Understanding the Environmental Issues in Diabetes Self-Management Education Research: A Reexamination of 8 Studies in Community-Based Settings

Leonard Jack Jr., PhD, MS; Leandris Liburd, MPH; Tirzah Spencer, PhD, MPH; and Collins O. Airhihenbuwa, PhD, MPH

Eight studies included in a recent systematic review of the efficacy of diabetes self-management education were qualitatively reexamined to determine the presence of theoretical frameworks, methods used to ensure cultural appropriateness, and the quality of the instrument. Theoretical frameworks that help to explain complex pathways that produce health outcomes were lacking; culture indices were not incorporated into diabetes self-management education; and the instruments used to measure outcomes were inadequate. We provide recommendations to improve research on diabetes self-management education in community settings through use of a contextual framework that encourages targeting multiple levels of influence—individual, family, organizational, community, and policy.

Methods

The U.S. Department of Health and Human Services Task Force on Community Preventive Services conducted the systematic review (2). The review team identified interventions, developed an analytic (theoretical) framework, systematically searched for retrievable evidence, summarized quality and strength of the body of evidence of effectiveness, translated evidence of effectiveness into recommendations, and identified research gaps (2). The analytic framework demonstrates the effects of DSME on short-, intermediate-, and long-term outcomes (Figure 1). The team evaluated intermediate-term outcomes (such as knowledge) and short-term outcomes (such as blood glucose level after fasting).

In their systematic review, Norris and associates (2) identified 11 studies that evaluated the effectiveness of DSME in community gathering places. Two studies were excluded because of limited quality, and 1 was excluded because it lacked relevant outcomes (2). On the basis of the outcome of glycemic control, 8 studies provided sufficient evidence of effectiveness to recommend DSME in community gathering places (Table). Evidence of effectiveness was insufficient for all other outcomes identified in the analytic framework.

Norris and associates concluded that more studies were needed to examine the effectiveness of DSME in community settings and to determine conditions for optimal use of community settings, who should deliver interventions in these settings, and whether certain ethnic and racial groups perceive the need for alternative settings (2).
Reexamination of the 8 Studies

We agree with Norris and associates’ recommendations but also recommend that the evaluation of evidence of intervention effectiveness should distinguish between the fidelity of the evaluation process used to detect the success or failure of an intervention and the success or failure of the intervention itself (11). It is standard practice to define the level of evidence in terms of the study design, primarily to determine credibility. The complexity of public health interventions delivered in community settings requires identification of criteria beyond study design to understand why interventions are effective.

Although evidence of the effectiveness of DSME on glycemic control was sufficient, it was not clear what aspects of the intervention contributed to its effectiveness. Using additional criteria that can improve the credibility of intermediate and short-term outcome measures, the lead author reexamined the 8 studies in Norris and associates’ systematic review to determine the extent to which specificiations of theoretical frameworks of the interventions (12), cultural appropriateness of interventions (13, 14), and instrument quality (12) were discussed. The primary purpose of this qualitative review is to examine factors beyond effect sizes to explain intervention effectiveness; the effect sizes of short-term outcomes identified in the systematic review are available at www.thecommunityguide.org.

Theoretical Framework

Theoretical frameworks can help researchers understand the causal pathways through which health is shaped and constrained. Identifying the nature and influence of these causal pathways (15) can reduce guesswork in determining cause and effect of interventions. Among specific groups, a consequence of omitting theory may be a lack of specificity in the definition of constructs and variables important to the culture (16). In addition to intermediate- and short-term outcomes, demographic characteristics of study participants, such as age, cultural values, education, income, language barriers, acculturation, time exposed to diabetes, and time since diagnosis, have been used to predict and explain complex pathways that contribute to variations in self-management behaviors and metabolic control (17). Intermediate- and short-term outcomes and demographic characteristics of participants focus exclusively on the individual.

Opinions differ about which outcomes are most important in evaluation of DSME (18). Construction of a theoretical framework that integrates individual-level outcomes with those at the levels of the family, organization, community, society, and geographic location will help to resolve some of the debate about which outcomes should be measured. Studies were reexamined to identify theoretical frameworks that seek to include multiple-level out-
comes that help elucidate direct and indirect links among individual factors, patient characteristics, and social and community factors. Such theoretical frameworks may help identify and acknowledge social networks and organizational and community characteristics.

**Cultural Appropriateness of Interventions**

Culture is the unifying structure of behaviors, ideas, attitudes, values, habits, beliefs, customs, language, rituals, ceremonies, and practices to a particular group of people. This structure provides the group with a general and coherent design for living and patterns for interpreting reality (19). These shared characteristics help to shape people’s perceptions about their surroundings, the roles of family, and community, and their place in society, which includes interaction with the medical community. The disproportionate burden of diabetes among ethnic minority groups supports the need for DSME to be delivered in a cultural context that is familiar and accessible. It is critical to understand how cultural differences influence the way in which messages about diabetes self-care are received and how these differences contribute to diabetes self-care practices.

Research on DSME has attempted to deal with aspects of culture by delivering culturally adopted interventions to ethnic minority groups in community settings that are familiar to them. In addition, it is believed that interventions should be administered by staff from the same cultural background and should be sensitive to cultural characteristics. Attempts to address cultural sensitivity include the use of indigenous settings to deliver interventions and incorporation of familiar music, clothing, and language and dialect in videotapes, printed brochures, television, and ra-

### Table. Diabetes Self-Management in Community Settings

<table>
<thead>
<tr>
<th>Study, Year (Reference)</th>
<th>Study Design</th>
<th>Participants, n</th>
<th>Demographic Characteristics</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnard et al., 1994 (3)</td>
<td>Before and after</td>
<td>652</td>
<td>Mean age: 59.4 y Sex: 37.4% women Race: Not reported</td>
<td>Pritikin Longevity “weight loss” Center</td>
</tr>
<tr>
<td>Brown et al., 1999 (4)</td>
<td>Randomized trial</td>
<td>247</td>
<td>Mean age: 54 y Sex: 64% women Race: Mexican American</td>
<td>Agricultural extension center, extension center, churches, rural health centers, health clinics, schools, adults, day care centers</td>
</tr>
<tr>
<td>Brown and Hanis, 1995 (5)</td>
<td>Before and after</td>
<td>7</td>
<td>Mean age: 61 y Sex: 60% women Race: Mexican American</td>
<td>County agricultural extension offices</td>
</tr>
<tr>
<td>Hahn and Gordon, 1998 (6)</td>
<td>Before and after</td>
<td>120</td>
<td>Mean age: Not reported Sex: Not reported Race: African American</td>
<td>Two local churches and supermarket</td>
</tr>
<tr>
<td>Heath et al., 1987 (7)</td>
<td>Retrospective cohort</td>
<td>79</td>
<td>Mean age: 43 y Female: 79% Race: Native American</td>
<td>Multiple community sites (authors did not specify)</td>
</tr>
<tr>
<td>Elshaw et al., 1994 (8)</td>
<td>Randomized trial</td>
<td>152</td>
<td>Mean age: 61 y Sex: 70% women Race: Mexican American</td>
<td>Church hall and health clinic</td>
</tr>
<tr>
<td>Wilson and Pratt, 1987 (9)</td>
<td>Randomized trial</td>
<td>79</td>
<td>Mean age: 62 y Female: 80% Race: Not reported</td>
<td>Senior and “nutrition” sites in rural counties in Oregon</td>
</tr>
<tr>
<td>Wang et al., 1998 (10)</td>
<td>Before and after</td>
<td>75</td>
<td>Mean age: 71.8 Sex: 52% women Race: Chinese American</td>
<td>Setting: Meeting hall</td>
</tr>
</tbody>
</table>
dio messages (4, 20). These examples of cultural characteristics have been termed surface structure. In contrast, other investigators believe that interventions should address not only surface structure but also deep structure, which includes cultural history, beliefs, and norms (21). We reviewed the studies to determine whether important aspects of surface structure were considered.

### Instrument Quality

Quality instruments to capture the effects of interventions are urgently needed. Without a theoretical framework and quality instruments, the "black box" effects of the intervention remain largely unknown. This "black box" involves intermediate outcomes, which are pathways by which the intervention will influence short-term outcomes (15). We paid particular attention to identification of instruments designed to capture intermediate outcomes because these outcomes are less frequently reported and because they are critical in helping to postulate and explain the effects of interventions.

### RESULTS

#### Theoretical Frameworks

Only 1 of the 8 studies included a description of its theoretical framework (Table). Wang and Abbott (10) used Orem’s Theory of Self-Care (22), which suggests that social support and diagnosis are basic conditioning factors that modify a person’s capacity for overall self-care. Researchers postulated that patients who receive support from friends in addition to family reported better diabetes-related self-care behaviors than those who did not have such support.
Review of the 8 studies revealed findings that may have resulted from failure to identify a theoretical framework and explanatory constructs. All 8 studies consistently reported measurement of short-term biomedical outcomes. Four studies identified intermediate outcomes: knowledge (4, 5), health beliefs (4), health behaviors (5), peer support (9), and family support (10) (Table). Brown and associates (4) used a diabetes knowledge instrument and a health belief instrument but did not report findings generated from their use. Only 1 of these 4 studies described a theoretical framework that linked the intermediate outcomes to short-term outcomes (4, 10), thus making it possible to explore what aspects of the intervention generated the study effects. Our finding is consistent with the observation of Sorensen and colleagues (15) that for community interventions, “few studies have clearly articulated the key hypothesized mediating variables (outcomes) and fewer still have measured and evaluated the impact of mediating and modifying mechanisms.”

Cultural Appropriateness of Interventions

All 8 studies were performed in community settings, which are an important aspect of surface structure (Table). Settings ranged from a weight loss center (3) to schools (4), adult day care centers (4), local churches (4, 6, 8), county agricultural extension offices (4, 5), multiple community sites (the specific settings were not identified) (7), senior and nutrition centers (9), and a local meeting hall (10).

Four of the 6 studies that targeted ethnic minority groups provided information on surface structure. Brown and associates (4) developed an intervention study based on extensive community feedback. Bilingual Mexican-American nurses and dietitians delivered the intervention, local leaders from the community appeared in educational videotapes, and dietary recommendations were sensitive to Mexican-American preferences and needs.

Brown and Hanis (5) focused on mostly Mexican-American women, and Hahn and Gordon (6), who did not report information on age or sex, primarily targeted African-American women. In both studies, community members participated in the development of interventions and printed educational materials. Brown and Hanis (5) consulted with local health care providers and conducted focus groups and an extensive literature review to develop their intervention. They also created a videotape featuring Mexican Americans and conducted tours in a local grocery store.

Elshaw and colleagues (8) used a culturally appropriate videotape and interactive small-group discussions, primarily with Mexican-American women. The remaining 4 studies (3, 7, 9, 10) did not address surface structure or failed to report how it was addressed, or both. Studies that addressed surface structure provided insight into the development of culturally appropriate interventions.

Instrument Quality

Brown and associates (4), Brown and Hanish (5), Wilson and Pratt (9), and Wang and Abbott (10) examined intermediate outcomes. Brown and associates (4) developed 2 instruments: diabetes knowledge and diabetes-related health beliefs. They attempted to ensure content validity of both instruments, as evidenced by their review of published literature and review of the instrument by diabetes experts. However, they did not address aspects of face validity for these instruments.

Brown and Hanis (5) collected data on intermediate outcomes related to knowledge and health behaviors. They also attempted to ensure face validity by soliciting input from members of the target audience (Mexican-American adults) and to adequately address content validity by recruiting diabetes experts who had experience working with this group. The format consisted of dichotomous responses (yes or no and agree or disagree) because Likert responses had proved difficult for this group in previous studies (5). Instruments were translated into Spanish, and the researchers reported a reliability score of 0.88 by using the Kuder–Richardson formula for nominal data. They also developed a data collection instrument to assess health behaviors, such as dietary habits, lifestyle, adherence to medication regimens, and diabetes self-management skills (5).

Wilson and Pratt (9) measured the intermediate outcome of peer support by using the Arizona Social Support Schedule. This assessment tool was developed in 1980 and was used to measure social support in the adjustment of pregnant adolescents (23). Wilson and Pratt (9) also used the Diabetes Educational Profile, a tool developed in 1980 to collect data on what was described as “other psychosocial variables.” No further discussion was provided of the rationale for selection of assessment tool, development of items, formatting, scoring, or method of administration. These omissions are particularly important because the study focused on adults older than 60 years of age, whereas the Arizona Social Support Schedule was originally used among adolescents. Furthermore, information was not provided on the ethnicity of the participants or steps taken to ensure face and content validity.

Wang and Abbott used the Diabetes Family Behavior Checklist II to measure patients’ perception of supportive or nonsupportive behaviors of family members and significant others (24). The Diabetes Family Behavior Checklist II was translated from English to Chinese, and the Cronbach α value was 0.65. Methods to ensure the face and content validity of this instrument were not described.

Of the 4 studies (4, 5, 9, 10) that examined intermediate outcomes, only 1 (5) described how face and content validity were addressed. In developing their instruments, Brown and Hanis (5) carefully considered formatting, method of administration, content, multicultural assessment procedures, and feedback from the target audience and health care professionals. Just as theoretical frameworks should be developed to specifically capture the
effects of the intervention being delivered, instruments must conform to the language, age appropriateness, and cultural relevance of the community. Without such cultural adaptations, biases may occur in data analysis, scoring, and interpretation of community-based intervention results (25).

**DISCUSSION**

Our qualitative review helps to facilitate discussion around the state of research on DSME interventions in community settings. The study has some limitations. First, we could only cover information that was presented. Researchers may have addressed these aspects but omitted description of them for various reasons, such as to adhere to publication submission requirements. Alternately, this information may have been published elsewhere. In addition, the 8 studies provided evidence that the DSME intervention had positive effects on glycemic control. Because discussion of theory, culture, and instrument quality was lacking, however, it is difficult to postulate what exactly contributed to the success of the intervention. Despite these limitations, our findings suggest that lack of discussion of theory, culture, and instrument quality in published research may hinder identification of future strategies to improve, maximize, replicate, and disseminate effective DSME interventions in community settings.

The interventions in the 8 studies were delivered in the community but focused on patients. Historically, small studies with less controlled program evaluation often resemble large-scale intervention studies, such as the Pawtucket Heart Health Program and the Minnesota Heart Health Project. According to Shiell and Hawe (26), “these major community interventions have used substantial fiscal resources and reached mass au-
dences but may have “underestimated the complexity of community dynamics, the intricacies of formal, as well as informal community structures, and countervailing societal and economic forces that impact on change processes” (26). These factors have been acknowledged in evolving ecologic frameworks that recognized these competing factors and their contributions to shaping or constraining health outcomes (14, 27–29).

Future research that fails to engage communities and to ground public health interventions in a relevant theoretical framework is unlikely to produce notable outcomes, justified results, and sustainable programs. More important, if these limitations are not addressed, future research will continue to narrowly focus on individual patients and miss opportunities to identify interventions that work to alter the context in which individual behaviors occur. By using a contextual framework for diabetes self-management (Figure 2), we propose multiple levels of influence at which interventions should be targeted and locations (such as family, workplace, and community) in which risk conditions are believed to exist.

This framework may help to identify the source of risk conditions at the level of individual, family, organization, and community. These important levels are shaped by historical, physical, and social influences. For example, appropriate environmental targets include political and policy influences on persons with diabetes and the preponderance of fast-food restaurants in minority neighborhoods. It makes sense to design interventions that focus on family and social networks, because key self-care practices (such as diet and recognition of illness) are derived from, filtered through, or developed out of a response to the inescapable emotional ties created by these networks. Interventions at this level can focus on such areas as the quality of relationships (30), problem solving (31), organization (32), family routines (33), and emotional support (34).

Organizational interventions target businesses in the community in which persons with diabetes and their family members work or seek goods, products, and services. The primary focus of interventions at this level is on changing the organization rather than depending on individuals alone to make changes. Organizational interventions include labeling healthier food choices on restaurant menus and in grocery stores, offering employees healthy food alternatives in worksite cafeterias, and implementing policies that allow employees to exercise during work hours.

Communities are characterized by strong help networks; trust in civic institutions; volunteerism; shared values; frequency of face-to-face interactions; and active memberships in churches, social groups, and neighborhood associations (35). These characteristics influence the ability of communities to adopt, support, and maintain social norms that validate the altruistic intentions of DSME at the community level. Inherent in this discussion of community is the need to recognize the role of social and physical environments in constructing health. Community partnerships can work to institutionalize cultural incentives for healthier eating and opportunities for leisure-time activity. Communities that show cohesion, social support, and trust are postulated to help patients achieve intervention targets (36). Future DSME research at the community level must involve a collaboration between residents and researchers to improve the cultural relevance of interventions, produce richer contextual information that will inform theory, generate hypotheses that consider context, and increase acceptability of data collection to generate interpretable results.

Our contextual framework offers a multilevel approach to prevention and control of diabetes that moves beyond the individual level. This framework will require that a broad spectrum of disciplines and resources, including health professionals and lay expertise, is used to create additional academic and public interest in future research on DSME.

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