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Health literacy: from the patient to the professional to the system

Christine Walsh, Carl Shuker, Alan F Merry

The Health Quality & Safety Commission (the Commission) defines health literacy as the degree to which individuals can obtain, process and understand health information and services they need to make appropriate health decisions.¹ In 2006, a survey showed that more than half of adult New Zealanders had health literacy skills “insufficient to cope with the health literacy demands they typically face” (see Box 1).^{2,3} Four out of five Māori males, and three out of four Māori females, had low health literacy levels of one or two (out of five). Groups including the poor, elderly, rural, Māori in older and younger age groups, and almost 90% of Pacific adults scored poorly. However, these groups are no sure guide in a clinical encounter or other health setting—in absolute numbers, Pākehā with poor health literacy outnumber those of all other ethnic groups combined.^{2,3}

Low health literacy is associated both with higher mortality in older adults and with a slew of missed opportunities, mismanagement and misadventure.⁴ People who find it hard to understand or interpret health information are less likely to be involved with preventive services such as screening; have less knowledge of their illnesses, treatments and medicines and are thus less likely to manage their long-term

or chronic conditions; are more likely to be hospitalised because of a chronic health condition; are more vulnerable to workplace injury; and are more likely to use emergency services.⁵⁻⁹

What is health literacy?—systemic and dynamic in nature

A chasm often separates what health professionals intend to convey in written or spoken communications with patients, and what patients actually understand.¹⁰

The term health literacy was first used in 1974,¹² but there has been no unanimously accepted definition.¹³ Health literacy can be defined in terms of a set of capacities patients possess that allows them to successfully navigate the health care environment; or it can be understood as the interaction between the individual capacities, attitudes and behaviors of patients, families and health professionals, and the health care environment in which they operate together.^{7-9,14} The distinction affects how improvement is sought—do we target the patient, the professional, or the system?^{9,15} The Commission takes the latter, broader view, in line with recent thinking,¹⁵ with the World Health Organization,¹⁷ and with inte-

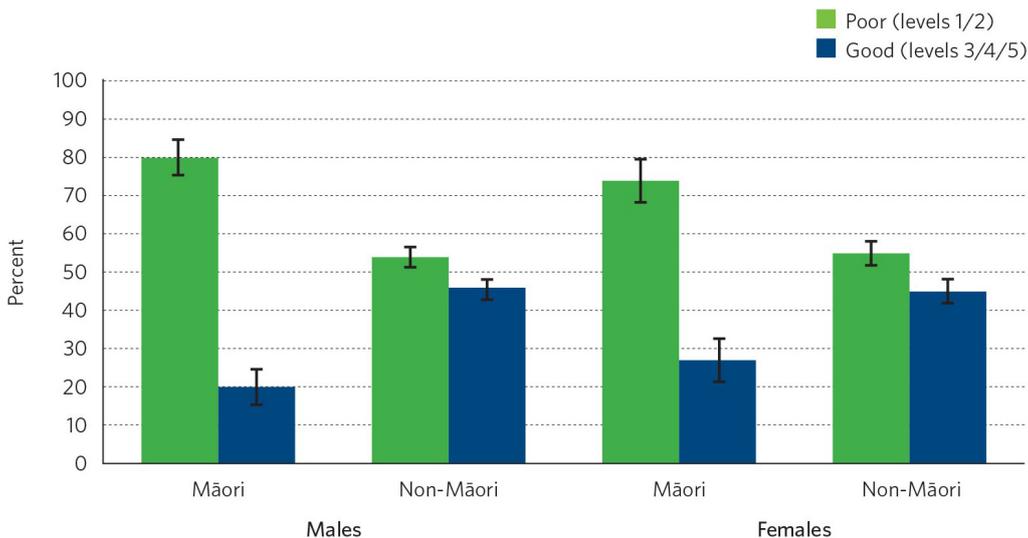
Box 1: How is health literacy measured?

The 2006 Adult Literacy and Life Skills Survey (ALL), a large-scale, comparative survey used in 13 countries, was used to test a representative national sample of 7,131 New Zealanders aged 16–65 years.¹⁰ A score from 0–500 was assigned, divided into five levels.

The 2006 ALL contained 191 health-related questions across four domains: prose literacy, document literacy, numeracy and problem solving. Questions addressed health promotion (60 items); health protection (64 items); disease prevention (18 items); health care maintenance (16 items); system navigation (32 items).

Respondents scoring at levels one and two (0–275) are defined in the Ministry of Health’s 2010 *Kōrero Mārama* report as having poor health literacy skills (see Figure 1).

Figure 1: The distribution of health literacy, for Māori and non-Māori, by sex, from the 2006 Adult Literacy and Life Skills Survey



Source: Adapted from Ministry of Health, *Kōrero Mārama: Health Literacy and Māori 2010*; Adult Literacy and Life Skills Survey 2006. **Note:** Prioritised ethnicity has been used.

grated conceptual models developed from systematic reviews.^{13,18} This is reflected in the Commission’s definition of health literacy (above).¹

This chasm between communication and comprehension has been and is often still attributed to a deficiency in the person on the receiving end of health or disability services. The view, whether actively articulated or passively assumed, that failures in the transfer of information reflect a deficit in the capacity of the recipient to understand that information necessarily promotes interventions that target the recipient.

In the US, the Institute of Medicine has been emphatic: health professionals have a key responsibility in lifting health literacy levels. It is their skills that drive health literacy levels.⁷ The central role of health staff in empowering or disempowering patients has been reinforced by Edwards and colleagues¹⁹ and by the New Zealand Ministry of Health:

“Health literacy should not depend on the skills of the individual patient and whānau alone. It is an organisational value that should be considered core business, incorporated into all levels of service planning delivery and even the way health centers and hospitals are laid out.”²⁰

The Ministry, in May 2015, published their *Health Literacy Review: A guide*, elaborating on this provider-focused approach to improving health literacy, to assist health care organisations in undertaking a health literacy review.²¹ The purpose of such a

review is “to gain a better understanding of the health literacy demands created by a health service and how they affect consumers and families.”²¹ The Ministry’s ‘Six Dimensions of a health literate organisation,’ which underpin the guide, draw on the Institute of Medicine’s ten attributes of a health literate organisation,²² tailored for the New Zealand setting (see Box 2).

Rather than viewing health literacy as a challenge for individual patients or even individual clinicians, the solution lies in a concerted effort across sectors, including schools, social welfare, ACC and other government agencies, and the entire health care system.² Health literacy should be seen as a construct with multiple dimensions, encompassing all aspects of the health services system (and other systems) each individual patient engages with, including the patient and the providers within that system and the way in which the system is designed and functions. This approach should be operationalised at all levels, including, explicitly, within each organisation delivering health or disability services.¹⁶

Knowledge and demand

Health literacy includes knowledge and skills—which of these skills and the specific knowledge required by patients and providers in any given situation is determined by the *demands* created by that situation.

Even a person who knows a great deal about health care in general (a health care professional for example) will have gaps

Box 2: The Ministry of Health's 'Six dimensions of a health literate organisation'²¹

- 1. Leadership and management.** How is health literacy an organisational value, part of the culture and core business of an organisation or service? How is it reflected in strategic and operational plans?
- 2. Consumer involvement.** How are consumers involved in designing, developing and evaluating the organisation's values, vision, structure and service delivery?
- 3. Workforce.** How does the organisation encourage and support the health workforce to develop effective health literacy practices? Has it identified the workforce's needs for health literacy development and capacity? Has the organisation's health literacy performance been evaluated?
- 4. Meeting the needs of the population.** How does service delivery make sure that consumers with low health literacy are able to participate effectively in their care and have their health literacy needs identified and met (without experiencing any stigma or being labelled as having low health literacy)? How is meeting the needs of the population monitored?
- 5. Access and navigation.** How easy is it for consumers to find and engage with appropriate and timely health and related services? How are consumers helped to find and engage with these services? How well are services coordinated and are services streamlined where possible?
- 6. Communication.** How are information needs identified? How is information shared with consumers in ways that improve health literacy? How is information developed with consumers and evaluated?

in his or her knowledge of the nuances of particular conditions. When he or she becomes ill, the patient's context-relevant capacity to grasp the highly individualised implications of a specific disease for him or her personally may not be adequate, particularly given the vulnerability created by illness.

Patients vary in relevant generic abilities, such as reading and comprehension, and they vary in their ability to interact with professionals of any type and to comprehend verbal information about technical matters. Even people with good communication and comprehension skills in a general sense can find it difficult to understand health care information.^{7,23-25} Furthermore, learning that one is personally unwell and must make decisions about the management of a specific health-related condition creates challenges far beyond those of most everyday interactions.

When acutely or seriously unwell, health *knowledge* demands increase dramatically—the basic requirement is for an understanding of disease theory and how the body works, knowing when and where to seek health advice, being able to evaluate the appropriateness of that advice (including medication), being able to interpret and describe health symptoms, and to act and speak confidently within a clinical setting. In addition, at least some information specific to the particular diagnosis in the particular individual must also be acquired and understood.^{7,14,23} None of the skills and abilities required for any of this can be assumed (not even of doctors, nurses or other allied health professionals).

“Even highly skilled individuals may find the systems too complicated to understand, especially when these individuals are made more vulnerable by poor health.”⁷

Health is only one of many competing fields that impact on the lives of people, even for those most motivated to improve their knowledge. It is likely to be more effective to teach providers to communicate well than to try to lift the capacity of patients to cope with a poor system, peopled with poor communicators.

The universal precautions approach—improving the skills of providers

Expert advice now recommends that rather than assessing individuals to evaluate their 'health literacy' and identifying those 'in need of help', health professionals should assume that all patients may have some degree of difficulty when in health environments. Health care workers should therefore apply the principle of universal precautions to health literacy.²⁴⁻²⁷ Universal precautions, familiar from the prevention of blood-borne disease, means using a common approach to all: it involves ascertaining in all patients what they already know, sharing clear information with them and then being active in helping them build their understanding of their health issues (and the relevant aspects of how their body works), and their proposed treatment. This approach has been endorsed by the US Agency for Healthcare Research and Quality,²⁰ and underpinned the Commission's recent Health Literacy Medication Demonstration Project training programme (see Box 3).

Box 3: Health literacy initiatives for professionals

A 2013 survey of health information producers and providers in the UK found a “clear appetite for practical guidance and case studies” to develop resources and services to address low health literacy.²⁸ Measures to improve literacy in New Zealand are scant. The New Zealand Guidelines Group report found that, for example, “Attention to health literacy with respect to medication safety beyond the provision of written resources and dedicated websites is rare.”²³ The report found only a limited number (seven were identified) of so-called “purposive interventions” designed to address the issue.³

The Health Literacy Medication Safety Demonstration Project

This health literacy improvement package was aimed initially at staff in two New Zealand community pharmacies from mid-March until mid-June in 2013 with a view, upon successful evaluation, to national roll-out.

The objectives of the Project were to support pharmacists, via a ‘train-the-trainer’ approach, using an evidence-based package of health literacy education, tools and resources. This involved improving participants’ understanding of how health literacy impacts on medication safety; improving their understanding of adult learning theory and its implications for patient safety; and improving their awareness of their communication styles, including use of jargon, acronyms and technical terms. Easy to implement techniques, skills and ideas were provided that could be put into practice in a clinical setting. A key technique included a simple three-part tool to structure consumer interaction that is adaptable to multiple settings and situations:

Step 1: Checking consumer knowledge—finding out what people know.²⁹

Step 2: Building health literacy skills and knowledge—linking back to what people already know.

Step 3: Checking or teach-back—check information was clear and if not, return to Step 2.³⁰

As a result of the Project’s findings, the Commission recommended a national roll-out,³¹ and has produced, ‘Three steps to better health literacy—a guide for health care professionals,’ available at <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2046/>.³² The methods and resources are now being promoted and disseminated by the Pharmaceutical Society of New Zealand.

Helping providers and patients to manage the challenge

The chasm in health literacy that confronts many patients today must be addressed from both sides.

Providers

There are few published data on effective interventions for improving health literacy within the New Zealand context (see Box 3).³ Understanding of health literacy and the relevant principles of adult learning theory varies across the health sector and, as such, “opportunities to create effective learning opportunities for patients in the course of meeting health needs appears underdeveloped.”³ The New Zealand Guidelines Group 2011 report on health literacy and medication safety in New Zealand recommended prioritising the up-skilling of the health workforce in understanding and applying principles of adult learning theory to the delivery of health services.³

Patients

Effective health care implies providing outcomes that accurately address the true needs and wants of patients. For each indi-

vidual patient, health providers need to understand not so much ‘What’s the matter with you?’ but, ‘What matters to you?’³³ This is about ‘doing the right thing’—which sometimes means agreeing not to intervene. Some of the problem of overtreatment or the wrong treatment lies in a failure by providers to establish what actually matters to people, and also of people being enabled to convey what really matters to them. This communication nuance is critical when discussing treatment options.

Patients can be supported and encouraged to ask questions and take information away to better understand their own health and the treatments available. *Let’s P.L.A.N. for better care* is a new tool developed by the Commission to help patients prepare for, understand and engage with their health care encounter so they leave it with clarity, confidence and a satisfactory level of comprehension (see Box 4).

Conclusion

‘Good’ health literacy means patients or consumers of health and disability services obtain, process, and understand information relevant to their care sufficiently well to make good health decisions. This depends

Box 4: Health literacy initiatives for patients

Let's P.L.A.N. for better care

- Prepare for your visit**
- Listen and share**
- Ask questions**
- Note down what you need to do next**

This health literacy tool provides an accessible structured format for patients to think about and write down what it is they want to get from their GP visit and what they want to know about their medicines from the pharmacist.

Figure 2: Let's P.L.A.N. for better care

Let's P.L.A.N. for better care
Four steps for your next health care visit

Planning for your next health care visit and asking questions will help you understand more about your health and treatment for an illness or injury.

Your doctor, nurse and others included in your health care want you to ask questions to help you make decisions together.

Let's P.L.A.N. for better care

Prepare for your visit

- Write down your main concerns or questions
- Make a list of your medicines and supplements
- Did you know you can take a support person with you and ask for a translator?

Listen and share

- Say if you don't understand and if a drawing could help
- Say if you're having problems with your medicines or treatment, or can't afford them
- Is there anything else you can tell your doctor or nurse about your health?

Ask questions

- What is my health problem?
- What happens next?
- Why is that important?
- Are there any other options?
- What can I do to help with my health?

Note down what you need to do next

When you collect your medicine from a pharmacy, you may want to ask these questions:

- What is the medicine for?
- What is its name?
- How and when do I take it?
- How long do I need to take it for?
- What could happen if I stop taking it?
- What are the side effects? What should I do if I get these?

What can we do to improve PLAN? Tell us what you think. Go to Facebook: Letsplanforbettercare

My questions

My medicines and supplements

What I need to do next and how my family/whānau can help

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Developed by the Commission out of a testing process and trialed in two primary health organisations (PHOs), the resource evolved with feedback from patients, GPs, practice administration staff and pharmacists. Let's P.L.A.N. is now in active use in GP practices and pharmacies, is a routine part of Auckland City Hospital inpatients' electronic discharge summary, and is being adapted by other health providers such as DHB outpatient services.³⁴

on a combined approach, in which patients and professionals both take responsibility. But the onus lies primarily with health professionals and the organisations they work within, because at times of substantial vulnerability people are simply not up to the considerable challenges of complex interactions within unfamiliar systems.

Improving health literacy is a dynamic systems issue reflecting the complexity of health information being presented, and the health care system being navigated.^{35,36} Health literacy is a “multi-dimensional construct that develops over time, across different health contexts and through social interactions.”¹⁹ It should develop along a continuum towards greater patient knowledge, greater self-management and

greater participation in decision making. Health literacy is about both a process and an outcome—the latter being the optimal management of health conditions at all times.¹⁹ As individuals take greater control over their own health and the decisions they need to make, care is likely to become more effective, but also more efficient, more equitable, and, by avoiding overtreatment, more *cost-effective*.³⁷⁻³⁹

Koh and colleagues have suggested that recent US federal policy initiatives at the public health level mean that health literacy is, “poised to make the transition from the margins to the mainstream.”³⁹

Now is the opportunity for New Zealand to be at the forefront of this change.

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