INTRODUCTION

African-American women with type 2 diabetes represent a high priority group for research efforts focused on reducing health disparities related to high rates of diabetes complications. As we seek to reduce these complications through improvements in self-management behaviors, an approach that incorporates individual as well as interpersonal factors within the social and cultural context may offer the greatest insight into relevant behavioral determinants. For the person with diabetes, this sociocultural context where self-care behaviors occur may be represented by the family context. This focus on the family setting takes on a more expanded view—beyond the family as a source of positive or negative support. Studies of the effects of family relational variables on diabetes self-care and metabolic control have shown family variables to be related to depressive symptoms and anxiety, diet and physical activity behaviors, and hemoglobin A1c levels. Among African Americans, low levels of family functioning have been shown to be associated with higher levels of perceived stress and poor glycemic control.

In the sociocultural context of the African-American family (especially when the patient with diabetes is female), this view of the family context may be better informed by not only an examination of family functioning in terms of factors such as cohesion and conflict, but also by investigating how social roles related to caregiving and family composition influence self-care practices. From the social science literature, studies of social support and multiple social roles offer some insights. Among older African-American and White women, we find that the number of social roles, marriage, and employment predict depressive symptoms. Research on the costs and benefits of social relationships and support-giving suggests that obligatory social roles (as a spouse, parent, relative, etc) can produce stressful demands (both physical and emotional) that outweigh the positive attributes of social interactions. These potentially negative effects of social roles and support-giving may also have similar effects on the day-to-day care of African-American women with diabetes. While qualitative research findings suggest that multiple caregiving (MC) responsibilities in the family context may negatively influence diabetes self-management in African-American women, research that seeks to quantify this relationship has not been done to our knowledge.

To help us examine this relationship between caregiving and diabetes self-management, we developed and tested a new measure among African-American women. In this report, we present two sets of data. First, we report the psychometric properties of this new measure and then test the validity of the empirically defined constructs. Second, we examine how MC factors (as measured by this new multiple caregiving measure) relate to demographic characteristics, household composition, and other psy-
Among African Americans, low levels of family functioning have been shown to be associated with higher levels of perceived stress and poor glycemic control.\(^5\,^6\)

cho social factors among African-American women with type 2 diabetes.

RESEARCH DESIGN AND METHODS

Study Population

The study population represents the combined samples of African-American women with diagnosed type 2 diabetes, living in North Carolina, who participated in two diet and physical activity intervention trials. The first sample (n=215) included patients from seven healthcare facilities, and the second sample (n=130) represented female study participants from 24 churches located in nine North Carolina counties. Women were eligible to participate in either study if they were African American, >30 years of age, diagnosed with type 2 diabetes (diagnosis of diabetes at age 20 or older and no history of ketoacidosis), and accessible by phone. Exclusion criteria included diabetes secondary to other conditions; pregnant or lactating; severe, acute, or self-limiting medical problems; and inability to speak English. Baseline data from the combined samples (collected in 1997 from the first sample and in 2000 from the second) are used in this report. Duplicate observations representing three participants who were enrolled in both intervention trials were identified, and all baseline data representing the second measurement values were removed prior to analysis.

Study Protocols

Questionnaires were administered by telephone (with the exception of perceived stress and stages of change for dietary and physical activity behaviors, which were staff-administered at the enrollment visit). Participants in both samples were reimbursed $15 for completing a series of questionnaires during three phone interviews.

Written consent was obtained from participants as part of the enrollment protocol for each research project. The institutional review board at the University of North Carolina approved protocols for conducting both intervention trials.

Description of the Multiple Caregiving Measure

Beginning with qualitative data from 10 focus group discussions with African-American women with type 2 diabetes,\(^6\) we developed a measure (Table 1) to quantitatively assess how patients with diabetes perceived their MC roles in relation to their diabetes self-care. Words and phrases describing their perceptions of giving support and help to family and friends were structured into survey items. Items were not a priori categorized into scales. Instead, we sought to capture all the themes that represented perceptions about their familial roles and support-giving. These themes included the positive feelings of being able to help family and friends who request or need help (items 1 and 2), the negative consequences of these helping roles (items 3, 4, 7, 8, 11) and feeling obligated to help or unable to say “no” to those who request aid (items 4, 9, and 10). We included two items to identify which women were assuming multiple caregiving roles (items 3 and 6) and one additional item (12) to quantify the number of people to whom support or help (both tangible and emotional) is provided.

Our next step was to identify the underlying structure of items in the measure and then test the internal reliability of empirically defined scales. Using factor analysis procedures, two factors or scales emerged from this set of 12 items. Items 1–5 and 10 formed one scale that represented what we termed the MC-role. The items in this scale include the justification, or reasons for assuming caregiving roles and identifying with the role. The negative perceptions of multiple caregiving roles are captured in the MC-barriers scale items. Two items (6 and 9) loaded on both factors, indicating that they tap into the underlying constructs of both scales.

The internal reliability of the two MC scales, as measured by the Cronbach coefficient α, is 0.72 for the MC-role scale (6 items; item:total correlations of 0.37–0.51) and 0.76 for the

<table>
<thead>
<tr>
<th>Table 1. Multiple care-giving measurement instrument*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Helping friends and family makes me feel good.</td>
</tr>
<tr>
<td>2. Being available for family and friends is important to me.</td>
</tr>
<tr>
<td>3. Friends and family come to me for help and support.</td>
</tr>
<tr>
<td>4. I believe it is my calling to help my family and friends.</td>
</tr>
<tr>
<td>5. Friends and family come to me for help with their problems.</td>
</tr>
<tr>
<td>6. I always place my family’s needs ahead of my own.</td>
</tr>
<tr>
<td>7. Taking care of family and friends interferes with caring for myself.</td>
</tr>
<tr>
<td>8. Having to take care of family and friends causes me stress.</td>
</tr>
<tr>
<td>9. It’s hard to say “no” when friends and family come to me for help.</td>
</tr>
<tr>
<td>10. I feel obligated to help my family and friends.</td>
</tr>
<tr>
<td>11. Caring for family and friends is a burden on my life.</td>
</tr>
<tr>
<td>12. How many people would you say regularly depend on you for help and support or regularly talk to you about their problems?</td>
</tr>
</tbody>
</table>

* Responses for items 1–11: four-point Likert scale—disagree a lot, disagree a little, agree a little, agree a lot. Responses for item 12: ≤2; 3–5; 6–8; >8.
MC-Role scale: 6 items (1–5, 10); MC-Barriers scale: 3 items (7, 8, 11).
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Table 2. Hypothesized relationships*

<table>
<thead>
<tr>
<th>Relationships among multiple care-giving variables</th>
<th>MC-Role Scale</th>
<th>MC-Barriers Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>MC-Barriers scale</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Place family’s needs ahead of own (item 6)</td>
<td>+</td>
<td>0</td>
</tr>
<tr>
<td>Difficulty saying “no” (item 9)</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Number of people who depend on you for help/support (item 12)</td>
<td>+</td>
<td>0</td>
</tr>
<tr>
<td>Relationships with selected psychosocial factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social and mental well-being (diabetes)</td>
<td>+</td>
<td>–</td>
</tr>
<tr>
<td>Perceived stress</td>
<td>0</td>
<td>+</td>
</tr>
<tr>
<td>Negative dietary competence</td>
<td>0</td>
<td>+</td>
</tr>
<tr>
<td>Positive diabetes competence</td>
<td>+</td>
<td>–</td>
</tr>
<tr>
<td>Negative diabetes competence</td>
<td>0</td>
<td>+</td>
</tr>
<tr>
<td>Perceived barriers to diabetes self-care</td>
<td>0</td>
<td>+</td>
</tr>
</tbody>
</table>

* (0) Relationship not predicted; (+) positive relationship; (–) negative relationship.

Construct Validation

In validating a construct measured by items in a scale, the main question to be answered is “Does the construct behave in the expected manner relative to other constructs?” For this research we selected a number of relationships between multiple caregiving and psychosocial factors where we felt predictions could be made based on the available literature. The psychosocial factors selected for this validation include perceived diabetes and dietary competence, social and mental well-being (diabetes quality of life), perceived stress, and perceived barriers to diabetes self-care. These hypothesized relationships are summarized in Table 2. Our predictions also include hypothesized relationships between the items and scales in the MC measure. A review of the literature on related constructs such as role strain, role expansion, caregiver appraisal, caregiving research conducted among older African Americans, and social support informed our predictions of how constructs would be associated. We made no predictions for relationships where the available data were limited or inconsistent.

Measurement Instruments—Psychosocial Variables

Below is a brief description of each psychosocial measure used in the construct validation and the examination of how items and scales in this new MC measure relate to selected psychosocial variables. Detailed information and psychometric data for these measures, when available, can be found in the references cited.

Perceived Diabetes and Dietary Competence (PDDC)

Perceived Diabetes and Dietary Competence (PDDC) is a 20-item validated measure of one's perceived level of competence and behavioral control in managing diabetes, with a focus on dietary behaviors. The PDDC measure includes three scales—positive diabetes competence, negative dietary competence, and negative diabetes control.

Diabetes Quality of Life

Diabetes Quality of Life is a 24-item validated measure of health status that was developed for African-American women with type 2 diabetes. It includes two scales measuring social and mental well-being and a physical symptoms index.

Perceived Barriers to Diabetes Self-Management

Six items measure the frequency of perceived barriers or problems interfering with self-management in the areas of diet (two items), physical activity, home blood glucose monitoring, taking diabetes medication, and foot self-examination. Responses are made on a 5-point frequency scale of “not often” to “very often.”

Stress Level

Perceived level of hassles and stressful events during the past month is measured by using a stress “ladder” ranging from 1 (little to no stress) to 10 (high levels of stress).

Social Support for Diabetes Regimen Adherence in African-American Women with Type 2 Diabetes

This 28-item diabetes-specific measure of social support is adapted from the “Diabetes Family Behavior Checklist II” (DFBCII), which measures family interactions specific to the diabetes self-care regimen that may support or interfere with appropriate behaviors in six regimen areas (diet, exercise, self-monitoring of blood glucose, self-examination of feet, taking medication, and visits to the doctor). Items assess frequency of supportive/non-supportive behaviors and the corresponding degree of helpfulness for each behavior. Frequency and helpfulness values are then multiplied to derive a cross-product score for each of 12 behaviors. While we did not include the social support measure in the construct validation because of slight variations in the survey used with the two study samples, it is included (with separate analysis by study sample) in our examination of how the MC factors (items and scales) relate to psychosocial variables.
Table 3. Participant characteristics (N=299)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, yrs</td>
<td>59.7 ± 10.8</td>
</tr>
<tr>
<td>Years with diagnosed diabetes</td>
<td>10.4 ± 9.7</td>
</tr>
<tr>
<td>BMI (n=295)</td>
<td>35.9 ± 7.9</td>
</tr>
<tr>
<td>Education, yrs</td>
<td>11.3 ± 2.9</td>
</tr>
<tr>
<td>Employed, %</td>
<td>34.4</td>
</tr>
<tr>
<td>Income &lt;$10,000/yr, % (n=156)*</td>
<td>48.1</td>
</tr>
<tr>
<td>Household characteristics, %</td>
<td></td>
</tr>
<tr>
<td>Living with spouse/person like spouse</td>
<td>40.1</td>
</tr>
<tr>
<td>Children (&lt;18 yrs) living in household</td>
<td>74.8</td>
</tr>
<tr>
<td>Diabetes treatment, %</td>
<td></td>
</tr>
<tr>
<td>Insulin only</td>
<td>26.8</td>
</tr>
<tr>
<td>Insulin + tablets</td>
<td>13.0</td>
</tr>
<tr>
<td>Tablets only</td>
<td>48.8</td>
</tr>
<tr>
<td>Diet only</td>
<td>11.4</td>
</tr>
</tbody>
</table>

Data are mean ± SD unless otherwise indicated.
* n=156; (48%) chose not to provide income data.

Statistical Analysis

For analysis of relationships between variables expressed as ordinal variables (measured on a four-point Likert scale) or not normally distributed, Spearman rank-sum correlation was used. Non-parametric one-way analysis of variance was used for analysis of relationships with dichotomous variables, and a general linear model for multivariate analysis was used with continuous outcome variables. All data analysis was performed with SAS—PC version 8 (SAS Institute, Cary, NC).

RESULTS

Participant Characteristics

Of the 345 participants in the combined dataset, 299 (87%) completed the MC questionnaire. In comparing the subset of participants who did not complete the MC questionnaire (n=46) to those who did, no statistically significant differences were found for age, years with diabetes, education, or body mass index (BMI). Characteristics of study participants are presented in Table 3. Participants were on average 60 years of age, with 10 years of diagnosed diabetes and BMI of 36. The average educational attainment of 11 years and 44% of participants earning <$10,000 annually suggest that the study population was generally of lower socioeconomic status. Most households (60%) were headed by women (no spouse/someone like a spouse) and included one or more children (75%). Participants living alone (no spouse, children, or other adults) comprised 10% (n=31) of the sample.

Results of Construct Validation

Construct validation results along with the hypothesized relationships are presented in Table 4. All predicted relationships between items and scales in the MC measure were confirmed. The MC-barriers and MC-role scales were not significantly correlated, but both scales were significantly associated with putting the family’s needs first (item 6), and difficulty saying “no” (item 9). As predicted, the MC-barriers scale was negatively associated with positive diabetes competence and positively associated with perceived stress, perceived barriers to diabetes self-care, and negative perceptions of the ability to manage diet and control diabetes. In line with our prediction, MC-role was
positively associated with positive diabetes competence, but contrary to our predictions, MC-role was not associated with either social or mental well-being. All predictions related to MC-barriers, however, were confirmed.

**Relationship of MC Factors to Demographic and Household Characteristics**

Table 5 shows the correlations between MC variables and demographic/household factors (expressed as continuous variables). No statistically significant relationships were found between either scale and education or years with diabetes. Age was, however, inversely associated with MC-barriers and the number of people who were regularly provided with help/support (item 12). With age and education inversely associated in this sample ($r = -0.34$, $P < .0001$), these results indicate that younger (and more educated) women reported a larger number of people who depended on them for help and support and perceived more barriers related to caregiving.

The household characteristic most significantly (though weakly) associated with MC factors was the number of adults in the household. Both MC-role and MC-barriers were positively associated with higher numbers of adults in the household; similarly, respondents were more likely to report placing the family’s needs ahead of their own when more adults lived in the household. The number of children in the household was positively associated with only MC-barriers.

Employment, income, and the presence of a spouse or significant other in the household were also evaluated relative to MC variables. Analysis of variance showed no mean differences in MC-role or MC-barriers scores by employment or income ($< or >$10,000/year). Only mean scores for item 6 (always putting family’s needs ahead of own) showed a significant relationship with income. Those who reported making <$10,000/year had lower mean scores ($P < .05$) for this item compared to women with higher income.

In comparing women by the presence or absence of a spouse, we found that women living with a spouse/significant other reported higher mean scores for MC-role scale ($P < .05$), putting the needs of family first (item 6) ($P < .0001$), and the number of people provided with help or support ($P < .05$). No mean differences were seen in scores for MC-barriers or difficulty saying no (item 9) between women who lived with a spouse/significant other and those who did not.

**Relationship of MC Factors to Psychosocial Variables**

Table 5 also includes the associations between MC variables (three items in MC measure) and selected psychosocial variables. Difficulty saying “no” to family and friends seeking help (item 9) was associated directly with both higher perceived levels of stress and barriers to self-
management and inversely associated with social and mental well-being. The number of persons provided with help/support (item 12) was also directly associated with levels of perceived stress but inversely related to negative perceptions about diabetes and dietary competence.

Our findings relative to social support are not presented in Table 5 but are important to note. Since social support was measured slightly differently in the two study populations, the analysis was done separately by sample. Only when social support is measured from a collective perspective, ie, support from all the people who help with diabetes management, is any relationship with MC variables significant. The only significant association between social support for diabetes and MC scales/items was with placing the needs of family first (item 6) \(r=0.25, P=.04, n=71\).

In addition to the bivariate associations and group comparisons noted above, we also examined on a multivariate level how perceived barriers of multiple familial roles (as measured by MC-barriers) related to household, demographic, and caregiving variables. Since MC-barriers scores were shown to be significantly associated with most of the psychosocial variables measured, we wanted to identify the caregiving factor(s) able to give us the most information about these perceived barriers, while controlling for demographic and household variables. The variables entered in the regression model, using a hierarchical approach, were demographic factors (age, education, years with diabetes) followed by household characteristics and MC variables. Using this model, 17% of the variance in MC-barriers was explained \(F=6.81, P<.0001; df=9; n=288\), with significant independent predictors of age \(B=0.01, P<.01\) and difficulty saying “no” to family and friends– item 9 \(B=0.25, P<.0001\). These results suggest that younger women and those who have difficulty saying “no” to family and friends perceived more MC-related barriers.

DISCUSSION

A new measure of MC roles (with acceptable psychometric properties) was tested in a sample of older African-American women with type 2 diabetes. The relevant findings from this research are summarized below:

- The constructs represented by the scales in this new MC measure were supported by associations with selected psychosocial variables in the predicted direction, ie, findings support (initially) the validity of constructs.
- Putting the family’s need ahead of self, and difficulty saying “no” to family and friends seeking help are two behaviors that identify women who assume MC roles and perceive more barriers associated with such roles.
- Neither assuming MC roles nor the number of people helped/supported predict higher perceived MC barriers. The number of children and adults in the household may, however, indicate more perceived MC barriers.
- Perceived barriers associated with multiple caregiving negatively impact feelings of well-being and perceived levels of control and competence in managing diabetes.
- Younger women and those who have more difficulty saying “no” to family and friends seeking help are more likely to experience higher levels of MC-related barriers.

As we put these findings in the context of other related research, a number of points may be highlighted. First, these findings suggest that simply assuming multiple caregiving roles does not translate into higher perceived barriers or levels of stress for women with diabetes.

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comitant increase in role strain or distress.13 Likewise, one’s assessment of satisfaction with caregiving roles, quality of the caregiver-receiver relationship, the impact of caregiving on one’s social life, and burden associated with caregiving are all factors that influence caregiving appraisals.15,27

If MC-barriers provide an assessment of quality or the negative consequences of multiple roles, then several significant relationships relative to how women feel about their diabetes self-care ability and their perceived well-being emerge from this research. In a review of research on stress, coping, and social support processes,6 data suggest that social ties (especially obligatory roles of spouse, parent, relative, etc) produce more stressful demands than positive consequences, resulting in more negative mental and physical health outcomes. The observed negative associations between MC-barriers and diabetes-related mental and social well-being are consistent with research conducted among urban African Americans with type 2 diabetes, where family problems and caretaker responsibilities were negatively associated with general mental and social well-being.26 Moreover, among African Americans, marriage, employment and the number of social roles have been shown to predict depressive symptoms.7

When these social relationships are viewed in terms of social support, research among African-American women
with diabetes suggests the personal cost of receiving support may be feeling obligated to help those giving the support. The observed positive relationship in this study between social support for diabetes and “putting the needs of the family ahead of your own” (item 6), supports this notion of costs as well as benefits derived from social roles. Related to this discussion of costs and benefits, we expected that assuming multiple roles would be associated with some positive psychosocial aspects. Our predictions were based on the theory of role accumulation, which identifies positive aspects (rewards, satisfaction, and personal resources) associated with accumulation of multiple roles. By using this theoretical framework we expected and found a significant positive association between MC-role and positive diabetes competence, but we did not find mental or social well-being to be positively related.

The second point to be made from these findings is that difficulty saying “no” to family and friends seeking help and putting the needs of family first are important cultural concepts to understand relative to caregiving and its associated negative consequences. From this work and that of others, we find that among women with diabetes, the family’s needs are often put ahead of personal health-related behaviors, and that the family’s well-being is central to the patient’s sense of well-being. Reciprocity as a cultural value in familial relationships may also be underlying the findings related to “difficulty saying no” when others ask for help (item 9). Moreover, the degree of MC-barriers can be predicted by this level of difficulty in saying “no.” What these findings suggest is that saying “yes” to those who come seeking help is culturally valued yet has some negative effects, then interventions that focus on changing behaviors in a familial (and cultural) context should emphasize strategies for lessening the negative impact associated with saying “yes” rather that learning how to say “no.” For example, a common strategy used in promoting lifestyle behavior change is to teach stress management skills. Learning how to say “no” is often a suggested strategy for reducing stress. From a cultural perspective, focusing on how to help others without placing undue burden on self may be more beneficial. This approach, for example, may involve teaching skills in deciding when to help (not all requests for help need to be acted on immediately, so selecting a time that works for everyone involved has the potential to reduce some of the negative consequences), or identifying who else could help (particularly for future requests).

The third and last point made by these research findings is that perceived caregiving among women with type 2 diabetes may be related to age (or life stage) and household characteristics. In this sample of African-American women with type 2 diabetes, where most women functioned as heads of families that generally included one or more adults and children, we find that while the number of people regularly provided with help/support was not significantly related to MC-barriers, these barriers were directly related to the number of adults and children living with the woman with diabetes. These findings lend further support to the study of family interaction variables in understanding the behavioral context related to diabetes.

The observed relationships among familial caregiving roles, household characteristics, and self-care behaviors require further research to gain a more complete understanding of how these factors interrelate in the African-American cultural context. If having information about the number of children in the household or the number of people who regularly depend on a patient for help/support can provide information relative to diabetes self-care, then gathering such information is clinically useful. From a familial and cultural context, these findings may not only have implications for what information we gather in the clinical setting to inform our understanding of self-care behaviors, but also suggest potential areas of research in culturally-relevant behavior change interventions. For example, if providing help and support to family is culturally and socially valued but often associated with burden or stress, then strategies that focus on how to help and where to find help (resources) may be more culturally acceptable than strategies emphasizing that the patient put her personal needs ahead of the family’s. In order to develop such strategies and test their effectiveness, more research that describes how family context variables affect diabetes self-care and family-based diabetes intervention research among African Americans are urgently needed.

Some limitations of this research relate primarily to generalizability of findings and measurement issues. Since the sample population for this research represents only a subset of African-American women with diabetes (namely, older southern women of lower socioeconomic status), these findings may not be applicable to a more representative group of African-American women. Findings relative to this new measure of multiple caregiving roles should be viewed as initial support for its validity. Additional research is needed to confirm its utility in other groups with type 2 diabetes. Despite these limitations, the findings of this research focused on familial MC roles of African-American women with diabetes support the family framework as relevant in the study of behavioral determinants of self-care, as well as the design of interventions to improve diabetes self-management.

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REFERENCES

AUTHOR CONTRIBUTIONS
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Administrative, technical, or material assistance: Carter-Edwards
Supervision: Samuel-Hodge, Skelly