

The Journal of Rheumatology

The Journal of Rheumatology

Volume 41, no. 1

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J Rheumatol 2014;41;150-152

<http://www.jrheum.org/content/41/1/150>

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

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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 unjust³. 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;

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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.

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Gender and sex; Religion; Education; Socioeconomic status; and Social capital⁴; “Plus” has been added to ensure consideration of other factors that may indicate potential disadvantage, such as age, disability, sexual orientation, and literacy⁵. In addition, marginalized groups with few social and economic resources and low education levels have the greatest difficulty understanding and accessing services⁶.

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 understanding¹⁶. 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 activities¹⁷. Patient education materials and informed consent forms are often written at a level that is too complex for many patients¹⁷. 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 patients¹⁷.

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

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 version²¹. 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.

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