

# How Do We Know?

## Reflections on qualitative research in diabetes

Each of us brings to our clinical encounters worldviews and behaviors shaped by a variety of cultural and psychosocial factors. In addition to having some of their views shaped in childhood, health care providers bring to their encounters a professional worldview that influences the way they interpret diabetes, explain its causes and progression, understand its symptoms, and orchestrate methods of treatment. This professional perspective may also differentiate providers from patients with respect to diabetes management goals and expectations. Although differences in perspective are not inherently problematic, they frequently become so when patients do not meet the goals and expectations of their health care providers. In these instances, patients are likely to be labeled "noncompliant," a pejorative term that implies a moral failure to behave appropriately. Our analysis of this blaming behavior is that it stems from the belief on the part of health care providers that the correct view of diabetes and its management is that of the clinicians. At the same time, there is an expectation that when they, as authoritative experts, make recommendations, the patient receiving those recommendations has an obligation to carry them out (1). The problem with understanding another's behavior as a moral issue is that it seldom leads to in-depth exploration of the reasons for the behavior or a rational approach to changing it.

We have learned that we can better understand the behavior of patients if we take the time to ask them about the psychosocial contexts in which they care for their diabetes (rather than by making judgments about their self-care behaviors). The choices that patients make appear quite sensible if one understands the demand characteristics of their environment. For example, in a recent study of Latinos with diabetes (2), our focus group research highlighted the pressure that Latino women feel to put the priorities of their family ahead of their own. Making dietary modifications to care for one's diabetes in such a milieu is extraordinarily difficult. Blaming such patients for being noncompliant with rec-

ommendations regarding diet and exercise only adds to their difficulties.

As behavioral scientists, we have been grappling with how best to learn from patients about the experience of having diabetes and of having to engage in a self-management regimen that impinges on such essential phenomena as family relationships, food preferences, level of physical activity, and beliefs about health and illness. We value research that helps us understand the perspectives that providers and patients bring to their clinical encounters because it can shed light on the causes of undesirable diabetes care and therapeutic outcomes as well as the dissatisfaction that often results from a provider's or patient's failure to meet the other's diabetes management expectations.

In our earlier work at the University of Michigan, we relied heavily on quantitative survey research methods to investigate and understand the perceptions of patients with diabetes (3,4). Over time, however, the limitations of these methods were made apparent to us through the actions of our survey respondents. On occasion, we would receive questionnaires in which the patient had checked both "agree" and "disagree," adding extensive margin notes to explain why both answers could be considered correct. As researchers, we found these communications frustrating because there was no way to use this information. We wanted patients to tell us about their experience of living with diabetes not in their own voices, but by responding "agree" or "disagree" to attitude descriptions we had written. On reflection, it is clear that the experience was probably more frustrating for the people we were asking to fill out the survey than for us. How would we feel if we were asked to violate the integrity and holistic nature of our psychosocial experience by reducing it to an "x" in one of five boxes? We realize that what we gained in terms of data reduction, analysis, and generalizations from our quantitative studies, we paid for in the loss of understanding. We have begun using focus group studies in an iterative fashion with our more quantitative research to achieve a more balanced, useful, and accurate description of

patients' experience, one that reveals its phenomenological richness and subtlety (5,6).

In this issue, Larme and Pugh (7) demonstrate that qualitative research methods can make an equally important contribution to deepening our understanding of the experience and behavior of primary care providers who treat patients with diabetes. We noted with interest that patients and health care providers, both of whom have been criticized for providing diabetes care that fails to meet standards, may be teaching us the same lessons. For example, we have learned that simply increasing the knowledge of a patient with diabetes does not necessarily lead to enhanced diabetes self-management. It is equally true that increasing the knowledge base of providers through continuing medical education and/or guidelines is unlikely to result in a significant improvement in the diabetes care they provide.

The study by Larme and Pugh (7) also shows us that the health care professionals shape their care on the basis of a variety of psychosocial and other contextual factors. The use of directives, guidelines, and continuing medical education courses is unlikely to be successful in reshaping health care practices unless health care professionals examine their own beliefs about diabetes and their attitudes toward its treatment. This study has added to our understanding of the stresses, demand characteristics, and attitudes of primary care providers. When we begin to appreciate that the behavior of such providers makes sense in the context of their own psychosocial situation, we can begin to develop more effective educational interventions.

We suspect that the development of programs and interventions to enhance diabetes care will have to be collaborative, involving primary care providers, diabetes experts, patients, and managed care executives, so that all participants can agree on what is realistic. As Larme and Pugh point out, the development and implementation of a chronic disease care system are required. Continuing to force diabetes care into an intellectual, financial, and psychological system designed for acute care will

continue to frustrate both patients and providers and will do little to reduce blood glucose levels, subsequent complications, or the costs associated with this disease. Studies such as this one provide important information for those organizations interested in developing and evaluating a truly collaborative approach to diabetes that is suited to the nature of this chronic disease.

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