Attributes and Skills of an Effective Musculoskeletal Consumer

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ABSTRACT. The OMERACT 7 Effective Musculoskeletal Consumer Workshop brought together people with rheumatoid arthritis, healthcare professionals, and researchers to discuss what they thought made a musculoskeletal consumer effective at managing their disease. Preliminary work before OMERACT provided a draft list of potential characteristics of an effective consumer. Participants at the workshop provided feedback about the list including relevance, missing items, format, and language. The feedback provided was useful and will be incorporated into a revised list to aid in the development of an instrument to measure health consumer effectiveness. (J Rheumatol 2005;32:2257–61)

Key Indexing Terms:
HEALTH CONSUMER
PATIENT PARTICIPATION
EFFECTIVENESS
OUTCOME MEASUREMENT

At the Effective Musculoskeletal Consumer Workshop at OMERACT 7, people with rheumatoid arthritis (RA), healthcare professionals, and researchers were brought together to discuss what they thought makes people effective at successfully managing their musculoskeletal (MSK) disease. This workshop, which was preceded by a survey sent to OMERACT participants, was an important step in the development of a core set of skills and attributes of an effective MSK consumer.

Prior to the workshop a draft list of skills and attributes was created, and the participatory approach at the Effective Health Consumer Workshop provided an opportunity to evaluate the preliminary list, its overall framework, and its clarity. It was also a unique setting to consult with a group of people who have MSK disease, and to take advantage of the creative interaction and dynamics of that group. Overall, participants of the workshop supported the development of such a core set as important and relevant, and helped to identify key skills and attributes and future directions for the development of a tool to measure an effective consumer.

Background

Defining and establishing an outcome measure for qualitative and quantitative assessments (cross-sectional and longitudinal) of an "effective health consumer" is timely. Over the past 2 decades, healthcare has experienced a shift towards increasing consumer participation in individual healthcare and in the healthcare system. It is argued that this involvement will lead to improved management of disease, improved health outcomes and patient satisfaction, better informed decision-making, increased compliance with healthcare decisions, and better resource utilization. Perhaps the greatest impact of benefits of consumer involvement will be most evident in people suffering from chronic diseases who interact with the healthcare system and make healthcare decisions on an ongoing basis.

Current initiatives worldwide aim to transfer knowledge and skills to consumers in order to empower them to manage their disease, and to improve their health and healthcare resource use. These initiatives assume that a health consumer has characteristics of effectiveness that can be defined and changed positively through interventions — in other words, that an effective health consumer exists. Further to this assumption is the concept that people completing and participating in these programs and initiatives will be effective consumers who can benefit. A recent review of this literature has shown evidence that people with chronic illnesses who participated in self-management interventions show improvements in disease symptoms, quality of life, and healthcare resource use[1].

But to date, there appears to be a lack of agreement on the mix of skills and attributes that constitute an effective health consumer and on how to measure those skills and attributes. The Arthritis Self-Management Program is an example of the interventions that teach consumers skills to solve problems, make decisions, and take action in order to manage

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their disease, while other programs focus on teaching consumers how to medically manage their disease[2]. Without an agreed-upon consistent set of measures of the characteristics of an effective consumer, it is difficult to evaluate and compare the success of such initiatives.

In 2003, the Canadian Institutes of Health Research granted funding for a collaborative research project between the University of Ottawa, Canada, and the University of Queensland, Australia, to determine what is and how to measure an effective arthritis and MSK health consumer. There are 3 main objectives of the project: (1) to develop an operational definition of an effective health consumer in terms of core skills, behaviors, attributes, beliefs, and norms as perceived by health consumers and clinicians; (2) to identify and define generalizable indicators that can be used to measure skills, behaviors, attributes, attitudes, beliefs, and norms; and (3) to develop an agreed set of valid and reliable measures of these indicators.

This project uses a participatory action research approach, involving people who are directly affected by the research: people with MSK diseases and their families; and people who are involved in activities to increase consumer effectiveness and use the results in practice — clinicians, academics, and health consumer organizations associated with MSK diseases. Both groups will be involved in all 6 phases of the project over the 3 year timeline.

Phases of the Effective Musculoskeletal Health Consumer Project

I: Archival search for definitions and descriptions of health consumers.
II: Develop an operational definition of an effective health consumer and conduct semistructured interviews with stakeholder groups. Stakeholder groups include people with MSK diseases and their family, clinicians, academics, and representatives from health consumer organizations. Interviews are to obtain views about what is an effective consumer.
III: Identify and define scales in the literature that can be used to measure an effective health consumer and survey stakeholders about the identified list of skills, attributes, and scales.
IV: Consolidate data from Phase I–III and analyze using the OMERACT filter of truth, discrimination, and feasibility.
V: Hold consensus conference and develop an agreed set of valid and reliable measures of the agreed skills and attributes of an effective health consumer. Determine research agenda.
VI: Disseminate and seek funding to carry out research agenda to validate measures.

In addition to participation of multiple stakeholders in the research collection phases, the research project is overseen by multidisciplinary teams from many countries. The Effective Consumer Steering Group Committee has 11 members from Australia and Canada, including rheumatologists and physicians; epidemiologists; science and social science academics with expertise in health communication and consumer decision-making; and consumer representatives. The project is also guided by a Consumer Advisory Panel of 5 consumer representatives from Australia, Canada, and the United States, representing the voice of consumers; panel members have a broad spectrum of MSK diseases including rheumatoid arthritis, osteoarthritis, and back pain.

Prior to OMERACT

Before OMERACT 7, Phases I and II were completed to inform a preliminary list of skills and attributes. A review of the literature was performed, an investigator workshop to develop an operational definition occurred, and in-depth interviews with relevant stakeholders were conducted and analyzed. The purposive review of the literature found definitions of consumers in the literature from multiple disciplines, including economics, sociology, psychology, and health. Reputable reference books and websites, and articles describing measurement scales of skills and attributes of a health consumer, were also retrieved. Definitions were analyzed and common themes extracted. A more detailed report of the search strategy and results is described by Brabant, *et al*[3]. Eight themes indicating characteristics of the skills and attributes of an effective consumer were identified from the literature review:

Themes from the Review of the Literature

1. Individual differences, including self-motivation and optimism;
2. Patient-centered idealism;
3. Informed decision-making;
4. Communication acts by patients;
5. Access to information and resources;
6. Rights and responsibilities;
7. Relationship between patient and professionals, others, institutions, and culture; and
8. Market metaphor, emphasizing the individual as consumer of products and services.

The results of the literature review were used to inform the first meeting of the Steering Group Committee, which took place in Brisbane, Australia, in April 2003. It was decided early in discussions there that the group would delay defining an effective health consumer conceptually, but would focus on the development of an operational definition, which would be consistent with the deductive process of this research. Therefore, a draft operational definition of an effective health consumer was created. Four main abilities were identified with a number of skills and attributes within each of the 4 categories. It was recognized that some themes, such as knowledge, awareness, confi-

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dence, and competence, span all 4 categories. Overarching all categories is the concept that the consumer is "person centric" — that even though the consumer is situated and influenced by society and the healthcare system, this project will focus on the individual and his/her individual characteristics of effectiveness. Also emphasized was the defining and measuring of a consumer who lives in an ideal world. The group agreed that personal, financial, societal, and social influences could limit or enhance the effectiveness of the consumer, but that these factors could be assessed in the future and potentially used as predictor variables (Table 1).

Semistructured interviews of the stakeholder groups were also completed. About 35–40 interviews were conducted in both Australia and Canada with people and family affected by MSK diseases, rheumatologists and physicians, and representatives from healthcare organizations associated with MSK diseases. Comment was invited from interviewees with MSK disease: "...describe a personal experience that you thought was especially effective or ineffective in handling your condition — please explain what was good or bad about it — what could have been different?"; other interviewees were asked to describe experiences of their family members, patients, or clients. Followup questions were also used to prompt further discussion but not lead the interviewees. In April 2004, after data collection and transcription, an interim analysis of the data was completed and feedback was obtained from the Steering Committee and Consumer Advisory Panel. That people believe there are specific behaviors and attitudes that help manage and cope with their disease was made clear in the interviews. Seven main themes emerged, as listed in Table 2.

At a meeting of the Project Team in April 2004, data from Phase I (the literature review and analysis) and Phase II (the operational definition and the interviews with quick analysis) were triangulated. A list of characteristics of an effective consumer, identified in the previous phases, was developed from the data. About 100 characteristics were compiled, which the team then worked to frame, organize, and simplify to about 50 characteristics.

Three weeks before OMERACT 7, about 200 OMERACT participants were sent a survey that included a background paper about the project, recent work, and the draft list of characteristics of an effective consumer. Participants were asked to review the list and rate how important each characteristic was and to indicate whether the item was clearly written. There were 59 respondents (30% response rate), which included 13 people with arthritic conditions, as well as researchers and healthcare professionals. Overall, people felt that most items on the list were very important, but that more work was needed to ensure the characteristics were not "double-barrelled" — one item often covered multiple skills and characteristics — nor "multi-interpretable" — items often had many meanings. Respondents had also been asked to suggest other skills and attributes they felt were important but were not in the draft list (we had a few suggestions). However, it was thought that this type of information would instead come out of the small group discussions during the workshop.

At OMERACT 7

The Effective Consumer Workshop was attended by about 50 people at OMERACT 7, including patients, researchers, and clinicians. The workshop began with a brief introduction and review of the work to develop the preliminary list of skills and attributes. Participants then broke out into 4 small groups. Groups were asked to discuss the following: "What characteristics do you think people with a musculoskeletal disease should have to handle their disease?" and to consider the preliminary list of characteristics for missing, confusing, or irrelevant items. A rapporteur from each

Table 1. Framework and operational definition of an effective health consumer.

Ability to Find and Understand Options	Ability to Clarify Personal Values
Searching skills	Awareness of basic values
Sources of knowledge	Consistent identification of societal and personal values
Ability to access resources	Priority setting and weighing options
Open mind/Questioning attitude	Evaluation skills
Ability to ask questions and question framing	Ability to anticipate consequences and outcomes
Discerning ability	Considers personal and others' past experience and use
Critical appraisal	Communication skills
Probability understanding	Clarification skills
Numeracy and literacy	Sense of personal and social identity, self-esteem
Tailoring information to self	Recognition of patient with disease versus person with disease
	Valuing time (discount)
Ability to Negotiate Chosen Roles	Motive and perception of disease
Assertiveness	
Communication skills	Ability to Negotiate and Achieve Preferred Options
Listening and negotiating skills	Persistence
Empathy	Change skills
Self-motivation	Organization skills
	Social influence (positive vs negative)

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Table 2. Themes identified from the stakeholder interviews.

1. Information seeking
   - Information seeking - sources, etc.
   - Knowledge - awareness of need, importance
   - Evaluating - who can and how to
   - Other skills: open-mindedness, questioning attitude, knowledgeable, able to access information, able to rely on others, proactive
2. Decision making considerations
   - Tailoring/adapting information to self
   - Setting goals
   - Determining values
   - Priority setting
3. Implementing decisions
   - Treatment strategies
   - Recognition of rights versus acting on rights
   - Lifestyle changes
   - Higher order/ tacit knowledge
   - Other skills: willing to comply with treatment, patience, responsibility for control over illness, flexible character, ability to change lifestyle, routine, etc.
4. Role negotiation
   - Reconstruction of self
   - Sense of control (patient label)
   - Self-efficacy (physician label)
   - Developing sense of normalcy or defining new normal
   - Dealing with invisibility of disease
   - Communication with family/friends
   - Patient's role with doctors
   - Other skills: ability to engage others and assess other's comfort level with illness, empathetic, able to maintain their own identity and not be defined by the disease, self-efficacy (belief that can do, manage and have control)
5. System negotiation
   - Trust and transparency in relationships
   - General physician's role
   - Specialist's role
   - Communication with physicians
   - Self-management (i.e., using system to get "better" physiotherapy, homecare, staying independent, medications, etc.)
   - Other skills: assertiveness, communication skills, knowledge of their body and disease, access to and willingness to work with organizations and health care professionals, trusting relationship with health care professionals
6. Interaction with social environment
   - Social connectedness
   - Support
   - Importance of consumer groups and support groups
7. Individual differences
   - Disease acceptance
   - Coping with the illness (facilitators and barriers)
   - Depression
   - Motivation for treatment
   - Significance of pain, disease stage, etc.
   - Demographics - gender, age, culture and education
   - Other skills: Positive outlook, realistic expectations, can cope with loss of independence, control over disease, strong coping skills, determination

group then presented the key issues that emerged from their discussion to the larger group at the end of the workshop. Participants had questions and suggestions about the overarching principles behind the list, specific items, and the format of the list itself.

Generally, there were questions about the definition of "effective." For example, if a person was effective, would it mean better disease outcomes, increased satisfaction with care, more "right" decisions, and/or one's own decisions? Was the list defining an "effective" consumer or a "super" consumer? Moreover, did the effective consumer only exist in an ideal situation? Many participants pointed out numerous external factors that can influence how effective people may or could potentially be in handling their disease: people interact with different healthcare systems and healthcare professionals, with their own level of effectiveness (e.g., the effective or noneffective physician); people are faced with substantially diverse economic or financial situations, and also hold different cultural beliefs.

Participants also suggested different ways to organize the list of skills and attributes. Some made a distinction between attitudes, knowledge, and skills and imagined a list divided into those domains. Others distinguished between skills and attributes that could and could not be modified, while others thought that the items should be divided into skills and attributes that were specific to a situation, for example, skills needed when working with the healthcare system or in the consultation process. In some groups, skills in managing the consultation process and developing the relationship with the healthcare professional were emphasized over other situations.

The importance of many of the items on the list was confirmed, but despite their number — over 50 items — participants indicated other noteworthy items were missing. Some referred to individual personality traits such as having stamina, a healthy scepticism, hope, and a fighting spirit or the ability to face fears and anxiety. Other items addressed the concept of role negotiation, including the perception of autonomy and independence, a sense of control or taking charge, an individual's role in society and how illness may affect that role. Specific skills were also identified including the abilities to weigh the quality and content of health information, to build a relationship with the healthcare professional based on mutual respect, and to use the Internet to find information.

With regard to format, participants indicated the list was too long, but that many items were double-barrelled and needed to be separated. They also felt that some items were repeated — only explained using different words. Wording itself also needed to be refined as there were items that could

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have many meanings. Thinking ahead, many participants suggested that the survey to stakeholders should follow a "yes/no" format.

Future directions

Using the feedback obtained from the workshop, the list of skills and attributes has been developed further. Items have been added and the framework of the list revised. Most important, the input of participants confirmed the relevance of many items on the preliminary list. The work at OMERACT 7 has also made the team aware of the need to refine the wording, and early psychometric involvement should be sought before the list is sent out to survey the stakeholders in Phase II.

The current draft list will be developed over the next year as more feedback about the identified skills and attributes is obtained from the large survey of stakeholders. A workshop at a Decision-Making Conference in June 2005 was also planned to ensure consensus about a core set of skills and attributes, at which point a literature search of measures and scales of the skills and attributes to inform the list will be performed. It was anticipated that there may be a limited number of applicable scales and measures that will need to be researched, and that it will also be necessary to test external validity and predictive value of the list of skills, attributes, and measures — a possible task for future workshops.

Developing a core set of outcome measures and an instrument for qualitative and quantitative assessments of an effective health consumer is necessary. Without identification of the skills and attributes of a consumer who can successfully live with their chronic disease, and without the knowledge of how to measure these, it will be difficult to evaluate and improve initiatives to empower consumers to participate effectively in their care. More work is needed to develop a validated instrument that measures an effective musculoskeletal consumer and to determine a future research agenda.

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