



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

ranging from 1 (“totally disagree”) to 5 (“totally agree”). All four questions asked whether caregivers were sure about performing certain behaviors (e.g., “to detect that the patient has low blood sugar”).

Sociodemographic and clinical characteristics

Respondents were asked to give their gender, age, education level, (former) professional medical education (e.g., as a nurse or doctor), relationship to the patient, disease duration of the patient, and experience with hypoglycemia (either in themselves or the patient).

All materials (including the questionnaire and the recruitment letter) were given in German, pretested with members (patients and caregivers) of the target group (N = 20) and validated by experts (specialized in diabetes treatment and privacy protection) to ensure understandability, ethical approval, and medical correctness.

Methods

Data were analyzed using SPSS (Version 22). Descriptive statistics were used to portray sample characteristics and information sources. Hierarchical and logistic regression analyses were used to examine predictors of information seeking and hypoglycemia-related knowledge, controlling for demographic and diabetes-related characteristics.

Results

Respondent characteristics

The sample consisted of 488 family members of patients with type 2 diabetes. Mean age of the participants was 60.6 (*SD* = 13.8) and 62.5% were female. Approximately two-thirds (67.8%) of the family members were partners, 18.2% were parents or children, and 12.5% had some other relationship to the patient (e.g., uncle, neighbor, or friend). Of these respondents, 21.9% had diabetes themselves; 61.3% of the patients they were related to took diabetes medicine regularly, and the patients had had diabetes for an average of 5.8 years (*SD* = 7.67). **Table 1** summarizes the demographic and clinical characteristics of the respondents and patients.

Information seeking and sources

The mean of information-seeking activity was 2.97 (*SD* = 1.25), and 33.6% of the participants never or only seldom sought information about hypoglycemia. The mean score for understanding information about hypoglycemia was 3.70 (*SD* = 1.03), and about 10%

Table 2

Caregivers' use and evaluation of information sources

Source	Use N (%)	Evaluation M (SD)
Health professionals	219 (44.87)	3.35 (0.69)
Newspapers or magazines	200 (40.98)	3.01 (0.61)
Patient	159 (32.58)	3.01 (0.66)
Family or friends	144 (29.5)	2.76 (0.74)
Brochures	130 (26.63)	3.06 (0.66)
Books	117 (23.97)	3.12 (0.61)
Search engine	70 (14.34)	2.97 (0.86)
Health insurance provider	68 (13.93)	2.94 (0.75)
Online encyclopedias	53 (10.86)	2.89 (0.79)
Internet newsgroup	35 (7.17)	2.87 (0.93)

of the study sample stated that the provided information was incomprehensible to them. **Table 2** presents the sources from which hypoglycemia-related information was obtained, and how helpful these sources were perceived to be. Respondents obtained the most hypoglycemia-related information from health professionals and print media, and evaluated health professionals and books as being most helpful. Online resources were used only by 24% of the study sample.

A regression analysis of impact factors for information-seeking activities revealed that the intensity of active information seeking was associated with age ($\beta = .131, p < .05$), medical education ($\beta = .233, p < .001$), and personal experience with hypoglycemia ($\beta = .227, p < .001$). Family members and other caregivers sought more information about hypoglycemia if they were older, already had experience with hypoglycemia, and were educated health professionals (see **Table 3**).

Information comprehensibility was neither influenced by any demographic or diabetes-related characteristics, nor by the information resources that respondents reported using for information seeking.

Hypoglycemia-related knowledge

The mean score for the detection of hypoglycemia symptoms was 4.43 (*SD* = 1.59), with 60.5% of the respondents being able to identify at least two of the right symptoms and 25.5% knowing none of the symptoms. Sweating and shaking (62.9%) and fatigue (42.2%) were quite likely to be identified as symptoms of hypoglycemia, but irritability (26%) and talkativeness (5.5%) were much less likely to be associated with hypoglycemia. Nearly one-third (32%) of the study sample were not able to list any correct treatment measures in the event of mild hypoglycemia. Most caregivers (69.5%) would supply fast-acting carbohydrates (e.g., sweet food or drinks), which would be the most helpful measure in the event of hypoglycemia. Only 1.8% knew how to administer glucagon injections. The perceived health literacy was rather low ($M = 2.70, SD = 1.11$).

Since we were interested in the associations of information seeking and information understandability with hypoglycemia-related knowledge, the independent variables were entered sequentially into the regression models as follows: demographic characteristics (Step 1), diabetes-related medical characteristics (Step 2), information seeking and comprehension (Step 3).

After controlling for demographic and diabetes-related factors, information-seeking activities and understandability of the information explained 15% of the variance in perceived knowledge about hypoglycemia (see **Table 3**). Caregivers with lower information seeking and lower understanding of the information reported significantly lower perceived health literacy than people with higher levels of information seeking. Information comprehension also positively related to knowledge of treatment measures, which was also associated with education and personal experience with hypoglycemia. Compared to caregivers with weak information

Table 1

Characteristics of caregivers of type 2 diabetes patients (N = 488)

	Mean (SD) or n (%)
Age	60.62 (13.84)
Female	305 (62.5)
Education	
High school diploma or less	192 (39.3)
Secondary education	207 (42.4)
College degree	82 (16.8)
Professional medical education	52 (10.7)
Relationship to patient	
Partner	331 (67.8)
Parent or child	89 (18.2)
Other relationship	61 (12.5)
Live in the same household	349 (71.5)
Family member has diabetes	107 (21.9)
Experience with hypoglycemia (in self or with patient)	42 (8.6)
Patient disease duration (in years)	5.83 (7.7)
Patient takes diabetes-related medication	299 (61.3)

Note: Some rows do not total to 100% due to missing data.

Table 3

Hierarchical and logistic regression analyses of the relationship between hypoglycemia-related information seeking, information comprehensibility, and knowledge about hypoglycemia, controlling for demographic and diabetes-related characteristics

Model variables	Information seeking	Perceived knowledge	Symptom detection	Treatment knowledge	
	β	β	β	OR	95% CI
1. Demographic characteristics					
Age	0.13*	0.07	−0.06	0.98	0.96–1.01
Gender (male)	−0.09	0.09	−0.08	0.89	0.50–1.57
Education	0.03	−0.10	0.03	2.28**	1.29–4.02
R ² /−2LL change	0.03*	0.02	0.02	18.08	
2. Diabetes-related characteristics					
Medical education	0.23***	0.10	0.06	0.88	0.36–2.17
Duration of diabetes	0.10	0.03	0.10	1.00	0.96–1.04
Own diabetes	0.08	0.00	−0.05	0.84	0.45–1.58
Hypoglycemia experience	0.23***	0.04	0.14*	2.35*	1.13–4.88
Diabetes medication	−0.01	0.05	0.03	1.32	0.77–2.24
R ² /−2LL change	0.14***	0.05**	0.04*	10.12	
3. Information measures					
Information seeking	–	0.18**	−0.04	1.15	0.91–1.46
Information comprehension	–	0.33***	0.11	1.31*	1.01–1.69
R ² /−2LL change	–	0.15***	0.01	6.55	
Adjusted/Nagelkerke R ²	0.15	0.19	0.04	0.14	

Note: * $p < .05$; ** $p < .01$; *** $p < .001$; β , beta standardized regression coefficient; OR, odds ratio; CI, confidence interval; R², coefficient of determination of regression analysis; −2LL, −2 Log likelihood, gender (1 = male, 2 = female), education (0 = low, 1 = high), medical education (0 = no, 1 = yes), own diabetes (0 = no, 1 = yes), experience with hypoglycemia (0 = no, 1 = yes), diabetes medication (0 = no, 1 = yes).

comprehension, less education, and no experience with hypoglycemia, those with higher comprehension, a college education, or hypoglycemia experience were significantly more likely to know effective treatments for hypoglycemia. However, no association between information seeking and health literacy was found for knowledge of hypoglycemia symptoms; in fact, knowledge about the indicators of hypoglycemia was only correlated with personal experience with hypoglycemia. When treating the symptom variable as a categorical scale (where two signs are needed to be categorized as recognizing hypoglycemia; Rothman et al. [6]), none of the factors that were being tested for influence were significant in the logistic regression. Diabetes medication, own diabetes of the family member or duration of diabetes were not relevant for any of the variables of hypoglycemia-related knowledge.

Discussion

Information seeking

The respondents in the present study reported a rather low degree of hypoglycemia-related information-seeking activities. While caregivers of patients with other illnesses like cancer [30] have previously reported high unmet information needs and strong motivations to seek out information, this seems not to be the case for caregivers of diabetes patients. This was rather unexpected as family caregivers of the American Indian population stated the need for more information about diabetes management [11] and our sample was mainly made up of patients who were new to a diabetes program, and who had therefore only relatively recently been diagnosed with diabetes.

As health-related information seeking activities have often been, overall, lower than expected [31], several barriers to information-seeking activities should be explored by further research. The first barrier might be that family members lack awareness of the risks associated with hypoglycemia, or may not know that they and their knowledge could be helpful. A second barrier to information seeking might be the caregiver's relationship to the patient. Although the closeness of the relationship with the patient was not a factor that influenced information seeking in the present study, the quality of marital relationships has been found to affect diabetes manage-

ment in two prior studies [12,14]. Future studies should explore the possibility that patients might either not want to concern their caregiver or might not want others interfering in their medical treatment; both of these factors might inhibit information seeking by family members.

A third barrier might be the understandability of the information that is available. Participants in our study reported that online information was less helpful than information they received from health professionals and print media, echoing findings by Ybarra and Suman [24] that there is a great need for understandable online information among caretakers. To improve comprehension in this target group, future studies should therefore further explore the required content and the preferred means of communication for caregivers of patients with diabetes.

Information sources

Although the Internet is currently a major source of health-related information [32], it was not the most important source for adults in our sample to find information about hypoglycemia. One explanation might be the persistently low level of Internet use among older adults in Germany, where 21.2% of the population between 50 and 59 and 58.5% of people over 60 do not use the Internet at all [33]. Another possible explanation might be the more positive evaluation of interpersonal information sources in this population. In the present study, medical staff were rated as the most useful source of health information. This was confirmed by Soederberg Miller and Bell [34], who found that older adults were less trusting of Internet sources, and therefore underutilized the Internet for health-related information. Given the enduring importance of interpersonal information sources in this population, future studies should explore how patient–provider relationships can stimulate caregivers' health-related information-seeking behavior.

Hypoglycemia-related knowledge

Hypoglycemia-related knowledge of family members is important for managing diabetes, detecting common symptoms, and preventing further complications. A lack of knowledge about how to cope with such situations puts the health of the patient at risk.

Therefore, we judge the stated level of knowledge about hypoglycemia among persons who are close to patients with diabetes mellitus to be insufficient. Although the level is better than the finding by Shilubane and Potgieter [35], who found that half of the caregivers in their study in South Africa were not aware of the warning signs of hypoglycemia.

The level of knowledge about hypoglycemia of family members in our study corresponds with the participation rate of outpatient education programs in Germany. According to Bergis-Jurgan et al. [36], about 70% of patients with type 2 diabetes had attended some form of education class. Future research might examine whether there is a relationship between the diabetes education participation of the patient and the knowledge of the family member. It could also be speculated that family members might be a potential target group to reach patients that cannot attend education classes themselves.

Further, the present study found that hypoglycemia-related knowledge was very uneven: While sweating, shaking, and fatigue were recognized by many participants as symptoms of hypoglycemia, irritation and aggressive behavior were much less well known. Lawton et al. [14] also found that family members often felt “ill prepared for the behavioral and personality changes that could accompany hypoglycemia” (p. 113); these researchers underlined the importance of educating and informing family caregivers.

Our analysis of the relationship between information seeking and different kinds of health literacy revealed mixed results. Information-seeking activities were significantly associated with perceived competence, but less so with knowledge about hypoglycemia symptoms and treatment measures. Although different results for indirect and direct measurements of health literacy are not unusual [37], this discrepancy might indicate conceptual differences between self-efficacy and the tested knowledge, which should be examined by further research. It is possible, for example, that intensive information seeking and perceived information understandability give a sense of health literacy without really increasing the necessary knowledge. Finally, since information comprehension seems to play an important role in health literacy, future studies should consider how to improve the understandability of health-related information.

Limitations

There were three notable limitations to the present study. First, the generalizability of findings may be limited due to selection bias in participant recruitment; as samples were drawn from a regional health insurance provider, the results of this study may not be generalizable to the rest of Germany. Second, caregivers' health literacy might have been overestimated: The comparably low response rate of 24.4% may reflect a bias toward more motivated and literate caregivers, as women and more educated people are more likely to participate in medical studies [38]. This may mean that real health literacy is lower than was found in the present study. Third, the use of a close-ended question to measure health literacy regarding the typical symptoms of hypoglycemia may also have allowed respondents to guess the correct answer, inflating health literacy scores. Finally, this cross-sectional study can only establish correlation, and not causation, between variables. Therefore, both open-ended questions' formats and longitudinal designs might be more appropriate in future studies in this area [6].

Implications for health education and promotion

Findings from this study have identified three areas for health education, particularly in hypoglycemia-related education for partners, family members and friends of patients with type 2 diabetes.

Firstly, the results give some support for the conclusion, that interventions should also be directed at partners. So far, most diabetes intervention programs are directed at the patients only, without engaging with or educating family members directly [10,39], although peer-led support with lay trainers [40] and intervention programs including partners can be quite successful [41]. One example is the intervention program HyPOS (Hypoglycemia Positive Self-Management) for type 1 patients with hypoglycemia problems, where family members are also educated as a part of the course [42].

Secondly, the findings provide a basis for the content of hypoglycemia-related information material. Messages about diabetes should directly target caregivers [21] to raise awareness of the risks associated with hypoglycemia and provide information about the importance of their role in diabetes management. Content of this health education materials should include information about symptoms (like irritation and aggressive behavior) that are rather unknown. In order to increase understandability of the material, this information should also be easy to comprehend for less educated family members [43], which could be realized via visual presentation as used for information about first aid measures.

Thirdly, the findings are important for the selection of appropriate channels to reach this target group. Medical/professional personnel was identified as the main source of hypoglycemia-related knowledge, followed by newspapers/magazines and the patient himself. Caregivers who are older or less educated may benefit more from information provided via medical staff or printed materials, rather than online resources. Therefore, brochures that are handed out by the physician or articles in customer magazines by the health insurance funds may be considerations for planning health education. In addition, public-health educators could develop interventions to assist professionals in order to improve the likelihood that they will encourage caregivers of their patients to seek out health information [16].

Conclusions

This study provides insight into caregivers' hypoglycemia-related information-seeking activities and knowledge. Our study has revealed that family members of patients with diabetes can be helpful resources in the management of diabetes-related emergencies. More consideration needs to be given to caregivers' special relationship to the patient, such as considering caregivers' health knowledge in the development of health-education programs. More information must be provided to those who live with diabetes patients; caregivers' knowledge should be improved, especially for events like hypoglycemia, for which patients depend on the help of others. With information seeking as a major factor in perceived health-related competence, family members should be informed about their important role in managing hypoglycemic incidents. Information about symptoms and supportive measures could enhance their motivation and behavioral skills in such situations. Providing family caregivers of patients with diabetes with such information could improve the prevention and treatment of hypoglycemia; however, further studies are needed to confirm these findings and to explore information-seeking activities in managing emergencies for other chronic diseases (e.g., asthma).

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Conflict of interest

The authors declare they have no conflicts of interest.

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