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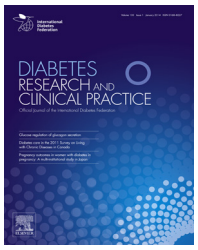

Identification of patient-centered outcomes among African American women with type 2 diabetes

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ABSTRACT

Aims: African American women carry a disproportionate diabetes burden, yet there is limited information on strategies to identify outcomes women perceive as important intervention outcomes (patient-centered outcomes). This study presents a brief strategy to solicit these outcomes and to describe outcomes identified using the highlighted strategy.
Methods: Thirty-four African-American women with type 2 diabetes were enrolled in group-based, diabetes/weight management interventions. A diabetes educator asked participants to write down their intervention expectations followed by verbal sharing of responses. Expectation-related themes were identified using an iterative, qualitative, team analytic approach based on audio-recorded responses.
Results: The majority of the expectation-related themes (6 of 10) were reflective of self-care education/management and weight loss-related patient-centered outcomes. The remaining themes were associated with desires to help others prevent or manage diabetes, reduce negative diabetes-related emotions, get rid of diabetes, and stop taking diabetes medications.
Conclusion: This study adds to a limited body of knowledge regarding patient-centered outcomes among a group that experiences a disproportionate diabetes burden. Future work could include integrating outcomes that are less commonly addressed in diabetes-related lifestyle interventions (e.g., diabetes-related negative emotions), along with more commonly addressed outcomes (e.g., weight loss), to increase the patient-centeredness of the interventions.

1. Introduction

African American women carry a disproportionate diabetes burden [1] and typically experience only modest benefit or short-term improvements from diabetes-related lifestyle interventions [2–5]. While the factors that contribute to this burden and limited intervention impact are not completely understood, factors such as cultural orientation [6] and multi-caregiver roles [7] are believed to play a role and are often integrated into intervention activities [8]. There has been little work, however, in identifying patient-centered outcomes [9], outcomes women perceive as important, as a way to further tailor intervention outcomes and goals.

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Patient-centered outcomes acknowledge the importance of the patient perspective in treatment and intervention delivery [9] and are believed to play a critical role in addressing healthcare disparities [10], such as the diabetes burden among African American women. While such outcomes may include meeting clinical therapeutic targets, they often extend to other outcomes, such as quality of life or functional status [11] that may be equally as meaningful for patients. From a research perspective, the Patient-Centered Outcomes Research Institute posits that interventions should include a focus on patient-centered outcomes [12]. However, there is limited information on how to identify and incorporate into interventions outcomes of most importance to patients.

Motivational interviewing, a behavioral counseling style designed to enhance patients' motivation for lifestyle change, includes a strategy known as an ''expectations'' exercise that may be an appropriate strategy for soliciting patient-centered outcomes [13]. The exercise is based on the premise that patients have better outcomes when there is congruency between what they expect and what actually happens [14]. Implementation includes asking patients to describe their treatment or intervention expectations. Here, we describe its use in identifying patient-centered outcomes among African American women with Type 2 diabetes enrolled in a lifestyle intervention. In the discussion, we describe how we addressed and prioritized some of these outcomes during implementation, based on both patient-centered outcomes shared during the exercise and our previous work among the target group [15,16].

2. Materials and methods

As part of two group-based, dietary and weight management interventions, African American women with Type 2 diabetes meeting the following criteria were recruited: (1) ≥34 years old; (2) Type 2 diabetes for ≥6 months; and either (3) HbA1c ≥ 7.0% or BMI ≥ 30. The interventions, 4 to 5 two-hour sessions, included an overview of diabetes self-care behaviors [17] and self-management strategies (e.g., self-care tracking) targeting medical nutritional therapy guidelines [18]. The Meharry Medical College Institutional Review Board approved the study and informed consent procedures.

During the first intervention sessions, the diabetes educator (educator) led participants in an audio-recorded ''expectations'' exercise. Prior to the implementation, a motivational interviewing consultant trained the educator in motivational interviewing principals and in implementing the exercise. Implementation consisted of participants writing their responses to one of these questions: (1) What is it that you hope to gain as a result of participating in this study?; (2) What are the most important reasons why you are here?; (3) What do you envision for yourself as a result of participating in this study?; and (4) If you could choose one thing that you would want to learn during this study, what would that be and why? The educator then facilitated 15 to 30 min of verbal sharing of responses among the group.

Participants' expectations were transcribed verbatim. A three-member team completed qualitative data analysis to explore emerging expectation-related themes. First, the PI reviewed all verbatim comments and grouped them into expectation themes (4-hour completion time); created when more than one comment referenced a similar expectation. Where applicable, sub-themes were created based on level of specificity of comments assigned to the same theme. For example, general expectations about diet were assigned to a different sub-theme than those referencing specific dietary behaviors. Non-assigned comments were grouped in an ''other'' theme. Second, without knowledge of which comments the PI assigned to different themes, the other two panel members individually reviewed the PI-developed themes and participant comments to determine whether comments warranted modification to the PI's proposed themes (e.g., addition of new themes). The two panel members also assigned comments to expectation themes based on either the PI's original scheme or, based on step two, a modified scheme (1-hour completion time/panel member). The time needed to complete steps two and three was approximately 1 h/team member. Next, all panel members met for 2 h to discuss their independent analyses. There were no recommendations to modify the PI's original scheme and discussions continued until a consensus was reached regarding comment assignment to the originally proposed themes. For example, though all panel members assigned comments to the same themes, there were minor differences in which comments were assigned to sub-themes. Differences were resolved through discussion of an individual analyst's rationale for comment assignment. Based on group consensus, the PI developed a list of final expectation themes and sub-themes (30 min completion time) for endorsement by the other panel members.

3. Results

Thirty-four women attended the sessions in which the expectation exercises were implemented. Demographic and clinical characteristics are presented in Table 1. Twenty-eight (82%) verbally shared their written responses to the expectations questions (a separate demographic and clinical profile was not possible for these women as all transcript data was de-identified).

Several expectation themes emerged (Table 2). Most comments were assigned to the ''diet'' theme, including three unique sub-themes, the majority related to specific dietary behaviors. For example, one participant stated that she expected to ''...learn the correct portions and how to prepare the correct foods...'' Another sub-theme represented comments linking diet to broader health goals (e.g., living longer). General education/control comments reflected expectations about education and management strategies, such as, ''... get

Table 1 – Participants demographic and clinical characteristics (*N* = 34).

Mean age (years)	53.7 ± 9.0
Some college or above (%)	79.4
Mean diabetes duration (years)	8.9 ± 7.0
Median Hemoglobin A1c (%, mmol/mol)	7.8, 62 (9.7, 6.6)
Mean BMI (kg/m^2)	38.0 ± 6.6