - ENCOURAGE people to seek help from whānau, friends or neighbours, as many people are willing to help when asked. Help can be reciprocal, as they may be able to do other things in return.
  - PROMOTE the integration of exercise into daily activities. Many people with LTCs find exercise challenging. This can be supported by families, workplaces and sporting/recreational facilities.
  - PEOPLE with LTCs may be eligible for the disability allowance, to help them pay for contractors to help with housework or home and garden maintenance.
- Check [www.workandincome.govt.nz](http://www.workandincome.govt.nz) for further information.
  - THE chronic disease self-management programme (often called the Stanford programme) is available in most places in New Zealand. This six-week self-management programme covers healthy eating, exercise, and the symptom cycle, among other things. Attending this programme may really benefit people with considerable self-care challenges. Some regions run programmes targeting specific conditions such as diabetes or chronic pain.
  - PAIN is a challenge for many with LTCs and may affect their ability to manage weight, to exercise or even remain mobile. Practitioners should ask about pain, even if it is not raised by the person themselves, so pain management techniques and exercise options can be discussed.
  - TO address equity, Māori and people with lower incomes should be prioritised for self-management programmes or for any self-management support activities offered in primary care or the local community.

number of the challenges people faced relate to things like home and garden maintenance and lack of money, which we know from another part of the survey are not things that many people feel their general practice team could or should help with. People should be encouraged to share these types of needs with their primary-care doctors/nurses as a first step. Among other options, referrals to social or community services can then be considered.

While we expected to find differences between Māori and non-Māori as a result of inequity, some differences were quite pronounced. Lack of money, healthy eating, social isolation, taking medications and whānau not understanding were identified as challenges by almost twice as many Māori as non-Māori.

Overall, people with LTCs may have more unmet need than those without. A 2019 study found people with LTCs report a broad range of barriers to life, such as physical restrictions, insufficient knowledge, lack of emotional support and

financial burden.<sup>2</sup> A Commonwealth Fund survey involving patients in the United States with two or more LTCs found they had greater unmet behavioural health and social needs than other adults. The researchers concluded that *“for health systems to improve outcomes and lower costs, they must assess patients’ comprehensive needs, increase access to care, and improve how they communicate with patients”*.<sup>3</sup>

Based on our findings, we encourage practitioners to take the first step by using the consultation to either complete a short holistic assessment or, at a minimum, ask people with LTCs what self-care challenges they face on a daily basis. Unmet need can then be addressed. •

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### References

- 1) Paskins, Z., Sanders, T., Croft, P. R., Green, J., McKinley, R., & Hassell, A. B. (2018). Non-disclosure of symptoms in primary care: An observational study. *Family Practice*, 35(6), 706-711.
- 2) Cheng, C., Inder, K., & Wai-Chi Chan, S. (2019). Patients' experiences of coping with multiple chronic conditions: A meta-ethnography of qualitative work. *International Journal of Mental Health Nursing*, 28(1), 54-70. doi: 10.1111/inm.12544
- 3) Ryan, J., Abrams, M. K., Doty, M. M., Shah, T., & Schneider, E. C. (2016). *How high-need patients experience health care in the United States: Findings from the 2016 Commonwealth Health Fund survey of high-need patients*. <https://pdfs.semanticscholar.org/226c/ed1f28d-7b6a0aac3fa3fc1d95ea66683d4b.pdf>
- 4) Ministry of Health. (2016). *New Zealand Health Strategy*. Retrieved from <https://www.health.govt.nz/new-zealand-health-system/new-zealand-health-strategy-future-direction/future-we-want>.