

New Zealand consumers' health information needs: results of an interpretive descriptive study

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ABSTRACT

INTRODUCTION: Health literacy is linked to better health outcomes and underpins effective self-management, yet over one-and-a-half million New Zealanders are known to have poor health literacy skills. An ability to access and understand health information is an important component of health literacy. Little is known, however, about New Zealand consumers' health information needs. This qualitative study sought to understand the perceptions of consumers related to their needs and use of health information.

METHODS: Four focus group interviews provided data for this qualitative descriptive study. Data analysis used a thematic inductive approach. Participants were from the general population, accessed through community-based health organisations. These consumers were predominantly of New Zealand European ethnicity, female, older, and most were actively engaged in managing their health.

FINDINGS: Four themes were identified: issues with current information provision; preferences for content; format; and sources of health information. These themes are described in the paper, using illustrative quotes from consumer participants.

CONCLUSION: This study indicates that consumers have varied health information needs. Health professionals cannot assume that consumers all have the same health literacy skills. The ideal is to provide personalised, relevant information in a manner the consumer can understand, within the current time constraints in practice. Health professionals can support consumers in their use of different strategies to ensure their health information needs are expressed and met.

KEYWORDS: Consumer health information; focus groups; health literacy; qualitative research

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Introduction

In response to the predicted increase in health care costs due to ageing populations, unhealthy lifestyles and the rising prevalence of long-term conditions,^{1,2} the World Health Organization (WHO)³ has recommended a shift in health care provision towards self-management. This involves supporting consumers to have a greater understanding of their conditions, treatment options, symptom management, healthy lifestyle choices and to have a shared involvement with health professionals in decision making. The New Zealand (NZ) government incorporated these recommendations in the Code of Health and Disability Services Consumers' Rights,⁴ which includes the right of consumers to be fully informed and to make informed choices. However, this requires

access to appropriate health information and adequate health literacy levels. Literacy is considered to be a major determinant of health⁵ and with 1.62 million NZ adults having poor health literacy,⁶ understanding the consumers' perspective on their health information needs becomes imperative.

Health literacy

Health literacy is described as the interaction between the knowledge and skills of individuals and the demands of the health care system.⁷ A person's health literacy is influenced by factors such as confidence levels, attitudes, values, and beliefs, available time and resources, and familiarity with the health topic and the health system.⁷ An adequate level of health literacy is

J PRIM HEALTH CARE
2014;6(3):203–211.

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required to access, use, and understand health information.⁸ A 2006 NZ Ministry of Health Adult Literacy and Life Skills Survey found that 56.2% of all New Zealanders have poor health literacy.⁶ Furthermore, health literacy is an equity issue, as four out of five Māori males and three out of four Māori females have poor health literacy. Poor health literacy can have many direct negative impacts on individuals, such as low knowledge of their conditions and medications; low abilities to self-manage any long-term health conditions and an increased likelihood of being hospitalised; and misunderstanding the expectations and goals of therapy.^{5,9} Health literacy can be improved by building the skills and knowledge of individuals, improving the readability of health-related information and improving information flow between the public, health professionals and the health system.⁷ These can better occur when the health information needs of NZ consumers are understood.

Consumers' health information needs

Consumers' ability to participate in their health care is dependent on health information being available, understood, retained, and utilised by individuals. A multitude of factors influence the amount, type and timing of information consumers need, such as age,^{10,11} gender,^{10,12} education level,^{10,11,13,14} culture,¹³⁻¹⁷ disease,^{11,18} stage of illness,¹⁹⁻²¹ emotional state,²² and motivation for seeking health information.^{13,15} In general, literature shows that health professionals are perceived by consumers to be the most preferred and trust-

ed source of health information.^{13,21,23} However, a gap exists between the information needs of at least some consumers and what is provided, or considered to be important information by health professionals. While verbal communication is favoured over written information,²⁴ consumers valued written information presented in simple language to refer to following a consultation,²¹ as well as guidance from health professionals as to what to read.²⁴ Although health professionals are the most trusted source of health information, time constraints and unmet information needs motivated individuals to seek information from other avenues, such as the internet, books and personal acquaintances.^{15,23} Unfortunately, the quality and reliability of health information derived from non-expert sources is highly variable and consumers often have difficulty assessing what information is valid and trustworthy.²⁵

Limited research exists about the health information needs of NZ consumers. The major study by the NZ Ministry of Health concerning health literacy was undertaken using a survey in 2006.⁶ Of three other studies identified, two evaluated the use of the internet as a source of health information.^{26,27} The third study evaluated the role of hospital libraries in providing health information to consumers, but did not ask consumers about their health information needs.²⁸ Given the paucity of research available, the aim of this study was to explore the health information needs of NZ consumers.

Methods

An interpretative descriptive approach was used.²⁹ Data were collected from four focus groups. Convenience sampling identified potential participants from health consumer groups in NZ's largest city. These groups were sent a letter of invitation to share with their members who responded if they were interested in participating. Focus groups were organised at times and locations convenient for participants. Two researchers facilitated each one-hour focus group, guiding the discussions and ensuring everybody had an opportunity to contribute. An interview guide ensured a consistent approach with each group. The guide used broad topic areas and open-ended questions (see Table 1).

Table 1. Interview guide

| | |
|--|--|
| Broad topic areas and open-ended questions included: | |
| <i>Health information</i> | |
| <ul style="list-style-type: none"> What health information do you think consumers find useful? What information is most useful to help you make decisions about your health and treatment? Should health information focus on specific common conditions? | |
| <i>Mode of delivery</i> | |
| <ul style="list-style-type: none"> What are possible ways to receive health information/resources? What ways have you found useful? Not useful? What do you think about web-based (computer) information/resources? | |
| <i>Factors impeding access and/or use of health information and resources</i> | |
| <ul style="list-style-type: none"> What helps or hinders you in finding or using health information? | |

Participants were provided with refreshments and a donation towards travel expenses. Ethical approval was obtained (NZ Health and Disability Ethics Committee NTY/09/110/EXP).

Focus groups were audio-recorded, then transcribed verbatim. Analysis of the data was conducted using a thematic inductive approach as described by Giorgi,³⁰ which is consistent with interpretative description.²⁹ Transcripts and audio files were evaluated as a whole, through repeated reading and listening to facilitate data immersion. Statements were examined to interpret meaning and emerging themes and subthemes were identified. Salient comments were highlighted to illustrate themes and preserve the richness of the data. The themes and subthemes were mapped to facilitate further analysis and reporting. Independent analysis of the data was undertaken by two researchers to verify and provide consensus for the findings.

Findings

Participants

In total, 30 participants attended the four focus groups. From the interviews, it was evident that most participants were actively engaged in managing a long-term condition. Each participant completed a demographic questionnaire. The average age of participants was 63 years (range, 36–88 years), with 63% female. In terms of ethnicity, most participants identified themselves as New Zealand European (24; 80%), 4 (14%) as Pacific, 1 (3%) as Māori, and 1 (3%) as 'Other'. English was the primary language for 27 participants (90%); two (7%) participants spoke Pacific languages. One participant did not specify a first language. The demographic data, including educational level of the participants, is summarised in Table 2.

Themes

Thematic analysis revealed four theme clusters (Table 3):

1. Issues with current information provision
2. Preferences for content
3. Format preferences
4. Source of health information.

WHAT GAP THIS FILLS

What we already know: Consumers' poor health literacy is a significant problem and is linked to poorer health outcomes. From international literature, many factors are known to influence the amount, type and timing of information consumers need.

What this study adds: This qualitative study heightens awareness of what health literacy means from consumers' perspectives as it illustrates the perceptions of consumers related to their use of health information and adds the consumer voice to the 2006 Adult Literacy and Life Skills Survey.

Table 2. Summary of participants' demographic data (N=30)

| | | |
|------------------------------|----------------------------|-------------|
| Gender | Male | 11 (37%) |
| | Female | 19 (63%) |
| Age | Mean | 63 years |
| | Range | 36–88 years |
| Ethnicity | NZ European | 24 (80%) |
| | Pacific peoples | 4 (14%) |
| | Māori | 1 (3%) |
| | Other | 1 (3%) |
| First language | English | 27 (90%) |
| | Pacific | 2 (7%) |
| | Not specified | 1 (3%) |
| Highest qualification | No formal qualification | 4 (14%) |
| | Secondary school | 14 (47%) |
| | Tertiary qualification | 8 (27%) |
| | Professional qualification | 2 (7%) |
| | Other | 1 (3%) |
| | Not specified | 1 (3%) |
| Employment | Employed | 9 (30%) |
| | Not employed/retired | 21 (70%) |
| Long-term condition | Yes | 24 (80%) |
| | No | 6 (20%) |

Illustrative quotes from participants are included for each theme cluster.

Issues with current information provision

In general, participants felt that they had sufficient information when they were provided with 'just the basics of what the problem is' and an 'understanding of what it is and what you have to do'. Participants suggested that it was useful to know what to expect for symptoms, medication

side effects and where to find additional information. However, they also gave examples of having access to too much or insufficient information.

There is reams of information. So much you could push it aside... it was rubbish.

Conversely, several participants were dissatisfied with the information provided and wanted more detail.

I knew nothing about it... I was just told by my doctor what I needed to take.

Lack of information led many participants to search independently, often using the internet. One participant noted that access to information had increased compared with 30 years ago, which now allowed him to avoid 'just following the doctor's orders'. Seeking information was stated as 'not just to prove that they're right or they're wrong', but to gain knowledge to better understand what health professionals were saying. Other participants sought additional information because their health professionals had not met their needs.

The doctor said to me he didn't know what the cure was; he said 'just try and find out what you can on the internet'.

Some participants took personal responsibility to obtain the information they required.

After all it's your health and you are the one affected by it.

They also indicated that a lack of information could lead to anxiety. However, other participants identified reasons for not seeking more information, such as shyness and 'not wanting to bother' health professionals.

The importance of considering the credibility, and methods for determining credibility, of information varied. Checking information with their doctor was the most frequently reported method for checking the quality of health information. Another method reported was to evaluate the source of the information.

You see things on the TV and it says it's going to do all sorts of things but you should check with your doctor first.

Anybody can put anything on the internet and... you have to find out what the source is first before you take on board what is being said.

I [searched for] specific organisations involved in that area and got information from their sites as opposed to taking one page with no acknowledgement or sources.

Generally, information obtained from research journals or endorsed by doctors was considered credible, while participants were generally sceptical of information from other sources. Comments were also made about the media.

So much of the information you get out of the newspaper is so slanted.

[About the internet] you have to be careful what you take from it.

[About advertising material] you've got to watch it isn't something the drug outfits are peddling.

Some participants reported verifying information from different sources and participants considered it important to make up their own minds

Table 3. Themes and subthemes identified

| Theme | Subtheme |
|---|------------------------------|
| Issues with current information provision | Amount of detail |
| | Credibility |
| | Language |
| | Other barriers |
| Participants' preferences for the content of health information | General health information |
| | Specific health information |
| | Medication |
| | Navigating the health system |
| Participants' preferences for the format of health information | Verbal |
| | Written |
| | Visual |
| | Interaction |
| Participants' preferences for the source of health information | Health professionals |
| | Internet |
| | Other sources |

and to decide whether the information corresponded with their personal views.

If I see something on the [internet] then read something in a book in a library, it verifies what I read on the [internet].

You've got to weigh up the pros and cons of what you're looking at.

If it fits with what I know or think then it must be right.

Two issues were identified relating to the language used in information currently provided—the language and terminology. Participants whose first language was not English expressed difficulty in understanding information provided, often relying on family members to translate information. There was general consensus among participants that, within NZ, written information should be presented in a range of languages, including English, Māori, Pacific and Asian languages. However, given the costs involved, it was considered acceptable for introductory pamphlets to be provided in various languages, with information about where to obtain further information in different languages. Participants whose first language was English experienced difficulties in understanding the accents of health professionals whose first language was not English. They suggested a translator for the health professional may be helpful in these circumstances.

English is not their first language and it is very difficult when you're not well to understand what they're talking about.

Participants also wanted information provided in a way that they could understand. It was considered important to use 'small words' that were not 'too technical'. Simplified language that people are familiar with was considered preferable to medical jargon. One participant added that the tone of language is also important.

It's got to be compassionate, because some of them [health professionals] are very brisk and talk down to you.

Participants identified several barriers that prevented them from accessing and using health

information. Some health professionals did not provide important information, perhaps because of time or organisational constraints. Participants also noted that their ability to retain information was a barrier, with one participant stating that, of health information received during a consultation he recalled 'only about 5% of it 24 hours later'.

Preferences for content

Participants' preferences for content included general and specific health information, information about medications and about how to navigate the health system. In terms of general health information, participants wanted information about how to maintain a healthy lifestyle, including 'healthy eating', 'exercise' and 'preventive information'. They were also interested in information on complementary and alternative medicines. In addition, participants expressed the desire for disease-specific information that is 'relevant to the condition you have'. Basic information about the condition and what the person needed to do was considered sufficient. However, with progressive conditions such as Alzheimer's disease, participants felt that it would be useful for 'the family to know how it progresses' and to understand 'why certain responses, which are very uncharacteristic, suddenly came about'. Personalising specific information was considered important.

Everyone's experiences of living with a condition is slightly different.

Participants stressed the importance of receiving information about medications and gave examples of being given an incorrect medication or dosage. It was suggested by participants that people be provided with a description of the specific medication along with what the medication was for. Some participants reported already receiving relevant information about their medicines. Receiving information about the side effects of medication was also considered important.

I've been told when I've picked up a repeat prescription that they're now called such and such else and the colour's different.

[You need to know] what the side effects are and to know when you should go back [to the doctor].

Knowing the services available and how to navigate the health system, such as which health professional to go to and what to expect, was important for most participants. Further information about emergency services, disease-specific services and support groups were discussed, and more publicity about these types of services suggested. Participants wanted information about waiting times in the emergency department, where to park, the cost of services and whether they may be eligible for financial assistance.

People always want to know about costs... it's always the big question mark.

Having a second person present when attending appointments was also suggested, 'because four ears are better than two'.

Format preferences

Participants generally agreed that having information presented both verbally and in writing was preferable. They valued receiving information face-to-face, either individually in a consultation or within a group, such as an educational or support group setting. Participants also appreciated being able to have personal contact through free telephone health information services. Additionally, they liked the convenience of written information provided in health centres where they could 'pick something up and take it away'. Pamphlets, certain general magazines, and disease-specific organisational magazines were reported as providing useful and reliable information. However, participants found the prescription leaflets within medication boxes to be too technical and the small print too difficult to read. There were mixed views about educational DVDs—one about women's health was considered useful, whereas another about the progression of Alzheimer's disease was perceived as 'quite traumatic' by a participant who was a caregiver. Participants found they were better able to retain information by interacting with it.

I find if I say it, I remember it.

If someone says it and I write it down, it seems to stick with me better.

Sources of health information

Analysis identified preferred sources of health information: health professionals, the internet and a variety of other sources. Provided they had 'a good caring doctor', participants respected and trusted their doctors and the health information provided. Some participants made contact by phone, while others preferred to visit their doctor.

I think the first call would be to my doctor.

If I've got a niggling thing I'll automatically ring my doctor.

Usually going in and seeing them [the doctor] is best.

Having an established relationship with the doctor who had prior knowledge of the person was considered important. Other health professionals, such as pharmacists and nurses, were also considered good sources of health information. Participants who had a long-term condition trusted information provided by a specialist health professional, noting that generalist health professionals often knew less than they did about their condition. However, a limitation to sourcing information from health professionals was that 'they haven't the time to spend with you'.

Participants were generally interested in having access to their health records. However, they were divided on whether other health professionals or family should also have access.

I don't think it would be right for everybody to have access to the doctor's records... only you have the information.

I think spouses should be told.

Approximately half the participants in this study used the internet as a source of health information. Some found the internet useful.

It was easy to find the information [on the internet].

[I] could understand the way it was put [on the internet].

One participant found the internet also provided examples of other people's experiences of some unusual symptoms that her husband had displayed as his condition progressed. She reported finding it reassuring to be able to attribute the symptoms to his illness. Another participant, with a congenital long-term condition, described the internet as 'an important tool' for enabling him to be informed of the most current research. Chat rooms were viewed positively by some who shared information by networking with other people with a similar condition, and less positively by others.

People give their opinions on how things are affecting them and it's all a bit doom and gloom.

A variety of other sources of health information were discussed. Participants found group education sessions interesting and informative, not only because of information provided by guest speakers, but also through providing the opportunity to talk to other people about their experiences.

You think, oh that's what happened to me and you pick up information that way and I think it's brilliant... you learn from other people.

Participants differed in the level of personal contact they wanted within support groups; some found personal contact important, while others were more hesitant.

Personal contact with other people in my situation [through a support group], quite frankly, is lifesaving.

We don't have personal contact [through a support group] and I don't really think we want that.

Other participants sourced information from disease-specific organisations, which was considered useful.

I get more information from [asthma group] than I get from my own GP [general practitioner].

Participants also described obtaining health information from friends and family members, but made their own decisions about whether or

not to follow the advice, or to pass information on to others.

Discussion

This study supports previous research indicating that consumer understanding of information may be improved by using simple, everyday terminology.¹⁶ A variety of formats, such as verbal, written and visual, is also recommended to aid the absorption of information and for consumers to refer to later.²¹ However, on a cautionary note, this study highlighted the need to balance the amount and level of information provided. Too much information was considered unnecessary or even traumatic for some, while others struggled to understand and retain information, especially when unwell. Learning may also be enhanced when information is provided within a social context,^{16,31} which may explain the enthusiasm of some participants in this study for support groups and group education.

Too much information was considered unnecessary or even traumatic for some, while others struggled to understand and retain information, especially when unwell

Translation services may be helpful when the consumer and health professional do not speak the same first language. An interesting issue raised from this study is that translation may be needed when the health professional has a heavy accent. Experiences described by participants in this study mirrored those reported in international research regarding barriers for those not speaking or reading the dominant language fluently,¹⁵ and the general desire for information to be provided in a person's first language.¹⁶

Furthermore, findings from this study support the notion that the health information needs of consumers vary widely and may be influenced by a range of factors.¹⁸ Allowing consumers to have more control over what information and how much detail they obtain are areas for further research. Preliminary findings from research

on tailored online health information systems suggest this may offer potential solutions for different information needs.³²

It is estimated that between 40% and 80% of information provided to health care consumers may be forgotten.³³ The importance of being able to remember information was raised in this study. Some participants had difficulty retaining health information, but this improved if they took notes, repeated the information, or had a companion with them during consultations. These are effective strategies described in the literature^{14,34,35} and should be encouraged.

It is estimated that between 40% and 80% of information provided to health care consumers may be forgotten

In keeping with the international literature,^{13,21,23} this study found health professionals to be the most popular and trusted source of health information for many consumers. However, health professionals were unable to meet all health information needs and consumers should be encouraged to seek further information if they are not satisfied with what has been provided. A similar finding was noted in another NZ study²⁸ where not all patients were provided with sufficient information about their conditions and health care. Possible reasons may include time constraints associated with a busy health care service, or the health professional lacking specific knowledge. As with participants in Akhu-Zaheya and Dickerson's study,¹⁵ an unmet need motivated many of this study's participants to seek information from other sources.

Strengths and limitations

Strengths of this study include the range of data obtained from four focus groups. However, using convenience sampling resulted in a non-representative study population, with under-representation of Māori and working adults. The higher prevalence of long-term conditions and lower employment rates may have influenced participants' interest, willingness and availability

to participate in the study. This study did not directly assess participants' health literacy, and a further study that explores health literacy in conjunction with health information needs is warranted. A study focusing on Māori consumers' health information needs is also indicated. In addition, repeating the study with a larger sample that is more representative of the general population is recommended.

Conclusion and practice implications

Our findings suggest health professionals cannot assume that consumers all have the same health literacy skills and health information needs. Health professionals need to continue to strive to provide personalised, relevant information based on the consumer's priorities and in a manner they can understand, with guidance to further sources of information if needed. The challenge for health professionals is to ensure that sufficient time is taken to assess and understand each individual's unique situation within the time constraints currently faced in health care provision. Simple, everyday language and access to information in a range of languages and formats is recommended. Additionally, health professionals can support strategies consumers use to ensure their health information needs are expressed and met. These include consumers taking notes, repeating information, or taking a support person to consultations, to enhance retention of health information provided.

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ACKNOWLEDGEMENTS

The authors would like to acknowledge and thank the individuals who participated in this study.

FUNDING

This study received funding support from the New Zealand Tertiary Education Commission through a grant from the Strategy to Advance Research (STAR) Fund.

COMPETING INTERESTS

None declared.