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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.

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Keywords

Diabetes; Self-management; African American women; African Americans; patient-centered outcomes; patient engagement

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.

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% (53 mmol/mol) 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 minutes 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 hour/team member. Next, all panel members met for two hours 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 minute 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 it [diabetes] under control*". "*I need to lose a little bit of weight...*" was typical of weight loss-related comments. An example of a self-care consistency-related expectation was, "...then I fell off the wagon. And I need to get back on..." The "no medication" theme-related sentiments were related to either avoiding or getting off diabetes medications; two specifically related to avoiding insulin. "Disease-free" expectations were exemplified by this statement, "I want to learn how to eliminate this Type 2 diabetes..." The "other" theme represents a grouping of single comments about learning to deal with stress, guilt and shame associated with having diabetes, getting motivated and living longer.

4. Discussion

Using the expectations exercise, we identified a variety of themes representing patient-centered outcomes among African American with Type 2 diabetes. Several themes, diet, general education/control, weight loss, exercise, blood sugar control, and self-care consistency, were consistent with our intervention goals and outcomes as well other diabetes-related lifestyle interventions (e.g., improved blood glucose control) [2-5]: While we are not aware of other studies identifying similar patient-centered outcomes using qualitative methodologies, other studies have also shown that African American women with Type 2 diabetes believe consistent diabetes self-care leads to positive outcomes in these areas (e.g., improved blood sugar control) [19].

Family prevention/management support themes and reducing diabetes-related stress, guilt, and shame from the "other" theme are reflective of patient-centered outcomes that are not as commonly addressed, compared to weight loss for instance, as part of lifestyle interventions in the target group. However, we anticipated some of them, due to our previous work [15] and others [20] documenting negative diabetes-related emotions and altruistic intentions [16] among African American women with Type 2 diabetes. For example, as part of the first session of the lifestyle intervention, we allotted time for participants to describe and elaborate on their emotions immediately following diagnosis. We envisioned that this sharing would acknowledge the relevance and pervasiveness of any negative emotions and also reduce the potential impact of such emotions on participation in intervention activities. We also included a diabetes-related distress [21] measure to assess whether the intervention impacted distress levels and a peer support component to acknowledge the perceived importance of helping others in their lifestyle change endeavors.

Outcomes associated with the "no medication" and "disease-free" themes were not a focus of our lifestyle intervention and we could find no other literature highlighting these outcomes as a focus among African American women with Type 2 diabetes. However, the sharing of the outcomes provided an opportunity to link planned intervention strategies to these outcomes. For example, relative to "disease-free" expectations, the educator advised that attention to diabetes self-care behaviors, such as those that would be targeted in the intervention, should remain a priority even when glucose levels are consistently in the normal range or when medication is no longer needed; the latter representing an instance when individuals might describe themselves as "disease-free".

The most notable study strength is the presentation of a brief and straight-forward strategy for soliciting patient-centered incomes. This is particularly salient given the increased focus on targeting patient-centered outcomes in research [9] and few reports highlighting strategies to solicit the outcomes along with solicitation results. An additional strength is the inclusion of examples of how we addressed some of the patient-centered outcomes that are not commonly addressed as part of lifestyle interventions in the target group. A limitation, however, is that though we used an iterative team approach to analyze the data, inaccurate interpretation and researcher bias are not impossibilities. In addition, while we solicited patient-centered outcomes as part of an ongoing research intervention, it may be more useful to use this strategy during both intervention planning and implementation; the former to develop a plan to address patient-centered outcomes as part of implementation and the latter to optimize the intervention, where possible, based on any unique outcomes shared by actual intervention participants.

We have described a strategy, using open-ended questions about intervention expectations at intervention onset, to assess patient-centered outcomes. This work adds to a limited body of knowledge regarding patient-centered outcomes among a group that experiences a disproportionate diabetes burden. Outcomes that are not commonly addressed as part of lifestyle interventions among African American women with Type 2 diabetes, as presented here, could be integrated into interventions, to insure that interventions prioritize patient-centered outcomes. Future work, however, should include exploring patient-centered outcomes among a larger group of African American women with Type 2 diabetes.

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REFERENCES

1. Giger JN. Diabetes: a major health disparity for pre-menopausal African-American women. *J Natl Black Nurses Assoc.* 2005; 16(2):vii–viii.
2. Samuel-Hodge CD, Keyserling TC, Park S, Johnston LF, Gizlice Z, Bangdiwala SI. A randomized trial of a church-based diabetes self-management program for African Americans with type 2 diabetes. *Diabetes Educ.* 2009; 35(3):439–454. [PubMed: 19383882]
3. West DS, DiLillo V, Bursac Z, Gore SA, Greene PG. Motivational interviewing improves weight loss in women with type 2 diabetes. *Diabetes Care.* 2007; 30(5):1081–1087. [PubMed: 17337504]
4. Keyserling TC, Samuel-Hodge CD, Ammerman AS, Ainsworth BE, Henriquez-Roldan CF, Elasy TA, et al. A randomized trial of an intervention to improve self-care behaviors of African-American women with type 2 diabetes: impact on physical activity. *Diabetes Care.* 2002; 25(9): 1576–1583. [PubMed: 12196430]
5. Stolley MR, Fitzgibbon ML, Schiffer L, Sharp LK, Singh V, Van Horn L, et al. Obesity reduction black intervention trial (ORBIT): six-month results. *Obesity (Silver Spring).* 2009; 17(1):100–106. [PubMed: 18997671]
6. de Groot M, Welch G, Buckland GT 3rd, Fergus M, Ruggiero L, Chipkin SR. Cultural orientation and diabetes self-care in low-income African Americans with type 2 diabetes mellitus. *Ethnicity & disease.* 2003; 13(1):6–14. [PubMed: 12723006]
7. Samuel-Hodge CD, Headen SW, Skelly AH, Ingram AF, Keyserling TC, Jackson EJ, et al. Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. *Diabetes care.* 2000; 23(7): 928–933. [PubMed: 10895842]

8. Dodani S, Kramer MK, Williams L, Crawford S, Kriska A. Fit body and soul: a church-based behavioral lifestyle program for diabetes prevention in African Americans. *Ethnicity & disease*. 2009; 19(2):135–141. [PubMed: 19537223]
9. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA : the journal of the American Medical Association*. 2012; 307(15):1583–1584.
10. Fleurence R, Selby JV, Odom-Walker K, Hunt G, Meltzer D, Slutsky JR, et al. How the Patient-Centered Outcomes Research Institute is engaging patients and others in shaping its research agenda. *Health Aff (Millwood)*. 2013; 32(2):393–400. [PubMed: 23381533]
11. Curtis JR. The “patient-centered” outcomes of critical care: what are they and how should they be used? *New Horiz*. 1998; 6(1):26–32. [PubMed: 9508255]
12. Selby JV. The patient-centered outcomes research institute: a 2013 agenda for “research done differently”. *Population health management*. 2013; 16(2):69–70. [PubMed: 23565922]
13. Miller WR. Motivational interviewing: research, practice, and puzzles. *Addictive behaviors*. 1996; 21:835–842(6)
14. Brown JM, Miller WR. Impact of motivational interviewing on participation in residential alcoholism treatment. *Psychology of Addictive Behaviors*. 1993; 7(4):211–218.
15. Miller ST. Diabetes and psychological profile of younger rural African American women with type 2 diabetes. *Journal of health care for the poor and underserved*. 2011; 22(4):1239–1252. [PubMed: 22080706]
16. Miller ST, Marolen K. Physical activity-related experiences, counseling expectations, personal responsibility, and altruism among urban African American women with type 2 diabetes. *The Diabetes educator*. 2012; 38(2):229–235. [PubMed: 22454407]
17. Boren SA. AADE7™ Self-care Behaviors: systematic reviews. *The Diabetes educator*. 2007; 33(6):866, 871. [PubMed: 18057260]
18. Franz MJ. Practice guidelines for nutrition care by dietetics practitioners for outpatients with non-insulin-dependent diabetes mellitus: consensus statement. *Journal of the American Dietetic Association*. 1992; 92(9):1136–1139. [PubMed: 1512376]
19. Skelly AH, Marshall JR, Haughey BP, Davis PJ, Dunford RG. Self-efficacy and confidence in outcomes as determinants of self-care practices in inner-city, African-American women with non-insulin-dependent diabetes. *The Diabetes educator*. 1995; 21(1):38–46. [PubMed: 7835203]
20. Cummings DM, Lutes L, Littlewood K, DiNatale E, Hambidge B, Schulman K, et al. Regimen-Related Distress, Medication Adherence, and Glycemic Control in Rural African American Women With Type 2 Diabetes Mellitus. *The Annals of pharmacotherapy*. 2014
21. Welch GW, Jacobson AM, Polonsky WH. The Problem Areas in Diabetes Scale. An evaluation of its clinical utility. *Diabetes care*. 1997; 20(5):760–766. [PubMed: 9135939]

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

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Table 2

Intervention expectations among African American women enrolled in a diabetes and weight management intervention

Theme/Sub-theme	Description (number of related shared expectations)
Diet	
-Specific Dietary Behaviors	-Learn about portion sizes, food preparation, shopping, eating schedules (8)
-General Diet	-Eat healthier (6)
-Linked to Broader Health Goals	-Longevity, stop taking medication, manage comorbidities, what impacts blood sugar (4)
General Education/Control	-Learn more about diabetes education management strategies (7)
Weight Loss	-Weight loss as primary expectation and goal (5)
Exercise	-Increase exercise or become more fit (4)
Blood Sugar Control	-Keep blood sugars in the normal range (3)
Self-Care Consistency	-Stay on track with self-care behaviors (3)
No Medication	-Get off or avoid oral medications and insulin (4)
Disease Free	-Get rid of diabetes (4)
Family Prevention/Management Support	-Help others prevent or manage diabetes (2)
Other	-Reduce diabetes related stress, guilt, and shame; Increase motivation; Extend life (4)