Personal Barriers to Diabetes Care: Is It Me, Them, or Us?

Preface

This From Research to Practice section focuses on personal barriers to diabetes care (Figure 1), emphasizing the need to see through the eyes of those with diabetes if we are to achieve the goals of high quality of life, community participation, and morbidity and mortality rates comparable to the rest of the population. We now know that, in the study setting, we can normalize pregnancy risk and greatly reduce the complications of both type 1 and type 2 diabetes. However, we also know that outside of the study setting, we are not doing so well. What is stopping us?

Perhaps the first step is to appreciate that “us” includes those with diabetes and those around them as well as diabetes health professionals. Toni Tripp-Reimer, PhD, RN, FAAN, and her colleagues (p. 13) point out that we should see many of the problems of providing care to those with diabetes as arising from the biomedical culture through which health care is generally delivered. Janice C. Zgibor, RPh, PhD, and Thomas J. Songer, PhD, MSc (p. 23), explain that modern health care is indeed delivered in a way that often makes it difficult for many people with diabetes to effectively carry out self-care. Beth Ann Coonrod, PhD, MPH, RN, CDE (p. 28), focuses on how physical factors can hinder self-care and how many of these factors can be overcome with appropriately delivered care. And Russell E. Glasgow, PhD, and his colleagues (p. 33) emphasize...
the many psychological factors that contribute to the decision making and actions of those with diabetes.

Throughout this collection of articles, common themes emerge. First is the notion that there are successful methods by which personal barriers to care can be and have been overcome. Second, these interventions and their associated assessments must be systematically incorporated into health services from the policy level up to those delivering care and on to those with diabetes. And finally, overcoming barriers often requires working with those outside the traditional health boundaries: in welfare, in the community, and in the workplace.

These problems are not isolated to the United States. Many of the barriers described here are present in the variety of health services found around the globe. The international generalizability of barrier types should not be unexpected in view of the similar ranking of barriers between different ethnic groups in the same area.

But whereas the broad descriptions of these barriers apply elsewhere, the detail and the solutions offered here are clearly tailored to the individuals, health systems, and cultural groups in question and thus require adaptation for use in other settings. It is also important to appreciate that cultural differences are not limited to those between ethnic groups. For example, attitudes and expectations often differ between older and younger people and between males and females.

We have intentionally avoided focusing on knowledge of diabetes as a barrier to care. While several studies have confirmed the importance of knowledge to optimizing self-care and avoiding complications, we wish to emphasize that knowledge itself does not necessarily create an ability to enhance self-care if other priorities and barriers exist. Furthermore, a substantial portion of diabetes education time is often spent explaining what diabetes is, when patients also need to learn how to carry out self-care tasks and cope with complex health systems. Providing counseling, guidance, and support should be a higher priority, along with the traditional clinical and educational responsibilities.

A practical example of such support, through case management, has been shown to substantially reduce HbA1c levels. The role of “diabetes care promoter” is an extension of this concept. In this model, a member of the existing diabetes care team takes on the responsibility of helping patients navigate through the maze that is the health care system, systematically identifying barriers and ensuring that relevant resources (human, welfare, educational) are made available to patients. A doctor, nurse, or any other member of the diabetes care team could play this role.

A number of other barriers to care have not been included in these reviews. Some have been touched on, such as prejudice (e.g., racism or against those with diabetes), group pressure, the need for greater understanding in the general population, and time limitations for patients and practitioners. Dr. Tripp-Reimer and her colleagues highlight different perceptions of the importance of health care as a priority. For many patients, the need to care for children and elders and to fulfill cultural commitments are of fundamental importance, at times to the detriment of self-care. The complex balance of the advantages and disadvantages of any of the diabetes-related self-care activities (including clinic attendance) could be seen in the same framework as the “stages of change” model. Indeed, we found this to be the most frequently reported barrier to care across three ethnic groups in New Zealand.

Overall, then, the barriers to care identified here do appear to be of potential importance across cultures and countries. One interesting exception may be the belief that the public, rather than the individual, should bear much of the costs of health care—a view common in those used to more socialized forms of health service funding and delivery. However, in many ways, this could be considered within the personal beliefs held about health and health care and who has responsibility for one’s personal health.

Dr. Glasgow and his colleagues emphasize the difficulty of integrating this information into a whole and translating that knowledge into effective action. He highlights the need for assessment tools not only to be developed and validated, but also to be used prospectively to assess the efficacy and effectiveness of interventions. Tailoring of both assessment tools and interventions to particular communities will be of major importance, and a detailed framework to systematically address barriers is urgently required.

Tools to address some external barriers to care (physical, systems, and other barriers outside of “self”) are now available. Tools have been developed to enhance services through an audit of available resources.
devices for monitoring blood glucose and injecting insulin and other new products have been developed on advice from patients. Blister packs (calendar packs that hold dosages of prescription drugs for a particular time of day) improve HbA1c as do case managers. The recognition of mental health problems, particularly depression and needle phobia, provides an opportunity to greatly assist patients. An empowerment approach is beneficial on the path to developing a more patient-centered approach to care but requires attention to locus of control and other behavioral characteristics, as Dr. Glasgow and his colleagues discuss. In addition, biomedical developments remain important to supporting our patients and overcoming some of their barriers to care.

We still require an overarching framework to allow a systematic approach to barriers, particularly internal and cultural barriers. The latter may require further health professional education (e.g., cross-cultural education). Our Patient Information tear-out page (p. 42) offers such an overall framework to help patients to identify their barriers to care. I would be interested in receiving feedback on its use prospectively in different populations. Table 1 offers a list of potential barriers that diabetes health care professionals must be prepared to help their patients overcome.

Diabetes care is complex; however, many of the barriers to both quality of life and clinical outcomes can now be identified and overcome from the patient, caregiver, and practitioner perspectives. An "us" or team approach seems most likely to succeed, with patients and, where appropriate, caregivers and family members as part of the diabetes team. This is likely to require a shift in the current biomedical and nursing models of care to an even more patient-centered approach. We hope that the articles and framework provided in this issue will help this to occur.

References