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Understanding how to reach the hard to reach in cancer rehabilitation

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ABSTRACT

Introduction: Regular exercise helps manage side effects of cancer treatment, however, less than 30% of survivors participate in regular exercise. Exercise-related barriers, facilitators, and needs of general populations of cancer survivors are described in the literature. No information exists describing this information for hard to reach populations. **Purpose:** To determine the barriers, facilitators, and exercise needs of hard to reach cancer survivors. **Materials and Methods:** Research design: Descriptive qualitative study. Population: Hard to reach cancer survivors, including young adults (18-39 years), those living in rural communities, and those living in areas of low socioeconomic status. Data collection: Semi-structured interviews were conducted with participants. Interviews were audio recorded and transcribed verbatim. Transcripts were coded independently by two researchers. Coded data was aggregated into nodes and grouped into themes. **Results:** Five themes were identified that influence exercise participation in hard to reach survivors: accessibility of exercise programs, appropriateness of exercise programs, social support, personal factors, and exercise information. Young adults described a lack of appropriate exercise programs for their age group, those in rural settings described availability issues, and those in areas of low SES described cost and social support as barriers to exercise. **Conclusion:** This project identified unique exercise-related barriers, facilitators, and needs of hard to reach cancer survivors. Results can be used by researchers and clinicians when creating exercise interventions for cancer survivors. Interventions must be tailored to the specific needs of each individual in order to facilitate accessible participation in regular exercise and facilitate sustained behaviour change.

Keywords: Exercise, physical activity, neoplasms, survivorship, hard to reach populations, barriers and facilitators

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INTRODUCTION

Approximately half of Canadians will be diagnosed with cancer in their lifetime. [1] Survival rates have significantly improved due to prevention, enhanced screening, early detection, and superior treatment strategies. [2] However, a large population of survivors are living with physical and psychological sequelae of cancer and its treatments for years after cancer treatments have ended, leading to reductions in overall levels of function and quality of life. [2-4] Understanding how to effectively manage the side effects of cancer treatment is necessary.

Regular exercise has been repeatedly reported in systematic reviews to help manage side effects during and after cancer treatment. [5-7] Additionally, observational research suggests that regular exercise can decrease cancer recurrence and improve all-cause and cancer-specific mortality rates. [8-9] While research and clinical guidelines [10,11] support exercise for cancer survivors, less than 30% of survivors participate in regular exercise. [12-13]

Hard to reach populations are defined as groups of the population that are difficult to involve in public health programming and research. [14] Hard to reach populations are known to have lower accessibility to cancer services and higher cancer-related incidence and mortality rates. [15,16] Furthermore, barriers and facilitators to exercise may be different for this group. In particular, barriers to exercise participation in the general population of cancer survivors include physical side effects such as pain and cancer-related fatigue, lack of knowledge on the benefits of exercise and proper exercise parameters, lack of time, and unawareness of available exercise programs. [13,17] Facilitators to exercise in cancer survivors include a previous positive experience with exercise, meeting exercise guidelines prior to cancer treatment, a feeling of control over health, and accessible exercise services. [13-17] Survivors describe needing more information related to exercise from their oncology care providers. [17] Limited information exists to describe the barriers and facilitators to exercise participation and the exercise-related needs of hard to reach populations. Collectively, these individuals are underrepresented in research and therefore are not likely targeted appropriately in programming and services aimed at increasing exercise. The current study aimed to explore this gap.

Purpose:

The objective of this study was to identify the exercise-related barriers, facilitators, and needs of hard to reach cancer survivors. The present study's findings will help define future research and clinical priorities aimed at improving and maintaining exercise for hard to reach survivors.

MATERIALS AND METHODS

Study Design:

This study used a qualitative description design. Qualitative description is suitable when clear descriptions of phenomena are desired and has a theoretical foundation in naturalism. [18,19] The phenomenon of interest in this study was exercise participation by hard to reach cancer survivors and the barriers, facilitators, and exercise-related needs of this population. The University of Toronto's, Office of Research Ethics approved this study (#36942).

Participants & Setting:

Eligible participants included (1) English speaking, (2) adult cancer survivors, (3) living in Canada, (4) who completed active treatment (chemotherapy and radiation therapy) for any form and stage of cancer. Purposive sampling was used, and recruitment was targeted to ensure inclusion of participants defined as hard to reach. This included the young adult population (18-39 years old), those living in rural or remote communities (towns or villages with a population less than 1,000 according to the current census [20]) and those living in areas of low socioeconomic status (SES) (based on participant postal code matched to 2016 Canadian Census data on average income by neighbourhood (https://censusmapper.ca/maps/1535?index=3#10/49.2490/-123.0750)). Participants were recruited regardless of their current or previous exercise

levels. Potential participants were excluded from the study if they: (1) were currently receiving chemotherapy or radiation treatment, or (2) self-reported having a cognitive impairment that prevented them from understanding consent forms and interview questions.

Recruitment:

Participants were recruited through four community cancer organizations. A recruitment letter was sent by email to members of the Active-Match (activematch.ca) and Enliven (http://www.enlivenmuskoka.ca) communities. Additionally, a study notice was posted for members at Wellspring (https://wellspring.ca) locations (in hard copy) and members of the Rethink Breast Cancer (https://rethinkbreastcancer.com) community (online). Interested members contacted study investigators for more information, to determine eligibility and, if appropriate, to schedule an interview date. The sample size for this study was determined based on the need to recruit participants until saturation of the interview data was achieved. Saturation was defined as the instance during analysis where substantial and consistent occasions of the same codes were occurring, while no new codes were coming forth from the data. [21,22]

Data collection:

Individual semi-structured interviews were conducted by one researcher (JST), in person or by telephone. Participants received a $20 gift card for participating in the interview. The interview guide was created based on a literature review, behavioural change theories, and purpose of the study. The interview guide was pilot tested with the first two participants and minor revisions were made before implementing the final version with remaining participants. Participants were asked questions that explored barriers (e.g., *What gets in the way of you participating in exercise?),* facilitators *(e.g., What helps you participate in exercise?),* and exercise needs *(e.g., What resources would you have found useful during treatment in order to participate in physical activity?*). Probing questions were used when necessary to elicit more detailed responses. Informed consent was obtained prior to each interview. Interviews ranged from 15 to 90 minutes and all interviews were audio-recorded. After each discussion, the interviewer made field notes recording overall impression of the participant in regard to mood and other noteworthy occurrences.

Data analysis:

The analysis and reporting were performed according to conventional methods for descriptive qualitative studies. [18] First, the interview audio recordings were transcribed verbatim and checked for accuracy and completeness by the interviewer. The first five transcripts were coded independently using line-by-line analysis by two researchers (JST and MV). They then met to identify themes and developed a coding manual for subsequent analysis. This involved two steps: firstly, data was aggregated into nodes and secondly the nodes were grouped into meaning categories based on the patterns that emerged from the data. After the coding manual was developed, the researchers split and independently coded the remaining transcripts. Code development was an iterative process; if new codes were identified in the subsequent transcripts, they were discussed and the coding scheme was revised. A factist perspective of data was taken on during analysis. This perspective assumes data to be accurate and truthful indexes of the reality of the interviewed group of participants. [19] All transcripts were uploaded into NVivo 12 (QSR International Pty Ltd., Doncaster, Australia) and the data was coded into the developed nodes. See **Table 1** for the coding scheme. While data collection and analysis were conducted in an attempt to be completely unbiased, investigators who completed this process (JST and MV) are health care professionals who support the use of exercise in oncology care.

RESULTS

Description of Participants:

Twenty-four eligible cancer survivors agreed to take part in an interview. See **Table 2** for characteristics of participants. All consenting participants were self-identified females. All

participants described themselves as 'inconsistent exercisers', meaning there was variability in the frequency and intensity of past exercise participation. Nineteen participants described themselves as currently exercising regularly (79%). Fourteen participants said that they did not exercise regularly during treatment (58%); of these 14, nine said that they now exercise regularly. When asked about their current exercise-related goals, participants described wanting to maintain or increase their time spent exercising, primarily to increase their strength, endurance, flexibility, or lose weight.

Table 1: Coding Scheme

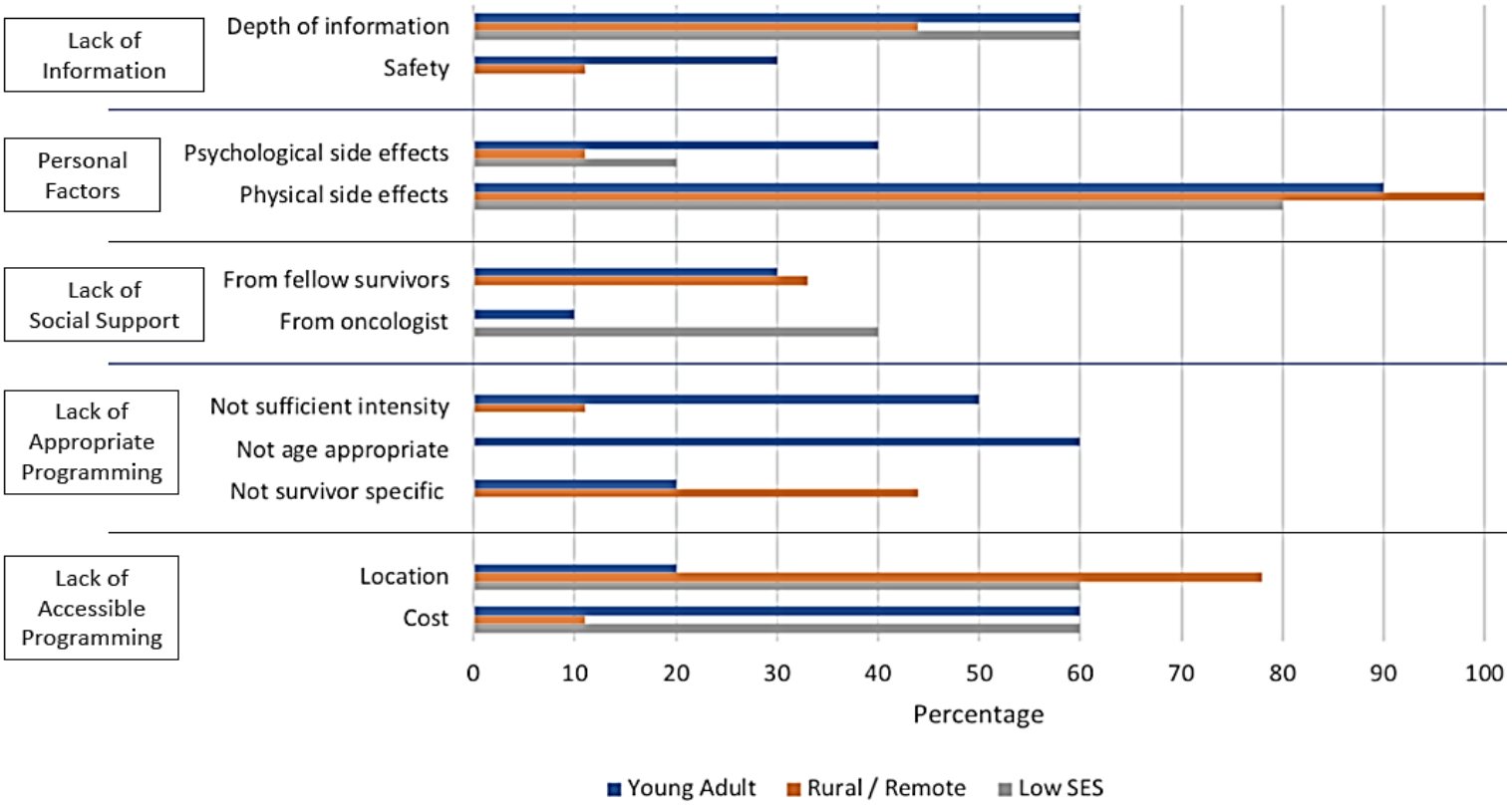
Category	Node	Sub-node(s)	Sample Quote
Accessibility of exercise programs	Barriers	Cost Location Weather	*"I didn't feel comfortable spending money on that thing [exercise] when I wasn't working. And also spending the money and then waking up and not feeling well and not being able to go…waste of money"*
	Facilitators & Needs	Access to health care professional Access to appropriate programming: Community programs for cancer survivors Gym membership No cost	*"Honestly, going back to the exercise program I was surprised at the effectiveness of just a little nudge and a plan. I think before my challenge was kind of really I didn't know where to start."* *"having the plan from the kinesiologist, as soon as she did the assessment and put that piece of paper in my hand I felt a lot of relief and motivation to exercise."*
Appropriateness of exercise programs	Barriers	Not age appropriate Not survivor specific Not desired intensity Other	*"I didn't [access Wellspring or Wellwood programs] just because a lot of the exercise programming was geared towards people who are older than me."*
	Facilitators & Needs	Format of programming: Timing / flexible sessions Online Survivor specific	*"If there was an app where someone preloaded exercises for me to do in a sequence, something simple … with videos, all you need is this resistance band and go through these motions and it was sort of guided. And then there is someone who would check in online once a week…I would have used that 100%."* *"I think maybe having … a group that is more fitting to certain age ranges and having some events, whether it is a yoga class or whatever, that is free for cancer survivors because cost can be a big limiting factor for some people who aren't working during treatment"*
Social support	Barriers	Oncologist not supportive No support of fellow survivors	*"It was isolating. I don't have a workout buddy or anything like that."*
	Facilitators & Needs	Peer support Exercising with similar others Oncologist characteristics: Support/encouragement of exercise Regular follow up (accountability)	*"It would have been nice to do that [exercise] with someone that understood what I was going through and sort of probably have a buddy. Because I think one of the most beneficial things I found throughout this whole process is just the support of my peers who are either going through it or have been through it."*
Personal factors	Barriers	Physical Side Effects Psychological Side Effects Lack of Motivation	*"Chemo, radiation, surgery twice and then I was on Herceptin for a year and a bit because I had a lot of lung problems due to the Herceptin…that pretty much put any kind of kibosh on doing any kind of exercise at all. I was just happy to be able to breathe."*
	Facilitators & Needs	Setting goals	*"The good news about having a base [exercise experience] like that is it gives you a goal throughout treatment to try to achieve again. You have to do a real mind shift throughout treatment that there are some things that you are just not going to feel like."*
Exercise information	Barriers	Lack of information: Due to Busy oncologist On Safety concerns Depth of information not adequate	*"There wasn't a whole lot given to me by the health care team. They gave general information on trying to stay active, but they never told me how much, how often or anything like that."*
	Facilitators & Needs	Information given: From health care team From family member From friend From cancer support organization Other	*"having the health care team talking specifics with the patient and then giving an actual handout that has specific frequency, intensity and time principles to it [would be helpful]."*

Table 2: Participant Characteristics (n=24)

Characteristic	*M* (*SD*) or *n* (%)
Age (in years)	48.67 (15.65)
Cancer type	Breast: 21 [A] (88%) Ovarian: 1 (4%) Non-Hodgkin's Lymphoma: 1(4%) Adenocarcinoma: 1 (4%) Thyroid: 1[A] (1%)
Stage of cancer	Stage 0: 1 (4.2%) Stage 1: 6 (25%) Stage 2: 7 (29.2%) Stage 3: 8 (33.3%) Stage 4: 1 (4.2%) Unsure: 1 (4.2%)
Time since of cancer diagnosis	> 5 years: 5 (20.8%) 1-5 years: 18 (75%) < 1 year: 1 (4.2%)
Hard to reach profile	Young adults (<40 years): 10 (41.7%) Living in a rural or remote setting: 10[B] (37.5%) Living in an area of low socio-economic status: 5[B] (20.8%)

[A]*One participant has been diagnosed with both Breast and Thyroid cancer, on separate occasions, and therefore has been listed for both cancer types;* [B]*One participant was both living in a rural/remote setting and area of low socio-economic status, and therefore has been included in both hard to reach profile*

Figure 1: Percentage of Barriers Reported by Hard to Reach Profile



Results:

Five main themes were identified that impact exercise participation across the three different hard to reach profiles (young adult survivors, rural and remote, and low SES). Constructed themes include: (i) Accessibility of exercise

programs, (ii) Appropriateness of exercise program- s, (iii) Social support, (iv) Personal factors, and (v) Exercise information. Refer to **Figure 1** for a description of findings based on hard to reach profile. Results are described based on theme within hard to reach profile, followed by a summary of results across all participants.

Young Adult Cancer Survivors:

Young adult cancer survivors described a common theme around a lack of appropriate exercise programs based on their unique needs. This was primarily in regard to the fact that available programs were not age appropriate:

"I remember going to a couple classes…where I was sitting with people who were 60 to 80, some 40-50 years older than me…with anything that is going to be made available to me…being connected to a community of people who are my age and going through this [cancer] is important." (Participant 7).

Young participants also repeatedly described a lack of intensity as a barrier to continued participation in exercise programs:

"When I went to the yoga class at Wellspring…it was good because it was a nice stretch … But, after one or two, I was looking for more. I need something a little more challenging…If I am feeling that in my late 30's…somebody younger than I would probably want something a little more challenging." (Participant 10).

Additionally, young participants were more likely than other profiles to describe personal factors related to psychological side effects of treatment as a barrier to exercise: *"…it was…fear to not push myself too hard. And really sort of I guess acknowledge what my body was going through.*" (Participant 12).

Suggested facilitators and needs to overcome the identified issues for young adult cancer survivors included more appropriate exercise programs for young individuals. When creating these programs, participants described unique needs in regard to program parameters to fit their schedules:

"Personally, I don't find that there are enough offerings at the right time…when I went back to work…I would have liked to go back but all classes are during the day, so it is mainly geared to either those who are retired or…going for treatment. So, it's hard to work out at weird times so maybe once a week at night…when you are young and trying to get back to normal…I think that would be really helpful." (Participant 13).

Overall, exercise participation of young cancer survivors depends on targeted programming considering the unique elements of this stage of life.

Survivors Living in Rural or Remote Settings:

Study participants who lived in rural or remote settings most commonly described barriers to exercise participation as a lack of accessible exercise programming (due to location):

"One of the problems in a rural area, unfortunately, is we don't have indoor pools. I would have loved to have gone swimming…because swimming is a nice gentle exercise. It would have been something I could have done, but it wasn't accessible to me because in order to go swimming I have to travel an hour and a half." (Participant 15).

They also described a lack of appropriate exercise programming as a barrier to exercise participation and related this to a lack of survivor-specific programming:

"I don't have a group in Huntsville that I can get together with. I did Gilda's Club. At Gilda's Club people…didn't have to wear their wigs, or cover their head, or worry about it, and it was really liberating to be in an environment where everyone was on the same page…it is a barrier when you go to a yoga class and you feel like you stand out." (Participant 19).

More appropriate exercise programs that are survivor specific and include exercise with similar others was described as a need in rural settings:

"I would love to have a place where…I could do exercises with other people who have had

cancer so that we can support each other and have a network." (Participant 19).

Overall, exercise participation of survivors living in rural areas is contingent on accessibility and appropriateness of programming and is based on region-specific attributes.

Survivors Living in Areas of Low Socio-Economic Status:

A majority of participants living in areas of low SES described accessibility, related to cost, as barriers to exercise participation:

"…financially having to go through everything that I went through and having to spend so much money on treatment, there was no way that I was in a financial position to join any kind of gym." (Participant 3).

Compared to the other two profile groups, many participants in this group described social support as a barrier to exercise and expressed a lack of support from their oncologists as an exercise barrier: *"I didn't really have a resource like an oncologist…to help me with that [exercise]. I think in that sense, I sort of fell through the cracks."* (Participant 3).

One suggestion to overcome accessibility issues related to cost and to facilitate exercise was to provide survivors with free access to community programming during and after treatment. Additionally, participants described needing access to a health care professional trained in cancer to help manage the side effects of treatment: *"I need the help of a physio...to control the lymphedema more effectively. They kind of put that on you to find someone to do it…you're not sure where to go."* (Participant 4). Overall, considerations regarding accessibility of programs and social support are needed to improve exercise participation of survivors living in areas of low SES.

Cross Case Analysis:

When looking across profile groups, three main themes emerged related to exercise barriers. Firstly, the majority of participants in this study described personal factors (related to physical side effects) as a barrier to exercise participation:

"There were honestly days that I could not even go up my own stairs … I would legitimately be in tears… the pain…then the nauseous feeling, being very tired and not being able to get out of bed, and then just the sores." (Participant 10, Young Adult (YA)).

Outside of these personal factors, exercise information was the most common barrier reported by all participants: *"…it would have been nice to have some information at the hospital…explaining that you should be doing certain exercises…nobody talked about that at all"* (Participant 20, Rural or Remote (RR)).

Overall, a commonly reported facilitator across groups included the provision of exercise-related information by the health care team: *"my oncologist told me about Wellspring. They had an exercise program which I enrolled in and did each week."* (Participant 3, Low SES). Building on this, improved accessibility to a health care professional was also commonly described as a facilitator to exercise participation: *"having the plan from the kinesiologist, as soon as she did the assessment and put that piece of paper in my hands…I felt a lot of relief and motivation."* (Participant 12, YA). Social support was also repeatedly stated as a facilitator to exercise across groups: *"going to classes where there were other young survivors really normalized the experience for me. That was hugely helpful."* (Participant 1, YA).

The most commonly reported exercise-related need across profile groups was improved accessibility: *"if you had a magic wand, I would want all…communities to have a community house with facilities, like an indoor pool…There is so much advantage I think for people's mental health"* (Participant 15, RR). Improved exercise information, via online resources, was also a commonly described need:

"If there was something…online…an app where someone preloaded exercises for me to do…something simple with videos, all you need is this resistance band and go through these

motions and it is sort of a guided. And then there is someone who would check in online once a week…to see how you are doing, how you are feeling. I would have used that 100%." (Participant 15, RR).

DISCUSSION

To our knowledge this is the first study to examine exercise-related barriers, facilitators, and needs for hard to reach cancer survivors. Five themes were identified that impact exercise participation (accessibility of exercise programs, appropriateness of exercise programs, social support, personal factors, and exercise information). Similarities and differences came forth during analysis between hard to reach profiles in regard to the concepts explored.

Results of this project support other reports of barriers, facilitators and exercise-related needs for general populations of cancer survivors. This includes the predominance of physical side effects as a barrier to exercise, a lack of exercise information available for survivors, and a lack of accessible programs for survivors due to location and cost. [13,17,23] Additionally, research examining barriers to exercise for hard to reach populations who do not have cancer found economic challenges (related to programming and transportation), environmental challenges (related to location of available programs), and social challenges as common barriers to exercise. [24] Common to this study, findings related to exercise facilitators and needs for general populations of cancer survivors consistently describe need for exercise specialists and more in-depth exercise information. [13,23] This study built on these findings by highlighting the need for online exercise-related resources for hard to reach cancer survivors. Together the barriers, facilitators and exercise-related needs described in these projects relate to common components of behavioural change theories, including the importance of self-efficacy, social support, and exercise-related knowledge for successful behaviour change.

Looking specifically at the young adult population, Wu et al. [25] examined the barriers and facilitators to healthy diet and exercise among adolescent and young adults with cancer. A lack of resources, negative thoughts and emotions, and negative social and environmental influences were identified as barriers to exercise. [25] The results of this project support and build on these findings, with additional barriers regarding a lack of age-appropriate and intensity-appropriate programming for young adults with cancer. Previous facilitators to exercise for young adults with cancer include cognitive motivators, tools for health behaviour implementation, and social relationships. [25] Together these results highlight the importance of social support to facilitate behaviour change. Behavioural change theories suggest that effective social support to facilitate change includes positive reinforcement about the desired behaviour from important others (family, friends, health care team) [26] and observing others in similar situations performing the desired behaviour. [27] Devising exercise interventions that are survivor-specific, age-specific, and tailored to the exercise needs of young adults will be vital to facilitating exercise behaviour in this population.

Individuals living in rural and remote communities take part in physical activity less frequently than their urban counterparts. [28.29] Approximately 24.1% of those living in rural communities are inactive; this is 50% higher than those living in urban communities. [30,31] Barriers to exercise for general populations living in rural and remote communities include social isolation and cultural differences, lack of transportation, lack of access to physical activity programming, and cost of programming. [32-34] These barriers are consistent with the present study in that a lack of available exercise programming and a lack of cancer specific programming were reported. Social support and availability of physical activity related amenities (e.g., trails, gyms) have shown to facilitate exercise in general populations living in rural and remote communities. [34] This study echoed the facilitator of social support, specifically participants' desire to exercise with other cancer survivors and highlighted the need for online/virtual exercise education to inform

survivors living in rural and remote areas. The importance of accurate, in-depth information is known to be critical in facilitating behavioural change. [26,27,35] However, it is also known that there is variability across rural populations in regard to barriers and facilitators to exercise based on community size, resources and infrastructure available, and poverty rates.[34] Therefore, community-specific factors must be taken into consideration when devising cancer specific exercise programs in different rural and remote communities. A one-size fits all intervention is unlikely to be effective across communities.

Physical activity levels are also consistently lower in low-income groups compared to high-income groups. [36] Barriers and facilitators to exercise for individuals of low SES who do not have cancer include cost (of programming and childcare), a lack of time, and low awareness of the benefits of exercise. [37] In the present study, participants living in areas of low SES also highlighted cost as the main barrier to exercise (cost of attendance, transportation, and parking). The literature demonstrates social support (e.g. a friend to exercise with or encouragement to exercise by family and friends) as a primary facilitator to exercise among individuals of low SES. [37] This finding contrasts our results where access to exercise related resources was the most commonly reported need and facilitator. Together, these findings highlight the importance of self-efficacy in facilitating behavioural change. Self-efficacy is an individual's confidence in their ability to successfully perform a behaviour; without access to services (due to cost) and support, self-efficacy is likely to be low. [26,27,35] Future interventions should work to include strategies to increase cancer survivor's self-efficacy for exercise, especially for individuals living in areas of low SES.

Recent research demonstrates that community programs are not meeting the needs of general cancer survivors to facilitate exercise behaviour change. [23] This study highlights the need for future programs to use interventions that are individualized, include a social component, have online options, and are survivor specific to meet the needs of hard to reach survivors. Exercise interventions for cancer survivors should work to enhance the competence of participants and promote autonomy to facilitate long-term behaviour change.

Limitations:

Results of this project should be considered with an understanding of its limitations. Firstly, all of our participants self-identified as female, and the large majority had a previous diagnosis of breast cancer. This may have occurred given two of our four recruitment organizations were specifically for females with cancer. Therefore, future research is needed to uncover whether similar barriers and facilitators are reported among hard to reach male cancer survivors. Additionally, in accordance with other literature examining recruitment methods for hard to reach populations, [38] it is difficult to determine if we were successful in reaching the hard to reach. We followed recommendations for recruitment in the literature, however, future work should continue to examine the most effective ways to recruit hard to reach populations in clinical research.

Conclusion:

The aim of this project was to describe exercise-related barriers, facilitators, and needs for hard to reach cancer survivors. Five main themes were identified that impact exercise participation across hard to reach profiles. Clinicians and researchers can use this information to design meaningful exercise interventions to meet the needs for this group of cancer survivors.

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