

The Group as a Basic Asset to Ethnic Minority Diabetes Patients

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Ethnic minority diabetes patients, providers, and health educators are frustrated by the problems inherent in teaching and learning about diabetes self-management. Too often, we hear the provider/educator lament that, "*I keep telling them, over and over and over, hat they must to X, but they don't do it.*" Too often, ethnic minority patients with extensive histories of diabetes care reveal critical basic gaps in their knowledge of the disease and the contributory role of their behaviors to their conditions. **Repeating a message that cannot be received and used suggests that providers/educators need more appropriate ways to convey information to patients** and provide them with supports in using that information.

Patients' Desire for Invisibility

Ethnic minority diabetes patients, particularly recent immigrants, share the general population's aversion to making their diabetes public. "*You ask me if this is something I want to share with someone. No. It is a curse. It is very disgusting.*" (Chinese patient) They reject being viewed as different within their family and social circles, having special dietary and other physical needs, being specially threatened, and engaging in invasive self-monitoring and treatment. **Diabetes marginalizes the ethnic minority diabetes patient from his/her main social supports and interactions**, just when these supports are needed to engage in appropriate and effective self-management. Keeping the disease invisible from the social group results in downstream failed self-management.

Education across Cultural Gaps

Health care providers/educators face major challenges in conveying the basic knowledge of

diabetes and self-management to patients from other nations and cultures, with serious language, educational, and conceptual barriers. Many health care providers/educators approach diabetic self-management as if it were a school subject and view their cultural and linguistic minority patients as if they were bad students, not learning their lessons or changing their behaviors.

However, **for many minority patients, there is no basis upon which critical messages can be built.** Minority patients often have different concepts governing the functioning of the body, the meanings of health and illness, and the role of behavior in altering health status. Many are unable to relate the scientific message to their own lives and fail to understand the entire constellation of self-management issues.

The Group as Solution

Educators should develop and facilitate group activities to both overcome the lack of social supports and contribute to effective learning. Ethnic minority patients benefit from formal and informal diabetic support groups, made up of people like themselves, in terms of nationality, ethnicity, language, age, and gender. Such groups give them some of the social visibility, safety, information, and support that they need, in the absence of supports from their families and friends.

Useful Principles

Some principles should guide the development and conduct of such groups:

- **There is no one model or recipe for the development or conduct of groups.** Groups are “local” solutions, devised with, for, and by the particular ethnic, professional, and organizational cultures involved; the solutions reflect rather than shape the cultures that are involved.
- Groups should appear to develop naturally and informally, starting, for example, with the

interactions that readily occur among patients waiting in a weekly foot care clinic. In such settings, patients share information about the disease, available medical, physical, and financial supports in the community, useful dietary practices, and personal feelings.

- Groups should be more patient-directed and informal than professional and formal; they should be supported, but not led by, providers, educators, and interpreters. Groups can listen to and interact with educators and nutritionists with more support and lower stress than in one-to-one sessions. Informal exchanges allow patients to casually exchange information with one another and professional staff, discuss more “current” practices, and share advice and direct experience. Groups comprised of patients who are in different stages of the disease provide hope and sequenced education based on experiences of persons more advanced in disease management. *“We need a group of people to come together, who are not selected but who choose to come together. There may not be some level where I can be completely honest with you. If they could talk to someone like me, I know the research, I can say, ‘This is a book on what you do if you are under stress and what is going to set off your diabetes.’ Something they can identify with. So they can help themselves. Then, they can feel in charge and in control. That, in itself, can add to people wanting to live, people wanting to conquer this, feeling like there is actually hope...we are talking about hope.”* (African American patient)
- Where possible, physicians, nurses, dietitians, and health educators with important messages should be drawn from within the ethnic communities, to make participation more attractive and overcome some of the cultural and language barriers; these should include, for example, bilingual physicians and nurses from local community health centers and medical and nursing associations.

- Agendas should be devised by the group and facilitated by educators. Members can debate among themselves the messages being transmitted and learn from one another and the professionals about the concrete implications in each of these messages, about such things as how to control diabetes through diet, what kinds of substitute foods to buy, where to buy them, what kinds of traditional medicines and foods are good for diabetics, interesting personal stories or relatives' stories, such as "*how can I explain this to my kids?*" They can re-transmit messages in more appropriate and direct forms. For example, in a Filipino patient group, where the meaning of "portion" was being debated, one patient clarified it by reference to a mainstay of Filipino social interaction -- "*a portion of meat is no larger than a deck of playing cards.*"
- Participation should be encouraged by the provision of ethnic foods, music, and other attractions that make regular participation more normal and attractive.
- Groups should be supported by "bridging" persons in the medical setting, such as cultural authorities from the community, medical interpreters, and outreach workers familiar with both sides of the exchange between Western biomedicine and the cultural traditions, preferences, expectations, and real-life constraints on immigrants to the United States.

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Resources

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