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Original Research

Optimizing Diabetes Literacy: Lessons from African Canadians in Calgary about Type 2 Diabetes Diagnosis

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ABSTRACT

Objective: With the aim of optimizing diabetes education, type 2 diabetes awareness, primary prevention and secondary prevention, we studied how African Canadians experience type 2 diabetes. Specifically, we studied stories told by African Canadians living in Calgary, Alberta, Canada, about significant events and experiences at the time of their diagnosis with type 2 diabetes.

Methods: From recorded interviews, we extracted themes from stories about diagnosis, using hermeneutic phenomenology. Participants included 11 African Canadians older than age 18 and at least 1-year post-diagnosis. Transcribed stories were analyzed for units of meaning describing significant themes/ experiences about the diagnosis. Extracted units of meaning were organized into themes that were presented to a focus group of African Canadians in Calgary to garner their perspective on the findings, discuss the implications and make recommendations for improvements.

Results: All participants reported experiencing shock, disbelief, fear and a sense of helplessness immediately after their diagnosis. These rendered them unable to think clearly or start their treatment regimen until propelled by additional forces. Also, 73% of participants reported experiencing anger/denial about the diagnosis for some time, whereas 18% reported a short-lived relief that they could finally put a name to their symptoms. However, the overarching issue associated with all of the themes appeared to emanate from a lack of type 2 diabetes awareness.

Conclusions: Emotions experienced by participants seemed precipitated by a lack of type 2 diabetes awareness. Some community-specific factors contributed to the lack of type 2 diabetes awareness, which appeared to impede primary and secondary prevention among participants. Recommendations for ameliorating these factors are presented.

RÉSUMÉ

Mots clés :
Afro-Canadiens
facteurs propres à la communauté
expériences
prévention primaire
prévention secondaire
diabète de type 2
sensibilisation au diabète de type 2

Objectif : Dans le but d'optimiser l'enseignement sur le diabète, la sensibilisation au diabète de type 2, la prévention primaire et la prévention secondaire, nous avons étudié comment les Afro-Canadiens vivent le diabète de type 2. Particulièrement, nous avons étudié les vécus racontés par les Afro-Canadiens vivant à Calgary, en Alberta, au Canada, au sujet des événements et des expériences qui les ont marqués au moment du diagnostic du diabète de type 2.

Méthodes : À partir de l'enregistrement des entrevues, nous avons extrait les thèmes des vécus au sujet du diagnostic en utilisant la phénoménologie herméneutique. Les participants incluaient 11 Afro-Canadiens de plus de 18 ans qui avaient au moins reçu le diagnostic depuis 1 an. Les vécus transcrits ont été analysés quant aux unités de signification décrivant des thèmes et des expériences ayant marqué le diagnostic. Les unités de signification extraites ont été regroupées en thèmes qui ont été présentés à un groupe de discussion composé d'Afro-Canadiens de Calgary pour obtenir leur point de vue sur les conclusions, discuter de leurs implications et faire des recommandations d'amélioration.

Résultats : Tous les participants ont rapporté le choc vécu, l'incrédulité, la crainte et le sentiment d'impuissance immédiatement après leur diagnostic. Ceux-ci les ont rendus incapables de penser clairement ou de commencer leur régime thérapeutique jusqu'à ce qu'ils aient été poussés par des forces supplémentaires. Également, 73 % des participants ont rapporté avoir ressenti de la colère et éprouvé des

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sentiments de déni par rapport au diagnostic durant un certain temps, alors que 18 % ont rapporté un soulagement de courte durée puisqu'ils pourraient enfin mettre des mots sur leurs symptômes. Cependant, l'enjeu principal associé à l'ensemble des thèmes semblait émaner du manque de sensibilisation au diabète de type 2.

Conclusions : Les émotions vécues par les participants semblaient être précipitées par le manque de sensibilisation au diabète de type 2. Certains facteurs propres à la communauté contribuaient au manque de sensibilisation au diabète de type 2, ce qui semblait entraver la prévention primaire et la prévention secondaire parmi les participants. Des recommandations pour améliorer ces facteurs sont présentées.

Introduction

Despite the escalating prevalence of type 2 diabetes, some populations at risk lack adequate type 2 diabetes literacy, are unaware of their vulnerability and therefore are unable to engage in appropriate primary prevention (PP) and/or secondary prevention (SP) (1). This renders them more vulnerable to the disease. Proper health literacy (HL) (the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions) is a key factor in health promotion (2), especially for type 2 diabetes, for which the best strategy is PP (3), and effective SP is the best way of limiting complications (3). Therefore, the promotion of type 2 diabetes awareness is critical to stemming the high prevalence of type 2 diabetes. Also, type 2 diabetes symptoms can appear innocuous to people who lack type 2 diabetes awareness, thus precluding early diagnosis and interventions that could improve the prognosis (4). Moreover, successful tertiary type 2 diabetes prevention requires knowledge and understanding of the basic diabetes pathology and physiology and the appropriate actions needed to minimize hyperglycemia (5,6). Type 2 diabetes information often is acquired at Diabetes Education Classes (DEC), which are reported to have high attrition rates, especially among ethnic minorities (7,8). However, meta-analyses of studies for Hispanics and African Americans living with type 2 diabetes, which offered collaborative and culturally competent interventions, showed improvements in attrition rates, awareness and self-care (9,10).

African Americans are a high-risk type 2 diabetes population (11), but the situation with African Canadians is less clear because research with this group is in its infancy (12). However, a study of youths with type 2 diabetes in a multi-ethnic Ontario hospital (13) found youths of African ancestry to be overrepresented more than 4 times the average of the same age group in the provincial population. Another Ontario study (14) found sub-Sahara African new immigrants to have a higher prevalence of type 2 diabetes than long-term residents. Together, these studies suggest that African Canadians may be a vulnerable population. However, few studies have examined how African Canadians experience type 2 diabetes and what their level of awareness is of this disease. Our study was designed to procure such information from African Canadians living with type 2 diabetes in Calgary, Alberta.

Methods

This qualitative study used hermeneutic phenomenology (HP), as proposed by Heidegger (15) and Gadamer (16). HP is recognized as a good methodology for researching lived experiences because it combines 2 important properties of people: descriptions and interpretations (17). HP tenets demand that researchers bracket their prejudices to lessen their interference with the understanding and interpretation of the emerging essence of the phenomenon of inquiry (18,19). To accomplish this, we allowed the stories to unfold from participants' perspectives by asking just one open question (stated under procedures in Methods). Follow-up questions were used sparingly for clarifications. We also invited another person, not affiliated with the study, to analyze the transcripts independently. All participants spent a significant proportion of the interview describing the experience of being diagnosed. Five participants reported being referred to DEC but only 1 patient described finishing the course. The other 4 patients stated that they stopped after the first class because they did not find the information culturally relevant or helpful. Three patients described supervision by their physician at regular intervals and the final 3 patients reported receiving just basic information of what to do at the time of diagnosis. Two of these patients indicated they would have liked to have access to someone who has managed their type 2 diabetes successfully for mentorship. Although the research garnered comprehensive type 2 diabetes experiences of participants from diagnosis to interview date, this article focuses exclusively on diagnosis experiences and how this information may aid in improving both type 2 diabetes awareness and DEC for African Canadians.

Eleven participants were interviewed individually for the study. Then, a focus group was conducted to access the larger Calgary African Canadian community's perspective on the findings and to obtain their recommendations on how to improve type 2 diabetes awareness, and type 2 diabetes PP and SP for African Canadians in Calgary. The study was approved by the Conjoint Faculties Research Ethics Board for the University of Calgary.

Participants

Recruitment of participants was by advertisements through posters and in-person presentations at churches, community centres, community events and African Canadian ethnic salons. Criteria for inclusion in interviews were as follows: age older than 18 years, being of African ancestry and being at least 1 year past a type 2 diabetes diagnosis to ensure participant's adequate experience with the tasks, demands and intricacies of living with type 2 diabetes.

Our biggest problem was recruiting participants. At first, we sought permission to place recruitment posters at a large Diabetes Education Centre in downtown Calgary and were told African Canadians rarely have ever been seen there. We tried another centre and received the same response. Although some studies have reported that DEC are underused (20,21) and ethnic minorities are sometimes reluctant to participate in research (22,23) because of historical mistrusts and culture-specific characteristics (24,25), we did not expect zero recruitment from education centres. We sought advice from African Canadian community leaders who advised us to clearly outline steps we will take to protect participants' identities during presentations. Therefore, we highlighted the use of pseudonyms for participants' identity protection at every presentation. We received our first call from a potential participant 8 weeks after our last formal recruitment presentation.

Table 1 shows the demographic information of the 4 male and 7 female participants. Some were Christians, some were Muslims and a few had no religious affiliations. There were also varying