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Time cost of diabetes: Development of a questionnaire to assess time spent on diabetes self-care

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ABSTRACT

Background: Methods to measure patient time spent on health-related activities are currently not well elaborated or standardized.
Aim: The purpose of this study was to develop a recall questionnaire measuring patient time devoted to diabetes self-care and to examine its feasibility and validity under field conditions.
Methods: The initial questionnaire was developed on the basis of instruments frequently used to assess self-care behavior in patients with diabetes, evaluated in two focus groups with patients with type 2 diabetes ($N = 15$) and tested in a random sample of patients with type 2 diabetes ($N = 178$). To assess the validity of the questionnaire, four hypotheses about expected differences in self-care time across various patient sub-groups were tested.
Results: The final questionnaire includes thirteen items estimating time spent on regular diabetes-related activities undertaken in the previous seven days. 78% of respondents completed the questionnaire without item non-response or other evident problems. As hypothesized, respondents receiving insulin treatment, those with poor self-rated health and those with diabetes-related emotional distress (PAID-5 score ≥ 8) reported spending more time on diabetes self-care than the rest of the sample. Contrary to our assumption, no differences in time spent on diabetes self-care between employed and retired individuals were detected by the questionnaire.
Conclusion: The recall questionnaire measuring patient time devoted to a broad range of regular diabetes self-care activities was developed and its feasibility was proved under field conditions. Ideally, the questionnaire should be further validated within a variety of populations. Exploration of the convergent validity between the recall method and prospective diary may be also useful.

1. Introduction

Diabetes management relies largely on activities carried out by patients, such as self-testing of glucose, insulin injections, foot care, dietary changes and exercise. Besides energy and commitment, time is required to perform these activities. Estimates of the time needed for self-care tasks recommended by the American Diabetes Association for a typical diabetic patient in a stable phase of care range from 2 to 3 h per day (Russell, Suh, & Safford, 2005).

Time invested in the self-management of diabetes cannot be spent on paid or unpaid work and leisure activities and may thus affect quality of life or willingness to engage in and adhere to self-care behavior.

The US Panel on Cost-Effectiveness in Health and Medicine used the term ‘time costs’ to refer to the opportunity cost of patients’ time spent in seeking care and treatment and recommended that patient time costs should be included as a cost in cost-effectiveness analysis (Gold, Siegel, Russell, & Weinstein, 1996). The Panel also recommended that changes in time spent on paid or unpaid work and leisure because of ill-health should be included in the denominator of the cost-effectiveness ratio because they are implicitly considered by respondents of health state valuations. This approach to separating time aspects into costs and effects has been the subject of controversial debate (for an overview of the debate see Brouwer & Rutten, 2003). As Brouwer and Rutten (2003, page 631) wrote:

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“Separating time aspects into costs and effects is one thing, ensuring that the separation proposed indeed yields valid and accurate results is another.” Theoretical discourse and related empirical research focused mainly on the measurement and valuation of time changes related to paid work (productivity costs), whereas issues related to the measurement of lost home production and lost leisure time were not so prominent (Brouwer, Grootenboer, & Sendi, 2009; Sendi & Brouwer, 2005). Even less attention has been paid to the measurement of direct patient time costs, i.e. time investments necessary to (self-) manage the disease. This is surprising, because estimates of time spent by patients on specific health-related activities are important also beyond economic evaluation. They are needed to improve our understanding of the time burden associated with ‘illness work’ (Jowsey, Yen, & Mathews, 2012) and can provide useful information to health care practitioners, patients, and caregivers to support informed decision making (Kamble, Weinfurt, Schulman, & Reed, 2013). Time-use surveys from a number of countries including Australia, US, Canada and many European countries include questions about health-related activities. However, relevant time use estimates are generally not reported in relation to chronic illness, nor are various types of health-related activities distinguished (Jowsey et al., 2012).

Diabetes self-management is a typical example of patients' time use, which is not yet systematically considered in estimates of the burden of disease, in costing studies and in economic evaluations of interventions (Kamble et al., 2013; Russell, 2009). We are aware of only few studies which reported patient time spent on diabetes self-care — whether alone or as part of cost-effectiveness analyses (Ettner, Cadwell, & Russell, 2009; Kamble et al., 2013; Safford, Russell, Suh, Roman, & Pogach, 2005; Yen, McRae, Jowsey, & Bagheri, 2013). It is difficult to compare results of these studies because different sets of self-care activities were included and methods to measure time spent on them also varied substantially. Safford et al. (2005) and Ettner et al. (2009) applied a recall method estimating time spent on diabetes self-care on a typical day. In a telephone interview, participants were asked to estimate the extra minutes they spent on a typical day caring for their feet, exercising, and shopping for/preparing food. Yen, McRae, Jowsey, & Bagheri (2013) also used a recall method to collect data on daily personal care activities. They applied a generic recall questionnaire measuring *total* time spent on self-care by people with chronic diseases, including diabetes, rather than time required specifically to address diabetes self-care. Due to co-morbidity it was difficult to isolate patterns associated with specific conditions (Yen, McRae, Jowsey, & Bagheri, 2013; Yen, McRae, Jowsey, Gillespie, et al., 2013). In a study by Kamble et al. (2013), data were collected in time diaries alongside a prospective, randomized, multicenter clinical trial. As a part of diary instructions, patients were provided with examples of diabetes-related activities that could be considered. However, only the total weekly time spent on diabetes related care – not the separate time estimates for various activities – was reported.

Two major time measurement methods are the diary and the recall method. For time use on a population level, the 24-h time diary method is considered to be the gold standard for data collection (Juster & Stafford, 1991). The 24-h time diaries ask respondents in telephone surveys or personal interview surveys for a detailed chronology of all their activities within the previous 24 h, with responses coded according to a standard list of activities (see, for example, American Time Use Survey available at: http://www.bls.gov/tus/). Yet, there is no consensus on how to measure time use over extended periods. A diary kept over a longer period of time, for example for one week or month, and filled out every day during this period is one possible option. Nevertheless, it is uncertain as to whether patients will fill it in concurrently or immediately prior to a return date. Moreover, the prospective diary requires a lot of time and effort from respondents and may lead to selective non-response and missing values, especially with increasing data collection periods. A retrospective questionnaire asking how much time respondents spent on a list of activities (e.g. on self-care) over some past period of time (e.g. during the previous week) is a less demanding method for both patients and researchers. A major concern with the recall method is its validity because of recall bias. For example, there is evidence that respondents appear to recollect days when the activity asked about was especially prominent, and treat that as an average day (Juster & Stafford, 1991). Both a recall method and diaries have been used to measure patient time use. However, validity and reliability of the chosen data collection methods are usually not reported and there is a lack of consistency in what is measured across studies (Jowsey et al., 2012). In summary, methods to measure patient time spent in health-related activities are currently not well elaborated or standardized. Hence, there is a need for further methodical work in this field in order to improve empirical research on time investments in health.

Taking into account the scarcity of research on the validity of methods measuring patient time use in general and time spent on diabetes self-care in particular, a questionnaire measuring patient time spent on diabetes self-care in the previous seven days was developed and extensively tested under field conditions. In this paper the process of questionnaire development and validation is described, a number of implications regarding challenges of retrospective method of patient time measurement are discussed and some areas for further research proposed.

2. Methods

2.1. Development of the initial questionnaire

Initial items for the purposes of time measurement were generated on the basis of established instruments frequently used to assess self-care behavior in patients with diabetes (Toobert, Hampson, & Glasgow, 2000; Van Der Ven, Weinger, & Yi, 2003; Weinger, Butler, Welch, & La Greca, 2005). The items were then reviewed by clinical experts from two diabetes research institutes: the German Diabetes Centre and the research institute of the Diabetes Academy Bad Mergentheim. The initial list of diabetes-related self-care activities included the following items: blood glucose monitoring; documentation (e.g. of blood glucose values); intake of antihyperglycemic medication; insulin injection; extra foot care; buying food; cooking; physical activity or exercise; shopping for medication or other health items; decision-making regarding therapy or nutrition; searching for information about symptoms, therapies, nutrition, etc. Two further items (blood pressure control and extra skin care) were added after the clinical experts' review of the instrument. Respondents were asked 1) whether they spent time on particular self-care activities *because of diabetes* and 2) how much time in hours and/or minutes they spent on these activities. Since not all self-care activities are performed on a routine daily basis, the question referred to the previous seven days.

2.2. Evaluation of the initial questionnaire in focus groups

The initial questionnaire was first tested in focus groups with individuals with diabetes type 2 in order to prove its content validity (the relevance and completeness of the chosen items) and to identify possible comprehension problems and processing difficulties. Two focus groups were conducted in spring 2013: one with 8 (2 male) and one with 7 (3 male) participants. Participants were recruited from members of a self-help group affiliated to the research institution. Each focus group was conducted by two researchers: one moderator and one observer, i.e. four researchers in total.

A questioning guide was developed to standardize both focus group discussions. The participants first completed the questionnaire without further explanations and gave their general comments on it immediately thereafter. Then specific aspects were discussed:

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