

Health Literacy and Communication

Conceptualising health literacy from the patient perspective

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ABSTRACT

Objective: A person's health literacy, i.e., their ability to seek, understand and use health information, is a critical determinant of whether they are able to actively participate in their healthcare. The objective of this study was to conceptualise health literacy from the patient perspective.

Methods: Using comprehensive qualitative methods 48 individuals were interviewed across three distinct groups in Australia: those with a chronic condition, the general community and individuals who had recently presented to a metropolitan public hospital emergency department. Purposeful sampling was employed to ensure a range of experiences was captured.

Results: Seven key abilities were identified: knowing when to seek health information; knowing where to seek health information; verbal communication skills; assertiveness; literacy skills; capacity to process and retain information; application skills.

Conclusion: This study identifies key abilities patients identified as critical to seek, understand and utilise information in the healthcare setting. These abilities are not reflected in existing measures for health literacy. Future measures of health literacy could consider incorporating abilities identified in this study and may provide guidance in developing health interventions to assist patients to participate effectively in their health.

Practice implications: More comprehensive measures to assess patient's health literacy are needed.

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1. Introduction

We live in an information-rich environment in which daily activities are negotiated through competing and sometimes contradictory sources of information [1]. This is particularly relevant in the healthcare setting where the advent of patient-centred care means that information seeking practices and patient actions and reactions towards information take on greater importance in managing their own healthcare [2,3]. This process assumes that patients have adequate 'health literacy'. The term health literacy encompasses an individual's ability to seek, understand and utilise health information. Research has shown that individuals with inadequate health literacy have less knowledge of their diseases and treatments and a lack of skills needed to

negotiate the healthcare system [4–8]. As such, health literacy has gained prominence amongst governments, health professionals and researchers. A report by the United States Institute of Medicine (IOM) identified health literacy to be one of the most important opportunities to improve population health [9].

Health literacy is a rapidly developing area and its meaning has expanded to encompass a range of concepts. Landmark reports such as the IOM recognise health literacy as a complex phenomenon that has moved from a narrow conceptual focus on patient literacy skills such as reading to being a far more multi-dimensional construct where patient skills or abilities interact with education, health, social and cultural influences [10–12]. Similarly the World Health Organisation, describes health literacy as "the cognitive and social skills that influence peoples' motivation and ability to gain access to, understand and use information in ways which promote and maintain good health" [13]. However as highlighted by Baker, the lack of a shared understanding of the central term in a field is problematic, particularly in the area of measurement. There is continuing debate as to the underlying constructs that should be measured

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based on whether health literacy is a capacity of a person or dependent on the relationship between individual capacities, the healthcare system and broader society [14].

An apparent gap exists between current definitions and measures of health literacy. The predominant approach to assessment has been direct testing of individual literacy (reading comprehension) and numeracy abilities, as assessed for example by the Test of Functional Health Literacy in Adults (TOFHLA) [15]. However these constructs do not reflect the range of attributes implied in existing definitions related to an individual's ability to seek, understand and utilise health information [10,13,16]. Future research directions in the health literacy field have consistently identified the need to develop broader measures [11,17–19].

In developing new measures, it is important that the assessment reflects aspects or constructs that are most important to the population of interest [20]. Qualitative research is advocated as the optimal approach to establish face and content validity of an assessment and ensure greater relevance of the content. Current views of health literacy encompass the larger concept of patient-centred care which is responsive to patients' needs and values and encourages active participation [21]. Despite increased utilisation of informal sources of information external to the healthcare setting such as the internet, the patient–health professional interaction still represents a critical juncture for the exchange of health information [22,23]. To support this exchange, abilities that are deemed important to patients in terms of seeking, understanding and utilising information, i.e., health literacy, need to be explored, understood and represented.

This study involved in-depth qualitative interviews to identify and understand what health literacy represents from the patient perspective and identify potential constructs for a broader measure of health literacy.

2. Methods

2.1. Participants

Individuals aged 18 years and over were recruited from three distinct population groups within Victoria, Australia using maximum variation (heterogeneity) sampling. These individuals were expected to have experiences relevant to the focus of the study, namely health literacy and healthcare utilisation [24]. Sampling specifically sought to capture insights from individuals across the disease continuum (i.e., acute to chronic). Participants were recruited:

- (i) from a research database held at the Centre for Rheumatic Diseases, University of Melbourne of individuals with chronic conditions who have participated in chronic disease self-management education programs across Australia;
- (ii) from a previous population-based study sampled from the 2004 Victorian Government Electoral Roll. Details of this survey have been described previously [25];
- (iii) through presentation to the Royal Melbourne Hospital Emergency Department (RMH ED), a metropolitan public hospital, with one of the following conditions:
 - diabetes with or without complications,
 - chest pain,
 - asthma, and
 - chronic obstructive pulmonary disease.

Individuals were recruited in two phases. Firstly, individuals from the chronic disease and general population groups were recruited based on self-reported age, gender and education levels (see Table 1). Individuals from RMH ED were then recruited for

Table 1

Key themes explored in the standardised interviews with participants.

Seeking medical help
Factors that identify the need to engage and access medical help (including accessing services and information at the appropriate time)
Access and navigation of the healthcare system
Barriers and enablers to accessing and navigating the healthcare system
Types and format of information required to decide which health service/treatment may suit individual best
Seeking and understanding health information (incorporates communicating with health professionals)
Barriers and enablers to seeking and understanding information about health (in particular reference to chronic condition(s))
Skills required to effectively communicate with health professionals
Enablers and barriers to understanding and following prescribed medical treatment
Abilities patients need to function in the healthcare system
Identification of abilities individuals need to seek, understand and utilise health information to maintain good health

theoretical sampling (i.e., saturation of themes) on the basis of self-reported age and gender and presenting condition.

This study was approved by The University of Melbourne (ID: 0710858.1), Cabrini Research Institute (No: 01-07-11-05) and the Royal Melbourne Hospital (HREC 2007.084) Human Research Ethics Committees.

2.2. Interview

Structured, in-depth, face-to-face and telephone interviews (based on participant preference) were undertaken between May 2007 and January 2008. The interview schedule was developed through in-depth discussions with clinicians and health service researchers, and was designed to explore individuals 'healthcare journey' from identification of a health problem to resolution in seeking, understanding and utilising health information (see Fig. 1 and Table 1). The interview was broad so as to not impose limitations on identifying factors that impact on individuals usual or regular health experiences and use of health information. Following written informed consent, interviews were tape recorded and transcribed.

2.3. Data analysis

Analyses were undertaken using a grounded theory approach as described by Strauss and Corbin [26]. The transcripts were thematically coded and subsequently categorised according to trends identified in the data. The two population groups (chronic disease and general population) were first analysed separately and then compared. Data from participants from the RMH ED were then analysed to ensure the adequacy of categories developed and saturation of emerging themes. Due to the large quantity of data collected, one-third of interviews were selected randomly for independent coding by an external experienced qualitative researcher. Syntheses from the two researchers were then compared and themes refined were necessary to reach consensus. For the validation of the themes identified, the findings were provided back to interviewees via written summaries. A randomly selected subset of participants across the three groups were followed up by telephone or email to determine that results were reflective of patient experiences [24].

3. Results

48 interviews were conducted across the three groups: chronic disease ($n=20$), general population ($n=14$) and individuals presenting to RMH ED ($n=14$). 23 face-to-face and 25 telephone interviews were undertaken. Interview length ranged from 20 min

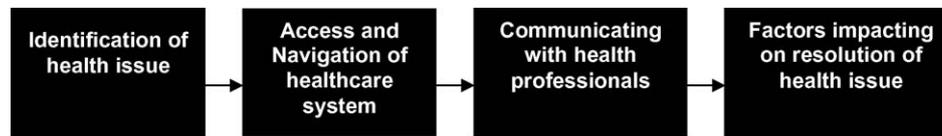


Fig. 1. Conceptual model of individual patient journey from identification of health problem through to resolution.

Table 2

Demographics of participants from 3 population groups.

Descriptor	Chronic disease	General population	Emergency Department	Overall
Participants (n)	20	14	14	48
Age (years): median (range)	57 (32–85)	74 (30–83)	49 (25–67)	56 (25–83)
Sex: % female	75%	64%	50%	63%
Education, n (%)				
Completed some high school	5 (25%)	4 (29%)	Not reported	9 (19%)
Completed high school	10 (50%)	8 (57%)	Not reported	18 (38%)
Completed university	5 (25%)	2 (14%)	Not reported	7 (15%)
Main health problem, n (%)				
Chronic obstructive pulmonary disease (COPD)	5 (25%)	1 (7%)	5 (36%)	11 (23%)
Chest Pain	0 (0%)	0 (0%)	8 (57%)	8 (17%)
Arthritis (osteoarthritis, rheumatoid)	4 (20%)	1 (7%)	0 (0%)	5 (10%)
Diabetes	3 (15%)	0 (0%)	1 (7%)	4 (8%)
Pain syndrome	2 (10%)	0 (0%)	0 (0%)	2 (4%)
Depression	1 (5%)	1 (7%)	0 (0%)	2 (4%)
Back pain	1 (5%)	0 (0%)	0 (0%)	1 (2%)
Cancer	1 (5%)	0 (0%)	0 (0%)	1 (2%)
Cardiovascular disease	1 (5%)	0 (0%)	0 (0%)	1 (2%)
Hepatitis C	0 (0%)	1 (7%)	0 (0%)	1 (2%)
Osteoporosis	1 (5%)	0 (0%)	0 (0%)	1 (2%)
Sjogren's syndrome	1 (5%)	0 (0%)	0 (0%)	1 (2%)
No health problems	0 (0%)	10 (72%)	0 (0%)	10 (21%)

to 2 h. Table 2 presents the demographic details of participants. The majority of participants interviewed were Caucasian and over half had completed a high school education. More females (63%) participated in the study and the health status of participants from the chronic disease group was poorer. Through the course of the interviews, four participants disclosed that they were illiterate.

3.1. Key abilities that reflect health literacy from the patient perspective

Seven key abilities emerged across groups that participants identified as important in seeking, understanding and utilising health information within the healthcare setting. These are presented below and discussed in the context of the 'patient journey'. There was strong consistency between themes identified by the primary and independent researchers. Ten participants followed up to verify results all conveyed strong verbal agreement of themes identified.

3.1.1. Identifying a health issue: knowing when and where to seek health information

Participants, particularly those from the general population and RMH ED were very reactive towards their health—if nothing is perceived to be 'wrong' then there is a tendency not to be motivated or receptive towards health information. A 'trigger' or 'health event' that impeded regular activities or lifestyle often prompted individuals to start seeking health information. A critical ability identified by patients during this process was *knowing when to seek health information* to determine if a health issue required immediate attention or could be self-managed:

"...knowing where to go, where to get help from and probably understanding a little bit about the urgency...is this a really urgent problem? Am I going to be sitting in Casualty

[Emergency Department] for six or eight hours or ten hours when I could just as easily make an appointment to see a doctor somewhere else tomorrow." [Female participant with a chronic condition]

Once a decision to seek information had been made, another important ability was *knowing where to find health information*. Surprisingly a large proportion of participants with a chronic condition disclosed that they were not aware of services within their area and therefore found it difficult accessing health information relevant to their health issue:

"...knowing what's available is very helpful. A lot of people don't know all that is available to them. I probably don't either but I have done a lot of community work and I have a fair idea of what's available, ...even just a list of specific places or counselling that is to do with disabilities or whatever..." [Female participant with a chronic condition]

"I don't know how to actually access a lot of the different things at this stage. Yeah. I find it very difficult to find out about things that would help...and that are appropriate to me...there doesn't appear to be much..." [Female participant with a chronic condition]

However for a large proportion of participants, particularly those from the general population, the issue of *where to seek health information* was different across health conditions and relevant health service:

"...if it's basic, we go to see a Medicare card doctor...if it's more serious I'll go to my general practitioner who is still practicing from when I was a kid...and then if it's an emergency and

there's no doctors, I reckon we go to one of our better hospitals.”
[Male participant, general population]

3.1.2. Accessing and navigating the healthcare system and communicating with health professionals: engaging in information exchange

In sourcing and understanding health information, the interaction between the patient and health professional was a primary focus for participants. Through this encounter, patients highlighted the importance of *verbal communication skills*. There was an emphasis on (a) being able to adequately describe the health issues the individual was facing as well as (b) understanding the response from the health professional:

“I think that the hardest thing for any patient is trying to explain what it [the health problem] actually is because you're not medically minded... I think that communication should be quite open... the doctor can't tell what it is with you, unless you tell him what it is... it comes down to straight out communication...” [Male participant with a chronic condition]

Linked to effective communication was the need for *assertiveness* to facilitate understanding of information. This was a stronger theme to emerge from participants with a chronic disease. Participants described the importance of actively clarifying information so they are able to fully comprehend the nature of the health issue and make informed choices:

“...I think I'm fairly assertive, but I don't think everyone's assertive and I think some people put up with a lot of ill-health because they don't want to question their doctor or make a fuss...” [Female participant with a chronic condition]

However for individuals presenting to the RMH ED, whilst assertiveness was also considered an important ability, the busy and stressful environment made it difficult to clarify information:

“...I did get the information...which was basically the reassurance that they had picked up no abnormalities [in heart]...it was rushed... I didn't get to really understand what I wanted.” [Female participant presenting to RMH ED]

Whilst *literacy skills*, namely reading and writing were also identified as a key ability, this was more in the context of following up information after the encounter with the health professional, particularly in a written format, rather than understanding health information during the consultation:

“Yes I think reading and writing plays a big part in it, because you can read something today and then go back another day and read it again and it gives you a bigger outlook...” [Male participant, general population]

3.1.3. Resolution of health issue by acting upon health information

Participants emphasised that for information to be utilised, it was necessary for individuals to have the *capacity to process and retain information* provided in the consultation. Rather than focusing on an individual's cognitive capacity, this referred more to a person's physical or emotional capacity to be able to comprehend and extract meaning from the information:

“...my thyroid became overactive and that was a new thing that happened and it was quite a shock and I didn't really fully understand exactly what was being told to me and I was also upset about it...if something gives me a shock or makes me feel

very stressed...my brain doesn't function very well...they need the capacity to mentally process the information...” [Female participant with a chronic condition]

Building on this, participants across groups indicated that for health information to be utilised, it had to resonate with patient health beliefs and attitudes:

“...[the doctor] gave me a bottle of tablets, then she said to me...I want you to take all of these tablets and make sure that you do, you know, I didn't take one. Valium, she gave me Valium. I don't want to take Valium, I mean even though I was agitated and stuff...you can get addicted to those things you know? So most of the time I listen to her, but just some things, I think I know what's better...” [Female participant, general population]

Additionally having the necessary *application skills* to follow instructions or implement procedures into their lifestyle was considered essential for participants to effectively address health issues:

“Well at the moment...I have got seven or eight medicines to take every day and you've got to take this one, an hour before food and another one with food...we start off at six o'clock in the morning and go 'til eight o'clock at night...so that's all day, all different hours, all different times and when am I going to do my ordinary things?” [Male participant with a chronic condition]

3.2. Broader factors that influence patient health literacy abilities

In discussing their healthcare experiences, participants across groups consistently identified a myriad of factors at both the healthcare system and community level that influenced their abilities to seek, understand and utilise health information. Key themes are presented below and shown in Fig. 2.

3.2.1. Healthcare system level

Participants highlighted a range of factors relating to both the patient and the health professional that influenced information exchange. Patients' attitudes, knowledge and prior health experiences affected *when and where they would seek health information* as well as their inclination to utilise information, i.e., *application skills*. Additionally participants highlighted that their physical or emotional disposition at the time of the patient–health professional interaction also influenced their *verbal communication skills*, *assertiveness* and *literacy skills*. This was a prominent theme for individuals attending RMH ED:

“...when you're sick, you haven't got the strength...you don't feel like talking, you don't feel like doing anything...you're just scared something will happen...” [Female participant presenting to RMH ED]

The time pressured clinical environmental was also consistently noted as hindering patients' *verbal communication abilities* and *capacity to retain and process information*. Participants were aware of this factor and often indicated they held back on discussing health issues during the patient–health professional interaction:

“...they see you for five minutes...and you're trying to cover the things that you have to cover or that they have to check while you're there...without going into how you're really feeling and what you've been experiencing...the time factor...you are

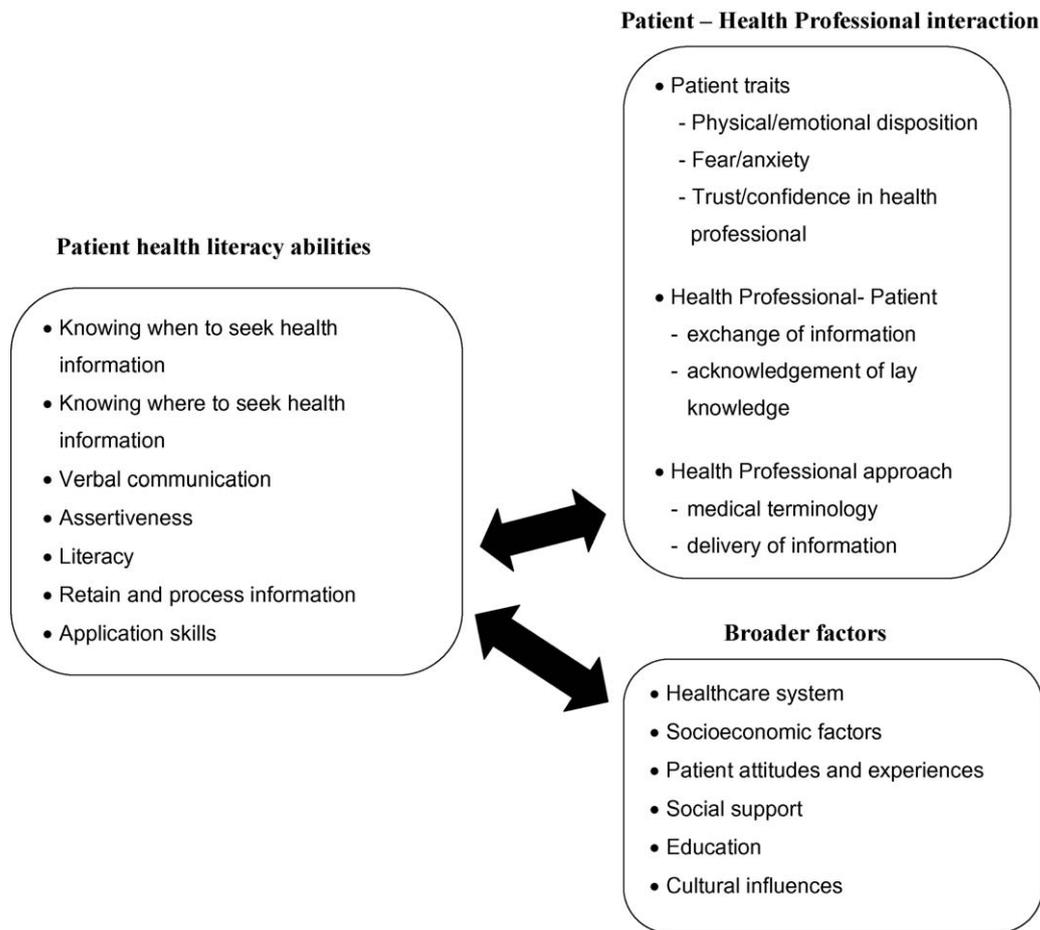


Fig. 2. The patient perspective: core individual abilities of health literacy and broader factors that affect abilities.

worrying that perhaps you're taking up too much time...there are other things I've noticed but you think I'll leave that until next time..." [Female participant with a chronic condition]

Within the time constrained environment, how health professionals delivered information emerged as a critical factor that influenced patients' *capacity to retain and process health information* and *application skills*. Complex medical terminology and overloading of information were consistently identified as hindering factors:

"Sometimes they [doctors] come out with big words and I don't know what to make of it...they don't say stomach or belly, they say something else, abdominal...I don't understand that." [Female participant presenting to RMH ED]

Participants across groups consistently emphasised the need for health professionals to tailor information to patient needs and indicated the use of different formats assisted understanding:

"I think depending on the patient, you have to pitch whatever information according to the patient's level of understanding. When I see my GP, he's got diagrams and so on that you can really see what's happening, what he's trying to do...so diagrams cut across languages. Basically it works." [Male participant, general population]

3.2.2. Broader community level

Participants also identified factors at the community level which also influenced abilities. Lifestyle commitments, whether

this was work, study, family or carer related often meant participants were unable to prioritise their health and utilise health information:

"It's time management and the business. I've got 12 guys working for me, plus all the subbies [subcontractors], plus 15 customers. So they sort of come first. I'll get to the doctor if I've got anything serious...but I don't know, they say go home and rest. Well the business needs decisions, it won't run itself..." [Male participant, general population]

Similarly financial considerations also hampered the ability of participants to be able to seek health information in terms of affording consultations with health professionals as well as purchasing medications or services. This was particularly the case for participants in managing an ongoing chronic condition:

"I find that services now are becoming very expensive...I can't afford to do the things to help my body...my fibromyalgia is really playing up and I'm going to hydrotherapy and to the exercise program as an outpatient now. It was fine while I was an inpatient because I didn't pay, but now, the hydro session is \$7 and the exercise program is \$15... I just don't know how much longer I can sustain doing it..." [Female participant with a chronic condition]

Participants also indicated that the presence of a good support network, i.e., family and friends played critical roles in knowing *when and where to seek health information* as well as helping *process and retain information*:

“I needed to take my daughter with me so that she could also think on my behalf. . . I’ve got three children and one of them would come along and help interpret what I’m not getting the gist of the information” [Female participant with a chronic condition]

Educational background and participant lay knowledge and previous experiences were also considered as important factors that influenced abilities to seek and understand health information, particularly in distinguishing between reputable and non reputable sources of information.

4. Discussion and conclusion

4.1. Discussion

This study identified seven key abilities patients identified as important in seeking, understanding and utilising health information within the healthcare setting: knowing when to seek health information, knowing where to seek health information, verbal communication skills, assertiveness, literacy skills, capacity to process and retain information and application skills. A range of factors at the healthcare system and community level that influence these abilities were also identified to be a key component of health literacy.

These abilities and factors were derived through in-depth consultation with individuals from different healthcare settings and disease status. Through purposeful sampling we appraised a broad range of groups to qualitatively identify and understand potential constructs of health literacy. This is in contrast to the majority of research in this field which has evaluated health literacy in a quantitative context. Importantly, our findings explored concepts that are often not amenable to quantitative research [27].

In comparing how health literacy has been conceptualised in this study to previous models in the literature there are some commonalities. Zarcadoolas et al. characterise health literacy through four central domains: fundamental literacy (reading and writing); science literacy (knowledge/understanding of scientific concepts); civic literacy (awareness of public issues); cultural literacy (social identity) [12]. This has similarities with several of our identified abilities, namely literacy skills, verbal communication and knowing where to access health information. Nutbeam’s model incorporates hierarchical levels of health literacy—*functional literacy* (reading and writing), *communicative literacy* (refers to more advanced cognitive and literacy skills) and *critical literacy* (skills to exert greater control over life events and situations) [28]. These descriptions partially identify with our empirically derived abilities—verbal communication, literacy skills and assertiveness. There are also several existing conceptualisations which have incorporated both abilities and broader factors such as the IOM model. Health literacy is conceptualised as a set of individual capabilities namely cultural and conceptual knowledge, speaking and listening skills and numeracy that are influenced by broader social, educational and cultural factors [11]. These are reflective of several abilities and factors identified in this study.

Results in this study expand conceptualisations of health literacy by identifying abilities relevant to patients which are required for their utilisation of health information, namely the capacity to retain and process information and application skills. Furthermore a range of factors at the healthcare and community levels were explored in-depth to show how they influence health literacy abilities. This process was more systematic and patient-centred than previous work in this area.

Differences in this study may be attributed to a different focus. Previous conceptualisations of health literacy have been pre-

dominantly derived from the experiences of health professionals, health educators and literacy specialists whilst we adopted the patient perspective. This is consistent with previous observations of differences between concepts of health of lay people and those of health professionals [29,30].

Our results show that an individual’s health literacy is dependent on the relationship between individual capacities, the healthcare system and broader society. This supports the concern that existing health literacy measures, which predominantly focus on individual literacy abilities, omit important domains [14]. Participant narratives revealed that even if individuals possess the necessary abilities to seek, understand and utilise health information, other influences such as socio-economic circumstances, social support as well as the nature of the healthcare setting can hinder the process. For example, a person’s usual abilities may be affected by physical and emotional factors in the setting of emergency care. The importance of these broader social, ecological and systemic factors is increasingly being recognised [31] and it may be prudent to include these in future measures of health literacy.

In reviewing the abilities and factors identified in this study, a large proportion of these constructs cannot be directly measured, which has been the dominant approach to assessing health literacy to date [15,32]. For example, it is difficult to directly test a patient’s assertiveness or comprehensively assess their knowledge about seeking health information. Self-report questionnaires, now commonly described as patient reported outcomes (PROs), present as an alternative approach when developing broader assessments of health literacy. This study has demonstrated that asking patients about their perceived abilities and the extent to which factors influence these abilities provide new insights for this area. This type of information could assist health professionals in better tailoring information to patient needs or identifying areas for the development of new interventions. Furthermore the use of PROs can avoid issues of shame and embarrassment patients may undergo when directly tested for health literacy abilities [33].

This study has some limitations. The abilities and broader factors identified may not be representative of all patient groups. Further research is required to verify these abilities in other patient populations. However the identification of common abilities and factors across groups provides evidence that at least some of the key issues for patients have been identified. Another attempt to verify the reliability of findings from this study was having an independent reviewer analyse a subset of interviews and confirming developed themes with participants.

4.2. Conclusion

A person’s ability to seek, understand and utilise health information is important in being able to access and benefit from healthcare services. In this study conceptualising health literacy from the patient perspective identified seven key abilities and a range of factors at the healthcare and broader community level that affect these abilities. Further work is necessary to develop ways to comprehensively measure health literacy from the patient perspective. Constructs identified in this study may assist in informing broader assessments to measure patients’ health literacy.

4.3. Practice implications

It is important for health professionals to be aware of the health literacy of their patients so that they can appropriately tailor their communication with them. Our study identified key attributes of health literacy that could be considered in making this judgement. Broader measures of health literacy are needed which assess

attributes important to patients to effectively seek, understand and utilise health information. This may provide clear information to support health professionals to communicate and implement interventions to assist patients.

Declaration

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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