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Response Shift: The Measurable and Desired Outcome of Chronic Disease Self-management Programs That Violates Pre–Post Assessment

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Chronic disease self-management programs are designed not only to empower participants and increase their knowledge but also to provide participants with existential insights into their health and ability to self-manage. The outcome of a self-management program is traditionally evaluated by comparing pre-intervention and post-intervention questionnaires, a methodology that assumes that participants answer questions from the same perspective before and after the program. Systematic reviews of the outcomes from self-management interventions that use self-appraisal outcomes identify small to no effects. This study of community-based self-management programs in Australia aimed to determine if changes in internal values or perspectives (termed a response shift) occurred in participants and if response shift is measurable with a paper-based questionnaire.

The HEI-Q-Perspective Questionnaire, a retrospective nine-item post-test questionnaire, was developed to measure potential benefits of self-management programs. Cognitive interviews with respondents elicited spontaneous answers about the reasons for their paper-based answers across the nine items. The sensitivity, specificity, and overall accuracy of the questionnaire were calculated using the interview as the gold standard. A response shift can be negative (i.e., after the course, participants report they now realize that before the course, they were worse than they thought they were), positive (i.e., participants now realize they were better before the course than they thought they were), or neutral (no change).

In-depth interviews (n = 39) and mailed questionnaires (n = 132) reflected that a “true” response shift occurred in about half of the questionnaire items. Of these, 33% had a negative response shift, 18% had a positive response shift, and approximately 32% had no response shift. The presence or absence of response shift could not be determined in approximately 17% of cases. Substantial concordance between interview and questionnaire were observed (average overall accuracy 0.79), indicating the questionnaire effectively identified response shift. A positive or negative response shift was found to have profound effects on patient-reported outcomes — even large positive or large negative program effects revealed in an interview could be concealed in an individual’s pre–post score. This clearly demonstrates that response shift can violate classic outcome assessment of self-management programs.

Response shift occurred in about half of the participants. This result suggests that classic outcome assessment (pre-test vs post-test) in many individuals is flawed. Response shift is a desirable outcome of courses but has not been formally measured. The strong concordance between the questionnaire and cognitive interviews indicates the HEI-
Q-Perspective can detect response shift. This new questionnaire will assist researchers and program evaluators to better estimate the impact of self-management programs and to understand the role of response shift in this and other settings.

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