The Importance of Leisure in the Lives of Persons With Congenital Physical Disabilities

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虽然职业治疗师强调自我护理、生产力和休闲这三个职业领域的平衡，但休闲常常被忽视，无论是研究文献还是临床实践。很少有研究关注成人先天性残疾者的休闲活动的好处。本文的次级分析是九名参与者（30-50岁）的访谈协议，这些参与者患有脑瘫或脊柱裂。访谈的主要目的是确定残疾人生活中的转折点的保护性过程。这项次级分析使我们能够确定休闲活动的好处和意义。参与者报告说，参与休闲活动提供心理健康和身体健康的益处，享受，发展自我概念和提高自尊，以及建立和增进社会关系的机会。所有这些效益使人们能够通过做事、归属和理解自己的世界来找到生活的意义。


职业治疗师相信职业是健康的一个决定因素（American Occupational Therapy Association [AOTA], 1993; Canadian Association of Occupational Therapists [CAOT], 1994; Law, Polatajko, Baptiste, & Townsend, 1997）。积极健康是当一个人有选择、能力和机会参与自我护理、生产力和休闲时实现的（AOTA, 1995; CAOT, 1996）。

虽然休闲在职业治疗师的临床实践中显得重要，但是Suto（1998）在过去的15年里在两个主要的北美职业治疗杂志中只发现了六篇关于休闲的研究文章——《American Journal of Occupational Therapy》和《Canadian Journal of Occupational Therapy》。”

Occupational therapists believe in occupation as a determinant of health (American Occupational Therapy Association [AOTA], 1993; Canadian Association of Occupational Therapists [CAOT], 1994; Law, Polatajko, Baptiste, & Townsend, 1997). Positive health is achieved when one has the choice, ability, and opportunity to engage in self-care, productivity and work, and leisure (AOTA, 1995; CAOT, 1996).

The Importance of Leisure

Occupational therapists emphasize the need for a balance in the three occupational areas of self-care, productivity, and leisure (Law et al., 1997). North American society, however, seems to place more value on the areas of self-care and work. Bathing, grooming, dressing, and eating are essential tasks performed daily and often are focused on by occupational therapists when helping persons develop or regain independence. Productivity holds high value, resulting in individuals characterizing their self-worth through employment (Reid, 1995). Leisure often is seen as activities to fill “extra” time available after caring for oneself and completing one’s obligations at work (Primeau, 1996). Leisure, however, also has been identified in various studies as an important factor in improving life satisfaction and overall well-being (Cassidy, 1996; Day & Alon, 1993; Kinney & Coyle, 1992).

Although leisure appears to be important in the clinical practice of occupational therapists, Suto (1998) found only six research articles about leisure published in the past 15 years in the two leading North American occupational therapy journals—The American Journal of Occupational Therapy and the Canadian Journal of Occupational Therapy.
The American Journal of Occupational Therapy (Bundy, 1993; Johnson, 1988; Jongbloed & Morgan, 1991; Krefting & Krefting, 1991; McKinnon, 1992; Primeau, 1996). Suto expressed surprise with this lack of theoretical and applied research on leisure. In being client-centered, occupational therapists theoretically focus on all occupations that are meaningful to clients, including leisure. To do so, however, occupational therapists need to gain a better understanding of how leisure affects the lives of persons with disabilities (Suto, 1998). Suto identified the need for a stronger knowledge base to enhance interventions and provide credibility for focusing on leisure occupations within occupational therapy practice.

In the research on leisure to date, findings indicate that involvement in leisure activities can have several positive benefits on physical health, mental health, life satisfaction, and psychological growth for adults without disabilities (Cassidy, 1996; Coleman, 1993; Tinsley, Hinson, Tinsley, & Holt, 1993). Although research literature exists on the leisure activities of adults with physical disabilities (Dempsey & Simmons, 1995; Liverton & Patterson, 1997; Lockwood & Lockwood, 1991; Pollock & Stewart, 1990; Stevenson, Pharaoh, & Stevenson, 1997), little research exists on the benefits of leisure for these individuals. Some studies have been completed with populations with acquired disabilities, including stroke, spinal cord injury, rheumatoid arthritis, and cancer (Drummond & Walker, 1995, 1996; Jongbloed & Morgan, 1991; Reynolds, 1997; Taylor & McGruder, 1996; Unruh, Smith, & Scammell, 2000). Overall, leisure appears to have similar benefits for persons with acquired disabilities as it does for persons without disabilities. The most common benefits identified for both populations include stress reduction, improved coping skills, companionship, enjoyment, relaxation, and a positive effect on life satisfaction and well-being. Involvement in leisure, however, appears to have an additional benefit solely for persons who have acquired a disability, and that benefit is an enhanced adjustment to living with a disability (Reynolds, 1997; Taylor & McGruder, 1996).

The literature on the benefits of leisure in adults with congenital disabilities is sparse. Kinney and Coyle’s (1992) study is unique because it included persons who had either a congenital or an acquired disability (e.g., spinal cord injury, cerebral palsy, multiple sclerosis, visual impairments). Similar to other studies, Kinney and Coyle found that leisure was an important component in the lives of persons with disabilities and was correlated positively with life satisfaction. Furthermore, they found positive correlations between leisure satisfaction and self-esteem as well as negative correlations between leisure satisfaction and depression. One interesting finding was that persons with acquired disabilities had lower scores than those with congenital disabilities on both life satisfaction and leisure satisfaction.

If we broaden the search to research on participation in society by persons with disabilities, the literature base expands, but the picture does not become much clearer. This lack of clarity is because of the different operational definitions of participation (participation in recreational activities, vocational activities, self-care, etc.) in addition to the different populations studied (persons with mental retardation, acquired disabilities, congenital disabilities). Participation, like leisure, provides the opportunity to form relationships, develop skills, achieve mental and physical health, and determine meaning and purpose in life (Kinney & Coyle, 1992; Lyons, 1993). We know that societal participation of adolescents with disabilities is less than that of adolescents without disabilities and decreases as adolescents with disabilities age (Brown & Gordon, 1987; Crapps, Langone, & Swain, 1985; Dempsey & Simmons, 1995). Furthermore, investigations of the activities of adults with disabilities have indicated participation in passive, often home-based activities (Dempsey, 1991; Liverton & Patterson, 1997; Pollock & Stewart, 1990). The most common leisure activities for adults with disabilities include watching television, listening to music, reading, and arts and crafts (Lockwood & Lockwood, 1991; Pollock & Stewart, 1990).

Although the studies discussed provide both quantitative and qualitative information about the impact of leisure involvement for persons with acquired disabilities, aside from the study completed by Kinney and Coyle (1992), very little research has investigated the meaning of leisure involvement to adults with congenital disabilities, such as spina bifida and cerebral palsy. These persons have had physical disabilities and associated difficulties their entire lives. Their patterns of leisure involvement, the benefits they receive from leisure involvement, and their perspectives on the importance of leisure and its impact on life satisfaction may be different. This difference may be especially true given that Kinney and Coyle demonstrated that persons with acquired disabilities had lower scores in both life satisfaction and leisure satisfaction than persons with congenital disabilities.

Furthermore, persons with congenital disabilities may have different needs related to leisure involvement. Persons who acquire a disability at a later stage in life are more likely to have leisure interests to which they want to return and to which they may or may not be able to return. The finding that leisure activities for young adults with congenital disabilities tend to be passive, socially isolating events, such as watching television and listening to music (Lockwood & Lockwood, 1991; Pollock & Stewart, 1990), may indicate
that persons with congenital disabilities may need more assistance in determining leisure interests and abilities because they do not have past experiences similar to persons with acquired disabilities. Finally, research has shown that persons with disabilities are at risk for a number of negative life outcomes and poor psychosocial adjustment (Clark & Hirst, 1989). Socially isolating activities may contribute to this risk for negative life outcome.

The Present Study

This article investigates leisure in the lives of adults with congenital disabilities. This secondary analysis was obtained from interviews that investigated turning points in the lives of persons with disabilities (King, Cathers et al., 2001). Turning points were defined as positive or negative, cumulative or sudden, understandings or events, and active decisions or fortuitous happenings in people's lives. Participants were interviewed on two separate occasions about the turning points and the meaning of these turning points in their lives. Qualitative analysis was used to get the rich source of information and understanding that can come only from people sharing their life stories (Clark, Carlson, & Polkinghorne, 1997).

Through the sharing of these turning points, many more issues emerged from the stories. In reality, we ended up with the life stories of 9 persons. Events from their lives as recounted to them by parents (e.g., being born and being told by physicians that they would not amount to anything) up to events of the past few years (e.g., divorce) were shared. In our first analysis, we examined the process of turning points and how they affected the lives of the persons we interviewed. Generally, meaning in life was derived from turning points that exhibited a sense of belonging, doing (either achievement or accomplishment), and understanding of self (King, Cathers et al., 2001). Clearly, occupation provided meaning to the lives of these persons. In reviewing the categories that we coded in determining the purpose of turning points, leisure emerged as a topic for 8 of the 9 participants. The purpose of the present study, therefore, was to gain the perspective of persons with congenital disabilities (i.e., spina bifida, cerebral palsy) through a secondary analysis of the data associated with the theme of leisure to determine the meaning of involvement in leisure occupations in these persons' lives.

Method

Participants

Nine persons (4 women, 5 men) between 30 and 50 years of age ($M = 38.4$ years) with congenital disabilities participated in this study. We decided to include persons between 30 and 50 years of age because Erikson (1963) characterized this period of middle age as one in which we take stock of our lives and can reflect on past experiences. Turning points can only be recognized as such when one has had a chance to live beyond the events and contextualize them in one's life history. We believed that interviewing participants younger than 30 years would not have provided as rich a context.

Five of the participants had cerebral palsy, and 4 had spina bifida. All had completed high school, and 4 had achieved a postsecondary education. At the time of the interview, 4 participants were employed for pay, and 4 were not (employment information was missing for the 9th participant). In terms of their physical functioning, 7 believed that their disability limited their lives somewhat, and 2 believed that it limited their lives to a greater or fair extent. We excluded persons currently receiving therapy or medication for psychological reasons because we believed that these might unduly influence their retrospective look at their lives. Given that we needed to audiotape the interviews for transcription purposes, it was necessary that someone unfamiliar with the person could aurally understand the information provided.

We advertised our study in local papers and through newsletters delivered to various community agencies. Potential participants telephoned the research assistant, who screened them for inclusion and exclusion criteria at that time. One person was excluded because her speech was unintelligible to the interviewer. Participants were paid a $50 honorarium for sharing their life stories.

Procedure

An introductory letter asking the participants to begin thinking about key turning points in their lives was sent before the first interview. Participants were given a broad definition of turning points (positive or negative, cumulative or sudden, understandings or events, active decisions or fortuitous happenings). Interviews were conducted either at the participant's home or in an interview room at the local treatment center where the interviewers were employed. Two experienced interviewers conducted all interviews. Before participating in the interview, all participants were free to ask questions and signed a consent form.

We used a process referred to as "recursive interviewing." In recursive interviewing, the participants are given a transcript of their first interview and asked to read it before the second interview. Recursive interviewing allows the interviewer to obtain all the details of a concept by relooping and asking for clarification until the interviewee can add nothing new (Bigelow, Tesson, & Lewko, 1996). In
In this case, turning points were the focus. By providing the participant with a copy of the first interview before participating in the second interview, he or she could review the turning points raised in the first interview and focus on the process in the second interview. We saw a number of benefits of recursive interviewing: (a) participants were able to give ongoing consent to having their stories used in the study (i.e., they were able to see the interview in print before the final report stage); (b) it may have helped to reduce performance anxiety by clarifying that the interview was not a test; (c) it was participatory on the part of the participant; and (d) it did not require writing skills (either fine motor or technical).

**Interview 1.** The goal of the first semistructured interview was to have participants identify the key turning points in their lives. The interview guide consisted of broad questions, allowing the interviewer to focus on a subject area while also wording some questions spontaneously and building conversation (Crabtree & Miller, 1991). Key questions were: (a) Have there been key turning points (important times, insights, or events) in your life? (b) What were they? (c) When and how did they occur?

At the end of Interview 1, the interviewer and participant generated a list of the key turning points identified by the participant. The first interview was transcribed, and a copy was sent to participants to stimulate thinking about each turning point, how it came about, what made it important in their lives, what reactions they had, and what helped or hindered adjustment.

**Interview 2.** Approximately 3 weeks later, participants met with the interviewer again. In the second interview, information was obtained about (a) the meaning and effects of the turning points in participants’ lives, (b) factors that helped them (and those that hindered their adaptation), and (c) the way in which these factors operated and interacted with one another. The interviewer explored themes raised in the participants’ own first interview.

All interviews were transcribed verbatim, and any identifying information was removed to protect the participants’ identity. To obtain background information, participants were asked to complete a questionnaire at the end of the second interview. This questionnaire provided information on general demographics (e.g., age, gender, marital status, educational background, employment) as well as on satisfaction with areas in their lives (e.g., perceived competence, ability to manage life, engagement in meaningful activities).

**Data Analysis**

We used a textual or content analysis approach to the data, which involves coding statements on the basis of their key concepts, clustering these coded concepts into themes, and revisiting themes several times to delineate and refine them (Crabtree & Miller, 1991; Fiese & Bickman, 1998). After all interviews were completed, all nine members of the research team (from the disciplines of occupational therapy, psychology, social work, sociology, and speech and language) carefully read the transcripts to gain an overall sense of the participants’ life stories. Individually, they generated a list of all the main ideas discussed in the interviews. These ideas were shared at research meetings. At this point, two of the investigators (one of whom was an interviewer) developed a detailed coding scheme. This coding scheme was shared with the other researchers for feedback. The coding scheme was systematically refined (a total of 12 versions) as new transcripts were read and thought about in terms of their major chunks of meaning. The final version of the coding scheme consisted of more than 1,400 codes, grouped according to 37 categories, such as turning points, life lessons, helpful factors, hindering factors, education, physical and cognitive health, leisure, and coping strategies. In the final analysis, we had 29 (of the 1,400) codes relating to the category of leisure. The final grouping of codes was done by a research assistant.

To ensure the codes were applied consistently and to check for coding drift, at three different times another researcher independently coded 10 randomly selected pages from a randomly selected transcript (between 20% and 25% of each transcript). The percentage agreement was 75% at the beginning of coding, 79% halfway through coding, and 83% at the end of coding. These levels of agreement are above the accepted levels of 65% to 75% that are considered to indicate good reliability in qualitative research studies (Boyatzis, 1998). The research assistant then entered all the coded text segments into Ethnograph software (Seidel & Clark, 1984). The researchers used this software program to select and extract sections of coded text and to see which codes tended to overlap. Using the coded transcripts and Ethnograph printouts, the research team made observations about important, recurring themes (e.g., turning points in life, major helping factors, major hindering factors, life lessons). The themes were discussed several times by the team to achieve consensus about emerging concepts.

All participants in the study were invited to attend a member-checking group to address the trustworthiness of the data (Fiese & Bickman, 1998; Lincoln & Guba, 1985). They reviewed the themes prepared by the investigators and had the opportunity to confirm or deny the interpretation of the information. None of the participants expressed concern with our interpretation of their stories.

Analysis of the sections of the transcripts related to the leisure category in the coding system was performed inde-
Results

The major themes that emerged with respect to leisure were mental and physical health benefits, enjoyment, proving self, and friendship building and belonging. In addition, the participants shared both barriers and enablers to engagement in leisure activities.

Mental and Physical Health Benefits

One participant identified “taking a vacation to the south as a priority every year.” This participant saved money specifically to go on vacation, stating “that vacation is my sanity.” Other participants identified the physical benefits of leisure involvement. One participant who had been at one time a competitive athlete stated, “I should be involved athletically to keep in shape.” For another participant, woodworking was important in “keeping [my] hands supple.” He also exercised daily, indicating that it “gets me real loose.” Overall, this participant believed that exercising and involvement in other leisure activities “allowed [me] to stay reasonably active.” These participants seemed to recognize the importance of leisure as a form of self-care; they seemed to believe that involvement in leisure contributes to both mental health and physical health.

Enjoyment

Several participants expressed the pure enjoyment of engaging in leisure activities. This process of seeing leisure as a state of mind rather than one of distinct activities has been discussed in the research on leisure activities (e.g., Kleiber, Larson, & Csikszentmihalyi, 1986). One participant described his experience as a drummer: “We weren’t a famous act, but we did raise sunshine into other people….I did get a lot of enjoyment with that.” A second participant described diving as “something that I thoroughly enjoy—it is just a very relaxing sport for me.” Traveling provided enjoyment for a third participant: “I enjoyed going to [the East Coast] because that is where I have family members….Those trips I really enjoy.” A final participant stated, “I really enjoy it over there [seniors’ center], so my life at this point is pretty full.”

Proving Self

A third theme identified in this study related to the role of leisure in proving oneself and developing self-worth. One participant in particular discussed this issue extensively. She was involved as an athlete, coach, referee, and member of a sports committee. All these accomplishments seemed to be very important to her concept of self. She described the meaning of being part of the team: “I always wanted to be a competitive swimmer, but I really never thought it would be possible…the next year I was named to the team. That was just like a dream come true.” She continued to explain the value of her accomplishments:

“Really, the medal is all part of that, but the medal hangs on a wall in a corner somewhere. That medal part is not important. The important part was learning that I was something, that I could do something….It is about being able to accomplish something.

This participant specifically stated that being a competitive athlete gave her “a bit more self-worth.”

Two participants discussed the importance of being acknowledged in magazine articles for their accomplishments. In keeping with the findings of King, Cathers et al. (2001) that accomplishments were important turning points for people, participants seemed to be able to make meaning in their lives because of their accomplishments. One was featured in a magazine for his woodworking: “I didn’t win a contest, but I got an acknowledgment in a scroll saw magazine.” This participant indicated that the payment he would receive for doing work featured in the article would lower his pension payment; however, for him “the pleasure of being able to do that and have it recognized like that….is worth it.”

The second participant wrote a one-page article about her scuba diving experiences. A reader of the article recognized the value of her expertise and asked her to write a more extensive article for a federal association. The participant identified recognition of her writing ability and expertise in diving as a turning point in her life. She also recognized her leisure pursuit as her greatest accomplishment: “Still my greatest accomplishment was learning how to dive.”

Friendship Building and Belonging

This theme relates to findings from King, Cathers et al. (2001), who determined that belonging is a key factor in helping persons with disabilities make meaning in life. Participants discussed meeting friends and building relationships while engaging in leisure activities. Traveling was identified as one leisure activity that contributed to friendship building. One participant discussed vacationing by herself in order to meet people: “I put myself in a situation. I go by myself on trips, and I have to meet people in order to make it a good trip.” A second participant identified meeting people with similar disabilities through her travels with a sporting team.
It’s extremely unique. You see people from countries all over the world. You see people that are similar to you. You see people who have more abilities than you have, who do less with it. You see all kinds. The spectrum is tremendous. Through meeting new people, this participant also stated that she learned how to cope with difficulties in her life.

The other component of friendship building that was evident for 3 participants was being part of a team. Interacting with team members helped establish relationships with others and provided these individuals with a sense of belonging. One identified recognition of being a team member as an important event in her life. She discussed being the scorekeeper for her sister’s baseball team: “They sent me a postcard, and they gave me a trophy for being scorekeeper. So that was kind of neat…to be recognized as part of the team and get a trophy and everything like that.” She discussed feeling part of the team, even though she could not play the sport. This participant also described bowling with friends and the importance of being able to contribute her score to the team score. Here we see the issues of belonging and doing contributing to her life meaning.

Similarly, another participant described being manager of the college broomball team. She stated, “I became a team player when I joined the broomball team, and they made you feel like a part of the team even though you weren’t an actual player….I had to make sure that certain things were done, and taking on that responsibility, it made me feel as important as they were on the team, which was really important.

**Barriers and Enablers to Engagement in Leisure Activities**

Aside from these benefit-centered themes, two other components related to a participant’s involvement in his or her leisure occupations became evident from analysis of the interviews. These components included barriers and enablers to leisure involvement.

*Barriers.* The barriers to engagement in leisure activities identified by the study participants varied depending on the individual’s leisure activity. One participant in a wheelchair discussed the difficulties that he had flying on an airplane: “It is hard for a handicapped person to travel, especially on the airplane.” He described having to use an airline wheelchair to get into the plane and then having to transfer into a seat on the plane. Because this process was long and tiring, this participant believed that it would be easier if seat openings were available on the plane into which wheelchairs could be wheeled and strapped in place.

Participants also identified transportation difficulties as barriers to engaging in occupations. One found it frustrating to always have to depend on wheelchair transit to do anything. He described having to schedule specifically when he wanted to go somewhere and when he wanted to be picked up. He identified the role of friends in helping him to overcome this barrier, stating, “It’s important for me to have friends that are willing to pick me up so that I can have a somewhat normal life, and my life isn’t so rigid.”

Another barrier identified by some participants was lack of support in engaging in various occupations. One of the main reasons for this lack of support appeared to be the result of a lack of awareness and knowledge regarding an individual’s abilities to engage in leisure activities despite his or her disability. One participant stated, “If I had stopped because people told me I couldn’t do it, I would have been out of the game a long time ago….Out of the game of life I mean.” Another participant discussed the physician’s lack of knowledge regarding her abilities to engage in scuba diving: “My doctor didn’t know anything about scuba diving. So she had no idea whether I could or couldn’t or whether I should or shouldn’t.” This participant also identified the lack of knowledge of instructors involved in the leisure activity: “The instructors have to know how to handle the person with the disability.”

Participants discussed the prejudice of others toward their disability and being involved in leisure occupations. One described the shock people expressed when she became a referee at a sporting event: “I was the first person with [a specific disability] to be a referee…the reactions from the players and coaches were astounding. They were all shocked. Nobody thought somebody with [a specific disability] could ref [a specific sport].”

*Enablers.* Participants discussed the support they received from others that enabled them to engage in leisure activities. The participant just identified was quick to indicate that although the coaches and players were shocked that she could referee, they also were very encouraging: “They’d all come up. The…team came up and they kept saying I did a brilliant job….To me that was the ultimate compliment because that came from the coaches and the players.” This participant also identified family and her physical education teacher in high school as major supports.

Another participant identified accommodations that enabled her to engage in her leisure occupations. She identified adaptations made to her equipment, such as adjusting the weight belt she used for scuba diving to accommodate for her ileal conduit. She also described accommodations that were made by a tour company during one of her vacations:

When I first got there, there were no hand rails up to the cottage, so it was hard because I couldn’t get up and down into the cottage. I had to go up about eight steps, and that
is hard for me to do without a handrail. I went out for a walk to look around a bit. When I came back, there was a handrail built.

Finally, one participant was part of an organization of athletes involved in public speaking as role models to children with disabilities. She believes that it is very important for children to hear about her accomplishments:

[I] get to talk to these kids about what I have done, and they turn around and see what they can do in their life… it helps them to encourage them to go after their own dreams. Just to realize that you don’t have to have a perfect life or body to be somebody. You make or break your own destiny.

This participant acts as an enabler herself for other persons with physical disabilities.

Discussion

Overall, it appears that for the participants in the present study, leisure provides similar benefits for persons with congenital disabilities as for those with acquired disabilities and those without disabilities. The themes identified in this study were very similar to those found in previous studies. Specifically, involvement in leisure occupations appears to provide mental and physical health benefits (Cassidy, 1996; Taylor & McGruder, 1996); enjoyment (Taylor & McGruder, 1996; Tinsley et al., 1993; Unruh et al., 2000); opportunities to develop a concept of self and increase self-esteem through proving one’s abilities (Kinney & Coyle, 1992; Reynolds, 1997; Taylor & McGruder, 1996; Unruh et al., 2000); and opportunities to build and enhance social relationships, which contributes to developing a sense of belonging (Tinsley, 1997; Taylor & McGruder, 1996; Tinsley et al., 1993). No benefits were identified that pertained only to persons with cerebral palsy and spina bifida; however, these findings still help to fill the gap of knowledge pertaining to the overall importance of leisure for persons with congenital disabilities. Further, these findings support the need for a focus on leisure occupations within occupational therapy.

In addition, the findings of the present study reiterated that barriers and enablers to engagement in leisure activities exist. Taylor and McGruder (1996) and Jongbloed and Morgan (1991) identified barriers for the leisure involvement of persons with acquired physical disabilities that are similar to those mentioned by participants with congenital disabilities in the present study. Access to recreational pursuits, architectural barriers, availability of transportation, proximity to a community center, and attitudes and behaviors of family members were identified as possible barriers. These barriers are consistent with those of the social, attitudinal, and physical barriers for children and adolescents with disabilities (Law et al., 1999).

Enablers to leisure engagement also have been identified in other studies. Studies have reported support from rehabilitation professionals, family, and friends to be important factors contributing to activity involvement (Jongbloed & Morgan, 1991; Taylor & McGruder, 1996). The participants in the present study also saw support as a helpful factor in engaging in leisure. Finally, studies completed by Day and Alon (1993), Drummond and Walker (1995, 1996), and Kinney and Coyle (1992) indicated that rehabilitation programs for persons with disabilities can provide the support needed to increase involvement in and satisfaction with leisure engagement.

Coleman (1993) identified the need to understand how leisure involvement provides health benefits to individuals in order to provide a rationale for focusing therapy on leisure pursuits and abilities. Findings from the present study not only illustrate that leisure is important for persons with congenital disabilities, but also help to identify how involvement in various leisure activities can contribute to better health by decreasing stress and increasing relaxation and enjoyment in life. Given that persons with disabilities may be at risk for poor life outcomes and poor psychosocial adjustment (Clark & Hirst, 1989), leisure may be a key link in helping these individuals improve their self-worth, self-esteem, and confidence in their abilities. Psychosocial adjustment may improve with engagement in leisure activities because of the development of friendships and a sense of belonging (Kinney & Coyle, 1992).

King, Cather et al. (2001) discussed the sense of belonging, doing, and understanding self as important contributors in making meaning in life. From the quotes of the participants in this study, it is evident that leisure contributes to all three of these aspects of life. Much of the literature that has assessed leisure activities of persons with disabilities reports a decline in activity as these individuals move toward adulthood (Lockwood & Lockwood, 1991). The research literature also reports that persons with disabilities tend to participate in activities that are socially isolating (Pollack & Stewart, 1990). Interestingly, the leisure activities that the participants in the present study chose to focus on consisted of those that were not socially isolating. It seems clear for the study participants that non-socially isolating leisure activities were a means to promote self-worth. These socially engaging activities may be especially important given that 48% of adults with disabilities are not employed (Statistics Canada, 1991). Given that North American society places such a high emphasis and value on paid employment, it may be important for therapists to focus the leisure activities for their clients who are not
employed toward those activities that are productive.

The boundaries between the three areas of occupation (i.e., productivity, self-care, leisure) are blurred in the stories of the participants in the present study. When we enter the realm of psychological or mental health, leisure may become self-care. Further, it seems that many of the participants used productivity in leisure to promote mental health. For example, the participant who was a woodworker felt very productive, which contributed to his sense of worth. Much of what we were told relates well to Csikszentmihalyi (1975), who proclaimed that we should not look at work as being any more important than play. The main focus of the individual should be on fulfilling potential and new abilities. The current stories seem to illustrate this point quite well. It seems that occupational therapy is situated to help individuals fulfill their potential by integrating productivity, leisure, and self-care.

One must be cautious in interpreting the findings of the present study. The majority of participants indicated that their condition limited their lives and their involvement in leisure activities somewhat. Only 2 participants believed that their condition limited their lives to a great extent or to a fair extent. Furthermore, measures of the participants’ feelings on their overall competence, ability to manage their own lives, ability to perform meaningful activity, and satisfaction with life indicated a high-level functioning group. It is unclear whether leisure involvement helped to contribute to their high level of functioning or whether their high level of functioning enhanced the benefits they received from their leisure engagements.

Nevertheless, these results, combined with the studies previously mentioned, identify the need for a greater focus on leisure interests in occupational therapy because of the benefit to the mental health of the participants. Studies involving persons with acquired disabilities have suggested the need for more time, energy, money, and concentration directed toward leisure rehabilitation programs (Day & Alon, 1993). Persons with congenital disabilities, however, may not require a “rehabilitation” program but rather a more general leisure program to identify and enable the development of leisure interests and abilities. Furthermore, given the findings of Pollock and Stewart (1990) that adolescents with disabilities tend to participate in passive activities, these programs may be most beneficial at a young age so that skills learned early can be used throughout the life span. Such programs may assist persons with congenital disabilities in choosing less socially isolating activities, thereby increasing psychosocial outcomes. Future research on the content of such programs is needed.

Barriers and enablers identified within this study are also very important in the development of leisure interventions. More research like that currently being undertaken by King, Law et al. (2001) examining the predictors of participation in a variety of leisure activities using structural equation modeling may help to identify additional barriers and enablers in order to enhance occupational therapy intervention outcomes.

Finally, Coleman (1993) stated that clients gain the most benefits from the ability to choose freely their leisure interests and endeavors. Therefore, in being client-centered, occupational therapists should focus on the needs and abilities of clients in order to guide them toward the most beneficial leisure interventions. Overall, the present study provides information regarding the importance of leisure in the lives of a small number of persons with cerebral palsy and spina bifida. Future research needs to be conducted with more participants with a variety of congenital disabilities to increase the knowledge of the importance of leisure engagement, how it improves health and well-being, and how these factors can be incorporated further into occupational therapy interventions.

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References


