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Assessment of information needs in diabetes: Development and evaluation of a questionnaire

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ABSTRACT

Aim: To develop a questionnaire suitable for assessing the information needs of individuals with diabetes mellitus types 1 and 2 in diverse healthcare settings (e.g. primary care or long-term care) and at different time points during the course of the disease.

Methods: The initial questionnaire was developed on the basis of literature search and analysis, reviewed by clinical experts, and evaluated in two focus groups. The revised version was pilot-tested on 39 individuals with diabetes type 2, type 1 and gestational diabetes.

Results: The final questionnaire reveals the most important information needs in diabetes. A choice task, a rating task and open-ended questions are combined. First, participants have to choose three topics that interest them out of a list with 12 general topics and specify in their own words their particular information needs for the chosen topics. They are then asked how informed they feel with regard to all topics (4-point Likert-scale), and whether information is currently desired (yes/no). The questionnaire ends with an open-ended question asking for additional topics of interest.

Conclusions: Careful selection of topics and inclusion of open-ended questions seem to be essential prerequisites for the unbiased assessment of information needs. The questionnaire can be applied in surveys in order to examine patterns of information needs across various groups and changes during the course of the disease. Such knowledge would contribute to more patient-guided information, counselling and support.

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1. Introduction

Diabetes mellitus is a largely self-managed chronic condition which demands day-to-day decisions related to the disease to be made [1]. Treatment usually involves complex requirements, such as individual behaviour changes, regular blood glucose and blood pressure monitoring, medication intake or even polypharmacy, all of which have to be integrated into work and leisure activities [2]. Studies indicate that self-management is significantly influenced by health- and disease-related information people acquire. Moreover, information seems to improve patients' active involvement in the disease-related decision-making process [3].

It is therefore not surprising that diabetes mellitus was identified as the chronic condition with the highest desire for information in comparison to cancer and gastrointestinal or respiratory diseases [4]. A qualitative study with 40 people newly diagnosed with type 2 diabetes in Scotland revealed a high desire for information and showed the importance of the need-driven provision of information after being diagnosed [5]. In-depth interviews were performed with people with diabetes that addressed the emotional reactions of the people concerned and their perceptions of the information provided during the diagnostic process. People required more information about diabetes management than they actually received, particularly regarding life-style changes and diet [5]. In later periods of the disease the focus may be different, and it is likely that information needs change when late complications develop. When a diverse sample of people with type 2 diabetes in Germany were asked for their online health information needs, they preferred information on secondary diseases, blood glucose control and basic disease-related information [6]. Adolescents with type 1 diabetes seem to have very specific information needs regarding their disease and may prioritise certain issues (e.g. alcohol consumption) [7].

Thus, there is some evidence that health related information needs may depend on socio-demographic characteristics (e.g. age, gender, education and ethnicity) [8–12]. Information needs of people with diabetes do not necessarily correspond with topics considered important by healthcare professionals [13–15]. For example, physicians expected secondary diseases to be the most important issue immediately after being diagnosed, while people with diabetes preferred to receive information concerning current treatment and the impact of the disease on their lifestyle [13].

Information needs may depend on individual goals, or may be influenced by perceived stress or self-efficacy. This is expressed in the definition of information needs provided by Ormandy (2010, page 99) who defines patients' information needs as "a recognition that your knowledge is inadequate to satisfy a goal that you have, within the context/situation that you find yourself at a specific point in the time" [10].

Research has demonstrated the importance of tailoring diabetes education to each participant's needs [16]. However, factors that may influence information needs are poorly understood. For example, it remains unclear whether the need for information is predominately driven by a lack of knowledge or significantly influenced by emotional factors, such as anxiety. Furthermore, the inter-relation of information needs

to other concepts is largely unclear, such as the inclination to participate in disease-related decision-making or to adopt specific coping styles.

In summary, deeper insight into the information needs of people with diabetes is required in order to better match information to individual needs. To the best of our knowledge, information needs of people with diabetes have not yet been assessed in large populations in a structured and comparable way. No questionnaire appropriate for use in large populations to assess information needs from the perspective of people with diabetes was identified by a literature search. Therefore, our aim was to develop and evaluate a questionnaire for collecting data on information needs in diabetes that is applicable for people with different types of diabetes throughout the whole course of the disease.

2. Methods

2.1. Development of an initial version of the information needs in diabetes (IND) questionnaire

The results of a systematic literature review on health-related information needs in Germany [17] were used to gain an overview of health-related information needs and assessment methods (search strategy, inclusion and exclusion criteria and the list of identified studies can be obtained from the first author). In addition, a search for reviews of studies investigating information needs in patients with diabetes or other chronic diseases was conducted in MEDLINE. We considered research related to other chronic diseases because overarching types of information needs and particularly the methods used to assess them are not necessarily disease-specific. No reviews of information needs in individuals with diabetes were identified. Two systematic reviews of information needs in patients with cancer were identified, both of which covered a broad range of studies and comprehensively discussed assessment methods [18,19]. These two reviews and the systematic review on health-related information needs in Germany were used to determine areas of information needs that could provide a basic structure for the questionnaire. Four broad areas of information needs were identified: information needs regarding (1) the disease in general, (2) treatment options, (3) health promotion and prevention and (4) support options. Subsequently, for each area, subtopics that may be relevant in relation to diabetes were developed based on the experience of the research team in the field of diabetes, resulting in a list of 21 items.

According to a systematic literature review on health-related information needs in Germany [17], information needs were assessed mostly using closed questions with Likert-scale ratings to show the level of importance of a particular topic or the desire for information. However, such ratings may lead to meaningless results because participants often tend to rate every item as important [20,21]. Therefore, methods to prioritise information needs seem to be more appropriate. One possible solution is adding a *choice task*, where participants have to choose a limited number of relevant topics out of a predefined list. The decision was made to consider this insight when delineating the first version of the questionnaire by

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