THESIS

SOCIAL ECOLOGICAL DETERMINANTS OF PHYSICAL ACTIVITY AMONG ADULT SURVIVORS OF CHILDHOOD CANCER

Submitted by

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ABSTRACT

SOCIAL ECOLOGICAL DETERMINANTS OF PHYSICAL ACTIVITY AMONG ADULT SURVIVORS OF CHILDHOOD CANCER

Purpose: Adult survivors of childhood cancer (ASCCs) are at high risk for cardiovascular disease from chemotherapy and radiation therapy-related cardiotoxicity. Physical activity can reduce this risk, but most ASCCs do not engage in sufficient physical activity. The Ecological Model of Physical Activity (EMPA) is a theoretical framework which suggests multiple factors facilitate or hinder PA. These factors exist at the individual (e.g., motivation, genetics), micro- (e.g., parents, neighborhood parks), meso- (e.g., transportation), exo- (e.g., two microsystems working together), and macro- (e.g., societal values) system levels. The purpose of this study was to identify barriers and facilitators of physical activity among ASCCs using the EMPA framework.

Methods: A concept elicitation survey was distributed to ASCCs (diagnosed with cancer before the age of 18, and currently 18-39 years old) and parent/legal guardians of an ASCC via Qualtrics. The survey consisted of open-ended questions asking about barriers, facilitators and resources for physical activity. Content analysis of open-ended questions categorized responses into levels of the EMPA and identified key themes.

Results: A total of 17 ASCCs, and 8 parents of ASCCs completed the survey. The majority of barriers were considered microsystem factors, and included proximity/access, social support and equipment. This study also identified financial resources as a macrosystem-level barrier to physical activity among ASCC. Seven themes emerged as factors impacting physical activity

among ASCC: proximity/access, social support, equipment, time/schedule, none, finances, and health-related barriers.

Conclusion: This is the first study to examine barriers and facilitators of physical activity among ASCC using the EMPA. Results from this study will provide a comprehensive understanding of physical activity determinants among ASCC to enhance future quantitative survey development.

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Wine. For obvious reasons.

DEDICATION

To Dylan Jeffrey Davis

Born premature

Survivor of liver cancer

On the autism spectrum

Best bud

Hero

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1. INTRODUCTION

In 2018, an estimated 10,590 children (birth-14 years old) and an additional 5,000 adolescents (15-17 years old) were diagnosed with cancer, and about 1,180 children died from the disease in the United States.[1,2] Fortunately, advances in curative treatment for children diagnosed with cancer have led to increased survival rates from 75-80% surviving 5 and 10 years post therapy.[3] In 2018, there were 420,000 survivors of childhood cancer in the United States, representing about 1 in 750 young adults. This number is expected to increase to over 500,000 by the year 2020 and although treatments such as chemotherapy and radiation therapy have improved survival rates, survivors of childhood cancer are at high risk for long-term negative side effects as a result of their therapies.[4,5] As many as two-thirds of survivors of childhood cancer report at least one chronic condition, and are 5 to 10 times more likely than their healthy siblings to experience cardiovascular disease (i.e., arrhythmias, myocarditis, congestive heart failure, restrictive and dilated cardiomyopathy, and acute myocardial infarctions) primarily due to treatment-induced cardiotoxicity.[6–11] Treatment-related cardiotoxicity is caused by anthracyclines and chest radiation, and is characterized by reduced left ventricular wall thickness and mass, which is indicative of decreased heart muscle and lowered left ventricular contractility, signifying unhealthy heart muscle.[12,13]

Fortunately, physical activity is a lifestyle factor that may reduce cardiovascular disease risk among adult survivors of childhood cancer (ASCCs) and presents a potential target that can be addressed through interventions.[6] Physical activity is associated with better health-related quality of life (HRQOL) outcomes across physical, social, and cognitive functioning domains in ASCCs,[14] and it has been suggested that adequate levels of physical activity may prevent or attenuate many of the long-term health problems that ASCCs experience, including

cardiovascular disease.[15] Based on the evidence linking physical activity to improved health, and reduced risk of cardiovascular disease among ASCCs, the U.S. Physical Activity Guidelines and the American Cancer Society recommend ASCCs engage in regular physical activity (150 minutes per week of moderate physical activity or 75 minutes per week of vigorous physical activity or some combination thereof.)[2] However, ASCCs report being less physically active, and are less likely to meet recommended physical activity guidelines compared to their healthy siblings,[16] and the general population.[17–19] Cancer survivors face a range of barriers when initiating and maintaining physical activity, some of which are experienced by the general population, but also some barriers specific to their cancer journey.[20] Previous studies have suggested that ASCCs face barriers to physical activity related to physical limitations incurred by cancer-related surgery, or treatment-related cardiotoxicity.[18,21] Thus, to increase physical activity among ASCCs, a more specific, and comprehensive understanding of barriers and facilitators to physical activity is needed.

A theoretical framework that accounts for factors at multiple levels may be most useful for identifying barriers and facilitators to physical activity among ASCCs.[22,23] Social ecologic models which integrate individual (e.g., demographic, medical, psychological), sociocultural, and environmental determinants of PA can be used to identify the numerous barriers and facilitators to physical activity that may exist among ASCCs.[24,25] However, to date, research examining barriers and facilitators to physical activity among ASCCs has primarily focused on individual determinants.[16,18,26] Among child and adolescent cancer survivors, Gilliam and Schwebel (2013) used Bronfenbrenner's ecologic framework for human development to summarize determinants of physical activity, and found that the leading barrier to physical activity was "lack of access to resources."[3] Lack of access to resources is considered an

environmental, or "macrosystem" factor, which may not have been identified if the theoretical framework used was limited to only individual factors.[27]

A social ecologic framework was well-aligned to identify barriers and facilitators among child and adolescent cancer survivors, but how these findings extend into ASCCs is unclear. Given the developmental disruption caused by a childhood cancer diagnosis, and cancer patients' increased reliance on family support during therapy, family relations may differ in child and adolescent cancer survivors compared to ASCCs.[3] Further, the application of an ecologic model developed specifically to understand physical activity may extend and improve Gilliam and Schwebel's (2013) findings.[16,18] Spence and Lee (2003) developed the Ecologic Model of Physical Activity (EMPA) (Figure 1) as a comprehensive model for understanding physical activity.[22] The EMPA posits that in addition to individual factors (e.g. self-efficacy, beliefs, and attitudes), it is necessary to address factors encompassed by the microsystem (e.g. neighborhood, school, verbal encouragement from family, peers, or clinicians), mesosystem (e.g. transportation between home and recreation center), exosystem (e.g. two microsystems working together outside of the individual), and macrosystem (e.g. social class, socioeconomic status).[22] For example, an ASCC may have cognitive deficits from cancer treatment that inhibits their ability to drive a car. The cognitive deficit is an individual-level factor that inhibits their ability to get to a nearby recreation center in their neighborhood. Therefore, they must rely on someone (parents or friends) to drive them from home to the recreation center, and vice versa. The parents, friends, home and gym encompass the microsystem, where they live, work, and play. Transportation to and from the recreation center is an example of the mesosystem, a dynamic linkage between micro-environments. During cancer treatments, clinicians discuss treatment plans with the parent, without the patient present. This is an example of how two micro-environments can work

together to encourage physical activity without including the individual. The sociocultural context of where the individual lives, the macrosystem, includes things like cultural attitudes and beliefs toward physical activity. Finally, each of the levels of the EMPA interact dynamically to influence physical activity for the individual. To date, the EMPA has not been applied to ASCCs. Thus, the first aim of this study was to categorize the responses for barriers, facilitators and resources into the levels of the EMPA. The second aim was to identify themes that emerged in the open-ended survey responses of the qualitative concept elicitation survey delivered to ASCCs.

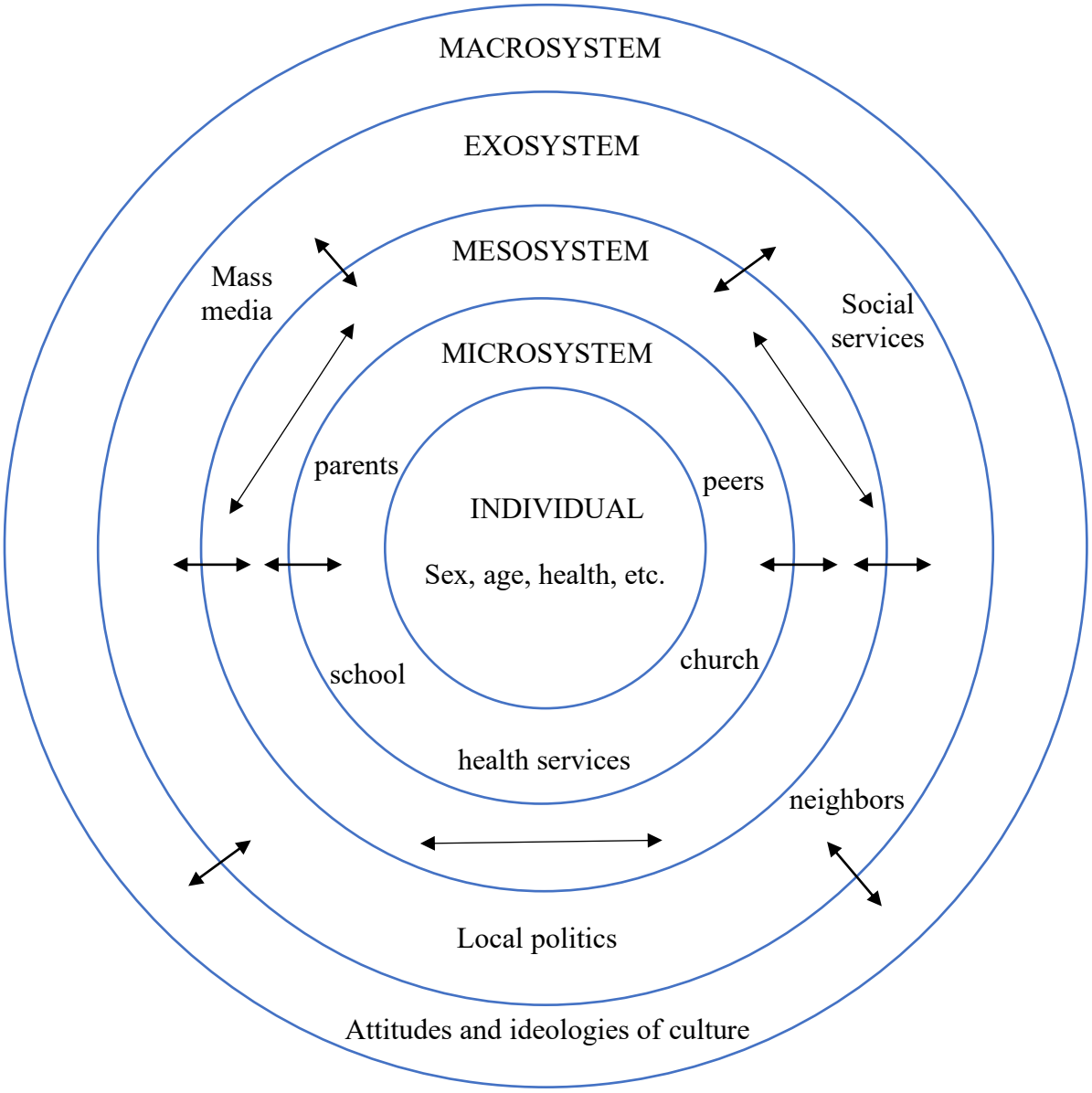

Figure 1: Spence and Lee's (2003) Ecological Model of Physical Activity (EMPA)

2. METHODS

A qualitative concept elicitation survey was developed and administered to ASCCs, and parents of ASCCs to gather information about barriers and facilitators of physical activity. Following approval from Colorado State University's institutional review board for the protection of human subjects (IRB #18-8349H), the survey was distributed via Qualtrics, a secure, web-based survey platform (Qualtrics, Provo, UT). Upon clicking the survey link, potential participants were taken to an informed consent page. After providing full informed consent, participants then gained access to the survey. Results were aggregated and summarized for analysis.

Participants

ASCCs and parents or legal guardians of an ASCC were eligible for the study. ASCCs were defined as individuals being (a) diagnosed with cancer before the age of 18, and (b) between the ages of 18-39 years at the time of the survey.[28] The National Institute of Health (NIH) defines young adults as 18-39 years old.[28] Due to physiological responses and tolerance to chemotherapy, patients under 39 are able to respond best for pediatric regimens compared to adult regimens.[28] Additional eligibility criteria included: able to read and write in English, completed active cancer therapy (e.g. chemotherapy, radiation) any time prior to the completion of the survey, and did not have an impairment that would hinder ambulation, such as using a wheelchair or crutches. Parents/legal guardians could participate independently, even if their child did not, as long as their child met the inclusion criteria. Parents of ASCCs completed the survey about their child, in addition to answering questions about their own physical activity.

Recruitment took place from January to March of 2019. Participants were recruited by purposive sampling,[29] via flyers posted in local clinics, email distribution to local summer camps

for children facing cancer, and on social media platforms that target ASCCs (e.g., Stupid Cancer).

Survey

Survey questions were developed with input from cancer researchers and practitioners. Prior to distribution, the survey was pilot tested with one ASCC and one parent of an ASCC to ensure the questions were clear, and elicited responses appropriate for questions being asked. The survey collected demographic information including age, gender, zip code, and cancer diagnosis information, as well as self-reported physical activity using the Godin Leisure-Time exercise questionnaire, which asks about leisure time exercise habits.[30] Participants were classified as "active" if their Leisure Score Index (LSI) score was ≥ 14 or "insufficiently active" if their LSI was < 14.[31]

Barriers, facilitators, and resources for physical activity were explored by using the following three questions: (1) "Over the last year or so, what factors have made it hard for you/your child to be physically active on a regular basis?" (2) "Over the last year or so, what factors have made it easy for you/your child to be physically active on a regular basis?" (3) "Which resources would you/your child need to participate in physical activity on a regular basis? (Resources include things like type of activities available, people in your life, access to places to be active, financial resources, etc.)"

Data Analysis

Descriptive statistics were calculated for demographic characteristics and self-reported physical activity. Means, standard deviation, range, or frequencies (*n*, %) were computed as appropriate, using SPSS statistical software (IBM SPSS, version 25).

Data were primarily analyzed using content analysis of open-ended responses to the three questions related to barriers, facilitators, and resources for physical activity (described above).

To ensure reliability, two researchers (KD, AC) independently organized responses to align with each level of the EMPA (individual, micro-, meso-, exo-, and macrosystem).[32,33] This was an iterative process as the coders identified, grouped into themes, and conceptualized patterns within and across the dataset which are salient to the participants.[34,35] For example, factors in the microsystem were further divided into themes of "school/work," "proximity/access," "people," and "equipment." For items on which there was disagreement, coders met to discuss final disposition of coding by item.[35] All coding discrepancies were recorded in analytic memos.[35] In cases where an agreement could not be reached, less-involved authors (HL,CC) reviewed and arbitrated.[34] Responses were coded until data saturation was reached. Saturation was determined when new data became redundant of data already collected.[36] Frequencies were computed and tabulated yielding a total number of responses for each level of the EMPA to identify the most commonly reported barriers and facilitators of physical activity for ASCC.[37] Responses were first categorized under the appropriate level of the EMPA. Next, responses were grouped into categories and themes were created based on the number of responses in each category. A natural break in the categories then emerged, with seven themes each having greater than ten responses, and subsequent categories having four or fewer responses.

3. RESULTS

A total of 17 ASCCs (*n*=13 women) and 8 parents (*n*=4 women) of an ASCC completed the survey. All ASCCs received chemotherapy, and a majority (59%) received ≥1 therapy modality such as: surgery (41%), radiation (18%), immunotherapy (18%), bone marrow transplant (12%), and/or stem cell transplant (6%). All therapies were concluded prior to survey completion. ASCCs' age at the time of survey completion was 19-39 years (μ= 26.59 ±6.60), and their age of diagnosis ranged from 10 months to 17 years (μ= 8.49 ±4.94 yrs). The average time since therapy completion was μ= 14.35 ±9.18 (1-33) years. Physical activity levels among ASCCs were evenly split between active (*n*=8, 47%) and insufficiently active (*n*=7, 53%). The remaining two did not answer the question. Most parents of ASCCs (*n*=7, 88%) were physically active. Additional characteristics of study participants are presented in Table 1.

ASCC Barriers, Facilitators and Resources for Physical Activity

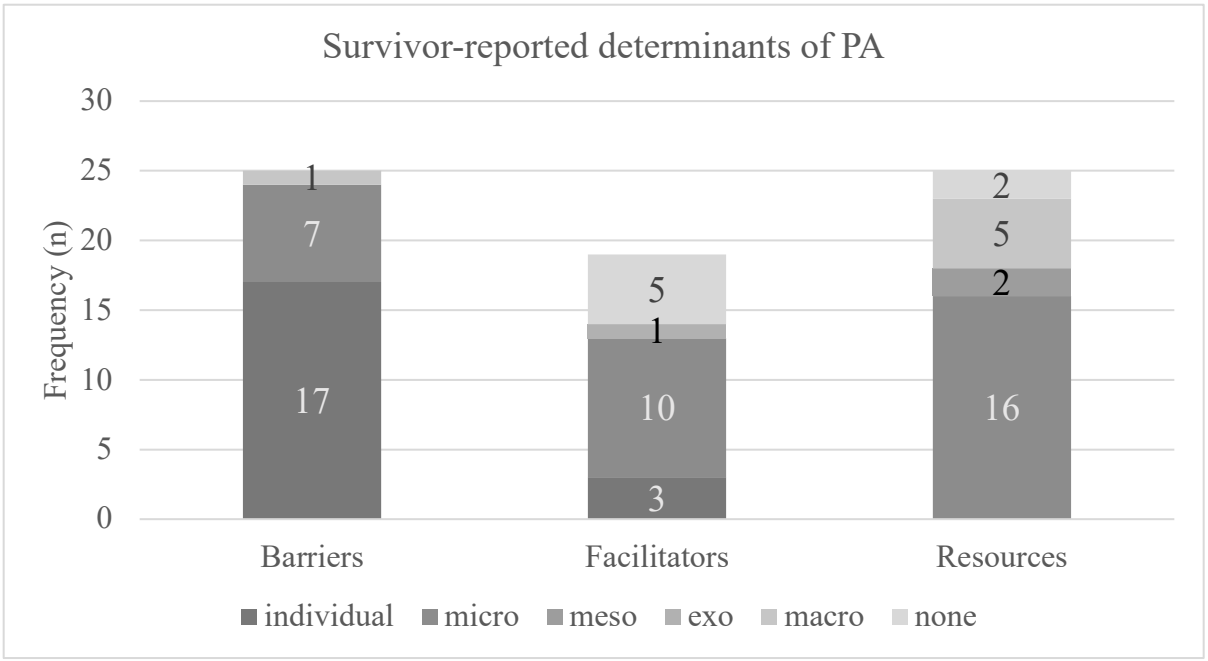

Figure 2: ASCC barriers, facilitators and resources organized by the EMPA

Twenty-five barriers to physical activity were reported by ASCCs. Most barriers (*n*=17, 68%) were categorized as individual-level factors, and were most commonly health-related (*n*=9). Other barriers (*n*=7, 28%) were categorized as microsystem factors, and were most commonly school or work (*n*=4). There were no barriers categorized as meso or exosystem factors, and only *n*=1 (4%) categorized as a macrosystem factor, which was finances. Examples of barriers to physical activity reported by ASCCs are shown in Table 3.

Nineteen facilitators to physical activity were reported by ASCCs. Most facilitators (*n*=10, 53%) were categorized as microsystem factors, which were most commonly social support (*n*=6) and proximity/access (*n*=3). Other facilitators were categorized as individual (*n*=3, 16%) and exosystem (*n*=1, 5%). In addition, several responses (*n*=5, 26%) were "none" or "nothing", which could not be categorized into a level of the EMPA. Examples of facilitators to physical activity reported by ASCCs are shown in Table 3.

Twenty-five resources for physical activity were reported by ASCCs. Most resources (*n*=16, 64%) were categorized as microsystem factors, and included proximity/access (*n*=6), and equipment (*n*=4). Examples of resources for physical activity reported by ASCCs are shown in Table 3.

Parents of ASCC Barriers, Facilitators and Resources for Physical Activity

For the three survey questions analyzed, there were *(n*=49*)* total responses from parents of an ASCC. Figure 3 summarizes the corresponding EMPA level in which parent-reported barriers, facilitators, and resources for physical activity were categorized.

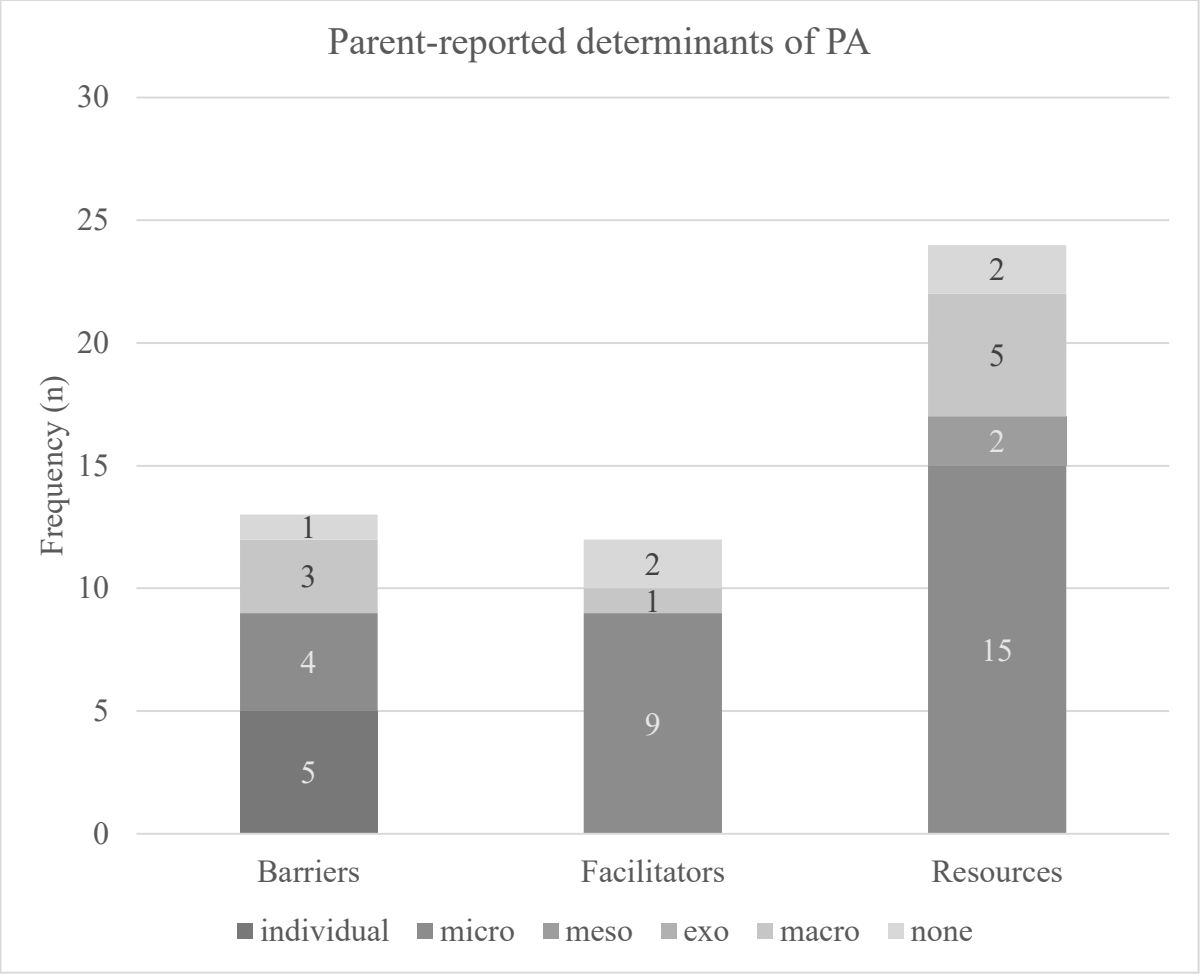

Figure 3: Parents of ASCC barriers, facilitators and resources organized by the EMPA

Thirteen barriers to physical activity (for their child) were reported by parents. Most commonly cited barriers (*n*=5, 39%) were categorized as individual-level factors, and were most commonly time/schedule (3 of 5). Examples of barriers for physical activity reported by parents of an ASCC are shown in Table 3.

Twelve facilitators of physical activity (for their child) were reported by parents. Most facilitators (*n*=9, 75%) were categorized as microsystem factors, and included social support (3 of 9). Examples of facilitators for physical activity reported by parents of an ASCC are shown in Table 3.

Twenty-four resources for physical activity (for their child) were reported by parents. Most resources (*n*=15, 63%) were categorized as microsystem factors, and included proximity/access and equipment. Examples of resources for physical activity reported by parents of an ASCC are shown in Table 3.

Themes

Seven themes emerged from survey responses from both ASCCs and parents. Of these, three themes were considered microsystem-level factors, two were individual-level, one was macrosystem-level, and one could not be categorized into the EMPA.

Theme 1: Proximity/access

Proximity/access was identified as the most common theme; as a barrier (*n*=3), facilitator (*n*=6), and resource (*n*=11) for physical activity. Examples of proximity/access as a barrier to physical activity were: *"physical proximity to area of exercise"* [ASCC] and *"limited ice time at the hockey arena [sic]"* [ASCC]. Examples of proximity/access as facilitators to physical activity were: "*proximity to classes,"* [ASCC] *"proximity to parks, gyms, etc., [sic]"* [ASCC] and *"quick access to trails [sic]"* [parent]. Examples of proximity/access as a resource for physical activity were: "*accessible activities,"* [ASCC] *"hiking trails"* [parent] and *"location relatively close to where I live"* [ASCC]. Responses in this theme were evenly reported among survivors (*n*= 10) and parents (*n*=10). Proximity/access was categorized as a microsystem factor. The microsystem is where people live, work, and play.

Theme 2: Social Support

Social support was the second most common theme, as a facilitator (*n*=9) and resource (*n*=9) for physical activity. Social support was not reported as a barrier to physical activity by any participants. Examples of social support as a facilitator for physical activity included: *"my*

supportive family," [ASCC] and *"mom or dad taking her places"* [parent]. Examples of social support as a resource for physical activity were: *"a doctor to solve my breathing issue"* [ASCC] and *"people to help with adaptive equipment"* [parent]. Social support was categorized as a microsystem factor for physical activity. The microsystem is where people live, work, and play, including people with whom they interact.

Theme 3: Equipment

Equipment was the third most common theme as a facilitator (*n*=4) and resource (*n*=11) for physical activity. Examples of equipment as a facilitator for physical activity were: "*adaptive equipment"* [ASCC] and *"having the gear to participate in the activities he wants to be involved in*" [parent]. Examples of equipment as a resource for physical activity were: "*I find it easier to work out when I'm in a class or have a video one to follow along with"* [ASCC] and "*online videos,"* [parent] and *"backpacking gear"* [parent]. Equipment was categorized as a microsystem factor for physical activity. The microsystem is where people live, work, and play.

Theme 4: Time/schedule

Finding time, or a busy schedule, was the fourth most common theme, as a barrier (n=12) and facilitator (n=2) for physical activity. Examples of time/schedule as barriers to physical activity were: *"I started graduate school"* [ASCC] and "*busy schedules"* [parent]. One example of time/schedule as a facilitator for physical activity was: "*I have more time in my schedule without worrying about homework deadlines*" [ASCC]. In some cases, time/schedule was categorized as a microsystem-level determinant such as "*being preoccupied with work*" [ASCC] and in others *"my class schedule is super busy"* [ASCC] was categorized as an individual-level factor for physical activity.

Theme 5: None

Interestingly, the fifth most common response was "none", "nothing" or "N/A" as a barrier (n=1), facilitator (n=7), and resource (n=4) for physical activity. None could not be categorized into a level of the EMPA.

Theme 6: Finances

Finances was the sixth most common theme as a barrier (n=3) and resource (n=9) for physical activity. Examples of finances as a barrier to physical activity were: "*financial hardships"* [parent] and "*limited financial resources"* [parent]. Examples of finances as a resource for physical activity were: "*finances to afford gym costs,*" [ASCC] and "*money*" [parent]. Finances were categorized as a macrosystem-level factor for physical activity. The macrosystem is where socioeconomic status, cultural attitudes and beliefs influence the individual.

Theme 7: Health-related barriers

The final theme was health-related barriers to physical activity (n=11). Examples of health-related barriers were: *"an exercise-related breathing issue"* [ASCC], *"fatigue and pain"* [ASCC], *"sickness and surgeries"* [ASCC], and *"he is blind"* [parent]. Health-related barriers were categorized as individual factors for physical activity.

4. DISCUSSION

Using a concept elicitation survey, this study examined barriers, facilitators, and resources for physical activity reported by ASCCs, and parents of an ASCC. Content analysis of open-ended questions categorized responses into levels of the EMPA and identified key themes. The implications of these findings for research and practice are described below.

Proximity/access was the most prominent theme that emerged from survey responses, for both barriers and facilitators to physical activity. Proximity/access was considered a microsystem -level factor of the EMPA. In terms of microsystem, access may require opportunities for physical activity that are close to home or work (i.e., proximity). Research with healthy children and adolescents indicates that access to resources significantly predicts physical activity, such that those enrolled in community programs, or have access to physical activity facilities show higher physical activity levels.[38,39] Our findings support that access may be an important determinant of physical activity for ASCCs.

Social support emerged as another common theme, only as a facilitator and resource for physical activity, and was also considered a microsystem factor. Lack of social support was not mentioned as a barrier for physical activity. Examples such as "*accountability from working out with a friend and motivation from other friends*." [ASCC], and "*my supportive family*" [ASCC] suggest that having support from friends and family is important for encouraging physical activity among ASCCs. This is consistent with previous literature which suggests that social support is necessary for long-term physical activity in adult cancer survivors.[40] Family and peer support have been shown to be predictors of physical activity among children, adolescents, and adults,[41–45] and findings from this study suggest that the importance of these sources of social

support for physical activity may also extend into adulthood for ASCCs. Grimmett et al (2019) found 'unspecified' social support was an important facet of physical activity behavior change interventions for cancer survivors. [46] The qualitative data collected in this current study adds to this finding by specifying who in particular (family and/or friends) are important sources of social support for physical activity among ASCCs.

In addition to these two themes, the majority of facilitators, barriers, and resources identified by ASCCs and parents of an ASCC were also microsystem factors, further emphasizing the importance of factors that exist in the immediate setting where individuals live, work and play.[3,27] [22]

In addition to microsystem factors, individual factors also emerged as important barriers, facilitators and resources for physical activity among ASCCs. Time/schedule limitations was a notable individual barrier for physical activity, consistent with literature in childhood cancer, other cancer populations, and healthy populations.[47–49] Participants also reported health-related barriers to physical activity, which was consistent with previous literature among ASCC.[16]. More specifically, of the health-related barriers mentioned, (*n*=9, 100%) were cancer-related. For example, the ASCC who reported "*sickness and surgeries"* [ASCC] also shared in their cancer diagnosis information that "*I get sick easily and it is hard to fight off.*" Immune compromise is a side effect of chemotherapy, radiation, and surgery, and is a barrier unique to understanding PA among ASCCs.[50]

As well as microsystem and individual factors, ASCCs and parents of an ASCC often reported 'finances' as a barrier to physical activity. Finances were categorized as a macrosystem level factor of the EMPA, which encompasses social class and socioeconomic status. To our knowledge, this is the first study to identify finances as an important barrier to physical activity

for ASCCs. Previous studies among ASCCs have predominantly focused on individual and health-related factors, but findings from the current study suggest that more research is needed to fully understand the extent to which finances influence physical activity among ASCCs. Many of the responses related to finances were vague (e.g., "*money*"). For example, based on the responses given we were unable to disentangle whether finances were a barrier to physical activity because ASCCs are unaware of free resources such as walking outside, or if ASCCs assume that physical activity requires an expensive gym membership, or equipment based on social/cultural norms? Interviews and/or focus groups with ASCCs are needed to understand financial barriers to physical activity.

Finally, an interesting finding of this study was the number of responses of "*none, nothing, or n/a*.", when asked "*what factors have made it easy for you/your child to be physically active on a regular basis*". These responses (*n*=8) were evenly split between active and insufficiently active, and between ASCCs and parents of an ASCC. ASCCs may be unaware or unsure of what is helping them engage in physical activity, or that participants were already physically active and thus, nothing could 'make it easier'. Further, parents may have been unsure of how to respond to this question for their adult child. Without further exploration of these responses (e.g., focus group, semi-structured interview) it is not clear why participants reported that 'nothing' could help them be more physically active.

Strengths and limitations of this study

Strengths of this study were the application of a social ecological framework and reaching saturation in the qualitative data collection. Utilizing the EMPA to organize the data helped identify themes that may not have emerged had we utilized theoretical models primarily focused on individual determinants of physical activity (e.g., attitudes,[51] perceived behavioral

control,[51] self-efficacy, [52] etc.) Reaching saturation ensured that we have a comprehensive depiction of barriers, facilitators, and resources for physical activity, from the perspectives of both ASCCs and parents of an ASCC.

With any research study, there are inherent limitations. First, most ASCCs (77%) and parents of an ASCC (88%) were currently active, indicating possible selection bias. However, due to the nature of these questions, we were able to gather valuable information about facilitators and resources for those classified as active. Additionally, using an online survey platform allowed for reaching a diverse sample but did not allow for additional follow-up, or probing. The wording of the survey questions, while carefully written, could have presumed that being physically active was already easy, hence, they wrote "none, nothing or N/A" for what factors have made it easy to be physically active because they did not perceive their physical activity to be easy in the first place. Finally, while including parents helped capture the extra-individual factors for ASCCs, parents and survivors were not dyads, thus, we were unable to determine if a survivor and parent would provide similar answers.

Future directions

To build on these findings, future studies should utilize semi-structured interviews and/or focus groups to increase the richness of the qualitative data. Questions would ask about cancer-related health barriers ASCCs experience, and how they impact their physical activity habits and how financial resources may facilitate physical activity with follow up questions to probe further if they answer "nothing" or "I don't know." Future studies should find ways to recruit more people that are inactive to a survey on physical activity. Electronic health records such as EPIC or OnCore could be utilized for capturing cancer diagnosis or other medical information. Findings from this study may be used in quantitative survey development to examine

associations between barriers/facilitators and physical activity. For example, a Likert scale question could ask, “On a scale of 1 to 7, please rank the importance of the following factors in helping you engage in physical activity.” Based on our findings, cancer-related barriers and finances should be listed as some of those factors.

5. CONCLUSION

In conclusion, this study categorized barriers, facilitators and resources for physical activity into levels of the EMPA. The majority of barriers were considered microsystem factors, and included proximity/access, social support and equipment. The present study also identified financial resources as an important macrosystem-level resource for physical activity among ASCCs. Finally, cancer-related barriers emerged as barriers to physical activity, such as fatigue and pain. ASCCs are at greater risk for future health problems compared to the general population, therefore it is critical to further our understanding of successful ways to promote physical activity. Increasing physical activity among ASCC can have significant, positive implications on the health of childhood cancer survivors to thrive into adulthood.

TABLE 1: Demographics	**ASCC Demographics (*n*=17)**	**Parents of ASCC Demographics (*n*=8)[a]**
Mean ±SD (range)		
Age at study	26.59 ±6.60 (19-39)	20.75 ±4.18 (18-31)
Age of ASCC at diagnosis	8.49 ±4.94 (0.83-17)	3.125 ±3.05 (0.17-10)
Time off therapy	14.35 ±9.18 (1-33)	15.75 ±7.76 (4-31)
<5 yrs	3 (18)	1 (12.5)
5-10 yrs	5 (29)	1 (12.5)
11-20 yrs	5 (29)	5 (62.5)
>20 yrs	4 (24)	1 (12.5)
Frequency n (%)		
Gender		
Female	13 (76)	4 (50)
Male	4 (24)	4 (50)
Cancer Type		
Leukemia	9 (53)	3 (38)
Lymphoma	3 (18)	1 (13)
Brain/CNS	3 (18)	3 (38)
Sarcoma	2 (12)	1 (13)
Metastasis	3 (17)	3 (38)
Relapse	5 (28)	1 (13)
Cancer Therapy[b]		
Surgery	7 (41)	4 (50)
Chemotherapy	17 (100)	8 (100)
Radiation	3 (18)	3 (38)
Immunotherapy	3 (18)	2 (25)
Bone Marrow Transplant	2 (12)	2 (25)
Stem Cell Transplant	1 (6)	1 (13)
Physical Activity	8 (47) insufficiently active 9 (53) active	
Parent physical activity		1 (13) insufficiently active 7 (88) active
Parent relationship to survivor		7 (87) Mother/stepmother 1 (13) Father/stepfather

[a] all are survivor data unless otherwise listed

[b] total over 100% because n=14 received >1 therapy

[c] none of the relapses were due to metastasis

Table 2: BARRIERS	**Survivor-reported barriers**	**Parent-reported barriers**
Individual (n=24)	Health related (9) *"An exercise-related breathing issue"* *"Fatigue and pain"* *"Sickness and surgeries"* Time/Schedule (3) *"My class schedule is super busy"* Motivation (3) *"There are days where I don't have/want to allow the time to get up and move."* Life changes (1) *"Having a baby"*	Health related (2) *"he is blind"* Time/Schedule (3) *"Busy schedules"*
Microsystem (n= 11)	School/Work (4) *"I am mainly sitting and working at my job all day"* *"I started graduate school"* Proximity/access (1) *"Physical proximity to area of exercise"* Moving (2) *"I moved states"*	School/work (2) *"He's still in high school"* Proximity/access (2) *"Limited ice time"*
Mesosystem		
Exosystem		
Macrosystem (n=4)	Finances (1) *"$"*	Finances (2) *"Financial hardships"* *"Limited financial resources"* Weather (1) *"Weeks with crummy weather"*
None (n=1)		*"None"*

Table 3: FACILITATORS	**Survivor-reported facilitators**	**Parent-reported facilitators**
Individual (n=3)	Time/Schedule (2) *"I have more time in my schedule without worrying about homework deadlines."* Motivation (1) *"Self motivation"*	
Microsystem (n=19)	People (6) *"Friends that like to be active"* *"My supportive family"* *"Accountability from working out with a friend and motivation from other friends."* Proximity/access (3) *"Proximity to classes"* *"Regionality to parks, gyms, etc."* Equipment (1) *"Adaptive equipment"*	People (3) *"Mom or dad taking her places"* *"Roommate who likes to be active"* Proximity/access (3) *"Access to quick trails"* *"Belongs to Colorado Sled Hockey"* *"Dance classes at school"* Equipment (3) *"Online videos"* *"Having the gear to participate in the activities he wants to be involved in"* *"He owns his own equipment"*
Mesosystem		
Exosystem (n=1)	Places and policy (1) *"Taking dance classes that I am required to attend and that are built into my school day"*	
Macrosystem (n=1)		Weather (1) "*Nice weather"*
None (n=7)	*"None"* *"Nothing"* *"n/a"* *"nothing"* *"none"*	*"None"* *"N/A"*

Table 4: RESOURCES	**Survivor-reported resources**	**Parent-reported resources**
Individual		
Microsystem (n=31)	People: 6 *"a doctor to solve my breathing issue" "Friend for motivation" "a friend to go with" "A trainer understanding my current health state" "Personal trainer for accountability"* Proximity/access: 6 *"accessible activities" "access to gym, park, etc." "location relatively close to where I live"* Equipment/activities: 4 *"I find it easier to work out when I'm in a class or have a video one to follow along with" "activities available and scheduled" "equipment"*	People: 3 *"People willing to help with adaptive equipment" "Hiking buddies"* Proximity/access: 5 *"access to more ice time" "proximity" "hiking trails"* Equipment/activities: 7 *"online videos" "Bike" "good shoes" "skis" "backpacking gear"*
Mesosystem (n=4)	Transportation: 2 *"a ride to the facility"*	Transportation: 2 *"Transportation"*
Exosystem		
Macrosystem (n=10)	Finances: 5 *"finances to afford gym costs" "financial resources" "Money"*	Finances: 4 *"financial resources" "Financial" "money"* Built environment: 1 *"mountains"*
None (n=4)	None: 2 *"N/A" "I'm not sure"*	None: 2 *"n/A" "unknown"*

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