

Qualitative Evaluation of a Community-Based Physical Activity and Yoga Program for Men Living With Prostate Cancer: Survivor Perspectives

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Abstract

Purpose: Physical activity (PA) programs for prostate cancer survivors have positive effects on many aspects of health-related quality of life. Translating this research into sustainable community-based settings is necessary to ensure access to programs for survivors. This study examines patient perspectives in the community-based TrueNTH Lifestyle Management (TrueNTH LM) program in Calgary, Canada.

Methods: Eleven men from programs at civic wellness centers participated in 2 small semistructured focus groups (n = 5 and 6) at the University of Calgary. Motivation for program initiation and adherence, benefits and barriers to participation, and individual satisfaction and feedback on program improvement were discussed. Audio recordings were transcribed and analyzed using thematic methodology guided by a pragmatic philosophy on the patient experience in the program.

Results: Themes identified included perceived benefits of participating (physical, psychological, and social), facilitators for involvement in the PA program (program design, initial free access, tailored to prostate cancer specific needs, psychosocial environment), and opportunities for improvement and sustainability (exercise as a part of standard care, cost structure, home-based options).

Conclusions: These findings provide valuable insight into patient perspectives on effective characteristics of prostate cancer and exercise programs. TrueNTH LM has implemented findings, and ensuring needs (benefits and barriers) are addressed for prostate cancer survivors when entering community-based PA programs.

Keywords

prostatic neoplasms, movement, oncology, adherence, barriers, motivation, sustainability, feasibility, qualitative, community programs

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Introduction

Physical activity (PA), stress reduction, and nutrition interventions in cancer survivorship have positive physical and psychosocial outcomes.^{1–3} In men with prostate cancer (PC), the evidence includes improvements to fitness indices, body composition, quality of life (QOL), fatigue, and mental health.^{4–10} Interventions presented in a group setting also provide social support from peers.^{11–17} Community-based PA programs for cancer survivors (ie, outside of controlled research settings) show similar benefits.¹⁵

A handful of studies have qualitatively examined PC survivors' perspectives after participating in a PA

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intervention.^{15–19} Participants perceive group exercise as an acceptable medium to achieve both fitness benefits and peer support.^{15–19} The PA setting may facilitate candid discussion about experiences with PC, and some find the exercise setting preferable to a peer support group.¹⁶ An exercise setting allows participants to engage in problem-focused, action-oriented coping strategies providing a sense of control, confidence in their abilities and body awareness, and a welcome distraction from disease-related side effects.¹⁵ Many survivors were active before diagnosis and experience discontent with their physical state during treatment. They often see PA programs as motivating them to safely return to their previous activity levels.^{15–20} The group dynamic also encourages adherence by fostering a sense of responsibility and obligation toward program peers¹⁵ and can contribute to feelings of empowerment.^{11,15–20}

Despite the benefits of group exercise programs for PC participants, no sustainable community-based programs are currently resourced within the standard PC care structure. Understanding participants' perspectives of the benefits of and potential barriers to such programs, and features that would make them sustainable as part of the care pathway are important for adapting programs to be feasible as part of standard care. Therefore, the purpose of this study was to examine patient perspectives on a community-based PC PA program, TrueNTH Lifestyle Management (TrueNTH LM). Objectives included examining participants' experiences with motivation, social interactions, exercise benefits, barriers, and preferences as well as perspectives on program improvement and sustainability.

Methods

This study used thematic analysis methodology²¹ guided by a pragmatist philosophy which emphasizes that social context, shared beliefs, and common worldviews shape experiences,²² and thus, it is well suited to examining group exercise programs for cancer survivors.

The Context

TrueNTH is a global initiative to improve the QOL of all men with PC through knowledge to action initiatives.^{23,24} In Canada, the TrueNTH LM solution was developed to improve survivor access to evidence-based PC wellness (PA, stress reduction, and nutrition) programs, resources, and professionals within the community setting.^{25,26} The community-based TrueNTH LM programs were 12 weeks, with 2 weekly 60-minute group classes (maximum 15 participants), consisting of 1 circuit-based resistance training class and 1 gentle yoga class. Qualified facilitators with cancer and exercise training supervised classes and included an emphasis

on enabling participant behavior change (for full details of the TrueNTH LM program, see Culos-Reed et al.²⁵). Facilities could limit the program to PC survivors or allow support persons (eg, spouses, adult family members) or survivors from other tumor groups to attend, in order to achieve sustainable enrollment numbers.

Participants

Eleven focus group participants were drawn from the TrueNTH LM classes in Calgary that were delivered in 2015 to 2017 (n = 100 participants). Individuals had participated in a TrueNTH LM program on average 13 months earlier (standard deviation = 7.3). All but 1 individual were enrolled in the maintenance program. All participants were over 60 years of age (range, 60–79), Caucasian, retired, married, and all but 1 participant lived within the Calgary city limits. All individuals rated their current level of general health to be good, very good, or excellent. Most (n = 10) also reported completing 150 minutes of moderate/vigorous intensity exercise per week. Ten had undergone a prostatectomy, 2 were currently or had previously received chemotherapy, 2 had previously received radiation, and 2 were currently or had previously received androgen deprivation therapy.

Procedures

Ethical approval was obtained from the Health Research Ethics Board of Alberta—Cancer Committee (HREBA, CC-16-0226). Participants were recruited via an e-mail invitation to program participants who had indicated interest in being included in research. Two semistructured focus groups (n = 5 and 6) took place in a meeting room at the university. Questions addressed motivation for joining, adherence, benefits, program characteristics (delivery, ideas for program improvement and sustainability, and fee structure), class dynamics, social relationships, exercising in a group setting, exercising with other PC survivors, and preferences for exercising with PC survivors, other cancer survivors, and support persons. The third author moderated the focus groups with the second or fourth author assisting. All moderators completed training on conducting focus groups with the last author, who has extensive experience with qualitative research with cancer survivors. Focus groups were approximately 60 minutes in duration and were audio recorded.

Data Analysis

Focus groups were transcribed verbatim and checked for accuracy, and an inductive thematic analysis was

conducted²¹ using NVivo 10 software.²⁷ Data analysis involved the third author reading each transcript to ascertain overall, rereading and inductively coding concepts relevant to the research question, reviewing codes and grouping similar ideas as themes, and developing higher order categories and connections among themes. The first, third, and last authors reviewed the themes and transcripts and came to a consensus on final themes. A description of the findings, incorporating illustrative quotations, was written. Quotations are not accompanied by identifiers to preserve confidentiality in this small, specialized sample. To address study quality,²⁸ we sought to (1) make a substantive contribution by addressing participant perspectives supporting sustainability of a novel community-based PA program for men with PC, (2) be impactful by considering practical problems and recommendations with the potential for broad international scope through TrueNTH programming, (3) be comprehensive by providing multiple perspectives in the report, and (4) enhance transparency by involving multiple authors to scrutinize interpretations.

Results

Perceived Benefits of Participating

Participants identified physical, psychological, and social benefits. Perceived *physical benefits* included improved fitness, energy levels, and ability to handle treatments. A participant who had completed treatment noted he had “More energy, definitely more energy.” Another participant who was in treatment following a recurrence expressed:

I'm in better shape now than when I was 8 years ago. And I'm handling the treatments better. I'm in better physical shape because of the exercise. But also, I had my CT scan in October and it's the first time in 4 years, 5 years, that I was able to get in, lie flat enough in the machine to get a proper scan. And that's when they found another tumor. But I'm convinced that without the yoga and the fitness, they may have missed it.

Participants had varied experiences with weight loss:

I don't know whether anybody else has, but I've lost some weight over the last while, so that's always good, you know.

Okay, maybe I'll come then. [group laughs]

I'm hoping for that too. [group laughs]

Psychological benefits included improved mood, outlook, and coping with stress related to cancer.

I always felt great after exercise. And it also gave me back my, I'd like to say my sense of humor. [group agrees] It gave me back my, my enthusiasm again to get back into exercise.

I can make myself work harder at home, but I don't get the same sort of bump in spirit that I do when I work out with the guys.

I knew that exercise was good for the body. But I needed to exercise in the mind and it was very important for me to get my mind around [PC] as well.

Social benefits included making a connection and communicating with other PC survivors who understood survivorship experiences. “I think there's a special thing about a cancer survivor though that binds the group.” Others felt connected because they were with men of similar age, “I think the fact that we're in that age category is as important as the fact that we're cancer survivors.” But the connection was also based on shared exercise experiences of exercise. “To me the dynamic is that we're all exercising together. The fact that we're all PC graduates, or survivors, whatever, is secondary really. You know, it was just an opportunity to join an exercise, yoga group.” Being among other survivors was important for being able to share first-hand experiences related to cancer.

Through the group, I have met other guys that have either done similar treatments, or are going, or have done treatment that I am going to be starting. So then it is easier to connect with somebody who you are exercising with, to say, you know, what I'm going to be starting this treatment, how has that impacted? Or have you had to adjust your physical activities? And you can bounce discussions back and forth. And you learn a little bit more about here, what can I expect. So it, because in the group there's all kinds, there's guys that have had surgery, there's guys that have had radiation, there's guys that have had chemo. And they're all different. Everybody in the group has had their own experience and they can share that if you've got a question, it's easier to ask in the social setting of the exercise class.

The shared survivor status also fostered feelings of implicit understanding.

I have a feeling that everybody understands the other person. And we've all shared, you know, some aspects of. Some have had surgery. I've had radiation, and

chemotherapy, and other, you know, other treatment. We all end up kind of realizing we've all in the same boat.

Facilitators for Involvement in the PA Program

Program design. Several logistical elements of the program were identified as facilitating participant involvement, including the community-based location, no cost, provision of educational materials, tailoring of exercise to the needs of PC survivors, and the variety of activities included. The *community-based location* was important in terms of both proximity and free or convenient parking.

If the location was too far . . . I might not have gone. It's you know, 10 to 15 minutes away from my home. That was a draw. So had it been, a half hour journey, I might not have gone.

That the initial 12 weeks was a *free program* (the maintenance program is fee-based) was important for encouraging survivors to try the program and to experience benefits that motivated continued participation:

- 1: That was a real incentive for us, to get us in the door.
- 2: That initial free one gave me the taste . . . it gave me the opportunity to learn and to self-recognize the benefits of being involved in that group. So much so that I've paid 3 more times to go.

Participants also found the provision of *educational materials*, including tours of the exercise facilities, print and online information about the exercises, instructional videos, and wearable PA trackers to be helpful.

That the content of the exercise program was *tailored for PC survivors* appealed to participants and made them feel comfortable and confident in participating. "The exercises were focused on my recovery from [PC] . . . It was the fact that, this is geared towards what you have gone through and this is part of your recovery." The idea of tailoring for survivors included both addressing concerns and rehabilitation needs specific to PC survivorship, and individualized instruction based on the variety of abilities, cancer experiences, and limitations due to comorbidities.

You exercise to your ability, where you're at. And even if you do have a little more case of cancer, or cancer treatment I should say, you may not have the strength to do the same amount as everybody else.

An appealing feature was that classes included a *variety of activities*.

I liked the variety. And I liked the fact that they incorporate some weight training, some core training, some cardio, so every week we're getting a little taste of different exercises. And, even today in yoga . . . we were doing yoga positions that I've never done before . . . The instructors are constantly adapting to our own skill level. My favorite thing is that we're doing something different all the time.

Including pelvic floor health, stretching, and stress-reduction activities was important to participants. Yoga appealed to many participants.

I'd never done any yoga and when it started up. I thought, well, you know, yoga. That's like men eating quiche and that sort of thing [laughing]. But I've quite enjoyed it . . . I'm surprised I like yoga.

Psychosocial environment. The opportunity to connect with other survivors and those of similar age, drawing motivation for exercise from the group, inclusion of caregivers, the engaging and knowledgeable instructors, and fun were appealing. The group provided *opportunity for connection with other survivors and men their age*, which created a relaxed and nonintimidating environment where they would not feel embarrassed due to deconditioning, inexperience, or PC-related factors like incontinence. The group was an important source of *motivation for exercise* through having others to participate with, encouragement, relaxed competition, accountability, and looking forward to spending time with peers.

When you see everybody around doing the exercises, you don't go for as little as you want, you go and you try and stay with the rest of the gang. And I think, the question has come up before in conversation, would you go home and exercise? My answer to that is no. I need the compe-, not the competition, but I need to see others around me . . . to make sure I am doing the exercises. And some of them are pretty difficult, but we do them.

Caregivers, spouses, partners, and the exercise instructors were also facilitators. The inclusion of *caregivers, spouses, and partners* was important to some men:

The relationship in my life is first with my wife. And we were for the last two 3-month sessions, we were able to bring our wives or partners into the group. And I know my wife enjoys participating with the PC survivors . . . I think that to me is important that spouses and, or partners should be able to take part.

Engaging and knowledgeable instructors effectively implemented the program, built positive personal relationships with many participants, but were sensitive and positive about adapting exercises to fitness level and limitations. “They don’t make any particular aspect of it seem negative. You know you’re not doing it as well as somebody else . . . so they’re right there to help so you don’t feel like, ‘I can’t do this.’” Overall, these relationships, coupled with many of the other facilitators identified, contributed to a positive and fun experience:

When I first started the group session I was like, this is really fun. Guys are great, you know, the instructor is good and, and the guys are just all fun. Everybody is relaxed about it and it’s no competitiveness . . . That was a surprise to me, how much fun it was.

Opportunities for Improvement and Sustainability

Participants shared ideas on how the program could be improved and reach more survivors. A dominant discussion and the most fundamental suggested change was to *make exercise a part of cancer care* by more systematically engaging newly diagnosed survivors via the health-care system. It was believed that sustainability could be improved by providing exercise information at multiple time points in the survivorship continuum and reducing direct cost to survivors by integrating PA programs into existing health-care systems. Participants believed that health-care professionals and cancer care clinics should be referring their patients to exercise programs. “It’s something we should just assume is being done . . . of how good exercise can be for your recovery and also for your maintenance.” Some participants were not motivated to take part in lifestyle changes soon after their diagnosis: “The last thing you’re thinking about is exercise when you find out you have cancer.” Others would have wanted information immediately after diagnosis to help cope, or prehabilitate, while waiting for treatment: “If you had something like [an exercise program] where you meet other people that went through it already . . . it would have made everything easier and maybe take some of the fear away.” They also emphasized the need for multiple invitations and points of entry to reach out to survivors when they are ready. “That would be good to make sure it’s incorporated at the prostate center . . . It should be something that is brought up at least regular, periodically but regularly, so every third or fourth opportunity.” “I saw an oncologist, I saw an urologist . . . sometimes we may see a dietician. Why don’t we see an exercise specialist, who can outline for us the opportunities we can get through exercise?”

There were also discussions about the *optimal cost structure*. This program was free for the first 12-week session, and then participants paid \$99 per subsequent 12-week session. Many participants expressed that they felt this price for the subsequent sessions was a bargain, and some expressed they would be willing to pay up to \$150 to \$200 per session, once they had experienced the benefits in the initial free session.

But there was also acknowledgement that programs needed to be subsidized for those who could not afford the fee and to encourage people to participate. “Cancer doesn’t discriminate what kind of financial situation you come from [group agrees]. So, I think, I think initially it should be free to attract as many people as possible. And then be moderately priced.” There were multiple ideas on where the cost-burden for subsidized programs should fall; however, there was unanimous agreement that if it could not be free, the costs should not fall solely onto the users. Suggestions for offsetting costs included providing tax credits and funding through not-for-profit foundations.

I think they should lobby the government to give tax receipts for the fees that are charged so that you could write it off on your income taxes as a medical wellness investment. And I think that the government would be foolish not to, because it’ll cost them a lot more in the long run for a lot of sick people.

The participants agreed that group-based exercise was more attractive and motivating than individual home-based exercise alone. But they suggested that providing an individualized *home-based program* as a complement to the group program was an important option for survivors who were uncomfortable in the group setting, or who were in rural locations. “I prefer group, I think it’s far more valuable that way, but the option (home) might be available for those that really are uncomfortable in group.” “People that live outside of Calgary have cancer as well. And they can’t necessarily come into these programs. So, I think it’s really important to make sure there are some options for them as well.”

The program provided considerable print and online resources. However, some of the participants had not accessed those resources and discussed that placing greater emphasis on drawing their attention to those resources may have facilitated them doing additional workouts.

Some of the stuff we do could be carried on at home if you had some sort of guidance. I mean, doing it once or twice in the class is great. And going to the next class great. But if you had some of that information. It’s, you know, you leave and . . . if you don’t do a lot of yoga, you get home and you think, ‘now what, how do we do

that? So if you had that information you could do some of those things on your own.

Finally, there were a few logistical suggestions to improve the program. Two participants indicated that *adding nutrition education* either as part of the online resources or through access to a dietician would be useful. To improve sustainability as the program grows, 1 participant noted that programs would need to be hosted in *larger facilities* so that they could serve more survivors. Finally, *adding classes at additional times in the day* would help to increase capacity and reduce scheduling conflicts.

Discussion

Relatively few sustainable community-based PA programs exist for cancer survivors.^{11,25,29–31} TrueNTH LM was designed to moving the substantial evidence into practice by providing wellness resources for men with PC^{25,26} and is implemented in communities across Canada.³² But there are challenges to sustainably making such programs part of the standard of care. This study aimed to understand participants' perspectives to ensure that this and other programs understand and address the wellness needs of PC survivors.

Consistent with previous research and community program evaluations, men identified physical and psychosocial benefits to participating in the group-based program. They identified facilitators to program participation, including the group nature of the class, instructor expertise, the tailored program, and educational resources that enhanced participation. Factors they felt would enhance the sustainability of the program included issues around cost and integration of exercise referral into standard PC care.

The current work provides the PC survivors' perspective on what a community-based program offers in their path to wellness, and how it can be best sustained to continue to support men with PC. To date, these results have been used for improvement of the TrueNTH LM project, to ensure that the program continues to deliver what the men reported as beneficial (ie, the yoga program and offering a variety of exercises within the 12-week structure) and necessary (ie, more nutrition educational resources; variety of classes offering different times).

Limitations to the current study include that all but 1 participant were at the time participating in the TrueNTH LM maintenance programming and thus may not accurately reflect the views of those who complete the initial 12-week program only. The convenience sampling of participants means that volunteers for the study with particular characteristics such as higher PA

levels or more positive views of the program may introduce self-selection bias. Although there was variety of men in terms of treatment status, the participants were primarily a Caucasian, older, retired sample.

These findings enhance our understanding about participants' experiences with and perspectives on sustainability of PA programs in PC care. Although guidelines currently exist advocating for the role of PA in cancer survivorship,^{33–35} there has been little translation of this evidence into practice.³⁶ Work conducted on understanding health-care providers', administrators', and cancer survivors' perspectives must be incorporated to move evidence to practice and build PA into standard PC care.

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