Outcome Measures for Arthritis Care Research: Recommendations from the CARE III Conference

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ABSTRACT. The Outcome Measures workshop at CARE III addressed the topic of selecting appropriate and relevant outcome measures for research of nonpharmacological, nonsurgical interventions. Consumers, practitioners, and researchers contributed to small and large group discussions following a series of 7 overview presentations. The importance of measuring what matters to consumers using measures that match the purpose of research studies was emphasized. It was generally agreed that care researchers have access to effective measures of disease status, physical and functional status, and quality of life. Gaps exist in the repertoire of existing measures, including satisfactory ways to measure engagement in more complex roles, the area that has come to be known as participation. It was proposed that client-centered outcome measures addressed this gap, but only in part. Research priorities proposed that new or improved outcome measures be designed for participation in employment, parenting, social relationships, leisure, and school, and that more attention be given to process measures that capture the mediating factors associated with improved health outcomes. (J Rheumatol 2006;33:1908–11)

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The third international conference on arthritis care research, CARE III, was held in Toronto, Canada, May 12-14, 2005. For the purpose of deliberations at CARE III, care research was defined as methods to address nonpharmacological, nonsurgical care for persons with arthritis[1]. The objectives of the outcome measures session at CARE III were (1) to summarize current knowledge and emerging approaches to measuring outcomes of arthritis care research; (2) to identify relevant domains to be measured and gaps between these domains and existing measures; and (3) to recommend an agenda for advancing the state of the art in outcome measures relevant to care research.

PROCEDURE

In the months prior to the conference, one-third of CARE III delegates were assigned to the outcome measures electronic discussion group, which generated and ranked potential topics (Table 1). The top 6 determined the content of overview presentations, intended to address the first workshop objective, as well as stimulate discussion among delegates. Presentations were clustered into 2 panels: (1) measuring relevant outcomes and (2) important measurement issues. Each panel was followed by round-table discussions (see discussion questions below) and general observations shared in a final large-group discussion aimed at achieving the second and third objectives.

Discussion questions

1. What outcomes are of greatest interest to you? Why?
2. Are there good instruments for measuring those outcomes?
3. Is the arthritis research community adequately involving consumers in the development and/or selection of outcome measures?
4. Did the presentations and/or your round-table discussion stimulate ideas for future research priorities regarding outcome measures best suited to arthritis care research?
5. Is a core data set for care research desirable? If yes, should it be any different than the outcome measures used in drug trials?
6. What domains or areas should be included in an international core data set for care research?
7. Can the CARE initiative play a role to facilitate consensus and standardization in this area?
8. What was the most important message you heard this afternoon about outcome measures in arthritis care research?

GENERAL ISSUES IN OUTCOME MEASURES FOR CARE RESEARCH

Ten years prior to CARE III, Lynch and Caughey summarized benefits of the team approach to managing chronic arthritis[2]. In citing selected studies of team care, they noted that the outcome measures chosen included traditional clinical and laboratory measures of disease status, as well as measures of pain, function, life satisfaction, depression, and psychological adjustment. They proposed the addition of patient satisfaction measures to this set of outcome measures. What progress have

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Table 1. Potential topics for CARE III Outcomes Workshop listed according to rank (mean rating scale of 1 to 5, 1 = highest priority, 5 = lowest priority).

Topic	Mean Rating
Patient/client-centered outcome measures	1.56
Consumers' perspectives on most relevant outcomes to be measured	1.62
Responsiveness (how to detect a meaningful change)	2.00
Outcomes to be included in core data sets	2.06
Outcomes to be used in standard practice/care	2.31
Modern psychometrics to consider in developing/ selecting outcome measures	2.56
ICF as a framework to guide selection of outcome measures	2.87
Theoretical issues/approaches to selecting outcome measures	3.12
Body region-specific outcome measures (e.g., foot, knee)	3.75

ICF: International Classification of Functioning, Disability, and Health.

we made in identifying relevant outcomes and appropriate measures of those outcomes, a decade later?

In her talk, "Measuring What Matters — The Consumer Perspective," Anne Fouillard spoke about living with osteoarthritis, navigating through the healthcare system, and dealing with the impact of arthritis on herself — her physical, economic, and social well-being — and on her family[3]. She posited that current outcome measures tend to focus on clinical outcomes immediately relevant to clinicians and scientists. However, from the patient's perspective many important issues were inadequately addressed, including fatigue, intimacy, sexual activity, relationships with others, self-employment, coping, communication, and self-management skills. While some of these may be difficult to measure and may vary in importance over one's lifespan as well as across individuals, they are nevertheless important to consumers' quality of life and their access to appropriate healthcare. Consumer input needs to be integrated in research models during the earliest stages of planning studies, to ensure that research questions and outcome measures address what matters most to consumers.

Given the pivotal role of general/family practitioners in helping consumers access health services, it was also suggested that they be more integrally involved in care research. It was also noted that many people with arthritis are not as effective in accessing healthcare as those consumers who are actively engaged as research partners, and future research priorities should address the unmet needs of this potentially underserved group of people.

Ways to best capture outcomes of relevance to consumers have been explored in presentations at the 3 international CARE meetings and other venues such as the patient perspective discussions at OMERACT. A progress report from OMERACT 7 suggests that in trials of rheumatoid arthritis interventions increasing attention be given to measuring fatigue[4], and recent work has attempted to better document the impact of fatigue from the patient's perspective[5]. Measuring what matters to consumers remains a priority for future arthritis care research.

Another way of ensuring patient perspective is by using client-centered (also known as patient-centered) outcome measures. Such tools consider individual patients' preferences or goals for intervention, and measure whether these goals are achieved. Typical goals tend to involve participating in activities or fulfilling a life role of importance to the individual person. Several CARE III delegates emphasized the need for measures of individual experiences that go beyond the traditional, standardized approaches to measuring functional or health status. Existing tools inadequately assess *participation* (i.e., complex tasks and involvement in life roles), as defined in the International Classification of Functioning, Disability and Health (ICF)[6].

In discussion of the concept of participation, some delegates pointed to a need to clarify how participation differs conceptually from quality of life; more specifically, it was contended that participation requires outcome measures that are different from established quality of life tools. Other delegates expressed concern that applying participation measures for comparison across groups of patients in research studies or for generalization beyond the individual experience might not be a valid approach. It was also noted that Stamm and colleagues[7] have embarked on important work linking concepts from the ICF to existing outcome measures, including client-centered measures that may address at least some aspects of activity (and activity limitations) and participation (and participation restrictions).

Alongside debate about appropriate and relevant outcome measures to determine effects of nonpharmacological care, there was discussion about the need to use process measures. Many rehabilitation and psychosocial interventions involve building knowledge and skills and changing behavior. Our interventions are often delivered by an interdisciplinary team, or any one of a number of models of care. In order to draw conclusions about outcomes and attribute those outcomes to the intervention, it is necessary to evaluate the process of care. For example, if it is hypothesized that better health outcomes will be achieved when a consumer is well informed and empowered, then it is necessary to measure specific attributes such as communication and coping skills as part of the causal pathway to better outcomes. To this end, current work on a tool to measure the effectiveness of consumers in managing their healthcare was presented[8]. An effective consumer was defined as one who is effective at using the healthcare system, managing their illness, and interacting in the social environment. The impetus for this work arises from the growing interest in self-management programs that aim to empower patients to take an active role in their healthcare, ensuring that services are centered on the patient and address the patient's needs. The skills identified as important to being an effective healthcare consumer include information seeking, decision making, negotiation, and interacting within the social environment.

Table 2. Summary of outcome measures discussion.

Issue	Key Points/Recommendations
Relevant outcomes (relevant to consumers and to care research)	• Involve consumers in design of studies and/or in identification of important outcomes • Determine the important outcomes relevant to study purpose, then select the best available measure(s). The choice of measures depends upon the research question(s) • Adopt more holistic approaches to evaluating how a person with arthritis is doing in general, rather than reducing outcomes to components of the person. Joint pain and basic functions like gripping or walking are relevant; however, they reflect a limited, biological perspective and do not capture aspects of life important to people living with arthritis
Process measures	• Because care research toward desirable health outcomes involves many different processes, these processes should be measured; e.g., the process of care delivery, of behavior change (the consumer's ability to navigate the healthcare system) • Process measures help identify mediating factors that influence health outcomes
Core data sets	• The idea of an international core data set for care research was supported, but opinions about what should make up that core set varied • In addition to traditional measures of disease status (e.g., swollen joint counts, strength, mobility) and basic functional activities (e.g., walking, dressing, bathing), core data sets for care research should include work, school, parenting, leisure, and social relationships. These latter domains require development of new and better measures • Longitudinal data collection would benefit from agreement on a core data set. Selected outcome measures could be incorporated into standard clinical care, so that patient-specific and group data are collected over time. Patient questionnaires yield data for clinical research and improved care[9]
Domains to be measured	• Many important outcomes are complex, e.g., extent to which one is able to adequately fulfill life roles as an employee, parent, spouse, and so on. Importance of these domains varies across individuals and frequently changes over the lifespan. Yet development of better measures of participation should be a research priority to better document the outcomes of nonpharmacological interventions • The need to clarify possible conceptual confusion between the idea of "participation in a life role" and "quality of life" was proposed as a theoretical and research priority. Existing quality of life measures, while useful, do not adequately measure some of the domains of greatest interest to consumers and care researchers • As an initial list of important domains, the following were recommended: physical and functional status, pain, fatigue, psychosocial status, self-efficacy and self-management skills, and participation in society including work, school, play, leisure, social interaction, intimate relationships, parenting, and household maintenance
Standardized measures of participation	• Important outcomes are dynamic, and values differ. Areas of participation may not be equally important to all people with arthritis, and measures need to account for individual differences. The need to refine and build upon existing client-centered outcome measures, or design new ones that account for patient preferences, is a research priority. Client-centered outcome measures offer a standard approach, but not necessarily standard content • Concerns were raised about the validity of conclusions if the outcome of care interventions is evaluated using individualized measures, i.e., each study participant evaluates what is important to them, rather than all participants being evaluated on the identical activity. Developing standardized tools to measure participation was viewed as a considerable challenge
Influencing public health policy	• The selection of appropriate outcome measures was viewed as essential to influencing public health policy. Public health priorities are an opportunity for setting arthritis care research priorities, demonstrating change, and influencing health. The current public health priority of improving physical activity, for example, is poor among the general population and worse among those living with arthritis, which has implications for disease prevention, progression, and management

The workshop next examined the current status of instrument development and psychometric principles. Areas that need greater attention were identified: item response theory, computer adaptive testing, and differential item function hold promise for improving approaches to measuring outcomes of interest. (Item response theory, as opposed to classical test theory, uses a mathematical model for test development that accounts for the difficulty of test items and their ability to differentiate individuals with different levels of the trait being tested.) Better understanding of the concept of responsiveness, or detecting a meaningful change in outcome measures, was also discussed. Given this background of classical and contemporary approaches to measuring outcomes, participants generated a list of recommendations for further consideration, of which highlights are presented here (Table 2).

CONCLUSION

Delegates had high expectations for better outcome measures that would adequately capture aspects of life most important to people living with arthritis, and people in general. While not always achievable, high expectations can guide the way to improving quality of care and quality of life. Points raised during outcome measure sessions at CARE III set the stage for further consensus development to establish a core set of relevant outcomes to measure effects of nonpharmacological interventions. A model for the identification of core and supplementary domains is provided by others, such as the IMMPACT recommendations for chronic pain clinical trials[10].

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