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Original Research

Willingness to participate in adapted pain and disease self-management programs: evaluating preferences of Black men

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Abstract

Background and objective: The health of Black men continues to be a discussion of public health concern. To address this concern, this exploratory study aimed to assess Black men's willingness and preferences for participating in tailored pain and/or disease self-management programs.

Materials and methods: Three program designs were presented, with varying delivery modalities. Participants responded to a series of questions regarding the content and form of program implementation. A total of 75 Black men, with an average age of 57 (SD = 14.8) years, were included for study participation.

Results: Responses to a set of closed- and open-ended questions showed that less than one-third (29.3%) had never heard of chronic disease self-management programs, with another 77.3% never participating in a self-management program. Overall, the majority of the men preferred receiving health information from books (73.3%) or brochures (74.7%). Few (15.0%) preferred receiving health advice from family. More than one-third however, preferred receiving information from friends (38.7%) or a religious leader (33.3%).

Conclusion: Results from this study contribute to our understanding of how more effective programming and systems tailored to the health needs of this gendered population is needed in order to promote safe and cost-effective approaches to prevention and treatment efforts.

Keywords

Black men; Pain; Self-management programs; Chronic disease; Healthcare disparities

1. Introduction

Data show that the health of men in general and Black men in particular, often goes un- or misdiagnosed, undertreated, and mismanaged. This may be the result of avoidant health seeking behaviors, marginalized resources and/or a lack of programming that meet the specific needs of this gendered and raced population. While endorsed across domains of physical and mental health, social adjustment, and emotional well-being, there remains the need to assess these outcomes across illness symptomatology, such as pain and other medical diagnoses. This however, may be problematic as this gendered group is often socialized to show strength and stoicism, while avoiding expressing emotion or vulnerability [1–3]. While defined as protective characteristics, these social constructions may increase health risks, risk-taking behaviors, and emotional distress, while diminishing health promoting behaviors [4]. This is all the more relevant when addressing pain and health outcomes among this group in general, and among Black men in particular. While pain requires attention from multiple perspectives, little is known about these experiences among Black men.

Considered a subjective circumstance, the pain experience is contingent on several factors including the history

of the illness, duration of the medical condition, type of pain (acute versus chronic), pain variability, physiological changes, cultural background, and sociodemographic factors such as gender and age [5]. The subjectivity of the pain experience is further characterized as a dynamic and complex process intertwined with affective, cognitive, behavioral patterns. Specifically, pain has been found to be highly comorbid with psychiatric disorders and various medical conditions such as sickle cell disease and traumatic brain injury [6–8]. Other examples, include the relationship between depressive symptomatology and pain reports, with each potentially exacerbating the other [9]. Yet, while the majority of these data focus on the pain experience among women, there remains a gap in how pain is perceived and experienced among men, particularly those from diverse race and ethnic populations [10]. Compared to women, men are less likely to report pain complaints to their primary care physicians and are more likely to withhold pain complaints [11, 12]. These behaviors are further promoted when acknowledging "traditional" gender roles and beliefs moderating pain, health outcomes, and other symptomatic tolerances [13].

While recognizing differences in health outcomes and the pain experience, Black men are particularly vulnerable to implicit and/or explicit behaviors bared by inept systems that often dismiss their medical, social and psychological needs. Black men have reported a distrust in the healthcare system due to the belief that it is motivated by profits or experiences of mistreatment due to their race [14–16]. The cost of healthcare has been a consistent barrier; Black households have historically had the lowest average household income over the past 60 years [17, 18]. Furthermore, Black patients may be receiving lower quality and more intensive hospital care when they do seek care [19]. Aymer [20] argued that systemic racism may promote internalized suppression, eroding people's abilities to recognize the short- and long-term detriments to their health imposed by their lack of willingness to seek medical attention [21]. This is all the more relevant in recognizing the benefit of tailored self-management programming designed to promote better health and treatment adherence.

Recognizing the relevance of chronic disease self-management programs (CDSMP) in disease prevention, screening uptake, managing symptoms, and reducing predisposing risk factors, suggests that a "one size fits all" approach is not an effective approach in meeting the health needs of Black men who are diagnosed with various illnesses. Specifically, self-management is a process by which individuals to monitor their illness and engage with family, community, and healthcare professionals to develop and use strategies to maintain an optimal quality of life. This contrasts with self-care, which is used by individuals to promote growth and development or maintain health [22].

While short-and long-term benefits of CDSMPs have been widely documented among White Americans [23, 24], few studies have assessed the impact and preferences of these programs among minority populations. A review of the literature found few studies focusing on the impact and benefits of CDSMPs among Black adults [25], with fewer attending to the needs of Black men [26, 27]. To address this lack of scholarly work, the current study presents exploratory data on Black men's willingness to participate in and preferences in the design and implementation of pain and/or chronic disease self-management programs. This scholarly research is considered exploratory, because there are no known theories and/or previous research describing Black men's perceptions and knowledge in participating in CDSMPs.

2. Methods

2.1 Participants

Participants were recruited from a local senior center, a community health event, and an existing database of patients willing to participate in research, all within a large metropolitan city in the Midwest United States. The eligibility criteria for study inclusion was self-identifying as Black/African American and as a male (or man gender identity). Although the participants did not have to complete a written survey, each was screened prior to participation to make sure that they were able to read and understand English and were able to complete the interview without the assistance of a proxy. Data were collected through telephone interviews or in-person, with participants completing a series of measures assessing physical health and behavioral outcomes, and preferences in the design of tailored pain and disease self-management programs. All interviews lasted no more than 45 minutes, with an average of an estimated 20 minutes. Timing of each interview depended on if the respondent was interviewed via the phone or at the senior center. All participants who completed the interview and survey were monetarily compensated $25.00 for their time in participating in the project. The project was approved by the university's Institutional Review Board (IRB).

2.2 Measures

Participants completed a series of questions assessing demographics characteristics and health, as well as their knowledge, perceived need, willingness, and preferences in participating in tailored self-management programs.

2.2.1 Demographic characteristics

Age was assessed as a continuous variable by asking participants their age in years. Education was determined by the total years of education completed. Marital status was measured with the following response choices: married, living as married, single/never married, separated, divorced, or widowed. Respondents were also asked how satisfied they were with their financial situation.

2.2.2 Knowledge of disease self-management programs

With a yes/no response choice, a listing of self-management programs was presented to each participant assessing if they had knowledge of and/or if they had participated in one of

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TABLE 1. Tailored self-management programs.

Program 1	Program 2	Program 3
Course offered at a community center in your neighborhood once a week for 6 weeks	Program will be conducted at home (information will be sent to you through the mail)	Will be given online (over the internet/web) for 6 weeks
Taught by a person who has been trained to offer this program	Can complete the program at your own pace	Taught by a person who has been trained to offer this program; will include groups of about 25 people who will participate over the internet
Will have to pay $30 to participate	Will have to pay $30 to participate	Program is free
Will learn the best way to take care of yourself, how to properly take your medications and live a healthy life so that you do not develop new illnesses	Will also complete a self-test, which will help you figure out where you need the most help with your health, and the best way to help you plan ways to stay healthy	Will be given information on healthy living and relaxation
Will be sent information sheets and a book that will include information on pain, physical activity, fatigue, health concerns, exercise, medications, healthy eating, finding resources in your community, dealing with your emotions, and the best way to talk to your doctor about your health	Will be sent information sheets and a book that will include information on pain, physical activity, fatigue, health concerns, exercise, medications, healthy eating, finding resources in your community, dealing with your emotions, and the best way to talk to your doctor about your health	Will be sent information sheets and a book that will include information on pain, physical activity, fatigue, health concerns, exercise, medications, healthy eating, finding resources in your community, dealing with your emotions, and the best way to talk to your doctor about your health

the following programs: Chronic Disease Self-Management Program, Better Choices Better Health Program, Healthier Living With Ongoing Health Problems Program, Cancer: Thriving and Surviving Internet Program, Diabetes Self-Management Program, Arthritis Self-Management Program, Chronic Pain Self-Management Program, and Positive Self-Management Program for HIV.

2.2.3 Examples of tailored self-management programs

Borrowing selected protocols from established self-management programs, three tailored pain/disease self-management programs were presented to participants. Follow-up questions asked their perceptions of and willingness to participate in the program, and preference in how the program should be delivered. Table 1 provides detailed content of each program.

Program #1 was presented as a 6-week self-management program delivered at a neighborhood community senior center; Program #2 was described as an at-home program, whereby the participant would receive information via mail; and Program #3 was presented as an online format. Subsequent to reading a description of each program, participants were asked questions/statements to determine its feasibility. Standard questions/statements asked of all three programs included: the program will be helpful, it would be hard to find time to participate in the program, my current health will prevent me from participating in the program, my past experiences in the healthcare system will prevent me from participating in the program, it would be hard to find the motivation to participate in the program, and I would only participate in the program if recommended by my doctor. Each question/statement was based on a 5-point Likert scale (0 = do not agree; 4 = strongly agree). Examples of program specific questions/statements included: "it may be difficult to find transportation to participate in the program", "because my neighborhood is not safe, I would not want to participate in the program" (Program #1); "I would prefer not to have anything mailed to my home", "it would be more convenient for the program to be done at home" (Program #2); and "it would be difficult to participate, because I do not have a computer, laptop, iPhone, iPad, or any other device that would allow me to participate in the program" (Program #3).

2.3 Self-management program delivery method

Participants were asked how and by whom they would like programs to be delivered. Response choices included: be given by someone of the same race, by another man, program delivered by a female, etc. The men were also asked an open-ended question; if you could design a program to address the health needs of Black men, what would it consist of/what would be the protocol?

3. Results

3.1 Participant characteristics

A total of 131 Black men were approached, with 75 agreeing to participate (with complete interviews). Reasons for not wanting to participate included, but not limited to: did not have time, interview was too long, and/or was not interested in the project. Participant recruitment was evenly distributed across the three recruitment sites (35.6% senior center; 27.1% community event; 37.3% hospital database), although slightly fewer men agreed to participate from the community health event.

As shown in Table 2, the total sample had a mean age of 57.1 (SD = 14.7) years, with an average of 13.3 (SD = 2.43) years of education. More than half of the men (56.0%) reported "good" or "excellent" health, with less than one-third reporting feeling discouraged, fearful, worried, or frustrated about their health at least some of the time in the past month. In general, most participants (85.3%) reported that

they would go to the doctor when they became sick. Many of the participants (93.3%) self-reported a chronic illness or a painful medical condition, with pain (48%), diabetes (31%), high cholesterol (35%), and cancer (35%) as the most prevalent medical illnesses. Being somewhat satisfied with their financial situation was endorsed by the majority.

TABLE 2. Sociodemographic characteristics of current study sample (N = 75).

Characteristic	$M \pm$ SD/%
Age	57.2 ± 14.77
Education level	13.3 ± 2.43
Marital status	
Married	40%
Financial satisfaction	
Completely satisfied	7%
Very satisfied	17%
Somewhat satisfied	44%
Not very satisfied	16%
Medical illnesses	
Pain	48%
High cholesterol	35%
Cancer	35%
Diabetes	31%

When questioned where they receive most of their health information, the majority (82.6%) reported receiving information from a doctor most or all the time, with more than half (58.7%) receiving information from a nurse. More than 73% preferred receiving health information from books (73.3%) or brochures (74.7%), with fewer preferring to receive information from family (48.0%), friends (38.7%), or a religious leader (33.3%).

3.2 General knowledge of self-management programs

Table 3 shows that less than one-third (29.3%) of the men reported knowledge of any of the listed self-management programs, with another 77.3% never having participated in one. The entire sample (100%) agreed that there is a need for chronic disease self-management programs, and nearly all the men reported programing specific to the needs of men (94.7%) and Black men (95.9%). When asked what specific features to include in the design of a disease self-management program 51% suggesting that programming be held in person and similar to a classroom setting. More than one-third (37%) preferred that sessions be given by someone of the same race. There was not a difference in gender preference of the instructor (43% for a man; 40% for a woman).

Data further showed the participants were more likely to endorse a program that taught them how to get the most of their healthcare (92%), followed by programs that taught them how to exercise healthy or understand treatment options (89.3%). Sixty percent preferred that a program be given at a local hospital or health clinic. Participants were less interested in a self-guided program, where materials were delivered at their home (40.5%) or a program delivered in a church setting (39.2%).

3.3 Program #1 (community center)

In assessing program specifics tailored for delivery at a community center, 61% reported that this program design would be appropriate, with most feeling that it wasn't necessary for the session instruction to be guided and/or administered by someone of the same race (77.3%), age group (60.0%), or gender (66.7%). Few (22.6%) men reported that they would not want to participate in this program format because of the length of time of the program (six weeks). Other reasons for not wanting to participate included lack of transportation (21.3%) and motivation (13.3%), the cost of the program (16.0%), familial and/or work responsibilities (10.6%), their current health (9.3%), discomfort with strangers (9.3%), being in an unsafe neighborhood (5.3%), and past history with the healthcare system (5.3%). One-third (33%) responded that they would only participate in the program if it was recommended by their doctor. Others responded that they would only participate with those with the same illness (17.3%), if someone they knew completed the program (17.3%), or if their family or friends thought it was a good idea (24%).

3.4 Program #2 (at home)

More than sixty percent (65.2%) reported that they would participate in a self-management program if instructional materials (e.g., brochures, etc.) were mailed to their home. Few responded that they would not participate in this type of program, because it required too much time (12%), lack of motivation (12%), costs (12%), or they did not want items sent to their homes (10.6%). A little more than 25% would only participate if approved by family and/or friends and 24% reported that they would participate if recommended by their doctor.

3.5 Program #3 (internet/online)

More than half of the men (56%) stated that a program tailored for online delivery would be helpful. Reasons for not wanting to participate included: difficulty accessing the internet (32%), lack of motivation (29.4%), not owning a computer (29.3%), the amount of time required (26.7%), and lack of knowledge of computers or the internet (26.6%). The majority of the participants mentioned that they would participate in the program, because it was free (82.7%, Table 4).

3.6 Self-designed disease management programs

A variety of responses were provided when participants were asked to design a disease self-management program addressing their health needs. Some expressed the need to address issues specific to Black men:

"most programs don't speak to health concerns for Black/African American males. I see that as a huge barrier" (age: 49)

"peers can teach peers; medical stuff for Black men has a bad history, see what works, find interesting ways to engage black men, address their need". (age: 53)

"barbershop talk. Every man gets their hair cut, so hold it

TABLE 3. Preferences for self-designed self-management program.

Program characteristic	Yes (%)
Mailed to me (with information sheets, booklets, etc.)	67.7
Include information related to your spiritual beliefs	36
Allow you to bring a friend to support and learn with you	64
Allow you to bring a family member to support and learn with you	75.7
To have the program be given using video-tape or a DVD to watch	68
Be given a Cassette Tape or CD to listen to	65.3
Be given by someone of the same race	37.3
Be given by another man	42.7
Be given by a woman	34.7
Be given by a Black/African American man	40
Be given by a Black/African American woman	38.7
Be given by someone with the same medical illness	68
Include discussions with other people who have an illness the same as you	90.7
Be given in a way like a classroom where someone is the teacher and you are the student	50.7

at barbershops" (age: 30)

"it will make them feel accepted and loved to help them get better health, (where it) won't manipulate Black men" (age: 54)

"be something where you didn't have to pay all the time. Be given to people who could afford it. Almost like taking it to the "streets". There are other obligations to live and not pay for the program; people are living day to day" (age: 58)

"Black men are at highest risk than others for chronic diseases" (age: 54) and

"We are at high risk due to socioeconomic conditions, stress, racism, internal and external cultural expectations, and PTSD in general due to our specific existence as Black men in America" (age: 39).

When asked what a program, specifically for black men, would include, some responded:

"include healthy eating, getting check-ups, frequently exercise, keeping low blood pressure" (age: 63)

"a preventative program that will target men, that will be easily accessible to them and will help them understand their health better" (age: 22)

"it consists of a lot of diseases that affect black men. Have nutritional and exercise (plans). Provide services for those without insurance" (age: 45)

"(have) integrity and will not discriminate among Americans" (age: 60) and

"not be expensive and will be very short. It will respect the integrity of Black men and encourage them to seek medical help" (age: 54).

4. Discussion

The health status of minority men in the United States has been described as an all-pervasive crisis. This is characterized by the perceptible increase in the rates of disability, morbidity, and mortality compared with their raced counterparts [3]. To fully understand the dynamics of this issue, data show that Black American men have a life expectancy similar to that of men in El Salvador, Iran, and Viet Nam [28]. The significance of this comparison is also evident in the diagnosis, treatment, and management of many chronic health conditions [29, 30].This is described as a paradoxical health disparities paradigm: being a Black man in the US. Addressing these domains is convoluted and remains as an untapped area of discussion, as little empirical data are available explaining the experiences, attitudes, and perceptions towards health behaviors and outcomes. Yet, in order to change the narrative of how Black men's health is addressed, there is an urgent need to provide services and programming specific to their physical health needs. More importantly, presenting tailored alternatives that allow for maximal adherence and optimal well-being is not by choice, but rather out of necessity.

In addressing this need, data from this exploratory study provided insight as to how such programming should be tailored to fit the needs of this gendered and raced group. Findings showed there was a general consensus underscoring the need for disease self-management programming specifically for (Black) men. When presented various scenarios in chronic disease self-management programming, there was an equal representation of participants preferring in-home sessions and those provided at a community center and/or online. There were however, noted differences in program preference. This is relevant as a many CDSMPs provide for a more "one size fits all" approach, which is not always as effective.

Data from this study acknowledge the ongoing issues regarding access and acceptability of health care services specific to the needs of Black Americans in the US. The long history of discriminatory practices underscores a perpetuation of mistreatment of these adults in the healthcare system [21, 31]. Some of the narratives highlight the awareness of this mistreatment and distrust. As responded by some of the participants, there is the need to "respect the integrity" of Black men.

The intent of these data is to demonstrate the importance of designing disease self-management programs specific to the health needs of Black men. While few, some studies have indicated the added utility of tailored management programs. Long *et al.* [27] for example, found the added benefit of

TABLE 4. Preferences for tailored self-management programs.

Program specific preferences	% Reporting "mostly true" or "completely true"		
	Program 1 (community center)	Program 2 (at home)	Program 3 (online)
The program will be helpful	65.5	60.0	56.0
It would be hard to find the time to participate in the program	22.6	12.0	26.7
It would be hard for me to find the motivation to participate in the program	13.3	12.0	29.4
It may be difficult to find transportation to participate in the program	21.3	N/A	N/A
Because my neighborhood is not safe, I would not want to participate in this program	5.3	N/A	N/A
My current health would prevent me from participating in the program	9.3	5.3	8.0
I would only participate in the program if recommended by my doctor	33.3	24.0	21.3
I would only want those with an illness the same as mine to participate in the program	17.3	N/A	16.0
I would only participate in the program if I knew someone who knew about the program or completed the program themselves	17.3	16.0	14.7
I would only participate in the program if my family and/or friends thought it was a good idea	24.0	27.5	14.6
My past experiences with the health care system will stop me from participating in the program	5.3	5.3	2.7
My family and/or work responsibilities will keep me from participating	10.6	5.3	4.0
It would be hard to pay the $30	16.0	12.0	N/A
I do not feel comfortable in participating in a program with people that I do not know	9.3	N/A	6.7
Six (6) weeks is not enough time to help me with my illness	12.0	N/A	12.0
The program needs to be shorter than six (6) weeks	10.7	N/A	9.4
I would feel more comfortable to participate in the program if there were people from the same race as me participating	20.0	N/A	N/A
I would feel more comfortable to participate in the program if there were people around the same age as me participating	37.4	N/A	N/A
I would feel more comfortable to participate in the program if it were only men participating	30.7	N/A	N/A
It is more convenient for the program to be done at home	N/A	41.3	N/A
I would prefer to not have anything sent (mailed) to my home	N/A	10.6	N/A
It is convenient that the program is free	N/A	N/A	82.7
Two (2) hours per week is too much time	N/A	N/A	25.4
Two (2) hours is not enough time	N/A	N/A	18.7
It would be difficult for me to have access to the internet (or something that would allow me to complete the program online)	N/A	N/A	32.0
My lack of knowledge on how to use the internet, a computer, or mobile-device (cell phone, iPad) would keep me from completing the program	N/A	N/A	26.6
It would be difficult to participate, because I do not have a computer, laptop, iPhone, iPad, or any other device that would allow me to participate in the program	N/A	N/A	29.3

tailored programming specific to Black men 45–60 years of age, as participants reported being knowledgeable about hypertension self-management, but less about cholesterol self-management. Whether it be medical compliance or medication adherence, recognizing the cost-benefit of these programs may similarly have positive short- and long-term implications. Others have similarly found that self-management programs provide participants with a sense of empowerment, thus allowing for an increased uptake in screening and medication adherence [32–34]. While relevant, some of the men also commented on the systemic and deliberate social issues that need to be addressed in program development and implementation, including cost, social support, familial obligations, and time commitment; all of which are important in addressing domains of empowerment and program adherence.

Data further confirmed an important observation regarding the percentage of men who acknowledged that they would only participate in the program if recommended by their doctor. This confirms the allegiance that some individuals may have to their primary care physicians, thus recognizing the importance of patient-physician trust and communication. This aligns with findings acknowledging the impact social factors have on the well-being of patients, and men in particular [35–37]. While not conclusive, the endorsement of these programs by the physician may be essential in encouraging better health practices.

Encouraging Black men to seek the necessary healthcare, and providing them with the knowledge to do so, may improve their health both short- and long-term. This could

begin by taking into consideration how some preferred a CDSMP to be specifically designed. As mentioned by one participant, delivering the information in a barbershop was important, and specifically referenced this approach as "barbershop talks". The concept of "barbershop talks" has been successfully rendered in reducing risky sexual behavior as well as improving knowledge regarding prostate cancer [38, 39]. This approach may be a viable alternative location to host informational-based programs, particularly when attempting to discuss health issues that are most pertinent and/or of a sensitive nature.

4.1 Limitations

Although these preliminary data show the utility of tailored disease self-management programs, there are some limitations that should be acknowledged. Firstly, this is an exploratory analysis, therefore no causal associations or predictions can be inferred regarding program preference and/or willingness to participate in a self-management program. Secondly, all data were self-reported which may result in potential reporting bias such as social desirability. It should be recognized that the entire sample was Black men, which was intentional and should not be interpreted as a limitation, but in the scope that these exploratory findings no generalization can be made to other groups. It is also acknowledged that no rigorous qualitative analyses were conducted on these data. Therefore, the quotes should be interpreted as such, with no implied formative themed inferences. Third, the reported data did not assess the knowledge of mental health programs. This however, does not imply that these programs are less important. Future studies are needed to better understand Black men's knowledge about these types of programs. Lastly, the selection criteria of the sample were based on those who were more physically active and able to attend the community event and/or participate in activities at the senior center.

4.2 Conclusions

Despite these limitations, this study was able to provide preliminary information on the planning and implementation of self-management programs specifically for Black men. Although few men had ever participated in a pain and/or disease self-management program, the current sample showed overwhelming support for such programming. More importantly, addressing the needs of this group by acknowledging the influence of determinants of health (e.g., family, finances) and other social and behavioral health outcomes could provide more insight regarding the participants' responses. Yet, what can be gathered from this important project is that by dispelling the stereotypes associated with masculinity and health, we can begin to comprehensively capture the meaning of health and well-being while acknowledging the need for more rigorous models that define the experiences among this group. This may contribute to more effective legislation promoting safe and cost-effective approaches to disease prevention and treatment, and symptom management.

Author contributions

TB designed and performed the research. PH analyzed the data. PH and TB wrote the manuscript.

Ethics approval and consent to participate

All subjects gave their informed consent for inclusion before they participated in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the IRB at the University of Kansas (FWA#: 00003411).

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Conflict of interest

The authors declare no conflict of interest.

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