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Barriers and Facilitators to Self-Care Communication during Medical Appointments in Adults with Type 2 Diabetes

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Abstract

Objective—Diabetes self-care is challenging and requires effective patient-provider communication to achieve optimal treatment outcomes. This study explored perceptions of barriers and facilitators to diabetes self-care communication during medical appointments.

Design—Qualitative study using in-depth interviews with a semi-structured interview guide.

Participants—34 patients with type 2 diabetes and 19 physicians who treat type 2 diabetes.

Results—Physicians described some patients as reluctant to discuss their self-care behaviors primarily because of fear of being judged, guilt, and shame. Similarly, patients described reluctant communication resulting from fear of being judged and shame, particularly shame surrounding food intake and weight. Physicians and patients recommended trust, non-judgmental acceptance, open/honest communication, and providing patients hope for living with diabetes as important factors for improving self-care communication. Further, patients stressed the clinical benefits of physicians directly addressing poor self-care behaviors while physicians described having few strategies to address these difficulties.

Conclusions—Physician-patient self-care communication barriers included patients' reluctance to discuss self-care behaviors and physicians' perceptions of few options to address this reluctance. Treatment recommendations stressed the importance of establishing trusting, non-judgmental and open patient-provider communication for optimal diabetes treatment. Medical education is needed to improve physicians' strategies for addressing self-care communication during medical appointments.

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Competing Interests

MJA is on the following speakers' boards: Novo Nordisk, Halozyme, and Boeringer Ingelheim. No other author has anything to declare.

Keywords

Self-care communication; Type 2 diabetes; qualitative research; patient-physician relationship

The physician-patient relationship is important in achieving optimal medical outcomes with diabetes and other chronic illnesses.(1) Patient-centered medical treatment promotes the paradigm of physician-patient collaboration.(2) Inherent to this collaboration are physicians' and patients' abilities to communicate effectively, develop a trusting interpersonal relationship, and discuss treatment-related decisions.(3) Patients' active participation in the treatment team is another important part of the patient-centered approach;(2) this participation is predicated on effective healthcare communication.

Individuals with type 2 diabetes face challenging self-care regimens. These self-care challenges can lead to frustrations and emotional struggles that may impede achievement of optimal glucose control, and thus increase the risk for diabetes complications.(4, 5) Patients' ability to inform physicians about their self-care successes and failures, and physicians' ability to openly and effectively respond to patients' self-care reports, discuss immediate and long-term disease concerns, and provide treatment recommendations are all vital factors in optimal diabetes care. Interactive processes are especially important given 1) patients' well-documented difficulties in successfully changing lifestyle habits and achieving treatment goals(6) and 2) physicians' frustrations from their inability to improve patients' self-care and manage psychosocial problems.(5, 7) Thus, we explored physicians' and patients' perceptions of diabetes self-care communication in medical appointments as part of a larger qualitative study of physicians' and type 2 diabetes patients' perceptions, attitudes and behaviors that support or impede the physician-patient relationship in type 2 diabetes treatment.(8–11)

Setting

An outpatient diabetes treatment and research center in the northeastern United States.

Methods

We used purposive sampling(12) to identify and select 1) English speaking physicians (endocrinologists and primary care physicians) with at least 5% of their practice consisting of type 2 diabetes patients and 2) English speaking patients, aged 30–70 years, diagnosed with type 2 diabetes for at least two years and with no severe psychopathology nor cognitive or visual impairment and HbA1c below 130 mmol/mol (14.0%). Physicians were recruited by emails, letters, personal communication, and telephone calls to medical area hospitals, clinics and practices, and referrals from other physicians. Adults with type 2 diabetes were recruited by direct mailings, advertisements in local newspapers and on the Internet, and flyers placed in medical area clinics and hospitals. Physicians and patients were not paired. The Joslin Diabetes Center Committee on Human Subjects approved the protocol, and all subjects provided informed written consent and received compensation for their time.

We devised a semi-structured interview guide consisting of open-ended questions and probes on physician-patient interactions with type 2 diabetes (see Beverly et al, 2012(10), Tables 2 & 3 for Interview Questions). Two experienced interviewers [MDR and EAB] conducted interviews at medical area hospitals, clinics, and practices. Interviews were digitally audio-recorded and transcribed. Interviews also were double checked as a quality measure. Participant recruitment continued until no new themes emerged from the interviews, and data saturation was achieved.

The multidisciplinary research team, consisting of a clinical psychologist, two health psychologists, an endocrinologist, and two research assistants analyzed data according to the principles of thematic analysis.(12, 13) For the first stage of the thematic analysis, the team independently read transcripts and open-coded the data by marking and categorizing key words and phrases to generate the initial codes. Initial codes were discussed and discrepancies resolved through consensus to develop the initial thematic framework, which was then applied to all the transcripts. After transcripts were coded and reviewed, they were entered into NVivo 8 software (QSR International; Victoria, Australia) to further organize and group codes into themes. The group then met to agree on the final themes. Credibility (validity) was maintained via triangulation of data sources, methods, and investigators. Dependability (reliability) was supported through the use of an audit trail, which recorded research decisions and processes.

Results

Nineteen physicians (74% endocrinologists; 26% primary care, 42% female, mean age=48.2±9.3 years) participated in 30–60 minute semi-structured interviews, and 34 type 2 diabetes patients (41% female, mean age= 59.9±7.1 years, mean HbA1c=65±18.6 mmol/mol (8.0±1.7%) participated in 30–90 minute interviews (See Table 1). We discuss findings in terms of the broader categories of physicians or patients because there were no differences in responses to interview questions by type of physician (i.e., endocrinologist or primary care physician) or type of patient (treated by endocrinologist or primary care), Transcript identifiers are used with quotations indicating patient or physician, number, and gender, i.e., Physician 100M or Patient 1F. The following themes emerged from the data analysis:

Barriers to Discussing Self-Care Communication

Physicians and patients described some patients' reluctance to discuss their self-care behaviors or share their difficulties with self-care during medical appointments. Both attributed reluctance to discuss self-care information to individual psychosocial factors as well as interpersonal factors between patients and physicians.

Physicians described some patients as reluctant to share information on blood glucose checking and blood glucose numbers, medication adherence, food consumption, and/or exercise.

> “A common thing is the glucose meter and we have a standard policy to always bring your meter with you. So if the patient comes in [and] they don't have their meter, ‘I'm like okay, fine. What are your blood sugars? Please tell me.' They're

> [Patient says] ‘They’re like 100, 150. Oh no, doctor, it never goes above 200.' Then we check their Hemoglobin A_{1c} and it's 10.5% (91 mmol/mol).” (Physician 118F)

> “I think sometimes the dietary indiscretions may be people will say, 'Gosh, I don't know what it is. I don't eat anything unhealthy I really stick to my diet.” And then you realize that for them a serving of rice is a huge plate of rice and that's just always the way it's been…It's a lack of awareness of where carbs are coming from. And with the medications it's a little bit more psychologically complicated. I think they think that they're supposed to take them when they don't feel well or they just don't want to be on them and it's hard to accept.” (Physician 112F)

Physicians rarely blamed patients for their reluctance to discuss self-care information; they primarily discussed patients’ fear of being judged, guilt, and shame as reasons for this reluctance.

> “I think the ones who feel guilty and ashamed are the ones who come to the doctor feeling like they’re being judged…. There are certain people if they think I’m judging them, they don’t tell me. It’s like I’m their mother.” (Physician 105F)

> “I think shame would be the only reason why they would withhold information like that from a physician or a medical team. Shame that their circumstances aren't allowing them to be as compliant as they'd like.” (Physician 117M)

Patients also discussed how fear of being judged and shame contributed to patients’ reluctance to discuss their self-care behaviors.

> “I mean some people have trouble being open and honest with the doctor. They are just afraid to say certain things or they treat a doctor like a God…. Well, I think if they haven’t followed what they’re supposed to follow, then they feel like they’re going to get yelled at or chided.” (Patient 16F)

In particular, patients described the influence of one’s shame surrounding food intake and weight.

> “You have people who sit there and say or imply that they’ve been doing everything that they should be doing and it’s difficult to believe because they haven't lost any weight…I’m having a feeling that sometimes they aren’t as honest either with themselves or their doctors as maybe they should be.”(Patient 23F)

> “I'm not sure people are always honest about what they eat…. people who are extremely overweight it's like,' well I don’t eat anything, how am I gaining weight?' You know they're eating something or they're not active enough or the combination of the two. So I think sometimes people … don't see it correctly. It's almost like a strange body image. It's like [they] don't see that what they're doing is not what they're supposed to be doing.” (Patient 16F)

Physicians further discussed patients’ reluctance to discuss self-care in medical appointments resulting from lack of recall and cultural background. For example, Physician 112F stated, “I think people commonly forget to mention that they're really not taking their medicine.” Physicians also commented on the influence of cultural background and the use

of alternative medicine/herbal remedies when discussing their patients' reluctance to share self-care information.

> "I know a lot of them [immigrant patients] don't share it [alternative medicine] because they don't think it's medicine." (Physician 109M)

> "Well, I don't think people do it [withhold information] intentionally. I think some people have used herbal remedies and they feel I'll be judgmental about it. They just don't mention it." (Physician 114M)

Facilitators to Discussing Self-Care Communication

Both physicians and patients suggested the importance of physicians creating an atmosphere of trust and acceptance in medical appointments. They noted that physicians' non-judgmental acceptance was a means of diminishing patients' shame and fears of being judged and thus encouraging more open self-care communication. For example, Physician 108M stated: "Your behavior has to be open enough…so that nothing they [patients] tell you would they feel ashamed of or feel like they surprised you." Similarly, Patient 3M stated: "Make them [patients] feel comfortable like they could tell any and everything that is on their mind." They further described the need to establish trust as the cornerstone for optimal self-care communication. For example, Physician 106M stated, "Establishing a relationship of trust with the patient so that you can be able to communicate the importance of the issues to the patient… listening to them and being thorough…." Patients also described how physicians' and patients' trust and collaboration might be the most salient means of addressing self-care communication with a chronic disease such as diabetes:

> "I mean just that there [should] be a very trusting relationship between the two of you [doctor and patient], that the doctor trusts you to fess up to whatever's been going on. Not to say, 'Oh, I've been doing fine….' Well, that the patient doesn't hold back on misbehavior." (Patient 23F)

> "I do think people get better when they have a relationship…with a doctor. I mean some diseases you are never going to cure but you can live better with them if you have this thing with the doctor, this rapport. You can talk about anything and they are going to listen to you and suggest something back. It's like working together with the illness, not only the doctor, not only you, but both together." (Patient 30F)

Further, physicians and patients expected each other to communicate openly and honestly. Physician 108M stated, "I think the patient's role is to be honest in talking to the physician, to the health care provider." Patients also recommended that physicians use direct and open/honest communication to improve their self-care behaviors and diabetes treatment.

> "I'd come in here, and I was grossly obese and the man told me I was… he showed me where I was wrong and where I was lying to myself." (Patient 4F)

> "I expect him [physician] to be honest with me. I may have told him, 'Don't paint the truth'…I have told him, 'Don't make it pretty for me if it's something significant." (Patient 28M)

Patients pointedly noted that physicians' direct communication should not include criticism or accusations, again suggesting the importance of physicians' non-judgmental acceptance.

> "I'd want him [physician] to…I don't know if confront is the right word but I would want him to certainly say….'this is getting higher, that's not good'…But it wasn't like you did bad. It was like this is not good because we need to get it under control. Here are the things we can do. Can you follow that or can you do that? Can you take this different medication? So you know it's never an accusatory thing." (Patient 16F)

> "Just be more up front with them (patients)…. Just be more truthful with them (patients)….just be forward and tell them you have diabetes and you should take that very seriously and I am going to recommend you do this and that. Just sit them down and explain to them in a way they can understand because they are pretty open to understanding and are very concerned about that." (Patient 31M)

On the other hand, physicians described a dearth of strategies when faced with patients' reluctance to share self-care information. A few described questioning the patient about the mismatch between reported blood glucose levels and the Hemoglobin A1c value. For example, Physician 106M stated: "You make a comment, like a question, 'I don't quite understand why your numbers don't quite correspond with your A1C. Could you explain it?'" Only one physician described generally questioning what might be underlying patients' behaviors in his attempt to understand why they were "exaggerating how good their adherence is."

> "I don't make a point of it except to try and figure out…what the right information is and then just encourage them…maybe I ask them why, what makes it difficult to take it [medication]." (Physician 111M)

Recommendations for improved self-care communication also included patients and physicians noting the importance of physicians offering patients a positive perspective for their future with diabetes. Physicians discussed overcoming negative views of diabetes while patients stressed both the need for positive and hope-filled communications, but also highlighted physicians inquiring about patients' lives, not only about their diabetes.

> "I think it's really important to have that positive attitude, that hopeful attitude, saying, 'you know you're having problems now, but there's ways we can help. So I think it's very important because I think they confront a lot of negativity. So I try not to add anymore to that…" (Physician 110M)

> "I think the doctor should develop more of a relationship with the patient… Talking to you and asking questions…A little more, 'How are you feeling? What have you been doing? Are you having problems at home?' …Give them a little hope that things will get better if you follow their directions." (Patient 30F)

Discussion

In this qualitative study, we explored self-care communication during diabetes medical appointments. Physicians and patients perceived some patients as manifesting reluctance to

communicate diabetes self-care information and described individual and interpersonal psychosocial factors that contributed to these diabetes communication barriers. Both suggested the importance of physicians creating an atmosphere of trust and non-judgmental acceptance in medical appointments so that patients can openly express their self-care behaviors without the fear of being judged. Patients further described physicians' direct communication as assisting them in better managing their diabetes self-care while physicians reported few options to address self-care communication difficulties.

Physician-patient communication is often cited as a necessary means of understanding and improving patient adherence.(14, 15) In our study, participants described patients' reluctance to communicate about their self-care behaviors because of fear of being judged, guilt, and shame. Our findings informed the development of a survey study assessing physicians' perceptions of diabetes self-care in medical appointments.(16) This recent survey study found 30% of patients reported they were reluctant to discuss their self-care behaviors with their doctors because of fear of being judged, not wanting to disappoint their doctors, guilt, and shame; however, patients who reported elevated depressive symptoms were more likely to be reluctant to discuss their self-care.(16) Importantly, neither physicians nor patients in the present study mentioned depression as a contributing individual psychosocial factor to patients' reluctance to discuss their self-care, suggesting they were unaware of the impact of depression on patients' self-care communication. Thus, this finding supports the recommendations of the American Diabetes Association, International Diabetes Federation, and the UK National Institute for Health and Clinical Excellence to regularly screen for depression for people with diabetes.(17–19) In addition, our patients' perceptions of the particular shame surrounding food intake and weight are supported by studies indicating physicians' negative bias towards overweight patients and the lack of medical education and research to address these negative attitudes and their influences on patients' health outcomes.(20, 21)

Understanding and exploring physician-patient communication needs to include addressing both the performance of specific communication tasks and behaviors as well as the interpersonal/relational skills involved in establishing a trusting relationship.(22) Recent studies note how medical education has paid more attention to specific communication tasks and behaviors than to interpersonal skills, but that interpersonal skills can be effectively taught to physicians at all levels of experience. (23–25) In our study, both patients and physicians noted the importance of establishing a trusting treatment relationship for effective self-care communication to occur. However, we also found that physicians reported having few options when faced with patients' reluctance to share self-care information. They rarely mentioned inquiring about the factors contributing to patients' communication difficulties. This lack of inquiry may result from inadequate training or lack of time and resources available during medical appointments.

Interestingly, patients in our study specifically valued their physicians' direct and non-accusatory communication when addressing their poor self-care. However, physicians infrequently mentioned using this direct approach with patients. This finding suggests that interventions are needed to help physicians develop ways to address poor self-care with direct and non-accusatory language. Further, a recent study of family medicine practices

found that the time physicians spent discussing self-care varied from 1 to 17 minutes suggesting that providers vary in their capacity to engage in support and problem-solving about self-care.(26) Thus, research needs to explore individual patient and physician factors as well as factors in physician-patient interactions to further understand how to enhance self-care communication in Type 2 diabetes treatment.

The limitations of this study include a small, homogenous sample (e.g., English-speaking, 82% non-Hispanic white) from a city in the northeast United States. Physicians and patients were not paired and therefore their perspectives were not explored from the same clinical encounters. Cultural and social variations regarding communication, attitudes and behaviors among varied ethno-cultural groups have not been addressed and warrant further study. Social desirability may have influenced both physicians' and patients' reporting of their treatment relationships.

Our findings highlight the need for medical education to increase physicians' awareness of factors contributing to diabetes self-care communication difficulties and to improve physicians' strategies for addressing these difficulties in order to make self-care communication more effective during the medical appointment. Future research should explore the possible interplay between patients' reluctance to communicate self-care behaviors and patients' individual challenges following diabetes treatment and lifestyle recommendations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic Characteristics of Physicians and Type 2 Diabetes Patients

	Mean±SD	Range
Physicians (n=19)		
Age (years)	48.2±9.3	34–63
Years in medical practice	20.8±10.1	7–38
Practice with Type 2 diabetes (%)	52.4±25.2	7.5–95
Female (%)	42.1	
Nonhispanic white (%)	79.0	
Endocrinologist (%)	73.7	
	Mean ± SD	Range
Type 2 Diabetes Patients (n=34)		
Haemoglobin A_{1c} (%)	8.0±1.7	5.2–12.6
Haemoglobin A_{1c} (mmol/mol)	64±18.6	33–114
Systolic blood pressure (mmHg)	131.0±14.0	111–171
Diastolic blood pressure (mmHg)	76.2±9.7	48–90
Body Mass Index (kg/m^2)	33.8±8.1	24.0–62.3
Age (years)	59.8±7.3	43–70
Diabetes duration (years)	12.0±8.8	3–51
Education (years)	15.1±2.3	12–19
Female (%)	41.2	
Nonhispanic white (%)	82.4	
Married (%)	55.9	
Diabetes treated by endocrinologist (%)	58.8	
Haemoglobin A_{1c} levels <53 or >70 mmol/mol (<7.0 or >8.6% (%)	29.4	