

## MANAGING UNCERTAINTY IN DIABETES: AN INTERVENTION FOR OLDER AFRICAN AMERICAN WOMEN

Emelia Amoako, PhD, APRN; Anne H. Skelly, PhD, APRN

**Objectives:** One out of four older African American women (OAAW) may develop diabetes. The disproportionate number of complications suffered by OAAW with diabetes may be due in part to uncertainty about how to manage diabetes and prevent or manage complications. The purpose of this study was to test the efficacy of an individualized psycho-educational diabetes uncertainty management intervention (DM-UMI) directed at managing diabetes-related uncertainties and delivered by a nurse via telephone to OAAW.

**Methods:** Sixty-eight participants with diabetes were randomly assigned to an experimental or a control group. Participants in the experimental group received the DM-UMI, which was delivered for four weeks. The DM-UMI was composed of four strategies (intervention variables): improving diabetes knowledge, patient-provider communication, problem-solving and cognitive reframing, which were expected to reduce diabetes-related uncertainty (outcome variable). The control group received their usual care. Measurement occurred at two time points for all participants: at Time 1: baseline and at Time 2: 6 weeks post baseline.

**Results:** Despite improvement in all intervention variables only problem-solving ( $P < .001$ ) was significantly related to decrease in uncertainty ( $P = .01$ ).

**Conclusion:** The study suggests that teaching problem-solving skills and assisting OAAW to apply these skills, via an individualized telephone intervention, may reduce ambiguities about diabetes care. (*Ethn Dis.* 2007;17:515–521)

**Key Words:** Diabetes, Uncertainty, African American women and intervention

### INTRODUCTION

Older African American women are one of the groups with the highest prevalence of diabetes in the United States. Currently, one out of four of these women develop the disease.<sup>1–3</sup> They are also least likely to receive timely and adequate health care, which results in devastating consequences.<sup>3–6</sup> Diabetes is the fourth leading cause of death in this population.<sup>1,7,8</sup>

The disproportionate number of complications suffered by older African American women with diabetes may be due in part to uncertainty about how to manage diabetes and prevent or manage complications.<sup>9–16</sup> Mishel, who proposed the *Uncertainty in Illness Theory*, defines uncertainty as an inability to make sense of illness when these events are ambiguous or highly complex, or when information is lacking, or outcomes cannot be predicted.<sup>17</sup> Mishel's theory suggests that uncertainty is higher in illnesses with ambiguous symptom patterns, in the initial diagnosis period during which individuals lack event familiarity, and when the individual's expectations of illness-related events are violated. Mishel, also identified the patient's educational level, trust and confidence in healthcare providers (credible authority), amount of

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social support, and cognitive capacity as influences on illness-related uncertainty.

Low educational levels, poverty, comorbid chronic diseases, multiple drug use, and age-related changes, make older African American women prone to experience uncertainty about diabetes management.<sup>2,13,18–21</sup> Our study examined the efficacy of an individualized psycho-educational diabetes uncertainty management intervention (DM-UMI), which was delivered by a nurse via telephone to older African American women with diabetes. The intervention was individualized to respond to a variety of contextual characteristics. Improving diabetes knowledge, patient-provider communication, problem solving skills and cognitive reframing ability were expected to reduce diabetes-related uncertainty.<sup>22–27</sup>

Our research questions were: 1) Does receiving the DM-UMI reduce uncertainty in the intervention group?; and 2) Does improved uncertainty management relate to decreased un-

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Address correspondence and reprint requests to Emelia Amoako, PhD; Assistant Professor; Adult/Gerontological Nurse Practitioner Program; The University of North Carolina at Greensboro School of Nursing; 410 Moore Building; PO Box 26170; Greensboro, NC 27402-6170. 336-334-5306; 336-545-3163 (fax); emelia\_amoako@uncg.edu

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From the University of North Carolina at Greensboro, School of Nursing, Greensboro, North Carolina (EA); and the University of North Carolina at Chapel Hill, School of Nursing (AHS & SF), Chapel Hill, North Carolina.

certainty regarding diabetes in the intervention group?

## METHOD

### Sample

Sixty-eight African American women age  $\geq 50$  in Guilford County, North Carolina, who had been diagnosed with type 2 diabetes within the past 2 years or more and were under the care of a primary healthcare provider participated in the study. All were English speaking, lived independently, provided their own diabetes self-care and had no cognitive deficiencies. All had access to a telephone.

Following approval from the institutional review board, 14 out-patient medical clinics and private physicians' offices were provided information on the study. These clinics and offices were chosen because  $>40\%$  of their enrolled patients were African Americans. Posters, which displayed the purpose of the study, inclusion criteria and a brief description of what the intervention and the control groups should expect, were placed in the waiting rooms of each site. Potential participants filled out a tear-off card and dropped it in a box or contacted the researchers through an 800 number provided on the tear-off card. Ninety individuals responded.

For potential participants assessed as coherent during an initial interaction, the first author set up an appointment for data collection in the home or a place convenient to the participant. Twelve individuals did not meet one or more of the inclusion criteria. They were thanked for showing interest in the study, and a packet of diabetes information and a small gift were sent to them. Two telephone reminders (a week and the day before) were made to each potential participant prior to Time 1 data collection. During this data collection, informed consent was obtained. Next, the brief Mini Mental State

examination was administered to screen for cognitive functioning.<sup>28</sup> For those who scored  $\geq 14$  points, data collection proceeded (10 women scored  $<14$  points). Participants received a gift of \$20 after completing Time 1 data collection. Participants were assigned an identification number and randomly assigned to the experimental or control group. Two weeks after delivery of the intervention, participants were contacted for Time 2 data collection. A research assistant, who was blind to the study group and was trained to follow the procedure, collected Time 2 data. Each participant received \$20 for completing the study. One person dropped out of the intervention group because of two admissions to the hospital. Four people dropped out of the control group due to lack of continued interest in the study and time constraints.

### Intervention

The DM-UMI was designed to address issues and concerns related to diabetes self-care in OAAW. The protocol was based on: 1) findings from the literature on uncertainty in chronic illness, diabetes self-care management; 2) focus-group interviews with diabetic OAAW; and 3) consultation with clinical experts working with diabetic OAAW. The intervener was an African American geriatric nurse practitioner with extensive clinical experience in management of diabetes and cardiovascular conditioners in minorities.

The intervention focused on four aspects of the women's experience with diabetes: diabetes diagnosis/prognosis, treatment concerns, social/economic/family issues, and self-care. The women's particular concerns (diabetes diagnosis/prognosis, diabetes management concerns, symptom/side effects, social/economic/family issues and self-management) drove the intervention. The intervention included weekly phone calls for four weeks and was embedded in a semi-structured clinical interview, which included open-ended

questions, direct exploration and use of reflective comments. The intervention guide involved four phases: warm up, assessment for problem identification, uncertainty appraisal and delivery of strategies to manage the uncertainty, and a closing section. The interactive processes used in the delivery of the intervention were guided by theories of counseling and behavior change.<sup>29,30</sup>

The calls ranged from 10 minutes to an hour, depending on the issues discussed. In addition, the women called the first author, as needed, using an 800 number. All phone conversations were audiotaped with the permission of the participant; this enabled the authors to listen and review participant's concerns and keep track of plans to resolve the problems.

The length of the phone calls varied depending on the woman's willingness to express her concerns, the number of problems identified, and the number of interventions delivered. One phone contact was scheduled per week and the women were encouraged to initiate other phone calls if needed. The intervention was delivered for four weeks. The number of problems varied between participants and across interviews, but the intervention dosage was based on the number of phone calls, not the number of problems.

The intervener kept records of all problems identified, the nature of the uncertainty associated with each of the problems (eg, if a participant was lacking information about the problem or if the problem occurred beyond expectation in terms of its duration) and the component of the intervention which was used to manage the uncertainty (eg, cognitive reframing or problem-solving strategies). The date, time and duration of the phone calls were also recorded.

Uncertainty management was expected to occur by: helping participants cognitively reframe diabetes-related concerns and issues in a manner to aid resolution of the problems; teaching

problem-solving strategies; providing information and resources aimed at increasing diabetes knowledge and self-care skills; and providing strategies to improve patient-provider communication. Strategies for delivering the cognitive reframing component of the intervention included: reframing illness-related responses; reframing time into discrete units; refocusing attention from uncontrollable to controllable areas in life; and using prayer to reframe control over problems. Problem-solving strategies were used to define a problem, generate alternative solutions, and choose, plan and implement the solution.

Participants were encouraged to try potential solutions and report on the result during the next phone call. For example, one participant identified time constraint and lack of a safe place where she could exercise. One place she felt safe was her church and was there at least three times a week. She was encouraged to explore walking around her church compound. By the end of the study she was walking 2–3 times a week for 30 minutes at a time. When solutions were successful, the intervener encouraged the participant to think of other disease-related problems to which the same solution could be applied. Interventions were thus applied to a variety of concerns, including diet, exercise, symptoms, and medications.

Strengthening patient-provider communications occurred through providing information to the participant about the problem to be presented to a physician. The intervener trained participants in how to ask questions and generate a list of questions for physician visits. To promote self-advocacy, the intervener taught participants assertive communication skills to enhance their participation in planning their care.

A list of resources that could assist with diabetes self-care in Guilford County was mailed to the participants along with printed information on various diabetes topics based on the

American Association of Diabetes Educators (AADE) Core Curriculum.<sup>31</sup> All materials were at the sixth-grade reading comprehension level. Additional printed materials were sent to participants at their request.

### Control Group

The participants in the control group received their usual care, which included regular visits for primary care and specialty visits for diabetes-related problems (eg, podiatrist, eye doctor). Usual care sometimes also included attending support groups for diabetes or scheduled classes for diabetes management. Phone calls were made to each of the participants in the control group to keep in touch with them and to remind them of the final data collection period (Time 2). At the final data collection, they were asked if they wished to schedule an appointment to receive one intervention phone call. Fifteen accepted and 11 declined due to time constraints. All the control group participants received information on diabetes self-care after Time 2 data collection.

### Data Analysis

Descriptive statistics were calculated for the following variables: age, education, income, marital status and health status (co-morbid condition, duration of diabetes, and smoking status). For each variable, frequencies and percentages were computed based on the responses given by participants to various categories. Chi-square and Fisher's Exact tests were used to identify statistically significant differences between experimental and control groups in sample characteristics at Time 1. A two tailed  $P$ -value  $\leq .05$  was considered statistically significant for the chi-square or Fisher's exact test. The reliability of the study instruments was evaluated using Cronbach's alphas for intervention and outcome variables. The number of items, possible scores, actual scores, and alphas are recorded in

Table 1 for Time 1 and Time 2. The alphas for all the instruments were above  $\alpha = .70$  for both Time 1 and Time 2, with the exception of the diabetes knowledge test and the diet and foot care subscales of the diabetes self-care activities scale. (The reliability of the medication subscale is not reported because only one item on the subscale was used in data analysis.) The diabetes knowledge test had a very low alpha of .29 at Time 1 but an alpha of .69, very close to the suggested minimum alpha of .70, at Time 2.

**Question One:** To test for the effect of the intervention on uncertainty, a change score for uncertainty was calculated for each person in both groups by subtracting the Time 1 scores from the Time 2 scores. An independent  $t$ -test of the difference between the intervention and the control groups on this change scores was then calculated.

**Question Two:** To test whether improved uncertainty management is related to decreases in uncertainty regarding diabetes in the intervention group, first the differences between Time 2 and Time 1 for uncertainty management (cognitive reframing, patient-provider communication, diabetes knowledge and problem solving) and uncertainty were calculated for the intervention group. Secondly, correlations between the change in uncertainty and the change in each of the uncertainty management variables were calculated. In the third step, regression analysis was conducted with change in uncertainty as the dependent variable and change in the DM-UMI variables as independent variables.

## RESULTS

### Demographics

The participants were all African American females ( $N=68$ ) recruited from clinics and physicians' offices in Guilford County. All could speak English and all had access to a phone.

**Table 1. Reliability of study instruments at Time 1 (N=68) and Time 2 (n=63)**

Instrument	Times 1 and 2	# of items	Possible score range	Actual score range	Alpha
<b>Demographic and background</b>	1	N/A	N/A	N/A	N/A
Investigator developed demographic data form (education and income as moderators) age, duration of diabetes, address, marital status and phone numbers.					
<b>Comorbid Diseases</b>					
Investigator developed diabetes comorbid disease form	1	22	22	N/A	N/A
<b>Intervention variables</b>					
Cognitive reframing scale	1	10	1-4	1.6-3.7	.73
Subscales of the Self Control Scale for cognitive reframing (Rosenbaum, 1983) <sup>48</sup>	2	10	1-4	1.8-4.0	.81
Problem solving scale	1	10	1-4	1.4-3.8	.84
Subscales of the self control scale for problem solving (Rosenbaum, 1983) <sup>48</sup>	2	10	1-4	1.5-3.9	.81
Diabetes knowledge test	1	16	0-16	3-13	.29
Diabetes Knowledge Test (Fitzgerald, Funnell & Hess, 1998) <sup>49</sup>	2	16	0-16	3-16	.69
Patient-provider communication scale	1	5	1-5	1.2-5	.74
Patient-Provider Communication Scale (Braden, Mishel & Longman, 1998) <sup>15</sup>	2				
<b>Outcome variables</b>					
Uncertainty scale- community-version	1	23	1-5	2-4.6	.87
Community version of the Mishel Uncertainty in Illness Scale (Mishel, 1988). <sup>17</sup>	2	23	1-5	2-4.3	.82

**Table 2. Sample demographic characteristics (N=68)**

	n	%
<b>Age</b>		
≤ 54	22	32.4
55-64	27	39.7
≥ 65	19	27.9
<b>Education</b>		
Less than or equal to 8 <sup>th</sup> grade	7	10.3
Less than high school	32	47.1
High school or GED	10	14.7
Less than college	13	19.1
College graduate (bachelors)	3	4.4
Graduate degree	3	4.4
<b>Monthly Income</b>		
≤ \$1000	44	64.7
> \$1000	24	35.3
<b>Marital Status</b>		
Married	14	20.6
Divorced/widowed/separated	41	60.3
Never married	13	19.1

Ages ranged from 49-83 years, with a mean of 61 ( $SD = 9.5$ ); 19 (28%) were above 65 years (Table 2). The majority had a high school education or less (49, 72%), and 44 (65%) earned \$1000 or less a month. Only 14 (21%) were married; the rest were divorced, widowed, separated or had never married.

### Health Characteristics

The number of comorbid conditions reported by the sample ranged from 1-13 with a mean of 5 ( $SD = 3$ ). The most common comorbid conditions were high blood pressure ( $n=56$ , 82%), arthritis (41, 60%), high cholesterol (41, 60%), and circulation problems (29, 43%). About a third (22, 32%) experienced respiratory problems, a fifth, (15, 22%) experienced depression or chronic pain, and 14 (21%) reported having a skin condition. The majority (49, 72%) had been diagnosed with diabetes for 2 years and were non-smokers (58, 87%). The intervention and control groups were similar in education, income and marital status. However, a higher proportion of the control group ( $n=28$ , 82%) than the intervention group ( $n=18$ , 53%) were 55 years and above ( $P=.02$ ). The two groups were very similar on comorbid conditions; however more women in the control group than the intervention group (9, 27%) reported circulation problems ( $n=20$ , 59%),  $P=.01$ . There were also more cases of thyroid condition in the control group (9, 27%) than in the intervention group (2, 6%),  $P=.02$ . In addition only 4 (12%) of the intervention group compared to 15 (44%) in the control group had diabetes for more than 2 years ( $P<.001$ ).

We found a significant difference between the intervention and the control group on uncertainty from Time 1 to Time 2. Participants who received the DM-UMI showed a greater decrease in uncertainty than did control participants ( $P=.01$ ).



**Table 3. Regression analysis predicting change in uncertainty from change in DM-UMI ( $n=33$ )**

	Std Beta	<i>t</i>	<i>F</i>
Variables			
Cognitive reframing	.24	1.51	
Problem solving	.44	2.73*	
Diabetes knowledge	.14	.88	
Patient-provider communication	-.04	-.27	
$R^2 = .32$			3.27*

\*  $P < .05$ 

Correlations below .30 were considered weak, .30–.60 were moderate and those above .60 were considered strong. Change in problem solving was moderately and significantly related to change in uncertainty ( $r = .50$ ,  $P = .03$ ). Change in cognitive reframing was moderately but nonsignificantly related to change in uncertainty ( $r = .30$ ,  $P = .09$ ). There were weak, nonsignificant correlations between change in uncertainty and patient-provider communication ( $r = -.10$ ,  $P = .75$ ) and diabetes knowledge ( $r = .18$ ,  $P = .33$ ).

Together, cognitive reframing, problem solving, patient-provider communication and diabetes knowledge accounted for 32% of the variance in uncertainty ( $R^2 = .32$ ). However, changes in cognitive reframing, diabetes knowledge and patient-provider communication did not contribute significantly to the prediction (Table 3), only change in problem solving significantly predicted change in uncertainty ( $F [4, 28] = 3.27$ ,  $P = .03$ ).

The most common problems presented by participants were related to the causes and consequences of diabetes and their ability to purchase diabetes management supplies. The symptoms/side effects most frequently reported by participants included constipation, pain, skin rashes, and infections. Many of the participants were not employed or were employed in low-income jobs. As a result, they reported a lack of health insurance, lack of access to health care and financial resources needed for managing their diabetes. Some partici-

pants were able to enroll in pharmaceutical assistance programs based on information provided on the list of resources. In addition, many reported a lack of resources to implement changes in diet, relaxation and exercise to help improve their diabetes.

## DISCUSSION

The need to manage uncertainty in chronic illness such as diabetes has been demonstrated by several studies including Callahan and Williams, Chin et al. and Koch et al.<sup>11,32,33</sup> Resolving uncertainty is a major factor in adjustment to illness. The most common uncertainties identified in this study included lack of meaning of a problem, lack of information on how to manage the problem, unknown outcomes of a problem, and lack of congruence between the expected outcome and the individual's experience. Other research has shown that what is often described as noncompliance with diabetes self-care activities reflects a belief held by diabetes patients that the disease will not affect their life outcomes.<sup>11,34,35</sup> According to Hernandez and Rodger,<sup>36</sup> uncertainty or not knowing what will happen in the future causes individuals with diabetes to develop a laissez-faire attitude as a means of easing their fears.

Intervention participants in this study received individually tailored information on the causes, diagnosis and management of diabetes, as well as a list of available diabetes related resource in

Guilford County. In addition, each participant received printed information on the components of diabetes management and referrals were initiated to agencies that assist with drug programs and blood-glucose testing supplies. Participants who received the intervention experienced significant improvements in diabetes knowledge post intervention. There is evidence, however, that many individuals with diabetes, despite receiving information about diabetes, do not use the information to initiate diabetes self-care.<sup>18</sup> In this study, participants were also helped to cognitively reframe their perceptions of and susceptibility to diabetes complications and to focus on activities that would improve their health. Participants were encouraged to reframe time/activities into discrete units to deal with situations that overwhelmed them. Many involved in religious organizations were encouraged to use their faith in God as a source of strength. Participants in the intervention group improved in cognitive reframing from baseline to post-intervention significantly more than the control group.

Participants also received information on the healthcare services they should expect during routine visits and the recommended frequencies of visits. The intervener probed into typical interactions between a participant and her healthcare providers and made recommendations if indicated. Participants reported a significantly greater improvement in patient-provider communication at Time 2.

However while the intervention participants improved significantly from baseline to post-intervention in diabetes knowledge, cognitive reframing and patient-provider communication, these three variables did not contribute significantly to the reduction of uncertainty. Only problem solving contributed significantly. These findings suggest that teaching problem-solving skills and assisting OAAW to apply these skills, via a individualized telephone interven-

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tion, may enable them to overcome barriers to lifestyle changes and maintain newly established behaviors to assist with diabetes self-care.

Efforts to decrease health disparities and improve health outcomes among OAAW are often hindered by the many issues these women face, including lack of transportation, high cost of health care, and the inconvenience of health-care program schedules.<sup>37-39</sup> Healthcare providers often lack the time to give the attention needed to explore issues and provide appropriate intervention.<sup>40,41</sup> This study has shown that an older form of communication, the telephone, which is available to most low-income individuals, can be used to deliver an individualized intervention, in the context of the African American culture and to provide highly needed support for diabetes self-care.

Similar to this study, Hayes, Boucher and Pronk<sup>42</sup> used telephone counseling to provide education to support life style changes. They reported that the use of the telephone gave individuals with diabetes immediate access to certified diabetes educators. Other telephone-based interventions have also shown improved outcomes for older patients with diabetes.<sup>43-45</sup>

### Implications for Practice

Improved health outcomes in African American women by the year 2010 have been targeted as a national objective.<sup>4,7</sup> However, the diabetes care and

education received by African American women falls below the recommended standards of care despite routine primary care and health visits.<sup>46-47</sup> Clearly there is a need for on-going contact to aid individuals with complex healthcare needs.<sup>48-49</sup> This study has shown that problem-solving skills may be the most useful tools healthcare providers can give their patients to reduce the burden of disease management.

In the current study, participants found the intervention convenient (indicated by their attitude and comments made) and valued the attention given to their needs related to managing diabetes. This study indicates that individualized telephone intervention designed to meet the needs of OAAW has the potential for reducing health disparities in this high-risk group. The average amount of time involved in phone contact with the participants was only approximately 15 minutes once a week. This interaction can easily be replicated in primary care settings. However, commitment for such interaction points to a need for change in reimbursement policies to allow practitioners to receive compensation for their time.

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#### AUTHOR CONTRIBUTIONS

*Design concept of study:* Amoako, Skelly

*Acquisition of data:* Amoako, Skelly

*Data analysis and interpretation:* Amoako, Skelly

*Manuscript draft:* Amoako

*Statistical expertise:* Amoako

*Acquisition of funding:* Amoako

*Administrative, technical, or material assistance:* Amoako, Skelly

*Supervision:* Amoako, Skelly