Cultural and Health Literacy Considerations with Diabetes

Reviewed by the AADE Professional Practice Committee

The chronic nature of diabetes underscores the importance of self-management education and support that promotes behavior skills that are necessary to optimize quality of life. Diabetes education and care specialists recognize that the most effective approach to management is individualized to the needs of each person with diabetes.[1] Specialists, likewise, recognize that the way a person obtains, processes and utilizes information depends heavily on health literacy and numeracy skills, prior life experiences and support networks; and that each of these elements is shaped by culture.[1-2]

Health Literacy

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.[2] In addition to core literacy skills such as reading and writing, health literacy includes speaking, listening, cultural knowledge and understanding of specific concepts that are necessary to interpret health information.[3]

Quantitative skill, or numeracy, is another element of health literacy. Evidence suggests it is independently associated with health behaviors and outcomes in diabetes and other contexts.[4,5] Low health literacy is more common among older adults, non-native English speakers, individuals with limited education, and members of racial and ethnic minority groups.[6-7] Individuals with low health literacy have more difficulty understanding medical instructions,[8-9] have worse self-reported health status[10] and have shorter life expectancy[11] than individuals with adequate health literacy.

The 2003 National Assessment of Adult Literacy Survey (NAAL) defined four categories of health literacy proficiency: below basic, basic, intermediate and proficient.[12] An individual with 'below basic' skills can effectively circle a date on an appointment slip.[2,5,12] Those individuals with 'basic' skills can understand simple handouts. 'Intermediate' skills translate to interpretation of medication labels and 'proficient' skills translate to the understanding of medical terms.

The NAAL survey found that 36% of the population has 'basic' or 'below basic' health literacy skills. The majority of the population is at an 'intermediate' level and only 12% are 'proficient'. This means that approximately 90 million adults lack the needed health literacy skills to navigate the healthcare system and effectively make decisions about their health care. This gap has clear implications for the ability of people with diabetes to self-manage their care as it can result in trouble understanding and carrying out a number of recommended self-care behaviors such as interpreting glucose readings, calculating appropriate carbohydrate intake, drawing up insulin with a syringe, calculating an insulin dose, understanding nutrition principles and managing medications. This has ramifications for maintaining good glycemic management and avoiding complications of diabetes.

Cultural Diversity

Awareness of the need for cultural sensitivity is just as critical as health literacy and numeracy sensitivity. It is more than a finite knowledge of cultural values, beliefs, customs, languages, thoughts and actions. The need to gain relevant insight necessitates the need to develop a certain amount of cultural humility. This will help develop a mutually respectful and positive relationship among individuals and healthcare providers.

The most recent estimates show that more than 30 million Americans have diabetes.[13] This public health epidemic has occurred in tandem with a shift in the American demographic landscape toward a high minority population.[14] The census population projects that by 2045, whites will compromise

49.7% of the population, Hispanics 24.6%, blacks 13.1%, Asians 7.9% and multiracial populations 3.8%. In comparison, the Centers for Disease Control and Prevention (CDC) reports that the percentage of US adults with diabetes is 15.1% American Indian, 8% Asian, 12.1% Hispanic, 12.7% blacks, and 7.4% white, non-Hispanic. Minority groups are affected by diabetes at significantly greater rates when compared to non-Hispanic white Americans for reasons that are multidimensional.

In the context of cultural effects germane to the minority groups affected most by diabetes, careful attention to cultural influences on self-efficacy and motivation are critical for fostering behavior changes. These behavior changes optimize diabetes clinical outcomes, health status and quality of life.[1] In 2015, 22% of the deaths attributed to diabetes were Hispanics. By 2030, this is expected to increase to 25%.[15] This further implicates the necessity for cultural preparedness of the diabetes care and education specialist of today and tomorrow across ethnicity and racial cultural sensitivity.

Impact on Diabetes

In type 2 diabetes, observational studies suggest that individuals with low health literacy have less diabetes knowledge and limited glycemic management than individuals with higher health literacy.[5,16-18] Additionally, a systematic review by Al Sayah and colleagues of 24 studies found consistent evidence that there is a positive association between health literacy and diabetes knowledge.[19] Similarly, lower numeracy is associated with lower perceived self-efficacy and modestly higher hemoglobin A1C.[4-5] The impact of low health literacy can also be seen on individuals under the supervision or care of another individual - such as children with type 1 diabetes. A study looking at 200 caregivers of children with type 1 diabetes found that inadequate health literacy as assessed by the Newest Vital Sign. (a valid and reliable screening tool available in English and Spanish that identifies people at risk for low health literacy) of the caregiver resulted in significantly higher hemoglobin A1C (HbA1C).[20]

In one randomized trial, participants in an intensive diabetes disease management program that included literacy-sensitive elements had better glycemic management than those who received usual care.[4-5] The low-literacy individuals in the intervention arm improved significantly more than individuals with adequate health literacy, suggesting that literacy is a key factor predicting who will

benefit from diabetes self-management interventions. In another trial, adding literacy and numeracy-appropriate components to a diabetes education program resulted in greater improvement in hemoglobin A1C after three months compared with training that did not include those components. The difference between groups was no longer statistically significant after 6 months, which suggests that a longer intervention period or ongoing support may be necessary to maintain benefits.[6-7] Trials of literacy and culture-sensitive interventions in ethnic minority groups such as Latinos have also demonstrated benefits.[15] A study by Schillinger and colleagues looking at 408 people with type 2 diabetes found that individuals with lower health literacy were two times more likely to have limited glycemic management with an A1C of 9.5% of greater.[5] Additionally, these individuals were also two times more likely to have retinopathy and almost three times more likely to have cerebrovascular disease. While not statistically significant, there was a positive trend in individuals with lower health literacy also having at least two times more risk of nephropathy, lower extremity amputation and cerebrovascular disease.

From a cultural perspective, ethnic minority groups have lower insulin usage rates than whites.[21-23] Beliefs ranging from insulin implying failure or leading to more complications, to lack of family support or religious obligations can all interfere with usage rates.

Role of the Diabetes Care and Education Specialist

To reduce the outcomes disparities that arise as a result of low health literacy, many organizations have called on health professionals to adopt clear communication principles in their written and oral communications.[2, 24-25] Following is a brief discussion of recommended strategies for carrying out this directive.

Assessing Health Literacy – Functional and Numeracy

Assessing health literacy can be challenging because a person with low health literacy learns ways to adapt or compensate. It is incumbent of the specialist to assess a person's diabetes health literacy skills, both functional and numeracy, as these are essential skills to understand health information, carry out the instructions and implement successful self-management.

It has been shown that health literacy is a pivotal component to self-management and clinical

outcomes.[26] The health literacy skill sets include functional, interactive, critical thinking, and numeracy.[27] A person with diabetes encounters many health-related daily activities that require an understanding of blood glucose levels, medication administration and complications.

Both informal and formal methods can be used for identifying functional and numeracy concerns. An informal assessment may identify signs that a person has difficulty with reading and math. Common responses given when asked to read or fill out forms include "I forgot my glasses" or requesting that the material be reviewed by a provider. However, the expansion of e-health alternatives has broadened the type of information being provided to and sought by a person with diabetes.[27] Health literacy now focuses beyond the basic skills of reading, writing and numeracy, to social and communication skills that enable the application of health information and empower the person to participate in their care.[28-29]

A number of rapid screening tests are available to assess health literacy more formally. When selecting the tool to measure health literacy, the specialist needs to consider not only the properties of the test, if it is condition specific (diabetes), and how it will be administered (self-administered or interview); but also consider if it is appropriate and based on the person.[26] Research indicates that it is more beneficial when assessing health literacy to use a context, condition specific tool, particularly in the case of diabetes.[30] Examples of diabetes health literacy tools include the Rapid Estimate of Adult Literacy in Medicine (REALM) short form[31] and Brief Health Literacy and Brief Print Literacy Screen[26,32], all of which can be administered in five minutes or less.

While research indicates that these tools are effective for assessing health literacy, there is concern that they could stigmatize and alienate individuals who do not wish to have their literacy status exposed so openly. However, research indicates the benefits play an important role in empowerment and improved self-management. Selection of the tool used should be person-centered as they vary based on the individual socio-demographics and condition specific.[33]

Diabetes numeracy is defined as a person's ability to understand and apply numbers in the context of acts of daily living and disease management. Understanding numeracy is a common problem for people with diabetes. It can go unidentified if it's not a part of the usual screening. In diabetes management, numeracy is associated with a variety of daily self-care actions including interpreting glucose monitoring results (self-monitoring and continuous glucose monitoring), medication administration, and dietary adjustments (carbohydrate and label reading). Common areas where people with diabetes encounter numeracy difficulty are reducing risk, problem solving, healthy eating and monitoring. Often there is difficulty with accurately calculating the carbohydrate content of a packaged snack, identifying glucose levels within range, and calculating an insulin dose based on their blood glucose and carbohydrate content.[34]

The Diabetes Numeracy Test (DNT) directly measures diabetes related numeracy skills. It comes in both a short (5-item) and long version (15-item) with a higher total score being equivalent to high numeracy skills and vice versa.

In comparison, those who received care at a diabetes center and/or from a diabetes specialist used numeracy skills more effectively in making medication adjustments according to their glucose readings better than those under the care of a primary care provider.[34]

Improving health literacy and numeracy is associated with improved self-care, self-efficacy and empowerment but mixed in the improvement clinical outcomes.[35-36] However, improving self-efficacy is directly related to improved metabolic outcomes including HBA1C.[29] Attempts to address health literacy may be more effective as part of a collaborative, person-centered, evidence-based treatment approach—components of which may include shared goal setting, empowerment and focusing on problem-solving and improving self-efficacy.[29,37] As compared with a more traditional didactic model of diabetes education, these approaches emphasize interactive communication between individuals and diabetes care and education specialists to develop a plan of care. Accordingly, they may be especially appropriate and effective in low health literacy populations because they encourage and empower people towards improved understanding of their disease and more active participation in their own care.

Plain Language -improving health literacy
Using plain language is an established strategy to reduce the complexity of medical information.[2,38] It encompasses a variety of techniques for overcoming barriers in printed and oral communications, including the selection of words that average people

use in their everyday lives, and the elimination of medical jargon. Organization and design are also key aspects of plain language communication.

Tips:

- The most important points should be presented first

- Sentences should be kept short

- In printed documents, headings and bullets should be used to help break up text and make it less imposing

- Images should also be incorporated to help clarify meaning for individuals with limited reading skills

- Diabetes care and education specialists should strive to communicate in a culturally appropriate manner, with respect for the racial, ethnic, and generational differences that may affect interpretation of health information. This includes engaging the services of an interpreter for those with very limited English skills

Teach-Back Method

Participants may understand and retain only half of what they are told during a clinical encounter.[39]

However, retention and comprehension improve significantly when they are asked to restate, in their own words, the information that has been communicated to them. This interactive technique, known as the Teach-Back Method, provides an opportunity for diabetes care and education specialists to assess comprehension and correct any misperceptions – a feature that may be especially important when communicating with low-literacy groups.[39]

Cultural Competency, Sensitivity, and Humility

The importance of understanding the term diversity has expanded and become a core focus in healthcare, which has led to the expansion of the Campinha-Bacote Model of Care for cultural competence to include: cultural sensitivity, competency and humility.[40-41] All three of these attributes are needed for providing tailored education and treatment plans. It is important to note the distinct differences between cultural competence, cultural sensitivity and cultural humility. Often these terms are used interchangeably but there are distinct differences (*refer to table 1*).

Table 1 Cultural Terminology[41-43]

Term	Definition
Cultural Sensitivity	The delivery of health information based on ethnic/cultural norms, values, beliefs, social, environmental and historical factors, unique to specific populations.
Cultural Competence	Knowledge and ability to work with culturally diverse population irrespective of language, customs, beliefs, values, communications and actions of people according to race and ethnicity.
Cultural Humility	Ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the person.

Competence refers to knowledge, humility is the interpersonal and openness to another person's culture, and sensitivity refers to the dissemination of information based on factors unique to the specific population. Based on the QIAN model, cultural humility emphasizes the importance of self-questioning, cultural immersion, active listening and negotiation skills.[44] The increased diversity in healthcare has led to a need for clarifying the meaning of cultural humility and its importance in providing inclusive and optimal care.[40]

In addition, culture, one's beliefs, knowledge, customs, and habits influence not only a persons' behaviors but also how they communicate. There are also cultural differences in the ways people communicate. In other words, a person's culture is interconnected with how they communicate and interpret health information. It is important to adapt skills that can improve cross-cultural communication; defined as communication between those who have differing traits such as age, nationality, race, gender, sexual orientation, etc.[45] It also encompasses cultural variance in language, gestures and body language. In other words, it is understanding how different cultures communicate and goes beyond speaking the language and knowing the meaning of the words but is expanded to include situational context.[46]

There are five cultural attributes that can influence communication: 1.) language, 2.) cultural norms and values, 3.) stereotypes (unconscious biases), 4.) cultural beliefs and 5.) cultural body language, eye contact and gestures. Some ways to overcome these barriers is attempt to use similar language and gestures, learn about the culture and their norms and ask questions such as: "what do you know?", "How do you feel about…?", or "What do you call the problem?." Minority groups are affected by diabetes at significantly greater rates when compared to non-Hispanic white Americans for reasons that are multidimensional.[47] Careful attention to cultural influences on self-efficacy and motivation are critical for fostering behavior changes for minority groups affected most by diabetes.[43,48] Considering cultural characteristics including a person's beliefs, rituals, customs, values and family structure is important for developing and providing culturally specific and sensitive health care.[49] The ability to communicate cross-culturally is essential to providing education to diverse populations, as it enables the use of proper verbal and non-verbal communication style

across cultures. The American Diabetes Association defines person-centered care to include "care that is respectful of and responsive to individual preferences, needs and values" and emphasizes that clinical decisions be driven by the person's values.[48]

eHealth Literacy Considerations

With technology such as portals, smart phones and mobile apps, there are growing opportunities to expand the reach of and follow-up of health care for people with diabetes and other chronic conditions.[49-51] However, this necessitates the need to evaluate and design various modes of technology for health literacy sensitivity. Literacy within health information technology is termed 'eHealth'.

eHealth is defined as the ability of people to use emerging information and communications technologies to improve or enable health and health care.[50-52] In a study by Neter et al individuals who categorized themselves as chronically ill had a significantly lower eHealth literacy score.[50] Not surprisingly, individuals with higher eHealth literacy reported having increased understanding of their health status, symptoms, self-management principles and healthcare behaviors. Mackert et al surveyed 4,974 adults, with an average age of 43.5, to determine the relationship between health literacy (assessed using the Newest Vital Sign) and use of health information technology.[51] The study found that participants with low health literacy were less likely to use these tools and those with greater health literacy had increased perceptions of ease of use and usefulness of the tools. Study results also indicated that health literacy is often not considered when designing technological resources and should be a focus in order to increase the benefit for all users.

Diabetes Sensitive Language

A task force was convened to evaluate and discuss language and effective communication for people with diabetes.[52] The recommendations of the task force were published in 2017 and identify five key considerations for person-centered communication.

These considerations are that language should be:

1. Neutral, nonjudgmental and based on facts, actions, or physiology/biology

2. Free from stigma

3. Strengths based, respectful, inclusive and imparts hope

4. Fosters collaboration between individuals and providers

5. Person centered

Strengths-based language emphasizes what people know and can do versus what is missing.[52] Person-first language places emphasis on the individual instead of diabetes. It is well described in literature that certain words or phrases can intentionally or unintentionally express bias. Consciously using diabetes sensitive language can enhance outcomes.

Conclusion

Many people with diabetes have low health literacy that impedes their ability to understand and implement self-management behaviors necessary to maintain glycemic management. Diabetes educators should address these limitations by adopting clear communication strategies to improve understanding of health information and lead to better health outcomes. Recommended approaches include the use of plain language, the Teach-Back Method and adoption of collaborative, evidence-based treatment approaches that engage individuals in their own care. Selected tools for implementing these strategies are listed under Practical Resources.

Practical Resources

- **Vanderbilt University Center for Diabetes Translation Research:** (https://labnodes.vanderbilt.edu/resource/view/id/10654/community_id/1136) many useful resources including the Diabetes Literacy and Numeracy Education Toolkit (DLNET) which is a comprehensive diabetes education guide designed for use with low health literacy. Comprised of 24 distinct modules covering different facets of diabetes self-management education, any of which can be used independently to support the learning needs of individuals. All DLNET materials are freely available.

- **The Agency for Healthcare Research and Quality (AHRQ):** provides a systematic review examining the effects of literacy on health outcomes and includes examples of interventions that have been tried to improve those outcomes. Additionally, AHRQ has published the Health Literacy Universal Precautions Toolkit (https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html)

- **Centers for Medicare and Medicaid Services: (**https://www.cms.gov/outreach-and-education/outreach/writtenmaterialstoolkit/index.html?redirect=/writtenmaterialstoolkit/) features a toolkit and guideline/tutorials on how to create written documents suitable for low-literacy audiences. Available for free download from the website.

- **National Network of Libraries of Medicine:** (https://nnlm.gov/initiatives/topics/health-literacy) provides a listing of resources about the prevalence of health literacy related problems and their impact on health and economic outcomes. Includes links to a variety of resources for addressing health literacy related problems.

- **Suggestions for Improving Language, Table 4**. Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. The Diabetes Educator. 2017;43(6):551-564.

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