

Health literacy in diabetes care: explanation, evidence and equipment



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Practice Points

- Multiple definitions exist for health literacy but the core concepts include skills needed in order to obtain, process, understand and communicate specific health information. Literacy includes not only print and oral literacy but numeracy, cultural and conceptual knowledge.
- Health literacy includes the interaction among patients, providers, systems and environment factors.
- There are limitations to the measurement of health literacy in both research and in the clinical setting. There is no best method agreed upon at this time.
- Health literacy is significantly related to diabetes knowledge, self-efficacy and self-care; however, the associations between health literacy and glycemic control vary. Numeracy may have a stronger association with diabetes outcome than health literacy.
- Racial disparities in glycemic control are in part explained by numeracy.
- Individual educational resources to facilitate patient–provider diabetes communication have been tested in randomized controlled trials including patients with limited literacy skills.
- Use of information technology is attractive; however, there is limited information available regarding the efficacy and burden among limited literacy patients with diabetes.

SUMMARY The exchange of complex health information among patients, providers, health organizations and the public is often described as health literacy. Low levels of health literacy is common and associated with processes of healthcare and important health outcomes. In diabetes, health literacy is related to diabetes knowledge, self-efficacy and self-care behaviors and glycemic control. Health literacy may also provide a better understanding of racial disparities observed in patients with diabetes. Strategies to address health literacy, based upon this understanding of its role, provide a means to improve diabetes care. This article describes the concept of health literacy and its assessment and the evidence of its impact on patients with diabetes, and offers suggested methods and tools that may be implemented to improve clinical care.

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In 2010, it was estimated that there were 285 million adults worldwide with diabetes, with projections that this will increase to nearly 440 million people by 2030 [1]. Despite innovative scientific discoveries to advance our understanding of the pathology of diabetes mellitus and to develop novel approaches to therapy, the burden of diabetes continues to escalate and treatment often remains substandard [2]. Optimal management of diabetes mellitus requires collaboration between multidisciplinary healthcare providers and patients to encourage effective self-care in many tasks including adherence and manipulation of complex medication schedules, executing detailed dietary recommendations, promoting physical activity and participation in preventative care strategies [3].

Although there are many determinants that contribute to the process of care and health outcomes for patients with complex chronic disease, over the past two decades the literature has been growing, illustrating the concept of health literacy as a relevant and influential factor related to diabetes mellitus. In the USA, it has been estimated that more than 90 million people have basic or below-basic literacy skills and more than 110 million have poor mathematical skills [4]. A low level of health literacy is common among patients with diabetes mellitus, with estimates ranging from 15 to 40% depending upon the population sampled [5–7]. Diverse patient populations and a variety of contexts of diabetes care have been examined to advance our understanding of the role of health literacy. In this article, we will define health literacy and methods of its assessment, review evidence of its role in the care of patients with diabetes mellitus and discuss strategies to equip providers and healthcare systems to address health literacy in their diabetes management practice.

Health literacy: definition & measurement

■ Definition

As the concept of health literacy has evolved, there has been heterogeneity in its definition and its interpretation regarding how it relates to health [8]. More recently, there has been greater emphasis on the perspective that health literacy represents not only the skills needed by an individual to process health-related information, but also the demands of the health system in terms of the delivery of information or instructions [8]. A recent adaptation of the commonly used definition from the Institute of Medicine (Washington DC, USA; 2004) is [8]:

“The degree to which individuals can obtain, process, understand and communicate about health-related information needed to make informed health decisions”.

As this definition suggests, health literacy is a broad concept including more than individual levels of intelligence, but rather a specific skillset that involves a variety of methods to communicate and interpret health information with unique demands, depending upon the person and their setting.

More specifically, literacy includes skills and demands related to print information (reading and writing), oral communication (speaking and listening), numeracy and attention to cultural relevance [9]. Each of these domains contributes to the practical care of patients with diabetes mellitus. Numeracy or the use of numbers in daily life [10] is closely associated to an individual's skills of literacy such as reading, but requires distinct expertise. Despite adequate literacy skills, people frequently have poor quantitative skills [10]. Finally, with the rising prevalence and severity of diabetes mellitus and escalating racial disparities [11], the incorporation of tailored cultural strategies into diabetes management by health providers is important to promote the equity of the demands of the health system together with the individual's ability to effectively use diabetes-care information.

■ Measurement

As with the definition, a variety of tools to measure health literacy and numeracy have been developed. The most widely used are the Rapid Estimate of Adult Literacy in Medicine (REALM) [12] – a word-recognition survey – and the Test of Functional Health Literacy Assessment (TOFHLA) and its shortened version [13,14]. Both of these surveys are commonly used in research; the REALM can be rapidly completed, although it requires interviewer administration, and the TOFHLA requires approximately twice the time at 12–15 min. However, there remain concerns about the ability of each of these instruments to characterize people with higher levels of health literacy skills [5]. Alternatively, there are simple questions proposed to screen for low health literacy that have demonstrated good correlations with the traditional measures of health literacy [15]. For the question, ‘How confident are you at filling out medical forms by yourself?’, persons responding

‘not at all confident’ or ‘a little confident’ have five-times higher odds of having low health literacy compared with those who respond with more confidence to this question [16]. A detailed comparison of the properties of these and other health literacy measures is available elsewhere [17].

Numeracy may be assessed either as a component of a health literacy evaluation (TOFHLA) or separately with several different methods [18]. In chronic disease care, such as diabetes, applied quantitative skills may be more closely aligned with the self-care demands for patients. The Diabetes Numeracy Test (DNT) is a valid and reliable assessment of diabetes-specific numeracy that evaluates a variety of quantitative skills using a word-problem-based format within the context of common diabetes tasks such as interpreting results from glucose self-monitoring, evaluating a nutrition food label and calculating medication requirements (Figure 1) [19]. A limitation of this instrument for uses other than research is that the administration time is usually more than 15 min. The development of numeracy screening questions, such as those for health literacy, may have a more practical use in clinical care.

Evaluation of health literacy or numeracy, either as a screen or in more detail, in clinical practice remains a source of debate. It has been

suggested that we should practice ‘universal precautions’ and adhere to clear communication strategies that all patients can use effectively [20]. In addition, it is important to recognize that poor literacy skills are often associated with strong feelings of shame and embarrassment for patients [21,22]. Considering this concern, more recent advocacy has been to evaluate patient’s learning and literacy skills [16] and, through organizational strategies, to equip providers to provide necessary psychological and emotional supports for patients, remembering that reducing the demands of our ‘system’ is at the core of improving health literacy [23]. We will further discuss some of these strategies specific to diabetes care.

Health literacy: evidence of impact on diabetes mellitus

There are several pathways via which health literacy influences important health outcomes, including the acquisition of new disease-specific knowledge, improving self-efficacy and adherence with self-care behaviors. The conceptual model by Baker (Figure 2) illustrates these hypothesized relationships by highlighting patient characteristics that are associated with literacy skill, the complexity of both written and spoken health information and other factors such

A You ate one and a half cups from the food labeled below. How many grams of carbohydrate did you eat?

Nutrition facts
Serving size: 3/4 cup
Servings per container: 10
Amount per serving
Calories: 150
Total fat: 7 g
Total carbohydrates: 18 g
Dietary fiber: 3 g
Sugars: 3 g
Total protein: 3 g

Answer: 36 g

B You test your blood sugar three times a day. You purchase a prescription of 50 strips on 5 March. Of the dates below, by when will you need to buy new strips?

21 March
21 April
21 May
21 June

Answer: 21 March

C You are given the following instructions: “take one unit of insulin for every 7 g of carbohydrate you eat.” How much insulin do you take:
– when you eat 98 g at supper?

Answer: 14 units

Figure 1. Example items from the Diabetes Numeracy Test.

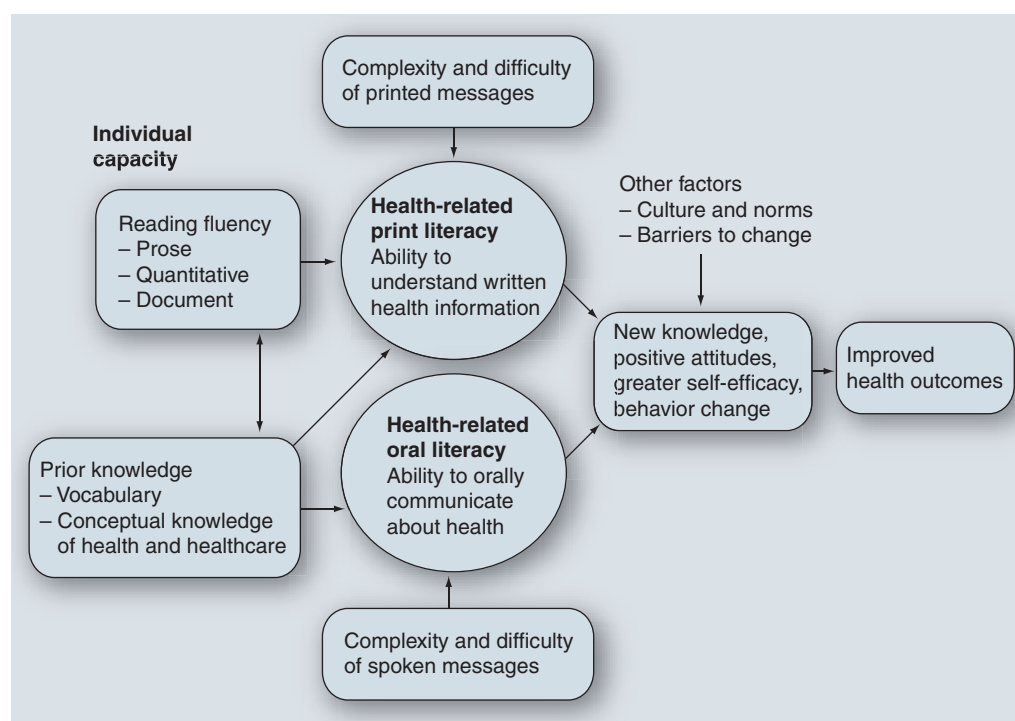


Figure 2. Conceptual model of the role of health literacy on health outcomes.

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as cultural norms that are relevant to successful self-care [24]. Although the depth of the literature is limited, each of these pathways has been examined in patients with diabetes, including important outcomes such as glycemic control.

■ Knowledge, self-efficacy & self-care behaviors

It is essential that patients with diabetes have an understanding of the signs and symptoms of hypoglycemia, hyperglycemia and how to properly self-administer medications to control diabetes. Low health literacy has been consistently associated with worse diabetes knowledge in a variety of settings including ambulatory and hospitalized older patients in the USA and Japan [6,25–27]. For example, despite the majority of participants reporting having attended a diabetes education class, only 50% of patients with inadequate literacy skills recognized the common symptoms of hypoglycemia such as feeling shaky, sweaty or hungry and, moreover, only 38% correctly reported the need to eat if experiencing the symptoms [27]. Low diabetes numeracy has also been strongly associated with low levels of diabetes knowledge compared with higher numeracy skills (52 vs 86%; $p < 0.001$) [5]. Efforts to improve diabetes

knowledge increasingly involve computer-based technology. A survey of patients with diabetes and low literacy showed that 83% reported a willingness to learn, and a basic knowledge of, computer skills to become further educated about diabetes care [28]. However, patients with low literacy may not improve their knowledge as recipients of multimedia and technology-based programs as much as those with adequate literacy; therefore, other supportive strategies may need to be included [29].

Self-efficacy of diabetes self-care has been significantly associated with self-care behaviors and glycemic control [30]. Using a variety of instruments, several previous studies have examined health literacy, diabetes self-efficacy and glycemic control, with only one study demonstrating an association between health literacy and diabetes self-efficacy [25,31,32]. By contrast, while we also observed that health literacy and numeracy were associated with diabetes self-care and self-efficacy, it was numeracy that remained more strongly related when examined together [33]. Self-care in diabetes relies heavily on quantitative tasks for interpreting glucose measures, adjusting medications and executing dietary recommendations. Therefore, it may have been anticipated that individuals who are facile with mathematics

applied to diabetes are also more likely to have greater confidence in performing self-care tasks. Interventions to encourage self-care, including specific approaches to improve self-efficacy, may have additional influence on patients with low health literacy levels.

Although health literacy has been associated with many health behaviors, there has been little evidence to date from patients with diabetes. Examinations of health literacy and diabetes numeracy have failed to demonstrate significant associations with adherence to diet, exercise, blood glucose monitoring or foot care under usual care circumstances [5,33,34]. In one small study of 77 participants (22% with limited health literacy), after participation in a diabetes educational program, the limited health literacy participants self-reported more frequent self-care including diet, glucose monitoring and foot care compared with those with adequate literacy, suggesting the potential benefit of educational counseling, especially for low health literacy patients [35]. While literacy has been identified as a factor in adherence to medications in other chronic illnesses such as heart failure [36], possibly related to difficulties with identifying medication, reading prescription labels and warnings [37–39], there is limited research examining this relationship in patients with diabetes. Given that medication management is fundamental to diabetes care, further research is needed to determine the magnitude of impact that health literacy skill may have on this important self-care behavior.

■ Glycemic control: hemoglobin A1C & hypoglycemia

The results describing the relationship between health literacy and glycemic control have been mixed. In 2002, Schillinger *et al.* reported that inadequate health literacy was associated with nearly twofold increased odds of poor glycemic control compared with adequate health literacy (adjusted odds ratio: 2.03; 95% CI: 1.11–3.73; $p = 0.02$) [7]. However, reports have failed to show a significant association between health literacy and glycated hemoglobin [5,27,40,41]. This is not surprising as glycemic control is most likely to be influenced by a large number of heterogeneous social and biologic determinants. In a recent examination of pathways by which health literacy influences diabetes control, social support was identified as a mechanism by which health literacy was indirectly related to glycemic control [26].

As discussed earlier, numeracy skills may be more closely related to the applied tasks required for successful diabetes self-care to secure and maintain optimal diabetes control. In nearly 400 patients from four primary-care or diabetes specialty clinics, we found that diabetes-related numeracy, as measured by the DNT, was modestly significantly associated with hemoglobin A1C (A1C) [5]. Low levels of numeracy skills may identify patients at high risk for poor diabetes outcomes and may also be an important consideration in the development of educational interventions. Furthermore, we examined the role of numeracy in explaining the commonly observed racial disparities in glycemic control [42]. African-American race was associated with higher levels of A1C ($r = 0.12$; $p < 0.01$) and also diabetes-related numeracy ($r = -0.46$; $p < 0.001$). When adjusted models were applied that included diabetes-related numeracy as a mediator in the path between race and A1C, the relationship between African-American race and A1C was reduced to a nonsignificant association ($r = 0.10$). While the role of socioeconomic status and education cannot be dismissed, numeracy – a distinct component of health literacy – may indeed have an important role in understanding diabetes care and outcomes.

Equally important in diabetes control is the risk of serious hypoglycemic events. Since low health literacy has been associated with poor knowledge of hypoglycemic symptoms and treatments, it was hypothesized that these patients may also be at higher risk of hypoglycemic events. In a community-based sample of over 14,000 patients with diabetes, 11% reported a serious hypoglycemic event within the past year and limited health literacy skills were associated with a 30% increased odds of experiencing an event (odds ratio: 1.3; 95% CI: 1.1–1.6; $p < 0.001$) [43]. Again, low health literacy characterizes a vulnerable patient population that is at high risk of poor diabetes outcomes.

Strategies to address health literacy in diabetes care

Recognizing that low health literacy is common and associated with many facets of diabetes care – including important outcomes – strategies to address health literacy have been developed, tested and promoted. The foundation of these strategies rests with the principles of clear health communication, including assessment of

PART 3 HOW TO FOLLOW MY EXERCISE PLAN

Why should I exercise?

- Exercise is good for diabetes
- Exercise helps lower blood sugar
- Exercise can help you lose weight
- Exercise can help you feel better

What kind of exercise will I do?

☐ Walk ☐ Ride a bike ☐ Dance ☐ Swim ☐ Other

When will I exercise?

☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday ☐ Saturday ☐ Sunday

Minutes a day _____ days a week _____

Write down the minutes you exercised in your log book.

Sometimes exercise can lower blood sugar too much. To prevent low blood sugar I should:

☐ No need to change anything

☐ Eat an extra snack before I exercise _____

☐ Take less insulin _____

☐ Test blood sugar _____

PART 13 SET DOSE INSULIN

How Much Insulin Do I Take?

My long lasting insulin is: _____ (Brand Name) _____

My short lasting insulin is: _____ (Brand Name) _____

Before Breakfast:

Take _____ units of _____ insulin before breakfast (long lasting insulin)

Take _____ units of _____ insulin before breakfast (short lasting insulin)

Before Lunch:

Take _____ units of _____ insulin before lunch (short lasting insulin)

Before Supper:

Take _____ units of _____ insulin before supper (long lasting insulin)

Take _____ units of _____ insulin right before supper (short lasting insulin)

At Bedtime:

Take _____ units of _____ insulin at bedtime (long lasting insulin)

Take _____ units of _____ insulin at bedtime (short lasting insulin)

Figure 3. Examples of Diabetes Literacy and Numeracy Education Toolkit materials.
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understanding, use of plain language, emphasizing few key points and using effective printed materials [44]. There are many methods that may be tailored to specific practice settings and we review in brief a selection of these here.

■ Tools to enhance patient-provider communication

Although there are many resources available in brochure, fact sheet and web-based formats to deliver information to patients with diabetes, the complexity of the content, including the reading level of the text, often surpasses the skill of patients and presents a barrier for information delivery to those with low health literacy [45,46]. Recently, several diabetes materials have been developed specifically to address low health literacy and to be used interactively between patients and providers to promote patient understanding, empowerment and improved self-efficacy with self-care behaviors.

The Diabetes Literacy and Numeracy Education Toolkit (DLNET) [101] is a comprehensive 24-module resource to facilitate communication between patients and providers to promote effective diabetes learning and self-care [47]. Module topics include blood glucose monitoring, medication administration and

dietary instructions (Figure 3). The toolkit format adheres to clear communication principles with a low-grade reading level, using color coding, pictures and step-by-step instructions. In two randomized controlled trials, the DLNET was tested as part of an enhanced diabetes-care program compared with standard educational materials. In 198 patients, the use of the DLNET reduced their hemoglobin A1C by more than those in the control group (median difference: -0.70 [95% CI: -1.10 to -0.20]; $p = 0.005$), but this difference was not sustained after the intervention was concluded [48].

Considering low health literacy, the American College of Physicians Foundation (ACPF) developed the 'Living with Diabetes Guide' as a resource for patient education and also to promote goal setting and shared decision making in diabetes care [49,50]. Similar to the DLNET, the guide includes materials related to blood glucose self-monitoring, medication and dietary adherence and exercise. Initial studies have demonstrated that interactive use of the guide with provider counseling resulted in more than 90% of patients successfully executing an identified behavioral goal [49]. There were no differences observed in health literacy status, suggesting that the guide has utility for diabetes patients of all skill levels.

While the individual patient encounter remains the cornerstone of care, there is a growing interest in communicating with patients by email or web-based technology portals. This mechanism is proposed to be an efficient means to deliver information and may address health literacy with customized content, use of audio or video, and assessments of patient's understanding. However, for vulnerable patients, including those with low health literacy, there may be a furthering of disparities related to access or utilization of these methods. Sarkar *et al.* evaluated the use of a patient portal that has been in use over the past 10 years in a large population of patients with diabetes and found that those with low health literacy were 70% less likely to use the resource at all, 40% less likely to use it even if they had created an account and were 30–60% less likely to use the individual functions of the portal once they entered the site compared with those without low health literacy levels [51]. A recent review suggests further areas of research, including care utilizing cell phones or other mobile device technology as a mechanism to enhance care delivery for patients of limited literacy [52]. As new health information technology systems are created to promote information sharing, ensuring equity of access and ease of use must be a priority.

■ Assessment & modifying health systems

Healthcare systems including hospitals, ambulatory-care organizations, insurance providers and community health centers are increasingly considering addressing health literacy as a means to improve processes of care for patients. Several tools have now been developed and validated to provide organizations with a way of evaluating their clinical practices with a focus on enhancing patient-centered communication. While none of these resources are specific to patients with diabetes, the strategies are universal and can be applied to complex chronic disease care.

In April 2010, the Agency for Healthcare Research and Quality (MD, USA) released the 'Health Literacy Universal Precautions Toolkit' [102]. This toolkit is available online and informs organizations regarding how to construct a team to address health literacy, methods to improve both spoken and written communication, specific guides to create action plans, empower patients and foster a supportive environment to engage patients. Included in this resource are examples of forms, letters, scripts for

telephone services, focus group guides, posters to gain buy-in from both patients and providers and much more. Organizations might consider adopting this as a comprehensive entity or may use sections tailored to their environment's specific needs. Other simplified lists of prompt questions for use by health plans to address health literacy covering written materials, web navigation, provider call lines and disease management programs have also been described [53].

Organizational assessment tools, specifically to evaluate the practice and quality of patient-centered communication, have also been recently validated by the Ethical Force program [54]. A unique aspect of this assessment is the inclusion of the opinions of not only patients but also providers, nonclinical personnel and administrative personnel who comprise the organization. Nearly 6000 patients were enrolled from across 13 heterogeneous health-care settings including urban and rural hospitals and federally qualified health centers. Patients with low health literacy, compared with those with adequate literacy, consistently had lower odds (28–79%) of reporting that their organizations 'always' delivered patient-centered communication on seven different domains [55]. It is the responsibility of the organizations and the participants within those organizations to reduce the system's demands to improve health literacy and provide useable information to all patients. Additional research in each of these important areas is needed to establish efficacious and feasible strategies that can then be widely disseminated and implemented. Achieving this goal may then build effective engaging relationships with patients to promote informed decision making, increase successful self-care and optimize health outcomes, especially for patients with diabetes.

Conclusion & future perspective

In patients with diabetes, low health literacy is common, associated with a lack of diabetes knowledge, self-efficacy and self-care behaviors. Low health literacy and poor numeracy skills are also associated with poor glycemic control, and addressing literacy in multidisciplinary diabetes educational and management programs improves important health outcomes. However, much remains unknown regarding the relative impact of different strategies to improve health literacy including those for patients, providers and health organizations. As the field continues

to evolve, more precise instruments to characterize health literacy will be developed and more directed interventions will be rigorously evaluated and implemented in practical clinical settings. Given the growing international support to improve the interaction between vulnerable patients and health systems, health literacy will likely be an important contributor to optimizing the delivery of diabetes care.

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