ORIGINAL ARTICLE



Exploring health behaviors, quality of life, and support needs in African-American prostate cancer survivors: a pilot study to support future interventions

Melinda R. Stolley¹ · Patricia Sheean² · Lauren Matthews¹ · Anjishnu Banerjee³ · Alexis Visotcky³ · Paula Papanek⁴ · Liana Woodley¹ · Kathryn E. Flynn¹

Received: 20 March 2019 / Accepted: 20 September 2019 / Published online: 8 November 2019 © Springer-Verlag GmbH Germany, part of Springer Nature 2019

Abstract

Purpose Prostate cancer incidence and mortality rates are highest among African-American men. Comorbidity burden and quality of life (QOL) challenges are also high. Many factors drive these differences; health behaviors are important modifiable contributors. Studies document positive results for lifestyle interventions targeting NHW prostate cancer survivors, but inclusion of African-Americans is limited. We conducted an exploratory mixed-methods study with AAPCS to inform the development of a culturally relevant lifestyle intervention.

Methods Twenty-two AAPCS completed questionnaires and a discussion group on dietary and physical activity patterns, QOL, and unmet needs related to lifestyle changes.

Results Seventy-five percent of the participants were overweight or obese, 82% had physical activity patterns considered insufficiently active and only 10% did resistance training at least twice weekly in accordance with current survivorship guidelines. Diets were high in saturated fat and sugar, low in fiber, fruit, and vegetable intake. PROMIS-29 scores indicated that AAPCS had worse physical functioning, pain interference, and sexual functioning, but less social isolation compared to the general population. Compared to other prostate cancer survivors, participants reported poorer status on all domains. Qualitative data highlighted barriers to healthy lifestyles including access, knowledge, and skills, as well as motivators including health benefits and building strength to feel more "manly." Participants shared high interest in programs to exercise, learn about affordable healthy eating, and bring survivors together to discuss survivorship issues.

Conclusions Lifestyle interventions targeting AAPCS are warranted. To increase impact of these efforts, consideration of environmental, cultural, and survivor contexts will be key.

Keywords Prostate cancer · African-American · Survivors · Quality of life · Lifestyle

Melinda R. Stolley mstolley@mcw.edu

- ¹ Cancer Center and Department of Medicine, Medical College of Wisconsin, 8701 Watertown Plank Road, Milwaukee, WI 53226, USA
- ² School of Nursing, Loyola University Chicago, Maywood, IL, USA
- ³ Institute of Health and Equity, Division of Biostatistics, Medical College of Wisconsin, 8701 Watertown Plank Road, Milwaukee, WI 53226, USA
- ⁴ Department of Exercise Science, Marquette University, Milwaukee, WI, USA

Introduction

Prostate cancer is the most commonly diagnosed cancer among men, with highest incidence and lowest survival observed in African-Americans (AA)[1]. Comorbidity burden is also higher among AA men with prostate cancer, which is important given that many prostate cancer survivors are more likely to die from these chronic conditions than of prostate cancer itself [2–4]. Numerous factors drive these differences, among which adiposity and health behaviors are important modifiable contributors [2, 3].

Despite the mortality disparities, prostate cancer remains highly treatable, and 5- (96%) and 10-year (92%) survival rates for those with localized disease are high [5]. Yet, survivorship for AA prostate cancer survivors (AAPCS) may be compromised by poorer health and quality of life characterized by pain, challenges with physical and sexual functioning, disrupted family roles, and greater disease worry when compared to white prostate cancer survivors [5-10]. Additionally, lower levels of social support and greater financial concerns contribute to worse QOL reports among AAPCS. Evidence from diverse survivor cohorts suggest that obesity, nutrition, and physical activity also impact cancer survivorship by influencing QOL, chronic disease burden, and PC recurrence risk [11]. Relatedly, the Commission on Cancer mandates survivorship care plans include information on healthy lifestyles [12]. Additonally, the American Cancer Society developed nutrition and physical activity guidelines available to providers and survivors to help survivors achieve optimal health and QOL, and to support secondary prevention efforts [13]. Many survivors are unaware of these guidelines, and AAPCS are more likely than white PC survivors to be non-adherent [2, 3]. Although lifestyle interventions demonstrate beneficial results for PC survivors [14, 15], inclusion of AA men is critically limited. Health behavior change can be uniquely challenging for many AAs due to a complex interaction of environmental, societal, and policy-related factors [16].

Recently, the American Society of Clinical Oncology identified research priorities to address the obesity and cancer link including (1) to evaluate whether behavior change (weight loss, improved diet and/or physical activity) after diagnosis improves prognosis and (2) to test best methods to help cancer survivors make changes in energy balance behaviors after diagnosis [17]. Given limited data from lifestyle interventions and the lack of information on needs and preferences of AAPCS, we conducted an exploratory mixed methods study to inform the development of a culturally relevant lifestyle intervention. Herein, we present the results summarizing AAPCS's QOL, dietary and physical activity patterns, and support needs related to lifestyle changes.

Methods

Study cohort

We relied on a convenience sample of 22 men who responded to recruitment letters and/or follow-up phone calls using hospital cancer registry contact information from an academic cancer center in Milwaukee, WI. Recruitment occurred over 3 months. Eligible participants were AAPCS (all stages) who were \geq 18 years of age, had completed treatment, and were willing to complete study activities. All study procedures were approved by the Institutional Review Board at the Medical College of Wisconsin.

Study procedures

Once deemed eligible, participants were given a choice of times for survey completion and a discussion session. All study activities were conducted at community locations. Participants provided written informed consent, followed by completion of questionnaires on demographics, nutrition, physical activity patterns, and QOL. The discussion session (with 6–8 men) focused on health behavior change and needs, interests, and preferences of a lifestyle intervention. Participants received \$50 for their study participation.

Demographics

Demographic data included age, marital status, education, occupational status, and annual household gross income.

Body mass index

Self-reported height and weight were used to calculate body mass index (BMI) and to classify patients as normal weight, overweight, or obese.

Dietary intake

To evaluate dietary consumption with minimal burden, we used the validated Block Fat/Sugar/Fruit/Vegetable Screener [18]. This measure takes about 10 min to complete and queries about usual consumption and portion sizes of 55 food items. Analyses include estimates of total fat, saturated fat, added sugars, fiber, fruit, and vegetable intakes.

Physical activity

The Godin Leisure Physical Activity Index asks about time spent engaged in light, moderate, and strenuous activities over the past 7 days. This measure is well correlated with VO₂ measures (r = 0.8) [19]. Outcomes allow respondents to be classified as sufficiently active (meets current physical activity guidelines of 150 min of moderate or 75 min of vigorous activity per week) or insufficiently active. Because the American Cancer Society's nutrition and physical activity guidelines recommend a minimum of twice weekly resistance training sessions [13], we also asked participants how many times per week they engaged in strength or resistance training activities.

Quality of life

QOL was measured using the Patient-Reported Outcomes Measurement Information System (PROMIS®) [20]. Scores are reported using a common metric (T-score with a mean of 50 and standard deviation of 10) and have been normed to the US population. Higher scores represent more of that domain. The PROMIS-29 v2.1 measures physical function, depression, anxiety, fatigue, sleep disturbance, ability to participate in social roles and activities, and pain interference using the 4item short forms for each domain, plus 1-item measuring pain intensity. We additionally included the PROMIS social isolation 4-item short form. For sexual function, we used the PROMIS Sexual Function and Satisfaction Brief Profile for Men (eight items) [21]. Based on recent work by Jensen et al., we considered 3 points as a clinically meaningful difference in scores between our sample and US population-based samples of prostate cancer survivors and non-cancer affected individuals [22].

Discussion sessions

An experienced moderator, assisted by note-takers, led the discussion sessions based on a structured guide that included questions related to (1) changes/challenges with health behaviors (diet, physical activity) post-diagnosis, (2) unmet survivorship needs, and (3) interest in lifestyle intervention and suggested format and content for AAPCS. A note-taker recorded participant responses. Based on prior work, we expected to reach saturation with three to four groups.

Statistical analysis

Data analyses were conducted for both quantitative and qualitative data. For quantitative data, categorical data are described using frequencies and percentages, while continuous data are presented using means and standard deviations. Analysis of the qualitative data from the discussion sessions relied on deductive strategies. First, the primary and third authors independently reviewed the discussion session notes to identify codes within each topic area. The coders then met to group codes into themes and to resolve discrepancies.

Results

Study participants

Of the 100 letters sent, 37 were returned for wrong addresses. We began contacting the remaining 63 by

 Table 1
 Characteristics of African-American prostate cancer survivors participants

Variable	Mean (SD, range) or n (%)
Age (years)	64.3 (4.0)
Body mass index (BMI)	31.2 (7.2)
% overweight	25.0
% obese	50.0
Marital status	
Married or in a domestic partnership or civil union	5 (23.8)
Divorced or separated	8 (38.1)
Never married	5 (23.8)
Other	3 (14.3)
Missing	1
Education	
Some high school, no diploma	2 (9.5)
High school graduate or GED	6 (28.6)
Associate's degree or 2-year certificate	1 (4.8)
Some college—no degree	5 (23.8)
College graduate	6 (28.6)
Missing	2
Income	
Less than \$20,000	9 (45.0)
\$20,000–39,999	6 (30.0)
\$40,000-\$59,999	2 (10.0)
\$60,000-\$79,999	1 (5.0)
\$80,000 or more	2 (10.0)
Missing	2
Employment	
Working full or part time	0
Not working—looking for work	2 (9.5)
Not working on disability	6 (28.6)
Retired	13 (61.9)
Missing	1
Time since diagnosis	5.56 (2.80, 1-10 years)
Missing	2

telephone. We achieved our sample of 22 following 30 phone calls. Eight men declined due to scheduling conflicts and/or lack of interest. Participants were 64.3 years (± 4.1) of age and a mean 5.6 years (± 2.8) from diagnosis (Table 1). The majority had been diagnosed with stage I or II prostate cancer, were divorced or never married, retired, and earned less than \$39,999 per year. Most had attended some college or were college graduates.

Quantitative data

Mean BMI was 31.4 (\pm 7.0); 25% were classified as overweight, and 50% were obese. Overall, our

Table 2	Diet and	physical	activity	patterns
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Variable	Mean (SD) or $N(\%)$
Dietary intake ^a	
Saturated fat, grams	21.2 (8.9)
Added Sugar, grams	60.7 (53.4)
Fiber, grams	12.1 (5.2)
Fruits, cup equivalents	1.7 (1.3)
Vegetables, cup equivalents	1.6 (0.8)
Physical activity ^b	
Insufficiently active	18 (81.8)
Sufficiently active	4 (18.2)
Resistance exercise 2× weekly	2 (0.09)

^a Measured by Block Fat/Sugar/Fruit/Vegetable Screener [18]

^b Measured by the Godin Leisure Activity Index [19]

participants reported dietary patterns high in saturated fat and added sugars and low in fruits, vegetables, and fiber (Table 2). Four men (18%) reported physical activity levels considered sufficiently active (a minimum of 150 min of moderate or 75 min of vigorous activity weekly), and two of these reported engaging in resistance or strength training at least twice a week.

 Table 3
 PROMIS quality of life domains^a of African-American prostate cancer survivors participants

Domain	Afican-American prostate cancer survivors Mean (SD)	Population-based prostate cancer survivors	General populatior
Physical function	45.3 (9.5)	50.2 (0.3)	50 (10)
Depression	49.1 (9.0)	45.4 (0.3)	50 (10)
Anxiety	50.1 (7.1)	45.9 (0.3)	50 (10)
Fatigue	50.4 (10.8)	47.3 (0.3)	50 (10)
Sleep disturbance	52.0 (7.4)	48.2 (0.3)	50 (10)
Ability to participate in social roles and activities	51.0 (8.5)	55.1 (0.3)	50 (10)
Pain interference	54.7 (9.7)	49.1 (0.3)	50 (10)
Social isolation	43.9 (7.3)	Not measured	50 (10)
Sexual functioning			
Interest in sexual activity	41.6 (8.1)	Not measured	50 (10)
Erectile functioning	43.6 (4.5) ^b	Not measured	50 (10)

^a US average = 50, SD = 10

^b Includes the 10 men who reported sexual activity (either with or without a partner)

QOL scores indicated challenges in several domains (Table 3). Compared to US norms for PCS, participant scores indicated poorer status across all domains. Compared to US norms for the general population, our sample reported greater burden (+ 3 points over population mean of 50) for physical function, pain interference, and sexual functioning but less social isolation [22].

Discussion session (Table 4)

Changes/challenges with health behaviors (diet, physical activity) post-diagnosis

Although several men reported none, many participants shared they had tried or were trying to make changes given their prostate cancer history. They strongly believed these changes would be beneficial. Most changes discussed were diet focused, including eating more fruits and vegetables, less junk food, and less meat (e.g., "no chittlings or ham hocks," "more blackberries and walnuts for energy"). "Diet is key to the healing." Several noted the value of supplements

Yes, my diet has changed. I'm eating less meat and making sure I'm eating more fruits and vegetables, and I've started taking vitamins.

Only a few were trying to do more exercise ("ab roller," "bicycling"), but all agreed that being more active was critical to health and quality of life. Confusion about where to start, what foods to eat, and what exercises to do was a prominent theme. No survivor was familiar with the ACS nutrition and physical activity guidelines, and only a few had discussed lifestyle changes with their oncology providers. Those whose oncology provider had addressed lifestyle expressed appreciation for these efforts. Pain and fatigue were cited as common barriers to physical activity, and financial limitations were frequently mentioned as both a stressor and a barrier to healthy eating and exercise.

My energy level is gone since the cancer. I've been a homebody since my diagnosis. I've got nothing to do and my arthritis pain gets in the way of activities.

Unmet survivorship needs

Participants related significant isolation in dealing with their cancer and survivorship concerns. "I feel like we

Problem	Barrier	Recommendation
Unhealthy eating patterns	Need for increased diet-related knowledge and skills	 Increase knowledge of ACS nutrition guidelines for survivors. Provide information and training to improve food choice, shopping, and preparation skills.
	Limited access to healthy eating resources	 Increase awareness of local healthy eating resources (i.e., farmers markets, community gardens). Provide information on alternatives to fresh produce available at local convenience stores (i.e., canned-rinsed, frozen).
	Financial challenges	 Increase knowledge and skills related to affordable healthy eating practices (buying in bulk, frozen, or canned produce; buying in season; proper storage of produce to extend freshness). Increase awareness of affordable shopping venues (Walmart, farmers' markets) and ways to access these (bus routes, church car pools)
Limited physical activity and strength training	Lack of knowledge	 Increase knowledge of ACS physical activity and strength training guidelines for survivors. Provide information and training on strength training exercises.
	Limited access to affordable physical activity resources	 Increase awareness of local physical activity resources (public recreation system classes, YMCAs, men's walking groups) Develop materials to guide strength training outside of supervised classes Provide virtual access to and support for strength training (YouTube videos of exercise classes with strength training)
Quality of life challenges	Limited social support related to survivorship concerns	 Provide opportunity for survivors to share their "cancer story." Integrate group time to discuss ongoing survivorship and personal concerns unique to AAPCS.
	Informational needs related to survivorship challenges such as cancer recurrence worry, incontinence, and sexual function	 Have health providers attend 1–2 sessions to directly address men's concerns. Provide information on methods for managing sexual dysfunction.
	Challenges with stress management	Integrate time to identify stressors that impact QOL.Provide instruction and guidance on mindfulness and meditation.

are alone with our thoughts after treatment is done. It would be good to have peer groups with other survivors." Common issues included low mood, feeling weak—"not like a man"—urinary incontinence, and sexual challenges. Financial stress was also frequently mentioned. "I can't be healed if I am stressed out over money." Specific requests were noted for access to a dietitian/nutritionist to advise and support healthy eating, information on how lifestyle impacts survivorship, peer group support, financial navigation, and greater clinician involvement in dealing with the effects of prostate cancer treatments.

Interest in lifestyle intervention and suggested format and content for AAPCS

Data highlighted participant interest in a healthy eating and exercise program, emphasizing the desire to become "more fit, gaining muscle and losing fat." The importance of "feeling like a man" was raised, as was the need for resources that would enable them to "feel stronger again." A prominent theme was the desire to have a program that would provide the opportunity to "unite with other AAPCS," "do something productive outside of the home," and "support efforts to be healthier." For the majority, the discussion session was one of their first opportunities to talk with their peers, and they commented on enjoying the comradery.

Related to intervention structure and content, men shared that they were not necessarily interested in weight loss, but instead wanted to focus on their eating and exercise habits. They expressed interest in learning practical information and strategies to make positive behavioral changes (e.g., "I need to cut down on my junk food and sweet tea") and having accountability to support these changes. Supervised exercise sessions were requested; preferred exercise modalities were walking, weight training, and yoga. All participants wanted an inperson group program (as opposed to individual or web-based). "I want to be with other men like me....we all need to be able to talk about what's goin' on, our struggles...our wins." Dedicated time to talk together was considered essential.

Most did not want significant others or family members in attendance. Reasons for this included wanting to have frank conversations with their peers, but also *not* wanting to further burden family members. However, participants did suggest creating a summary they could take home after sessions to share with family and/or inviting family and friends to attend occasionally.

Additional desired components included information on sexual functioning and how lifestyle might impact this, as well as financial considerations and guidance on healthy eating and exercise on a budget. Participants expressed interest in cooking instruction since many lived alone and cooked for themselves. They also wanted a session where they could ask questions of a health care provider. Finally, technologybased tools such as activity monitors and text messaging (for reminders and motivating messages) were mentioned as "luxury items" that could provide support and accountability outside group meetings.

In terms of practical issues such as location and group leader, participants were vocal about holding the program in a neighborhood location: "It needs to be someplace you can get to by bus or walking." Safety was also discussed with a robust conversation around the need for daytime programming given reported local and national problems with police interactions. However, younger men who were still employed emphasized the need for evening programming. In response to questions about group leadership, participants did not express strong opinions about race. Most, however, noted a preference for a male to lead discussions around cancer support, and all wanted a certified trainer to lead the exercise portion.

Discussion

This study is among the first to focus on the lifestyle behaviors and intervention needs of AAPCS. Although small, our sample was comprised of an important underserved population that has received limited attention in the survivor literature. Findings reflect diet and physical activity patterns contributing to a high prevalence of overweight and obesity, and, perhaps to, QOL challenges. Men reported a strong interest in a community-based lifestyle program that could provide practical and strategic information on healthy eating and exercise practices, as well as social support and accountability.

Seventy-five percent of our sample had BMIs in the overweight or obese range, higher than the national prevalence of 69% documented for non-cancer affected AA men [23]. A study of SEER data showed consistently higher obesity rates among AA cancer survivors compared to non-cancer-affected individuals from 1997 to 2014 [24]. Obesity is associated with increased risk of PC recurrence and mortality [25]. Current cancer models propose that obesity promotes PC growth and progression by (1) altering hormone production, (2) contributing to leptin and adiponectin dysregulation, (3) increasing serum insulin levels, and (4) stimulating chronic inflammation [26]. Obesity is also associated with cardiovascular disease, an important cause of mortality among prostate cancer survivors [3, 4]. Obesity, more specifically excess adiposity, results from an unequal balance between energy consumption and energy expenditure; thus, consideration of lifestyle behaviors is key.

While several participants discussed efforts to eat more healthfully, particularly more fruits and vegetables and less junk food, our results reflect dietary patterns high in saturated fat and added sugars and low in vegetables and fiber. Physical activity levels were insufficient for the majority of the men, and strength training was particularly infrequent. These dietary patterns are markedly similar to those at baseline for female AA breast cancer survivors participating in the Moving Forward lifestyle intervention trial [27, 28]. Cancer survivor guidelines recommend a plant-based diet low in red/processed meat and added sugars, along with regular moderate physical activity and resistance training [13]. These behaviors can help to ameliorate or prevent long-term and late effects associated with prostate cancer treatments [11]. Additionally, large cohort studies including the Health Professionals Follow-Up Study (HPFS) and the Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE) study report significant associations between regular moderate or vigorous physical activity and lower overall or prostate cancer-specific mortality and disease progression [29, 30]. Dietary patterns also play an important role in PC survivorship [31]. Several studies suggest that dietary fat from animal sources (e.g., meat, high fat dairy) increases risk for disease progression, PC specific, and/or overall mortality [32–34]. The Health Professionals Follow-Up Study supports a protective effect for fatty fish, a higher consumption of vegetable-derived fats, and adherence to a Mediterranean diet [2, 7, 32, 35]. In the CAPSURE study, high intakes of cruciferous vegetables were associated with a decreased risk of PC progression [36]. Despite this evidence, many PC survivors do not follow health-promoting guidelines [2, 3]. Limited data indicate that AAPCS are more likely than

NHW survivors to be non-adherent [2, 3]. This may be due, in part, to the socio-environmental challenges faced by many AA cancer survivors, including those participating in our study, who are more likely to live in areas characterized by high segregation, high crime rates, low neighborhood socio-economic status, high traffic density, and low access to full-service supermarkets and PA resources [16].

Related to QOL, our results reflect substantive challenges with physical and mental functioning compared to other PCS survivors and to the general population. These contrast with a recent US population-based study documenting equal or better PROMIS scores among PCS compared to the general population and other cancer survivors [22]. However, studies with AAPCS report greater struggles with general health, bodily pain, physical function, role function, disease worry, and bowel function relative to whites [5-10]. Matthews et al. examined correlates of QOL among AAPCS and found that lower levels of social support were associated with poorer mental functioning, while financial concerns and comorbidities were associated with lower physical functioning [5]. Penedo et al. examined sociodemographic, medical, and health behavior factors as predictors of QOL [9]. Although comorbidities partially explained lower QOL among AAs relative to whites, health behaviors (physical activity and sleep) were also important. Data from the HPFS further support the association between physical activity and QOL. Inactive men reported higher global distress, anxiety, symptom burden, and unmet needs compared to active men [37], while those engaging in > 5 h of nonvigorous activity or > 3 h of walking per week reported higher vitality scores [38]. Other studies report enhanced sexual functioning and higher social participation among physically active PC survivors [39, 40]. Our participants had low levels of physical activity and social support which likely contribute to their QOL challenges.

Behavioral, OOL, and discussion session results reflect intervention opportunities to improve multiple aspects of survivorship. Trials with PC survivors report positive results [14, 15, 41], including improved diet, increases in physical activity and strength, enhanced psychological status, and/or physical and social function. Recently, Hanson et al. targeted AA men on ADT (n = 17) in a strength training intervention, with results supporting significant increases in strength and lean mass [42]. However, no other studies have targeted AAPCS or any other AA male cancer survivors either through recruitment or by tailoring an intervention to meet their specific needs. Pilot study participants expressed strong interest in a community-based intervention that would support behavioral changes. Further, they identified important barriers to address in such programs including knowledge of survivor nutrition and physical activity guidelines and their impact on survivorship, confusion with how to achieve a healthier diet, problem solving around access to full-service supermarkets and PA resources, financial concerns, and limited social support.

These concerns are highlighted in studies with AA men in the general population. Griffith and colleagues examined the perceptual differences of factors influencing fruit and vegetable consumption between AA men that met or did not meet recommended guidelines [43]. Interestingly, both groups identified access, knowledge, and social support, but adherent men saw these as facilitators, while non-adherent men saw these as barriers [43]. Although it is critical to address the built environment and social conditions that limit access, knowledge, and social support, it is equally important to help men identify and implement effective strategies to navigate unhealthy environments. Assisting men in finding ways to manage their barriers so they can become facilitators will increase intervention relevance and efficacy. Pilot study participants also identified motivators for lifestyle changes which included understanding the relationship between lifestyle and their health and survivorship, as well as the opportunity to participate in supervised exercise classes allowing them to build strength and feel more "manly." This is in keeping with Campbell et al.'s work with AAPCS showing that perceived dependence on others was interpreted as diminished masculinity [44]. The authors theorized that enhancing men's physical ability to be more self-reliant would positively impact QOL. Finally, our participants emphasized their interest in having a group program where they could be with other AAPCS noting they have few, if any, opportunities to speak frankly with others about their prostate cancer experiences. QOL researchers document the critical role of social support for quality of life among AAPCS [5]. In sum, lifestyle interventions that integrate the needs and preferences of AAPCS should offer group-based programming that allow AAPCS to come together and address the barriers limiting access, knowledge, skills, and physical strength.

Our study is not without limitations. We relied on a convenience sample thus selection bias is likely, and results cannot be generalized to all AAPCS. However, our sample does reflect diversity in age, income, and time since diagnosis. Further, although all study measures were well validated, diet and physical activity data were based on self-report.

Conclusions

Given high prostate cancer incidence rates among AA men and the efficacy of prostate cancer treatments, the AAPCS population continues to grow. Comorbidities and QOL challenges highlight the importance of survivorship programming. Yet, efforts to date among AAPCS focus on social and emotional support with minimal attention to lifestyle behaviors [5–10]. This is despite strong data showing that obesity, diet, and physical activity impact PC and comorbidity outcomes and are also strong indicators of QOL. Our results support the importance of addressing lifestyle behaviors and QOL among AAPCS. Interventions that are group-based; target increased knowledge, skills-building, and social support; provide supervised exercise with strength training; directly address financial challenge; and can be easily accessed will best meet the needs and address the many barriers of this underserved survivor population.

Acknowledgments We want to thank the participants for their valuable time and thoughtful comments.

Funding information Financial support was provided by the MCW Cancer Center and the Greater Milwaukee Foundation for this work.

Compliance with ethical standards All study procedures were approved by the Institutional Review Board at the Medical College of Wisconsin.

Conflict of interest The authors declare that they have no conflict of interest.

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