



Original Research

Hypoglycemia-related information seeking among informal caregivers of type 2 diabetes patients: Implications for health education

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ABSTRACT

Aims: To examine information seeking and knowledge about hypoglycemia among partners and family of type 2 diabetes patients and to identify associations between information seeking, knowledge and demographic, and disease-related characteristics.

Methods: Caregivers of adults with type 2 diabetes (N = 488) completed surveys assessing information seeking, knowledge of hypoglycemia symptoms and treatment, perceived competence, demographic information, and diabetes-related characteristics. Hierarchical and logistic regressions were used for data analysis.

Results: Nearly two thirds of family members and friends actively sought information about hypoglycemia, while health professionals and print media were reported as the main sources. Many respondents (74.5%) were able to identify at least one correct warning sign. But 32% could not state any correct treatment measures. Health professionals were the main and most helpful source of their knowledge. Education, past experience with hypoglycemia, and comprehension of information were associated with knowledge about treatment. Caregivers' perceived competence about hypoglycemia correlated with medical education, information-seeking, and comprehension of information.

Conclusions: Our results indicate the importance of the hypoglycemia-related information seeking of caregivers in managing incidents of hypoglycemia. These findings suggest the need to consider caregivers' health knowledge when developing health education programs in diabetes care. More attention must be focused on providing interventions that motivate information seeking and improve the comprehension of information. Interventions should inform caregivers about hypoglycemia to enhance their knowledge.

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Introduction

More than 350 million people worldwide have diabetes [1], and prevalence is predicted to increase tremendously over the next two decades [2]. This means that symptoms associated with diabetes, like hypoglycemia, will also increase. *Hypoglycemia* (low blood glucose) is a very common short term complication of diabetes therapy [3], and is associated both with serious health risks (e.g., coma) and high monetary costs [4]. For the average patient with type 2 diabetes, the national cost of managing hypoglycemia that becomes severe enough to require professional medical assis-

tance was estimated at values ranging from €533 (Germany) to €691 (Spain). Often, help from emergency healthcare professionals is requested, and inpatient hospital treatment is necessary [5].

Patients with diabetes (about 49–64%) have little to no awareness of when they are experiencing hypoglycemia [3] and also often do not know about signs of hypoglycemia [6]. Those patients who are unaware of their symptoms or who are – due to experiencing coma, confusion, or seizures – no longer able to manage their blood glucose require external assistance to recognize and treat hypoglycemia [5]. Family members or friends are usually the first people to recognize hypoglycemia, prevent severe cases of hypoglycemia by providing fast acting carbohydrates, and probably those with the highest motivation to conduct lifesaving measures in a case of severe hypoglycemia. The engagement of family members is especially crucial in older adults with diabetes [7,8], and, for patients of all ages, family members play an important role in ensuring the medication adherence, glycemic control, and dietary routines of patients [9,10].

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In order to detect and treat hypoglycemia, family members not only need information about the risks and progression of hypoglycemia [11], but also information to increase their self-efficacy and behavioral skills, preventing helplessness and fear in the case of an emergency [12,13]. Family members of patients who have frequent hypoglycemic incidents, or who are unaware of when they have low blood glucose, should also be educated about the use of glucagon injections. Clearly, family members need to engage in information seeking to be sufficiently informed about hypoglycemia prevention, symptoms, and treatment measures [14]. However, the social influences of health knowledge – i.e., how a person's health literacy affects the health outcomes of others – are not often addressed in research [15].

Wanting information to help someone else is a common reason for seeking health-related information [16], and a number of studies have been conducted about the information seeking of caregivers of adults with other chronic health conditions (for a systematic review, see Washington et al. [17]). Most of this research has concentrated on information seeking in the family members of patients with cancer; these studies have often found that the information requirements of caregivers were poorly fulfilled, and that insufficient information was supplied by health professionals [18–21]. Although health information seeking includes not only the access to information but also the motivation to search for it [16].

Given the lack of attention that has been paid to the information activities of family caregivers, only a few studies have explored the information-seeking behavior of caregivers of diabetes patients and its outcomes on the patients (e.g. Aikens et al. [22]). Lawton et al. [14] conducted qualitative interviews with family members of type 1 patients with hypoglycemic unawareness, and found that most family caregivers “had to rely on knowledge passed on to them by their partner/relative about hypoglycemia treatment” (p. 113). In addition, research about type 1 diabetes self-management suggests that information from family and friends is often triggering change or influencing decisions of patients [23].

However, other key factors relating to information-seeking activities, such as the preferred sources of information, associated demographic or diabetes-related characteristics, or the resulting levels of health literacy remain unexplored.

To address this lack of research about caregivers of diabetes patients, we investigated: (1) their degree of information seeking, (2) the information sources they used and found helpful, (3) their level of health knowledge about hypoglycemia, and (4) the associations between information seeking, demographic or disease-related factors, and hypoglycemia-related knowledge. Knowing how family members could be motivated to seek information to support persons with diabetes is important for policy makers, health insurance providers, and health professionals who work in diabetes management. Understanding which hypoglycemia-related knowledge is needed and where it is sought for can help health educators to tailor health information or interventions.

Subjects

Recruitment letters and questionnaires were sent to 2000 patients with type 2 diabetes, all of whom had been participants in a disease management program offered by AOK PLUS (a German health insurance provider) for 3 to 18 months. All participants were between 18 and 79 years old and were not hospitalized at the time of the study. By including these limitations of the sample, we wanted to insure that patients and caregivers were relatively new to the disease (as most people join this diabetes management program when they are first diagnosed), and could remember their information-seeking activities about diabetes and hypoglycemia. The study also excluded hospitalized patients so as to focus on those

who lived at home and were therefore mostly cared for by family members, as opposed to by medical professionals.

The diabetes patients were asked to pass the questionnaire on to a family member or close friend. Out of the 488 completed surveys we received, 95.1% stated that they felt “close” or “very close” to the patient, with a mean score of 4.74 ($SD = 0.59$) on a 5-point Likert scale from 1 (“very distant”) to 5 (“very close”). This high score indicates that we reached our target population of emotionally invested and motivated caregivers.

Materials and methods

Measures

Information seeking and information comprehension

Information-seeking activities and information comprehension were measured with two items [24], using a 5-point Likert-type scale ranging from 1 (“totally disagree”) to 5 (“totally agree”). The first question was “I have repeatedly and intensively looked for information about hypoglycemia,” and the second item was “Information is often too hard to understand” (reverse-coded).

Information source use and evaluation

Respondents were asked to state the sources of information that they used to inform themselves about hypoglycemia. The list of given sources included intentional media sources (e.g., newspapers, magazines, books, brochures, and the Internet) and interpersonal sources (e.g., medical professionals, family, friends, or care providers); both of these types of sources represent active health information seeking [16]. Participants were also asked to rate these sources' usefulness [25]. The question was “With regard to information about hypoglycemia, how helpful do you consider the following sources to be?” Possible responses were scored on a 4-point Likert-type scale ranging from 1 (“not at all helpful”) to 4 (“very helpful”).

Detection of symptoms

Although most health literacy scales for diabetes focus on knowledge of the pathophysiology of the disease, we wanted to focus on the practical knowledge of family members [6] regarding the symptoms and treatment of hypoglycemia. To do this, we developed two measures to assess caregivers' knowledge of the symptoms and treatments of hypoglycemia based on diabetes-related tests of health literacy [26]. The first question asked which of the nine items were possible symptoms of hypoglycemia [27]. Of the nine possible responses, six were right (e.g., shivering) and three were wrong (e.g., excessive thirst). Participants received one point for each correct answer and zero points for each incorrect answer, for a maximum score of nine.

Knowledge of treatments

Respondents were asked to list three measures they would take if a patient had mild hypoglycemia; this question was open ended to avoid potential test inflation from guessing [6]. The answers were coded and approved by a medical doctor. Responses of giving the patient fast-acting carbohydrates (i.e., sweet food or drinks) were given one point, because this represents the standard treatment of mild hypoglycemia [27].

Perceived health literacy

In addition to assessing the level of actual knowledge, we also tested perceived competence as an indicator of caregiver self-efficacy, which has proven to be an important aspect of health literacy [28]. Respondents' perceived health literacy about hypoglycemia was measured using four items ($\alpha = .87$) adapted from Swor et al. [29]. Agreement was measured using a 5-point Likert-type scale

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