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ORIGINAL ARTICLE



Using participatory action research to examine barriers and facilitators to physical activity among rural adolescents with cerebral palsy

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ABSTRACT

Purpose: The purpose of this study was to use a qualitative, community-based participatory action research method – Photovoice – to identify perceived facilitators and barriers to physical activity among adolescents with cerebral palsy (CP) in a rural community.

Materials and methods: Fifteen participants including adolescents with CP ($n=7$) and parents ($n=8$) were included in this study. The researchers followed the nine-step methodology recommended for Photovoice. During the training session, participants completed versions of the Barriers to Physical Activity Questionnaire for People with Mobility Impairments. This questionnaire was used to generate descriptive information about participant barriers and facilitators. Participants were given 14 days to take photographs after which researchers used in-depth and focus group interviews structured by the SHOWeD method. Content analysis of transcripts was used to identify common themes.

Results and conclusions: Photographs and accompanying text were presented to local stakeholders and an action plan to increase physical activity for adolescents with CP was created. Perceived barriers included lack of inclusiveness, family isolation, and limited accessibility of equipment and resources. Facilitators included support services for families and adaptive sport leagues. Photovoice serves as a powerful tool to initiate change to promote physical activity among rural adolescents with CP.

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Cerebral palsy; photovoice; physical activity; participatory; barriers; facilitators

► IMPLICATIONS FOR REHABILITATION

- Adolescents with cerebral palsy living in rural areas face unique barriers to physical activity.
- Accessibility of equipment and the structural environment can serve as barriers to participation.
- Lack of accessibility can lead to feelings of isolation.
- Families need support services outside of rehabilitation settings to support physical activity for their children and overcome potential barriers.

Introduction

Impairments to body structures and functions can limit participation in physical activity, which in turn, negatively affects quality of life [1]. Even in environments built for youth with disabilities, this population participates in little physical activity [2]. Therefore, young people with physical and sensory disabilities experience lower levels of health-related fitness than same-aged peers [3,4]. Cerebral palsy (CP) is the most common movement disability in children [5,6] and prevalence remains stable at an average of 2.11 per 1000 live births [7]. Individuals with CP experience significantly higher mortality rates [8–10], poorer quality of life [11–14], and are less active than their peers [15].

The short and long-term health benefits of physical activity are well known, and because of these benefits, young people with CP should be encouraged to participate in regular physical activity [16]; however, activity programming must take into account potential barriers and modifications needed based on the unique abilities of an individual [17]. Children and adolescents with CP have lower levels of participation in physical activity than typically

developing children [18,19], leaving these individuals with low aerobic and anaerobic capacity and poor health-related fitness [15,20,21].

In the last decade, multiple studies have examined the underlying factors associated with reduced participation in physical activity in youth with CP. Motor capacity (i.e., level of Gross Motor Functional Classification System) has been associated with physical activity; young people with CP who had higher functional levels were consistently more active [22], but even at higher functional levels of the Gross Motor Functional Classification System, most youth with CP do not meet minimum physical activity recommendations [23]. While intervention studies to increase physical activity in children and youth with CP show promise, there is little evidence of effective interventions [24].

An overlooked mediator of physical activity in youth with CP is rurality. In adults, there is evidence that individuals, including young people, in rural environments are less active than urban peers [25–27]. Rural areas possess unique challenges to physical activity, as environmental factors such as county sprawl serve as a barrier to positive health behaviors [28]. In rural areas, young

people with disabilities and their families face disparities in the availability of and access to competent service providers [29,30].

The current evidence suggests caring for a child with CP presents many challenges due to the nature of the disability and these may be exacerbated by living in a rural area [31,32]. Children with CP often have complex neurological and musculo-skeletal impairments and youth with CP face unique barriers to physical activity [33]. Because youth with CP in rural areas have difficulties accessing service providers, some may experience poor cognitive and motor development [34,35]. Compared to urban young people with CP, rural youth are less likely to have adequate insurance and the presence of the condition is more likely to have a negative effect on familial employment [31]. One of the only studies to compare physical activity levels between urban and rural youth with physical disabilities found no difference in an examination of environmental barriers to recreational, community, and school participation [36]. However, socioeconomic status was a significant predictor of barriers, possibly confounding results as families living in rural settings may be of lower socioeconomic status. It is clear that a rural environment may compound the difficulties of children with CP participating in physical activity and activities of daily living [37].

Environmental barriers to participation for children with CP should be identified [38]. Previous studies have effectively used qualitative methods to elucidate personal and environmental barriers and facilitators to physical activity specific to youth with CP by including both children and parents [33,39]. However, there are no studies that have examined barriers to physical activity in youth with CP in rural environments.

One qualitative method to document the consequences of disparities on participation and address actions for change is Photovoice. This type of participatory action research is grounded in Freire’s empowerment theory that posits persons who share their lived experience promote critical analysis and dialog about

social concerns that can lead to action-based change [40]. Photovoice uses photography to collect data to support the overall aim of participatory action research. Photovoice works in the cultural context of participatory action research because the photographs are captured by individuals living the experience and describes their everyday realities [41,42]. The three overarching goals of Photovoice are to: record and present everyday realities using photography; promote critical dialog and knowledge about the personal, community, and/or program strengths and weaknesses; and reach decision makers [43]. Therefore, the purpose of this study was to examine barriers and facilitators to physical activity in rural youth with CP from the perspectives of children and parents and to elicit in-depth responses.

Methods and materials

This study used Photovoice to collect data on the lived experience of adolescents with CP and their parents regarding barriers to participation in physical activity in a rural community. The research questions were:

- 1. What are the perceived limitations to physical activity as identified by adolescents diagnosed with CP?
- 2. What are the perceived facilitators to physical activity as identified by adolescents diagnosed with CP?
- 3. What are the perceived limitations to physical activity among adolescents diagnosed with CP as identified by the parents?
- 4. What are the perceived facilitators to physical activity among adolescents diagnosed with CP as identified by the parents?

Participants

Wang and Burris [44] recommend a nine-step methodology when employing Photovoice. Refer to Table 1 for a list of recommended steps. Step 1 was to recruit participants. Photovoice methodology

Table 1. The recommended nine-step photovoice methodology adapted from Wang and Burris (1997).

Recommended step	CP application
1. Recruit photovoice participants. A sample should include six to ten people. This provides efficiency in collecting data and adequate discussion.	The sample was 15 participants. Parents ($n = 8$) and adolescents diagnosed with CP ($n = 7$) were recruited to participate. For each group this aligned with the recommended sample.
2. Select a target audience of decision makers. The participants select this group based on the target audience’s ability to make decisions that will improve the problems identified through Photovoice activities.	The participants identified key community stakeholders during the training session in-depth interviews and focus group to target. The participants identified state representatives, school administration, University personnel, and local recreation staff as stakeholders.
3. Introduce photovoice to the participants. The researcher must conduct a workshop or training session to introduce Photovoice This session is also used to review ethical considerations with the participants.	The researchers conducted one training session for both parents and adolescents. Make-up training sessions were implemented for participants who could not attend the group session.
4. Obtain informed consent. The researcher must obtain informed consent from each participant.	Informed consent was completed during the training sessions.
5. Brainstorm with participants. A brainstorming activity is highly recommended to familiarize the participants with initial themes for taking photographs	This was completed at the group training session and at each make-up session. Parents and adolescents participated in separate training and brainstorming sessions. It lasted approximately 20–30 minutes.
6. Distribute cameras. Each participant will need a camera to complete the Photovoice activity.	Eight digital cameras were distributed to parents and 7 tablets with cameras were distributed to adolescents at the end of the training session.
7. Provide time for participants to take pictures. Participants need at least seven days to take photographs. This provides each participant enough time to take a sufficient quantity of pictures related to the research questions.	In this study, the participants were allowed 14 days to take photographs.
8. Meet to discuss the photographs. Participants are asked to return with their cameras and discuss photographs taken. Focus groups are recommended. The facilitator will then work with participants to select and contextualize their photographs using the SHOWeD Method. Common themes are identified and discussed with participants.	Adolescent participants participated in one on one interviews. Parent participants participated in one-on-one interviews and then a focus group.
9. Plan a format to share photographs and stories. The facilitator and participants will choose the best medium to present the photographs.	A community forum was planned and conducted to present the photographs and recommended actions to the audience selected in Step 2. Before invitations were sent the parents reviewed the invite list and made additional suggestions as needed. The participating families were invited to attend the community forum.

recommends a sample of 6–10 participants to allow for enough in-depth discussion of the photographs taken [43,44]. A sample of 15 participants was purposefully recruited of youth with CP ($n=7$; age range 14 years 10 months – 21 years 0 months; 3 females, 4 males) and parents ($n=8$; 8 females, 0 males) in rural, southeast Georgia. Youth participants included a variety of functional levels (Gross Motor Function Classification System Levels I–IV). Adolescents were eligible to participate in the study if they had a diagnosis of CP; were between the ages of 10–21; were able to take a photograph using a digital device; and could communicate either verbally or with an assisted device. All seven adolescent participants had parents participate in the study and all parent participants were female; one family chose only to have a parent participate. The Institutional Review Board from the researchers' University approved the study and all participants completed the appropriate informed consent and minor assent documents prior to participation.

Photovoice

As recommended by traditional Photovoice methodology, individuals interested in participating in a study attended a 2-h training session. The training session covered Photovoice Steps 2–6. Training sessions were scheduled at convenient times for a parent and child. Parents and children attended separate training sessions to ensure each participated as independently as possible and each perspective was illustrated throughout the participatory action research process. During the training sessions, participants were provided an overview of Photovoice and presented with the study purpose. Individuals who signed informed consent then participated in a brainstorming session that lasted approximately 20–30 min after the training. Brainstorming as part of the training is highly recommended [44]. It familiarizes participants with initial themes for taking photographs and provides a clear focus for picture ideas. During the brainstorming session, parents and adolescents completed respective versions of the Barriers to Physical Activity Questionnaire for People with Mobility Impairments (BPAQ-MI).

Instrumentation

The BPAQ-MI [45] was administered to participants during brainstorming. The BPAQ-MI was developed in an ecological framework of health behavior [46,47] to assess intrapersonal, interpersonal, organizational, and community barriers to physical activity. The BPAQ-MI has eight subscales: health, beliefs and attitudes, family, friends, fitness-center-built environment, staff and policy, community-built environment, and safety. The instrument demonstrates good test-retest reliability and acceptable ($\alpha=0.792$) to excellent ($\alpha=0.935$) internal consistency [45]. The BPAQ-MI also displays good criterion validity as higher scores (e.g., more barriers) were negatively correlated to physical activity.

The survey begins with a two-prompt sequence. Children were asked if there had been a recent situation where they wanted to participate in an activity and could not or it was made more difficult by an identified barrier. If children answered yes, they were asked to quantify the barrier on a scale of 1 (*no barrier*) to 5 (*significant barrier*). The original BPAQ-MI was developed for adults with mobility impairments but without intellectual disability, so administration was modified to accommodate children with CP who completed the instrument with assistance from a member of the investigative team. Assistance included reading questions, providing clarification, and circling responses. Parent participants

completed a modified version of the survey with altered prompts that asked them to think of a recent situation where a child wanted to participate in an activity and could not or was made more difficult by an identified barrier. Parents then quantified the barrier using the 1 – 5 scale. Domain scores are calculated using item weights from a correlation matrix with the original factor score and are calculated by summing the products of each item score with each item weight [45]. Although not suitable for measurement purposes, the modified version of the survey was useful to generate examples of barriers in a larger ecological perspective and provide descriptive data of participants.

Data collection

At the end of training, parents were given a digital camera to complete the Photovoice portion and adolescents were given a tablet with camera functions. Tablets were given to adolescents to improve ease of use. Researchers also informed participants of the ethical concerns surrounding taking photographs. Participants were instructed to obtain written consent prior to taking an individual's photograph. The researchers distributed photo consent and release forms to participants. The participants had ownership of their photographs; therefore, the researchers were required to obtain consent to publish participants' photographs. The researchers completed this task at each in-depth interview session. This protocol aligns with consent protocol followed in other studies employing Photovoice [48].

Participants were given 14 days to complete the photography portion of the study (Step 7). Wang and Burris [44] recommend a minimum of 7 days. After 14 days, the participants scheduled a meeting with one of the researchers to participate in an in-depth interview (Step 8). The participants brought back the camera and/or tablet and met with a researcher. The participants and researcher met in a conference room or in one of the University's classrooms with access to a computer, projector, and projection screen. One researcher met with a child participant, while a different researcher met with that child's participating parent. The photographs were transferred from the digital camera and tablet to the conference room or classroom computer, and the pictures were projected onto a screen. During the training session, the researchers asked the participants to aim to take eight photographs (representing both supporting factors and barriers). Providing a minimum number of photos is highly recommended [44]. The participants ($N=15$ [8 parents and 7 adolescents]) took 81 photographs.

Data analysis

The participants and researchers reviewed the photographs during the interview session. Following Photovoice methods [43], the researchers asked each participant (both parent and adolescent) to choose the photographs to discuss in detail. Each participant was asked to choose the most significant photographs representing barriers and the most significant photographs representing facilitators. Of 81 photographs taken, 47 were chosen by parent and adolescent participants to discuss. To facilitate discussion, the SHOWeD Method was used. SHOWeD is the recommended question format to help participants contextualize the meaning of their photographs. The questions are (a) What do you see here? (b) What is really happening here? (c) How does this relate to our lives? (d) Why does this problem or strength exist? and (e) What can we do about it? [44].

After interview sessions, parent participants attended a focus group to review and contextualize the photographs chosen to illustrate the collective thoughts of the cohort in more detail. At the focus group, parents were presented the photographs from their interviews and photographs from the adolescent interviews. The SHOWeD Method was used again during the focus group. Parents further narrowed these photographs from 47 to 12. This narrowing of the number of photographs is required by Photovoice methodology [42–44]. Using these photographs, the researchers asked probing questions to encourage participants to elaborate on responses. Parents and adolescents identified common themes in the photographs [43,44]. This method with the Photovoice activities enhanced study authenticity and consistency.

The in-depth interviews and the parent focus group were audio-recorded. The audio-recordings were transcribed verbatim. The researchers analyzed audio interview transcripts using content analysis to identify and validate the significant themes and patterns from the dialog with parents and adolescents. The researchers reviewed the transcription manually, line by line. As the researchers coded transcripts, emergent themes were grouped in two categories: barriers to physical activity and facilitators to physical activity. The photographs were used as the visual source of themes with the verbal interpretations.

Finally, the analysis of the photographs and themes was presented during a community forum attended by 13 influential stakeholders. Participating parents identified community stakeholders and the stakeholders were invited to attend the forum. The community forum was held on campus at the researchers' home institution. The attendees included University administration, leaders from local community organizations, state government officials and local families including some of the adolescents who participated in the study. Photographs selected during the focus group with parents were displayed for attendees to view in a gallery format. The photographs were enlarged, placed around the room, and each photograph included a supportive quote contextualizing the image. The second portion of the forum included a brief presentation followed by an open

discussion of the photographs using guided questions. The guided questions were: (a) Based on the photographs, what are some major barriers to physical activity observed? (b) In the local community, what areas of improvement are needed? (c) What are the local community and regional strengths? and (d) What are the next steps to improve physical activity opportunities? The forum was conducted by the two lead researchers. Field notes were taken and the community forum was audio recorded (Step 9).

Results

Descriptive statistics of the adolescent and parent BPAQ-MI domain scores are displayed in Tables 2 and 3. The weighted scores for the BPAQ-MI ranged from 0 (*no barrier*) to 5 (*significant barrier*). Among adolescents, there was both variation and commonalities between individual responses among the subscales. For adolescent participants, the community-built environment had the highest mean score with health and beliefs/attitudes toward physical activity as additional barriers. Family and friends were both reported as the least significant barriers to physical activity.

Parental reported barriers were similar to adolescent scores with the community-built environment as a significant barrier. However, staff/program/policy barriers were reported as the most significant barrier, with health the third highest.

Adolescent interviews

Seven adolescents completed the Photovoice portion of the study and met with a researcher to review their pictures and discuss barriers and facilitators to physical activity. The primary perceived barrier to physical activity illustrated by the adolescent participants was accessibility. Accessibility barriers were environment and equipment related. Adolescents took pictures of the built environment. In rural areas, there were poorly constructed parks, sidewalks, and buildings (i.e., doorways) that limited accessible space. This also supports the findings indicated in the adolescent responses to BPAQ-MI that community-built environment is perceived as a significant barrier.

Table 2. Adolescent reported barriers to physical activity for people with mobility impairments questionnaire weighted scores.

	Individual weighted scores (n = 7)							Mean	SD
	1	2	3	4	5	6	7		
Health	1.928	1.536	2.679	1.365	1.975	0.000	1.768	1.607	0.823
Beliefs/attitudes towards physical activity	3.403	0.914	1.522	0.381	1.160	4.155	0.062	1.657	1.543
Friends	0.628	0.568	2.064	0.000	0.716	0.810	0.340	0.732	0.647
Family	0.577	0.000	1.818	0.414	0.000	0.000	0.000	0.401	0.669
Fitness center built environment (FC_BE)	0.844	0.942	0.000	0.165	2.785	5.635	0.000	1.482	2.072
Staff/program/policy	0.000	0.719	0.000	0.096	2.000	5.330	0.000	1.164	1.977
Community built environment (C_BE)	1.795	0.367	0.423	2.225	3.460	5.715	2.815	2.400	1.858
Safety	0.745	0.518	0.144	0.000	1.315	3.575	0.681	0.997	1.215

Table 3. Parent reported barriers to physical activity for people with mobility impairments questionnaire weighted scores (n = 8).

	Individual weighted scores (n = 8)								Mean	SD
	1	2	3	4	5	6	7	8		
Health	0.864	1.573	0.398	1.491	0.000	1.114	3.079	0.810	1.166	0.934
Beliefs/attitudes towards physical activity	0.933	0.068	0.000	2.079	0.000	0.000	0.774	0.186	0.505	0.736
Friends	0.374	0.000	0.000	1.940	0.000	0.272	0.504	0.000	0.386	0.659
Family	0.640	0.000	0.000	0.622	0.000	1.477	1.085	2.105	0.741	0.774
Fitness center built environment (FC_BE)	5.542	0.275	0.000	2.648	0.000	0.000	0.720	0.000	1.148	1.992
Staff/program/policy	5.810	1.260	0.000	2.762	0.226	0.000	4.845	1.130	2.004	2.256
Community built environment (C_BE)	4.915	1.059	0.000	3.657	0.940	0.000	4.016	0.210	1.850	2.012
Safety	1.135	0.000	0.000	0.168	0.000	1.193	2.667	0.000	0.645	0.965

Adolescent participant 5

...they (those who built the facility) were not thinking about special needs – what I am – what I'm gathering from all the – from the disability standpoint, they don't think ahead. I hate to put them down, but they don't – they're not sufficient in the way they constructed the building.

The perceived facilitators to physical activity were a sense of independence and inclusiveness. The adolescents illustrated the importance of being independent and included. Having access to an accessible environment improved their perceptions of their ability to be physically active. This was important because the adolescent participants noted this reduced the stress on their family.

Adolescent participant 3

That's a handrail thing ...so I can walk up like this and being able to get up to my... into the door or to the door so, yeah, without somebody helping. It definitely made life a lot less stressful for my parents.

Community resources that provided adapted physical activity demonstrated inclusivity. Unfortunately, these resources were usually far away from families.

Adolescent participant 1

...that's a pro that's representing, that there are organizations that do the special adaptive sports. There is one tiny con to that... that I have to travel to get to a place where like camp, a sports camp that they have every year, camp place. I had to travel to [city name]. That exact place...to go to this place for [camp names] or, that's where it's held every year, along with a bunch of other cool camps or important camps, other disabilities.

Parent interviews

Eight parents completed the Photovoice portion of the study and met with a researcher to review their pictures and discuss in detail the barriers and facilitators to physical activity for their adolescent. Parents identified accessibility, independence, inclusiveness, isolation, and advocacy as influential factors to their adolescent's ability to engage in physical activity. A majority of the factors identified in the interviews related to adequate accessible facilities, properly-adapted equipment, and design of built environments to promote safe and inclusive activity. These factors served as either barriers or facilitators. One parent shared how her adolescent was frustrated in attempts to be physically active until she received a bicycle with adaptive features. This created an important new opportunity for physical activity:

Parent participant 6

I know she get – she gets frustrated 'cause for the longer – well before she was able to get one of those adaptive bikes, 'cause she just couldn't get riding a bike without training wheels, and we couldn't find one that was big enough and that we could put training wheels on.

Another parent discussed how her son would often struggle to maintain interest in activities, which she thought was a common characteristic in teenage boys. However, this challenge was exacerbated by his disability and living in a rural area, as the local community had limited services and resources to promote adapted activity.

Parent participant 1

I think if he had opportunities, a variety of opportunities, there would be something that he would find that he would like. But because there's a limited amount of activities here, that he could do here in [city name], he's not pushed or like, oh, that interests me, or I could try

that. Because maybe he tried, and it didn't work out well. So, I think if there were activities that he was interested in, at least trying, and they were able to adapt it towards his disability, he might feel like oh, I want to go try that again.

Parent focus group

Several common themes emerged during review of the focus group transcripts. During the focus group session, parent participants selected 12 photographs that best illustrated barriers and facilitators of physical activity representing the overarching themes of the parent and adolescent perspectives. The selected photographs were shared at a community forum along with suggested actions identified by participants to increase access to physical activity by adolescents diagnosed with CP. Highlighted in this section are common themes representing barriers and facilitators along with a commitment to action from members of the community forum presentation.

Barriers to physical activity

Participants agreed major barriers to physical activity were a lack of inclusiveness, family isolation, and accessibility of equipment and resources. Families identified the need for easy accessibility to facilities to improve a child's ability to be included in community events and community resources like parks, local recreation centers, and playgrounds. The two most noted barriers affecting family participation were accessible bathrooms and parking. Parents agreed companion care bathrooms (family bathrooms) were needed for their child to participate in the local community. The image in [Figure 1](#) illustrates the reality families faced when making the decision to venture to a local park in their neighborhood.

Parent participant 7

...if she is with her dad she has to go in the bathroom with him. So, she has to go in the men's bathroom...if we were at this park and she had to go to the potty...and both bathroom doors was like this, but she would have to go in the men's restroom...as you can tell it's, you know, it's not clean. It's not accessible. Um, there's no privacy...

Another participant explained how companion care bathrooms were needed to improve family capacity to use other local resources. A majority of parents in the focus group had older children. Parents stated accessibility of bathrooms becomes more of a reality as the child ages, specifically to the families who are still dependent on changing tables. [Figure 2](#) illustrates an example of what families need.

Parent participant 5

Like companion care, these are the type bathrooms that we need and most places do not have them. It's equipped with an adult changing table. So...a lot of the kids end up having to lay on the floor or be in a public bathroom and...be changed in front of them...

Accessibility was also hindered by transportation barriers such as parking availability. The parents discussed this as a major barrier. When community agencies hosted adapted/inclusive physical activity, many families wanted to participate, meaning that parking was inadequate.

Parent participant 3

...all of those are taken up, 'cause the pool at [local community agency] is probably the busiest one, if all those are taken up then we have to park way back in the back so by the time we get inside he's already tired from having' to walk from the back to the front so he's ready to go home by then.



Figure 1. Inaccessible bathroom at a local parks and recreation facility.



Figure 2. An example of a companion care bathroom equipped with adequate changing table for adolescents and adults.

Limited parking made it difficult for families in need of wheelchair accessibility. In many instances, the parking behaviors of others affected families' access to wheelchair-accessible parking spaces.

Parent participant 8

I can't get my child back in or out the car 'cause you parked there. But, again, it's just people I don't think really understand that they're – like just because you're not in the handicapped spot, if you've taken up any of the handicapped spot it can make ... make a difference.

Parents explained how inclusivity affected isolation. Environmental barriers that restrict participation of adolescents with CP can isolate both parents and children. Figure 3 illustrates the sense of isolation literally and figuratively. During the focus

group the parents discussed how this image showed how a child's access was limited by the sidewalk ending. The sidewalk did not lead all the way to the more accessible playground, but also represented the challenges faced when families tried to access resources. While services might have been available, something limited participation, whether it was the availability of equipment or the cost of programing. As the participant said "you can see it, but you can't touch it."

Parent participant 7

But it just limits your possibilities ... getting in, having access to other kids her age, um, going to ball games, um, or accessing that playground, the – the better playground that's back there. So, it's really sad because it's like you can see it, but you can't touch it.



Figure 3. A poorly planned sidewalk ending before reaching the most accessible playground.

Another participant explained how a lack of accessibility lead to a lack of socialization.

Parent participant 2

Well, we have to access areas that are handicap accessible, which that means where most of your people with disabilities are gonna go. So, for her to access, um, neuro-typical or people without disabilities is more difficult when she has barriers such as this. Um, she can't get to those kids to interact with them. Um, so, you know, it makes it difficult and then it keeps me from interacting, you know, because I have to go where she goes. So, it keeps me from not being able to socialize or interact.

Poorly-made adapted equipment was identified as another barrier. All the parents took photographs of local playgrounds and the use of sand or bark chips as a primary choice for ground surface emerged as a limiting factor. Parents emphasized they understood local communities and schools chose these surfaces because of cost and maintenance but explained these surfaces limit places families could access. The shifting surfaces impeded their child's ability to move around and was particularly difficult for a child who was a wheelchair user see Figure 4.

Parent participant 2

I would say sand is not, um, it shifts so much and even for someone who's ambulatory like because they're probably like draggin' her foot. You know it's not as, um, as steady, you know, and so she kinda loses her balance.

Furthermore, when facilities tried to improve accessibility, it was common to have poorly constructed or maintained equipment meant to facilitate adapted activity. One participant illustrated this barrier in Figure 5.



Figure 4. Sand surface at a local parks and recreation playground.

Parent participant 5

... And then we started talkin' about lifts that are safe, lifts that are not safe. Because some of these lifts are really ... when places have to put 'em on pools, they might not always be that safe as what they look with a person like[son's name], where you're still gonna have to pick him up out of the chair to turn the lift to get him in there.

Facilitators to physical activity. Participants identified similar themes representing facilitators. Families illustrated positive forms of inclusiveness specific to available community resources and advocacy support groups. The parents discussed strengths of the



Figure 5. An example of a chair lift.

local community that included family support groups that sponsored sporting events for family participation. The focus group centered on the need to multiply these support groups across the region. Parents explained that, while there was great benefit in what certain organizations provided, development was dependent upon grassroots movement from parents and caregivers. Figure 6 highlights one of the local community groups formed 10 years ago by parents looking to get their children involved in various activities.

Parent participant 3

I think every county, or every area should have one of those [non-competitive league]. Um, that's one of the few in the state of Georgia that's, um, that's made up like that where it's not competitive. You have somewhere that they have the college students is coming out. They call them like miracle leagues and other teams are coming out working with them and stuff, but this is family

In addition, parents identified formal adapted-sports leagues supported by state and national organizations as facilitators. For example, one participant discussed how a national organization increased her child's level of interest in physical activity by offering an opportunity to engage in a variety of activities outside traditional sports. The participants expanded on the wealth of resources available with a local regional university.

Parent participant 1

They [National Sports League] do community activities and they do a lot of sports, adaptive sports, and so my hope is that that gets here, in Statesboro, is my hope. Because we have [local University], and there's no reason we're not using the rock-climbing wall, wheelchair basketball. I mean, we have those things and that's what they do ...

The parents agreed the local University enhanced chances of getting organizations to partner, because of the opportunities to



Figure 6. A positive community resource and noncompetitive sports league.

Table 4. Proposed action items.

Identified problem	Proposed action	Groups responsible
Accessibility	Increased funding for remodeling and making recreation facilities pools and physical activity locations more accessible.	Local/state government representatives.
Opportunities for involvement	Reach out to the new recreation centers Coordinate annual Events Seek involvement from local University athletes After school programs for adolescents with disabilities	Faculty/parents Local parks and recreation representatives Existing support groups
Engaging the community	Bring in kids without disabilities for integrative activities Connect parents with other parents Peer programs Create social media presence	Local parks and recreation Existing support groups Faculty/parents

train students as part of service-learning experiences. The University offers well-equipped facilities and knowledgeable faculty and staff to implement adapted opportunities.

Beginning support groups and implement programming requires stakeholder support, particularly community members. To gain community buy-in, increasing awareness is needed. Another facilitator identified by parents was advocacy through awareness. Parents understood many community members were simply unaware of challenges faced by families caring for a child with CP. The highlighted barriers were likely a result of a lack of knowledge and lived experiences. Because a community member does not possess the appropriate lens through which to view the environment, effective programming may be difficult to plan and implement. Raising awareness around the lived experiences of families caring for children with CP was identified as an important step. It was also important community stakeholders understood the importance of adequate representation from these families when developing and planning programs. It is not easy to understand what accessibility means if you have not had it limited.

Parent participant 8

...I will tell you, a lot of times I find that people can't fix what they don't know about and if they don't realize it's a problem... They don't live our life, so they don't think about it and it's not that they mean not to think about it, but it's just not on their radar, so until a parent approaches them or a caregiver approaches them to say, "Hey, listen, I would love to utilize this program, but – or participate in this or have you thought about that" ...

Community forum

The two overarching themes of the community forum were:

1. Increased accessibility to recreation facilities, pools, and physical activity areas for families with cerebral palsy is crucial. Consider not only physical accessibility, but also restroom, educational, and sociocultural access as well.
2. Awareness is a key step in community improvement for families with cerebral palsy. There is a call for stronger advocacy from parents and community members/leaders, education for the general population, and understanding the needs of the public.

The forum attendees agreed accessibility was important and was not limited to physical access; as a community, consideration for education and sociocultural access is important. The local region was rich with resources and opportunities, but the community lacked awareness of the lived realities of families caring for a child with CP. The families who attended echoed that awareness and advocacy also falls on parents. Parents caring for children should be bold and ask for more resources and better facilities for their families.

The most immediate action needed by the forum attendees was community involvement and awareness. One attendee said,

We got like the next generation. If we can like get that just awareness, that's the first thing is you get the awareness and say, "Hey, this is the problem, but look what we can do. Let's work on these, but let's also focus on these are the positive things

Assessing what the communities have and what works well (i.e., support groups, adapted-sports leagues) may empower communities to promote recreational activities for the families caring for a child with CP. Table 4 includes a list of identified problems and proposed actions for future consideration.

Discussion

The purpose of this study was to examine barriers and facilitators to physical activity for rural adolescents with CP from the perspectives of children and parents using Photovoice. Emphasis was placed on participants exploring aspects of their environment that threatened or reinforced a child's ability to participate in frequent physical activity. Use of Photovoice required *pre-thought* from participants to answer the research questions that provided in-depth meaning to their lived experiences. Participant pre-thought was facilitated in the brainstorming step. During this step, participants completed the BPAQ-MI, a survey that uses an ecological framework to examine barriers to physical activity for individuals with mobility impairments.

While health has been reported as the most significant barrier to physical activity among individuals with mobility limitations [45] here, the community-built environment served as the most significant barrier for adolescents with CP and was the second most significant barrier for parents. This may be due to the environment of the participants in the present study, as the BPAQ-MI developed for use in an urban setting. Family and friends were reported as the least significant barriers for adolescents and parents in the present study, which is consistent with findings from previous research [45]. For parents, staff/program/policy barriers were the most significant, possibly indicating parents had a greater understanding of the social factors in an environment that prevent children from participation.

Photographs informed the stories contextualized by participants, which served as the basis for capturing barriers and facilitators to physical activity. The results of this study support previous findings where participation in physical activity was both hindered and supported by environmental factors such as accessibility and inclusiveness [33,49]. The participants in this study identified contrasts between equipment that was built to be accessible. but was poorly constructed or maintained and therefore not truly accessible to adolescents with CP. Increasing accessibility was important and appreciated by families caring for children with CP, but they emphasized the difference between

just having equipment available and having quality equipment available. As noted by Earde et al. [49], appropriateness of assistive equipment serves as either a barrier or facilitator to activity. Because the quality of equipment and appropriateness of design can influence the level of safety in physical activity participation, this may affect the likelihood a family will use certain community resources on a regular basis. Parents may avoid certain recreational facilities if they do not believe the assistive devices or equipment are safe for their child.

The findings indicate access to adequate equipment is important and design of a physical environment influences participation; a design might result in a greater sense of isolation, because families cannot access a facility. This supports findings from Law, Petrenchik, King, and Hurley [36] who surveyed 427 parent-child pairs living in urban and rural areas around Ontario, Canada. The participants completed the Craig Hospital Inventory of Environmental Factors and the researchers found physical and structural environments were perceived as significant barriers by parents. In addition, these perceived barriers increased in effect with age. The closer to adolescence, the greater the barrier. The families in this study emphasized structural concerns such as bathroom accessibility, limited parking space, and use of materials like sand/bark chips as playground surfaces as deterrents because of the age and sex of a child. Ease and convenience of use can minimize the perceived and actual barriers to increase a family's willingness and motivation to ensure a child engages in recreational activities. Rurality might play a mediating factor between environmental factors. The families discussed how large cities have better access to adapted recreational activities and sports leagues and overall, more awareness of children living with CP compared to a local area with fewer resources. This compliments findings by Hammal, Jarvis, and Colver [37] who found an association between location (rural versus urban) and the level of participation by children living with CP. Furthermore, one intervention study [50] found home-based strategies are useful to improve activity levels of children with CP; however, the researchers recruited participants from an organization in South Australia that provides community-based therapy, equipment, and family support services to young people ages up to 18 years with physical disabilities and acquired brain injuries. Participants already had access to more services than our participants in a rural area where such clinics are a 3–4 h drive away. Examining the barriers for families living in rural areas is important when considering what type of intervention best fits a goal to increase physical activity.

The families identified the rich resources available in the local community and explained how leveraging resources to improve access and increase opportunities was vital to encourage participation. A part of creating the shift is advocating and raising awareness to change person, family, and societal attitudes [33,51]. Changing perceptions and family expectations while battling stigma associated with CP were important to promote physical activity. The recommendations from the community forum regarding the need for a community effort reflect what other research has supported to build and maintain healthy and inclusive environments for children with CP [33,36,49,52].

Although this study identified important barriers to and facilitators of physical activity participation, it had limitations. The study used a small, convenience sample of parents and children with CP, although the sample size of both parents and children was within the recommendations for Photovoice methodology [44]. The results of the present study only reflect stories from this specific area. Furthermore, like other qualitative studies, the

results may not be generalizable to other families and children with CP; however, the results can provide insight into physical activity barriers and facilitators for this specific diagnosis. The findings might also offer other communities some understanding of the perceptions of families as they engage stakeholders to find solutions to the challenges associated with physical activity access among youth living with a disability. Incorporating more opportunities for families, children and adults with CP and other mobility impairments to develop specific programming is crucial to ensure accessibility of programs, equipment, and public spaces. The development of awareness campaigns and community education is a starting place for advocacy efforts to design inclusive environments in rural areas. This study represents an important first step to understand barriers and facilitators in a rural community and provides a foundation for local change and fills a unique niche in the literature.

Currently, there is limited objective evidence on physical activity levels of youth with CP in rural environments. There is a disparity in the published evidence on physical activity and related research in typically-developing youth compared to youth with CP and mobility limitations. There is a need for intervention-based studies to improve physical activity in individuals with CP, specifically in rural areas. In recent years, there has been a plethora of studies that have promoted physical activity in typically-developing youth in light of the childhood obesity epidemic. Given the importance of physical activity to mortality rates and health outcomes for youth with CP [8–11,53,54,55] evidenced-based physical activity interventions at multiple ecological levels are noticeably absent.

Disclosure statement

The authors report no declarations of interest.

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