Chapter 1

Communication and Engagement



Key Messages

- People with diabetes want supportive health professionals with whom they can discuss any aspect of living with and managing the condition.
- An open, empathic communication style is important in enabling people with diabetes to talk about their emotional and mental health.
- The language that health professionals use can affect people's willingness to talk about the challenges of living with diabetes, their motivation, self-confidence, self-management skills, and diabetes outcomes.
- As with any skill, communication skills can be acquired and improved with practice, and confidence increases over time.



Practice Points

- Seek to "meet the person" where they are in their life—rather than where you would like them to be, where you think they should be, or where you are.
- Active listening and open, empathic communication (verbal and nonverbal) improves the quality of the interaction and is essential for best clinical practice.
- · Reflect on the proportion of the appointment time that you spend talking rather than listening. Is the balance right? Appointments are typically more effective when the person with diabetes talks more than the health professional.

Talking about Emotional Health Is an Essential Part of Diabetes Appointments



The great enemy of communication, we find, is the illusion of it.

-William H. Whyte1

Arguably, the fundamental skills in any healthcare visit are communication and engagement. These are essential tools that health professionals use every day to gather information, establish the problem/diagnosis, discuss options, and agree on an action plan. These skills are relevant no matter whether the issue is physical or emotional.

The most obvious reason for being attentive to emotions and mental health is to recognize the person's need for support. This is true in relation to general psychological distress, such as depression and anxiety, but also to the emotional impact of living with diabetes. Having a conversation about how diabetes affects the person's emotional health can help them feel that someone understands their perspective and is "on their side." For example, they may no longer feel isolated by feelings of guilt and frustration about getting "off-track" with their diabetes management. This change can be very powerful because the way a person feels about their diabetes can have a significant impact on their motivation and ability to manage it.



Patients have their agenda... [and if that's] not dealt with they cannot move on. Anything I say or recommend will not be taken in if the patient's issues are not dealt with first.

-Practice nurse²

Health professionals can assist people with diabetes to develop or strengthen their skills and confidence for effective self-management—but first a conversation is needed to establish what challenges the person is facing, and how to assist the person to overcome them. However, this conversation is not (yet) part of routine practice.

Numerous studies demonstrate that people with diabetes want support with the psychosocial aspects of diabetes.3-7 Yet, distress related to living with diabetes is not often acknowledged by health professionals.8 While half of health professionals report asking their patients with diabetes about emotional issues, only one quarter of people with diabetes report that a health professional has asked such questions of them. 10 Why might this be the case?

Perhaps the person with diabetes is not expecting emotional issues to be discussed during that visit. Or, perhaps, health professionals are not asking the right questions, or not allowing time for the person to offer a considered response that actually reflects how they feel about living with diabetes.

Research shows that the person's agenda is elicited in just 36% of clinical encounters - more so in primary care (49%) than in specialist care (20%).11 Health professionals interrupt the person within an average of just 11 seconds, typically with statements or 'closed questions' (see Box 1.1). This further reduces the opportunity to orient the clinical encounter towards the priorities of the person.11

Seeking to understand the individual's priorities, preferences, and everyday challenges will enable you, together with the person, to establish a management plan that is achievable and reflects their life or well-being. Indeed, having the conversation may help you realize that the person needs more help than you can provide for example, from a diabetes educator, endocrinologist, or a mental health professional.

To achieve this, using an open, empathic communication style (see Box 1.1) can create a safe and supportive environment, build rapport, and engage the person.



A systematic review found high continuity of care is associated with lower mortality rates.12 The authors could only speculate about why this might be, but suggested that trust and open communication leads to greater disclosures and better tailoring of care to the person's needs, with a greater likelihood of optimal self-care and taking medications as recommended.

BOX 1.1 Open and Closed Communication Styles

People with diabetes seek out health professionals as much for their personal communication skills and interaction style (e.g., care and empathy) as for their clinical expertise.

As demonstrated in the table below, the immediate outcome of open, empathic communication is an honest exchange of ideas and challenges. 13 Indeed, this may be the only tangible effect that the health professional is aware of—but it is likely to lead to other benefits.

In contrast, the immediate outcome of closed, directive communication is stereotypically brief, in which the person with diabetes leaves with a prescription, some pamphlets, or a referral. At face value, this may appear both effective and efficient. However, the person may have queries and concerns that affect their outcomes and matter to them, which they did not raise; they may leave the appointment with misunderstandings and mistrust. Importantly, they may also feel that they have not been "heard."

Other potential consequences of these distinctly different communication styles are summarized below. In the longer term, these can translate into consequences for health (and healthcare costs), as well as quality and quantity of life.

0	utcomes of open, empathic communication:	Outcomes of closed, directive communication:
>	increased trust in the health professional	mistrust and lack of confidence in the health professional; desire to change care provider
>	increased knowledge, confidence/self-efficacy	> not seeking further care, lack of confidence
>	increased engagement in decision-making/ collaborative decision-making/better decisions	> lack of engagement in decision-making (wasted efforts and opportunities)
>	increase in coping skills to overcome daily challenges (proactive coping)	> increased reliance on health professional directives
>	increased motivation	> decreased motivation
>	personal care plan	> general care plans
>	increased engagement with self-care activities (e.g., medication taking)	 at best, passive "compliance"; at worst, active disregard of health professional's advice and recommendations
>	increased satisfaction with the health professional/system	> increased complaints and negligence claims
>	realistic expectations (for both parties)	> unrealistic expectations (by both parties)
>	and reduced errors/mistakes (e.g., in prescribing or taking medication).	> and misunderstandings and misinterpretation of advice/ recommendations.

Enhancing Your Communication Skills



Communication is a skill that you can learn. It's like riding a bicycle or typing. If you're willing to work at it, you can rapidly improve the quality of every part of your life.

-Brian Tracy14

As a health professional, you bring considerable experience and a certain perspective to your interactions. So, too, does each person with diabetesthey bring their life experience and their awareness of how diabetes does or doesn't fit into their life.

Having a conversation about the emotional aspects of living with diabetes can be challenging. Many of the general techniques for effective communication (see Box 1.2) are applicable but, like any other skill, they are not necessarily intuitive. It takes time and practice to develop, and they can always be improved, but anyone can learn these skills and the community will notice the difference. 15,16 Take this opportunity to reflect on how you incorporate these general techniques into your appointments.

BOX 1.2 The ABC's of Effective Communication

Active listening

- Active listening is a fundamental communication technique that includes a range of verbal and nonverbal skills.
- Listen to what the person says AND how they say it (hesitations, timing, emotion, etc.).
- Demonstrate that you are paying attention by nodding your head, adopting a forward leaning posture, and using verbal facilitators, such as "go on...," "uh huh...."
- > Avoid interrupting too quickly—some health professionals worry that the person will keep talking for several minutes, but in reality, people tend to only talk for about two minutes (on average).

Body language

- Look for signs that someone is not doing OK, despite what they may be saying verbally.
- Observe the person's nonverbal communications (i.e., facial expressions, body language) and any inconsistencies between their verbal and nonverbal communications.
- > Keep in mind cultural variations (e.g., eye contact is not appropriate in all cultures). What is their body language telling you?
- What is your body language saying about you? Maintain eye contact, if appropriate, and avoid being distracted by the computer or telephone. Be aware of crossed arms or legs (which can appear unwelcoming and even judgmental).

Clarify information and paraphrase

- Reflecting and paraphrasing are important techniques to acknowledge that you have been listening to the person and to make sure you have understood.
- > Repeating some of the person's own words back to them (reflecting) as a question can help to prompt further detail. Doing this with a deliberate pause and invitation to say more can encourage them to continue their conversation. For example, "You said it has been very hard to [...]?"
- > Paraphrasing means capturing the meaning in your own words: place the onus of understanding on yourself. For example, "So I can be sure I've got this right, you are saying that [...]. Is that right?"
- Similarly, encourage the person to ask you questions, and check their understanding by asking them to paraphrase what you have just said. For example, "I want to check that I've explained this clearly, so can you please tell me in your own words" If your message has not been understood, explain it again in a different way.
- > Repeat key information (in different ways, if necessary).

Develop rapport

- Most people with diabetes want someone on their side, someone who can help and support their self-management efforts, rather than someone who tells them what to do or criticizes them.
- Use motivational, collaborative language to appreciate the efforts the person makes and gain their confidence. For example, "I can see how hard you have been working on your [blood glucose/activity levels/weight] since we last met."
- > Keep a good balance to the conversation; ideally, the person with diabetes should be talking as much as (if not more than) you.
- Build trust through repeated appointments and interactions.

Use plain language—avoid jargon, acronyms, or shorthand without explanation. Explain Provide information in writing that is appropriate to the audience—use plain English, clearly dot points, and short sentences, and consider readability design principles (e.g., large font size). > Use diagrams, pictures, or models, where appropriate. Anecdotes and storytelling can be useful for explaining difficult concepts. Or, you may have visual aids or culturally appropriate or translated resources that you can use to improve the explanation. > Ensure the person has ample opportunity to tell you how they feel about your advice/ **E**eedback the action plan, and how realistic it is for them. For example, "We talked about doing blood glucose checks before every meal. How do you feel about giving this a try in the next few weeks?" > Also, ask for feedback about your service. This can be done routinely and anonymously. It will be enlightening. > Set up expectations at the start of the appointment (e.g., how much time is Give clear available, what will happen at the end, and what will happen next time). signals > Let the person know (by signposting) that you need to move onto another issue or to draw the appointment to a close. > It is important that the person does not feel dismissed or irrelevant. If the issue they are concerned with needs further discussion, arrange for them to return another day when there will be more time. If you are referring the person to another health professional, let them know why you are doing this and make sure they feel comfortable with it. **)** Don't feel obligated to fill every pause with questions or advice. ear the > Silence allows the person time to gather their thoughts and express themselves. sound of silence If a pause becomes too long, ask what they are thinking about. > Remember that the person's body language will offer clues. > Summarize the main issues at the end of the appointment, including action plans, In to make sure there is mutual understanding of what has taken place and how to conclusion move forward. Offer an early follow-up appointment to demonstrate that you are interested in continuing the conversation and finding out what happens when they try their action plan.

Having a Conversation about Diabetes and Emotional Health



I try to put patients at ease, be affirmative and responsive.... I hope to improve my skills for the areas where I don't feel comfortable.

-Practice nurse²

I'm confident and comfortable with bringing out the issues and giving the patient the space to discuss these, but I don't know what to do next.

Diabetologist²

It is not always easy to know how to begin a conversation about emotions. Similarly, it can be difficult to know what to say when someone expresses their distress or shares that they are not coping well with their diabetes. You can help by asking open-ended questions, which enable the person to respond by describing their experience, thoughts, or feelings about a particular issue, rather than with simple "yes" or "no" answers. Creating an empathic and supportive environment will be conducive to having conversations about the emotional aspects of diabetes. 11,17

Start the Conversation

Begin the conversation with an opening comment to build trust and rapport (e.g., normalizing statement, or referring to a previous conversation/visit), such as:

- > "Some people talk to me about how their diabetes affects how they feel, and that they don't always find it easy to live with this condition."
- > "Over the past couple of months we have been working together to get your diabetes management on track. How has this been for you? Is there anything you've found particularly challenging that you'd like to talk about?"

Ask **open-ended questions**, to show the person that you are interested in their experiences. Open-ended questions allow for longer responses and more detail, they require more than just a brief, one-word response (e.g., "yes," "no," or, "OK"). For example:

- > "What brought you here today?"
- > "Tell me, how are you doing with [aspect of diabetes management]?"
- > "You've been [using medication] for about [a month now]. Tell me how that has been going."

- You've had diabetes for [a year] now. What is going well for you? What is the most challenging for you?"
- > "What thoughts do you have about why that keeps happening?"
- "How does that make you feel?"

Normalize the issues raised by the person, by helping them to view their experience as common, "natural," or "human." For example:

- > "That's understandable. You know, many people with diabetes feel that way, too."
- "This seems to be a normal reaction to struggling with this."18

Normalizing helps:

- > the person to disclose an experience, thought, or feeling that may be very sensitive for them
- > to see that they are not alone in experiencing certain feelings or thoughts, and this can enhance their sense of self-esteem
- > to reduce secondary emotional reactions, such as feeling anxious about revealing that they fear, for example, hypoglycemia, or that they feel guilty about not coping well with diabetes
- and the person to feel they can confide in you. 17,19

Continue the Conversation

Afford the person time to share their experience (without interruption, question, or judgment). This makes it more likely that you will identify the issues of concern. You have earned their initial trust, but you have to retain it.

Be prepared for the response. How will you interpret the person's response and what actions will you take next? There are myriad questions you could ask, and there are many ways in which the person can respond. Box 1.3 offers some examples of responses that you may want to consider. Attempts by you to redirect the questioning to elicit an honest response need to be handled sensitively. Refer above to "normalize the issues"—did you do enough to put the person at ease to share openly and honestly with you? The person may not be ready to discuss the matter with you now, so offer them the option to talk about it another time. Or, perhaps they do not feel comfortable discussing it with you (e.g., for personal or cultural reasons). In this case, offer the person an opportunity to discuss the matter with another health professional who may be more acceptable to them (e.g., someone they feel they can trust more or a person of the same sex or cultural background).

Be prepared for what to do next. What can or will you do if you discover, from open-ended questions or from a questionnaire, that the person is not OK? What resources are available to you and to the person with diabetes? First, you have this practical guide. Each chapter will guide you through the options relevant to the particular types of emotional or mental health issues you may identify. At the end of each chapter, there is a list of relevant resources and further reading (both for you and for you to recommend to the person with diabetes).

Accompanying this practical guide is a series of handouts, which cover the same topics as Chapters 2-8 and Appendix B. You can give these handouts to the person with diabetes—they are designed to help them understand the issues they are facing and what help is available to them. These materials can be accessed at https://professional.diabetes.org/meetings/ mentalhealthworkbook.

Close the Conversation

Finally, how you close the conversation is just as important as how you open it.

Acknowledge the confidence that the person has shared with you. For example, "Thank you for sharing that with me today [I can see it has been difficult for you]. I hope it has helped you. Would it be a good idea to talk about this some more at vour next visit?"

A general closing might be to invite the person to consider what they would like to talk about next time, and agree to put it as the first item on the agenda of the next appointment. You could offer a list of possible topics, including emotional health issues for them to choose, if they want such a prompt.

BOX 1.3 Be Prepared for the Response

Here are some practical tips about what to do in various scenarios, for example, if the person:

- Does not reply immediately to a question. We often feel awkward when conversation is not free flowing, and we feel a need to fill silences. However, it is OK to give the person an attentive look (not a stare) and allow some time for them to gather their thoughts. Then, acknowledge their reluctance and gently prompt with "take your time." Ask if it is OK to ask another question or if they would like to ask you something instead.
- > Responds with "no" or "nothing." Ask if they would like to add anything more. Acknowledge that the question may have been irrelevant. Ask, "What would be useful for us to talk about?"
- **Stops talking.** Periods of silence are OK. They can help the person gather their thoughts and express their emotions. You may feel concerned that the silence will go on too long, but most people will break the silence within two minutes.
- > Starts crying. Let them see that you accept their emotions and tell them, "It's OK to feel this way," or "I can see how upsetting this is for you." Do not try to reassure the person with words like "It will be alright, you'll see" this is not necessarily helpful or true.

- **> Becomes extremely distressed.** In times of extreme emotional distress, nonverbal support (e.g., sitting alongside someone and creating a calm environment) can often speak louder than words. Do you need to arrange an urgent referral to another health professional?
 - It is unlikely that the person will be able to take in or recall much of what you are saying because they are experiencing strong emotions. Could you provide some written information for them to take home? Would they like to bring a friend or family member to provide support and take notes at the next appointment?
- > Seems to need more time than you have available in this appointment. Proactively, you can set the time at the beginning. For example, "We have about 15 minutes today to discuss these issues; what we don't finish today, we can discuss next time." If time is becoming an issue during the appointment, acknowledge this. For example, "Your feelings seem overwhelming at the moment, is that right? We have about [10] minutes left. What can we do in this time together that would help you most at the moment?" This is a better strategy than moving onto something that you think will be quicker.

Overcoming Barriers to Talk about Emotional Health in Diabetes



[I was] uncertain of the correct advice to give—and worried in case the patient became aware of my own discomfort.

-Diabetes specialist nurse2

I feel less confident dealing with psychological problems... [I] want to pass them on as quickly as possible. I don't have the training to deal with them.

-Diabetes specialist nurse2

Even if I had the skills, I only have 20 minutes....

Diabetes specialist nurse²

As these quotes show, health professionals face many challenges and barriers in providing adequate psychosocial support to people with diabetes.^{2,20} The health professional is required to make a shift from the role of "authoritarian" (i.e., someone with all the expertise who tells the person with diabetes what to do) to the role of a listener and collaborator.²⁰ While, at first, it may take more time to listen and gain insight into the person's perspective, it will lead to establishing a trusting relationship with mutual respect. Some of the key barriers are described below, to enable you to reflect on which might apply to your appointments and what you can do to reduce those challenges.

Lack of time/fixed appointment times: From a practical perspective, lack of time remains a perennial barrier to a more person-centered approach—but many health professionals do manage to overcome this. Listening to the person's experiences and needs, and acknowledging their own way of experiencing their diabetes, is a vital component of person-centered care.20 Ask yourself, is it ritual or rigid practice that limits your time? Do you think that if it does not concern diabetes directly it is not important? If you choose to interrupt at this point, you may lose the opportunity to elicit the person's agenda or the concerns.REF11 One way to deal with time constraints is to agree with the person at the beginning of the appointment on the priority issues and manage their expectations about the time available. If there is more to be discussed, encourage the person to come back and book an extended

- appointment time. Even if initial appointments take some time, there are long-term benefits to be gained. Remember that when the person is distressed, they may not be able to assimilate what you are saying about managing their diabetes better and may remain focused on managing their emotions. Furthermore, if emotional health is not addressed, the problem is likely to become worse. Ultimately, by building rapport, your subsequent interactions will be much more effective. People with diabetes are then more satisfied and feel more empowered.
- **Lack of confidence:** Many health professionals lack confidence in their own skills and report sticking to their own agenda as a mechanism for not having to adopt a person-centered approach. Confidence comes from within, and your skills will improve with practice. Health professionals may be fearful of what might be disclosed, or of issues that they cannot solve. Remember, you are not there to solve all of the person's problems. Often, all the person with diabetes wants is to be heard, to have their feelings validated, and to know that "someone is on my side."
- **Lack of skills or expertise:** Many health professionals perceive their skills or expertise to be limited when it comes to talking about emotions, but most have well-developed communication skills. If you feel you need training, working through this guide is the perfect first step. It is a learning process, so allow time and practice to improve your skills. For some psychological problems, a referral to a mental health professional will be necessary and it is important to acknowledge when this will be the case. For many other issues, you may find that emotional distress is related directly to the experience of dealing with diabetes on a daily basis. People with diabetes who experience psychological problems often prefer to talk about this with their diabetes health professionals or their primary care physician (PCP) rather than with a mental health specialist.3 For example, as diabetes distress (see Chapter 3) is so common and intertwined with diabetes management,21 it is best addressed by a diabetes health professional, or the PCP if they are the main health professional.
- **Lack of referral options:** Lack of psychological services (specifically those with expertise in both mental health and diabetes) is well documented. The American Diabetes Association (ADA) Mental Health Provider Education Program and the Mental Health Provider Directory^a are excellent resources, as are ADA

a The ADA Mental Health Provider Directory helps people with diabetes locate mental health professionals in their area that have expertise in diabetes care. To learn more about the directory or how to apply to be listed, visit https://professional.diabetes.org/mhp_listing.

Recognized Diabetes Self-Management Education and Support (DSMES) programs. You may be able to identify a mental health professional with an interest in diabetes through these networks. It is also important to realize that only a small number of people with diabetes may need a referral. People with diabetes may not need specialist services. Rather, they may need a diabetes health professional with whom they can talk about how distressing it is to live with diabetes (see Chapter 3). In the DAWN2 study, significant diabetes distress was reported by nearly half of the participants, but only 24% of them reported that their healthcare teams asked them how diabetes affected their lives.²² They may also benefit from the support of other people with diabetes (see Appendix B).

- **Different agendas:** You and the person with diabetes may come to the appointment with different agendas. The best way to find out the individual's agenda is to ask. For example, "Tell me why you're here today," "How can I help you today?" or "What would you like to get from today's visit?" People with diabetes may not be aware that they have the right to ask questions during appointments,²⁰ especially about psychosocial issues. Asking guestions, giving them a voice and an opportunity to teach the health professional about what it is like to live with diabetes will establish trust, improve rapport, and assist in building a collaborative relationship.
- **Costs:** Some health professionals may believe it is too time-consuming and expensive to integrate routine monitoring of emotional health into their appointments, or that offering psychological support adds a further financial burden (e.g., on the health system or on the person with diabetes). However, there is no doubt that people with diabetes who are distressed fare worse than those who are not. For instance, depression (see Chapter 6) increases the risk of long-term complications, healthcare costs, and mortality.^{23–25} So, psychological distress needs to be considered a cause—not merely a consequence of complications, and reducing distress can be considered as a clinically meaningful way to reduce other diabetes-related complications.²⁶ This provides an economic rationale for improving communication about emotions and mental health.
- Health literacy, language barriers, and passiveness: One of the key barriers to effective communication is understanding. Check the person's understanding—don't settle for the "smile and nod."

Ask the person to explain their understanding of what you have told them in their own words. Do you know why they don't understand? Is there a language barrier or health literacy issue? Is your explanation too complex? If they don't understand, take the time to explain again in a different way.

Stigma/myths about mental health and diabetes: Fear of stigma and negative stereotyping can reduce the effectiveness of a visit. In extreme cases the relationship may become a sterile, ineffective exchange based on what the person thinks you want to hear and/or what the person is prepared to share with you. Experiences of stigma may discourage a person from engaging in self-care activities, attending future appointments, or seeking professional support.²⁷⁻³⁰ Health professionals may convey stigmatizing attitudes unintentionally in their language, actions, and reactions. Consider how your words and actions might inadvertently reflect negative attitudes about mental health31 and diabetes.32

It is worth finding ways to overcome any of these barriers if you are experiencing them. The reality is that we work more effectively and efficiently when we seek to understand the person's feelings and their reasons for distress, particularly when these underpin their self-care behaviors. Clinical psychologist, Dr. Mark Davies, notes:

"Many diabetes professionals have highly developed communication skills and years of experience of dealing with people whose lives have been affected by diabetes. Whilst lack of time can frequently be an issue, it may well be that many... underestimate the skills they possess."26

Despite initial apprehensiveness, many health professionals report feeling positive about their handling of emotional health issues once they have tried engaging in such conversations. Furthermore, they realize that they had the skills to do so and that they applied them successfully during the appointment.2



At the end [of the psychosocial discussion] I felt pleased with the outcomes and the patient seemed more at ease.... I think I make patients feel comfortable and able to talk openly.

-Health professional²

What Else to Consider?

A Few Words about Language



Words are, in my not-so-humble opinion, our most inexhaustible source of magic. Capable of both inflicting injury and remedying.

> -Albus Dumbledore in Harry Potter and the Deathly Hallows³³

A key element of communication is the use of language. Words can be incredibly powerful, so it is important to choose them carefully.

The ADA and Diabetes Australia have published guidance about the use of language in diabetes care,32 34 which highlights that:

- > Words have impact. Words can positively or negatively affect the person with diabetes. The language you use can affect the person's willingness to confide in you; it can also have an impact on their motivation, confidence, and, ultimately, their diabetes outcomes.
- Words can label the person or perpetuate negative stereotypes. For example, the label "diabetic" defines the person by their medical condition, and "patient" implies dependency on the health system. In contrast, referring to the "person with diabetes" acknowledges other facets of their identify/life/personality that are equally salient for them, and that they are functioning successfully in their own home/work environment.
- Words can be judgmental or demotivating. Many people with diabetes report feeling criticized for not managing their diabetes well, yet they often feel they are doing the best they can. For example, criticism may be implied by phrases like "poorly controlled" or "failing to manage," and can leave people with diabetes feeling demoralized and that their efforts are under-valued. The words you choose to use may stay with that person long after you have forgotten the appointment. It is important to acknowledge how challenging diabetes can be.
- Words can lead to missed opportunities—or create them. Diabetes is a lifelong condition and people will, naturally, have times when diabetes is not their main priority, or when they are struggling with self-management. Labeling the person as "noncompliant," "poorly controlled," or "uncooperative"

- can lead to missed opportunities to engage the person in a conversation about why things are not going well and how you can support them.
- Words can affect the relationship between the health professional and person with diabetes. It is best to use words that neutralize any judgment about the outcome. Instead of referring to "good control" or "poor control," refer to blood glucose levels being "in target" or "above target." Rather than directing the person with phrases like "you must..." or "you should...," choose words like "you have some choices here...," and "let's discuss your options...," which respect the individual's autonomy and indicate a collaborative relationship.

Using Questionnaires to Inform Appointments



I am just aware that I have a tendency to concentrate on my own agenda and feel I should improve my skill at focusing on the patient's agenda.

Diabetes specialist nurse²

Questionnaires can be very helpful for monitoring the emotional and mental health of people with diabetes. In particular, questionnaires about diabetes distress (see Chapter 3) can help to focus the agenda of the appointment on any challenges the person may be experiencing related to living with and managing diabetes.

Questionnaires can be used effectively in specialist care^{6,7} and primary care settings.³⁵ People with diabetes and health professionals alike value the assessment and discussion of outcomes, and generally express greater satisfaction with appointments in which this has taken place. 6,36 Followup studies have shown that using questionnaires and discussing the outcomes, leads to reductions in diabetes distress and improvements in A1C.6,37

There are several well-validated, reliable, and easyto-use questionnaires for assessing the emotional health of people living with diabetes. They are featured in relevant chapters of this guide (Chapters 3 to 7). Additionally, you may print copies from the PDF version of the guide, available at this website: https://professional.diabetes.org/meetings/ mentalhealthworkbook

Before using questionnaires in your practice, here are some points worth noting:

- **Have a good reason.** Be clear about why you are asking someone to complete a questionnaire. For example, it is appropriate to use a diabetes distress questionnaire on a routine basis because the issue is relevant to most people and because the person's responses can help you tailor the visit and plan to their needs. You can also monitor their distress over time. However, asking people to complete a large quantity of unnecessary questionnaires just so you have their "score" on record is a waste of their time and yours.
- > Explain your reasons for asking the person to complete a questionnaire. Explain why the questions are relevant to their individual situation. People will be more inclined to respond (and tell you how they really feel) if they realize you are trying to understand their experience of living with diabetes so you can be of greater help to them. Otherwise, they may perceive it as a waste of time and resources. Importantly, reassure them it is not a "test" and there are no right or wrong answers. Also, reassure them that the information will be treated as confidential and tell them what you intend to do with the completed questionnaire (e.g., will you keep the questionnaire in their medical notes?).
- **Choose your method and timing wisely.** Select a method for administering the questionnaire that will be most suitable and convenient for the person with diabetes and yourself. Some people may prefer completing a questionnaire using their smartphone, a tablet computer, or via a website. Electronic versions may also be more convenient if they automatically calculate total scores and link with the person's electronic health records. However, some people may not feel comfortable with the technology and will prefer traditional pen and paper. Similarly, consider your timing-often people will be more willing to complete a questionnaire if they are asked to do so in the waiting room before an appointment, rather than at home or during the appointment.
- Questionnaires can save time and help you get to the heart of an issue. Inviting the person to complete the questionnaire in the waiting room before they come in to see you can prepare them for the conversation to follow. You can then quickly skim their questionnaire responses to enable you to start a conversation about the issues of most relevance to them.
- > Consider individual circumstances, needs, and capabilities. Health literacy, language barriers,

- disability, and other factors may affect a person's ability to understand and/or complete a questionnaire on their own. Differing cultural perceptions of health and mental health may impair the validity and interpretation of the questionnaire (see "Cultural and Linguistic Diversity" page 13). If you have concerns about the suitability of a questionnaire for the person, consider other options. For example, can you read the questions and response options out loud to them? Is there a suitable questionnaire in their first language or validated for their cultural group? Could you ask open-ended questions instead?
- Questionnaires may not always be the best way of gathering information. Asking openended questions is a valid and practical alternative. Questions such as, "What is it about living with diabetes that you find most difficult?" and "How does that make you feel?" can help you gain some insight on these issues without using a questionnaire, and it makes the conversation more personal.
- **Do something with the results.** Screening alone is not enough to improve health outcomes.³⁸ If you ask someone to complete a questionnaire, it is important that you always find a way to discuss and use the information. Ignoring it or just placing it "in the file" is unethical.26

Creating an Enabling Environment



I don't mind discussing sensitive issues. The problem is finding enough privacy.

-Health professional²

The room setup is very important for enabling personal disclosure. Ideally, the room needs to be guiet and private. The furnishing and décor should create a welcome, safe, and supportive environment. Think about your environment and what you can do to improve it:

- **Waiting room:** This is where the person gets their first impression. What messages do your posters, magazines, and brochures send to people? Are there campaign posters involving scare tactics, pictures of medical procedures and/or complications, or magazines focused on diets and body image? Perhaps it is better not to have these types of materials lying around—what is motivating to one person may fill another with guilt, despair, or irritation.
- **Consultation room:** What do people see when they enter? Similar posters as in the waiting room? Is the

room set up as an exam room? Do you sit behind a desk or a computer? What do these things say about the power balance or your interest in having a conversation? Will the person feel comfortable raising sensitive issues with you in the space?

- **Computer:** It is difficult to type and talk at the same time; it's even harder to type and listen at the same time. Give the person in front of you your full attention. Show that you are listening and, above all, that they matter to you.
- **Lack of privacy or interruptions:** If you do not have a private room or are continually distracted by interruptions or noise, this can make the person with diabetes feel unimportant or that this is not necessarily a safe space to open up to you. Can interruptions be prevented? Can you put a sign on the door, close the blinds, and put your phone on silent?

Considering Social Determinants



We do not see things as they are, we see them as we are.

-Anonymous39

Social determinants of health are defined as the economic, environmental, political, and social conditions in which people live and are responsible for a major part of health inequality worldwide. 40,41 The ADA now recommends that health professionals assess food insecurity, housing insecurity/homelessness, financial barriers, and social capital/social community support, and apply that information to treatment decisions.⁴² In this guide, we refer to people with diabetes from the general adult population but, of course, we live in a very diverse country and world. It is beyond the scope of this guide to consider the specific needs of every social and cultural group, or the specific approaches they may require. Guidelines and checklists are less important than "a reflective approach that avoids stereotypes and assumptions in providing care that is person-centered, culturally respectful, and aware."43

Social and cultural factors play an important role in determining:

- > why and when people attend healthcare appointments
- > the relationship between the health professional and the person with diabetes ("patient")
- > beliefs about (emotional, mental, and physical) health and illness

- > attitudes to (emotional, mental, and physical) health and illness
- > the extent to which lifestyle can be modified to manage a chronic condition such as diabetes
- > people's willingness to take medications
- and people's preferred communication styles.

Health professionals have a responsibility to develop appropriate communication strategies to meet the needs of all members of the community. The majority of this chapter advocates for an open, empathic communication style; however, keep in mind that this approach may not be suitable for every person-consider diversity and be reflective in your approach to communication.

Being aware of your own personal attitudes, assumptions, and stereotypes will help you to put these to one side and minimize their influence on the discussion. You can then focus on understanding the values and wishes of the individual as they discuss their health with you.

In certain situations, the individual may feel more comfortable if a family member, friend, advocate, community/spiritual leader, or other trusted person can attend the appointment. Make sure people know they are welcome to do this.

Health Literacy

Health literacy is more than basic literacy and numeracy skills; it includes a person's ability to understand and apply health-related information and their ability to navigate the health system. 44 Low health literacy is very common—approximately 80 million adults in the U.S. are estimated to have limited or low health literacy⁴⁵ so be aware of the signs (see Box 1.4). Do not assume that people will tell you openly; many will not say anything for fear of judgment or embarrassment.⁴⁶ People with lower health literacy can be very reliant on the verbal information passed on to them by health professionals.

Think about what is required of a person with diabetes during a standard appointment—they need to provide information to their health professional, understand and make decisions based on the information that their health professional gives them, and remember to ask the right questions. When they go home, they need to remember everything that took place and was said during the visit and apply it. Imagine how challenging that might be for a person who has not clearly understood the message that their health professional has tried to convey to them, and how it might affect their self-care and health outcomes. Now, imagine having to do this not only for diabetes but

BOX 1.4 Signs That Someone May Have Low Health Literacy

Signs that the person is having difficulty understanding and applying health information include⁴⁶:

- answering knowledge-based questions incorrectly (e.g., questions related to written information you have given them)
- being nervous about, or avoiding, complex learning tasks
- > "forgetting" record books (e.g., blood glucose readings, food intake, or medication records)
- making errors in calculations (e.g., carbohydrate counting or insulin dosage)
- submitting incomplete forms
- showing up at appointments seeming to have not "prepared" beforehand (e.g., not reading instructions you have given them previously) or missing appointments altogether where "preparation" is required
- "forgetting" to bring their reading glasses
- offering to complete a form "at home"
- handing written documents to an accompanying person
- or holding written documents close to their eyes and following the text with their fingers.

To check, you could ask the person "How confident are you in filling in forms by yourself?"47 If you choose to do this, be sensitive and tactful in your approach.

for eye screening, foot care, and other aspects of health care relevant to diabetes.

Some of the strategies listed in Box 1.2 will be particularly helpful for people with lower levels of health literacy. These tips include using plain language and anecdotes/storytelling/visual aids, encouraging questions, repeating key information, and checking understanding (yours and theirs).

Cultural and Linguistic Diversity

The U.S. is one of the most culturally diverse countries in the world. Some populations are more disproportionally affected by diabetes and in order to effectively provide

care and education, professionals need to be cognizant of social, cultural, and linguistic diversity.45

"Culturally and linguistically diverse" is a broad term describing a wide range of people with regard to their country of origin, culture, religion, primary language, and other characteristics. Given this, it is impossible to provide specific advice to meet the needs of everyone, but here are some broad considerations on which to reflect:

- **Appreciate cultural differences.** Culture plays a large role in shaping values, beliefs, and practices. People from diverse backgrounds may have different beliefs, values, and practices from your own. It is ethical practice to reflect on your own cultural bias and to be aware of how this may influence your practice, and to be mindful of this in your communications and care.⁴⁸ For example, people may have varied:
 - understandings of and beliefs about health (e.g., mental health and diabetes)49,50
 - · communication styles (e.g., a preference for written, pictorial, or verbal communication, or a passive or assertive manner)49,51,52
 - and expectations and preferences for their healthcare (e.g., the expected role of the health professional,⁵² a preference for a same-sex health professional,53 or a preference for traditional cultural remedies over modern medicines).50

Ask questions to clarify their knowledge and point of view; don't assume that you know this information.54

- Recognize and adapt to language challenges. While English is the primary spoken language in the U.S., at least 21% speak another language in their homes and may have limited or no English-language skills.55 It is also important to be aware that being proficient in English does not mean someone is proficient in medical terminology. Language barriers can impede communication and affect the quality and uptake of care, and physical and mental health outcomes. 56,57,58 Be willing to adapt the ways that you communicate and work to meet the needs of the person. It is also important to use an accredited interpreter rather than rely on family or friends.
- > Cater to individuals' needs and preferences. 43,58 A one-size-fits-all approach is not appropriate⁵³ and does not work.
- **Seek advice and engage other experts.** Familiarize yourself with culturally appropriate services in your local area.⁵² With the agreement of the person with diabetes, consider contacting:

- Transcultural/multicultural health services in your area for advice regarding communicating with specific cultural groups and for help identifying appropriate services for referral.
- Multi-lingual health workers to provide advocacy, support, counseling, and interpretation for the person with diabetes. They can also provide sociocultural insight for health professionals⁵⁹—some may specialize in diabetes or mental health.60
- Trained and accredited interpreters for help overcoming language barriers 43,52,53,61 and preventing miscommunications and mistakes. 58,62 It is advisable to consult guidelines for working with interpreters.

- **Upskill.** Consider participating in accredited cultural awareness or cultural safety training.57,63
- **> Be cautious with questionnaires.** While several questionnaires have been translated into other languages, their cultural appropriateness may not be guaranteed. In a multicultural population, exercise caution when administering questionnaires originally developed and validated in English.64

Disability

Finally, bear in mind that disabilities (e.g., physical, intellectual, or cognitive) may affect a person's emotional state, and their ability to communicate or understand. Making appropriate arrangements to help people with these challenges is also part of recognizing diversity.

Resources

For Health Professionals

Books

> The Art of Empowerment: Stories and Strategies for Diabetes Educators, 2nd edition

Description: A unique and valuable resource for any health professional working with people with diabetes, with real life experiences, interactive techniques, and philosophical as well as practical approaches.

Source: Anderson R and Funnell M. The Art of Empowerment, 2nd ed. American Diabetes Association, Arlington, VA. 2005.

> Life with Diabetes, 6th edition

Description: A complete curriculum to deliver high-quality diabetes self-management education and provide support, information, and tools with an emphasis on integrating psychosocial and behavioral strategies with self-management and clinical care.

Source: Funnell MM, Kloss KA, et al. Life with Diabetes, 6th ed. American Diabetes Association, Arlington, VA. 2020.

> 1,000 Years of Diabetes Wisdom

Description: A book of stories and lessons compiled by health professionals and what they learned from people with diabetes.

Source: Marrero DG, Anderson R, et al. 1,000 Years of Diabetes Wisdom. American Diabetes Association, Arlington, VA. 2008.

> Approaches to Behavior

Description: A toolbox for bringing thoughtful, empowering practices and strategies to the relationship between health professionals and people with diabetes.

Source: Roszler J, Rapaport WS. Approaches to Behavior. American Diabetes Association, Arlington, VA. 2014.

> Complete Nurse's Guide to Diabetes Care, 3rd edition

Description: The comprehensive resource for all aspects of diabetes care and self-management for nurses who work with people with diabetes.

Source: Childs BP, Cypress M, et al. Complete Nurse's Guide to Diabetes Care. American Diabetes Association, Arlington, VA. 2017.

Book Chapters

> Tips and tricks on effective communication with people with diabetes: Helping people achieve their goals while achieving your own

Description: A chapter providing advice and strategies on how to achieve person-centered appointments.

Source: Cradock S and Barnard KD in the book by Barnard KD and Lloyd CE, eds. Psychology and Diabetes Care: A Practical Guide. Springer, London, 2012.

> Theoretical and behavioral approaches to the self-management of health

Description: A chapter comparing and contrasting behavioral and educational theories, models, and approaches that support selfmanagement and psychosocial health to help health professionals to use strategies to address the emotional, cultural, and health literacy issues that significantly influence self-management behaviors and quality of life.

Source: Piatt GA, Anderson RM, et al., in the book by Mensing C, Cornell C, et al., eds. The Art and Science of Diabetes Self-Management Education. American Association of Diabetes Educators, Chicago, IL. 2017.

Peer-Reviewed Literature

> The use of language in diabetes care and education

Description: Provides recommendations for personcentered language to be used by health professionals and others when discussing all aspects of diabetes and self-management.

Source: Dickinson JK, Guzman SJ, et al. Diabetes Care. 2017;40:1790-9.

> Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators and the Academy of Nutrition and Dietetics.

Description: Defines the four critical times to offer people with type 2 diabetes education and strategies to provide ongoing emotional and behavioral support.

Source: Bardsley J, Cypress M, et al. Diabetes Care. 2015;38:1372-82.

For People with Diabetes

> Diabetes Burnout: What to Do When You Can't Take It Anymore

Description: Addresses the emotional issues that can become barriers to optimal self-care.

Source: Polonsky WH. Diabetes Burnout. American Diabetes Association, Arlington, VA. 1999.

> How to Thrive: A Guide for Your Journey with Diabetes

Description: This 40-page booklet contains the "need to know" information to manage and cope with about diabetes.

Source: American Diabetes Association, Arlington, VA.

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