Including Health Equity Considerations in Development of Instruments for Rheumatology Research: An Introduction to a Novel OMERACT Paradigm

Jennifer O'Neill, Tamara Rader, Francis Guillemin, Annelies Boonen, Robin Christensen, Anne Lyddiatt, Jordi Pardo Pardo, Vivian Welch, Jasvinder A. Singh, and Peter Tugwell

ABSTRACT. The Outcome Measures in Rheumatology (OMERACT) Equity Special Interest Group (SIG) was established in 2008 to create a preliminary core set of outcome measures for clinical trials that can assess equity gaps in healthcare and the effectiveness of interventions to close or narrow gaps between advantaged and disadvantaged populations with musculoskeletal (MSK) conditions. At the OMERACT 11 meeting in 2012, the Equity SIG workshop focused on health assessment scales and their applicability for disadvantaged patients with MSK conditions. The intent was to determine whether the items and domains in 2 common questionnaires, the Health Assessment Questionnaire and the Medical Outcome Study Short Form-36 Survey, are appropriate for the activities and life experiences of certain disadvantaged populations, and whether completion of any of the scales would present a challenge to disadvantaged persons. To generate discussion, we considered the reading level of items in these questionnaires and whether they would be accessible to people with different levels of literacy. The group concluded that the choice of measurement instrument may contribute to "outcome measure–generated inequalities" because disadvantaged groups might have difficulty understanding some of the questions. The future work of the Equity SIG will explore the appropriateness of different measurement scales as they relate to inequities in arthritis as well as the risk of exacerbating disadvantages for patients with low literacy. (First Release Oct 15 2013; J Rheumatol 2014;41:150–2; doi:10.3899/jrheum.130812)

Key Indexing Terms:
HEALTH EQUITY MUSCULOSKELETAL CONDITIONS RHEUMATOLOGY

Health inequities are universal. They exist in every country of the world for most diseases and conditions[1,2]. Health inequities are differences or disparities in health outcomes between and within populations that are unnecessary and avoidable as well as unfair and unjust[3]. To determine whether an outcome is inequitable one has to make a judgment about the fairness/justice of the situation. For example, increased adverse cardiovascular and mental health outcomes in shift workers compared to workers with regular hours would be considered inequitable. Conversely, a higher rate of musculoskeletal (MSK) injury in people who choose (freely) to participate in high-risk sports is an example of an avoidable health difference, which would not qualify as inequitable by these criteria. Health and social outcomes of importance may be different for disadvantaged populations compared to relatively advantaged populations across all the domains of PROGRESS-Plus (Place of residence; Race/ethnicity/culture/language; Occupation;

From the Institute of Population Health, University of Ottawa, Ottawa, Ontario, Canada; Université de Lorraine, Nancy, France; Maastricht University Medical Centre, Maastricht, Netherlands; The Parker Institute, Department of Rheumatology, Copenhagen University Hospital, Copenhagen, Denmark; Birmingham VA Medical Center and University of Alabama at Birmingham, Birmingham, Alabama, USA; University of Ottawa, Department of Medicine, Department of Epidemiology and Community Medicine Faculty of Medicine, Ottawa Hospital Research Institute, Clinical Epidemiology Program, Institute of Population Health, University of Ottawa, Ottawa, Ontario, Canada.

P. Tugwell is supported in part by the Canadian Institutes of Health Research. J. Singh has received consultant fees, speaking fees, and/or honoraria (less than $10,000 each) from Allergan, Ardea, Savient, and Novartis; and (more than $10,000) from Takeda; and an investigator-initiated grant from Savient and Takeda.

J. O'Neill, MSc, Coordinator, Campbell and Cochrane Equity Methods Group; T. Rader, MLIS, Knowledge Translation Specialist and Trials Search Coordinator, Cochrane Musculoskeletal Group, University of Ottawa; F. Guillemin, MD, PhD, Ecole de santé publique, Faculté de Médecine, Université de Lorraine; A. Boonen, MD, PhD, Department of Internal Medicine, Division of Rheumatology, Maastricht University Medical Centre, and Caphri Research Institute; R. Christensen, MSc, PhD, Head of Musculoskeletal Statistics Unit, The Parker Institute, Department of Rheumatology, Copenhagen University Hospital, Frederiksberg; A. Lyddiatt, BA, Consumer Coordinator, Cochrane Musculoskeletal Group, University of Ottawa; J. Pardo Pardo, LDO, Cochrane Musculoskeletal Group, University of Ottawa; V. Welch, PhD, Deputy Director, Centre for Global Health, University of Ottawa; J. Singh, MBBS, MPH, University of Alabama at Birmingham; P. Tugwell, MD, MSc, Canada Research Chair in Health Equity, Professor of Medicine and Epidemiology, Department of Medicine, University of Ottawa.

Address correspondence to J. O'Neill, University of Ottawa, Institute of Population Health, 1 Stewart St., Ottawa, Ontario K1N6N5, Canada. E-mail: Jennifer.ONeill@uottawa.ca

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on March 19, 2024 from www.jrheum.org

Gender and sex; Religion; Education; Socioeconomic status; and Social capital[4]; "Plus" has been added to ensure consideration of other factors that may indicate potential disadvantage, such as age, disability, sexual orientation, and literacy)[5]. In addition, marginalized groups with few social and economic resources and low education levels have the greatest difficulty understanding and accessing services[6].

Arthritis is well known to be more common among disadvantaged populations[7,8,9,10,11]. Therefore, examining the appropriateness of outcome measurement instruments for patients with low literacy is important for ensuring these patients benefit optimally from evidence-based health practice. The Outcome Measures in Rheumatology (OMERACT) Equity Special Interest Group (SIG) at the OMERACT 11 meeting focused on the health literacy attributes of 2 of the most common disability and quality-of-life scales [the Health Assessment Questionnaire (HAQ) and the Medical Outcome Study Short Form-36 Survey (SF-36)] and their accessibility for different levels of literacy with the aim of beginning a discussion about their applicability for disadvantaged patients.

METHODS

Using low literacy as a case example, we explored whether the HAQ and SF-36 would be suitable for people with low numeracy and literacy skills or problems with comprehension[12,13]. Both these scales have been validated in numerous studies; however, none discusses validity among low literacy populations[14,15]. The intent was to consider whether the items and domains included in the scales would be appropriate for the activities and life experiences of disadvantaged populations and whether the completion of the scales would present a challenge to someone with a disadvantage (using the factors in the PROGRESS-Plus acronym). Two groups were formed to objectively discuss the items and domains of these 2 questionnaires.

RESULTS

After small group discussion, several themes emerged about the limitations of common questionnaires.

Cultural Differences

There was a sense from the group that the questionnaires were geared toward a North American or Western European lifestyle. For example, 1 item in the HAQ asked about the patient's ability to take a bath. It is possible that this may not be relevant to people in parts of Asia, where taking a shower is more common. After the discussion, a participant remarked on another item inquiring if someone was able to "cut their own meat." This item is inappropriate in many contexts. In some cultures knives and forks are not used, or people eat with their hands. In addition, some cultures and religions include predominantly vegetarians.

Socioeconomic Status

Some items in the questionnaire assume a level of income that is not inclusive of all people. For example, one item asks whether someone is able to vacuum their home. Owning a vacuum may not be applicable to all populations. Similarly this item fails to consider homeless people. In addition, some members of the group suggested there was a possible gender bias by focusing on domestic tasks.

Language and Literacy

There were instances of outdated language or phrases in the SF-36. Non-English speakers may have difficulty understanding the meaning, and some patients might struggle with longer, complex sentences. Examples from the SF-36 (Item 20 and Item 22) might challenge these readers: "During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?" The Flesch-Kincaid scale rates text according to how many years of education are required for understanding[16]. The above question obtained a Flesch-Kincaid grade score of 15. The general rule is to write questions at grade 6 level (Flesch-Kincaid grade score of 6); therefore, this item is much too difficult. Another example: "How much of the time during the past 4 weeks did you feel full of pep?" The term "pep" is not commonly used and may not be familiar to people who have a limited understanding of English.

DISCUSSION

We focused on the issue of literacy as a case example to demonstrate that considerations of factors of disadvantage are important for primary research.

Literacy includes a person's ability to read and write at a level adequate to fulfill their daily activities[17]. Patient education materials and informed consent forms are often written at a level that is too complex for many patients[17]. Medication instructions are also often written at reading and comprehension levels above those of the patient. This can result in decreased compliance and adverse events for patients[17].

As demonstrated in the examples above, even questions from standard and widely used instruments may be inappropriate for some groups of patients. Patients with inadequate literacy or poor health literacy may respond to standard questionnaires inaccurately. Patients from disadvantaged groups may feel that certain questions are not applicable to their situation and may not respond. This raises questions related to both the content validity and the accuracy of measurements when using the instrument in disadvantaged populations. Using scales that are inappropriate for the literacy level of the user can influence not only our understanding of the effect of the intervention on important disadvantaged groups but also clinical trial results and ultimately, patient care, if potentially eligible patients are deemed ineligible for a trial or for a treatment that may be beneficial for them.

Other important considerations for literacy are the

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on March 19, 2024 from www.jrheum.org

inherent problems presented when translating standard health education materials or measurement tools into other languages. Direct translation may not be appropriate because the activities described within items of the questionnaire may not be applicable for different cultures[18,19]. For example, the HAQ item related to "vacuuming or yard work" was adapted for the Arabic version to "praying from the standing position (kneeling) or do chores such as home cleaning"[20], and to "sweep and mop" in the Thai version[21]. In addition, certain words may not be translatable, or the meaning may be completely different. This is the rationale for using translation that includes adequate safeguards for comprehension by the target populations, so that such problems may be avoided.

According to the feedback received at OMERACT 11, outcome measurement instruments may indirectly create or exacerbate inequities if disadvantaged groups do not understand the questions being asked in scales such as the SF-36 and the HAQ, and these instruments are being used to evaluate healthcare interventions or needs. This could create "outcome measure-generated inequalities." We anticipate that the exclusion of individuals with low health literacy because of their failure to understand the outcome questionnaires could increase the gap between the most and least disadvantaged groups within a population.

Arthritis is more common among various disadvantaged groups. Therefore, designing and implementing interventions for disadvantaged populations with arthritis is essential to target the reduction of health inequities in arthritis care and optimize the use of effective treatments in patients who stand to benefit the most. This includes paying special attention to health equity aspects of health assessment scales, because clinical trials may use these as primary outcome measures. The future work of the Equity SIG will explore the effects of interventions and the appropriateness of different measurement scales as they relate to inequities in arthritis, as well as the risk of exacerbating disadvantages for patients with low literacy and those for whom completion and/or comprehension of health assessment scales is difficult or impossible.

REFERENCES

1. Mill J, Astle B, Ogilvie L, Opare M. Global health and equity. Part 1: setting the context. Can Nurse 2005;101:22-4.
2. Ogilvie L, Astle B, Mill J, Opare M. Global health and equity: part 2: exploring solutions. Can Nurse 2005;101:25-8.
3. Whitehead M. The concepts and principles of equity and health. Int J Health Serv 1992;22:429-45.
4. Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. Inj Control Saf Promot 2003;10:11-2.
5. Health promotion, inequalities and young people's health. A systematic review of research. 2008. [Internet. Accessed July 15, 2013]. Available from http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=2410
6. Coulter A, Ellins J. Patient-focused interventions: a review of the evidence. London: Health Foundation; 2006.
7. Hochberg MC, Thomas J, Thomas DJ, Mead L, Levine DM, Klag MJ. Racial differences in the incidence of gout. The role of hypertension. Arthritis Rheum 1995;38:628-32.
8. Zhu Y, Pandya BJ, Choi HK. Prevalence of gout and hyperuricemia in the US general population: the National Health and Nutrition Examination Survey 2007-2008. Arthritis Rheum 2011;63:3136-41.
9. Mackie SL, Dasgupta B, Hordon L, Gough A, Green M, Hollywood J, et al. Ischaemic manifestations in giant cell arteritis are associated with area level socio-economic deprivation, but not cardiovascular risk factors. Rheumatology 2011;50:2014-22.
10. Borkhoff CM, Wieland ML, Myasoedova E, Ahmad Z, Welch V, Hawker GA, et al. Reaching those most in need: a scoping review of interventions to improve health care quality for disadvantaged populations with osteoarthritis. Arthritis Care Res 2011;63:39-52.
11. Brennan S, Turrell G. Neighborhood disadvantage, individual-level socioeconomic position, and self-reported chronic arthritis: a cross-sectional multilevel study. Arthritis Care Res 2012;64:721-8.
12. Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. Arthritis Rheum 1980;23:137-45.
13. Brazier JE, Harper R, Jones NM, O'Cathain A, Thomas KJ, Usherwood T, et al. Validating the SF-36 health survey questionnaire - new outcome measure for primary care. BMJ 1992;305:160-4.
14. Bruce B, Fries JF. The Stanford Health Assessment Questionnaire: a review of its history, issues, progress, and documentation. J Rheumatol 2003;30:167-78.
15. McHorney CA, Ware JE Jr., Rogers W, Raczek AE, Lu JF. The validity and relative precision of MOS short- and long-form health status scales and Dartmouth COOP charts. Results from the Medical Outcomes Study. Medical Care 1992;30:MS253-65.
16. Kincaid JP, Fishburne RP, Rogers RL, Chissom BS. Derivation of new readability formulas (Automated Readability Index, Fog Count, and Flesch Reading Ease Formula) for Navy enlisted personnel. Memphis: Naval Air Station; 1975.
17. Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC, et al. Inadequate functional health literacy among patients at two public hospitals. JAMA 1995;274:1677-82.
18. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine 2000;25:3186-91.
19. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. J Clin Epidemiol 1993;46:1417-32.
20. El Meidany YM, El Gaafary MM, Ahmed I. Cross-cultural adaptation and validation of an Arabic Health Assessment Questionnaire for use in rheumatoid arthritis patients. Joint Bone Spine 2003;70:195-202.
21. Osiri M, Deesomchok U, Tugwell P. Evaluation of functional ability of Thai patients with rheumatoid arthritis by the use of a Thai version of the Health Assessment Questionnaire. Rheumatology 2001;40:555-8.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2014. All rights reserved.

Downloaded on March 19, 2024 from www.jrheum.org