

Barriers to community participation: Teens and young adults with spina bifida

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Abstract. This study identified the baseline participation rates for 101 teens and young adults ages 10–32 years old with a diagnosis of spina or lipomenigocele bifida in various domains: school, employment, community activities, physical activity and peer social relationships. The goal of the study was also to identify barriers to community participation. Our findings demonstrate that overall participation is low in several domains. Community participation is low with only 30% partaking in an organized community activity at least once a week. Multiple individual, family, and environmental barriers were identified by participants and their family. The most frequent barriers identified were low motivation (38%), lack of information (25%) and time constraints (21%). Barriers need to be addressed on an individualized basis as well as addressing the community as a whole. Future plans are to intervene based on the barriers and reassess participation at 6 months and a year with the goal of increased long term participation, employment, quality of life and social relationships.

Keywords: Participation, barriers, spina bifida, young adults

1. Introduction

Adults with spina bifida are an increasing population due to advancements in medical and surgical management for hydrocephalus, back closure, and neurogenic bladder. Survival to adulthood is now over 85–90% for people born with spina bifida [10]. The advancements in medical management as well as the fields of rehabilitation, mobility aids, accessibility, and technology have improved community access for people with disabilities. Changes in law and policy have also helped increase the integration of all people with disabilities during the last 50 years. Despite these changes, participation and integration in society for many people with disabilities still remains low.

Participation has become an important component of rehabilitation research, both in pediatric and adult care. The World Health Organization's revised International Classification of Functioning and Disability (ICF) framework defines participation as "involvement in life situations" [30]. Participation takes place in a variety of domains and is affected by the interaction of health related factors with environmental and personal factors.

The nine domains of participation include learning and applying knowledge, general tasks and demands, communication, mobility, self care, domestic life, interpersonal interactions and relationships, major life areas and community. The ICF model also highlights five external barriers which may influence participation: products and technology, natural and man made environments, support and relationships, attitudes, and services, systems and policy.

Participation in leisure and recreation activities is important for people with and without disabilities. Leisure activities not only provide enjoyment, but provide an opportunity to develop a positive self concept, build social relationships, and benefit mental and physical health [25].

Participation in community activities remains low for children and young adults with disabilities compared to peers without disabilities [7,18,20]. Brown and Gordon found that children with disabilities participated in less varied activities, more sedentary activities, spent less time with peers, and participated in more activities at home [7]. Law et al. reported that children with physical disabilities participated less often in formal

activities. Formal activities have structure, rules, and planning, which help develop life skills. Their study found that only 60% of children participated in a formal activity at least once a week [18].

Previous research found that people with disabilities participate less in physical activity [18,20,28,30]. Physical activity is important for strength and function, as well as mental health. Maher et al. found that adolescents with cerebral palsy were less physically active and involved in less structured and lower intensity activities in comparison to matched peers without a disability [20]. As well, Law et al. found that children with complex physical disabilities participated on average in only 3 out of 10 physical activities, which was concerning due to the high levels of childhood obesity [18]. The data from Healthy People 2010 reports that 56% of adults with disabilities do not participate in physical activity compared to 36% of adults without disabilities [28].

Studies on acquired disabilities have also shown that participation is an important factor in quality of life [1, 26,27,30]. Tonack et al. found that community participation was one of the few variables that made a significant impact on predicting life satisfaction in a sample of adults with spinal cord injury [27]. As well, Kinney and Coyle indicated that leisure satisfaction was the most significant predictor of life satisfaction [16]. Tasiemski et al. reported higher satisfaction with life for participants who were involved in sports or physical recreation compared to those who were not [26].

We know from the literature that there are multiple barriers that affect participation in various activities for individuals with disabilities. Barriers have been identified in several contexts including the individual, family and environment [3,4,14,15,19,21,24,29,30]. King et al. conceptualized a theoretical model which highlights 11 environmental, family and child factors which are related to children's participation. The major significant factors predicting participation include the child's functional ability, the child's activity preference, and the family's participation in social and recreational activities [15]. Bent et al. found that both health status and psychological factors impact participation for young people with physical disabilities [4]. Law et al. reported on various environmental barriers including accessibility, accommodation, recourse availability, social support, and equality [19]. These studies highlight the multitude of factors affecting participation and the importance of intervening on multiple levels.

The authors of this study are not aware of any studies which assess participation rates and barriers for youth

and young adults with spina bifida. From the literature, as well as clinical observations, it is known that baseline community participation for young adults with spina bifida is low. In order to address this issue, the clinic developed the role of a transition coordinator to directly work with teens and young adults. For quality assurance and program development, clinical information was collected on baseline participation and barriers in order to plan and prioritize services. The purpose of this paper is to describe this baseline data in order to better understand the population and design services that are related to patient needs.

2. Method

2.1. Participants

Data was collected during individual clinic visits at the Spina Bifida Clinic at Children's Memorial Hospital (CMH) in Chicago, IL and the Adult Spina Bifida Clinic at the Rehabilitation Institute of Chicago (RIC). Inclusion criteria were a minimum age of ten with a diagnosis of spina bifida or lipomeningocele, willingness to meet with the transition coordinator during their clinic visit day, and medically stable. Exclusion criteria were imminent plans for surgery or illness, which would preclude participation in activities. A convenience sample was used, with the goal of meeting with all youth and young adults attending clinic.

2.2. Procedure

Patients met with the clinic transition coordinator, a licensed social worker, during a visit at either CMH or RIC. Information was gathered through the clinic visits as well as chart review on the patients' medical condition, secondary conditions of spina bifida, function/mobility, psychosocial assessment, education, employment/volunteer, community activities, physical activity, and social time with peers. In addition, barriers to community participation were assessed. For patients with cognitive delays, parents/guardians provided the majority of the information for the assessment. The social worker targeted patients that were ten years and older when they attended the clinic. Referrals were also made to the social worker from the clinic physicians and nurses. Some patients were seen by the social worker multiple times at various clinic visits. Most patients had phone follow up with the transition coordinator after their initial visit in order to reassess com-

munity participation goals and referrals. Patients that were not followed did not need additional support to increase community participation at this time. Data was collected from September 2007 to March 2008. The information presented here is part of a larger transition study, with hospital ethics approval.

3. Results

3.1. Participant characteristics

The sample included 101 patients (45 males and 56 females). Of the 101 patients, 66% were seen at CMH and 34% at RIC. Patients' type and level of spina bifida were 6% lipomeningocele, 14% sacral level, 55% lumbar level and 25% thoracic level. A majority of patients have a shunt (70%), although data was missing for 11% of the sample. Patients' age was categorized into 4 age cohorts, 10–14 (12%), 15–17 (19%), 18–24 (47%) and 25–32 (23%), with a mean age of 20.8. Patients were predominately Caucasian (50%). In addition 28% were Hispanic, 18% Black, 2% Asian and 3% other. Of participants 18 years and older, the majority were living at home with a parent or guardian (68%). A smaller group live alone (23%) or with a roommate (9%). Of the 22 individuals living alone or with a roommate, 50% live in an apartment building created for people with spina bifida. The tenants live independently and have access to a program director during the day whose role is to promote adult life skills and community participation. From the sample, 60% receive Medicaid or Medicare, 31% have only private insurance, and 9% have both private and public insurance. The key informant during the interview was the young adult (58%), both the young adult and parent/guardian (36%) and the parent primarily (7%). Table 1 highlights the characteristics of the sample.

3.2. Education status

Of patients up to 21 years old ($n = 35$), the majority are currently in high school (77%) and 23% are in middle school. Of those who completed high school ($n = 62$), 34% have had no further education after high school, 19% previously completed some college classes, 27% are currently in college, and 19% completed a college degree program. Only 3 of the 17 young adults attending college live on campus at a four year university. Lastly, of the 12 young adults who have completed a college degree, only 3 are currently employed full time.

Table 1
Characteristics of patient sample ($n = 101$)

Characteristic	Number	%
Sex		
Male	45	45.6
Female	56	55.4
Age, Y		
10–14	12	11.9
15–17	19	18.8
18–24	47	46.5
25–32	23	22.8
Diagnosis		
Lipomeningocele	6	6.2
Sacral Level	14	14.4
Lumbar	53	54.6
Thoracic	24	24.7
Shunt		
Yes	71	70.3
Missing	11	10.9
Ethnic Background		
Caucasian	50	49.5
Hispanic	28	27.7
Black	18	17.8
Asian	2	2.0
Other	3	3.0
Clinic		
CMH	67	66.3
RIC	34	33.7
Living Arrangement		
>18 years and old		
With parents	47	68.1
With self	16	23.2
With roommate	6	8.7
Insurance		
Medicaid/Medicare	61	60.4
Private	31	30.7
Both	9	8.9

3.3. Employment/volunteer status

We looked at employment and volunteer rates of patients 18 years and older. Of this group ($n = 70$), 14% are currently competitively employed full time and 10% are working part time, under 30 hours a week. However, the majority (67%) are unemployed. Of those unemployed, only 14% are currently seeking employment either on their own or using a vocational rehabilitation program and 7% are unable to work due to medical problems or cognitive delays. Patients working full time are 20 years and older, the majority live on their own or with a roommate (60%) and all have middle to low level lesions. In comparison, young adults working part time are 18 years and older, mostly live at home with a parent/guardian (86%) and include individuals with high level lesions. A small group (9%) volunteer at least twice a week. See Fig. 1 for employment and volunteer participation rates.

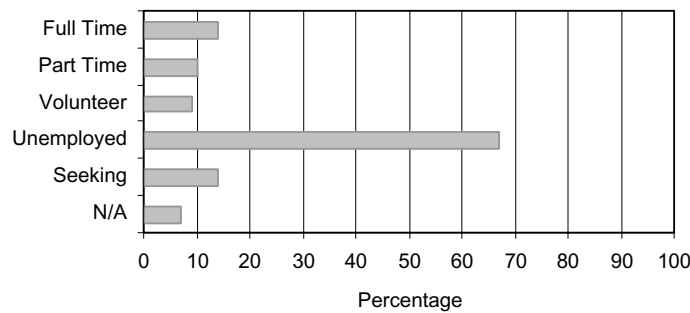


Fig. 1. Employment rates of participants 18 years and older.

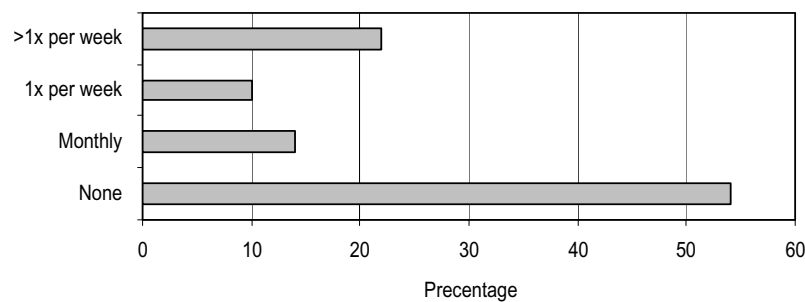


Fig. 2. Community participation rates.

3.4. Organized community participation

Our clinic wished to document current organized community participation rates. This includes extracurricular and community activities that are structured, such as organized sport programs, church programs, and volunteer opportunities. This does not include paid employment. We found that 54% are uninvolved in any organized activities, 14% participate monthly, 10% participate at least once a week and 22% participate more than once a week. Overall, 32% are involved in community activities at least once a week. These participation rates did not appear to vary significantly by age. Of patients aged 10–17 years, 34% participate at least once a week and 50% are uninvolved. Similar rates were found for patients ages 18–32, with 32% involved at least once a week and 56% uninvolved. In terms of the level of lesion, we found that young adults with lower level spina bifida, such as lipomeningocele and sacral level, are involved less in weekly community activities (23%) compared to young adults with lumbar (34%) and thoracic (35%) level lesions. As well, within these community activities, 8 individuals have some type of leadership role, such as responsibilities on an event committee or managing a team. These leadership roles may be important because they offer opportunities and experiences for active participation such as

skill building and planning. See Fig. 2 for community participation rates.

A small group of 4 young adults are uninvolved in any type of educational program, employment or community activities. They report boredom and spending their time playing video games, watching TV, or using the internet at home. This small group includes young adults ranging from 20–30 years of age.

3.5. Physical activity

Physical activity was measured by the number of times a young adult participated in physical activity, which included physical education, team sports, and independent exercise. The scale included high (activity more than once a week), medium (activity once a week), low (activity at least once a month) and none. We did not focus on the duration of the activity, as this varies greatly for each person based on their physical abilities. Twenty percent participate in high frequency, 5% medium, 12% low and 58% none. Overall, 25% participate at least once a week. Only 7 people of 17, both male and female, are involved in an organized sports activity, including adaptive and non adaptive programs.

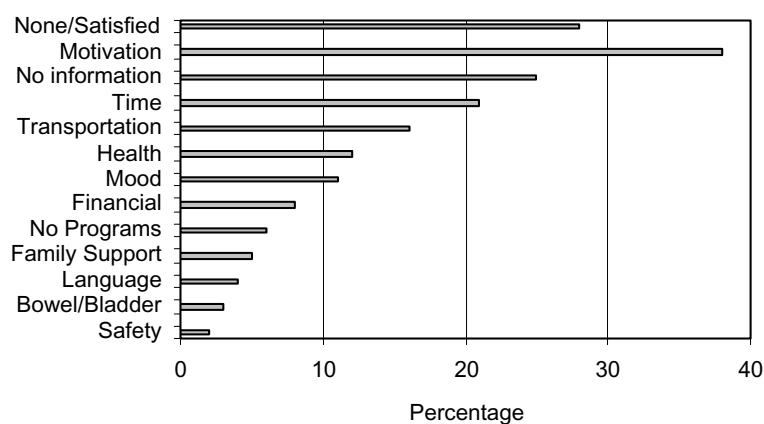


Fig. 3. Barriers to community participation.

3.6. Peer social relationships

Peer social relationships were measured by the number of times meeting with peers outside of school, community activities, and work. In our sample, 58% meet with friends at least once a week, 10% meet monthly, and 32% have no peer interaction outside of school or other activities. As well, 15% of the young adults reported that they were currently dating.

4. Barriers to community participation

In order to assess barriers, during clinical assessments patients and families were asked the question: "What prevents you from being more involved in extracurricular and community activities?" Other barriers were identified through the psychosocial assessment. Patients were allowed to identify multiple barriers. Barriers noted from most common to least common included no motivation/desire for participation (38%), lack of information (25%), time constraints (21%), transportation, health, mood/fear, financial, lack of programs in community, lack of family support, language barriers, bowel/bladder, and safety. About 30% percent of the sample describes being satisfied with their community involvement, and did not identify other barriers. See Fig. 3 for frequency of barriers reported.

4.1. Social work intervention

Based on these barriers, interventions were formulated and carried out to reduce the impact of the barriers. We documented the amount of contact over a 6 month period to understand the amount of resources

used with each individual. The majority of follow up was done through phone contact, depending on the patient's needs. Levels of follow up intervention were classified as follows: high (contact 2–5 times a month, provide information, facilitate referrals, assist in communicating with doctors and other agencies, follow up on goals and offer emotional support), medium (monthly follow up, provide information, set goals, support), low (less than monthly follow up), none (no intervention needed after clinic visit), and unresponsive (patient and family not returning calls). The level of intervention required varied: high (18%), medium (25%), low (33%), none (17%), and unresponsive (7%).

5. Discussion

Our findings of participation rates in a variety of domains match the existing literature on participation. The literature indicates that young adults with disabilities frequently live with their parents into adulthood, have lower rates of employment, experience social isolation, less physical activity and lower levels of community participation. Bowman et al.'s review of adults with spina bifida also showed that the majority of young adults were still living with a parent/guardian [6]. Our current study was conducted at the same facility and may have some overlap of participants. Since Bowman et al.'s study was published, a new transition housing program opened in Chicago, which may attribute to the increase in young adults living independently.

Our sample also had very low employment rates, consistent with Bowman et al. and other literature [6]. Participants in our study included younger individuals, which may also explain the lower employment rates.

Similar to Hetherington et al., no individuals with high level lesions are employed full time [11]. Their study was a cohort that was prospectively followed, whereas our group is a convenience sample of those attending clinic. Individuals from our study may be more likely to have health issues, and have a higher frequency of visits to the clinic. Other factors affecting employment rates may be due to balancing work with disability entitlement programs. Some individuals choose to stay unemployed, volunteer or work part time in order to continue receiving their state health insurance and financial entitlements.

Our rates of community participation were lower compared to research by Law et al., which reported that 60% of participants with various disabilities aged 6–14 years old were involved at least once a week in an organized activity [18]. Law et al. did note a drop in participation for teens versus preteens. We did not find any difference in community participation for those under 18 years and over 18 years old. However, we did find lower participation rates in community activities for young adults with low level spina bifida such as lipomeningocele or sacral level compared to patients with lumbar and thoracic level. This may be due to the fact that individuals with lower level lesions may be more involved in college or employment, which may leave less time for community activities. We did not find any literature on adult community participation to compare our data.

We also found low rates of physical activity. There may be many barriers to accessing opportunities for physical activity which are highlighted in the literature [24]. These findings are also consistent with data from the Center for Disease Control and Prevention on physical activity in adults with disabilities. They report that only 37.7% of adult with disabilities met the national recommendations for physical activity compared to adults without a disability (49.4%) and were more inactive (25.6% versus 12.8%) [9].

Lastly, we identified individuals' participation with peers. Literature on young adults with spina bifida and cerebral palsy has highlighted the importance of friends for young adults [5]. However, these peer relationships are often limited to in school contact. This was a common theme heard among patients in our sample as well. There is a significant number of individuals who do not initiate peer contact. Blum et al. also reported that dating was low among adolescents with spina bifida which is consistent with our sample [5].

The second focus of our study was to identify barriers to community participation and intervene based

on these barriers. We found a variety of barriers in multiple contexts including the individual, family, and environment, similar to the literature [3,4,14,15,19,21,24,29,30]. This confirms the need for interventions focusing on multiple systems. Overall, we were surprised to find that financial, transportation and bowel/bladder were reported less frequently in the sample. Lack of time was a common barrier, and many young adults who are in college or employed may have less time for involvement in other community activities. Low motivation was the most prevalent barrier. Understanding how to influence motivation may help us clinically intervene with patients. Individuals with disabilities who grew up with fewer life experiences may feel unmotivated because they have never experienced high levels of participation and may not see an alternative way for themselves. If they have lived with limited experiences, then there may be no motivation or reason to change behavior. As well, during the adolescent developmental stages, peers become the primary focus, which can often motivate decisions and preferences. As we have seen, adolescents with disabilities often have limited peer interactions and may be less influenced to participate in the activities of their peers [5,12]. There is also some suggestion that youth with spina bifida have reduced goal directed and initiation behaviors. Whether this is learned or innate and whether it can be changed will be a key question for future studies [17]. From clinic observations, it appears that intervening at a younger age may increase the likelihood for change. We have noted that patients in their late 20s and older appear to be more resistant to change. This has implications for our program development and key ages to target interventions.

Research by King et al. has also highlighted the importance that family and children's preferences can have on participation and that they are a strong predictor of youth's participation [19]. King et al. also discuss the importance of assessing individuals for their own interests and creating a plan based on their preferences. It is unlikely that patients will gain motivation for participation in an activity, if it is not meaningful to them. Techniques from motivational interviewing can be used to help patients identify the pros and cons of remaining inactive versus increasing participation.

From this study we identified multiple barriers on multiple levels as is described in the ICF [30]. The ICF model states that participation is affected by the interaction of health related factors with environmental and personal factors. Most of the existing literature has focused on environmental barriers. Our study

highlights that the most frequent barriers are personal factors (motivation and time constraints). This helps us plan and focus our efforts for resources and development of adolescent services in our clinic

6. Study limitations

The purpose of this study was to understand our population and develop programming with the goal of community participation at least one time a week. This study was completed from clinical assessments and chart review, and was collected via self report from patients and families, without a validated measurement tool. A number of community participation outcome measurement tools were considered including the Children's Assessment of Participation and Enjoyment (CAPE), the Preferences for Activities of Children (PAC), the Life-H and others. These tools were not found to be helpful in planning interventions to increase community participation, as they do not measure frequency of participation, which was a key outcome in this study.

In addition, our study used a convenience sample. The participants may have more medical needs, transition issues, and other needs, because patients with these concerns are more likely to come to clinic. Patients who are more healthy or integrated into the community may not be seen in clinic as often. As well, the majority of the sample was 18–32 years old, due to the fact that many of these individuals needed immediate social work intervention to help transfer to adult care. This study was not a formal research study, but the baseline data was used to help develop our transition program. In the future we would like to compare participation with a set of matched peers. We continue to measure changes with intervention prospectively.

7. Conclusion

This study aimed to document the baseline participation levels for a sample of 101 teens and young adults with spina bifida and collect information on patient and family identified barriers of community participation. We found that participation was low in a variety of domains including independent living, employment, community participation, physical activity, and dating. Barriers to community activities were more personal than external factors. We are using this information to plan patient need related services, and prioritizing the

transition coordinator's roles. The overall goal is to increase community participation in hopes that it will lead to increased long term participation, employment, social relationships, and ultimately quality of life.

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