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### African American Prostate Cancer Survivorship: Exploring the Role of Social Support in Quality of Life After Radical Prostatectomy

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ARTICLE

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## African American prostate cancer survivorship: Exploring the role of social support in quality of life after radical prostatectomy

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### ABSTRACT

*Purpose:* The aim of this study was to explore the African American prostate cancer survivorship experience following radical prostatectomy and factors contributing to quality of life during survival. *Design:* African American men who were part of a larger prostate cancer cohort were invited to participate in a focus group. Eighteen open-ended questions were designed by the study team and an experienced moderator to elicit participants' survivorship experiences. *Results:* Twelve men consented to participate in the study. Emergent themes included views of prostate cancer in the African American community, perceptions of normalcy, emotional side effects following radical prostatectomy, and social support involvement and impact during recovery. *Conclusions:* Previous findings suggest that African American men may experience more distress than Caucasian men when facing typical prostate cancer side effects. Traditional masculine role norms and negative perceptions of "disease disclosure" in the African American community could be contributing to the distress reported by some in this study. Strengthening social support systems by promoting more prosocial coping and help-seeking behaviors early in the survivorship journey may help bypass the detrimental health effects associated with masculine role identification, resulting in improved quality of life throughout the lengthy survival period anticipated for these men.

### KEYWORDS

African American; prostate cancer; quality of life; radical prostatectomy; social support

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## Introduction

Despite being the second most common cause of cancer-related death for all men, the number of prostate cancer survivors is steadily increasing (DeSantis et al., 2014). This increase can be attributed, in part, to advancements in treatment, including radical prostatectomy (RP; DeSantis et al., 2014; Alicikus et al., 2011; Birkhahn et al., 2011; Nam et al., 2014). Following RP for the treatment of prostate cancer, 5-year survival rates are almost 100%, with 10-year survival rates close to 98.8% (DeSantis et al., 2014). As of 2015, there are almost 3 million prostate cancer survivors in the United States alone, and that number is expected to increase 30% to over 4 million by 2024 (DeSantis et al., 2014).

While RP can increase survival, it presents with a variety of side effects that can have a profound influence on long-term quality of life for survivors (Ku et al., 2009; Potosky et al., 2000). These side effects can include, but are not limited to, urinary incontinence, erectile dysfunction, and emotional distress (DeSantis et al., 2014; Alicikus et al., 2011; Birkhahn et al., 2011; Nam et al., 2014; Resnick et al., 2013). Men treated with RP report more urinary incontinence, impairment in erection, and decreased libido compared to men who choose to monitor their cancer with “watchful waiting” over surgical intervention (Bill-Axelson et al., 2013). Additionally, men treated with RP report worse urinary and sexual functioning compared to those treated with radiation (Eton, Lepore, & Helgeson, 2001). African American (AA) men may be especially susceptible to urinary, bowel, and physical problems when compared to their Caucasian peers (Eton et al., 2001; Lubeck et al., 2001). This can result in more difficulties during recovery for AA patients following RP surgery (Eton et al., 2001; Lubeck et al., 2001).

It is common for patients with cancer to feel a loss of control or experience feelings of helplessness (Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000). As a result, the American Cancer Society (2013) recommends screening for emotional distress as part of routine cancer care (American Cancer Society, 2013; Orom, Nelson, Underwood, Homish, & Kapoor, 2015; Skolarus et al., 2014). Research suggests that about 60% of patients with prostate cancer experience some psychological distress (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004), which may include fear, worry, sleep disturbances, and feelings of isolation during diagnosis and prevalent even 8 years after treatment (Bill-Axelson et al., 2013; Bisson et al., 2002; Schag, Ganz, Wing, Sim, & Lee, 1994; Krebber et al., 2014). This is further supported by Sharpley, Bitsika, and Christie (2010), who found that 24% of men with prostate cancer reported anxiety symptoms, and 26% experienced depressive symptoms (Sharpley et al., 2010).

A few studies have proposed that AA men may be more vulnerable to emotional distress following prostate cancer treatment (Campbell et al., 2004; Orom et al., 2015; Schroeck et al., 2008). Orom et al. (2015) reported that merely identifying oneself as African American was a risk factor for developing higher distress after a prostate cancer diagnosis (Orom et al., 2015), while other studies have suggested

that AA men report more feelings of dissatisfaction and regret after undergoing RP treatment due to lower urinary, bowel, and hormonal functioning (Schroeck et al., 2008). Another study comparing health-related quality-of-life outcomes between AA and Caucasian men reported that despite AA men actually scoring higher for sexual functioning, they presented at diagnosis with lower quality-of-life scores and had a slower recovery than their Caucasian counterparts (Lubeck et al., 2001). Conversely, there are some quality-of-life studies following prostate cancer diagnosis that have found that AA men reported lower levels of depression and anxiety (Rodrigue, 1997) and better self-reported emotional well-being than Caucasian men (Halbert et al., 2010). These studies, however, may be limited by self-report bias, and there has been research suggesting that prostate cancer patients overall are less likely than other cancer patients to report their feelings of depression and anxiety (Salvo et al., 2012; Colloca & Colloca, 2015).

The side effects of prostate cancer challenge traditionally recognized masculine beliefs, which may induce more emotional distress for African Americans, a vulnerable population (Kunkel et al., 2000; Campbell, Keefe, McKee, Waters, & Moul, 2012). Derived from the Bem Sex Role Inventory proposed by Sandra Bem in 1974, masculine traits have typically been centered on the ability to work and provide resources, including traits such as leadership ability, ambition, athleticism, independence, and self-reliance (Bem, 1974; Harris, 1994). Others have added physical strength, emotional control, competitiveness, and avoidance of help-seeking to this list (Helgeson & Lepore, 2004; Hammond, 2012; Powell, Adams, Cole-Lewis, Agyemang, & Upton, 2016). Some researchers have theorized that AA men may be more likely to adopt these traditional views than Caucasian men, pointing to social marginalization and minority status as instigating constructs (Courtenay, 2000). Given that these stereotypic male traits have been linked to worse health outcomes in numerous studies (Courtenay, 2000; Harvey & Alston, 2011; Kalmuss & Austrian, 2010), AA men diagnosed with prostate cancer may be facing a much greater burden than Caucasian men, contributing to the overall disparity in quality-of-life outcomes (Lintz et al., 2003).

Social support is important for increased quality of life among men with prostate cancer post-treatment (Eton et al., 2001; Kunkel et al., 2000; DiIorio et al., 2011; Zhou et al., 2010). Zhou et al. (2010) found that baseline levels of social support were significant predictors of men's quality of life 2 years following prostate cancer treatment, suggesting that higher levels of social support may protect survivors against the stressful burden of treatment (Zhou et al., 2010). Social support positively improves attitudes toward disease management, psychological adjustment, and coping efforts, which also act to buffer against stress, further contributing to increased survival rates (Kunkel et al., 2000; Zhou et al., 2010; Mishel & Braden, 1987).

Low levels of social support are linked to increased psychological comorbidity and mental health concerns, which can contribute to increased prostate cancer mortality rates (Kunkel et al., 2000; Mehnert, Lehmann, Graefen, Huland, & Koch, 2009). A study examining quality of life among AA and Caucasian cancer survivors found that AA

participants were more likely to report lower quality of life and lower social support scores (Matthews, Tejada, Johnson, Berbaum, & Manfredi, 2012). Similarly, Rodrigue (1997) reported that AA men were more likely than Caucasian men to have smaller social support networks, to report more cancer-related disruptions in personal relationships, and to use more avoidant methods of coping (Rodrigue, 1997). Gray et al. (2000) suggested many factors that may encourage men to adopt avoidant coping strategies (Gray et al., 2000). They cited low perceived social support needs, fear of stigmatization and embarrassment associated with erectile side effects, career implications from being “sick,” and avoiding disease discussion as a means of retaining a sense of normalcy and minimizing the disease threat (Gray et al., 2000). Additionally, studies comparing coping methods of AA and Caucasian men have found that AA men tend to rely on religious coping much more than Caucasian men (DiIorio et al., 2011; Wittink, Joo, Lewis, & Bard, 2009). These findings point to the existence of cultural differences in the role of social support. These social support systems, however, have not been fully examined, and researchers acknowledge that there is limited discussion about this disease concern in the AA community (Rodrigue, 1997). The aim of this study was to further explore the AA prostate cancer survivorship experience and the potential unique factors contributing to the quality-of-life outcomes among AA survivors.

## Methods

### Participants

Potential participants for this study were identified from a larger cohort in the longitudinal Prostatectomy, Incontinence, and Erectile function study, or PIE Study (IRB #201011787). The PIE Study recruited prostate cancer patients from 2011–2014 at Washington University School of Medicine and Brigham and Women’s Hospital. All men undergoing radical prostatectomy for clinically diagnosed prostate cancer were eligible. Further exclusion criteria included any previous prostate cancer treatment, radiation to the pelvis, any type of major pelvic surgery, a history of urethral stricture, colostomy, or inability to urinate requiring chronic catheterization. Data were collected from 440 men across the 2 sites, 40 of whom were African American. This 12-month study explored pre-surgical physical activity and body mass index, and participants’ associated postsurgical urinary and erectile functioning throughout their recovery.

All African American men enrolled in the PIE Study were eligible to participate in the focus groups. Due to feasibility concerns, only participants residing in the state of Missouri ( $N = 34$ ) were contacted. Recruitment efforts included mailing study invitations, and follow-up calls or emails were made depending on the contact information available. Excluding two men who were not able to leave home and one man who was deceased, 31 men were invited to participate. The number of participants and focus group sessions were not preset, but determined by data saturation. The final sample consisted of 12 African American men, all living in Saint Louis, Missouri.



## **Materials and procedure**

Three 90-minute focus groups were hosted on campus over 4 weeks in May 2014. Groups averaged 3–5 participants, were audio-recorded, and were led by an experienced facilitator. Individual informed consent was collected prior to beginning each session, and participants were compensated with a \$30.00 gift card upon completion. The 18 open-ended questions were designed by the study team and the group facilitator to address the post-prostatectomy prostate cancer survivor experience including side effects, patient–provider communication, physical activity, and social support (Appendix A). Four of the questions directly asked about participants' support networks, perceptions of support, and help-seeking, and many of the other questions led to discussion topics that addressed social support. The study was approved by the Institutional Review Board at our university.

## **Data analysis**

Focus groups were audio-recorded and transcribed verbatim. The first two coders initially reviewed the transcripts to familiarize themselves with the data expressions of survivors in regard to their experiences post-treatment. Next, they independently conducted a line-by-line analysis of the data, identifying meaningful statements and creating appropriate labels. Common concepts to emerge between the two coders were then identified and categorized into themes, bearing in mind not to disrupt the original meaning of what participants said. Two additional coders then conducted independent review of the categorized themes. The few discrepancies noted were resolved through discussion and verification of the first two coders' coding schemes, referring to the original transcripts wherever necessary to ensure accurate reflection of the participants' experiences. Thematic saturation was reached when no new themes emerged between coders.

## **Results**

A total of 12 AA men who were treated with RP for prostate cancer participated in the study. Participants' demographic characteristics are displayed in [Table 1](#). Qualitative analysis revealed four prevalent themes: views of prostate cancer in the AA community, perceptions of normalcy, emotional side effects following radical prostatectomy, and social support involvement and impact during recovery, including both unstructured and structured support systems.

### ***Prostate cancer in the African American community***

An African American-specific view of prostate cancer emerged as a leading theme. Participants shared that AA men do not talk about their personal information, including cancer and the associated side effects.

**Table 1.** Participant demographic data.

Variable	Frequency	Percent
Demographic characteristics, <i>n</i> = 12		
Age at diagnosis (range: 49–79 years): mean (SD), <i>n</i> = 12	61 (9.4)	
Education		
8–11th grade	1	8.3
Completed high school	3	25.0
Graduated college	2	16.7
Postgraduate	2	16.7
Unknown	4	33.3
Marital status		
Married or living as married	2	16.7
Never married or divorced or widowed	5	41.6
Unknown	5	41.6
Employment status		
Employed for wages	3	25.0
Self-employed	1	8.3
Unable to work	1	8.3
Retired	7	58.3
Household income		
<\$19,999	1	8.3
\$20,000–39,999	2	16.7
≥\$40,000	4	33.3
Unknown	5	41.7
Type of insurance		
Public (including Medicare, Medicaid, and Tricare)	4	33.3
Private	7	58.3
Unknown	1	8.3
Clinical characteristics, <i>n</i> = 12		
Surgery type		
Open	5	41.7
Robotic	7	58.3
Time elapsed since surgery (range: 7–31 months): mean (SD), <i>n</i> = 12	19.8 months (7.3)	

Nobody talks about prostate cancer- black men, probably because we don't communicate like that/we don't divulge personal information to other people.

This idea of being “sick” may threaten the traditional masculine traits expressed by some within this community.

Oh no because you don't talk about erectile dysfunction and black men, no, you don't talk about it. For a black man to tell you he's got prostate cancer, you don't hear that too much, it's that macho thing about them.

Accordingly, some AA men may report feeling more acceptance from non-health profession social support networks (e.g. community, friends, family) when avoiding medical care and treatment.

I come from a family where they didn't go to doctor, the men in my family.

### **Perceptions of normalcy**

For most of the men in the focus groups, returning to “normal” was their main goal after prostate cancer treatment. Everyday tasks such as sleeping, staying hydrated, and sitting were compromised by RP side effects, consequently reducing survivors' abilities to regain their old routines.

Normalcy for me was just being able to do normal things such as sleep on your stomach, sleep on your side, turn over, turn while you sleep and in your sleep. Be able to get out of bed without feeling like you are going to draw blood through your urine or have blood in your urine. Being able to find that optimal amount of water that you can drink to keep from having to not make it to the bathroom quick enough. Just be able to get on a regular routine of walking, being able to sit in a chair...

Participants also reported that “normal” meant being able to exercise and regain strength, return to work, and overcome sexual dysfunction.

Yes, normal, healthy, back in the gym, back on the job.

For me, it was getting fit again. I want to get back to where I felt like I was fit and strong. I mean having sex was a priority because I enjoy sex, so that was a priority for me. And so being fit and been able to have sexual function again, those are my priorities...

### ***Emotional side effects following radical prostatectomy***

Multiple participants shared the emotional impact of the RP procedure and the associated side effects. Insecurities regarding their partner relationships and stress from sexual dysfunction were commonly cited.

You talk to women and they say, ‘we still love you, no matter what,’ but in my psyche, I don’t believe them. It’s hard to believe because we think with that part of our bodies so to believe that a woman will still love me and I couldn’t perform like I used to, I still have trouble with that. I was scared of getting laughed at.

...I was scared that she [wife] was going to laugh or look at me different but she understood, that made it all worthwhile.

Participants also mentioned having to rely on others for basic daily tasks due to postsurgical weakness.

After my surgery, I noticed one thing- I was weak. I had to have somebody to help me.

Specifically, one participant felt he should be able to continue his life as normal because he was not “sick.”

Here you are sixty years old and man you are getting ready to break down pretty quickly. Family members and neighbors would constantly tell me, you need to just slow down, and I’m telling them no, I’m not sick.

### ***Social support***

All participants reported social support involvement during their RP recovery. Participants shared their experiences with both unstructured support systems that encompass naturally occurring relationships, and structured support systems that include formal organized groups.

### ***Unstructured social support***

Examples of unstructured social support that participants described as useful during their recovery included family, a partner (wife or girlfriend), and coworkers.

I would say my support group pretty much is my family. They just took care of me.

I am married and my wife had been there the whole time.

I did know a couple of guys at work who had gone through various types of prostate cancer, so in confidence I would talk to those guys.

My other coworkers, they were very supportive, and everybody was supportive and sending stuff to the house and all that.

### ***Structured social support***

Most men who attended organized social support groups mentioned the importance of a specific AA prostate cancer support group (The Empowerment Network, or TEN), while one man just cited “prostate cancer support meetings.”

The Empowerment Network is a real good group, and I get a lot of support from that group.

...the TEN network which is an African-American support group...They were very supportive and connected me with guys who have gone through this before me.

Others attended support groups hosted by local hospitals.

I'm in a support group over at Mercy [hospital].

## **Discussion**

Focus groups addressing prostate cancer survivorship experiences enabled the identification of four major themes that influenced participants' quality of life following surgical intervention. The most pervasive of these themes appeared to be the existence of a minority-specific outlook on prostate cancer that influenced the entire survivorship experience. This unique view of prostate cancer in the AA community seemed to frame participants' perceptions of normalcy related to their cancer recovery, and it appeared to contribute to the emotional side effects reported by some of the participants.

Researchers have posited that traditional masculine norms (e.g. self-reliance, restrictive emotionality, dominance, competition, and avoidant coping) may be more prevalent in the AA community, and these traditional masculine norms have been associated with increased distress following prostate cancer treatment (Campbell et al., 2004; Mahalik, Pierre, & Wan, 2006; Burns & Mahalik, 2006; Griffith, Gunter, & Watkins, 2012; Courtenay, 2000). Others have gone a step further to say that a perceived threat to one's masculinity may result in worse prostate-related functioning over time (Hoyt, Stanton, Irwin, & Thomas, 2013). A prostate cancer diagnosis then would present a significant threat with side effects such as urinary and sexual

dysfunction infringing upon the dominant masculine norms typified by the AA community.

Most participants in this study exemplified these traditional norms through their accounts of the specific AA views of prostate cancer and their perceptions of normalcy. There was also a trend in reporting an overall community-level lack of communication about prostate cancer and its associated side effects, which could be synonymous with self-reliance, restrictive emotionality, competition, and avoidant coping style (Griffith, Gunter, & Watkins, 2012). Participants' views of normalcy included masculine ideals as well: gaining strength, returning to work, and functioning sexually (Griffith, Gunter, & Watkins, 2012; Hooker, Wilcox, Burroughs, Rheaume, & Courtenay, 2012). An AA view of prostate cancer, community-specific perceptions of normalcy, and the resulting emotional side effects following cancer treatment may act synergistically to perpetuate vulnerability within the AA community.

The theme of social support involvement emerged as a potentially powerful coping mechanism and buffer for this vulnerable population. Social support has been widely researched for its implications on increasing quality of life, revealing a correlation between strong social support and improved physical and emotional functioning for cancer survivors (Eton et al., 2001; Kunkel et al., 2000; Campbell et al., 2004; DiIorio et al., 2011; Zhou et al., 2010; Colloca & Colloca, 2015). All of the participants mentioned some form of social support involvement during their cancer survivorship journey, primarily through either unstructured systems, which included romantic partners (i.e. wife or girlfriend), other family members, and coworkers; or through structured systems like formal prostate cancer support groups. Strengthening social support involvement may result in less emotional distress (e.g. less anxiety, less depressive symptoms, and a buffer against stress), improved physical functioning (e.g. better symptom control and less pain), decreased mortality, and improved quality of life (Eton et al., 2001; Kunkel et al., 2000; Campbell et al., 2004; Zhou et al., 2010; Colloca & Colloca, 2015; Lafaye et al., 2014).

Observing that avenues of support are already established for all of the participants in this study and likely a majority of other prostate cancer survivors, the next step is to uncover novel ways of utilizing these support networks to result in meaningful change. Understandably, interventions must first aim to increase community awareness and acceptance of prostate cancer screening, diagnosis, and treatment side effects without emasculating survivors. Further, successful interventions should acknowledge the potential influence of masculinity and measure levels of trait exhibition to help inform more individualized programs that better evoke behavior change. For example, many studies have highlighted the importance of spousal support in prostate cancer recovery, physical functioning, and emotional health (Campbell et al., 2004; DiIorio et al., 2011; Eton et al., 2001; Kunkel et al., 2000; Lafaye et al., 2014). Given that sexual dysfunction is a common issue resulting from prostate cancer treatment, and many of our participants reported

distress related to it, Gray et al. (2002) suggested that interventions should teach men alternate ways of expressing intimacy with their partners (Gray et al., 2002). Support groups can organize fitness classes or programs for survivors that may also encourage communication and support seeking. Hooker et al. (2012) suggested that recovery programs focusing on physical activity may be successful in helping men feel “stronger” while also reducing treatment side effects (Hooker et al., 2012).

Social support thus provides a unique pathway for researchers and clinicians to implement intervention strategies to reduce the common side effects associated with cancer treatment and survivorship. Social support intervention may help eliminate the observed inequalities in quality of life between AA and Caucasian prostate cancer survivors. Future research should seek to better understand masculine norms in the AA community and their influence on support-seeking behaviors, potentially uncovering ways to reduce the social stigma associated with prostate cancer. In addition, understanding the adoptive patterns of AA men in relation to the types of social support is required to inform intervention design for implementation.

Though this study presents many insights into the AA prostate cancer survivorship experience, it is not without limitations. Results cannot be generalized to the AA community at large due to the small sample size. This small sample size is consistent with previously reported difficulties associated with minority participant recruitment (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997), further evidenced by the limited AA participation in the larger cohort study (about 9% AA enrollment). Focus group enrollment of roughly 38% of those eligible AA men can, therefore, be considered quite successful. It should also be noted that the sample’s household income and education levels may not reflect that of the general AA population. These factors could be attributed to the overall climate of inequality in healthcare seeking and access among members of vulnerable populations. As with many focus groups, another limitation is the openness and willingness of participants to talk about personal experiences. We acknowledge the sensitive nature of many issues surrounding prostate cancer experiences, and we attempted to encourage our participants’ comfort by using an African American male facilitator who was trained in focus group moderation. Despite this study’s limitations, the insights gained from these focus groups add a unique perspective to the existing body of literature about the role and potential impact and direction of social support interventions for improving the AA prostate cancer survivorship experience following RP.

## Conclusion

The aim of this study was to explore AA prostate cancer survivorship and quality of life after RP. As screening and treatment methods have become more advanced, prostate cancer survival rates have drastically increased to suggest that nearly all

patients (98.8%) will survive up to 10 years following surgical intervention (DeSantis et al., 2014). This prolonged survivorship period presents an opportunity for researchers to examine influential factors necessary to maximize survivors' quality of life. Previous research has exposed inequalities that exist in prostate cancer-related outcomes between AA and Caucasian men, indicating an area where vulnerabilities may exist (Eton et al., 2001; Lubeck et al., 2001; Orom et al., 2015; Campbell et al., 2004; Lintz et al., 2003). This study sought to explore these vulnerabilities to reveal potential factors contributing to the inequalities apparent in prostate cancer survivorship. We conclude that a community-level idealization of traditional masculine trait expression may act to shape individuals' perceptions of normalcy, and when faced with a disease that threatens the basic premises of masculine identity, there may be an increased risk of emotional distress. Emotional distress greatly reduces quality of life, and is therefore an important point of analysis for cancer survivorship. Efforts to foster more prosocial coping methods and help-seeking behaviors in the African American community, particularly for men who exhibit more traditional masculine ideals, may have an effect on many facets of prostate cancer recovery, including reducing emotional distress, alleviating physical side effects, and consequently reducing disparities in quality-of-life outcomes. These findings need to be replicated in a larger-scale study incorporating mixed-method design. Future studies should also seek to explore the implementation and adoption rates of different types of social support, and to qualify their impact on improved quality of life among AA prostate cancer survivors.

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## Appendix A. Focus group questions

1. How do you feel about the side-effects associated with the prostatectomy procedure affecting you? Did you and your partner expect it?
2. Please tell me about your priorities in your postsurgery management?
3. During your recovery, do you have sufficient support from your partners, friends and family in general?
4. Do you know there are ways to improve your urinary and sexual functions? Who do you turn to or where do you go to get this information?
5. Do you know that physical activity can improve sexual and urinary function after prostatectomy?
6. What is your perception on physical activity?
7. Would you consider walking as a form of physical activity?
8. How much physical activity did you do before the diagnosis of prostate cancer?
9. How do you feel about activities or exercise that require muscle strength, such as leg muscle toning and exercise?
10. Are you familiar with any recreational facilities or exercise programs in your community?
11. Would you be willing to participate in a mall walking program?
12. Would you be willing to come to a location that has facilities for resistance training?
13. What are the barriers that you've experienced in getting active?
14. Would you be more willing to become more active if you had the support from your partners, friends and family?
15. If asked to take part in a program aimed at increasing your physical activity participation, which of the following questions would you have?
16. What suggestions do you have for me, as I seek to promote physical activity among prostate cancer survivors?
17. Thinking about all the issues we've discussed, what can be done to make physical activity more accessible to you?
  - a. How will the physical activity engagement affect my quality of life?
  - b. How much will it cost and how much time will it take?
  - c. How difficult will the program be and how much physical effort will be needed?
18. Do you have any questions for me?