Patient Perspectives brought to the Fore for Diabetes Care: Descriptions as well as Development and Testing of the Diabetes Questionnaire

Akademisk avhandling

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SAHLGRENSKA AKADEMIN
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Abstract

Aim: The overall aims were to describe perspectives of living with diabetes, to develop a patient-reported outcome and experience measure for the Swedish National Diabetes Register, and to initiate the evaluation of evidence of measurement quality for that measure. A further aim was to describe health-related quality of life and to assess its associations with glycaemic control.

Methods and results: In study I, aspects important to adults with diabetes embracing experiences of daily life and support from diabetes care were identified through 29 semi-structured qualitative interviews. In study II, those aspects were used to develop the Diabetes Questionnaire. Expert reviews, six cognitive interviews, and a regional survey of 1,599 adults with diabetes yielded supporting evidence for content and face validity, test-retest reliability, and answerability. For studies III-IV, the Diabetes Questionnaire and the SF-36v2 were presented to 4,976 adults with diabetes in a nationwide cross-sectional survey. In study III, adjusted regression analyses showed that adults with high-risk glycaemic control have lower health-related quality of life than those with well-controlled glycaemic control. In study IV, correlation, machine learning and adjusted regression analyses demonstrated support for construct validity. The Diabetes Questionnaire captures some SF-36v2 dimensions while adding information not targeted by clinical variables or the SF-36v2 and it is sensitive to differences between groups of glycaemic control.

Conclusion: The Diabetes Questionnaire has the potential to support clinical meetings and assessments and hence help to bring patients’ perspectives to the fore for diabetes care.

Keywords: Diabetes Mellitus; Patient-Reported Outcome Measures; Qualitative Research; Surveys and Questionnaires; Cross-Sectional Studies