Review

# Diabetes-related emotional distress instruments: A systematic review of measurement properties

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A R T I C L E   I N F O

A B S T R A C T

Objectives: The objectives of this study were to identify all available diabetes-related emotional distress instruments and evaluate the evidence regarding their measurement properties to help in the selection of the most appropriate instrument for use in practice and research.

Design: A systematic literature search was performed.

Data sources: PubMed, Embase, CINAHL, and PsycINFO were searched systematically for articles on diabetes-related emotional distress instruments.

Review methods: The Consensus-based Standards for the Selection of Health Measurement Instruments checklist was used to evaluate the methodological quality of the identified studies. The quality of results with respect to the measurement properties of each study was evaluated using Terwee's quality criteria. An ancillary meta-analysis was performed.

Results: Of the 2345 articles yielded by the search, 19 full-text articles evaluating 6 diabetes-related emotional distress instruments were included in this study. No instrument demonstrated evidence for all measurement properties. The Problem Areas in Diabetes scale (PAID) was the most frequently studied and the best validated of the instruments. Pooled summary estimates of the correlation coefficient between the PAID and serum glycated hemoglobin revealed a positive but weak correlation.

Conclusions: No diabetes-related emotional distress instrument demonstrated evidence for all measurement properties. No instrument was better than another, although the PAID was the best validated and is thus recommended for use. Further psychometric studies of the diabetes-related emotional distress instruments with rigorous methodologies are required.

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## What is already known about the topic?

- Diabetes-related emotional distress is associated with poor self-care activities, poor glycemic control, and low health-related quality of life. It is crucial that health professionals assess diabetes-related emotional distress in clinical practice.
- Emotional distress is usually measured using a patient-reported outcome instrument.

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- There has been no previous systematic review of the published literature on diabetes-related emotional distress instruments, which would help clinicians and researchers to select the most suitable instrument for use in both practice and research.

**What this paper adds**

- Six instruments for measuring diabetes-related emotional distress were identified through a systematic review.
- This systematic review provides levels of evidence for the measurement properties of those instruments. None of the instruments appeared to be superior to the others; however, the strongest evidence in current was found for the Problem Areas in Diabetes scale (PAID).
- A meta-analysis of the pooled correlations between the PAID and serum glycated hemoglobin revealed a positive but weak correlation.

## 1. Introduction

Diabetes has become a global health problem. About 387 million people have diabetes worldwide, and the number is estimated to rise to 593 million by 2035 (International Diabetes Federation, 2014). Many of those with diabetes must perform complex self-management (diet, exercise, foot care, and medication adherence) to maintain adequate metabolic control and to prevent or treat the potential associated long-term complications (American Diabetes Association, 2014). Patients with diabetes experience emotional burdens associated with their disease such as concerns about food, guilt regarding uncontrolled blood glucose, and worry about developing complications (Power, 2009). These negative emotional responses to the demands of diabetes and its treatment are referred to as diabetes-related emotional distress (Polonsky et al., 1995), and they are considered to be distinct from depression and a far broader affective experience than major depressive disorder (Fisher et al., 2008b; Polonsky et al., 1995); they reflect the worries, concerns, and fears of individuals struggling with this demanding disease (Fisher et al., 2010).

The diabetes literature contains far more information about depression, depressive symptoms, and anxiety than about diabetes-related emotional distress. However, this distress has been reported to occur in 18–45% of diabetes patients (American Diabetes Association, 2014; Fisher et al., 2015; Pouwer et al., 2013), and it is associated with poor self-care activities, low health-related quality of life (Aikens, 2012; Fisher et al., 2013; Graue et al., 2012), and poor glycemic control, but not with clinical depression or anxiety (Fisher et al., 2008b, 2010). It is therefore crucial that health-care providers assess diabetes-related emotional distress in clinical practice. The American Diabetes Association (2014) recommends routine screening of psychological problems among patients with diabetes, such as diabetes-related emotional distress.

Certain issues need to be considered when measuring diabetes-related emotional distress in practice or research. This distress is experienced within the context of diabetes and its management, and so it is not appropriate to use instruments measuring general (i.e., nonspecific) emotional responses to an external demand (Fisher et al., 2014). Furthermore, distress is a subjective concept (Ridner, 2004), which makes a patient-reported outcome (PRO) instrument more appropriate than a proxy instrument. However, many clinical professionals lack knowledge about PRO instruments (Beverly et al., 2012), including their reliability, validity, and responsiveness (see the Supplementary content A). Especially, a short-PRO instrument would be preferred in busy practices, whereas more detailed measures of the diabetes-related emotional distress would be helpful for research purposes. However, both short and long instruments need to demonstrate satisfactory validity, reliability, and responsiveness (United States Food and Drug Administration, 2009). A systematic review performed with these considerations in mind will help clinicians and researchers to select the most suitable instrument for use in practice and research.

The aims of this systematic review were to identify currently available instruments that can be used for measuring diabetes-related emotional distress and to evaluate the evidence for their measurement properties. This systematic review adhered to the PRISMA statement (PRISMA, 2009) for its reporting.

## 2. Methods

### 2.1. Literature search

The following electronic databases were searched from their inception up to July 31, 2014 for articles on instruments for measuring diabetes-related emotional distress: PubMed, Embase, CINAHL, and PsycINFO. In accordance with the guidelines of de Vet et al. (2011), a searching strategy was determined by establishing the search terms for the following aspects: the construct of interest ("emotional distress" and its synonyms), the target population (e.g., "diabetes," "mellitus," and "diabetic"), the measurement instrument (e.g., "questionnaire," "instrument," and "scale"), and the measurement properties (e.g., "content validity," "internal consistency reliability," and "responsiveness"). The search filter used for the construct of interest is presented in Supplementary content B. The Diabetes Filter of Li and Lu (2013), the Patient-Reported Outcome Measures (PROMs) filter developed by the PROM group (http://phi.uhce.ox.ac.uk), and the Measurement Properties Filter and Exclusion Filter developed by Terwee et al. (2009) were used for the target population, measurement instrument, and measurement properties, respectively. The reference lists of the identified studies were searched manually to identify any additional relevant studies.

### 2.2. Eligibility criteria

The following study inclusion criteria were applied: (1) assessment of diabetes-related emotional distress, (2) involved patients with type 1 or type 2 diabetes, (3) use of a PRO instrument, (4) development of a measurement instrument or evaluation of the properties of an instrument, and (5) full-text original articles published in English in a peer-reviewed journal. The exclusion criteria were (1)