

# Seeing the Person, Not the Illness: Promoting Diabetes Medication Adherence Through Patient-Centered Collaboration

David D. Schwartz,<sup>1</sup> Sean D. Stewart,<sup>2</sup> James E. Aikens,<sup>3</sup> Jennifer K. Bussell,<sup>4</sup> Chandra Y. Osborn,<sup>5</sup> and Monika M. Safford<sup>6</sup>

■ **IN BRIEF** Nonadherence to diabetes medications is a primary contributor to health complications and avoidable hospitalizations. This article discusses the evidence for taking a person-centered (as opposed to illness-centered) approach to promoting medication adherence among diabetes patients, provides suggestions for ways in which diabetes clinicians can best promote medication adherence, and argues for needed changes in how health care systems support providers in their efforts at adherence promotion.

Suboptimal medication adherence is a primary cause of preventable health complications, health care utilization, and mortality. It has been estimated that <50% of medications are taken as prescribed (1), yet difficulties with adherence are often not identified until they have become entrenched, making them even harder to change (2). Why is adherence so difficult? Diabetes management imposes a substantial burden on patients and their families. Patients have to take daily medications, make substantial lifestyle changes, and keep track of health parameters such as blood glucose levels and blood pressure, which together becomes the equivalent of a part-time job that takes up a substantial portion of time each day (3) and may eventually overwhelm patients' capacity for handling the diabetes workload (4). When patients struggle with adherence, many diabetes clinicians focus on trying to increase patients' self-management skills (5), but these approaches, which place the onus for diabetes management heavily on the patient, may only serve to further burden patients who are already overloaded (4).

A landmark report of the World Health Organization (1) character-

ized nonadherence as a multifactorial problem that reflects interactions between patients, health care providers (HCPs), and the health care system; the specifics of the condition and its treatment; and broader socioeconomic factors. In other words, nonadherence is not specifically or solely a "patient problem." Another implication is that targeting only one factor for improvement (e.g., patient understanding) is unlikely to have much of an effect on population adherence. Instead, approaches to adherence promotion will need to be multifactorial if they are going to be broadly effective (6), involving concurrent changes in patient and provider behavior as well as in the health care system itself.

In this article, we highlight some of the important factors contributing to nonadherence at different levels. At the patient level, we discuss the need for a better understanding of the patient experience with taking diabetes medications. Understanding the challenges of diabetes management from the patient's perspective will give providers better insight into adherence barriers and provide a foundation for stronger collaboration. At the level of patient-provider

<sup>1</sup>Baylor College of Medicine, Houston, TX

<sup>2</sup>Park Nicollet Health Services, Minneapolis, MN

<sup>3</sup>University of Michigan, Ann Arbor, MI

<sup>4</sup>Northwestern Memorial Hospital, Chicago, IL

<sup>5</sup>Vanderbilt University Medical Center, Nashville, TN

<sup>6</sup>Weill Cornell Medical College, New York, NY

Corresponding author: David D. Schwartz, [ddschar@bcm.edu](mailto:ddschar@bcm.edu)

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interaction, we focus on the relationship patients develop with their health care team (7). Providers are unlikely to be effective in promoting patient engagement in both self-management and the therapeutic alliance unless they gain their patients' trust and make recommendations based on an understanding of how diabetes fits into their patients' lives. Finally, we discuss the need for the health care system to be specifically designed to foster patient-centered collaboration. Without systemic supports, HCPs are unlikely to be able to do much beyond what they already do to promote medication adherence in their patients.

### The Patient Experience

Medications represent one of the major therapeutic modalities in the treatment of diabetes. Just as patients have experiences navigating the health care system, so too do they have experiences taking their medications. The "medication experience" has been defined as an individual's subjective experience of taking a medication in his or her daily life (8). This experience begins as soon as a patient is prescribed a medication, fills that prescription, and takes the first dose. It is often thought of as a reaction to the symbol that a medication holds, the feeling that one is putting a substance into one's body to treat, cure, or mitigate a disease. These experiences can be both positive and negative and have serious implications for whether a patient chooses to continue taking a medication. Thus, for optimal diabetes management, it is paramount that the clinician strives to understand what medication-taking means to each patient. Understanding these experiences will help clinicians better comprehend why patients make the decisions they do and tailor diabetes pharmacotherapy accordingly.

Shoemaker and Ramalho de Oliveira (8) conducted a meta-synthesis of three qualitative studies of patients' medication experiences. They identified four underlying

themes: a meaningful encounter, bodily effects, unremitting nature, and exerting control. The *meaningful encounter* is often experienced by patients as a sense of losing control, a sign of age, a questioning of the true cause of the disease, and the encountering of a stigma such as "a pill for every ill" (8). Patients may interpret their first encounter with a diabetes medication as losing control of their health. They may also believe that if they cannot control their diabetes without medication, then they must be getting worse and are failing to adequately manage their disease (9). As diabetes progresses and more medications become necessary, the meaningful encounter can manifest as patients saying they feel like "an old person" who now "has to take all these pills" (8). During the initial encounter with a medication, many patients will question the need for the medication and its perceived benefits. Indeed, a perceived lack of benefit is a commonly cited reason for nonadherence to diabetes and other primary prevention pharmacotherapies (10–12). This can be interpreted by clinicians as resistance or nonadherence; however, it should be seen as a way for patients to reclaim some control.

*Bodily effects* occur from a medication's expected benefits, anticipated side effects, and unanticipated adverse events (8). Because diabetes can affect patients differently, the impact of bodily effects may also differ. For patients with diabetes complications such as peripheral neuropathy, vision disturbances, or sexual dysfunction, medications that relieve these symptoms will create a positive experience. However, patients who are asymptomatic are more likely to be affected by side effects or adverse events, either real or anticipated, than by pharmacological benefits (13–15). Many patients ultimately decide whether to continue to take a medication based on their perception of the benefits relative to the perceived risks.

*Unremitting nature* refers to the burden of taking chronic medications (8). Often medication becomes a symbol of dependence to keep a condition under control. Because diabetes is a progressive condition that ultimately involves multiple medications, it is easy for patients to feel as though they are held captive by their medications. Multiple studies have demonstrated that medication adherence declines as the complexity of their regimen and the number of treatments increase (16–18). Thus, it is crucially important for clinicians to discuss the impact of medication burden with patients and to tailor therapy to be as convenient as possible.

*Exerting control* is a common practice in patients who take medication chronically (8). After taking a medication for a certain period of time, patients become familiar with how it affects their bodies. As a result, they discover ways of managing medications such as taking them on demand, skipping doses, and doubling doses. This is perhaps most evident with insulin therapy. Patients will ultimately become very familiar with the relative changes in blood glucose elicited by certain doses of insulin and will change their dose or dosing frequency day to day or even hour to hour. Providers often label this practice nonadherence when it might instead reflect patients exerting control over their medications. Clinicians should recognize this and empower patients to self-manage in ways that both meet clinical guidelines and serve their patients' goals. Similarly, when patients are uncertain about medication risks and benefits or are asymptomatic, they may choose not to take a medication rather than to experience or potentially develop a side effect. Intentional nonadherence is especially likely when the actual benefits of a medication are relatively modest.

The medication experience is a concept that should be explored to understand patients' perceptions and

practices regarding chronic medications. Medication nonadherence can often be managed if providers consider each patient's unique medication experience and implement strategies to adapt to it. Understanding a patient's medication experience is also an important part of developing a positive patient-provider relationship, which is another crucial factor in patient adherence, as discussed below.

### The Patient-Provider Relationship

Successful diabetes management requires patients to incorporate complicated medical tasks into their daily routines, make significant lifestyle changes, and track progress and difficulties. Given these complexities, diabetes management is not a "do-it-yourself" endeavor; it requires expert guidance and teamwork between patients and providers. The patient-provider relationship lies at the heart of the patient-centered model of care (19). A good relationship fosters communication, improves patients' understanding of illness and treatment, and allows patients to feel comfortable asking questions and participating actively in their own care. The patient-provider relationship also has a demonstrated impact on adherence and health outcomes. For example, the Diabetes Attitudes, Wishes and Needs study, which included 5,104 patients from 13 countries, found a strong association between the patient-provider relationship and adherence to medications (20). Access to providers was not independently associated with adherence, suggesting that the *quality* of the patient-provider exchange—not just the quantity of time spent—was important. Meta-analyses have also found a significant association between physician communication skill and patient adherence (21) and have shown that improving the patient-provider relationship has a positive impact on health outcomes across a range of chronic conditions (22).

Provider empathy is fundamental to the therapeutic relationship. Providers who show empathy tend to be more effective in guiding patients and fostering behavior change and medication adherence (23), and patients are more likely to disclose nonadherence when they believe their provider cares about them (24). Physician empathy is associated with blood glucose control (25) and a lower incidence of acute metabolic complications (26). However, many patients say their providers show little empathy or understanding of their struggle to manage diabetes (27,28).

Despite genuine concern for patients, many HCPs do not effectively communicate empathy and support (23). Patient-provider collaboration hinges on effective communication (29). Unfortunately, many patients struggle to understand what their providers tell them, yet are reluctant to tell their provider when they feel confused (27). This reluctance is exacerbated for patients with low health literacy, who may feel ashamed of their literacy skills and try to hide their lack of understanding (2). Patients may also be reluctant to disclose medication nonadherence, and therefore their true medication-taking behavior often remains hidden. As many as 83% of patients say they would never tell a provider if they were not going to fill a new prescription (30). At the same time, many providers do not ask about adherence or recognize adherence difficulties until problems become too big to miss (2). In one study examining physician communication when prescribing new medications, physicians discussed adverse effects, the frequency of medication, and timing of dosing <60% of the time, and the majority did not address the duration of therapy (31). Even fewer providers ask about patients' mental health and quality of life, which patients identify as their most important concerns (5).

How a provider enquires about medication-taking behavior is also crucial. Simply asking, "Are you tak-

ing your medications?" is inadequate to reveal medication nonadherence. The reconciliation process of reviewing the medication list, addressing needed refills, and discussing side effects is likewise insufficient for revealing patients' true medication-taking behavior; one cannot assume that an updated medication list equates to a patient taking those medications. To uncover nonadherence, HCPs must ask patients in a non-judgmental way if they are regularly taking their medicines, have stopped or missed a medicine, or are worried about taking a medication (2). A blame-free environment must exist for patients to feel comfortable openly discussing their medication-taking behavior. Brown and Bussell (2) offer some concrete examples of how one might ask about medication-taking behavior in a patient-centered and supportive manner.

Patients are more likely to disclose nonadherence, as well as improve medication adherence, when they trust their HCP. Trust is developed over time as the long-term relationship between a physician and a patient is formed and is a crucial factor in an effective relationship. A combination of the patient's perception of the physician's competence and the caring demonstrated by the physician is needed to develop trust (32). Patient-centered communication can enhance patient trust and promote active patient involvement in the medical decision-making process. Assuming that some degree of nonadherence is a normal and expected part of daily diabetes management will lead to improved recognition of adherence problems. If a patient discloses nonadherence, it is imperative to show empathy, validate and reinforce the disclosure, and work together to identify adherence barriers.

Interventions to improve provider communication skills have a significant effect on patient adherence (21). Patients can also be encouraged to initiate better communication and

become more active members of their health care team. For example, the National Patient Safety Foundation provides a communication tool, *Ask Me 3* (33), which encourages each patient to ask:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Communication and relationship-building can be hindered by the fact that patients and providers often have very different perceptions of illness and treatment. Patients tend to focus on their experience of illness, such as how they feel and what being ill means to them, whereas providers focus more on the physiological aspects of a disease and its management, such as achievement of A1C goals (34). Although both aspects are important to patients' health and well-being, differences in views can result in patients and providers talking past each other or being misaligned in their communication (35). This discrepancy is also echoed in views on nonadherence. Reviews of qualitative studies suggest that a majority of providers view nonadherence narrowly in terms of patients' skills and understanding, whereas patients "describe a much wider range of problems . . . that arise from the personal, social, and practical challenges of living with diabetes" (5). In study after study, patients express a desire to be "perceived as persons, not illnesses" and suggest that providers who focus exclusively on medical problem-solving often leave them feeling "reduced to their disease" (5). It can be difficult for patients and providers to communicate effectively if they lack a shared understanding of the target goal. Aligning agendas by way of effective health communication, empathy, and shared decision-making can facilitate shared goals, better adherence, and potentially better outcomes.

Developing truly collaborative relationships may be more challeng-

ing when patients and providers come from different racial or socioeconomic backgrounds (35). Physicians use more biomedical language with African-American and poorer patients and are less likely to engage minority patients in shared decision-making or ask about their lives and well-being (36,37). On the positive side, there is evidence that the use of patient-centered communication can help reduce perceived differences between patients and providers and foster more patient-provider collaboration around medication adherence (38).

### Adherence and Health Care Policy and Delivery

Most HCPs acknowledge the importance of trying to understand their patients and to build a therapeutic relationship with them, and many medical schools now include training in communication skills (39). Unfortunately, implementing these skills is often challenging in the typical fee-for-service health care system, in which providers have too little time to ask about patients' diabetes control (40), let alone about their broader lives, well-being, and mental health. Patients frequently complain that providers "go too quickly" (27) and do not have time to get to know them and their concerns (5). Providers report that they lack the training to assess barriers to adherence or to know what to do when certain barriers are identified. For example, despite the widespread recognition that psychosocial problems can impair diabetes management, and current American Diabetes Association (ADA) guidelines recommending routine psychosocial screening of all diabetes patients, many providers report insufficient training in assessment and management of psychological difficulties in their patients (41). In addition, many patients lack a consistent provider for diabetes care, creating significant frustration (27) and negatively affecting medication adherence and health outcomes (42,43).

U.S. health care policy and delivery are changing and providing new opportunities to address these concerns. There has been a dramatic shift in priorities from a reactive approach of managing problems as they arise toward a focus on preventing hospitalization and other negative outcomes of chronic illness, with the ultimate goal of improving population health. In many ways, these changes trace back to the emergence of the Chronic Care Model, which aims to promote evidence-based modifications to health care delivery, provide self-management support and tracking systems for patients with chronic conditions, and encourage strong links between health systems and the communities they serve (44). In 2010, these principles received new impetus under the Patient Protection and Affordable Care Act (Public Law 111-148), which advanced a broad variety of initiatives via its "triple aim" principle to improve health care coverage and access, the quality and value of care, and health outcomes. The Patient-Centered Medical Home (PCMH) is a promising model for delivering comprehensive patient-centered care and increasing the extent and effectiveness of care coordination under these new policies. According to the Joint Principles of the Patient-Centered Medical Home (45), the five key principles of the PCMH are:

1. An ongoing relationship with a physician who provides consistent care
2. Team-based care that is directed and coordinated by the primary physician
3. A whole-person orientation
4. Care that is integrated across all levels of the health care system
5. A focus on quality and safety

The Centers for Medicare and Medicaid Services (CMS) announced plans to link the bulk of Medicare fee-for-service payments to providers' achievement of quality indicators and to adopt various alternative pay-

ment models for meeting rigorous PCMH standards (46). The National Committee on Quality Assurance has a formal recognition process for meeting PCMH criteria and presently certifies nearly 7,000 practices (47).

Unfortunately, the initial wave of pilot studies on practice transformation have shown rather disappointing results. Although meeting rigorous PCMH standards may yield small benefits in patient experiences, preventive services delivery, and emergency department (ED) utilization, there is minimal evidence that it improves clinical outcomes, quality metrics, or costs for the majority of patients (48–51). Specific to diabetes, becoming a PCMH seems to only benefit patients with extremely poor initial glycemic control, whereas those with moderately poor glycemic control at baseline may see glycemic control worsen slightly, and a substantial number of patients remain far outside of the ADA-recommended glycemic control target range (52).

Practice transformation into PCMHs is in its early stages, and it has been argued that most of the available evidence comes from studies that have only tested the addition of a care manager rather than a comprehensive implementation of the PCMH model (53). One way to enhance the impact of the PCMH concept on diabetes care (and to accommodate time constraints during the clinical visit) is through incorporation of diabetes self-management education and support services provided by physician's assistants, nurse practitioners, and diabetes educators (54). Multidisciplinary team approaches have been shown to improve self-management, glycemic control, and quality of life and have significant potential for broadening delivery of care, although utilization of these programs has so far been low (55,56). At the same time, it is important that team-based care complement the work of the clinician and not take the place of relationship-building or move clinically important

conversations away from the primary physician. Another way to strengthen patient- and relationship-centered care in the PCMH is through payment reform, so that time spent in care coordination and other support activities can be reimbursed (57), allowing physicians to spend more time counseling their patients. Future studies and use of quality improvement methodology can help determine how best to balance competing priorities within the PCMH model in the interests of improving patient-provider collaboration.

Another aspect of practice transformation that has important implications for patient-provider collaboration is the emphasis on implementation of electronic health record (EHR) technology. EHRs enhance care coordination and information-sharing and can be used to identify patients with poor glycemic control and infrequent clinic attendance (57). Thus, a primary use of EHRs is to develop registries and provide risk-stratified care. Screening tools that automatically flag high-risk patients can be built into EHR systems to reduce the incidence of patients who “fall through the cracks” before problems are identified. For example, evidence is accumulating that low income, concomitant mental illness, and substance abuse are risk factors for nonadherence and avoidable diabetes-related ED visits and rehospitalizations (e.g., readmissions within 30 days of hospital discharge). Patients with these issues can be identified earlier and targeted for preventive interventions to promote adherence and potentially reduce the likelihood of avoidable hospitalizations.

Although EHRs have substantial potential to benefit patients, they also threaten to interfere with patient-provider collaboration. The need for physicians to enter data into an EHR can take time away from clinical interactions, and the use of an EHR in exam rooms can impede patient-centered communication,

especially for clinicians with poor skills in communication or computer use (58). Training physicians in using the EHR as a communication tool itself has been suggested as a way to enhance its patient-centeredness (58), although there is still much to be learned about how to do this effectively.

Another area for improvement in the care of diabetes patients is in broadening efforts to include community, public health, and social service sectors in initiatives to improve population health (59). The initial focus of population health management has been largely to prevent ED utilization for nonemergent or preventable situations and to reduce readmissions within 30 days of hospital discharge. Insulin-related decompensations directly reflecting poor medication self-management are a substantial proportion of preventable ED visits for patients with diabetes (60). Nonadherence to diabetes medications also plays a significant role in rehospitalization within 30 days (61). A large proportion of such patients are initially admitted for heart failure, and their medication regimens are frequently complex and have suboptimal medication reconciliation, resulting in confusion about the medication regimen to be taken after hospital discharge. Regimens are frequently modified during these hospitalizations, compounding this confusion at discharge and potentially leading to readmission for hypo- or hyperglycemia. Poor medication adherence may play a substantial role in preventable ED visits, underscoring the need for practice transformation to identify individuals at risk for such episodes, coordinate their care, and improve communication about medication changes.

As population health management efforts mature, ED use and rehospitalization will eventually be minimized, requiring attention to a more upstream approach to population health management that keeps

diabetes patients out of the hospital in the first place. Once population health management reaches this stage, improving diabetes medication adherence will play a central role in reducing preventable hospitalizations and complications (62). This phase of population health management will be greatly facilitated by practice transformation into PCMHs because success will depend on the use of registries and risk stratification methods to proactively identify individuals who require special efforts to achieve control.

For many patients who struggle to adhere to their treatment regimen, active outreach may be required with specific skills in engaging minorities and those living with limited economic means. This will require considerable re-engineering of most primary care practices. However, the hope is that population health management will result in the engagement of high-risk individuals and the implementation of evidence-based interventions to improve medication adherence and achieve better risk factor control, which will eventually improve health and wellness.

### Conclusions

When patients struggle with adherence, providers often intensify their focus on disease management and assume patients lack the understanding, skills, or will to sustain the necessary behaviors (5). Although this may sometimes be the case, evidence suggests that this focus may have the unintended consequence of further distancing patients from participating in their own health care. A counter-intuitive approach to working with patients struggling with adherence might be to spend *less* time talking about diabetes and its management, and more time discussing what is going on in the patient's life. Time spent building the therapeutic relationship may have better long-term payoffs for patient engagement than narrowly focusing on adherence, which can sometimes be perceived by the pa-

tient as “shaming and blaming” (63). Trust tends to develop when providers spend time getting to know their patients, and patients listen to the people they know and trust (64, 65).

Evidence suggests that HCPs are beginning to see their role shift from telling patients what to do to listening to patients, although many still feel limited in making this shift by a lack of time and resources (41). In fact, most HCPs recognize and share the values of relationship- and patient-centered care and would love to spend more time with their patients, but cannot afford to do so in a fee-for-service environment that rewards volume over quality. In many ways, the practice changes recommended above depend on incipient changes in the health care system that prioritize value-based care and support HCPs' time and effort spent on building relationships with their patients.

Initiatives to improve adherence will likely also benefit from focusing on patients at highest risk for suboptimal health outcomes. High-risk patients account for a majority of health care spending, preventable hospitalizations, morbidity, and mortality (66), so interventions successfully targeting adherence in this group are likely to have an enormous impact on population health. Patients from racial and ethnic minority groups form a disproportionate number of the highest-risk patients, are less likely to have a consistent provider (67), and are more likely to experience problematic communication with HCPs (36). It has even been argued that communication difficulties may be a primary contributor to racial and ethnic health disparities (35). Efforts targeting relationship-building with minority patients and other vulnerable groups may therefore be an especially fruitful way to increase adherence and reduce health disparities (38).

Recently, the National Diabetes Education Program at the National Institute of Diabetes and Digestive

and Kidney Diseases developed a web resource titled “Promoting Medication Adherence in Diabetes,” which is available at [www.niddk.nih.gov/health-information/health-communication-programs/ndep/health-care-professionals/medication-adherence](http://www.niddk.nih.gov/health-information/health-communication-programs/ndep/health-care-professionals/medication-adherence). This resource was informed by the recognition that optimal adherence reflects a collaborative process of communication and understanding between patients and their health care team. “Promoting Medication Adherence in Diabetes” gives providers the evidence and tools to help them promote optimal medication-taking behavior among patients and within their health care teams.

Our hope is that, if patients and providers are given the tools *and* the time to use them, they can better work together to improve medication adherence.

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### Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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