Obstacles to community participation among youth with spinal cord injury

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Objective: Examine caregiver-report of obstacles to community participation for youth with spinal cord injury (SCI), and explore relationships between obstacles and child, caregiver, and community characteristics.

Design: Two hundred and one primary caregivers of youth with SCI ages 7–17 years were interviewed at three pediatric SCI centers within a single-hospital system. Caregivers answered an open-ended question assessing obstacles to youth participation. A mixed-methods approach was incorporated, where qualitative methods analyzed caregiver-reported obstacles, and exploratory multivariate analyses examined relationships between obstacles and demographic variables.

Results: Caregivers were primarily mothers (74%), married (69%), employed (54%), had college experience (67%), and lived in small towns (55%). Youths' mean age was 12.60 years at interview and 7.19 years at injury, 70% had paraplegia, and 55% had complete injuries. Analyses revealed that youth participation was limited by obstacles across six domains: community, disability-related, practical concerns, child-internal, social, and other. Child, caregiver, and community characteristics were related to overall report of obstacles, and report of community obstacles, disability-related obstacles, and practical concerns. Caregiver college experience and small town living predicted overall report of obstacles. Having a child injured at a younger age, caregiver college experience, and small town living predicted community obstacles. Having a child with an incomplete injury and recent medical complication predicted disability-related obstacles. Caregiver employment predicted practical concerns.

Conclusion: Youth from small towns, those injured younger, those with incomplete injuries, and those experiencing recent medical complications may need additional supports and resources to maximize participation. Clinicians should work with caregivers to identify and problem-solve obstacles to youth participation.

Keywords: Barriers, Community participation, Disability, Participation, Rehabilitation, Pediatrics, Spinal cord injuries

Introduction

Participation in school, community, and social relationships is instrumental in teaching children the skills they need to function in the world around them.^{1–4} Although the relationship between participation and outcomes has not been extensively studied among youth with spinal cord injury (SCI), participation has been linked to overall health and life satisfaction for adults with SCI.^{5,6} As SCI impacts on a child's life during a dynamic developmental period, it typically disrupts participation.^{7,8} It is important that children resume healthy activity levels as soon as possible after injury. This can be challenging, as participation may be

limited by social, community, and personal obstacles that may not have affected youth prior to injury.

Research has demonstrated lower participation rates among youth with disabilities than their able-bodied peers;^{1–3,9} this discrepancy can be partially attributed to barriers to participation.^{10–13} Barriers to participation have received attention in disability literature, perhaps most notably by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF).¹⁴ The ICF discusses individual functional level as resulting from the interaction between one's health condition and environmental factors; although the disability is real, its effects are not inherent, but are rather determined by the facilitators and barriers present in the environment. The ICF discusses the environmental barriers that affect participation across five categories: products

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and technology; natural environment and human-made changes to the environment; support and relationships; attitudes; and services, systems and policies.¹⁴ These barrier categories outlined by WHO contain many of the factors affecting child participation.

In addition to the WHO environmental barriers listed above, existing research has explored other obstacles that limit participation, including obstacles in the physical and social environment, and obstacles relating to the child's psychological and physical needs.^{10,12,13,15} Obstacles within the *physical environment* (i.e. accessibility, geographical distance) can influence a child's desire and ability to participate,^{10–13,16,17} while the availability of activities and resources within the community determine a child's participation options.^{10–12,16,17} Additionally, *social obstacles* like parental support/hesitation, family cohesion, or attitudes from peers, teachers, or coaches may range from supportive/inclusionary to limiting/exclusionary, two extremes that can impact on a child's activity-level.^{9–11,16,17} *Child-specific obstacles* also impact participation: both internal attitudes (i.e. motivation, discomfort),¹² and health/disability-related issues (i.e. mobility, fatigue)^{11,12,16,17} interact to facilitate/limit activity levels. Finally, *practical concerns* (i.e. scheduling, finances), which often arise from family characteristics (i.e. marital status, income), have been shown to affect participation.^{4,11–13,17} Practical concerns are not disability specific, but may be more problematic for families of children with special needs, as their care may require more time and financial resources.¹³ Overall, pediatric disability research has shown that unique circumstances comprise each child's world, determining his/her participation level.

Although pediatric disability research has begun to explore obstacles that limit participation, most studies have focused on cerebral palsy^{11,13,17} or multidisability samples.^{1,3,12} SCI-specific findings are needed: because SCI is often acquired later in childhood, most affected youth have previously participated as able-bodied children, and now must adapt their participation post-injury. Research has shown low participation rates among youth with SCI^{2,4} and related these rates to demographic/family factors,⁴ but little is known about the specific obstacles that limit participation.

The purpose of this study was two fold. First, this study aimed to identify caregiver-reported obstacles to participation for children with SCI. Based on the literature reviewed above, it was expected that youth participation would be limited by environmental, social, child-specific, and practical obstacles. Second, this study explored relationships between these obstacles and child, caregiver, and community characteristics.

This second purpose was pursued with the intention of identifying youth and families at greater risk of experiencing obstacles to participation; with this knowledge, interventions can be developed for those in greatest need of additional supports and resources. A mixed-methods approach was incorporated, where reported obstacles were analyzed using qualitative methods, and exploratory multivariate analyses assessed relationships between obstacles and child, caregiver, and community characteristics.

Methods

Participants

Participants were recruited as part of a larger research study examining participation and psychosocial outcomes among youth with SCI and their primary caregivers. For the current study, enrollment criteria were as follows: English- and Spanish-speaking primary caregivers (typically parents) of youth ages 7–17 years who had sustained SCI at least 1 year prior to interview and were receiving care at one of three pediatric specialty centers within a single-hospital system. As assessed by clinical staff, families of youth with cognitive barriers that would prevent youth from answering age-appropriate survey questions were excluded. Of the 247 caregivers who were enrolled, 201 (81%) answered an open-ended question assessing obstacles to their child's participation (*What things, if any, have kept your child from participating in more school and community activities?*); the remaining 46 chose not to answer this question. Only the 201 caregivers who answered the open-ended question were included in the current analyses. Of these 201 caregivers, 74% were mothers, 16% fathers, 6.5% grandmothers, and 3.5% other family members. Eighty-four percent of caregivers were female, 69% were married, 67% had at least some college experience, and 54% were employed, either full- or part-time. Fifty-five percent of families lived in small town/rural areas; 45% in urban/suburban communities. Their children were an average of 12.60 years old, 52% were female, and 65% Caucasian. Seventy percent had paraplegia, 55% complete injuries, their mean age at injury was 7.19 years, and 22% had recently experienced a significant medical complication. Table 1 contains complete demographic information.

In order to assess the representative nature of the sample, we examined differences between the 201 caregivers ('participants') who were included and the 46 caregivers who were not included in the current study ('non-participants'). The 201 caregiver participants had children who were significantly younger, more likely to be female, and were less likely to have experienced a

Table 1 Participant demographics and comparison of participants and non-participants

	Participants (<i>n</i> = 201) % or mean (SD)	Non-participants ¹ (<i>n</i> = 46) % or mean (SD)	Value and significance χ^2 and/or <i>P</i> value
<i>Child age</i>			
At interview (years)	12.60 (3.10)	13.65 (3.14)	<i>P</i> = 0.039
At injury (years)	7.19 (5.40)	8.11 (5.82)	<i>P</i> = 0.306
<i>Child gender</i>			
Female	52%	33%	$\chi^2 = 5.488$, <i>P</i> = 0.019
Male	48%	67%	
<i>Child race</i>			
Caucasian	65%	60%	$\chi^2 = 0.322$, <i>P</i> = 0.571
Latino	21%	20%	
African American	7%	9%	
Asian	2%	4%	
Native American	2%	–	
Other	3%	7%	
<i>Injury-related factors</i>			
Paraplegia	70%	61%	$\chi^2 = 1.492$, <i>P</i> = 0.222
Tetraplegia	30%	39%	$\chi^2 = 0.895$, <i>P</i> = 0.344
ASIA A (complete injury)	55%	47%	
ASIA B, C, or D (incomplete injury)	45%	53%	$\chi^2 = 6.703$, <i>P</i> = 0.010
Significant medical complication in the last 4 months	22%	41%	
<i>Type of community</i>			
Urban/suburban	55%	48%	$\chi^2 = 0.816$, <i>P</i> = 0.366
Small town/rural	45%	52%	
<i>Caregiver relationship to child</i>			
Mother	74%	91%	$\chi^2 = 7.346$, <i>P</i> = 0.196
Father	16%	9%	
Grandmother	6.5%	–	
Aunt	1.5%	–	
Step-mother	1%	–	
Grandfather	0.5%	–	
Sister	0.5%	–	
<i>Caregiver factors</i>			
Married	69%	67%	$\chi^2 = 0.069$, <i>P</i> = 0.793
At least some college experience	67%	55%	$\chi^2 = 2.046$, <i>P</i> = 0.153
Employed (part- or full-time)	54%	50%	$\chi^2 = 0.171$, <i>P</i> = 0.680

¹Non-participants included those who were enrolled in the larger study but did not respond to the open-ended question about factors limiting their child's participation. Therefore these individuals were not included in the current study.

Note: Variables listed in bold were significantly different for participants vs. non-participants.

ASIA = American Spinal Injury Association Impairment Scale Classification.

recent medical complication (Table 1). There were no other demographic differences between the two groups.

Instruments

A medical record review form was completed for each participating youth that included child's sex, date of birth, and injury-related factors. Caregivers completed a demographics form that assessed family characteristics, type of community, and issues specific to their child's injury, and included the following question: 'What things, if any, have kept your child from participating in more school and community activities?' This question formed the basis of data analyses.

Procedures

Families meeting eligibility requirements were approached during regularly scheduled inpatient hospitalizations or outpatient clinic visits. Caregivers signed a consent form, and were given the option of completing

the questionnaire independently or with assistance. The Institutional Review Board at each hospital approved this project and the Ethical Treatment of Human Subjects protocol was followed.

Data analyses

The current study incorporated a mixed-methods design, where qualitative methods were used to analyze caregiver-reported obstacles, and exploratory multivariate analyses were used to evaluate relationships between obstacles and child, caregiver, and community characteristics. Each of these procedures is described below.

Coding of open-ended responses

The 201 participating caregivers answered an open-ended question assessing obstacles to their child's participation in school and community activities. Consistent with qualitative research methodology,

inductive coding was incorporated, in that codes grew out of the data. Specifically, the first author of this study reviewed all caregiver responses and created a 23-obstacle coding scheme to capture the range of answers. The first author then grouped these obstacles into six overarching categories: *Community Obstacles* (obstacles related to school/community accessibility and resources), *Social Obstacles* (obstacles related to relationships or social support), *Disability-Related Obstacles* (obstacles related to functional or health issues), *Practical Concerns* (obstacles related to family practical issues like scheduling or finances), *Child-Internal Obstacles* (obstacles related to child psychological issues), and *Other Obstacles* (obstacles reported by parents that did not fall into other categories). To facilitate credibility, investigator triangulation was incorporated,^{18,19} and the first and second authors each independently coded all caregiver responses using the 23-obstacle coding scheme, compared results, and discussed codes until any differences were resolved. Table 2 contains a complete list of the caregiver-reported obstacles to participation, along with

frequency of reports. In addition, participant quotes are presented in-text to illustrate obstacles; to ensure representativeness no more than one quote is presented from any one participant.

Statistical analyses

Quantitative analyses were conducted using SPSS 17.0. Descriptive statistics were used to summarize demographics and obstacle reports. Due to the low number of people reporting obstacles that fell in the *other* category ($n = 6$), these obstacles are described below but were not included in any statistical analyses. χ^2 analyses were used to explore differences in report of the remaining obstacles according to the following (dichotomous) characteristics: child sex (male/female), injury level (paraplegia/tetraplegia), extent of injury (complete/incomplete), medical complications (yes/no), caregiver marital status (yes/no), education (college/no college), employment (yes/no), and community type (city/small town). Independent-samples t -tests were used to explore differences in report of *Community*, *Disability-Related*, and overall

Table 2 Caregiver-report of obstacles to youth participation ($n = 201$)

Obstacles	Percent endorsed* % (n)
No obstacles were reported	22% (45)
At least one obstacle was reported	78% (156)
<i>Community Obstacles</i>	33% (66)
Lack of accessibility in community/school	17% (35)
Lack of/limited availability of appropriate activities	13% (26)
Lack of disability resources in community/school	4% (7)
Lack of knowledge of disability in the community	3% (6)
Geographical distance from activities	1% (2)
<i>Disability-Related Obstacles</i>	32% (65)
Child's physical limitations and/or lack of independence	21% (42)
Fatigue, pain, or other health issues	8% (15)
Bathroom issues	5% (10)
Frequency of medical visits and/or time required for medical routines	2% (4)
Wheelchair issues, including hassle of traveling with/loading a wheelchair	2% (3)
<i>Practical Concerns</i>	12% (25)
Time and/or scheduling issues	7% (13)
Transportation issues	6% (12)
Cost and/or financial issues	2% (4)
Family factors (including custody issues and family-size)	1% (2)
<i>Child-Internal Obstacles</i>	12% (24)
Child's concern about fitting in, embarrassment, and/or difficulty relating to peers	7% (14)
Child does not wish to participate	3% (6)
Child's self-esteem and/or psychosocial issues	3% (5)
<i>Social Obstacles</i>	7% (14)
Child not accepted by coaches, peers, or teachers	4% (7)
Activity leaders prevent child from participating due to liability/safety concerns	3% (6)
Changes in child's social circle	1% (2)
<i>Other Obstacles</i>	3% (6)
Climate/weather concerns	2% (4)
Safety concerns	1% (2)
Child's age (too young for activities or has aged out of appropriate activities)	1% (1)

*Percent of entire sample that endorsed each obstacle category/subcategory. Many caregivers endorsed multiple obstacles, and as such, percentages do not sum to 100%.

report of obstacles, according to the following (continuous) characteristics: child current age and age at injury. Due to small group sizes, the Mann–Whitney test was used to explore differences in report of *Practical Concerns*, *Child-Internal* and *Social* obstacles, according to the continuous characteristics listed above. Finally, logistic regression modeling was used to assess the predictive relationship between child, caregiver, and community characteristics and report of obstacles. Logistic regression equations were tested for each of the obstacles found to be significantly related to at least one child, caregiver, or community characteristic. For each equation, the presence of obstacles was included as the dependent variable and independent variables included the child, caregiver, and community characteristics that were significantly related to the obstacle in univariate analyses. Prior to conducting regression analyses, Pearson, and Phi correlation coefficients were computed to assess for multicollinearity,²⁰ and expected frequencies were computed²⁰ and sample size calculations were conducted to assess for sufficient power.²¹ These preliminary analyses indicated no issues with multicollinearity and determined there was adequate power to assess each regression equation. Due to incomplete data on some demographic variables, sample sizes varied for each analysis; therefore, sample size information is presented in text and in the tables to aid in interpreting results.

Results

Describing caregiver-report of obstacles to youth participation

Fifty-one percent of caregivers reported that only one obstacle limited their child's participation, 27% reported multiple obstacles, and 22% reported no obstacles to their child's participation. *Community* and *Disability-Related Obstacles* were most common, reported by 33 and 32% of caregivers, respectively. Examples of caregiver responses coded as *Community Obstacles* included: 'not all areas are wheelchair accessible,' 'lack of knowledge in the community,' and 'there are not enough local community activities that can include someone with a physical disability ... most programming is geared towards individuals with cognitive disabilities.' Responses coded as *Disability-Related Obstacles* included: 'bowel program,' 'level of injury too high,' 'just the problems associated with being in a wheelchair. Sometimes she will just stay at home because she doesn't want the hassle of loading the chair, unloading the chair, etc.'

Following these, *Practical Concerns* and *Child-Internal Obstacles* were each reported by 12% of

caregivers. Examples of caregiver responses coded as *Practical Concerns* included: 'family size (four kids),' 'timing and scheduling. Mak[ing] my schedule fit with his schedule,' 'the thing that limits our child's activities is that there are not any carpool options – so we have to ensure that my wife or I are available for transportation.' *Child-Internal Obstacles* included: 'self esteem,' '... my child's lack of desire to participate. My child is somewhat shy and not particularly outgoing. This was also true prior to his injury,' and 'feeling that he 'cannot do that', or 'would not fit in'.

Social Obstacles were reported by 7% of caregivers. Examples of caregiver responses coded as *Social Obstacles* included: 'he has friends but I do not feel that the kids would encourage my child to play on their sports team; they would feel that it may make them lose,' 'people worry that he will get hurt and they will be liable,' and 'PE (physical education) teacher in high school did not think she could participate in PE although she had been doing PE since fifth grade, so they put her in marching band.'

Finally, *Other Obstacles* were reported by 3% of caregivers. Example of caregiver responses coded as *Other Obstacles* included: 'weather (winter bad roads),' 'too young,' and 'the fear of getting more injuries.'

Analyses revealed relationships between caregiver-report of *Disability-Related Obstacles* and *Community Obstacles*, and also between caregiver-report of *Disability-Related Obstacles* and *Practical Concerns*. Specifically, those reporting that *Disability-Related Obstacles* limited their child's participation were less likely to report *Community Obstacles* as a barrier (15%) than those who did not report *Disability-Related Obstacles* as a limitation to their child's participation (41%) ($\chi^2(1, N = 201) = 13.266, P < 0.001$). In addition, those reporting that *disability-related obstacles* limited their child's participation were less likely to report *practical concerns* as a barrier (5%) than those who did not report *disability-related obstacles* as a limitation to their child's participation (16%) ($\chi^2(1, N = 201) = 5.398, P = 0.020$). No other relationships between categories emerged.

Relationship between child, caregiver, and community characteristics in caregiver-reported obstacles to participation

Univariate analyses revealed that child, caregiver, and community characteristics were related to overall caregiver-report of obstacles to their child's participation, as well as to the report of *Community Obstacles*, *Disability-Related Obstacles*, and *Practical Concerns*. *Social Obstacles* and *Child-Internal Obstacles* were not

related to the child, caregiver, and community characteristics studied (Table 3).

Logistic regression equations were then tested for each of the obstacles found to be significantly related to at least one child, caregiver, or community characteristic. Specifically, four logistic regression equations were evaluated with the following dependent variables: the report of any obstacles, *Community Obstacles*, *Disability-Related Obstacles*, and *Practical Concerns*.

Predicting whether or not caregivers reported any obstacles to their child's participation, extent of injury, caregiver education, and community type were included as predictors. A test of the full model with all predictors against a constant-only model indicated good model fit,

with report of overall obstacles correctly predicted in 80% of youth (Table 4). Caregiver education was a significant predictor of reporting any obstacles, such that caregivers with college experience were two-and-a-half times more likely to have reported at least one obstacle. Community type also significantly predicted report of obstacles, in that caregivers from rural areas were three times more likely to report any obstacles as caregivers from rural areas. Child extent of injury did not significantly contribute to the report of obstacles.

Predicting whether or not caregiver-reported *Community Obstacles* were limiting their child's participation, child age at injury, caregiver education, and community type were included as predictors. A test of

Table 3 Univariate relationships between obstacles to participation and child, caregiver, and community characteristics

Characteristics	Obstacles					
	Any obstacle reported	Community obstacles	Disability-related obstacles	Practical concerns	Child-internal obstacles	Social obstacles
<i>Child</i>						
Age						
Sex						
Injured Younger ¹		$P = 0.013$				
Injury level						
Incomplete injury	$P = 0.027$		$P = 0.024$	$P = 0.043$		
Recent medical complications			$P = 0.001$			
<i>Caregiver</i>						
Marital status						
College education	$P = 0.011$	$P = 0.006$				
Employed				$P = 0.047$		
<i>Community</i>						
Small town/rural areas	$P = 0.008$	$P < 0.001$				

¹Example interpretation: Caregivers of youth injured at a younger age were significantly more likely to report a community obstacle to participation.

Table 4 Logistic regression analysis predicting caregiver-report of any obstacles to participation ($n = 188$)

Predictor	β	SE β	Wald χ^2	Df	P	e^{β} (odds ratio)	95% CI lower	95% CI upper
Constant	1.785	0.46	15.024	1	0.000	5.962		
Complete injury	-0.725	0.402	3.248	1	0.072	0.484	0.220	1.066
Caregiver College Experience	0.947	0.385	6.045*	1	0.014	2.578	1.212	5.485
Urban community	-1.151	0.388	8.814**	1	0.003	0.316	0.148	0.676

Note: Model $\chi^2(3) = 19.91$, $P < 0.001$.

** $P < 0.01$, * $P < 0.05$.

Table 5 Logistic regression analysis predicting caregiver-report of community obstacles ($n = 198$)

Predictor	β	SE β	Wald χ^2	Df	P	e^{β} (odds ratio)	95% CI lower	95% CI upper
Constant	-0.528	0.391	1.842	1	0.177	0.590		
Age at injury	-0.066	0.031	4.544*	1	0.033	0.936	0.880	0.995
Caregiver College Experience	1.040	0.374	7.728**	1	0.005	2.829	1.359	5.888
Urban community	-1.177	0.341	11.928**	1	0.001	0.308	0.158	0.601

Note: Model $\chi^2(3) = 25.65$, $P < 0.001$.

** $P < 0.01$, * $P < 0.05$.

the full model with all predictors against a constant-only model indicated good model fit, with report of overall obstacles correctly predicted in 69% of youth (Table 5). Age at injury was a significant predictor of report of *Community Obstacles*, such that caregivers of children who were younger at time of injury were slightly more likely to have reported a *Community Obstacle*. Caregiver education was also a significant predictor of report of *Community Obstacles*, in that caregivers with college experience were almost three times more likely to have reported a *Community Obstacle*. Community type also significantly predicted the report of *Community Obstacles*, in that caregivers from rural areas were more than three times more likely to have reported a *Community Obstacle*.

Predicting whether or not caregivers reported *Disability-Related Obstacles* were limiting their child's participation, extent of injury, and medical complications were included as predictors. A test of the full model with both predictors against a constant-only model indicated good model fit, with report of *Disability-Related Obstacles* correctly predicted in 72% of youth (Table 6). Child extent of injury was a significant predictor of report of *Disability-Related Obstacles*, in that caregivers of children with incomplete injuries were more than two times more likely to have reported a *Disability-Related Obstacle*. Having a recent medical complication also significantly predicted report of *Disability-Related Obstacles*, such that caregivers reporting their child had a recent significant medical complication were four times more likely to have reported a *Disability-Related Obstacle*.

Finally, predicting whether or not caregiver-reported *Practical Concerns* were obstacles to their child's

participation, child extent of injury and caregiver employment were included as predictors. A test of the full model including both predictors against a constant-only model indicated good model fit, with report of *Practical Concerns* correctly predicted in 88% of youth (Table 7). Caregiver employment was the only significant predictor of the report of *Practical Concerns*, in that employed caregivers were almost three times more likely to have reported a *Practical Concern*.

Discussion

This research explored obstacles to participation for youth with SCI, and investigated the relationship between these obstacles and child, caregiver, and community characteristics. Seventy-eight percent of caregivers reported at least one obstacle to their child's participation, indicating that this issue affects a significant portion of families. As seen in previous research,^{10–13} caregivers reported obstacles across environmental, social, child-specific, and practical domains. The most common types of obstacles were *Community Obstacles* (i.e. accessibility issues) and *Disability-Related Obstacles* (i.e. fatigue). Some of these obstacles are not disability-specific, and may limit the participation of youth regardless of disability status. However, these obstacles may have a greater impact on the participation of youth with SCI, due to the variety of additional issues that their families must confront as a result of their child's disability.¹³

Analyses revealed relationships between the types of obstacles to participation for youth with SCI. Caregivers who reported *Disability-Related Obstacles* to their child's participation were less likely to also report *Practical Concerns*, perhaps indicating that

Table 6 Logistic regression analysis predicting caregiver-report of disability-related obstacles ($n = 188$)

Predictor	β	SE β	Wald χ^2	Df	P	e ^{β} (odds ratio)	95% CI lower	95% CI upper
Constant	−0.681	0.242	7.933	1	0.005	0.506		
Complete injury	−0.842	0.335	6.322*	1	0.012	0.431	0.223	0.831
Medical complications	1.410	0.379	13.869***	1	0.000	4.098	1.951	8.608

Note: Model $\chi^2(2) = 19.86$, $P < 0.001$.

*** $P < 0.001$, * $P < 0.05$.

Table 7 Logistic regression analysis predicting caregiver-report of practical concerns ($n = 188$)

Predictor	β	SE β	Wald χ^2	Df	P	e ^{β} (odds ratio)	95% CI lower	95% CI upper
Constant	−2.196	0.462	22.639	1	0.000	0.111		
Complete injury	−0.884	0.470	3.537	1	0.060	0.413	0.164	1.038
Caregiver employed	1.006	0.504	3.987*	1	0.046	2.735	1.019	7.342

Note: Model $\chi^2(2) = 8.43$, $P = 0.015$.

* $P < 0.05$.

disability/health concerns are paramount for caregivers or are so limiting that time/scheduling concerns rarely arise. Caregivers who reported *Disability-Related Obstacles* to their child's participation were also less likely to report *Community Obstacles*. This may suggest a difference in perception: some caregivers may see their child's disability as the primary obstacle to participation, while others may blame an unsupportive environment. For example, when asked about obstacles to participation, one caregiver replied '[His] wheelchair... not being able to walk,' while another responded 'not all sidewalks are paved, so [he is] unable to get to the gym or cafeteria.' This difference indicates that perception is important: while the disability cannot be changed, the physical environment can, and parents may be more likely to seek solutions to reparable barriers. This finding complements the results of a 2004 study of the influence of wheelchair technology on perception of participation for adults with SCI. In this study, adults with SCI named their wheelchair as more limiting to participation than the disability itself. The authors suggest that this finding may be due to a healthy adjustment to SCI: once an individual accepts impairment as a part of him/herself, it is no longer seen as a barrier, rather, external factors are seen as the obstacles that prevent him/her from participating in the community.²²

Caregiver-report of obstacles to child participation varied by child characteristics. Multivariate analyses indicated that caregivers of youth with incomplete injuries reported more *Disability-Related Obstacles* than caregivers of children with complete injuries. Incidence of certain types of medical complications has been shown to vary by completeness of SCI among adults: spasticity, contractures, and pain have been found to be more common after incomplete injuries.^{23,24} It is possible that children with incomplete injuries also experience more of these types of complications, which may limit participation. This seems evident in the finding that *Disability-Related Obstacles* were also more common among children who experienced a recent medical complication, likely indicating that their health issues impact their participation. Another study of adults with SCI indicated that those with incomplete injuries faced many of the same medical complications as their peers with complete injuries; however, the authors of this study expressed concern that because these individuals have higher levels of functioning, they may not anticipate these challenges, leading to frustration or depression.²⁵ It is possible that this same phenomenon occurs in youth: perhaps youth with incomplete injuries feel more frustrated by

obstacles to participation if their functioning is too high for adapted sports, but too low to compete with able-bodied peers.

Child age at injury was also related to caregiver-report of obstacles: specifically, being injured at a younger age was associated with *Community Obstacles*. This may indicate that younger children have fewer opportunities to participate than older youth, or that parents of younger children are more likely to supervise activities and thus witness these obstacles first hand. This compliments findings from a study investigating factors that enhanced the participation of youth with SCI; specifically that caregivers of youth injured at an older age were more likely to have found something in rehabilitation helpful to their child's future participation.²⁶

Caregiver-report of obstacles to child participation also varied by caregiver characteristics. Caregivers who were employed were more likely to report *Practical Concerns*; these concerns likely result from juggling family and work responsibilities. Further, caregivers with college experience were more likely to report *Community Obstacles* to their child's participation, and were also more likely to report obstacles to their child's participation in general. Parental education level has been linked to other outcomes in the pediatric disability literature, such as use of positive coping strategies,²⁷ having higher expectations for their child's educational achievements,²⁸ and a higher rate of diagnosis for intellectual disabilities/autism among youth.²⁹ These findings seem to indicate that families with greater educational resources are more likely to recognize and request assistance with disability-related challenges. In the same way, perhaps college exposes caregivers to a broader range of people, circumstances, and resources, making them more aware of the effect of environment on life opportunities. With this background, caregivers may be more likely to identify and seek solutions to internal and external obstacles to participation.

Caregiver-report of obstacles to child participation also varied by community type; both overall reports and reports of *Community Obstacles* were more prevalent in small town/rural areas than urban/suburban communities. This is likely a function of geographical environment; youth with SCI living in small towns may not have access to adapted activities or may have to travel long distances to find them. This finding is consistent with recent research on physical activity among adolescents with disabilities, which identified distance to exercise facilities as a barrier in rural communities.¹²

Implications

This study has clinical implications. First, clinicians should work with families to address obstacles to youth participation, particularly with higher-risk families, like those in rural communities, those injured at an earlier age, those with incomplete injuries, and those who recently experienced a medical complication. Clinicians should help families identify and advocate for solutions to these obstacles. Second, it is important to understand caregivers' perception of these issues, and help them think critically about obstacles to their child's participation. Caregivers who see their child's SCI as the main obstacle to participation may not identify external factors. With the help of the clinical team, families can understand their child's full potential, and learn strategies to promote his/her participation.

This study also has implications for future research. First, research should identify relationships between obstacles and actual rates of participation. Understanding these relationships can help prioritize what obstacles are most important to address in the short- vs. long-term. Second, research should investigate relationships between obstacles and psychosocial outcomes of youth and their caregivers. Longitudinal data are necessary to identify the direction of these relationships; in some cases, obstacles may contribute to poor outcomes (e.g., depression), whereas in other cases, poor outcomes may contribute to obstacles to participation. Understanding causality is essential to the development of effective interventions.

Limitations

This study had some limitations. First, participants were recruited from a single-hospital system, and thus may not be representative of the general pediatric SCI population. Second, analyses revealed a few significant differences between the participants who were included in analyses and those who were not; thus, the group reporting barriers may not accurately reflect the entire study sample. As stated above, these 'non-participants' were excluded because they did not answer the open-ended question about obstacles. Future research should attempt to ascertain information about obstacles to participation from the broader group of youth with SCI and their caregivers. Third, because caregivers reported obstacles to their child's participation in an open-ended questionnaire format, details were sometimes sparse. Obstacles were categorized as appropriately as possible given the information available; however, future research should further investigate how these obstacles can best be classified. Finally, obstacles to child participation were identified via caregiver-report;

future research should examine whether these obstacles are a function of the child's disability status, caregiver perception of their child's situation, or some interaction of these. Related to this, future research should explore child-reported obstacles as well. Interestingly, no parent-internal obstacles emerged from responses; it is possible that some caregivers may limit their children's involvement, but do not recognize that they are doing so. Asking for youth-reported obstacles might yield more balanced results.

Conclusion

This mixed-methods study examined caregiver reports of obstacles to participation for youth with SCI. Analyses revealed that obstacles limit participation for the majority of youth with SCI, and are related to child, caregiver, and community characteristics. Clinicians should work with youth and families to identify and address these obstacles, in order to increase participation in school and community activities. This study enriches our understanding of youth with SCI and their caregivers, and adds to the body of research on participation for youth with disabilities. This knowledge is essential to providing families with the services and supports they need.

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