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A Culturally Sensitive Diabetes Peer Support for Older Mexican-Americans

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Introduction

Diabetes has become universally recognized as a worldwide epidemic (WHO, 2010). The World Health Organization reported in 2000 there were 17.7 million people with diabetes, which is expected to rise in 2030 to 30.3 million (WHO, 2010). The top ten countries with the highest prevalence of diabetes were in rank order: India, China, USA, Indonesia, Japan, Pakistan, Russia, Brazil, Italy and Bangladesh (Wild et al., 200). In 2008 the prevalence in Texas, one of the largest states in the USA, was 11.1% Hispanics, and this is expected to double by 2040. Of this group, 34.8% were 65 years and older (Texas Diabetes Council, 2010).

Adherence to a diabetes regimen involves the active role of the client in managing personal health by changing daily lifestyle habits to prevent secondary complications of uncontrolled diabetes (Drotar, 2000). Behavioral change for anyone can be difficult, but an exploratory process can help reduce one's ambivalence toward that change (Miller and Rollnick, 2002).

Considering the massive numbers of the adult population with diabetes and its biopsychosocial aspects, there has been a call for development of practical psychosocial interventions (Delamater, et al., 2001), which have been considered essential to coping with the daily challenges of diabetes (van der Ven, 2003; Funnell, 2006; Peyrot, et al., 2005; NHS Evidence, 2010).

Toljamo and Hentinen (2001) found that elderly individuals who were asked to make lifestyle changes to adapt to T2DM late in life had difficulty making changes to life-long habits. Williams and Bond (2002) emphasized that elderly may need additional help to motivate them to find reasons to change.

A New Role for OT

As one's reluctance to adhere to recommendations to follow a diabetes lifestyle regimen can result in further health complications, and increased health care costs, many have called for development of interventions that could have a positive impact on individuals, groups and populations (Duncan et al., 2009; Wens et al., 2008). Since occupational therapists are skilled in helping people adapt to lifestyle changes in self-care, work, leisure and social participation (American Occupational Therapy Association, 2008) they can facilitate adaptation to diabetes self-management routines for secondary prevention of long term complications. Several important studies in lifestyle redesign with older people have demonstrated cost savings related to improvement in functional capacities, quality of life, and self-efficacy (Pyatak, 2010). Limited articles have highlighted a role for occupational therapists engaged in prevention of the deterioration that occurs with poorly managed diabetes at individual, group or population levels (Scott et al., 2001; Pyatak, 2010).

Statement of the Problem

In a southwestern city in the United States where diabetes was at epidemic levels, diabetes educators prioritized screening, training and education over other support services. Psychosocial support occurred spontaneously before or after diabetes education classes among attendees. In an effort to gain insight about the needs of Mexican-American elderly in the city, an informal discussion with local diabetes educators and nurses from four facilities was held. They identified common client barriers to adherence to the diabetes regimen as: the inability to perceive the need to change habits and motivation to change, no insurance, and lack of resources.

Since peer-led support has been utilized as a cost effective intervention for people with physical illnesses, whether peers had little or no interactions with professionals (van der Ven, 2003), the author chose this as a practical intervention approach to provide psychosocial support. Van der Ven found that peer support groups were more advantageous than individual formats because they provided role models for imitation, reduced turmoil and anxiety of participants, and developed a sense of emotional connection, belonging, and wellbeing from people who shared common conditions.

In a previous pilot study, the Bridges Diabetes Support Group Manual© (BDSGM©) was developed by the first author to guide a community-based peer-led support group intervention with English-speaking Mexican-American elders in El Paso, Texas (Haltiwanger, 2007). The BDSGM© was written to provide structure for an active, empowered, self-sustaining community network support system for people with diabetes that could be adopted and used city-wide.

Guiding aims and research question

The research question was: Can the Bridges Diabetes Peer Support Group intervention change adherence behaviors in people with T2DM? The five aims of this study were to: 1) compare intervention vs. usual care (control) group outcomes 2) use focus (discussion) groups to gain insight barriers to adherence and cultural issues of Mexican-American elderly living with diabetes 3) determine if trained peer-mentors could lead the group without supervision 4) test the clarity of the Spanish translation of the BDSGM© 5) demonstrate how occupational therapists could develop and consult with community health groups (American Occupational Therapy Association, 2008).

Conceptual foundations of the intervention

The conceptual foundation for the program was sparked by the Alcoholic Anonymous addiction model, where peers with alcoholism and other addictions have been guided toward recovery by peers who use a structured manual and support program that has expanded worldwide (Alcoholics Anonymous, 2001). An addictive model was not suitable for people with T2DM. Therefore, a chronic illness model was created.

Reading Level and the Translation Process

The BDSGM© was written for 8.0 grade reading level, according to Flesch-Kincaid readability evaluation tool in Microsoft Word (RFP Centers, 2011). The document was forward and backward translated from English into Spanish by three university professors in the Linguistics Department at a state university to assure clarity of documents. A volunteer committee of 12 study participants of various reading levels was recruited by peer-mentors to check the translation. Unclear words were submitted for revision to the linguists. Proverbs were expanded to reinforce concepts in each chapter, cultural meanings and enable

contributions by group members. This manual can be obtained from the first author by researchers who want a copy by emailing emilyh@utep.edu.

Methods

Participants

The University of Texas at El Paso Institutional Review Board approved the study and all participants signed the informed consent. A convenience sample was formed from two diabetes community organizations. Mexican-Americans were studied because of their issue of health disparities, and high prevalence of diabetes.

Operational Definitions

Peer-mentors were over the age of 60 of Mexican-American descent with T2DM, who demonstrated 1) glycosylated hemoglobin test (HbA1c) levels below recommended guidelines for the elderly of 8.0 mg/dl (ADA, 2003) 2) followed dietary recommendations, exercised regularly, tested blood sugars daily for six or more months 3) and wanted to help others. Peer-mentors received peer mentoring training from the principal investigator (PI) to lead the Bridges Diabetes Support Group Program during the first year study. Novice peer-mentors were paired with an experienced mentor for training and to co-lead groups. Peer-mentors helped identify local resources for free medications, glucometers, and test strips for those in need.

Mentees were defined as any person over the age of 60 of Mexican-American descent with T2DM, who had diabetes education classes and reported difficulties on a simple habits questionnaire that documented anxieties about dietary management, physical activity, or reduced frequency of glucose or urine checks.

Sampling and Statistical Analysis

The mixed-method design used subjects as their own controls study randomized participants into four groups from a convenience sample. The statistical power analysis used a two sample t-test that was based on year one statistics, which revealed that to attain a statistical power of 0.80, it was necessary to have 12 subjects per group. Null hypothesis stated that there would be no difference between pretest and posttest responses of support group participants. Qualitative design enhanced the study by providing insight about cultural issues of Mexican-American elderly that may affect development of adherence behaviors.

Procedures

Two bilingual research assistants (RA) screened all inquiries by phone about the study in response to posters displayed at two local diabetes education agencies, to identify appropriate volunteers. Pre-testing occurred one day prior to the first intervention session. Posttest questionnaires and HbA1c testing were administered at two, four, and six months, to avoid conflicts with fall holidays. Positive indications of improvement in adherence were anticipated to be 10% reduction of HbA1c over baseline, and increased frequency of recordings of blood sugar checks, eating habits and exercise in weekly logs. The names of participants were sorted into Spanish-only or bilingual speakers. Spanish-only speakers were randomized into three groups by drawing numbers one to three. Then, bilingual speakers were randomized into any group by drawing numbers from one to four. Each group began with 12 participants.

Led by a health educator, the usual care group (control) called *Amigos Dulces* [Sweet Friends] provided meetings for participants and spouses for 1.5 hours per month for six

months. Participants asked questions about their concerns in the supportive classroom environment created by the health educator.

There were three intervention groups: 1) The *Sustaining group* was comprised of bilingual speakers that were led by two experienced peer-mentors with no contact from the PI for 10 weeks, to determine if the program was self-sustainable 2) there were two *Spanish-speakers groups* led by one experienced mentor and one novice mentor. These three groups used the BDSGM© and followed the program structure outlined by the workbook. Following these group sessions, the PI answered questions from peer-mentors, discussed group management issues, and furthered leadership skills.

Qualitative data was obtained from audio-recordings of weekly group discussions in each intervention group for 10 weeks. Each meeting was treated as a focus group that used semi-structured questions from the BDSGM© as topics to be explored during 1.5 hour discussions. This yielded 30 focus group discussions (32 participants) to increase trustworthiness and saturation of data (Creswell, 1998). Sometimes groups met longer until all members reached consensus that data had been saturated. Clarity of translations and relevance of the content of chapters were evaluated weekly. Research assistants attended all support group meetings to manage digital tape recorders, listen to discussions to enable accurate transcription and translation of notes, and collect session feedback sheets.

Intervention

The BDSGM© was a workbook that guided group discussions with questions to be answered that triggered self-appraisal on topics important to developing adherence such as: support, spirituality, health care beliefs, values, personal goals, stages of adjustment to the condition, assertiveness issues and mentoring others. Each chapter had educational tutorials with illustrative stories depicting people with diabetes whose behavior was considered maladaptive or adaptive when dealing with the content that was covered.

Instruments

HbA1c blood tests were obtained from subjects by finger prick at baseline (pretest), two, four, and six months. Questionnaires used were: Diabetes Attitude Survey (University of Michigan Diabetes Research and Training Center, 1998); Diabetes Empowerment Scale Short Form (DES-SF) (University of Michigan Diabetes Research and Training Center, 1998); Trans-theoretical questionnaire modified by the investigator to assess readiness and stages for change-specific behaviors (eating, exercise, testing blood sugars, and recording blood sugars or urine sugars) (Cropley, Ayers and Nokes, 2003; Kim, Hwang and Yoo, 2004); Personal Resource Questionnaire (PRQ 2000) (Weinert, 2003); and Diabetes Self-efficacy (Stanford Patient Research Education Center, 2000).

Demographics

Demographic information about participants is provided in Table 1 to enhance transferability of data (Trochim, 2006).

Results

Quantitative

Data was evaluated in two ways. First, the three intervention groups that all experienced common treatment were considered as one group (n=32) that was compared with the usual care (control) group (n=10). HbA1c Posttest 2 and 3 results were highly significant at $p < 0.001$. Pretest, Posttest 1, and Posttest 2 mean values of Self-Efficacy scores were significant at $p < 0.03$; Personal Resource Scale questionnaire scores at Posttest 1 and Posttest 2 were

very significant at $p < 0.0042$; Trans-theoretical change questionnaire at Posttest 1 and Posttest 2 were highly significant at $p < 0.001$. Attitude toward Diabetes and Diabetes Empowerment questionnaires were not different between comparison groups.

Next, data was compared between the intervention groups. HbA1c at Posttest 1 was significant at $p = 0.05$, but at Posttest 2 results were very significant $p < 0.002$ for the Sustaining Group. This group had the most subjects that were actively experiencing serious complications of diabetes..

Group logs indicated that at baseline, 60% of mentees had one non-adherent behavior, and 40% had two or more non-adherent behaviors. Adherent behaviors were identified by recording blood testing, exercise and dietary regulation in BDSGM© weekly logs in order to instill the positive habit of keeping records for physicians. At completion, 100% of mentees in the intervention group had achieved gains in all three areas and met personal goals. In the usual care group, participants did not keep logs.

Qualitative

All transcripts were checked for accurate translation by the two Mexican-American research assistants, and entered into ATLAS.ti 5.0 (ATLAS.ti Scientific Software Development GmbH, 2004), a qualitative analysis system for coding data. To insure triangulation of data, three Mexican-American research assistants coded data and derived themes with the investigator. Three qualitative themes emerged. To increase trustworthiness of data, themes were presented in Spanish to the 32 mentees in a large discussion group format for member checking to achieve consensus (Creswell, 1998).

Themes

Theme One: Don't trust the system—This theme voiced a general mistrust of physicians who lacked *personalismo* (cultural value of personalism) (Haltiwanger, 2010). Doctors were perceived as uncaring, lacking *respecto* [cultural value of respect for others] (Haltiwanger, 2010) as they rushed time with patients. Subjects felt devalued when doctors referred them to other professionals. Most were dissatisfied with treatment, feeling that doctors made mistakes in their care. They believed that doctors and their office staff did not think that elders were capable of taking care of themselves.

> I contacted my doctor's secretary six times before she would talk to the doctor about me getting more test strips. I had to argue with her and be assertive. She said, "You don't need more than a 30 day supply." I said, "Tell my doctor, I want control over my disease, I need power. I want what I want! He needs to let me test my postprandial blood sugars to get feedback about how I am doing. One test a day just isn't enough! If he won't help me, I will change doctors!"

Another participant said,

> There is no such thing as *personalismo* anymore. Doctor's take so little time with us. Then, they think we are not worth spending money on because we are old. Doctors spent more than five or ten minutes with their patient before.

One gentleman with an ulcerated foot seemed angry.

> I have a hole in my foot down to the bone from a careless podiatrist who cut my callous when he trimmed my toenails one year ago! It is finally healing after one year of perfect blood sugars. I have had trouble walking because of this hole!

Second Theme: Choice + Control = Power—The second theme was about making the choice to use tools of diabetes give one power over the disease to prevent diabetes

complications. This began with discussion of content in the chapter stories and expanded exponentially as members began to view themselves in charge of their health and became more assertive.

The oldest man said,

> When I got my second HbA1c [at 2 months], I was so disappointed. The change in your behavior doesn't show up for a while! It makes sense though that the more we know and test [blood sugars] [and] the more we exercise, the longer we will live and the more powerful we will become in getting what we need the most. If I don't take care of me, I won't see my grandchildren get married! We are taught in our culture to believe that God will provide, but it is our responsibility to take care of what burden he gives us and not wait for God to step in to fix the problem.

The oldest woman said,

> I used to feel so depressed, now I feel powerful to control my disease and not let it control me. Just knowing how I can eat a little bit of menudo [traditional Mexican soup], makes me feel less restricted. I always test afterwards now to see how me and the menudo did.

As peer-mentors role modeled positive adaptation behaviors, participants engaged in shared feedback and trial and error problem solving approaches. For example, one woman said, *I cheat on my diet all the time*. A mentor replied to that comment, *Just carry a little bag of fructose [fruit sugar] to dip your finger in, then lick it to stop your craving! It's your choice, mija [my dear one]. You're in denial!*

For each person there was a resistance for complete adherence to the regimen. One said, *Mostly, I do things to help myself, but every now and then I cheat when I eat.* Another rationalized, *If I exercise all week at the YMCA, on Sunday I give myself my reward, a Hershey's chocolate bar.*

However, with gentle confrontations from peer-mentors and mentees, insight regarding choice, control and power over the disease developed rapidly. One mentee shared,

> I used to think that I was entitled to something. I would be lazy about walking and look for any excuse not to. I am not perfect. Nobody is. Everyone has their issues. Here, I have learned that it is the overall good that we do to take care of ourselves which is important. We all make mistakes. I used to think that I was bad. I felt guilty. I would procrastinate doing what I was supposed to. Now I think that everything is trial and error. If I make a mistake, I learn not to do that again!

Theme Three: Social Cost of Diabetes—One male participant summarized the social cost of diabetes for Mexican-American men (Sobralsk, 2006),

> *There is a social cost to having diabetes. I keep my mouth shut; it is not macho* [manly] *to tell someone that you are weak. Mexican-American men just don't feel comfortable sharing their weakness in public*

Many participants were socially awkward, especially in social family gatherings. One female participant stated,

> You know, *familiasmo* [cultural value of importance of family] (Haltiwanger, 2010) is so important to us. You eat whatever your family puts in front of you. You do not complain because of *respecto.* So you follow their diet, not yours.

Another person spoke of the lure of forbidden sweets in social situations,

> Some people hand me servings of flan [custard dessert] and I cannot resist! You just can't insult them. Sometimes my sister says, 'You can't eat menudo! You have sugar diabetes!' [and then], it embarrasses me.

Members discussed the pressure from spouses and family members to sustain a diet of culturally familiar foods and deny the need for medication.

> I never know what to say to my spouse when he wants just tortillas and tacos for dinner. I feel he is the worker in the family, and he gives me money for food, so I should please him. He tells me that pills are a sign of weakness and that the food for the diabetes diet is too expensive.

Peers gave each other feedback, which resulted in social problem solutions. One mentee said,

> I never ask for anything when I go to a party, and I don't tell the host that I cannot eat, but I don't bring my own food. From now on, when I am invited, I will bring things that I can eat that are healthier. Aye, the Mexican food is so bad for us!

Another person shared,

> [During the meeting], I am uncomfortable interrupting someone who is telling their story, even if they take too long. It is not polite. I like the five-minute group rule that we came up with to be able to say, 'Anyone want to give feedback to him'? With a rule, I just say, five-minute rule…and we don't worry about *respecto*.

Discussion

Group members had a wide range of duration of diabetes, which agrees with the literature indicating social support can be necessary at any time during the illness (Delamater et al., 2001; Funnell, 2006) depending on context, and environment.

Sustaining Group members gains were achieved and sustained without contact with the PI, indicating that peer-mentors could provide powerful support to each other in groups, given training, structural guidelines, and rules of interaction to follow. Peer-mentors modeled desirable behaviors and self-acceptance through respectful and problem-solving attitudes. The *Sustaining Group* had more members with complications, which may have influenced their significantly higher improvement in HbA1c readings. It is possible that these members sent the negative message, *Don't do what I did.* It may be possible to develop a support system for very little cost by taking the intervention to churches and community centers, where space might be donated and distribution of the BDSGM© could be purchased at cost or given freely.

During the year one study, questionnaires measuring attitudinal change and feelings of empowerment were very significant, but in this second year study they were not. In looking for an explanation as to why the data was not consistent with the previous study, it was discovered that nine subjects (21%) responded to pretest questionnaires showing no room for improvement. Posttest 1 numbers declined as these individuals became more realistic, honest or less embarrassed about sharing their self-appraisals with the PI. Later levels returned to pretest levels at Posttest 2, but this may have impacted overall statistical significant levels in the study. In addition, all participants made changes in attitude and feelings of empowerment, thereby reinforcing the value of additional support from peers or health educators.

General themes provided insight about the perceptions of Mexican-American elderly, who felt they needed help with issues of social discomfort, identifying reasons to change, and

guidance in formation of daily goals. Themes revealed Mexican-American attitudes and barriers that may have impacted their willingness to adhere to recommendations for behavior change. Though not evaluated quantitatively, the program enabled acquisition of practical diabetes knowledge through shared information.

The group format facilitated self-acceptance, expression of opinions, willingness to try new things, and the sense of caring and cooperation that is achievable in cohesive groups (Schwartzberg, Howe and Barnes, 2008). Consensus of mentees was that the group format improved self-acceptance and self-empowerment, and conveyed the feeling that one was not alone in their struggles to adjust to diabetes.

Participants believed that physicians held a belief that elders were incapable of modifying their behaviors. By understanding that blood sugar testing, diet and exercise gave them power over the disease that was controlling them; participants changed perspective and felt empowered rather than overwhelmed and incapable. The exploration of social situations and value clarification through story method, discussion groups with modeling by peer-mentors seemed to enable mentees to problem-solve and devise strategies for handling social issues more effectively.

Implications for Occupational Therapy

This research documents a potential new role for OT. Future studies will continue the process of creating justification for reimbursement for secondary prevention strategies which may not exist now in provision of individual or group treatment in the profession. Cultural expectations must be considered that can impact client adherence to our recommendations for lifestyle change. Practitioners must make efforts to show *familismo, respect.* and *personalismo* that are so important to Mexican-American clients. The way that we frame our statements and show personal interest in them and their families can make all of the difference! Studies such as this remind us of how skillful occupational therapists are at inspiring and facilitating lifestyle redesign, and how clients may need extra help in order to change habits in order to secure their healthy futures at individual, group or population levels and impact this worldwide public health issue.

Limitations

The study was limited by the small number of participants in a convenience sample and a small control group. Achievement of significance on two questionnaires may have been swayed by 21% of participants whose scores were inflated on the pretest. There was no thematic analysis of control group questions generated by participants. Qualitative data may only be transferable by readers by identification of similarities between demographic descriptions and situational context.

Conclusion and future research

This study demonstrated how a well written culturally-sensitive group program could create a potential role for occupational therapists to change the health of world communities. Peer-mentors were found to be more effective in some ways than a health educator without the disease, by role modeling and encouraging behavioral changes in their peers.

The BDSGM© intervention had significant effect on HbA1c, Self-Efficacy for Diabetes, and the Trans-theoretical measures. Diabetes Attitude and Diabetes Empowerment questionnaires were not significant, as all groups improved on these variables. Themes identified in 30 focus groups gave readers insights about practical concerns of Mexican-American people with T2DM. The Bridges Diabetes Support Group system demonstrates potential to be duplicated in cities around the globe and should be tested further.

Future experimental research in the Bridges Diabetes Support Group intervention should be longitudinal with a large sample that is focused on additional mediating and moderating variables such as attitudinal, mood, quality of life and level of function. Future qualitative research should describe participant perspectives about the peer approach and explore ambivalence regarding behavioral change to validate the effectiveness of the Bridges Diabetes Support Group Program. Other studies are necessary to expand the role of occupational therapists in secondary prevention and pave a path for reimbursement.

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Table 1

Demographic composition all groups

Sex	26 females, 16 males all Mexican Americans
Age	60 years to 85 years; Median 74 years Mean: 72 years
Marital status	26 married for 3 to 67 years (mean: 48 years), 12 deceased spouse; 1 single. 2 divorced, 1 separated
Highest year of education completed	8 years to 16 years (mean: 11 years) 6 with high school equivalent diploma
Work History	27 unskilled workers, 7 business owners, 1 social worker, 1 teachers, 1 nurse, 6 housewives, 1-church secretary
Work status	6 currently working, 35 retired, 17 receiving d7:15,000–$19,999, 5:$20,000isability.
Annual Income	7: $5,000–$10,000, 7:$11,000–$14,999, 7:$15,000–19,999, 5: $20,000–$29,999; 8:$30,000–$39,999 3: $40,000–49,999; 5: $50,000+
Insurance	18 Medicare, 14 Medicaid, 4 other, 6 No insurance;
Number of children	0–10 children.
Duration of Diabetes	5:1–5 years, 15: 5–10 years, 10:10–15 years, 2: 16–17 years, 5:18 –20 years, 3: 30–38 years, 2: 40–45 years
Range of Glycosylated Hemoglobin A1C readings	4.7–13.8 mg/dl
Diabetes Medication	32 on oral medication such as thiazolidinediones and biguanides, 6 on insulin injections, 4 without medication, 40 on medications for conditions other than diabetes
Other conditions	1 multiple sclerosis, 1 macular degeneration, 17 high blood pressure, 3 retinopathy, 1 cerebral vascular accident, 1 Parkinson's disease, 1 testicular cancer, 8 heart disease, 6 neuropathy, 1 plantar decubitus ulcer, 1 amputation toes, 3 periodontal disease,
Preferred language	Mentees: 29 Spanish, 13 bilingual; Mentors: All bilingual
Dropouts	6 mentees left the study due to caregiving issues, missed sessions or inability to complete the final posttest during winter holidays