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ABSTRACT. This report summarizes the proceedings of the first Outcome Measures in Rheumatology Clinical Trials (OMERACT) Health Literacy Special Interest Group workshop at the OMERACT 10 conference. Health literacy refers to an individual's capacity to seek, understand, and use health information. Discussion centered on the relevance of health literacy to the rheumatology field; whether measures of health literacy were important in the context of clinical trials and routine care; and, if so, whether disease-specific measures were required. A nominal group process involving 27 workshop participants, comprising a patient group (n = 12) and a healthcare professional and researcher group (n = 15), confirmed that health literacy encompasses a broad range of concepts and skills that existing scales do not measure. It identified the importance and relevance of patient abilities and characteristics, but also health professional factors and broader contextual factors. Sixteen themes were identified: access to information; cognitive capacity; disease; expression/communication; finances; health professionals; health system; information; literacy/numeracy; management skills; medication; patient approach; dealing with problems; psychological characteristics; social supports; and time. Each of these was divided further into subthemes of one or more of the following: knowledge, attitude, attribute, relationship, skill, action, or context. There were virtually no musculoskeletal-specific statements, suggesting that a generic health literacy tool in rheumatology is justified. The detailed concepts across themes provided new and systematic insight into what needs to be done to improve health literacy and consequently reduce health inequalities. These data will be used to derive a more comprehensive measure of health literacy. (J Rheumatol 2011;38:1791-7; doi:10.3899/jrheum.110406)

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HEALTH LITERACY

OUTCOME MEASURES

A new health literacy special interest group (SIG) convened for the first time at Outcome Measures in Rheumatology (OMERACT) 10. At its inaugural meeting, the concept of health literacy and its development was presented, from its inception as a term first used in 1974 to argue that school curricula should include health education to ensure pupils become "literate" in health¹, to subsequent, more technical meanings such as the skills patients need to negotiate a complex healthcare system². The importance of measuring an

individual's health literacy to inform the clinician, and measuring population health literacy to inform policy-makers and researchers, was discussed. The strengths and limitations of the ways in which health literacy is currently assessed were also presented.

In determining whether a new SIG for health literacy should be formed, we considered the potential overlap with 2 other OMERACT groups: the Effective Consumer SIG and Health Equity SIG. Poor health literacy can undermine

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attempts at health equity and a person's ability to be an effective consumer; in this way, health literacy can be considered to be one factor that underpins both these issues³. The Effective Consumer Scale (EC-17) measures how effective people are at dealing with their chronic condition and making decisions about their healthcare^{4,5}. It comprises 5 domains: (1) use of health information; (2) clarifying personal priorities; (3) communicating with others; (4) negotiating roles and taking control; and (5) deciding and taking action. For an individual to have any chance of being an "effective" consumer, they first need to have the right and the means to access healthcare, and the skills and knowledge to pursue the care needed.

Health literacy is also central to health inequalities; it is the marginalized groups with low personal and economic resources and low education that have the greatest difficulties understanding and accessing services⁶. Major advances in reducing social inequalities in health are likely to be derived through greater attention, at both the clinical and policy levels, to health literacy. Given this, it was fitting that the Effective Consumer and Health Equity SIG members participated with the Health Literacy group to advance our understanding of measurement in this field and to support OMERACT to improve outcomes equitably for people with musculoskeletal disorders.

The participants at the Health Literacy SIG meeting also took part in a structured group discussion using the nominal group technique in which they explored health literacy from the patient and health professional perspectives. These data were then discussed and compared with a recently developed patient-centered conceptual framework⁷, and measure of health literacy developed by some of the authors (unpublished observations). The discussion centered on the relevance of health literacy to the rheumatology field; whether measures of health literacy were important in the context of clinical trials and routine care; and, if so, whether disease-specific measures were required.

It is intended that the data collected at OMERACT 10 will be used to inform the development of an improved health literacy measure that will be tested to ensure that it fulfils the criteria of the OMERACT filter⁸. The purpose of this report is to summarize the proceedings of the first OMERACT Health Literacy SIG meeting and to outline the future plans of the group.

The Concept of Health Literacy and Why Measure It

There are several definitions of health literacy (Table 1)^{2,9,10,11,12}. Each fundamentally includes reference to an individual's capacity to seek, understand, and use health information⁷, although many also consider the interaction between an individual's skills or abilities, and education, health, and social and cultural influences¹⁰.

Irrespective of how it is defined, health literacy has an important influence upon health and is likely to be a signifi-

cant determinant of health inequity^{13,14}. In patients with rheumatoid arthritis and other chronic diseases, low health literacy has been associated with a lack of knowledge about their condition and medications^{15,16}, greater problems communicating with healthcare providers¹⁷, poorer self-management skills¹⁸, and greater use of outpatient services¹⁹. Low health literacy has also been associated with infrequent receipt of preventive services²⁰, increased hospitalization and use of emergency care^{21,22,23}, and increased mortality²⁴. More positively, interventions that improve health literacy have the potential to improve population health and reduce health inequities²⁵.

With the increasing focus upon patient-centered approaches and augmentation of self-care for people with chronic diseases, the concept of health literacy has become highly relevant in many settings. At the clinical level, healthcare professionals need to know patients' capacity to process and understand health information, to be able to communicate with them effectively and assess their ability to navigate the healthcare system appropriately. At the population level, policy-makers need to understand the community's capacity to gain access to and understand health information, to be able to set appropriate policies, and provide appropriate resources. In addition, researchers need to understand these issues to make correct judgments about research methods and findings.

Current Measures of Health Literacy

Several measures exist to assess health literacy at the individual (clinical) and population level. However, they vary in content and purpose and none appears comprehensive²⁶. The most widely used clinical measures include the Rapid Estimate of Adult Literacy in Medicine (REALM), which tests ability to read and pronounce a list of words²⁷, and the Test of Functional Health Literacy in Adults (TOFHLA), which tests reading comprehension and numeracy²⁸, whereas the Newest Vital Sign (NVS) is designed to be a quick clinical screening instrument²⁹ (Table 2). In a recent population-based survey of health literacy using these 3 measures conducted in Victoria, Australia, the prevalence of inadequate health literacy ranged between 7% and 21%, depending upon the measure³⁰.

At the population level, proxy measures of health literacy have also been derived from national surveys of literacy that use health-related materials²⁶. The items and scoring properties are not publicly available and, like the individual measures, it is not clear that the scoring categories discriminate between groups with different levels of health literacy, or how this information can be applied in a clinical or public health context²⁶.

All the currently available measures of health literacy have focused primarily upon measuring reading, comprehension, and numeracy skills, yet, as the definitions of health literacy in common usage suggest, the concept of health literacy is much broader than literacy skills alone²⁶.

Table 1. Some definitions of health literacy.

World Health Organization⁹

Health literacy is the cognitive and social skills that influence people's motivation and ability to gain access to understand and use information in ways which promote and maintain good health.

Ad hoc Committee on Health Literacy for the Council of Scientific Affairs, American Medical Association²

Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment. Patients with adequate health literacy can read, understand, and act on healthcare information.

USA Institute of Medicine — Health Literacy: a Prescription to End Confusion¹⁰

The degree to which individuals have the capacity to obtain, process and understand basic information and services needed to make appropriate decisions regarding their health. Health literacy also encompasses the educational, social, and cultural factors that influence the expectations and preferences of the individual and the extent to which those providing healthcare services can meet those expectations and preferences.

UK National Consumers Council¹¹

The capacity of an individual to obtain, interpret, and understand basic health information and services in ways that are health-enhancing.

Kickbusch 2001¹²

Health literacy is the ability to make sound health decisions in the context of everyday life — at home, in the community, at the workplace, the healthcare system, the market place, and the political arena.

Table 2. The Rapid Estimate of Adult Literacy in Medicine (REALM)²⁷, Test of Functional Health Literacy in Adults (TOFHLA)²⁸, and Newest Vital Sign (NVS)²⁹ instruments.

Rapid Estimate of Adult Literacy in Medicine (REALM)

Stated purpose is to identify patients with low reading ability in primary care settings. Respondents are asked to read aloud a list of 66 health-related words arranged in 3 columns of ascending order of difficulty. Points are given for correct pronunciation to derive a raw score out of 66, which is converted to a USA school grade estimate of reading ability.

0–18: third grade or below (may not be able to read most low-literacy materials; may need repeated oral instructions, materials composed primarily of illustrations, or audio- or videotapes)

19–44: fourth to sixth grade (may need low-literacy materials: may not be able to read prescription labels)

45–60: seventh to eighth grade (may struggle with most currently available patient education materials)

61–66: ninth grade and above (should be able to read most patient education materials)

Test of Functional Health Literacy in Adults (TOFHLA)

Stated purpose is to measure “functional” health literacy defined as reading, writing, and numeracy skills in relation to healthcare in healthcare settings.

Respondents read 3 passages of health-related text with words omitted and select the appropriate response from 4 options (reading comprehension: 50 items). They are also given series of health-related written prompts and an interviewer asks questions that test numeracy (17 items converted to a score out of 50). Total score out of 100:

0–59: Inadequate health literacy (may be unable to read and interpret health texts)

60–74: Marginal health literacy (has difficulty reading and interpreting health texts)

75–100: Adequate health literacy (can read and interpret most health texts)

Newest Vital Sign (NVS)

Stated purpose is to screen for limited literacy in primary healthcare setting. Respondents are given a nutritional label for ice cream and an interviewer asks 6 questions relating to information on the label with a point for each correct response (0–6).

0–1: Suggests high likelihood (50% or more) of limited literacy

2–3: Indicates the possibility of limited literacy

4–6: Almost always indicates adequate literacy

Health Literacy from the Patient and Health Professional Perspective: Methods and Results of a Nominal Group Technique Exercise

To develop a model of health literacy that can be generalized across settings, and to provide new and deep insights from both the patient's perspective and the healthcare professional perspective, participants who attended the Health Literacy SIG session were separated into 2 groups: one comprising patients with a range of rheumatic conditions (n = 12), and one comprising healthcare professionals and researchers (n = 15). Separation of the 2 groups in this way facilitated frank discussion, and broad and rapid brainstorming. A nominal group process, a means for obtaining the most comprehensive possible range of ideas from individuals on a topic of inter-

est³¹, was undertaken within each group to maximize the richness and depth of the data obtained.

A carefully crafted seeding statement, based on the core elements of the health literacy definitions, was presented to individuals who worked alone to generate ideas in response to the statement. The seeding statement for patients was, “Thinking broadly about your experiences in trying to look after your health, what abilities does a person with arthritis need to have, in order to get, understand, and use health information to make informed decisions about their health?”. The seeding statement for the health professional/researcher group was, “Thinking broadly about your experiences in looking after people with arthritis, what abilities does a person with arthritis need to have, in order to get, understand, and use

health information to make informed decisions about their health?”.

Participants were asked to write their responses according to the following rules: one idea per statement, use bullet points, make them brief, and work alone for 5 minutes. The nominal group technique uses a facilitator, who then asks that the ideas be presented to the group in an egalitarian manner, whereby each participant in turn presents one item on their list, starting with the first, until all items have been presented. Participants were discouraged from passing judgments about the statement but were encouraged to seek clarification of the nature or content of the statement if necessary. The critical advantage of this approach is that the perspective of individuals is collected in a manner that is not influenced or biased by the researcher or influenced by other (and at times dominant) group members. At the group process of this task, the 2 groups combined and the concepts generated by the 2 groups were discussed and any differences were highlighted.

The statements generated are shown in Table 3. A semi-grammatical approach to coding each statement was taken. Within each statement, the subject and the object(s) of the sentence were identified and then the defining details noted. We also characterized the nature of that to which the statement is referring (e.g., knowledge, skills, attributes, etc.). Once coding was complete, categories were mostly derived from the objects embodied in the statements. In some cases, the groupings were derived from a combination of the “nature of statement” and the object column, for example, Knowledge of Disease.

In response to the seeding statements, the 2 groups produced 98 statements, 45 from the patients and 53 from the health professionals/researchers. Using the coding approach, 16 themes emerged and each of these was divided further into subthemes of one or more of the following: knowledge, attitude, attribute, relationship, skill, action, or context (Table 3).

The statements were generated in response to the seeding statement, which in turn was based on the core elements of the definitions of health literacy, namely “ability to access, understand, and use health information to make informed decisions about their health”^{2,9,10,11}. The emergent themes, as expected, cover virtually all the elements of the extended definitions (Table 1) in one way or another. Two themes were somewhat different: Finances (e.g., Having money to get healthcare; Access to a healthcare plan; Get enough money and use it for health) and some elements of the Health Professionals theme. It is also important to note that while the seeding statements included the term “musculoskeletal,” there were virtually no musculoskeletal-specific statements, suggesting that a generic health literacy tool in rheumatology is justified. Some of the new elements also included trust in and getting time from health professionals, and general practitioners being up to date.

The concept of trust in health professionals is a particularly important one. Trust or lack of trust may be based on the adequacy of past experiences with health professionals or it may

reflect more personal issues. Trust is clearly an important issue in determining a person’s receptivity to health information.

A New Concept of Health Literacy and the Health Literacy Measurement Scale (HeLMS)

Preliminary work by Jordan, *et al*⁷ to conceptualize health literacy from the patient perspective was presented to participants at the conclusion of the workshop. The development of this conceptualization included consultation with patients and members of the community and used the same definition of health literacy as used for the nominal group technique exercise at OMERACT 10. Qualitative methods were used to develop the conceptual framework and included interviews with 48 individuals across 3 distinct population groups: those with a chronic condition, the general community, and individuals who had recently presented to a metropolitan public hospital emergency department.

Seven key abilities were identified as being needed for an individual to be able to seek, understand, and use health information: (1) knowing when to seek health information; (2) knowing where to seek health information; (3) verbal communication skills; (4) assertiveness; (5) literacy skills; (6) capacity to process and retain information; and (7) skills in applying health-related information.

Just as in the nominal group technique exercise at OMERACT 10, broader contextual factors such as the healthcare system, socioeconomic factors, social support, education, cultural influences, and personal health attitudes were identified as important, as were factors related to the patient-health professional relationship. The latter may include patient traits such as their physical and emotional disposition, fear and/or anxiety, and their trust and confidence in the healthcare professional; factors for healthcare professionals include the use of complicated medical terminology and how they deliver information; and interaction factors include how the patient and healthcare professional exchange information and acknowledge their respective expert and lay knowledge.

Based on specific elements of health literacy identified as important by patients, a promising new health literacy measure, the Health Literacy Measurement Scale (HeLMS), has been developed for application at either an individual (clinical) or a population level (unpublished observations).

DISCUSSION

The nominal group process performed at the health literacy workshop at OMERACT 10 confirmed that health literacy encompasses a broad range of concepts and skills that existing scales currently do not measure. It identified the importance and relevance of patient abilities and characteristics, but also health professional factors and broader contextual factors. It also provided further evidence that health literacy is an important concept to measure, as it is clearly a modifier of treatment outcome, particularly in those individuals with fewer resources and/or those marginalized in society.

Table 3. Concepts derived from workshop participants in response to seeding statement grouped by theme (disease or health system). The theme was usually based on the grammatical “object” of the phrase.

| Theme (Object*) | Knowledge, Attitude, Attribute, Relationship, Skill, Action, Context | Statements |
|-----------------------------------|--|--|
| 1. Access to information | Context Skills | Access to information; physical access to information services; have access to information, e.g., internet, data; adaptive equipment to access computer/library; access to medical dictionary Being able to use Web for access to information; recognize reputable information/Websites/library; IT skills |
| 2. Cognitive capacity | Attribute | Good memory; ability to shift paradigm |
| 3. Disease | Attitude Knowledge | Learn to accept and live with your disease; acceptance of condition Understanding active arthritis state compared to [chronic] disease-related effect; knowledge of side effects; learn about disease/diagnosis; understand results (blood tests, scans); understand medical terminology about specific issues; understanding of the specific disease; understand risk/prognosis/impact of disease |
| 4. Expression/communication | Skills | Ability to say no; guidance to improve communication and coping skills; ability to negotiate; social skills; ability to communicate with health professionals; ability to express values and priorities to healthcare professionals; ability to ask for information |
| 5. Finances | Context | Having money to get healthcare; access to a healthcare plan; get enough money and [to] use it for health |
| 6. Health professionals | Attitude Context Knowledge Relationship Skills | Trust and be able to mistrust healthcare professional (healthy skepticism) Time — get time from healthcare professional/GP/rheumatologist; physician who is truthful when they don't know; having GP who will refer to specialist; physician who is willing to treat within your life expectation; access to health professional in a timely manner; health professional time GPs being trained and up to date Building effective relationships with healthcare professionals Know how to access physician |
| 7. Health system | Context Knowledge Skills | Access to public health/free healthcare To know/recognize who is the right person/players to help; understanding the health system/ reimbursement/incentives Knowing how to access/navigate the system if lack funds |
| 8. Information | Attribute Context Skills | Clear diagrams are required for information; short statements Having accurate information available Read, understand, retain information; learning how to work with health information; ability to put information into context; ability to be critical/skeptical; ability to discern reliable from unreliable information; ability to synthesize information; sense of perspective (relative importance of all information and experiences); capacity to understand disease, receive knowledge; ability to work out what you want to know |
| 9. Literacy/numeracy | Skills | Speak same language as person from whom information is sought; numeracy skills; ability to read |
| 10. Management skills | Attitude Skills | Consciousness of responsibility for lifestyle and taking medication Ability to understand a problem is a side effect of treatment; ability to understand what food is unhealthy; ability to make comparisons/weigh up options/make choices; priority setting; ability to seek alternative options; time-keeping skills |
| 11. Medication | Knowledge | Knowledge of ramifications of medications |
| 12. Patient approach | Attitude Skills Skills | Motivation to seek information/intention; willingness to take personal responsibility; interest in own health; ability to integrate/change/reconcile own cultural/personal beliefs with medical information; allowing oneself permission to seek alternative help; team player willingness; ability to grow from adversity; initiative to go and get it; assertiveness to ask for information Build own boundaries, rules for wellness; ability to change behavior Problem solving skills; stress management; deal with fear of medications/hospital/healthcare professional |
| 13. Dealing with problems | Skills Skills | Problem solving skills; stress management; deal with fear of medications/hospital/healthcare professional |
| 14. Psychological characteristics | Attitude Skills | Willingness to care about yourself; persistence; patience; sense of humor; confront own issues before can communicate; learn to accept you as you are; feeling able to reconsider/permission to do this; self-confidence; locus of control; confidence to go and get it [what's needed] Understanding negative prior experiences in context of own history (“once bitten twice shy”) |
| 15. Social supports | Action Context Relationship | Become a member of a patient organization Family network; support and learning from patient organization Someone to help get information; ability to engage with social network to either get or use information; social support to assist in understanding |
| 16. Time | Context | Time to do it |

* Object: e.g., disease, health system [In statements with intransitive verbs or verb phrases the inferred grammatical object was simply the noun form of the verb phrase itself; thus the object of “Patient is persistent” is the characteristic, “Patient persistence.”]

Participants endorsed the development of a generic, in contrast to a disease-specific, measure of health literacy that reflects the patients' perspective and would be relevant across different cultural settings. This point was evidenced by the absence of statements and overarching concepts that could be regarded as musculoskeletal-specific (Table 3).

Overall, the detailed content of the themes across knowledge, attitude, attribute, relationship, skill, action, and context provided tangible actions by which health literacy interventions could be operationalized. This contrasts with the health literacy definitions (Table 1) and most currently available tools (e.g., REALM, TOFHLA, NVS; see Table 2), which only go some distance toward identifying potential health literacy difficulties a person might have and offer little about what may be done about it.

When the content of the HeLMS is compared with the concepts derived from the nominal group technique exercise at OMERACT, it is obvious that greater depth and breadth has been achieved with the OMERACT exercise. These differences may have occurred because of the different processes of data analysis (cluster analysis vs thematic analysis), as well as the somewhat different samples (the OMERACT sample was from an international audience). While the limited range of constructs in the HeLMS in part reflects the rigorous psychometric processes required to generate a parsimonious, but useful, set of scales, the Health Literacy SIG output provides new insights into how the field can be advanced. For example, future work should include some or all of the following dimensions: dealing with disease, health professional attributes, trustfulness, knowledge of the healthcare system, and self-management and problem-solving skills.

The concept of health literacy as enumerated by the OMERACT 10 workshop participants is also much broader than the individual skills and attributes identified as being important to be an effective consumer in the EC-17. Although many of the EC-17 items have relevance to one or more of the 16 health literacy themes⁴, the EC-17 does not identify health professional and broader contextual factors. In an evaluation of the EC-17 in Ireland, people with arthritis showed deficits in 2 domains (negotiating roles and taking control, and making decisions and taking action), which persisted even after people completed self-management programs⁵. This suggests that also addressing health professional and broader contextual factors may be essential to optimizing an individual's health literacy and consumer effectiveness.

The detailed concepts across themes also provide new and systematic insight into what needs to be done to improve health literacy and consequently reduce health inequalities. Clear guidance is embodied in the themes across a broad range of an individual's life and across the healthcare and social services sectors that can assist in improving services and designing interventions. The themes also provide guidance for the development of improved measures of health literacy.

The OMERACT Health Literacy, Equity and Effective Consumer special interest groups now have the opportunity to use the data obtained from this workshop to expand or redevelop the current health literacy assessment tools. Over the next 2 years, we will undertake further consultation with patients and health professionals within OMERACT to derive a more comprehensive measure that fulfils the OMERACT filter⁸, and advances measurement of health literacy in clinical practice, clinical trials, and community interventions. The methods that will be used to improve health literacy questionnaire measurement will include concept mapping³², item testing in target populations of people with low literacy, and rigorous validation in clinical and community settings³³. The utility of a new questionnaire becomes evident through the value researchers, clinicians, and health services place on the data it returns. While both health literacy and effective consumer scales are appealing concepts and these 2 approaches are likely to be valuable complements to other, more traditional disease-specific measures, it will be important to document how the results from the scales inform practice and research such that improvements in patient outcomes occur.

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