

Perspectives

Priorities for Action: Recommendations from an international roundtable on health literacy and chronic disease management

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Summary

Understanding the nature and impact of health literacy is a priority in health promotion and chronic disease prevention and treatment. Health literacy comprises the application of a broad set of skills to access, comprehend, evaluate, communicate and act on health information for improved health and well-being. A complex concept, it involves multiple participants and is enacted across a wide variety of contexts. Health literacy's complexity has given rise to challenges achieving a standard definition and developing means to measure all its dimensions. In May 2013, a group of health literacy experts, clinicians and policymakers convened at an Expert Roundtable to review the current state of health literacy research and practice, and make recommendations about refining its definition, expanding its measurement and integrating best practices into chronic disease management. The four-day knowledge exchange concluded that the successful integration of health literacy into policy and practice depends on the development of a more substantial evidence base. A review of the successes and gaps in health literacy research, education and interventions culminated in the identification of key priorities to further the health literacy agenda. The workshop was funded by the UBC Peter Wall Institute for Advanced Studies, Vancouver.

Key words: health literacy, chronic disease management, measurement, policy

INTRODUCTION

Health literacy has been conceptualized as the application of a set of skills—including reading, numeracy and problem solving—to the processes of accessing, comprehending and using health-related information in support of health and well-being (Ratzan and Parker, 2000; Coleman *et al.*, 2011). As ‘the link between literacy and health outcomes’, [health literacy] empowers people with skills to improve their health (Berkman *et al.*, 2011). Finding, understanding and acting on health-related information, however, do not depend solely on an individual's

competency in these skills. Health literacy is also predicated on the provision of appropriate and readily available information by the healthcare and health information systems, and the dissemination of comprehensible advice and information by health information providers (Coleman *et al.*, 2011). While research into the impact of health literacy is in its relative infancy (AHRQ, 2011), early evidence indicates that deficits in health literacy are associated with poorer health outcomes and higher health-related costs for both individuals and systems (Sudore *et al.*, 2006; Berkman *et al.*, 2011). Improved health

literacy has been associated with reductions in risk behaviors for chronic disease (CPHA, 2006; Taggart *et al.*, 2012), higher self-reported health status (OECD, 2013) and decreased rates of hospitalization (Cho *et al.*, 2008). Health literacy is a critical and under-examined mechanism of health disparities so the problem of limited health literacy should primarily be understood as an issue of health inequality and justice (Volandes and Paasche-Orlow, 2007). In the past decade, much research on the impact of health literacy on health outcomes have been conducted across the globe, substantial numbers of conceptual and theoretical models have been proposed and different measures have been developed. However, most research has focused on individuals with very little attention on providers, systems and certain high-risk groups. As such, there is a lack of emphasis on research related to equity and the social context with few applications to practice and policy. In addition, there is a lack of standardization in measurement tools and agreement on what needs to be measured (e.g. key outcomes) (Jordan *et al.*, 2011). Researchers have suggested undertaking research and developing tools and measures to better understand context-specific variation including over the life course (Baker, 2006; McCormack *et al.*, 2010; Berkman *et al.*, 2011; Pleasant *et al.*, 2011; Sørensen *et al.*, 2012).

Gaining a greater understanding of the impact of health literacy is a key priority. In 2012, the Public Health Agency of Canada prioritized actions to improve health literacy to be taken at national, provincial and local levels—facilitating discussions about health literacy among practitioners, researchers and policymakers, and organizing a comprehensive framework for improving health literacy in Canada (Mitic and Rootman, 2012). Likewise, the United States Department of Health and Human Services (United States Department of Health and Human Services, 2010) announced a *National Action Plan to Improve Health Literacy* with three goals: ensuring equitable access to health information; creating ‘person-centered health information and skills’ and supporting the development of the skills needed to attain and maintain good health. At the healthcare system level, considering the least well-off in terms of health literacy, the most equitable framework would be one that ensured the healthcare system was designed to benefit all users but especially those with limited health literacy (Volandes and Paasche-Orlow, 2007).

At the patient population level, good health literacy is foundational to successful management and prevention of chronic disease. As the leading cause of global mortality (WHO, 2013), with increasing rates worldwide (WHO, 2005), chronic disease constitutes a complex, long-term challenge for patients, providers and the healthcare system (U.S. Department of Health and Human Services, 2010).

With a protracted and often asymptomatic onset and a need for ongoing management, these conditions present patients with a steep learning curve about risks, treatments and self-care. Self-care, an essential dimension of treatment, depends on the ability of systems and providers to teach—and patients to learn—effective self-management skills (Canadian Council on Learning, 2007; Harris *et al.*, 2010).

Yet, while chronic disease prevalence increases, levels of health literacy remain low (Villaire and Mayer, 2007; OECD, 2013), and efforts to understand health literacy’s definition, mechanisms and effects are ongoing (Baker, 2006). The Institute of Medicine (The Institute of Medicine, 2004) and researchers (Rootman and Ronson, 2005; Sørensen *et al.*, 2012) have identified persistent gaps in our understanding of health literacy and its link to chronic disease and suggested a need for ‘integrated research and program and knowledge development and dissemination’ with regard to health literacy and chronic disease management [(Rootman and Gordon-El-Bihbey, 2008), Ch. 6, p. 6].

Recognizing that advancing the health literacy agenda depends on addressing these gaps, a multidisciplinary group consisting of health literacy experts, clinicians and policy makers from several countries met at a roundtable at the University of British Columbia (UBC), Vancouver, Canada, in May 2013 to further consolidate the definition of health literacy, address measurement challenges and identify its role within chronic disease management (for further information on the program and the attendees, please see <http://internationalroundtablehealthliteracy.pwias.ubc.ca/roundtable-health-literacy-and-chronic-disease-management>).

ABOUT THE EVENT

The roundtable was sponsored by UBC Peter Wall Institute for Advanced Studies. We invited 26 researchers, practitioners, health literacy academics and thought leaders from Canada, USA, UK, China and Australia for an interdisciplinary exchange on: (i) the definition and conceptual framework of health literacy; (ii) the development of best methods for its measurement and (iii) its role within chronic disease management. We structured this roundtable with the following overall objectives: (i) to build insight through dialog and sharing of research; (ii) to promote collaboration among researchers—across and between disciplines—and build research capacity; (iii) to provide an opportunity for students and junior researchers to participate and share their work; (iv) to provide a forum for community leaders, healthcare administrators and providers to work with the research community to set the agenda for health literacy and chronic disease research and practice in Canada; (v) to showcase health literacy interventions being piloted

and implemented with patients with chronic disease and (vi) to generate and disseminate knowledge that will contribute to the growing knowledge domains for health literacy and chronic disease management, in Canada and beyond.

BACKGROUND

Health literacy defined

In previous workshops and conferences, health literacy has been conceptualized as the use of patient skills (e.g. reading, numeracy) to source, understand and use health information to support positive health outcomes (IOM, 2004). Early conceptualizations focused almost entirely on patients (Nutbeam, 2000) but more recent constructs incorporate the healthcare provider into the health literacy framework, recognizing that they bear a critical responsibility in the exchange of health information (Rudd, 2010). Freedman *et al.* applied a public health lens to health literacy definition, emphasizing the individual's capacity to make decisions that benefit the health of the community (Freedman *et al.*, 2009). Efforts to acknowledge the larger social context have also emerged. Issues of equity, for example, have been identified, with consideration of the relative abilities of marginalized groups to develop requisite skills and access necessary health information (Pleasant *et al.*, 2011). The experts in our roundtable suggested a need to seek agreement on key health literacy elements, which were summarized as: *different types* (prose; document and numerical), *different content* (health promotion; disease prevention and treatment management), *different media* (written; oral; electronic and visual) and *different levels* (simple to complex).

Furthermore, in order to develop practical measures that accurately assess health literacy, the roundtable emphasized the role of health literacy developers, knowledge-users and end-users in health literacy outcomes. Three categories were identified: (i) *individual providers* (as knowledge developers): including health practitioners, support staff, journalists, family members, friends; (ii) *system providers* (as knowledge users): including health and other organizations, media, governments social networks and (iii) *end-users*: including general public, patients, providers.

Health literacy measurement

Measurement of health literacy capacity began in the early 1990s (Baker *et al.*, 1999) by pioneers such as Davis *et al.* who developed the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis *et al.*, 1991), which evolved to the Health Literacy Skills Instrument (HLSI) (McCormack

et al., 2010). Later, some researchers suggested measuring health literacy skills, such as the ability to *access/find* information and attempted to measure participants' abilities to read, listen, speak and understand such information. Some measures were then created to evaluate the influence of prior knowledge (e.g. vocabulary) on patient success engaging with the health system (Baker, 2006). Others focused on measuring core skills, such as the International Literacy and Skills Survey (IALSS), which measures writing and numeric skills (Rootman and Gordon-El-Bihbey, 2008). Due to the multidimensional aspect of health literacy, some experts suggested measuring, *understanding and apprising* skills of patients (Elwyn *et al.*, 2001; Walter *et al.*, 2004). One practical example is the Health Activity Literacy Scale (HALS), which looked at broader domains including health promotion, disease prevention and system navigation (Nutbeam, 2000). Participants at an international conference on health literacy that produced the Calgary Charter for Health Literacy recommended measuring health literacy at three levels: individual, care provider and system to consider the comprehension, evaluation and communication of health information (Coleman *et al.*, 2011). Following these recommendations, recent measurement efforts have focused on assessing the capacities of healthcare providers (information developers) in addition to care-receivers (patients). As an example, the Health Literacy Universal Precautions (HLUP) toolkit examined, among other elements, how healthcare professionals communicated with patients (DeWalt *et al.*, 2011).

Further, Pleasant *et al.* identified a series of deficits to overcome before health literacy's impact can be consistently and reliably evaluated, including: reliance on instruments that do not measure patients' ability to improve their health and a dearth of formal intervention evaluations (most notably randomized trials) (Pleasant *et al.*, 2011).

The roundtable further discussed the deficiencies of existing measurement tools and agreed that since most assessment tools focused on health literacy among individuals, there was very little information on providers, systems and high-risk groups such as elderly, people with lower levels of education, and various cultural groups. The roundtable also mentioned the general lack of standardization in testing health literacy skills across measurement tools, and an agreement was made on what needs to be measured (e.g. key outcomes). Finally, the roundtable discussions mentioned the lack of practical research related to equity and social context and the fact that few applications of health literacy to practice and policy have been studied. After much discussions and debate, the recommendation was made to focus on measurement in relation to health information providers (knowledge developers) and health information systems (knowledge

users), in addition to patients and public populations (end-users). In terms of *health information provider*, recommendations included the need for developing measures to assess the accessibility and appropriateness of health information (i.e. information quality) to facilitate better care and support. In terms of *health information systems*, there needs to be an emphasis on assessing how systems support the efforts of providers to improve information provision and support, and how health policies can encourage health literacy improvement.

Health literacy and chronic disease management

As diseases of ‘long duration and generally slow progression’ (WHO, 2013), chronic conditions are complex, requiring patients to grasp sophisticated concepts. With a long ‘silent’ onset and asymptomatic periods after diagnosis, health needs are often not overtly tied to symptomatic cues (Hardie *et al.*, 2002), and a thorough understanding of these factors is vital for successful self-management. Self-care has emerged as an important determinant of positive health outcomes and decreased hospitalizations (Johnston *et al.*, 2008). The ability to participate in self-management is compromised when a patient is unable to fully comprehend his or her diagnosis and treatment (Gazmararian *et al.*, 2003). Since health literacy levels can be low among middle-aged and senior adults (Wolf *et al.*, 2005; Speros, 2009), there are concerns about the impact that gaps in knowledge and comprehension may have on decision making, self-management and treatment adherence. The importance of informed patient engagement, and concerns about levels of health literacy among those most at risk, make the integration and evaluation of health literacy within chronic disease management a priority for health policy makers and providers.

EVENT PROCEEDINGS

We envisioned our four-day knowledge exchange as laying the groundwork for an interdisciplinary *Health Literacy and Chronic Disease Knowledge Hub* (for further information on the program and the attendees, please see <http://internationalroundtablehealthliteracy.pwias.ubc.ca/roundtable-health-literacy-and-chronic-disease-management>). The mandate for this Knowledge Hub would be to inform ongoing research and practice efforts toward increasing the awareness and importance of health literacy in the development of strategies for better chronic disease management, with an emphasize on generation of policy- and practice-relevant data. The multidisciplinary composition of the group ensured that multiple perspectives were represented.

TOPICS OF DISCUSSION

The roundtable exchange had four main topics of discussion: (i) *where are we at?* (review of current conceptual considerations and measurement tools); (ii) *where do we want to be?* (assessment of current strengths and weaknesses in health literacy measurement and integration into chronic disease management); (iii) *how will we get there?* (strategies for measuring and integrating health literacy in chronic disease management) and (iv) *what next?* (setting priorities for the agendas for research, practice and policy). The roundtable (the term ‘roundtable’ is used to denote the collective group of participants) explored these topics through workgroup sessions, followed by a collective roundtable synthesis.

Conceptual considerations for defining health literacy

Considerable effort has gone into the development of a holistic understanding of health literacy over the last decade; however, no complete agreement on definition has been reported yet so a single, authoritative definition remains elusive (Peerson and Saunders, 2009; The National Archives, 2009). One early observation put forward and endorsed by the roundtable was that both *health* and *literacy* are evolving dynamic terms that are heavily context-dependent. Therefore, perhaps a single definition is not desirable or achievable because the constituent parts of health literacy are not static in all circumstances and it is not merely a one-dimensional skill (Coleman *et al.*, 2011; Sørensen *et al.*, 2012). Another viewpoint was that health literacy is not only multidimensional—it is longitudinal, with different foci, priorities and purposes over the life course. The roundtable concluded that these characteristics argued for flexibility and multiplicity in defining health literacy so that definitions could reflect the variable interplay of patients, providers and systems across different health, disease and social contexts.

While there was general consensus that a ‘one-size-fits-all’ definition may not be attainable or practical, there were countering observations that there is a profound need for clarity and consistency of terms, and agreement on health literacy’s core principles. In the words of one workgroup, ‘definition is the point of departure’: there is a need to identify both *who* and *what* one needs to measure. There is also recognition that if there is a need to evaluate health literacy in the area of self-management or other condition-specific areas, there must be a static instrument for each chronic disease area. However, over time, such an instrument might undergo modifications in terms of condition (specific) and general (social) contexts.

In the discussion around the ‘*who*’ and the ‘*what*’ aspects of health literacy should be assessed, support was voiced for an encompassing construct that included ‘both sides of the coin’ (Rima Rudd). The roundtable endorsed the trend away from a singular focus on patients and their deficits toward an inclusive framework that articulated the roles of providers, and ensured their communication skills are also assessed. Further, as providers work within a complex system, it too was affirmed as a principal concept in health literacy.

In the discussion on ‘*what*’ needs to be assessed, multiple targets were identified, including individual skill levels, system practices and resources and financial and health outcomes. A shared understanding of key outcomes was considered critical: a meaningful definition of health literacy needs to delineate desired outcomes for all actors, such as ready access to information (health system), appropriate dissemination of information (providers) and ability to understand and act on information and meet purposes within a health context (public/patients).

In assessing further desired refinements to the conceptualization of health literacy, the roundtable identified the need to acknowledge that health literacy is enacted in the larger social context and is subject to shifts and trends in social reality. There was much discussion about the importance of the broad aspects of health literacy that included community influences and interactions, and the fact that most people do not make health-related decisions in isolation but rather within complex interpersonal networks. It was noted that many still believed clinicians to be the most reliable source, but patients’ immediate social circle also impacted how they understand and use health information. Also, in the age of Web 2.0 and social media, the system, providers and patients must master information exchange in the virtual realm—requiring a specific skill set and access to technology. Cameron Norman shared his definition of eHealth literacy, namely ‘the ability to seek, find, understand and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem’ (Norman and Skinner, 2006). This definition was supported by the roundtable, and seen as further evidence in support of a dynamic construct of health literacy so it can evolve as needed to reflect its particular (condition-specific) and general (social) contexts.

Despite recognizing that contextual considerations argue for a range of definitions, the roundtable remained focused on a shared foundation for understanding and measuring health literacy. As a common platform encompassing many of the desired elements, the roundtable discussed the relative merits of the Calgary Charter definition. By incorporating the three players, this definition

posited that health literacy ‘applied to all individuals and to health systems’: for patients it encompassed the use of skills to ‘find, understand, evaluate, communicate, and use information’; for providers it involved the presentation of information that ‘improve[s] understanding and ability of people to act’ and for the system, it is the provision of ‘equal, easy, and shame-free access to . . . health information’ (Coleman *et al.*, 2011). While the roundtable was relatively comfortable with this framework, they noted that it failed to overtly address the overarching influence of social context. It was agreed that the true test of its value will emerge as it is operationalized and tested across the domains of health promotion, disease prevention and treatment—including chronic disease management.

Assessment of current strengths and weaknesses in health literacy measurement

The roundtable then turned its attention to measurement, focusing first on clarifying ‘*why*’ measurement is undertaken. Multiple responses emerged, which identified the need to assess a range of capacities, including: the relevant skills of patients and providers and how these contribute to the successful exchange of information; the validity and reliability of current measurement instruments; the quality, cultural appropriateness and availability of system resources, as a measure of equitable access to needed information; the financial costs associated with both improving and failing to improve health literacy, as an input to resource allocation and program development and the effect of health literacy interventions on health outcomes, as a measure of clinical effectiveness. As each of these scenarios has a different target audience (e.g. health policy makers, clinicians), it was recommended that measurement methods be developed that ensured the production of data that would be deemed appropriate and actionable by its intended recipients.

The roundtable then undertook a gap analysis, identifying a range of deficits and challenges in measurement efforts to date. At the most fundamental level, it was acknowledged that health literacy is an inherently complex construct, and many of its important nuances are challenging to operationalize. How does one adequately develop a measure that accounts for context—e.g. clinical, community and social—or is able to parse the multiple literacies that exist under the umbrella of health literacy?

Despite these existing challenges, many different instruments have been developed to measure health literacy. Jordan *et al.* evaluated 19 measures for reliability, validity and feasibility—finding that content varied widely between survey instruments, reliability was often low and no tool examined how patients understand and use health

information (Jordan *et al.*, 2011). Measurement of health literacy's impact is also relatively nascent. More recently, Haun *et al.* conducted a systematic review on 51 existing health literacy instruments and discovered that most health literacy measurement tools currently available generally represent a limited set of conceptual dimensions with inadequate modes of administration, for instance using different social media tools. These tools also lack information on key psychometric properties; therefore the authors suggest significant work is required to establish important steps in the development and validation of the new comprehensive tool. Although some studies report an association between health literacy and health outcomes (Baker *et al.*, 2002; Wolf *et al.*, 2005), a review of randomized trials assessing the effects of health literacy questioned the validity of many studies' findings, and observed that even when health literacy seemed beneficial, its mechanisms remained inadequately explained (AHRQ, 2011). One possible explanation is that health literacy is so highly context-dependent that a myriad of variables come into play in assessing what the term means and what means of measurement are most appropriate.

Reviewing existing capacity measures, it was noted that some measures of skill confused or conflated *outcomes* of learning and *processes* of learning—thereby muddying the assessment of capacity (Pleasant *et al.*, 2011; Haun *et al.*, 2014). There are two interconnected aspects of health literacy learning *outcomes*: population outcomes and social outcomes. Population outcomes include health-related knowledge and attitudes, behavioral intention and self-efficacy, whereas social outcomes include connections between people that serve to advance one's health and well-being through cooperation with others. The *process* of health literacy learning progresses from having basic theoretical and practical health knowledge to being able to think critically and be self-aware about it; the last stage of the process involves having citizenship, which is the sense of social responsibility to participate in health promoting actions. Some assessment tools were seen as narrow in their relevance, assuming one way of learning without accounting for cross-cultural differences in learning and comprehension. In general, the roundtable felt that there was a lack of systematic information about health literacy levels and barriers for ethno-cultural and immigrant communities, people with disabilities and rural residents.

Another critical deficit was the lack of comprehensive research base on the economic burden of reduced health literacy and the potential cost-effectiveness of interventions that might improve health literacy. In light of the importance of an economic evidence base for garnering support from policy makers, the roundtable identified addressing this gap as a research priority.

Discussion of measurement-related deficits turned to the identification of resources that allow measurement needs to be met. A 'wish list' emerged that included: a broader set of measurement tools for individual skill levels, including web-based instruments; access to economic data on costs associated with health conditions and reduced levels of health literacy, as well as interventions' cost-effectiveness and an initial set of health and health literacy outcomes to be prioritized in intervention studies. A set of preliminary outcome variables were suggested, namely: (i) communication competence in providers, (ii) cultural competence in providers, (iii) patient comprehension levels, (iv) patient satisfaction, (v) self-reported health status, (vi) rates of system use, (vii) costs associated with health literacy education and interventions and (viii) cost savings associated with improved health literacy.

The identification of potential measures led to discussion of potential challenges operationalizing these variables. For example, how does one define cut-points (e.g. low versus high) for health literacy? If one is measuring the effect of clinicians' communication skills, how does one control for the effect of the overall patient-physician interaction (e.g. length of the appointment, ambiance of the office, patient's emotional state)? This latter concern raised a fundamental question about the link between health literacy and outcomes: measuring it presupposes that the successful transmission of information will result in patient action (e.g. compliance with treatment). The roundtable agreed that this assumption is simplistic, pointing out that health literacy is just one of many determinants of behavior, and measuring outcomes may not always accurately reflect the influence of health literacy. This was seen as a critical and complex problem: success in measuring the effects of health literacy on outcomes rests on a clear understanding of its mechanisms of action—an understanding that is as yet undeveloped. Creating better methods to 'isolate' health literacy's effects was identified as a key research priority; a preliminary set of considerations to this end included clear operational definitions of health literacy in evaluation studies and rigorous identification of potential confounders.

The multiple dimensions of chronic disease prevention and management

Rima Rudd helped set the stage for the discussion on health literacy and chronic disease management and pointed out that chronic disease presented significant challenges for health literacy yet also offered important opportunities. The roundtable delineated challenges first. One challenge was the tendency of patients (and in many cases healthcare providers) to use 'an acute paradigm' that anticipated rapid

onset, overt symptoms and a timely resolution. With chronic diseases, however, there is a need to accept chronicity, and to understand complex concepts such as multifactorial risk and the interplay of co-morbidities. Ted Bruce pointed out that the existing healthcare system reinforced the ‘acute’ mindset, being designed and resourced to deliver episodic care, and was not yet fully equipped to deliver ongoing management of chronic conditions. Given the complexity of chronic conditions, and the nature of the patients (e.g. the elderly), participants suggested that there was an elevated risk of misunderstanding diagnoses, treatment regimens and/or instructions on self-care, which in turn may lead to nonadherence to treatments or misuse of medications. Health literacy is, therefore, required to ‘enhance understanding and awareness about chronic disease . . . and facilitate patient engagement in self-management’ (Scott Lear).

Challenges were identified in clinical practice, with concerns raised about low levels of health literacy awareness among providers. Given the requirement for on-going patient–provider engagement in the management of chronic diseases, this was flagged as an issue needing attention. Ensuring that providers are able to effectively communicate with patients with chronic diseases requires the development of particular skills and awareness. Cultural competence is critical, given the variety of patient populations affected. Developing approaches to education and management of co-morbidities is another priority for providers. Many chronically ill patients have multiple conditions (Health Council of Canada, 2007). The most responsible provider, therefore, is tasked with finding ways to help patients understand how these conditions interact, the potential for adverse interactions between treatments and controlling for risks associated with patients seeking care from multiple specialists and potentially receiving conflicting advice.

On the opportunity side, the roundtable agreed that the domain of chronic disease management offers a rich environment in which to mature our understanding of health literacy. The importance of patient education—and the need for information uptake to translate to on-going patient engagement—provides an invaluable forum for exploring the impact of health literacy interventions on patient comprehension and enactment. Given the plethora of information sources for chronic disease ‘outside’ the system (e.g. internet, family members, support groups and mainstream media), there is an opportunity to examine differences in information quality, means of dissemination and levels of patient confidence across sources. Understanding what factors would facilitate information uptake should also be explored. The role of the community, the private care sector and family

caregivers in support of patient self-care are key considerations. The study of self-management successes and failures, and their determinants, will provide valuable insight into how patients use health information in their daily lives. Chronic disease management also provides the opportunity to study novel treatment approaches, such as group care, which rely heavily on patient education and health literacy. Addressing the risk for multiple, conflicting informational inputs could facilitate the study of information management, identifying the best strategies for managing and reconciling these conflicts. The prevalence of co-morbidities also presents an opportunity to discover how transferable skills are from one condition to another, and whether clusters of conditions lend themselves to a common approach.

PRIORITIES FOR ACTION

In order to advance health literacy by deepening its evidence base, further integrating it into clinical and public health practice, and securing its place on the policy agenda, the roundtable discussions culminated in the identification of immediate and long-term priorities for research, policy and practice.

Research agenda

The attendees of the roundtable suggested that the following items should be considered when developing a research agenda for a health literacy intervention:

- Patient experience
- Role of new technologies
- Communication proficiency and cultural competence of healthcare providers
- Quality of information resources
- Cost implications
- Chronic disease management

Haun *et al.* in their systematic review indicated that to set a research agenda for health literacy as it relates to chronic disease management, it is important to create new measurement tools that included all aspects of health literacy (Haun *et al.*, 2014). For example, including a more representative sampling of diverse patients in assessments, as well as considering patients’ characteristics while implementing new social media technology, will allow for a more sophisticated and practical approach to health literacy research. Given the importance of a solid evidence base to inform policy and practice, the preponderance of roundtable recommendations are multifaceted, yet include a particular emphasis on the generation of policy- and practice-relevant data.

As a starting point, participants identified a basic need to widen the research lens—expanding the field of focus beyond the traditional emphasis on patient abilities to capture and evaluate the contributions of providers and of the healthcare system. Providers' ability to anticipate and meet their patients' informational needs is a pivotal piece of the health literacy puzzle; assessing their communication skills and cultural competence, therefore, are key research priorities. Evaluating system capacity for supporting knowledge exchange (e.g. training for providers, information materials for patients) is critical to understanding system stewardship of health literacy. Given the importance of self-care, research should not be centered on the measurement of skills *per se*, as it would be more advantageous to devise measures that assess the 'demand side', namely the need to integrate self-management tasks into daily routines. Managing a condition like arthritis or diabetes is not just about reading or numeracy—it is about managing multiple dimensions of daily life, such as finding time in the day to measure capillary blood sugar and inject insulin. There is also a need to better understand the supportive roles played by families, caregivers and community members.

The roundtable further observed that successful evaluation and implementation of strategies to improve health literacy is heavily context-dependent; there is a need to understand context-specific variance in information needs, access and uptake. One research focus that needs more attention is the exploration of the nature of information exchange and uptake within the context of different health conditions—including those that fall under the umbrella of chronic disease management. The roundtable also prioritized research that will broaden our understanding of how information needs—and preferences about information sources—vary over the life course.

Consideration was also given to research methodology. While acknowledging the need for flexibility in definition, there was a call for researchers to isolate elements of health literacy in a consistent manner—to develop clear operational definitions that support comparative evaluations. The assessment and refinement of existing measurement instruments, together with the development of new tools, emerged as a priority. While validated instruments exist, these are typically designed to assess patients and often do not have the flexibility to work across multiple contexts. There is a requirement for a suite of measures and instruments for evaluating providers' capacity for supporting patient uptake of health information. In parallel, there is also a need to measure system capacity for providing readily accessible, relevant information resources. Finally, the roundtable assigned priority to the development of measures to assess the cultural competence of

both the system and its providers in accommodating the needs of diverse patient populations.

The means by which research is conducted also needs a broader perspective. There was a call for a greater emphasis on randomized controlled trials to test health literacy interventions and their associations with health outcomes. To gain insight to the role of the community in health literacy, the potential of community-based participatory research needs to be better realized. Patient populations outside the 'mainstream' often have specific needs, aligning with different health beliefs and practices. Involving these patients and their communities in the development and assessment of health literacy supports would avail researchers of a critical additional perspective on the processes of successful information uptake.

A variety of specific research foci were discussed. The foci deemed most time sensitive included: (i) the patient experience (e.g. preferences for information sources, expectations of providers); (ii) role of new technologies and social media in information dissemination and chronic disease management; (iii) communication proficiency and cultural competence of providers; (iv) quality of available information resources, formal and informal; (v) health literacy cost implications, both investment and return; (vi) the interplay of health literacy and other social determinants of health (e.g. socio-economic status, ethnicity) and (vii) all aspects of health literacy in chronic disease management.

Practice agenda

The roundtable discussed a number of practice considerations, some general and some specific to the management of chronic disease. The basis for greater integration of health literacy into daily practice comes with the entrenchment of health literacy and cultural competence training in the curricula of the institutions that educate providers. Knowledge gained through training must then be enacted in the environments where information exchange takes place. The roundtable stressed that all providers must elevate awareness of health literacy within their practices. Office environments need to provide a patient engagement experience—from check-in through to coordination of care with other providers—that facilitates access to comprehensible, current health information. Care processes need to be tailored to meet the information needs of various populations and various health conditions. The roundtable emphasized the importance of culturally appropriate educational aids for self-management, including not only information about self-care, but also about key community and online resources. Participants recommended that providers embrace new and alternative

technologies to support decision-making and self-care, from videos to mobile apps to social media. Integrating new educational and support models, such as peer-to-peer education and group care programs for chronic disease management, was identified as a means of prioritizing the goals of health literacy within daily practice.

Two types of outreach efforts were identified as practice priorities: chronic disease management and integration of information exchange processes. In the domain of chronic disease management, the roundtable discussed the need for most responsible providers (typically family physicians) to work on building the necessary communication links with specialists, ancillary providers and support services to facilitate integrated information management—ensuring that patients did not have to assume the primary responsibility for transferring and assessing multiple information inputs from providers on their healthcare team.

A second key communication outreach priority was the integration of information exchange processes for family members and caregivers. With chronic disease or debilitating conditions such as dementia, these individuals play a critical role in assisting patients to access, understand and act on information. Developing means to assist the patient ‘support team’ to understand the patient’s condition, and how best to support and care for them, is critical. Success depends on accommodating their educational needs through inclusion in consultations, and the development and dissemination of targeted information materials. Recognizing the community as a locus of education and support is similarly important since the ‘golden rule is to engage the community early and often’ (Andrew Pleasant).

Policy agenda

Roundtable discussions on how to elevate the visibility of health literacy and ensure its rightful place on the policy agenda acknowledged challenges translating this complex concept into meaningful terms for politicians and policy makers. Multiple sectors need to be engaged, and messages must be crafted and supported using data and language that resonates with each target audience. Direct efforts to secure buy-in must be bolstered by capitalizing on unexpected opportunities. In the words of one participant, it is important that health literacy proponents be prepared for ‘windows of opportunity’—to capitalize on opportunities that provide an opening to demonstrate the powerful contribution health literacy can make to health promotion, disease prevention and care.

A preliminary agenda outlined foundational steps to be taken, the first being the development of a shared conceptual framework that characterizes the domains and

determinants of health literacy in policy-relevant terms. A challenge for this framework is to ensure that it identifies, and resonates with, all the key stakeholders in the management of the determinants of health literacy. The roundtable felt it critical that this framework be supported with evidence from economic and policy models to clearly delineate the relationship between the required investments in health literacy education and interventions, as well as the returns on those investments in terms of health outcomes and long-term cost savings. Successful advocacy and outreach is needed in order to bring the health literacy framework, and its economic rationale, further forward in the public and policy discourse. The roundtable suggested that advocacy for health literacy must be broad in its scope, engage all levels of decision makers from sector-specific policy makers, to educators, to leaders of professional organizations and to the public at large. An important instrument in these efforts is the media. Efforts must be made to engage both conventional and social media since the ubiquity of chronic disease and the rapidly increasing coverage of its determinants, consequences and management provide a ready-made venue for integrating the narrative about the role of health literacy.

CLOSING THOUGHTS

Presentations of current research and discussions on key issues revealed that work in health literacy has made great strides in the last decade, yet there is still much ground to cover. The roundtable supported a conceptual framework for health literacy comprising dimensions of accessing, understanding, assessing, communicating and acting on health information. Furthermore, there was agreement that progress had been made in the measurement of certain aspects of health literacy, but that many existing measurement instruments should be further validated and refined, and new approaches must be developed to assess the health literacy capacity of providers, caregivers and the healthcare system itself. Moreover, the knowledge exchange on chronic disease management highlighted ways in which health literacy makes critical contributions to the information exchanges that are an essential component of the complex, multidisciplinary care processes associated with these conditions.

Successful integration of health literacy into practice and policy rests on having the solid evidence of its contribution to health and policy outcomes. The roundtable identified priorities in research, from patient and caregivers involvement in chronic disease management, to assessing the cultural competence of providers and services, to expanding the number of health literacy interventions. Considerations for practice focused primarily on clinical

settings, identifying the requirement for provision of accessible and appropriate information, the opportunities for capitalizing on new communication technologies and the need to prioritize information management across broad multidisciplinary teams in chronic disease management. Finally, the roundtable was resolute in their consensus that health literacy must be a greater priority on the policy agenda—a challenging goal given its complexity and the need for cross-sectoral cooperation. Raising awareness, through policy-relevant evidence, advocacy and engagement with media were seen as key tactics toward achieving this end.

NEXT STEPS

The field of health literacy is still in its formative stages. Although health literacy is recognized as a determinant of health, a key knowledge gap exists in understanding how health literacy influences overall health, especially chronic diseases. This roundtable provided an invaluable opportunity to advance its knowledge base, and launch an international Knowledge Hub in support of further policy, practice and research agenda development. There are clearly different levels where, according to the roundtable discussants, health literacy applies (provider–patient–system): (i) healthcare professionals awareness of the challenges we face in healthcare delivery in the presence low health literacy society, (b) the importance of using educational materials to facilitate chronic disease management that involve the participation of patients from ethno-cultural groups, (ii) *patients* gaining greater awareness for their personal health journey, (iii) *systems* level leadership to ensure that curricula for healthcare workers training contain information on the importance of health literacy in their clinical practice, (b) health system administrators provide signage and educational materials that are at appropriate literacy levels and representative of the languages and cultures of patients. Moving the health literacy agenda forward will require the collective efforts of key stakeholders—across disciplines, sectors and borders. Being able to bring together a concentrated group of established local, national and international multidisciplinary professionals in an intimate setting afforded us a unique forum to explore the domains of health literacy and chronic disease prevention and management.

We need now to emphasize the power of health literacy rather than the negative framing of health literacy as a deficit and burden. Recognizing the absence of a comprehensive instrument to measure peoples' capacities and to capture the power of health literacy (to improve health and lower costs), some members of the network have

applied for funding to NIH and CIHR to develop such an instrument. The proposal aims to incorporate the knowledge gained during the roundtable and build off of the recommendations suggested by IOM and Calgary Charter on Health Literacy. Such measures will help to clarify how health literacy influences chronic disease management and will identify areas where further work is needed to improve health literacy skills.

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