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Research Letter

Patient's Engagement in the Identification of Critical Outcomes in Sarcopenia

The identification of relevant clinical outcomes of sarcopenia could be helpful for health professionals to improve sarcopenia management and for designing valid and useful clinical trials and outcome studies. Through observational studies, a flow of outcomes associated with sarcopenia has already been identified.^{1–4} However, to ensure that the outcomes measured reflect those that matter most to patients, incorporation of the patients' perspective in clinical research is also critical.^{5,6} Qualitative interviews with experts and patients are a wise way to generate original outcomes not usually observed in studies designed with large cohorts of patients. This study aims therefore to identify critical outcomes for sarcopenia using rigorous research methodologies and to select the 5 most important outcomes that will be used in a further discrete-choice experiment (DCE) to get further insight into patients' preferences at a large scale.

Methods

The identification and prioritization of outcomes was conducted following a 3-step procedure: (1) a literature review to generate an initial list of health outcomes of sarcopenia; (2) an expert panel consultation [a European Society for Clinical and Economic Aspects of Osteoporosis, Osteoarthritis and Musculoskeletal Diseases (ESCEO) working group in sarcopenia, composed with authors of this paper] to restructure initial outcomes and validate them; and (3) 3 focus groups with sarcopenic participants (recruited in Belgium and Spain) organized to include patients' opinions on outcome identification, ensure content validity of the list of outcomes, and prioritize the outcomes (from the most to the least important ones). The final selection of the 5 most important outcomes was made by our expert panel based on focus group results and expert's knowledges. Approval for this study was obtained from the Medical Ethics Committee of the University of Liège that coordinated the project and by the Ethics Committee of the Hospital Universitario Ramón y Cajal, where one of the focus groups was conducted.

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Results

In the first step, the initial list comprised 6 different outcomes: mortality, functional decline, hospitalization, falls, fractures, and length of hospitalization. With the second step, the list was extended to 9 outcomes including mortality, hospitalization, falls, fractures, institutionalization, quality of life, difficulties in self-care, difficulties in moving, and difficulties in domestic duties. In the third step, thanks to the dynamic aspect of the 3 focus groups organized with sarcopenic volunteers ($n = 19$, 6 men and 13 women, mean age 78 years), 20 additional outcomes were added to the list. A ranking of the most important outcomes for participants was then performed (see [Figure 1](#)) and, based on those results, the expert panel agreed on the 5 most important outcomes: “quality of life,” “mobility,” “difficulties in domestic activities,” “fatigue,” and “falls.”

Discussion

This study identified 5 important sarcopenia outcomes that have been used to design a DCE to further assess the preference of patients across Europe for sarcopenia outcomes, which is the next step of our work.⁷ DCEs have been increasingly used to elicit patients' preferences for health care and could be used as a survey design to identify the most important outcomes of sarcopenia from a patient's perspective.^{8–10} To generate a list of potential attributes for inclusion in DCE, it is highly recommended to broaden the data source spectrum. We consequently used 3 different sources of research: literature, experts, and sarcopenic patients. We truly believe that this rigorous, broad, and systematic methodology ensures content validity to the DCE. This is reinforced by the fact that all the 3 sources did not agree on all of the outcomes and that the final list contained outcomes identified in each source. A limitation of this study could be in regard to the focus groups. Indeed, only 3 focus groups involving 19 participants in only 2 different countries were conducted. It is therefore possible that additional focus groups could have generated other outcomes, but it is worth noting that the 3 focus groups organized already led to a saturation of data. Moreover, the final ranking is not exclusively based on the results of the focus groups but also on knowledge of the experts involved in our study and their clinical experience. All the experts have demonstrated high expertise in the field of sarcopenia and are considered reliable sources for outcomes generation.

Conclusions and Implications

Using patients' input, this study identified and prioritized relevant outcomes for sarcopenia. The 5 important outcomes, namely difficulties in moving, lower quality of life, falls, difficulties in domestic activities, and fatigue, were incorporated in a European DCE survey to further assess patients' preferences for sarcopenia

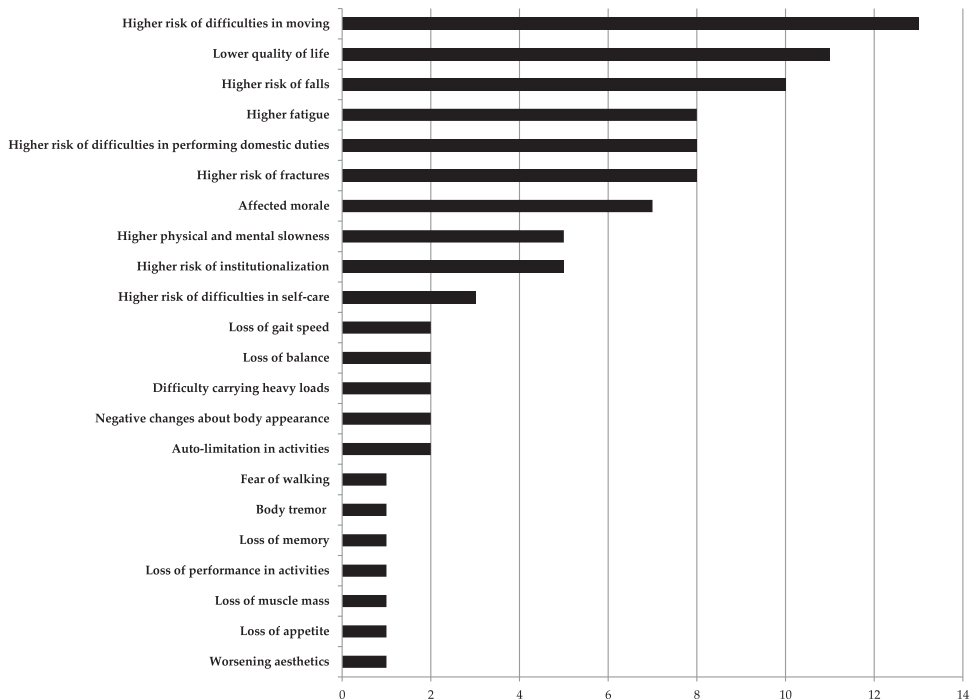


Fig. 1. Number of times an outcome was ranked in the top 5 of the most important outcomes during focus groups (maximum number = 19).

outcomes in a larger group and investigate patient trade-offs between them.

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