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Applying Qualitative Methods in Developing a Culturally-tailored Workbook for Black Patients with Hypertension

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Abstract

Objective—To apply qualitative research methods in developing a culturally tailored, educational workbook for hypertensive black patients.

Methods—The workbook was developed using formative qualitative data from 60 black primary care patients with hypertension. Participants were interviewed using qualitative methods and data were analyzed through sequential steps of open-coding, axial coding, and selective coding. From these analyses, themes describing patients' cultural beliefs about hypertension were derived and used to develop the workbook.

Results—The workbook, “*Living With Hypertension: Taking Control*” is a 37-page illustrated workbook with 11 chapters based on patients' perceptions of hypertension. These chapters focus on strengthening participants' ability to take control and manage hypertension and on providing knowledge and health behavior techniques.

Conclusion—Qualitative research methods were used to inform the development of a culturally tailored educational workbook.

Practice Implications—The workbook developed in this study may offer a practical and effective means of educating patients about blood pressure control in primary care settings.

Keywords

Hypertension; Blacks; Qualitative; Patient education

1. Introduction

According to the Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC7), supplemental patient education

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materials are an inexpensive and effective means of maximizing blood pressure control.(1) This is particularly relevant to the treatment of black patients with hypertension who in comparison to hypertensive whites, are significantly more likely experience hypertension-related fatal stroke, end-stage kidney disease, and myocardial damage.(2–7) Blacks also experience greater challenges in achieving optimal blood pressure control. Much of the challenges in blood pressure control in blacks have been ascribed to poor patterns of medication adherence and dietary indiscretion. (8,9) Improving knowledge about hypertension, its treatment and complications has important implications for medication adherence and blood pressure control. (10) Therefore, culturally relevant patient education materials are needed.

In order to develop materials that contain culturally relevant personal experiences, the health perceptions of representatives of the target audience must be elicited. Qualitative research is a methodological approach that is often used to understand the experiences of a particular group or community. Grounded theory is a method within qualitative research that can be employed in order to gain greater insight into the social and cultural factors that influence the management of a chronic condition. Grounded theory methodology attempts to make theoretical sense of a particular life experience or phenomenon. For the purpose of this study, the process of living with hypertension is the life experience of interest.(11) The objective of this paper is to describe the process of using a grounded theory approach in developing a culturally-targeted, patient education workbook that is designed for blacks with hypertension.

2. Methods

The workbook was developed in two phases: a formative phase and workbook construction phase. Study participants were 60 adult black patients, who had uncontrolled hypertension (defined as BP \geq 140/90 mm Hg) and who were recruited from a primary care practice of an urban academic medical center.

2.1 Formative phase

The goal of the formative phase was to collect relevant patient information through qualitative interviews that could be used in developing the content of the workbook.

2.2 Sampling

The study methods and protocol employed in developing the workbook were approved by the Institutional Review Board on the Conduct of research. Eligible patients had to self identify as black or African-American, have documentation of uncontrolled hypertension, and had to be on at least one antihypertensive medication. Ineligible patients were those who were deemed clinically or mentally unstable by their primary care physician or those who were unwilling or unable to provide informed consent.

All eligible patients who provided informed consent were interviewed. Each interview began with the following probe: *“While doctors have special ways of understanding illness, you may also have ideas, which may be different from what doctors think. It will help us to better help people with high blood pressure if we understand how it affects you and what high blood pressure means to you.”* This opening probe was followed by a series of questions on their understanding and perception of the term high blood pressure or hypertension, experiences with having high blood pressure, and advice that they would give to others with high blood pressure.

2.3 Coding

Responses to all interviews were audio-taped and transcribed verbatim. Each interview was then analyzed line-by-line through a series of consecutive steps known as open coding, axial

coding, and selective coding. Open coding is an analytic process in which data are “opened-up” and analyzed line-by-line to reveal the underlying meaning of the phenomenon of interest or categories. In the next step, axial coding, categories were then divided into discrete components or subcategories that further described their unique characteristics. Finally, selective coding was done to identify central groups of categories or themes that represented the main ideas that were being conveyed by the participants.

2.4 Workbook construction phase

Themes that emerged during the formative phase were reviewed and incorporated as individual chapters in the workbook. The content of the workbook was also supplemented with other hypertension-related patient information material developed by the American Heart Association(12) and the National Heart Lung and Blood Institute, and incorporated relevant literature on medication adherence in hypertension.(1,13,14) (15) (16) (17)

3. Results

3.1 Formative phase

Qualitative interviews were conducted among 60 study participants. The mean age of participants was 61 years. Of these, 92% were female, 54% were married, and 88% completed high school, 14% completed college, 12% completed graduate school and 40% were employed. The average duration of hypertension was 13 years. Several themes emerged from the qualitative responses which are described elsewhere. (18) However, four main themes which summarized 80% of patient responses were used in developing the content of the workbook: meaning of hypertension, fear and consequences, social network experiences and social support, and advice.

3.2 Final Workbook

The final workbook “Living With Hypertension: Taking Control” is a 37-page illustrated workbook with 11 chapters that were based on the formative phase and supplemented by selective sampling of the literature.

The workbook included culturally-relevant illustrations and free space for patients to write their thoughts. “Living with Hypertension: Taking Control” was selected because the workbook content was derived from actual people who were living with hypertension and includes descriptions of their experiences. The first four chapters: *What is Hypertension*, *Common Medications for Hypertension*, *Taking Medications Regularly*, and *Controlling Your Hypertension* were written to provide an overview of what hypertension is and the importance of medication adherence. These chapters were developed based on the themes “the meaning of hypertension” and “fears and consequences”. The goal of these chapters was also to dispel myths about hypertension and to provide patients with ways of controlling their blood pressure in order to reduce the risk of hypertension-related consequences.

The next two chapters, *Gaining the Confidence to Control Hypertension* and *Personal Success Stories of People with Hypertension*, provided patients with exact quotes of what patients in the qualitative phase offered as strategies to gain control over hypertension and how they made changes in their lives. These chapters were developed based on the theme of advice. The chapters entitled *Partnering with Your Doctor* and *Working with Your Support System* emphasized the importance of social support and how social support networks can be incorporated in disease management. These chapters were developed based on the theme of social support/social network. The chapter *Making a Contract with Myself* was included to provide patients with a practical tool for taking control and was based on the theme of advice. The chapter *Staying Positive* was included because positive thinking was the main strategy for

medication adherence employed in the randomized trial in which the workbook was tested and applied. This was a randomized controlled trial that used positive affect and self-affirmation as techniques for improving medication adherence in hypertensive African-Americans. Baseline data and rationale for the positive affect/self-affirmation trial are reported elsewhere. (19)

The last chapter *Getting More Information* provides additional educational resources for patients. This chapter was based on the themes “meaning of hypertension” and “advice”.

3.3 Preliminary evaluation of the workbook

Preliminary efforts to evaluate the workbook were done as part of the positive affect/self-affirmation trial described above. It was distributed to patients in both the intervention and control group. These patients were demographically similar to the participants who were involved in developing the workbook. The workbook was evaluated among 182 adult blacks with uncontrolled hypertension who were enrolled in the positive affect/self-affirmation trial. (19) The mean age was 60 ± 12 . Of these participants, 77% were female and over 90% completed high school. The average duration of hypertension was 12 ± 11 years.

Over the 12 month study period, research assistants who were not part of the original workbook development contacted patients via telephone in an attempt to assess the degree to which they felt the workbook was helpful. Two items were used to evaluate the workbook. Patients were asked to respond to the question, “was the workbook helpful” with 1) yes, a lot, 2) yes, somewhat, 3) yes, a little, 4) no, or 5) that they did not use the workbook. The second item asked patients to describe specific ways in which it was helpful. Pearson correlation was used to look for associations between age, gender, marital status, and education with rating of helpfulness.

The workbook was rated as being a lot or somewhat helpful by 73% of participants, a little helpful by 12%, not helpful by 4%, and 11% of the participants said they did not read it. Neither demographic characteristics nor duration of hypertension correlated with perceived helpfulness.

4. Discussion and Conclusion

4.1 Discussion

“Living With Hypertension: Taking Control” is a workbook that was designed specifically for blacks with hypertension in an effort to enhance their understanding of hypertension and to facilitate better disease management. The rationale for developing this workbook was the result of qualitative interviews which demonstrated, poor knowledge or a misunderstanding of several aspects of disease management among patients with hypertension. This was addressed throughout the workbook and more specifically in the first 4 chapters of the workbook: *What is Hypertension*, *Common Medications for Hypertension*, *Taking Medications Regularly*, and *Controlling Your Hypertension* and the chapter *Personal Success Stories of People Living with Hypertension*. It was developed using a grounded theory approach. Rather than relying solely on health care providers’ notions of what patients need to know about managing hypertension, this educational workbook was formulated based on patients’ attitudes and values about the management of hypertension.(20)

This workbook provides a framework for developing future educational materials. However, there were limitations in how it was developed. The population sampled in this study was largely black patients with 3% of patients identifying themselves as Hispanic or Latino. Although the majority of participants were racially similar, they may not be culturally similar. Therefore, the contents of the workbook may not reflect cultural views of all black patients. Another limitation of the sampling strategy was that there were relatively few men compared

to women. This reflects the higher ratio of women to men in this setting. Future testing of the workbook among a larger population of men is needed in order to make sure that it is applicable to a male population with hypertension. Our preliminary data suggest that the workbook was perceived as helpful, however there is insufficient evidence to support that this workbook causes significant changes in knowledge, patient satisfaction, health behavior, or outcome. There is the potential to test the impact of this workbook on these outcomes in future randomized trials.

4.2 Conclusion

Despite these limitations, this paper helps to delineate steps in developing print educational materials for patients with hypertension. The strength of the workbook is that it was developed based on patient-derived concepts and using qualitative methods. The process that has been outlined in developing this workbook provides a framework for developing other culturally targeted educational materials. The next phase of workbook development will include a rigorous evaluation of the knowledge with pre-workbook exposure and post-workbook exposure evaluation of knowledge, change in health behavior, and change in actual blood pressure.

4.3 Practice Implications

Although this workbook was developed for a clinical trial, there is the potential for testing its effectiveness in a primary care setting. It can also be modified and used in the clinical setting as supplementary patient information that could complement communication with healthcare providers. The methods used can also be applied to developing similar educational material for other racial and ethnic groups. This workbook has the potential to improve the self-management of hypertension by improving patient knowledge about the etiology and treatment of hypertension and by providing patients with practical skills for disease self-management.

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Table 1

Workbook chapters

| Chapter headings | Description of chapters |
|---|---|
| What is hypertension? | Describes categories of hypertension, the causes of hypertension, the populations at risk for hypertension, stresses that there are no classic signs and symptoms of hypertension, dispels myths |
| Common Medications | Describes the most common categories of antihypertensives and their mechanisms of action |
| Taking Medications Regularly | Describes strategies for medication adherence |
| Controlling Your Hypertension | Describes other mechanisms of controlling blood pressure such as diet, exercise, smoking cessation, and stress reduction; This chapter also emphasizes that adverse consequences can be reduced by taking control |
| Gaining Confidence | Describes the importance of having self-efficacy for self-management and providing strategies on gaining confidence; Provides verbatim quotes of what patients said about living with hypertension and their experience in overcoming barriers to medication adherence |
| Personal Success Stories of People Living with Hypertension | Provides verbatim quotes of what patients said about living with hypertension and their experience in overcoming barriers to medication adherence |
| Partnering with your doctor | Describes the role and importance of good doctor- patient communication and strategies on what patients should ask their doctors about their hypertension and their medications |
| Working with your support system | Describes the role and importance of having strong social support networks and provides strategies on involving social networks in patients' care |
| Making a Contract | Describes the concept of a health contract and provides steps and a template for patients to make their own contracts for self- management of hypertension |
| Staying Positive | Describes the benefits of having positive a outlook and strategies for maintaining a positive perspective |
| Getting more Information | Provides a list of resources for obtaining more information about hypertension |