**ORIGINAL ARTICLE**

**Diabetes self-management support for patients with low health literacy: Perceptions of patients and providers**

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**Abstract**

**Background:** The aim of the present study was to explore perceptions and strategies of health care providers regarding diabetes self-management support for patients with low health literacy (LHL), and to compare their self-management support with the needs of patients with LHL and type 2 diabetes. This study serves as a problem analysis for systematic intervention development to improve diabetes self-management among patients with LHL.

**Methods:** This qualitative study used in-depth interviews with general practitioners (n = 4), nurse practitioners (n = 5), and patients with LHL (n = 31). In addition, we observed 10 general practice consultations.

**Results:** Providers described patients with LHL as uninvolved and less motivated patients who do not understand self-management. Their main strategy to improve self-management was to provide standard information on a repeated basis. Patients with LHL seemed to have a different view of diabetes self-management than their providers. Most demonstrated a low awareness of what self-management involves, but did not express needing more information. They reported several practical barriers to self-management, although they seemed reluctant to use the information provided to overcome them.

**Conclusions:** Providing and repeating information does not fit the needs of patients with LHL regarding diabetes self-management support. Health care providers do not seem to have the insight or the tools to systematically support diabetes self-management in this group. Systematic intervention development with a focus on skills-based approaches rather than cognition development may improve diabetes self-management support of patients with LHL.

**Keywords:** diabetes, health literacy, self-care.

**Significant findings of the study:** Patients with low health literacy are reluctant to take up provider information in their self-management. Health care providers do not seem to have the insight or the tools to work on this complicated problem. Systematic intervention development should focus on skills-based approaches rather than cognition development.

**What this study adds:** This study provides an insight into health literacy as a relatively new concept in diabetes care. It also explores the perceptions and strategies of health care providers regarding diabetes self-management support for patients with low health literacy, and the needs these patients have in terms of self-management support. The findings have implications for self-management support and further research.
Introduction

Self-management has become increasingly important in the treatment of type 2 diabetes (T2D). From a biomedic- cal perspective, self-management is defined as a patient’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic disease. Diabetes self-management consists of addressing the areas of nutritional management, physical activity, blood glucose monitoring, and medication use. Patients with low health literacy (HL) tend to be less likely to successfully manage their diabetes, resulting in preventable health damage and loss of life years. “Health literacy” is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" and is often divided into functional, interactive and critical HL. Low HL is considered an important barrier to effective self-management of T2D. Von Wagner et al. developed a framework that proposes that HL influences diabetes self-management through sociocognitive motivational and volitional determinants. Motivation and HL are considered as two related, but different concepts. Previously, we used this framework to investigate the association between HL and diabetes self-management. The few studies we found suggested that patients with low HL have little knowledge about diabetes and lower self-efficacy towards diabetes self-management.

Because targeted support may help improve diabetes self-management among patients with low HL, we initiate a project to systematically develop a strategy to assess its use in general practice using the intervention mapping method. The present study serves as a problem analysis. The aims of the study were to: (i) explore perceptions and strategies of health care providers regarding self-management support for T2D patients with low HL; and (ii) compare providers’ self-management support with the expressed needs of T2D patients with low HL, including perceptions, experiences, attitudes, and preferences regarding diabetes self-management support in general practice.

Methods

Design

We performed a qualitative study using in-depth individual interviews with general practitioners (GPs), nurse practitioners (NPs), and T2D patients with low HL, as well as observations of general practice consultations. This qualitative design ensured the exploration of respondents’ own ideas by giving them the opportunity to address themes that researchers may not have anticipated.

The Medical Research Ethics Committee of the Academic Medical Centre, University of Amsterdam approved the study protocol under expedited review. The study protocol conforms to the provisions of the Declaration of Helsinki.

Setting

In the Netherlands, GPs work in close collaboration with NPs. The protocol for diabetes self-management support of the Dutch College for GPs (see https://www.nhg.org/standaarden/samenvatting/diabetes-mellitus-type-2; accessed 1 August 2014) recommends quarterly patient visits to their NPs to discuss general well being and problems in self-management, and to have their blood glucose, body weight, and blood pressure assessed. The GP performs annual control examinations. In the present study, T2D patients, GPs, and NPs were recruited from three general practices selected from a collaborative network of 30 general practices and the Academic Medical Centre in Amsterdam.

Subjects

We purposively sampled male and female GPs and NPs with varying years of clinical experience from five practices. Patients were eligible for participation in an interview if they had a diagnosis of T2D, had received primary and/or secondary education in the Netherlands (to prevent mingling language and HL barriers), and scored low on HL. To determine HL we used the Dutch “Newest Vital Sign” (NVS), a six-question tool that assesses an individual’s ability to find and interpret information on an ice cream nutrition label. A score of four or more correct answers out of six indicates adequate HL, whereas scores below four indicate low HL.

We purposively sampled male and female patients from different ages, Dutch and non-Dutch ethnic backgrounds, and various educational attainment levels. The total number of interviews was based on data saturation, meaning that we stopped recruitment when the interviews did not yield any new data for the purpose of this study.

Interviews and observations

Interviews with GPs and NPs

Using the framework of Seeleman et al., we developed a topic list to explore practitioners’ perceptions of HL and diabetes self-management, along with their experiences,
attitudes, and strategies to support the self-management of patients with low HL (see S1 interview design, available as Supporting Information for this article). The interviews were performed by one of the authors (MF) who, at the beginning of each interview, explained what HL involves using the definition and levels described above.

**Patient interviews**
The topic list for the patient interviews was guided by the results of our literature review. We used the results of interviews with GPs and NPs for further specification of the list (see S2 interview design, available as Supporting Information for this article). The process was iterative, meaning that we frequently adapted and focused the questions on topics that came up or remained unclear in earlier interviews.

**Observed consultations**
One of the authors (MF) observed nine sessions between NPs and patients with T2D to assess whether specific strategies, tools, and techniques were applied in supporting patients in their self-management. The observer was in the room with the patient and the NP, but did not take part in the interaction. For the observations, we used a topic list for GPs and NPs that was previously developed by one of the authors (EB) to elicit immigrant patients’ perspectives on hypertension. To assess to what extent motivational interviewing techniques were applied, we used the 1-pass coding system.

**Analyses**
All interviews were recorded digitally and fully transcribed. Fragments were selected and coded using MAXQDA software for qualitative data analysis (1989–2014; VERBI Software – Consult; Sozialforschung, Berlin, Germany) by two reviewers (MPF and a research assistant). To increase reliability, interviewers discussed five independently coded interviews to achieve intercoder consensus. To ensure validity, the project group discussed the plausibility of the main results.

**Results**

**Characteristics of research participants**
The sample of five NPs and four GPs had relevant clinical experience ranging from 15 to 30 years. Three GPs and one NP were male. Two of the female NPs participated in the consultation observations (NP1 and NP3). The NVS was assessed among 84 patients with T2D, with 74 of these patients scoring <4 on the NVS. Table 1 lists the background characteristics of the 31 patients who participated in the interviews.

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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>Age</strong> (years)</td>
<td>68.3 ± 12.4</td>
</tr>
<tr>
<td><strong>No. women</strong></td>
<td>16 (52%)</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>16 (66%)</td>
</tr>
<tr>
<td>High</td>
<td>4 (17%)</td>
</tr>
<tr>
<td><strong>No. with a Dutch ethnic background</strong></td>
<td>25 (81%)</td>
</tr>
<tr>
<td><strong>NVS-D score</strong></td>
<td></td>
</tr>
<tr>
<td>0–1</td>
<td>19 (61%)</td>
</tr>
<tr>
<td>2–3</td>
<td>12 (29%)</td>
</tr>
<tr>
<td><strong>Time since T2D diagnosis (years)</strong></td>
<td>8.5 ± 6.6</td>
</tr>
<tr>
<td><strong>HbA1c (%)</strong></td>
<td>7.44 ± 1.39</td>
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<tr>
<td><strong>HbA1c (mmol/mol)</strong></td>
<td>58 ± 15</td>
</tr>
</tbody>
</table>

Data are given as the mean ± SD or as the number of patients in a given group with percentages in parentheses.

*Data missing for one subject.
†Data missing for seven subjects.
‡Data missing for three subjects.

NVS-D, Newest Vital Sign–Dutch; T2D, type 2 diabetes.

**Providers’ perceptions and strategies in supporting patients with low HL**

**Role of perception in diabetes self–management support**
The GPs and NPs generally considered diabetes self-management a relatively new approach in the treatment of T2D (see Table 2, GP2). Contrary to the literature, in which the goal of self-management is achieved by forming patient–provider teams, the practitioners referred to self-management as the extent to which patients control their own disease, thereby placing the emphasis on the patient’s ability to achieve a healthy diet, take up exercise, quit smoking, and adequately take medication (see Table 2, GP3, NP5).

**Perception of patients with low HL**
Although GPs and NPs did not assess HL in their patients, they made assumptions about the extent to which their patients had low HL, which included the following impressions: they generally described patients with low HL as uninvolved, less motivated, and low educated, and who did not understand the importance of self-management (Table 2, NP2). Adequate support of patients with low HL was considered to be very important, but difficult to achieve because of the patients’ low motivation. Some practitioners expressed resignation, having given up trying to support these patients after many years without achieving success (Table 2, NP3).

**Strategies to support T2D patients with low HL**
The GPs and NPs mainly tried to stimulate diabetes self-management among patients with low HL by pro-


In the interviews, NP2, NP4, and GP1 proposed that providers should learn to apply a methodological approach when working with patients with low HL. Low motivation was considered a problem, and they mentioned that methods like motivational interviewing (MI) could improve self-management. The NPs and GPs followed MI training, but they had not received specific training in diabetes self-management education.

**Patients' needs for diabetes self-management support**

Responses from patients with low HL regarding diabetes self-management support can be categorized as follows: perceptions of diabetes (perceived impact); experiences in diabetes self-management; attitudes towards diabetes self-management; and preferences for self-management support (Fig. 1). None of the patients had received diabetes self-management education other than the quarterly visits to their NPs.

**Perceived impact of diabetes: lives barely changed**

Over half the patients were unaware of the consequences of being diagnosed with diabetes and had not incorporated standard areas of self-management into their daily lives. Participants described how their lives had barely changed since being diagnosed (see Table 3). Their perceptions contrasted with those of the GPs and NPs, who generally considered diabetes self-management a very complicated task for patients with low HL, with serious implications for their daily lives.

Among the changes mentioned, almost every patient reported taking medication and changing their diet. Only eight patients seemed to be more nuanced in their awareness of what adequate diabetes self-management requires, mentioning the importance of exercise, quitting smoking, or blood glucose monitoring (Table 3). Although these patients seemed more aware of what was expected of them, they identified multiple barriers and seemed reluctant to use their providers' support to overcome these barriers.

**Experiences in diabetes self-management:**

**Implementation problems**

Although most patients initially expressed no difficulties in self-management and some perfectly described
adequate self-management activities, nuances arose when we asked specific questions about barriers to performing diabetes self-management activities. One issue came up around medications, showing that consistent adherence reporting does not always translate into taking pills in prescribed ways. One patient mentioned that she takes all her pills at one time, rather than throughout the day as her provider prescribed (Table 3).

When we probed, almost all patients seemed to have problems implementing regular exercise into their daily lives. Patients reported little social support, physical impairment, and lack of time and motivation as barriers to increasing physical activity (Table 3).

**Attitude towards diabetes self-management: fear and ambivalence**

Many patients said that they would take better care of themselves if their disease got worse in the future, indicating that they did not seem to understand the concept of prevention. They particularly expressed a fear of insulin dependency and other more immediate complications (Table 3). A few patients expressed ambivalence towards lifestyle adaptations that adequate self-management requires, which seemed related to the impact on quality of life (Table 3).

**Preferred support: personal approach rather than information**

Most patients expressed that they did not want to receive any more information on diabetes and self-management because they felt that they knew enough about their disease or because it scared them (Table 3). When information was given, patients generally preferred material that was customized and delivered verbally rather than in written form. Patients said that they did not search for supplementary information on the Internet or in books. A few patients expressed difficulties comprehending the information they had received from their NP or GP (Table 3).

**Observations of self-management support in general practice**

The observations showed that screening tools to assess levels of literacy were not used. More than half the consultation time was spent on medical assessments. The NPs asked questions about self-management activities (e.g. “How is your diet going on?”). They provided information and gave advice about self-management activities. They applied simple language and frequently asked whether patients understood what they were being told. The NPs listened carefully to the patient and sometimes summarized and reflected on what the patients said. They did not use teach-back methods to check patients’ comprehension. Patient perspectives on diabetes and self-management were not elicited to then tailor the provision of information. Providers rarely applied MI techniques. Most asked closed questions, gave unasked-for advice and information, did not explore patients’ motivations, and did not confirm their self-efficacy. However,
providers did express empathy and frequently accommodated patient resistance.

Discussion

The findings of the present study indicate that GPs and NPs have a low awareness of what HL actually involves and how to adequately support patients with low HL in diabetes self-management. These findings are in line with other studies showing that providers have limited knowledge of HL and of the role it plays in health outcomes. Providers generally overestimate their own knowledge of HL, suggesting that they have a long way to go to recognize that they need to consider their patients as more complex actors than they typically allow. A possible reason is that no or little attention is paid to HL in the curriculum for medical professionals. Providers are unable to accurately identify patients with low HL and tend to overestimate patient’s HL and their own communication skills.

Because GPs and NPs seemed to consider low HL as lack of motivation, they are limited in positively strategizing about specific techniques or guidelines that better support patients. They try to stimulate diabetes self-management in this group by providing and repeating information. However, the patient interviews indicated that providing and repeating information does not fit patient needs. Many patients seemed to have a different attitude towards diabetes self-management than practitioners. They showed a low awareness of the need for diabetes self-management in biomedical–behavioral terms and the potential for personal gain. Patients’ needs seemed to be focused on developing skills to implement adequate diabetes self-management into their lives rather than cognition development.

This is one of the first studies to investigate perceptions of patients with low HL towards diabetes self-management. The qualitative design of the study yielded rich data that we will use to develop an intervention to improve self-management support of patients with T2D and low HL. A limitation of the study is that we did not assess to what extent the perceptions of low HL patients are comparable to or distinct from the perceptions of patients with more advanced HL skills.

This study has several implications for practice and scientific research. Without acknowledging where patients are coming from and meeting them there, providing and repeating the same information is doomed to fail, and indeed seems to be doing just that. Patient interventions should focus on skills-based approaches rather than cognition development. Low HL patients are clearly reluctant to take up provider information in their self-management, but GPs and NPs do not seem to have the insight or the tools to systematically work on this complicated problem. This calls for attention to curriculum development, and the addition of resources in the Dutch healthcare system to systematically improve providers’ awareness, knowledge, skills, and motivation to guide patients in self-management. Courses in diabetes education with specific attention to low HL, guidelines to recognize and address the problem of appropriate communication with low HL patients, and the use of teach-back methods, interactive information materials, and patient-centered approaches (e.g. MI) offer possible mechanisms to improve self-management among diabetic patients with low HL. Motivational interviewing is a particularly promising patient-centered strategy for patients with low HL who have different perspectives on diabetes self-management than health care providers. Instead of providing didactic information, the provider assesses the patient’s perspective including feelings of ambivalence and uses these insights to activate motivation for change.

Our findings further indicate that the association between HL and diabetes self-management may not be that straightforward. Variations in educational attainment level, knowledge, perceptions, attitude, and self-management behavior raise questions about the influence of functional HL on diabetes self-management, and may explain why so few studies actually found evidence for this association. Context-specific interactive and critical HL skills may serve as a better predictor for diabetes self-management and should be taken into account in further research.

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Disclosure

None declared.

References


**Supporting information**

Additional Supporting Information may be found in the online version of this article at the publisher’s web-site:

S1 Interview design health care professionals.

S2 Interview design patients.