Literacy and Numeracy Toolkit for Diabetes Provider's Manual

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Disclaimer
These materials were designed to improve educational interactions between diabetes providers and their patients. These materials are intended only for use by qualified health professionals in conjunction with their patients. Professionals opting to use these materials take responsibility for any liability issues related to their use. Specific recommendations to patients by providers may vary from what is included in these materials.

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Background

Literacy has been defined as "an individual's ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential." [1] In 1992, the National Adult Literacy Survey (NALS) estimated that over 90 million adult Americans have inadequate literacy skills. Twenty-three percent of adults surveyed could not perform the most rudimentary of prose and quantitative skills or had extremely limited skills, and another 25-28% of respondents had only marginal skills. These subjects could perform simple one-step arithmetic problems if the numbers were explicitly stated to them, but they could not perform multi-step arithmetic, or determine what math skills were needed when reading a problem. For example, these subjects could not interpret a bus schedule to figure out how much time it would take to go from one location to another.[2]

Recently there have been several studies to examine the role of literacy in the health care setting.[3-7] Patients with low literacy can have trouble reading prescriptions, following medical instructions, and interacting with the health care system. Patients with low literacy skills have lower disease specific knowledge, report lower quality of life, and have poorer health related outcomes – even after adjusting for potential confounders such as education, insurance, and other socioeconomic factors.[8-15]

Low literacy is common among patients with diabetes, and diabetes patients with poor literacy skills may have less knowledge of diabetes self-management, and worse clinical outcomes.[14,16-22] A recent study of patients with diabetes at two urban public hospitals found that 55% of patients had inadequate literacy.[14] Of patients with inadequate literacy, 50% did not know the symptoms of hypoglycemia, 62% did not know how to treat hypoglycemic episodes, and 42% did not know the normal blood glucose range - despite the fact that 73% of the patients had attended multiple diabetes education classes. Another recent study, of over 400 patients with type 2 diabetes, found that poor literacy was associated with worse glycemic control and higher rates of retinopathy.[18]

Most of the studies to date on the role of literacy in health care have focused specifically on verbal literacy with little examination of quantitative skills. While there is a strong correlation between verbal literacy and quantitative skills[2], there are many patients who have adequate verbal literacy but are still unable to use math skills appropriately. Many patients may have had difficulty with math skills during their primary education, and are still intimidated about the prospect of using math skills. Numeracy may be particularly important to patients with diabetes because diabetes requires self-management skills that rely on mathematics such as: counting carbohydrates, interpreting blood glucose monitoring results, applying a sliding scale/correction dose for insulin, and calculating insulin doses based on insulin to carbohydrate ratios. These skills require the patient to deduce what arithmetic skills are needed for certain situations and to then perform complex multi-step math skills. Consequently, patients with poor numeracy skills may also be more likely to have hypoglycemic episodes or wide variability in their daily glucose measurements. Developing accommodations that aid patients with poor numeracy skills could greatly improve their self-management and metabolic control.

Assessment of Patient's Literacy and Numeracy Skills

Assessment of patients' literacy and numeracy skills prior to diabetes education can help to customize educational instruction. This can help to avoid the intimidation experienced by low literacy patients and optimize time available to provide diabetes education. On the other hand, studies have demonstrated that even patients with higher literacy skills often prefer lower literacy materials. Assuming that all patients have lower literacy and numeracy skills may help to improve patient comprehension and adherence.

It can be difficult to ascertain which patients have low literacy or numeracy skills. Some patients with low literacy may appear to be well poised and articulate. In one study, physicians could identify only 20% of their patients who had literacy skills below the 3rd grade level.[23] Many patients are ashamed of their literacy status and have learned to hide the fact that they have literacy problems. These patients may tell providers that they left their glasses at home, or that they want to read the instructions at home or with their family, rather than admit to their literacy problems.[24] In one study, 67% of a low-literate urban population did not reveal their reading problems to their spouses and 19% had never told anyone.[25]

Asking a patient's education status is not always an accurate way to assess literacy either. Studies have found that many adults with limited literacy skills still report that they completed high school.[25-27] Patient's literacy skills can be 3-4 grades below their reported educational status.[28] Although directly asking patients about their ability to read or their educational level will not adequately assess literacy[7,27], several easy to use literacy assessment tools are available. Health care related literacy can be assessed by using standardized tests such as the REALM and S-TOFHLA (Short Test of Functional Health Literacy in Adults), which take less than 2 and 15 minutes to administer respectively.[29-31] Another, less accurate, but quick way to assess literacy is to ask patients to read a pill bottle and explain how they would take their medication.[32]

The Diabetic Numeracy Test (DNT) is an assessment test designed to investigate the numeracy skills in patients with diabetes. The questions in the DNT were formulated from directions given by health care practitioners to patients with diabetes during a routine clinic visit. In addition, question development was guided by reviewing validated math and literacy tests. Arriving at the answers will require not only the ability to perform a variety of math skills, such as addition, subtraction, and multiplication, but also the application of those skills in the daily setting. The DNT can be written or orally administered. It consists of 43 questions in five domains: nutrition, exercise, blood glucose monitoring, oral medications and insulin. In addition, the scale consists of eight math problem types: addition, subtraction, multiplication, division, fractions, multi-step mathematics, time, and numeration/counting/number hierarchy. The estimated time for administration of the test is 30 minutes.

Communicating to Patients with Low Literacy and Numeracy Skills

Consider the following general guidelines:

1. Use low literacy oriented educational materials:

Unfortunately, a majority of the health education material is written at the 9th grade level or above.[26,33] In one small study[34], 87% of the diabetes educational materials used were assessed at the 9th grade level or above. In another study, diabetes related nutritional material was analyzed and estimated to represent a mean reading grade level of 8.9, and 62% of patients were unable to adequately comprehend the material.[26] It is recommended that health education material be written towards the 6th grade level. Even college level readers preferred materials written in easy to read formats.[28] Instructional guides for creating easy to read, attractive, graphics based materials can help to ensure a proper design. The text should focus on desired behavioral changes rather than medical facts. Replacing technical words with everyday terminology and culturally relevant context encourages recall and incorporation of knowledge into daily life. Readability formulas, which typically assess the number of syllables per word or sentence can help to assess the complexity of written materials, but do not take into account the familiarity of words or cultural relevance.[33,35-39]

2. Use Communication Strategies that Are Helpful

These strategies included: focusing on selected critical behaviors, decreasing the complexity of information, using concrete examples, limiting the number of topics covered in one session, avoiding jargon, and using "teach back" to demonstrate adequate comprehension. The "teach back" technique involves asking patients to teach information back to you to confirm that they have understood your instructions. If the patient does not "teach back" the information correctly, you continue to teach the concept until you can confirm understanding. These strategies may improve patient comprehension, [12,33,35,36,40,41] and a recent study found that patients with diabetes, who have physicians that use interactive communication skills such as teach back, have better glycemic control.

3. Be encouraging and supportive

If the patient is having difficulty, please encourage the respondent to continue. Appropriate comments are "you're doing fine." However, do not establish a pattern, such as saying "good" only after correct responses. If the patient does not want to resume the education session, please respond by saying, "I am not trying to embarrass, humiliate, or put your down in anyway. We can stop now, but I would like to pause to let you know that you are very important to this study, and the information you are providing could be used to help patients with diabetes. May I continue…"

Use of the Diabetes Literacy and Numeracy Toolkit (DLNT)

The DLTN has been specifically designed to aid in the education and self-management of patients with Diabetes. It has been designed to help patients with Type 1 or Type 2 Diabetes regardless of their current medical regimen or health status. The DLNT has been broken down into individual modules so that education can be customized to each patient. To avoid overwhelming patients with too much information, it is recommended that providers give patients the modules as they are needed. The modules and log sheets for self-management can be easily maintained in the included 3 ring binder. Each module focuses on key education concepts that are important for patients to know. Modules also often focus on key behaviors or goals for patients to follow. An emphasis is placed on limiting information to just the key concepts or behaviors needed for improved self-management.

Specific Modules Include:

1. Introduction to Diabetes
2. Testing Your Blood Sugar
3. Exercise Plan
4. Examining Your Feet (BD Materials)
5. Intro to eating with Diabetes
6. Applying Carbohydrates (The Plate Method)
7. Counting Carbohydrates (The Scoop Method)
8. Fixed Dose Carbohydrates using Scoops
9. Applying Carbohydrates (Carbohydrate Counting)

9B. Appplying Carbs to a Recipe
9C. Fixed Carbohydrate Plan (with Carb Counting)

10. Oral Glucose Lowering Medication dose schedule
11. Drawing up Insulin
12. How to use an Insulin Pen
13. Insulin for Fixed Dosage
14. Insulin for Fixed Dosage plus Correction Dosage
15. Insulin for Flexible Dosage (based on Scoops) plus Correction
16. Insulin for Flexible Dosage (based on Carb Counting) plus Correction
17. Titration of Basal Insulin Regimen

18A. Logbook for Patient Not on Insulin, but counting Carb grams
18B. Logbook for patient not on insulin, but using Scoops
18C. Logbook for patient not on insulin, and not tracking Carbs at all
19A. Logbook for Patient on Fixed Insulin with no correction, Counting Carbs
19B. Logbook for Patient on Fixed Insulin with no correction, Using Scoops
19C. Logbook for Patient on Fixed Insulin with no correction, Not Tracking Carbs
20A. Logbook for Patient on Fixed Insulin with correction scale, Counting Carbs
20B. Logbook for Patient on Fixed Insulin with correction scale, Using Scoops
21A. Flexible Dosing (Wheel), Counting Carbs
21B. Flexible Dosing (Wheel), Scoops

22. Insulin for Snacks

23A. How to use Symlin for Patients with Type 1
23B. How to use Symlin for Patients with Type 2

24. How to use Byetta

Each module is explained in detail in the subsequent pages:

1. Introduction to Diabetes
This module includes general information explaining the pathophysiology of diabetes and general goals of self management. We recommend that provides try to avoid intricate discussions about the pathophysiology of diabetes – and instead limit discussion to the key components necessary for daily self-care.

2. Testing Your Blood Sugar
This module provides information about why it is important to check blood sugar, how to check one's blood sugar and how to react to blood sugar readings. It is recommended that you show the patient how to perform glucose monitoring and then watch to see that they can perform this successfully. It would also be helpful to give the patient sample blood glucose measurement readings to ensure that they can interpret the number correctly. For example, if a patient is told that their blood sugar is 59, they need to recognize that they need to take immediate action.

3. Exercise Plan
This module includes information about why exercise is important and sets a self-management plan for an exercise regimen. Providers are encouraged to perform shared decision making with the patient to set realistic exercise goals. Patients should also recognize if they need to make any changes to their diet, medication, or monitoring if they exercise. Providers need to be cognizant of any physical limitations or other relevant health conditions that my impact on the patient's ability to exercise. Providers should not give this module to a patient unless they feel that it is safe for the patient to exercise.

4. Examining Your Feet
This module provides picture material for how patients should check their feet. Providers should encourage patients to check their feet daily.

5. Intro to Eating with Diabetes
This module provides basic information about the major dietary components including Carbohydrates, Protients, and Fats/Oils. A simple explanation of how food affects blood sugar is provided. Common carbohydrates, proteins, and fats/oils are presented. To ease patient understanding, we recommend referring to carbohydrates as "Carbs". A list of "free foods" are also provided. This includes foods that do not contain significant carbohydrates and will not significantly raise blood sugar. Patients are encouraged to fill up on "free foods". Patients are also provided a list of healthy, low-calorie snacks that have minimal impact on blood sugar.

6. Applying Carbohydrates (The Plate Method)
For patients with extremely poor numeracy and literacy skills, providers may want to consider focusing on the "plate method" for diet control. This approach will greatly limit patients' flexibility, but may provide them some structure on how to limit carb intake. For breakfast, patients are given choices from narrow lists of food. Additional items can be added to these lists if patients have specific preferences that are not listed. Providers can indicated how much carbs, protein, and fat the patient should strive for – in order to help control dietary intake. For lunch and dinner meals, patients are encouraged to split their plate as shown in pages 2 and 3: ½ of the plate can be used for free foods such as vegetables, ¼ for meat or other protein, and ¼ for carbohydrate containing foods. These two pages can be unfolded and used as a place mat to help the patient keep track of their

intake. It is also recommended that you provide the patient with a sample plate to take home with them. This figure can be easily drawn onto a paper plate, or commercial products are available. Bowls that also provide recommended intake of breakfast cereal and milk are also available.

7. Applying Carbohydrates (The Scoop Method)
This module provides a novel method for counting carbohydrate intake. Rather than focusing on counting carbohydrate grams (which can be very complex), it is recommended that you instead teach patients the "Scoop Method". The Scoop Methods involves converting foods into 15 gram allotments that can be easily measured with different size scoops. Scoops are also color coded to aid patient performance. All scoops, no matter what color (size) used, will provide 15grams of carbs per scoop. For foods that do not fit into a scoop (ex. bread), the scoop equivalent (# of scoops) is provided. A list of common foods converted into scoop equivalents should be given to the patient. A second list of fast food/restaurant foods can also be provided. Common foods that the patient consumes should be highlighted and the use of the scoops for these foods should be practiced. Patients should be encouraged to tell the dietician of any additional foods- that will be added to the scoop list as suggested.

8. Fixed Dose Carbohydrates with the Scoop Method
This module is designed for patients who are on a fixed dosage of carbohydrates but have difficulties counting actual carbohydrate grams. Instead patients can be given carbohydrate goals in "Scoops" using the Scoop method described above.

9. Applying Carbohydrates (Carbohydrate Counting)
For patients with more complex numeracy skills, one can attempt to teach them actual carbohydrate counting. Carbohydrate counting actually requires a large amount of numeracy related skills including: calculations, fractions and percentages, estimation, and understanding of proportions. The module helps patients to identify where on the nutrition label carbohydrates are located. The module further provides information about how to determine carbohydrate intake based on amount consumed and serving size information. In our experience, patients have particular difficulty when they eat more or less than 1 serving size of a product, or when a product contains multiple portions in a single serving size. It is strongly recommended that you have patients work through the examples provided to make sure that they can calculated carbohydrate grams correctly. In addition, showing patients additional products, particularly ones they consume to test their ability to count carbohydrates would be helpful. Patients also need to be able to add carbohydrate grams from multiple products consumed. Patients can also be provided with reference books that contain supplemental information about the carbohydrate content of foods.

9B. Calculating Carbs from a recipe
This module provides specific instructions for figuring out the carb grams when cooking from a recipe. The module teaches patients how to determine the amount of carbs in the whole recipe – and then how to determine how many carbs are in one serving of the recipe. This module should be reserved for the most advanced patients.

9C. Fixed Carbs Meal Plan
For patients who can count carbs, and need to be on a fixed amount of carbs per meal, this module can be used to help the patient keep track of recommendations. A copy of this chart can be filled out and photocopied so the patient can keep it on their refrigerator as a reminder.

10. Diabetes Pills
This module provides specific instructions for patients as to what oral medicines they are taking for their diabetes and when to take them. For patients who have difficulty reading their prescription bottles there are several approaches that might be helpful: 1. tape actual pills or pictures of pills onto the page so patients are aware of what pills they need to take when, 2. ask patient to bring pill bottles to the visit and write a color coded letter on the pill bottle that matches with a color coded letter on the page (example, put a big red M on the metformin pills and on the page where metformin dosage is described).

11. Drawing up Insulin in a Syringe
This module provides illustrations to help guide patients through drawing up insulin in a syringe. For patients who have difficulty using a syringe, you may want to consider using an insulin pen or other insulin delivery device (see below). Providers may also want to consider using pre-drawn syringes, or putting a colored mark on the syringe for where patients should draw to.

12. Using an Insulin Pen
This module provides illustrations to help guide patients through administering insulin with an Insulin Pen. Providers should consider insulin pens for patients who have difficulty reading the syringe number scale or manipulating the syringe. For patients with poor vision, Insulin delivery devices that have larger numbers are recommended. Patients with very poor vision can be taught to count the audible clicks emitted by the pen as each unit is dialed in.

13. Insulin for Fixed (Set) Dosage
This module provides specific instructions for patients as to what insulin they are taking for their diabetes and when to take it. This module is specifically designed for patients who are on a fixed dosage of insulin. This includes patients who do not adjust their insulin based on blood sugar, exercise or carbohydrate intake

14. Insulin for Fixed Dosage plus Correction Dosage
This module provides specific instructions for patients as to what insulin they are taking for their diabetes and when to take them. This module is specifically designed for patients who adjust their short-acting insulin based on their blood sugar. Rather than trying to teach patients how to calculate a correction dosage and add it into a fixed dosage of insulin (as is usually done), the module automatically integrates the sliding scale into the recommended dosage. This helps patients with poor numeracy who may have trouble performing multiple calculations.

15. Insulin for Flexible Dosage (based on Scoops) plus Correction
This module provides information on how to adjust insulin based on carbohydrate intake. Rather than adjusting insulin for grams of carbohydrates consumed, patients will be able to adjust insulin based on number of “Scoops” consumed. Each “Scoop” is equivalent to 15grams of carbohydrates. For example, a patient may take 1unit of rapid acting insulin for each “Scoop” consumed (similar to being on a carb ratio of 1unit:15grams of carbs). Another patient may take 5 units per “scoop” (similar to being on a carb ratio of 1 unit: 3 grams of carbs). The patient will be able to use the wheel to help determine how many units of insulin to take. The wheel will include a correction for the amount of scoops consumed and for the most recent blood glucose level.

16. Insulin for Flexible Dosage (based on Carb Counting) plus Correction
This module provides information on how to adjust insulin based on carbohydrate intake. Patients will adjust insulin based on grams of carbohydrates consumed and most recent blood glucose level. Patients will need to be proficient in calculating carbohydrate gram intake. The patient will be able to use the wheel to help determine how many units of insulin to take. The wheel will include a correction for the amount of scoops consumed and for the most recent blood glucose level.

17. Titration of Basal Insulin Regimen
This module helps a patient to titrate a basal insulin regimen. For example, this table could be used to help titrate a nightly basal regimen of insulin. Patients are instructed to measure their fasting blood glucose each morning and to increase the basal insulin if the blood sugar remains elevated. Providers need to fill in the blanks in the table to determine the type of basal insulin, when the insulin should be taken (am or pm), and parameters for titrating the dosage. It is strongly recommended that the provider give the patient some sample blood sugar readings to ensure that they can read the table correctly. It is also recommended, if feasible, to call the patient every 3rd day to confirm titration until the patient has reached their optimal dosage.

18. Logbooks for Patient Not on Insulin
These logbooks are designed for patients not on insulin. Version A is for patients not counting carbs at all. Version B includes space for patients on “scoops”. Version C includes space for patients counting carbohydrates. Note that the Goal column can be used to set weekly goals for each item.

19. Logbooks for Patient on Fixed Insulin with no correction
These logbooks are designed for patients on fixed dosage insulin. Version A includes space for patients counting carbohydrates.Version B includes space for patients on “scoops”. Version C is for patients not counting carbs at all. It is recommended that you write the amount of insulin prescribed into the Goal column.

20. Logbooks for Patient on Fixed Insulin with correction
These logbooks are designed for patients on fixed dosage insulin with a correction scale. It includes space to write in blood sugar measured, recommended insulin dosage (based on fixed insulin plus correction (as calculated in Module 14). There is also a space for patients to write down their carb intake (in scoops (Version A) or carbs (Version B)).

21. Logbook for Patient on Flexible Insulin and Scoop Method
These logbooks are designed for patients on flexible insulin using either carb counting (Version A) or the scoop method (Version B). Patients are encouraged to record blood sugar and amount of carbs or scoops consumed. They then use their Insucalc wheel to determine the amount of insulin to take (as explained in Modules 15 or 16). They then record the amount of insulin recommended and the amount actually taken. The goal column can be used to help patients with their goal blood sugars, and carb intake.

22. Insulin for Snacks
This module provides specific guidelines for how much insulin to take for snacks. It assumes that patients will take a fixed dosage of insulin for their snack.

23. How to use Symlin for Patients with Type 1
This module provides information for how to titrate Symlin for a patient with Type 1 Diabetes.

24. How to use Symlin for Patients with Type 2
This module provides information for how to titrate Symlin® (pramlintide) for a patient with Type 2 Diabetes.

25. How to use Byetta
This module provides information for how to titrate Byetta® (exenatide) for a patient with Type 2 Diabetes.

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