Journal of Diabetes and Its Complications 32 (2018) 384–392

Contents lists available at ScienceDirect

Journal of Diabetes and Its Complications

journal homepage: WWW.JDCJOURNAL.COM

Measurement of psychological adjustment to diabetes with the diabetes acceptance scale

Andreas Schmitt [a,b,c,*], André Reimer [a,b,c], Bernhard Kulzer [a,b,c,d], Andrea Icks [c,e,f], Rainer Paust [g], Klaus-Martin Roelver [h], Matthias Kaltheuner [i], Dominic Ehrmann [a,b], Michael Krichbaum [a,b], Thomas Haak [a,b], Norbert Hermanns [a,b,c,d]

[a] Research Institute of the Diabetes Academy Mergentheim (FIDAM), Johann-Hammer-Str. 24, 97980 Bad Mergentheim, Germany
[b] Diabetes Center Mergentheim (DZM), Theodor-Klotzbuecher-Str. 12, 97980 Bad Mergentheim, Germany
[c] German Center for Diabetes Research (DZD), Ingolstaedter Landstr. 1, 85764 Muenchen, Neuherberg, Germany
[d] Otto-Friedrich-University of Bamberg, Department for Psychology, Markusplatz 3, 96047 Bamberg, Germany
[e] German Diabetes Center (DDZ), Institute for Health Services Research and Health Economics, Auf'm Hennekamp 65, 40225 Duesseldorf, Germany
[f] Institute for Health Services Research and Health Economics, Faculty of Medicine, Heinrich-Heine-University, Moorenstr. 5, 40225 Duesseldorf, Germany
[g] Institute for Psychosocial Medicine, Elisabeth-Hospital, Klara-Kopp-Weg 1, 45138 Essen, Germany
[h] Diabetes Center Quakenbrueck, Christian Hospital Quakenbrueck, Danziger Str. 2, 49610 Quakenbrueck, Germany
[i] Specialised Diabetes Practice Leverkusen, Kalkstr. 117, 51377 Leverkusen, Germany

ARTICLE INFO

Article history:
Received 9 October 2017
Received in revised form 21 December 2017
Accepted 12 January 2018
Available online 31 January 2018

Keywords:
Diabetes integration
Illness acceptance
Psychological adjustment
Self and identity
Diabetes-related distress

ABSTRACT

Aims: To develop a psychometric measure of diabetes acceptance.
Methods: An item pool was developed and pilot-tested using a sample of 220 people with diabetes; item selection resulted in the 20-item 'Diabetes Acceptance Scale (DAS)'. 606 people with diabetes were then cross-sectionally assessed with the DAS to evaluate its reliability, validity and clinical utility; concurrent measurements included diabetes-related coping (FQCI), diabetes distress (PAID-5), depressive symptoms (PHQ-9), quality of life (EQ-5D), self-management (DSMQ), glycaemic control (HbA_{1c}) and complications.
Results: Internal reliability was high (Cronbach's $\alpha = 0.96$). Factorial and criterion-related results supported validity. Higher diabetes acceptance scores correlated with more functional coping styles, lower distress and depression levels, higher treatment adherence, better glycaemic control and better quality of life (all $P < .001$). Persons with low diabetes acceptance (22% of the sample) were four times more likely to have HbA_{1c} values over 9.0% (75 mmol/mol), two times more likely to be diagnosed with long-term complications and each over two times more likely to have had episodes of severe hypoglycaemia and ketoacidosis in the past year; the prevalence of major depression in this group was fivefold increased (all $P < .05$).
Conclusions: The DAS is a reliable and valid tool to measure diabetes acceptance. It may help identify patients with significant problems of accepting diabetes, a putative high-risk group in need of tailored care and support.

1. Introduction

Psychological adjustment to diabetes can be characterised as a developmental process towards acceptance which involves actions of toleration, approval, integration and identification. To reach an attitude of acceptance regarding diabetes, the concerned person may need to develop tolerance and approval towards the negatively valued illness, integrate its impacts on one's life and identify with having the condition [1–4]. While appropriate adjustment to diabetes (i.e. development of functional acceptance) usually results in maintained or recovered self-integrity (i.e. feeling of personal adequacy), low diabetes acceptance can be characterised by dysfunctional attitudes and behaviours such as antagonism, avoidance and repression regarding the illness, probably representing self-protective strategies to prevent devaluation of oneself [5,6].

Dlugosch et al. [3] defined diabetes acceptance as the 'extent to which a person accepts the condition as a part of one's life and integrates its psychosocial impact and emotional burden' (translated from German). This understanding is closely related to Welch et al.'s concept of diabetes integration, regarded as the level of integration of the condition into one's self-concept and considered to determine whether the illness 'will become a psychological problem [thought to be likely with insufficient integration] and what a person's behavioural response will be' [4,7].

* Corresponding author at: Diabetes Center Mergentheim, Theodor-Klotzbuecher-Str. 12, 97980 Bad Mergentheim, Germany.
E-mail address: schmitt@diabetes-zentrum.de (A. Schmitt).

https://doi.org/10.1016/j.jdiacomp.2018.01.005
1056-8727/

A process of psychological adaptation ultimately leading to acceptance had also been proposed for people facing terminal illness by Kübler-Ross in the late 1960s, [8] and this model was later used to explain the process of psychological adjustment to diabetes [9,10]. However, as research could not support the assumption of a universal stage sequence towards acceptance (including phases of denial, anger, bargaining and depression), [11] application of this phase model to diabetes appears questionable.

Diabetes acceptance (or illness acceptance in general) must be distinguished from the multi-dimensional concept of illness perception which comprises personal ideas about a specific illness (including its identity, i.e. name and characteristics, its causes, consequences, timeline, controllability and illness-related emotional responses, e.g. anxious feelings) but does not include illness acceptance or integration [12,13]. However, it is likely that specific ideas such as perceived causes, consequences, course and controllability of an illness (diabetes) may influence the adjustment process and thus determine acceptance levels.

Diabetes acceptance may be related to the concept of resilience (the ability to cope with critical events or stressors using personal – e.g. cognitive abilities, self-efficacy, spirituality – and environmental resilience factors – e.g. supportive family relationships, positive work environment) in that a person's ability to 'accept the unchangeable' is considered as one relevant resilience factor [14,15]. However, it has not been assessed how this trait-like acceptance concept relates to individual process of adjusting to diabetes.

As suggested above, low diabetes acceptance can be characterised by antagonism, avoidance, denial or neglect of the condition. It is thus reasonable to assume that suboptimal diabetes acceptance may interfere with effective diabetes self-management and accordingly lead to worse metabolic control [16,17]. In fact, low acceptance of diabetes has been associated with reduced self-management and higher HbA_{1c} in both adults [17–19] and adolescents with diabetes [20,21]. Moreover, poor adjustment to diabetes has been proposed as risk factor for emotional distress, [1,3,4] thus probably impacting on the affected persons' quality of life and potentially contributing to the increased risk of comorbid depression in diabetes [22]. Accordingly, several studies found evidence of lower quality of life [23,24] and elevated levels of depression and distress [17,25,26] in persons reporting low diabetes acceptance.

Despite the high clinical relevance of this issue, research in the field is scarce and the current understanding limited. Data enabling an estimation of the size of the problem (i.e. rates of persons with dysfunctional adjustment strategies such as non-acceptance) are lacking. Moreover, prospective data are missing; thus, predictive associations with long-term outcomes cannot be assessed.

The lack of research is probably due to the limited number of relevant measurement tools and the lack of satisfactory ones. Some studies made use of classical generic measures regarding illness acceptance such as the Acceptance of Illness Scale (AIS) or the Acceptance of Disability Scale (ADS) originating from the 1970s and 1980s [18,19,24]. Although this approach appears valid, utilisation of a diabetes-specific acceptance measure including items to address the specific problems of accepting and integrating this particular condition with its specific characteristics might be preferred.

As a diabetes-specific instrument regarding non-acceptance of diabetes Gregg et al. established the Acceptance and Action Diabetes Questionnaire (AADQ) [25]. In a previous cross-sectional study, we used this tool to assess a sample of 320 people with type 1 or type 2 diabetes and found that the acceptance score explained more variation in essential self-management activities and HbA_{1c} levels than concurrent measures of depression and diabetes distress [17]. However, we also found evidence of psychometric limitations of the scale (i.e. suboptimal properties and fitting of five of the eleven items). Moreover, since the AADQ was developed by simply adapting items from a generic experiential avoidance measure towards diabetes, [25] a more systematic development approach (i.e. theory-driven item design and empirical selection) might yield a more effective instrument.

We identified two other diabetes-specific measures addressing diabetes acceptance, the 'Illness Identity Questionnaire' [20] and the 'Ideas About Diabetes–Revised' [27]. However, the former was designed to measure illness identity in people with diabetes during adolescence and transition to adulthood and assesses several aspects besides acceptance such as enrichment, engulfment and rejection. The latter was intended to measure diabetes acceptance specifically, but appears to cover diabetes-related problems and distress rather than acceptance according to the item contents (as provided by McDonald et al. [28]); moreover, the original scale cannot be easily accessed.

In summary, although several generic and specific measurement instruments enabling assessment of diabetes acceptance have been introduced, a satisfactory diabetes-specific tool is still lacking. Therefore, we developed a new measurement tool, the 'Diabetes Acceptance Scale (DAS)', whose development, psychometric evaluation and clinical utility is to be described here. To validate the new scale, we assessed a set of psychological variables and clinical criteria which were expected to be related to diabetes acceptance. Based on the previous findings, [16–26] we hypothesised that higher diabetes acceptance would be associated with more adherent self-management and thus better glycaemic control; lower levels of emotional distress and depression; higher well-being and quality of life; and more functional coping regarding diabetes. Furthermore, the AADQ was used as a convergent measure of diabetes acceptance; thus, a high correlation with the DAS was expected. If higher diabetes acceptance is associated with better self-management and glycaemic control, it is reasonable to expect higher risks of long-term and acute metabolic complications of diabetes in those with low acceptance; accordingly, associations between these variables were also analysed. Finally, if diabetes acceptance is the result of a process of adjusting, it might be expected that persons with a shorter diabetes duration report lower acceptance.

2. Subjects, materials and methods

2.1. Study design

The DAS was developed at the Research Institute of the Diabetes Academy Mergentheim, Germany. Its evaluation is based on cross-sectional data from four specialised diabetes centres (Diabetes Center Mergentheim (DCM); Diabetes Center Quakenbrueck; Diabetes Center at the Elisabeth Hospital Essen; German Diabetes Center Duesseldorf), collected between 09/2015 and 08/2016. Inclusion criteria were type 1 or 2 diabetes, adult age (18 years and above) and written informed consent. Exclusion criteria were cognitive impairment and guardianship; we did not specify additional exclusion criteria such as established diagnoses of mental disorders to reduce risk of a non-representative sample. Eligible persons were approached and informed about the study. Persons who consented were assessed using a set of questionnaires including the DAS; HbA_{1c} was analysed, and demographic data were collected (self-report).

While study participants were generally enrolled on opportunity, 59 persons (9.6% of the sample) were collected for problems regarding diabetes acceptance specifically. These persons attended a special group treatment for people with significant problems regarding diabetes acceptance which is offered at the DCM. Participants are referred to this treatment by their diabetes specialists, i.e. the clinical relevance of a person's problems is affirmed by the treating physician. When collecting our study sample, we approached several acceptance groups to ask the attending persons whether they were willing to participate. We aimed to enrol these persons in order to yield a higher representation of clinical cases in our study. Moreover, we used this group to define a cut-off criterion for a low diabetes acceptance on the DAS. Willingness to participate was high, as all approached persons consented.