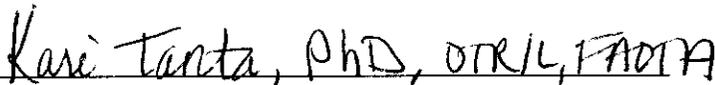
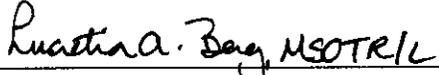


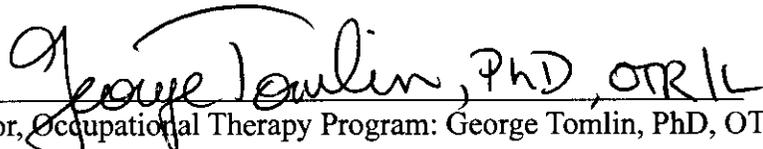
Experiences with a Service Dog of an Adolescent
with Spinal Muscular Atrophy

May, 2011

This research, submitted by Sarah Onsager, has been approved and accepted
in partial fulfillment of the requirements for the degree of
Master of Science in Occupational Therapy from the University of Puget Sound


Committee Chairperson: Kari Tanta, PhD, OTR/L, FAOTA


Reader: Lucretia Berg, MS, OTR/L


Director, Occupational Therapy Program: George Tomlin, PhD, OTR/L


Dean of Graduate Studies: Sarah Moore

Abstract

Adolescents with Spinal Muscular Atrophy (SMA) may receive occupational therapy services and may at times use service dogs. Literature suggests that service dogs can provide social and physical benefits to children and adults with physical disabilities, however little research has been published, especially with adolescents. A qualitative methodology was used to best gain insight on the daily life experiences with a service dog of a thirteen year old female adolescent with a diagnosis of SMA and her mother. Major themes that emerged from interviews included: A Process, A Special Bond, A Sense of Security, Increased Independence and Participation in Life, Empowering, Social Aspects, and The Future. The information gained from this study may lead occupational therapists to suggest clients apply for a service dog, assist client's with the transition of obtaining a service dogs, and incorporate service dogs into occupational therapy interventions.

Keywords: Spinal Muscular Atrophy, physical disability, service dog, occupational therapy

Spinal Muscular Atrophy (SMA) is a hereditary disease that causes progressive muscle weakness (National Institute of Neurological Disorders and Strokes, 2008). Those affected require assistance with self-care tasks and almost all are fully dependent for mobility, ultimately requiring the use of a power wheelchair (Spinal Muscular Atrophy Foundation, 2010). Adolescents with SMA are frequently referred to or seek occupational therapy (OT) services for suggestions of accommodations for daily tasks or referrals to other professionals to address areas of difficulty that are important to this age group. One such accommodation for adolescents with SMA is the use of a service dog. Research has shown that there are many benefits of owning a service dog for people with disabilities, including improving independence in activities of daily living (ADL), increasing social opportunities, and providing psychosocial benefits, many of the areas in which adolescents with SMA have difficulties. Although the exact number has not been documented, the Muscular Dystrophy Association of Washington confirmed there are some adolescents with SMA who own a service dog (S. Kleiver, personal communication, December 2010). Furthermore, service dogs are often used by adolescents (Delta Society, 2009), however their experiences have not been published. Research on the daily life experiences of adolescents with SMA with a service dog, and their families, can provide occupational therapists a better understanding of the contributions service dogs can make toward helping adolescents with SMA participate in their daily occupations.

Background

Spinal Muscular Atrophy. SMA is a genetic and incurable disease that currently affects approximately 25,000 Americans (Spinal Muscular Atrophy Foundation, 2010). SMA is characterized as Type I (severe), Type II (moderate), and Type III (mild), with a life expectancy of around 2 years of age for Type I and into adulthood or normal life expectancy for Types II and III (Spinal Muscular Atrophy Foundation, 2010). SMA causes progressive muscle weakness

throughout the entire body (National Institute of Neurological Disorders and Strokes, 2008) and weakness usually occurs first in the lower extremities, causing those affected by SMA to quickly become wheelchair dependent at a relatively young age. Eventually, weakness progresses through the upper extremities, trunk, and internal muscles, such as those associated with breathing. Though the main impairment for people diagnosed with SMA is physical weakness, cognitive impairments are sometimes involved. One study reported a 40% incidence of cognitive disabilities in those with Type II SMA and 10%-22% of those with Type III SMA (Chung, Wong, & Ip, 2004). However, another stated that, "Patients with spinal muscular atrophy tend to be very verbal and intellectually precocious" (Iannaccone, 2007, p. 975).

Adolescents affected by SMA require assistance with most self-care tasks and almost all are fully dependent for mobility (Chung et al., 2004). Due to mobility dependence, adolescents with SMA usually require a power wheelchair and a full-time caregiver. According to the Spinal Muscular Atrophy Foundation (2010), those with SMA, especially with Type II, are completely dependent on their caregiver for dressing, bathing, toileting, and transferring because their endurance is often insufficient for the task. Additionally, adolescents with SMA may have difficulties with social participation due to the stigma associated with having a disability and being in a wheelchair. Eisenberg (1982) confirmed that people with a visible disability often feel socially rejected. Children with SMA often receive therapy services, including occupational therapy, to address these areas of difficulty and increase independence in their daily life tasks (Kakazu, 2005).

Occupational therapy. Occupational therapists work with all ages of people, evaluating the person, task, and environment together for the best outcome for their clients (Rogers & Holm, 2009). Occupational therapists teach clients compensatory strategies that enable them increase participation in the activities that are of value to them. These activities are referred to as

areas of occupation, which include ADL such as dressing, bathing, mobility, and hygiene; instrumental activities of daily living (IADL) such as caring for others, community mobility, shopping, and household management; as well as rest and sleep, education, work, play, leisure, and social participation (AOTA, 2008).

Using the *Occupational Therapy Practice Framework - II*, occupational therapists address client factors such as values, beliefs, and spirituality; body functions; body structures; and performance skills including motor skills and praxis, sensory-perceptual, emotional regulation, cognitive, and communication and social skills (AOTA, 2008). Occupational therapists also consider an individual's context and task demands during evaluation.

Occupational therapists use a variety of treatment modalities to help clients reach their goals, such as meaningful ADL and leisure activities, peer and family involvement and technology. Occupational therapists also provide accommodations that will help a client to be successful in his or her environment, which may include adaptive strategies or assistive devices. Using a service dog is another strategy that is sometimes used to help improve a person's ability to participate in leisure activities, dress his or her self, or socialize with others. Referrals are sometimes provided by occupational therapists for service dogs to help clients who need assistance in one or more areas of occupation.

Service dogs. Service dogs are gaining in popularity as an adaptive strategy for people with physical disabilities. The Delta Society, a non-profit organization that funds service dog training and provides service dog resources for people with disabilities, defines a service dog as a dog who has received special training to do tasks that are specifically related to a person's disability and has met all requirements on a minimum standards service dog checklist (2009).

Service dogs are trained to assist their owners with a variety of tasks, such as retrieving dropped objects, opening and closing drawers and doors, turning lights on and off, pulling a

wheelchair, carrying items, and alerting for help (Delta Society, 2009; NEADS, 2010). People who own a service dog have voiced that they feel more independent than they did before they had the help of a service dog (Fairman & Huebner, 2000). In a qualitative study, Camp (2001) found that having a service dog allowed several adults with physical disabilities to be more independent with self-care tasks and to increase their community participation. Other adults with physical disabilities said they felt less frustrated because their service dog can open doors or pick items up from the floor for them, when they would otherwise have to wait and ask someone for help (Rintala, Matamoros, & Seitz, 2008).

Researchers have confirmed that service dogs provide assistance with ADL and IADL for their owners (Allen & Blascovich, 1996; Camp, 2002; Fairman & Huebner, 2000; Ng, James, & McDonald, 2000; Rintala et al., 2008). When adolescents with physical disabilities were given a service dog, improvements in mobility and home-care tasks were observed (Ng et al., 2000). Participants in one study indicated having a high level of satisfaction with the assistance provided by their service dogs for general daily activities (Rintala et al., 2008).

In addition to the contributions service dogs can make toward a higher level of independence, service dogs are also a cost effective form of assistance. Research has found that paid human assistance significantly decreased for participants in several studies due to the amount of assistance service dogs are able to provide people with physical disabilities (Allen & Blascovich, 1996; Fairman & Huebner, 2000; Ng et al., 2000; Rintala et al., 2008). People were also able to stop using at least one assistive device because of the help provided by their service dog (Rintala et al., 2008).

Service dogs not only provide benefits for people with disabilities with ADL and IADL at home, but have also been shown to increase participation and performance in education and other community related activities (Allen & Blascovich, 1996; Ng et al., 2000). Researchers

have found that service dog owners with physical disabilities show vast improvements in school-related tasks (Ng et al., 2000), attend school more frequently and have significantly increased part-time work hours (Allen & Blascovich, 1996). Fairman and Huebner found that community mobility also improved (2000). Service dog owners felt it was easier to leave their home and use community transportation with their service dogs by their sides (Fairman & Huebner, 2000). Similarly, other researchers found that service dog owners used public transportation more frequently and had a significant increase in their ability to take part in community activities (Allen & Blascovich, 1996; Ng et al., 2000).

Beyond physical tasks and community involvement, researchers found that service dogs increase social acknowledgements and social participation for adults and children with physical disabilities (Allen & Blascovich, 1996; Camp, 2001; Fairman & Huebner, 2000; Ng et al., 2000). Eddy, Hart, and Boltz (1987) conducted an experiment which revealed that adults in wheelchairs receive obvious stares and do not get approached very often in social situations. A participant in this study said he felt as though people look through him in social situations. According to Camp (2001), owning a service dog increased social opportunities for service dog owners and allowed them to better form relationships with others. Research has shown that when a service dog is present with an adult, the service dog owner is approached more frequently and receives more smiles (Eddy et al., 1987; Fairman & Huebner, 2000). Similar results were found in a study involving children with a physical disability, and results indicated that when children had a dog present, the quality of conversation with passersby was much higher than with those without a dog (Mader, Hart, & Bergin, 1989).

Emotional support and companionship is a major benefit of owning a service dog (Camp, 2001; Rintala et al., 2008). Owners of service dogs consider their dog as a companion and playmate (Fontaine, 2000), a source of love and friendship and a member of the family (Camp,

2001). In addition, Allen and Blascovich (1996) found that service dog owners show significant improvements in “self-esteem, internal locus of control, and psychosocial well-being” (p. 1004). They feel safer, better about themselves, more in control of their life, and better able to cope with stress than they were without a service dog (Fairman & Huebner, 2000).

Furthermore, research has shown that play and leisure activities have improved for people with disabilities through the use a service dog (Camp, 2001; Fairman & Huebner, 2000). In one study, 202 service dog owners responded to a survey and over sixty percent said that their service dog allowed them to “engage in play and leisure activities more often than before” (Fairman & Huebner, 2000, p.45). Camp (2001) interviewed four adults with physical disabilities who each voiced that their service dog allowed them to have fun. One reported that her service dog pulled her in her wheelchair while playing broomball. Another said while talking about life with her service dog, “It just wouldn’t be as fun. Life would be more boring” (Camp, 2001, p. 514). Such supportive evidence may be contributing to a rise in the use of service dogs among people with disabilities.

As described earlier, service dogs may be gaining in popularity because of the many benefits they have shown to provide people with disabilities (Allen & Blascovich, 1996; Camp, 2002; Delta Society, 2009; Eddy et al., 1987; Fairman & Huebner, 2000; Fontaine, 2000; NEADS, 2010; Ng et al., 2000; Rintala et al., 2008). To meet this need, many organizations in the United States, such as Canine Assistants®, provide service dogs to people with cognitive and physical disabilities, who are typically wheelchair dependent, free of charge (2010). Canine Assistants® (2010) does not have an age requirement to apply, however, some organizations have minimum age requirements for applicants, ranging from young children to young adults. At Canine Assistants®, those who are interested in obtaining a service dog must first complete the application process, demonstrate a certain physical or cognitive need, and wait until their

name is at the top of the waiting list. The wait can last from one to five years depending on the applicant's needs and place on the waiting list (Canine Assistants, 2010). There are organizations that have a shorter list, but they may charge thousands of dollars to train and match the interested person with a qualified service dog (Delta Society, 2009). Such a high demand for service dogs indicates a need for efficient and effective therapy services. This may be one area in which occupational therapy practitioners may contribute.

SMA, OT, and service dogs. Those affected by SMA experience difficulties in many areas of occupation, and therefore may seek occupational therapy to support functional abilities in daily life activities (Spinal Muscular Atrophy Foundation, 2010). Kakazu (2005) surveyed occupational therapists to find out their knowledge about and experience with people with SMA. Kakazu (2005) found that very few occupational therapists work with children with SMA and very few have received education about the disease.

According to researcher Susan T. Iannaccone (2007), occupational therapists working with children with SMA provide therapy to maintain mobility, maintain or increase independence, and enhance overall quality of life. Similar interventions were seen being used during several hours of personal observation by the researcher in 2008 at a pediatric clinic located in western Washington. Occupational therapists were observed teaching an adolescent with SMA adaptive strategies, such as using adaptive techniques to pick up light items out of reach and how to do daily activities such as dressing and cooking, independently.

Research has shown that service dogs can improve independence with ADL and IADL (Allen & Blascovich, 1996; Camp, 2002; Fairman & Huebner, 2000; Ng, James, & McDonald, 2000; Rintala et al., 2008), such as those the adolescent with SMA was observed working on. As stated above, adolescents with SMA may also experience difficulties with social participation due to the social stigma of being in a wheelchair and having a disability (Eisenberg, 1982).

Service dogs were found to increase social participation for children in wheelchairs (Allen & Blascovich, 1996; Camp, 2001; Fairman & Huebner, 2000; Ng et al., 2000) and may provide similar benefits to adolescents with SMA. Therefore, adolescents with SMA may benefit from owning a service dog.

Most research documenting the benefits of owning a service dog has been completed with adults. The same benefits found with adults may also apply to adolescents with disabilities, however there is limited research on the topic. In addition, as Kakazu (2005) found, occupational therapists have limited knowledge of SMA. As a result, occupational therapists may be limited in their knowledge of the benefits service dogs may provide those with SMA. Learning about the daily life experiences of adolescents with SMA and their families would provide occupational therapists a better understanding of the capabilities of service dogs and their abilities to help adolescents with physical disabilities participate in their daily occupations. As a result of this increased knowledge, an occupational therapist may suggest that a client who would benefit from a service dog apply for one. The service dog could potentially be utilized in therapy interventions as well.

Therefore, the purpose of this study was to describe the daily life experiences with a service dog of a thirteen year old female adolescent presenting with a diagnosis of Spinal Muscular Atrophy Type II/III, and her primary caregiver.

Method

Research Design

In order to best gain insight into the daily life experiences of an adolescent with SMA and her caregiver with a service dog, an ethnographic research method was used. Ethnographic research aims to “describe the insider’s view” of a unique experience (Kielhofner, 2006, p. 331). This approach was also chosen because it would provide information well-suited to meet the

client-centered principles of occupational therapy. “The ethnographic tradition shares with occupational therapy the desire to work to learn, not predefine, people’s own meaningful desires habits, values, and actual life settings as well as perceived challenges and resources” (Kielhofner, 2006, p. 331). Using a qualitative method allowed the insider’s point of view to be discovered in a holistic and natural manner (Kielhofner, 2006), providing a way to understand what a service dog means to the adolescent with SMA and the caregiver.

To best understand the experiences of the research participants, data was gathered through a series of interviews, direct observation, and field notes, which are typical forms of data collection in an ethnographic approach (Kielhofner, 2006). Data was collected until the point of data saturation in order to best describe the adolescent’s and caregiver’s experiences with a service dog.

Participants

Participant recruitment was initiated through a convenience sample in the state of Washington. Details about the study and contact information for the author were sent to the Delta Society, to the Washington office for the Muscular Dystrophy Association and to the researcher’s personal contacts through email to recruit two to three families. One family responded and met the inclusion criteria. The family was provided a clear explanation of the informed consent and research procedures. The caregiver signed a consent form and the adolescent signed an assent form each giving written consent to be interviewed three to four times as well as for video and audiotaping.

The participant was a thirteen year-old female, diagnosed with SMA Type II/III, who had owned a service dog for six years, and her mother. The researcher previously knew the participants from providing in-home care for the adolescent for approximately one year in 2009.

The adolescent was diagnosed with SMA at 14 months old. She was able to walk for a

total of six months as a toddler, but needed a manual wheelchair by the time she was two years old, and a power wheelchair by age four years. The adolescent underwent spinal rod surgery to prevent further functional impairment. However, following surgery the use and strength of her upper extremities and trunk declined. She also had no functional use of her lower extremities. She required maximum assistance for transferring out of her wheelchair. She attended seventh grade at the local public school. One of her younger brothers lived with their father and she lived with her mother, her mother's boyfriend, her youngest brother, her service dog, and two other family dogs.

Instrumentation

An interview guide was developed to support an in-depth face to face conversation with open-ended questions (see Appendices A and B). Each interview was videotaped with a Canon ZR-930 with an external microphone input and audiotaped with a Sony ICD-PX720 Recorder. Video recordings were uploaded onto a password protected MacBook Pro laptop and transferred to a DVD-R disc. Audio recordings were downloaded onto the same laptop, transferred to a CD-R or uploaded onto the transcriptionists website using Dropbox (2011), then transcribed verbatim by a paid transcriptionist. Field notes and personal reflections were recorded by hand in a notebook before and after each interview to ensure credibility and dependability of the findings, serving as a method of triangulation (Krefting, 1991).

Procedure

After approval for this study was granted by the University of Puget Sound Institutional Review Board, participants were sought. The family who responded to participate in the study was found through a convenience sample. The researcher met with the adolescent with SMA and the adolescent's mother to explain the study and go over the consent and assent forms. The mother signed the consent form, and the adolescent signed the assent form.

Interviews were conducted one to three weeks apart in a quiet and comfortable setting at the participants' home and at a time of day that was convenient for them. An interview guide (see Appendices A and B) was approved by the research project's chair. In order to begin data collection, interviews were scheduled with the adolescent with SMA and her mother when consent and assent forms were being signed. Questions were asked separately to the adolescent and her mother; however, the mother was present during the interview with her daughter. Each interview was videotaped and audiotaped. The transcriptions were used as a source for data analysis. The videotapes were used to document any service dog - adolescent interactions during the interviews that could not be documented in an audiotape. The videotapes were also used as a way to note non-verbal communication from the person being interviewed, such as facial expressions and body language.

The purpose of the first interview with each participant was to establish rapport and obtain general information. The subsequent interviews were to expand on topics discussed during the first interview and to ensure vital information was not missed. Three interviews were conducted with the adolescent with SMA with the mother present and three interviews were conducted with the mother. The purpose of multiple interviews was to reach a point of data saturation so that little to no new information could be gained (Kielhofner, 2006). Each interview lasted 45 minutes to one hour. The first interviews began with a grand tour question, "What is it like to own a service dog?" Open-ended questions and appropriate follow-up questions were then asked to make sure issues of importance to the participants were brought up naturally and topics raised could be explored (Kielhofner, 2006).

Personal reflections of the researcher were recorded before and after the interviews to document changes in perspective and permit reflexive analysis. Field notes were taken during interviews to record interactions between the service dog and participant and to document any

other relevant information that could not be found on the audiotape or videotape. To provide further trustworthiness, member checking was performed by providing a copy of the interview transcript to each person interviewed, so they were able to review the transcript and ensure accuracy (Kielhofner, 2006). Once video and audiorecordings were downloaded onto a disc, they were deleted from the MacBook Pro laptop. Video and audiorecordings were then kept in a locked file at University of Puget Sound (UPS) in Warner Hall. Consent forms and identifying documents were kept in a locked file in an office at UPS in South Hall. All information will be destroyed one year after the interviews in case of publication.

Data Analysis

To identify themes amongst participants, information was broken down into stories, quotes, concepts, and repetitive phrases or terms (Kielhofner, 2006). Themes obtained from interview content, video recordings, field notes, and personal reflections were repeatedly analyzed by hand (Huberman & Miles, 1994) and topics were classified, sorted, and arranged. Themes were coded in a similar manner using Inspiration (2011). Accuracy of themes was supported through direct quotes from the interviews. Index codes of concepts were created from quotes to help connect themes (Kielhofner, 2006). Themes were verified through the processes of active reading, coding and recoding, and by discussing the emerging themes with the participants. The different forms of data analysis and the different sources of data served as a method of triangulation to ensure the themes were consistent with the actual perspectives of the participants. Member checking was used to explore data inconsistencies with the participants to further ensure accuracy.

Results

The following themes describe the experiences with a service dog from the perspectives of an adolescent with SMA and her mother.

A Process

Receiving a service dog is a long process and can take approximately five years. The mother of the adolescent with SMA applied for a service dog for her then three year old daughter (the adolescent with SMA). The adolescent with SMA did not receive the service dog until she was seven. Even though their wait was only four years, the adolescent and her mother found that it was a work in progress after bringing the service dog home.

“Give it time.” The service dog had already learned 90 commands before being matched with the adolescent. However within approximately the first year of having the service dog, the adolescent explained, “I didn’t use her like I should, I kind of just dragged her around with me because I could still do things.” When the adolescent was not home, she explained that her service dog “would just lay around the house all day. I would barely use her.” The mother expressed that she had high hopes immediately after returning from training with Canine Assistance® by saying, “I expected them to just conquer the world.” The mother explained that she contacted Canine Assistance® and they told her that she needed to “give it time” and be patient so the adolescent and her service dog could build a relationship. The mother said, “It was hard for me to sit back because I wanted the magic to happen.” However, the mother explained that in time her expectations had been exceeded and said, “it has worked out.” The adolescent also recognized that it took time to build that working relationship with the service dog and explained, “Now that I am using her, this is amazing.” In contrast to when the service dog first came home, the mother called the service dog her daughter’s other half. When talking about the relationship they had she said, “I absolutely love seeing the two - the dog and [the adolescent] - both grow and mature together and work together and change together.” In addition to giving it time, the mother attributed a lot of their success to following the rules.

Rules. During the first year of owning a service dog, the mother explained, “We have to

follow the rules.” They were told by Canine Assistants® that no one was to “interact, talk, touch, [or] speak” to the service dog in general except for the adolescent and that when the service dog was leashed to the adolescent’s wheelchair, “nobody could interrupt them.” The family also had to follow a “rigid routine” of kenneling the service dog whenever the adolescent was not around. The adolescent was the only person who was permitted to take care of the service dog or give her treats. The adolescent and her mother explained that this was so the bond between the adolescent and the service dog could be formed and prevent confusion for understanding whose service dog she was. Otherwise, the mother said if they did not follow the rules, “the dog would become a regular family pet.” The mother explained that, “the first year definitely is a lot of commitment of following the rules,” and “it doesn’t work unless everyone is on board and everyone is following the rules and you give it a 100% try.” After a year or two, when it was obvious that the bond between the adolescent and the service dog had been formed, the family and their friends were allowed to interact with the service dog. The mother explained that not petting the service dog was really difficult, but after the adolescent and the service dog had “that bond” the family began petting the service dog and treating the service dog like “a member of the family.”

A family member. The mother said sometimes having the service dog was like having “another kid” which she explained could sometimes be difficult. It was especially hard for the mother when the adolescent first received the service dog as she had an infant in addition to her two other children. The adolescent’s mother explained that it was difficult leaving the house because she had “a baby, a wheelchair...a dog, and a two seated stroller.” Because of the difficulty this posed she explained, “We picked and chose what [the service dog] could go to.” Even after her children were older the mother said having such a large family, including the service dog, made it hard for all of them to go places - including to therapy for the adolescent.

The adolescent and her mother also said the service dog was like a regular dog in some cases.

“She’s still a dog.” The adolescent and her mother both emphasized that the service dog was “still a dog” regardless of training. Some of the responsibilities that came with owning a new service dog were the same as owning a new typical dog. They explained that the service dog had food and veterinary costs, although the mother said if they experienced serious financial hardship they could most likely apply to Canine Assistants® for reimbursement. The adolescent explained that the service dog also has to be let out to “potty” and if she is not let out, she may “potty” in an inappropriate area. This happened once when the adolescent, her mother and the service dog were in the airport. The adolescent said she was in the airport with her mother and the service dog in the airport, “and then [the service dog] peed. It was awful.”

The mother also explained that if the service dog is not leashed up to the adolescent’s wheelchair, the service dog could see a raccoon and “react like a dog” by running off. This is one of the reasons, she said the service dog needed to be connected to the adolescent’s chair at all times when they left the house. Another typical dog characteristic that emerged was the service dog’s behavior in large crowds when they would leave the house. The adolescent explained, “There is food, there are loud noises, there are people - like auditoriums. A lot of body movement. A lot of standing up, and sitting down, cheering and stuff like that. It is a lot for a dog to take in - for any dog to take in.” Because of this, the mother said they really had to pick and choose where they would take the service dog.

The adolescent and her mother both agreed that the service dog frequently begged for food. The adolescent explained, “The only negative thing about having a service dog is that they are normally so food-motivated they are going to be in your face begging no matter what.” The mother also said she was worried if the service dog ever needed to help the adolescent in the pantry and implied that the service dog would eat the food because, “[The service dog] is very

motivated with food [because] that is how they are trained.” Even though they were not permitted to give food to the service dog when she begged, the adolescent said it was very hard to resist because the service dog is her “best pal.”

A Special “Bond”

A special bond and friendship between the adolescent and the service dog was emphasized several times. The adolescent explained the bond began the instant they met in Georgia during the service dog matching process with Canine Assistants®. The adolescent and her mother said that the service dogs would be taken around to each recipient by a trainer and would receive a command by the potential recipient. If the service dog listened to the command that meant they might work well together. The adolescent said, “It was the first command that snapped the bond with me and [the service dog].” The mother described the special bond that developed between the adolescent and the service dog by saying, “It’s [her] other half and I absolutely love seeing the two - the dog and [her] - both grow and mature and work together and change together.” This strong bond was described by the adolescent and her mother in two different ways, the service dog was a friend and companion to the adolescent and the service dog was someone who was always there to check in on the adolescent throughout the day.

“Friend and companion.” Because of how the matching process works, the adolescent and the service dog had similar personalities. The adolescent said, “I am a tomboy, [my service dog] is a tomboy. I like getting loved. She likes getting loved.” The mother similarly explained that, “they are both social butterflies, they both like attention, and are both very outgoing.” Matching personalities seemed to make it easy for them to become friends. The mother described the service dog as the adolescent’s “ultimate best friend.” The adolescent confirmed this by saying, “The best thing about these service dogs is when you grow up, they learn to read you, and it is like they are your buddy, and she is a part of you.”

When describing her relationship with her service dog, the adolescent said, “you have one person, your dog, that really cares about your emotions.” The mother further explained why she thought the adolescent and the service dog were so close, “They don’t care what you look like. They don’t care what’s going on. They are just there. But I think dogs especially are really sensitive to [feelings] and they want you to be happy.” The mother said that the adolescent can rely on the service dog for her emotional needs and said, “she is kind of a comfort in that she knows that is her girl, and that is number one. She doesn’t just leave [the adolescent] and come hang out with us. She kind of just keeps an eye on her.”

She is always there. The adolescent and her mother both frequently expressed that the service dog was always near the adolescent. The adolescent explained this by saying, “She is always kind of there...I am sitting there watching TV and, oh, here is [my service dog].” The adolescent said it was like the service dog was always checking on her. The mother similarly described that whenever the adolescent would lay in bed sick, the service dog would not leave her side and that it seemed the service dog was making sure the adolescent was alright. The mother also said that when the adolescent would be upset about something or would start choking “[The service dog] kind of tunes in to that and stays with her.” The adolescent said when she was in pain, the service dog would “visit with me and look at me, like ‘it’s okay’.” When the service dog was left at home, the mother explained that the service dog “would curl up and sulk,” indicating that the service dog did not know what to do without the adolescent. The mother described instances when the adolescent had to be hospitalized and they were able to bring the service dog to visit her. She said that, “When [the adolescent] has been in the hospital I will bring [the service dog] and she gets all excited, and [the service dog] gets all excited, they are happy.” She said that the service dog would lay on the hospital bed with the adolescent and the adolescent would pet her. The mother said the adolescent would then feel more at ease and

happy. Because of the strong connection between the adolescent and the service dog and because the service dog was always “checking in” on the adolescent, the family expressed feeling a sense of security.

A Sense of Security

When talking about feeling safe with the service dog, the mother said, “[The service dog] brings [the adolescent] a great amount of security and I know she feels safer. She knows she can rely on her.” The mother explained two different commands that the service dog had performed that increased their sense of security and said that the service dog would alert others when something was wrong.

One command that proved to be helpful was “Brace.” The adolescent described one instance where her trunk fell forward while she was sitting in her wheelchair and her head landed on the service dog’s head. The adolescent did not have the muscle strength to sit back up, so instead told the service dog to “Brace” and called for her mother to come and help. The mother explained that this command could potentially allow the adolescent to get back in her chair or at least keep her from falling further. The other command they both talked about in regards to providing a sense of security was, “Go get mom.” The adolescent explained, “If I am on the toilet and mom is upstairs and need to get off the toilet and I can’t get her, I can get [my service dog] really excited and say, ‘Go get mom!’ And she will run upstairs and go get mom and say, ‘Hey, let’s go’.”

Similarly, the mother said that the service dog will come get her without a command if something is wrong. She said “[The service dog] will come and sit right in front of me and stare dead straight in my face. And it will be like, okay, either she has got to go to the bathroom, she is hungry or something is wrong.” She also explained that the service dog barked if something was wrong with the adolescent so that “someone will pay attention to what is going on.”

The mother explained that if there was an intruder in the house, the service dog would react and alert the family. The service dog had done something similar to this once when suspicious looking people were approaching the adolescent and her mother when they had been outside walking in the dark. The mother said that because the service dog had been able to alert the family of danger it also had “brought a great sense of peace and comfort to [the adolescent],” especially since her room was on a different floor than the rest of the family.

Increased Independence and Participation in Daily Life

One theme that was talked about the most was how the service dog allowed the adolescent to participate in her daily life more frequently and more independently. Although the service dog was trained to mainly provide physical assistance to the adolescent, the mother explained that the adolescent did not want to use the service dog at first because she was still able to complete her daily life activities independently. However, the adolescent explained “After my back surgery in February 2010, I was like, wow, I am really limited right now.” By the end of that school year she started realizing that she needed more assistance and explained this by saying,

I have a rod in my back. It is really difficult to move with a rod in your back. I mean, you can move, but you are really tippy... So all of a sudden I couldn't move as much and I was getting weaker because I gained 20 pounds since last year. I am packing on weight. I am 13 years old. I am about 5'1", I am 80 pounds, I have a rod in my back and the strength of a three year old. I need help. I can't do as much as I could before...because I am bigger, I am straighter, I am not so accessible anymore to myself.

The mother explained that the service dog's physical contribution slowly progressed throughout the years, but started coming into play more when the adolescent was twelve. When talking about what she could do to help the adolescent physically, she got emotional talking about it and

said “That dog is everything that I can possibly give her basically. I can’t cure it...What can I do? I can get her a dog. I don’t know how else to put it, but that is a comfort to me, I guess. It is all I can do.” This especially seemed to be a comfort to the mother as she said the adolescent had become a little more “fumbly” with objects and dropped things more often. The mother described the service dog as, “the extra arms and hands for [the adolescent].”

When the adolescent was asked about the commands the service dog was taught in training, she said, “they teach the dog the basics, they don’t try to bond with the dog, and then they give the dog to you.” She said the service dog then became her “own personal everything dog” and said she had begun using her so much that she said “If I did not have [the service dog], I would be helpless.” She continued to explain that sometimes the service dog had helped her by opening and closing doors and drawers and turn lights on and off. The majority of the time, the adolescent and her mother explained that the service dog picked up dropped objects or items out of reach. The adolescent did voice minimal frustration when trying to get the service dog to pick up something off the couch when there were many items to choose from. She said she had a hard time explaining to the service dog what exactly to get. Although this seemed to frustrate her, she only spoke of one instance this occurred.

The service dog specifically helped the adolescent become more independent in her daily life in the following areas of occupation:

Activities of daily living. Specifically related to ADL, the service dog was able to help the adolescent with dressing. The service dog was observed tugging on ties that were tied to the drawers to pull the drawer open. The service dog was also able to nose the drawer closed. The adolescent described getting help from the service dog when dressing in the morning, “I will have [the service dog] tug open the drawer and get me pants or a shirt. And I will have her get a couple because normally the first pair of pants or shirt is not going to match.” The adolescent

required maximum assistance to dress, but her mother said it was nice that the service dog could help with some of the steps. The service dog had helped somewhat with taking items of clothing off the adolescent. The adolescent's mother explained that the service dog could be told, "Pull" and "Tug" to help remove a jacket, socks, or gloves. The adolescent said the service dog had helped her with grooming and feeding by mainly picking up an item that she had dropped, such as a brush.

Instrumental activities of daily living. With the help of the service dog, the adolescent said she was able to help with chores around the house. The adolescent said her main chore was keeping her room clean. She explained that she did this by having the service dog reposition items, pick up objects off the floor and place them in her lap, or move objects to her desk or bed. The adolescent said she sometimes used the service dog to help her sort laundry. The adolescent and her mother both explained that it would be possible to train the service dog to make the adolescent's bed using the commands she already knows, such as "Tug" and "Pull" and that after practicing with the adolescent for around a year, "you can say 'Make my bed' and they can." However, she said that she once had the service dog pick up her pillow, and the service dog had just drunk water, therefore there was slobber all over her pillow. She said if the service dog was going to help with the bed it could not be after she drank water.

The mother said that the adolescent was able to help around the house because the service dog followed the adolescent around in her wheelchair. The service dog then could pick up the feather duster if the adolescent dropped it when she was dusting around the house. The mother said the adolescent could also have the service dog pick up objects that are out of place in the living room. The adolescent could do this by using the command, "Give" while placing an object in the service dog's mouth and then saying, "Go get mom." The service dog could then bring the object to the mother.

The adolescent was able to participate more independently in shopping tasks with the help of the service dog. The adolescent and her mother explained that the service dog was able to grab money and place it on the cashier stand when going through a checkout line. They explained that she had to do this for the first time at Walmart when she was training with Canine Assistants®. The adolescent and the service dog had to pick out a toy for the service dog, take it to the cashier, and pay for it while only using the service dog and the commands. The mother also explained that with the adolescent's weak arms and hands she would not be able to pick up a can of soup but the service dog could grab it for her. The main area, the adolescent explained, that the service dog had helped with shopping was when the adolescent had dropped her wallet when she was at a store. The adolescent said, "If I was in a store...and I dropped something and it was money - Who do you think is going to pick it up and give it back? I am a grown up. It is money. They would probably take it." She explained, however, with the help of the service dog, she could make sure her money stays safe. She said she appreciated not having to ask a friend to help her pick up her wallet.

Leisure. The adolescent said she enjoyed going to the movies and on walks with her friends. The mother said that "[The service dog] can easily go to a movie with [the adolescent] and that is perfectly fine. She will just sit down there and snooze through the movie." When going on walks with her friends, the adolescent and her mother both said that the other kids in the neighborhood would, at times, bring their dogs along. The mother described it as having "a little dog party," indicating that the dogs brought the neighbors together to play.

Other leisure activities the adolescent said she enjoyed were drawing, writing, and watching television. The adolescent and her mother both explained that in all instances the service dog picked up items the adolescent dropped or was unable to reach items so she did not have to ask other people for help. They both described similar benefits with the adolescent

taking the service dog to school with her.

Education. When talking about the adolescent having the service dog at school, the mother said, “I feel good now that she is at school with her because there is just that extra person because [the adolescent] doesn’t have a para all day with her. And I want to make sure she has someone helping her and I think her friends are getting tired of doing everything for her too.” The adolescent described her day at school saying that they would load the bus hooked up to each other and then the service dog would stay with her all day except for lunch and assemblies. When talking about the service dog helping her at school, the adolescent said, “I drop pencils a lot - I move around at my desk and I drop things. And surprisingly enough, she can do it without me even telling her to do it. I drop a pencil and she is like, ‘Oh, let me get that for you’.” If the service dog didn’t automatically pick up the item, the adolescent said she could point to the object and whisper the command, “Get it.” She further explained that the service dog helped her by picking up papers and her water bottle when she dropped them. She did say that the service dog had not learned how to pick up a binder and so she had to ask someone else to help her whenever she dropped one. The service dog also provided assistance when the adolescent was doing homework. The adolescent described an instance when she was working on an “earth project” with little pieces of paper and said “all the scraps dropped to the ground, so I made her pick them up.”

When the mother was describing the areas in which the service dog helped the adolescent, she explained that it was more than just increased independence it was also a “confidence boost” for her.

Empowering

The mother said that she thought the adolescent was proud of the service dog and provided a support for the adolescent. She explained this further when she said, “It is giving her

the confidence to go out and feel like she can hold her head up high and she doesn't need to ask anybody. I think it is something where she will feel more confident and if she doesn't feel confident, all she has to do is say, 'Come here' and pet the service dog and refocus." The adolescent similarly said several times, "This dog is amazing" and that the service dog "protects" her. When talking about what the service dog meant to her as far as a physical assistant, the mother said, "To her, I am sure that is huge, more than it is to me. There is a lot that I don't have to do and her brother doesn't have to do because she has got her dog. And that has to feel empowering for her. And that is all I wanted is for her to feel like she doesn't need to be helpless or feel helpless."

Social Aspects

Social aspects of owning a service dog came up several times during interviews. The adolescent and her mother both described the different social aspects of owning a service dog that fell into three separate themes: The service dog as a social ice breaker, the focus is on the dog, and having many opportunities to promote and educate the public about service dogs.

Social ice breaker. The mother explained this best when she said, "[The service dog] has broken a lot of social barriers that otherwise people would still gawk." She said several times that when the adolescent goes out, people were always staring at the chair. But she explained that, "[The service dog] is definitely an icebreaker...When she goes out with [the service dog], it is different. They are like, 'Oh my gosh, look at that dog.' Nobody cares why she is in a chair." The adolescent's mother explained that because of this, the adolescent had become known as "the girl with the dog" in their community as opposed to "just that kid in a wheelchair." She said that when they go to places like Safeway, people will often remember them and say hello to the adolescent and the service dog. The mother said, "In the beginning [the adolescent] was taken aback by all the attention on the dog," because so many people were asking questions about the

dog. She described the attention as positive and said she presents it to the adolescent in that way. However the adolescent described several instances of being annoyed at having to answer questions.

The focus is on the dog. “People don’t think,” is something the adolescent repeatedly said when talking about people approaching her and the service dog when she was in public places. She said that at first she was okay with people asking questions, but the questions were “annoying” and she “started to get fed up with it.” She explained this annoyance by saying, “People are just always there asking about the dog like, ‘Oh. Hi! I want to be your friend because you have a dog. Tell me about yourself,’ while petting the dog. People will come up without permission to pet the dog.” The mother explained that she saw negative aspects of social interactions by saying, “The focus is completely off [the adolescent]. Everybody wants to know about your dog - what your dog can do.” The adolescent said when people would approach her they were mostly “going to be interested about [the service dog].” The mother said at first they would try to avoid the public but, she explained, “we have adjusted and we end up teaching people along the way.”

Educating others. The adolescent described having to educate the students and teachers at school about the rules regarding interacting with her service dog. The adolescent and her mother said they had to educate them about the service dog so that the adolescent and the service dog could be successful together at school. The adolescent said she introduced the service dog to her class and told them, “She is just basically going to lie under the table and if I drop something she will pick it up for me. So try not to pet the dog or talk to the dog or give any attention to the dog. Even eye contact could get her excited, so ignore it.” The mother also said there had been times where they had spontaneously educated families on appropriate service dog interactions at places like doctors’ offices. She seemed excited about this because, she explained, “I know

there have been other people that have learned about service dogs or looked into it because they met or saw us.”

In addition to educating the public to improve the adolescent’s personal experience with the service dog, the adolescent and her mother explained they also had voluntarily spoken about or had been an advocate for service dogs. The adolescent had done a photo shoot with Canine Assistants® and Milk Bone®, had been interviewed for books and documentaries about service dogs, and had spoken on several occasions about her service dog at conventions for the Muscular Dystrophy Association.

The Future

The adolescent and her mother explained that the service dog provided physical assistance and a sense of companionship to the adolescent. They also indicated that as her abilities decrease the service dog’s assistance will increase. Because of this, the mother explained that having the service dog made her feel better about the future for the adolescent by saying, “There was someone looking out to see what can come next. That is what these dogs are - they are the next step in life. That is what I see in [the service dog], is me breaking away from her nest and those guys just walking along together.” However, the mother also had concerns, “The hard part now is seeing [the service dog] get older - her face is getting gray.” They both explained that service dogs retire at around age 10 or 11. The adolescent said that she would like the service to retire with them and get a new service dog. The mother said this worried her saying, “the thought of going and getting another dog, that would be really hard for all of us, especially [the adolescent], because she would have to start with a new partner. And then where would we keep [the current service dog]? Would [the current service dog] be jealous?” Therefore although the service dog provides assistance and companionship to the adolescent, there is a shift that will have to be made in the future.

Discussion

The resulting themes in this study support many of the findings from previous studies with service dogs including increased independence and social participation. Additional themes that emerged were related to educating others about service dogs, the evolving relationships with the service dog, and the future considerations regarding retiring a service dog. The most powerful and unexpected finding was the significant social aspects of owning a service dog for the adolescent with SMA.

There were many aspects of owning a service dog that affected the daily life of the adolescent and her mother. It was emphasized that once the service dog was home, there was still a transition process before the bond was made and benefits were noticed. Having to follow the strict rules and guidelines of owning a service dog added to the transition. Camp (2001) similarly found that there was an “adjustment period” when a service dog was introduced into her adult participants’ lives (p. 514). Camp (2001) explained that the participants in her study felt their service dogs were “closer than family” (p. 513). The adolescent and her mother similarly described the service dog as a member of the family, but also found that the mother had difficulties going places because she had to care for her three children and the service dog. The service dog was said to be, “still a dog,” which was noted in research studies by Camp (2001) and Rintala et al. (2008).

Many areas of occupation for the adolescent were positively affected specifically due to the service dog being able to pick up dropped objects and open and close doors and drawers. This is consistent with the literature. These areas included increased overall independence and participation in daily life (Camp, 2001; Rintala et al., 2008), increased abilities in ADL and IADL (Camp, 2001; Fairman & Huebner, 2008), increased ability to participate in leisure activities (Camp, 2001), and increased ability in educational settings (Ng et al., 2000).

The literature indicates positive social aspects of owning a service dog (Camp, 2001; Eddy et al., 1987; Fairman and Huebner, 2000; Mader et al., 1989). This study found that the service dog served as a sort of “social ice breaker” and also turned the attention away from the wheelchair to the dog instead. However, the adolescent and her mother indicated that this led to difficulties going in public with the service dog because of too much attention on the service dog as well as too much attention being detracted away from the adolescent. One other study similarly mentioned having a service dog brought on too much attention (Rintala et al., 2008).

There are many studies that have found that a service dog is a friend and companion (Camp, 2001; Fairman & Huebner, 2000; Ng et al., 2000), as this study indicated. The theme, “She is always there,” emerged as it did in another qualitative study regarding adults and their service dogs. It was indicated that the service dog provided a sense of security as well as empowerment. These results were similarly found in the literature (Allen & Blascovich, 1996; Camp, 2001; Fairman & Huebner, 2000; Rintala et al., 2008).

While the results indicated that there were social and physical benefits related to owning a service dog, the emerging themes suggested that the social benefits outweighed the physical benefits, especially in the first few years. The adolescent and her mother indicated, however, that the physical benefits may steadily increase as the adolescent’s functional abilities decrease. Something that was not found in other studies were the opportunities available to educate the public about appropriate interactions with service dogs or the issue of transition and retirement of a service dog.

Limitations

Although efforts were made to obtain more than one family with an adolescent with SMA who owned a service dog, only one family responded to participate. Including the perspectives of two more families would have allowed the themes to be cross-referenced, therefore

strengthening the results of the study. Because the adolescent and her mother had a relationship with the researcher prior to this study, attempts were made to avoid bias. However, regardless of efforts, a bias may have been unavoidable. To further avoid a bias, the researcher could have had an occupational therapist review the data to see if similar themes emerged.

Interviews were conducted one to three weeks apart due to scheduling conflicts. The time between interviews may have impacted the information reported by the adolescent and her mother due to forgetting what was already discussed in previous interviews, causing repeated information. In addition, the mother was present during the interviews with the adolescent. If the parent had not been present, the adolescent might have been more candid and provided more information about her experiences with the service dog.

Future Research

Research regarding service dogs and SMA is very limited, specifically research on adolescents with physical disabilities who own a service dog. This study provided insight into how a service dog affected the daily life of an adolescent with SMA and her mother. Completing a similar qualitative study with more than one family would increase the validity of this study's findings. Further research on Spinal Muscular Atrophy would also help occupational therapists better understand the needs of this population.

There is limited research on adolescents who include their service dog in therapy. Further research on this topic would be helpful for therapists who work with people who own service dogs. Understanding the transition process from retiring a service dog and receiving a new service dog would be beneficial for families who own a service dog. This information would help them know what to expect when service dogs are placed in their homes. Further research would also be beneficial to examine how an occupational therapist could play a role in training service dogs or complete in-home occupational therapy interventions with their client

and client's service dog.

Implications for Occupational Therapy

The service dog specifically contributed to several areas of occupation for the adolescent with SMA, increasing independence and participation in her daily life activities. These areas were specifically ADL, IADL, leisure activities, education and social participation. In addition, the service dog was able to compensate or enhance many of the client factors of the adolescent including movement related functions and mental functions such as emotional aspects and self-esteem. All of which are focus areas in the *Occupational Therapy Practice Framework - II* (AOTA, 2008).

Occupational therapists work with children with SMA (Kakazu, 2005) and provide adaptations to clients with physical disabilities to improve their functional abilities in daily life. It was indicated in one study that children can benefit from adaptations to improve their participation in areas of occupation (Isabelle, 2002). Therefore, it may be suitable for occupational therapists to suggest appropriate families to apply for a service dog. It may also be appropriate for an occupational therapist to work with a client who owns a service dog in his or her home. The occupational therapist could help the client and service dog work together to facilitate the transition of first getting a service dog and to help the client and service dog work together efficiently in daily life activities. Further training for the occupational therapist in working with service dogs may be appropriate.

This study may provide valuable information to occupational therapists about the aspects of owning a service dog. Information from this study will enable occupational therapists to be better informed about when to recommend a family to apply for a service dog or working with clients who already own a service dog.

An adolescent with a physical disability, such as SMA, who owns a service dog most

likely uses the service dog to assist in their daily life activities. Therefore it may be appropriate to include the service dog in occupational therapy sessions, whether in a clinic or at home. The themes from this study, along with further research on this topic, would provide occupational therapists information on how a service dog is generally used by adolescents with SMA to guide them in appropriate interventions while incorporating the service dog.

Summary

The purpose of this study was to describe the daily life experiences with a service dog of a thirteen year old female adolescent presenting with a diagnosis of SMA Type II/III, and her mother. Their perspectives were taken into account through face-to-face interviews. Eight major themes emerged after data analysis: A process, a special bond, a sense of security, increased independence and participation in life, empowering, social aspects, and the future. Many of the themes found are consistent with the literature, specifically that there are social and physical implications of owning a service dog. The most powerful and unexpected finding was the significant social aspects of owning a service dog for the adolescent with SMA. The results of this study further indicate an occupational therapist's potential role with service dogs in providing assistance with the transitions involved with owning a service dog, training clients with their service dogs, and suggesting that families apply for a service dog.

References

- Allen, K., & Blascovich, J. (1996). The value of service dogs for people with severe ambulatory disabilities. A randomized controlled trial. *Journal of the American Medical Association, 275*, 1001-1006.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy, 62*, 625-683.
- Canine Assistants®. (2010). *Frequently asked questions*. Retrieved from <http://www.canineassistants.org/faqs.html>
- Camp, M. M. (2001). The use of service dogs as an adaptive strategy: A qualitative study. *American Journal of Occupational Therapy, 55*, 509-517.
- Chung, B., Wong, V., & Ip, P. (2004). Spinal muscular atrophy: Survival pattern and functional status. *Pediatrics, 114*, 548-553.
- Delta Society. (2009). *Service animal basics*. Retrieved from <http://www.deltasociety.org>
- Dropbox. (2011). Dropbox [Computer software]. Retrieved from <https://www.dropbox.com/>
- Eddy, J., Hart, L. A., & Boltz, R. P. (1987). The effects of service dogs on social acknowledgements of people on wheelchairs. *Journal of Psychology, 122*, 39-45.
- Eisenberg, M. G. (1982). Disability as stigma. In M. G. Eisenberg, C. Griggins, & R. J. Duval (Eds.), *Springer series on rehabilitation: Volume 2. Disabled people as second-class citizens* (pp. 3-12). New York, NY: Springer.
- Fairman, S. K., & Huebner, R. A. (2000). Service dogs: A compensatory resource to improve function. *Occupational Therapy in Health Care, 13*(2), 41-52.
- Fontaine, K. L. (2000). *Complementary and alternative therapies for nursing practice (2nd ed.)*. Upper Saddle River, NJ: Pearson Education.

- Huberman, A. M., & Miles, M. B. (1994). Data management and analysis methods. In N. Denzin and Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 428-444). Thousand Oaks, CA: Sage.
- Iannaccone, S. T. (2007). Modern management of spinal muscular atrophy. *Journal of Child Neurology, 22*, 974-978.
- Inspiration Software, Inc. (2011). Inspiration (9) [Computer software]. Retrieved from <http://www.inspiration.com/>
- Isabelle, S. (2002). Assistive technology for children with disabilities. *Occupational Therapy in Health Care, 16*(4), 29-51.
- Kakazu, P. (2005). *Current practice of occupational therapy for children with spinal muscular atrophy* (Unpublished master's thesis). University of Puget Sound, Tacoma, WA.
- Kielhofner, G. (2006). *Research in occupational therapy: Methods of inquiry for enhancing practice*. Philadelphia, PA: F. A. Davis.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*, 214-222.
- Mader, B., Hart, L. A., & Bergin, B. (1989). Social acknowledgements for children with disabilities: Effects of service dogs. *Child Development, 60*, 1529-1534.
- National Institutes of Neurological Disorders and Stroke. (2008, July). *NINDS Spinal Muscular Atrophy Information Page*. Retrieved from <http://www.ninds.nih.gov/disorders/sma/sma.htm>.
- NEADS (Dogs for deaf and disabled Americans). (2010). *About needs*. Retrieved from http://www.neads.org/services_new/service_dog.shtml
- Ng, P. W., James, M. A., & McDonald, C. (2000). Service dogs for disabled children: Effects of level of independence and quality of life. *Topics in Spinal Cord Injury Rehabilitation, 6*,

96-104.

Rintala, D. H., Matamoros, R., & Seitz, L. L. (2008). Effects of assistance dogs on persons with mobility or hearing impairments: A pilot study. *Journal of Rehabilitation Research and Development, 45*, 489-504.

Rogers, J. C., & Holm, M. B. (2009). The occupational therapy process. In E. Crepeau, E. Cohn, & B. Schell (Eds.) (2009). *Willard & Spackman's occupational therapy*. Philadelphia, PA: Lippincott Williams & Wilkins.

Spinal Muscular Atrophy Foundation. (2010). *FAQ*. Retrieved from <http://www.smafoundation.org/faq/#answer3>

Appendix A

Experiences with a Service Dog of an Adolescent with Spinal Muscular Atrophy

Interview Questions, Mother of The Adolescent

What is it like to own a service dog (SD)?

What was the process like getting your SD?

Can you walk me through a typical day for the adolescent and how her SD is incorporated in her day.

-What are some of the daily activities that the SD helps the adolescent with?

-Getting ready for the day?

(Listening for key words/or ask follow up question regarding these:

Bathing, showering; toileting, toilet hygiene; dressing; personal
devise care; personal hygiene and grooming)

-Does her SD help her at all during mealtimes? (Eating and Feeding)

-How does her SD help her move around or move things? (Functional

Mobility: moving objects, moving in bed, moving things in way of w/c)

-Does the SD play a part in the adolescent's sleep routine? (Rest and Sleep: Rest,
sleep, sleep preparation, sleep participation)

What do you feel the SD helps with the most?

Are there things your SD can do that the adolescent doesn't use her for?

Is there anything you wish the SD could do?

What are some things that she likes to do?

-Play preferences - things she chooses to do on her own or with her friends?

-How does her SD play a part in this?

-Leisure activities?

-I noticed she likes to draw, does she have difficulties with this?

-What other leisure activities does she enjoy? (church group?)

-Does she have difficulties doing any of this and need assistance?

-How does she complete things that are hard for her?

-Family or friend help?

-Does the SD play a part in this at all?

What are some chores or responsibilities the adolescent has?

-Does SD help at all with these? (chores: cleaning, care of other pets, cooking: meal prep and clean-up)

-Does the SD help you with anything? (watching the adolescent when you can't (Child rearing?))

-Safety/emergency alert?

Walk me through a typical day for your SD.

How do you feel about the SD?

Do you think children or other adolescents with SMA would benefit from owning a SD?

-In what way? or why not?

What specific things related to SMA does a SD provide benefits?

What are some of the negative aspects of owning a SD

Can you tell me about your family dynamics?

-How does your SD play a part in that?

-responsibilities?

-What is the SD's interaction with other family members?

-other pets?

How much does your SD go out in the community with the adolescent? with you?

-Where does your SD go?

-shopping? Does your SD help with this at all?

-school?

-vacation?

-anywhere else??

How is your SD in the community?

-How is it accessing places?

-How do people in the community react to the adolescent and the SD?

-Do they react differently when the SD is present or not?

What is it like going out with your SD and your whole family?

-loading the car.

In what way does the SD play a part in the adolescent's education?

-homework?

-school?

-physical activities?

-friends?

How do others seem to act around your SD?

-How do you feel the SD helps or hinders the adolescent socially? Does the SD help the family at all socially?

-Do you feel you are approached more because of the SD? Less?

-Has people's attention shifted away from the w/c since the adolescent got an SD?

Shifted away from the adolescent? Not changed?

What coping mechanisms does the adolescent seem to have to deal with having SMA and being in a w/c?

-What about you?

How much would you say you pay a month for your SD?

Tell me more about the adolescent.

-When was she dx with SMA?

-Hospitalizations related to SMA?

-Surgeries related to SMA?

-Medications?

-Other medical conditions?

-medical equipment?

Does she use any adaptive devices?

Has she ever received therapy services?

-What kind?

-How would you feel having an SD present? yours? or a trained therapy dog?

Is there anything else you want to add?

Areas of Occupation

ADL: Bathing, showering; bowel and bladder management; Dressing; Eating; Feeding;

Functional Mobility; Personal device care; Personal hygiene and grooming; Toilet Hygiene

IADL: Care of others; care of pets; child rearing; communication management; community

mobility; financial management; health management and maintenance; home establishment and

management, Meal prep and clean-up, Religious observance, safety and emergency maintenance;

shopping;

Rest and Sleep: Rest, sleep, sleep preparation, sleep participation

Education: formal education participation; Informal personal educational needs or interests

exploration; Informal personal education participation

Work: Chores? Volunteering?

Play: Play exploration, play participation

Leisure: Leisure exploration, Leisure participation,

Social: Community; family; peer, friend

Appendix B

Experiences with a Service Dog of an Adolescent with Spinal Muscular Atrophy

Interview Questions, Adolescent

What is it like to own a service dog (SD)?

Tell me a little about yourself?

Can you tell me about having spinal muscular atrophy (SMA)?

-How does having SMA making you feel?

-the good?

-the bad?

When did you get your SD?

-Can you tell me more about that?

-How did you get her?

-What was it like when she first came home?

What is your SD like?

What do you like about owning a SD?

-What do you not like about owning an SD?

Tell me about some things you really like to do.

-What do you chose to do when you are at home?

With other kids?

Recess?

Anything else?

-Does your SD ever help you with any of these activities?

-Is your SD present when you take part in any of these activities?

What is your typical day like?

How does your SD play a part in your day?

-Getting ready for the day?

(Listening for key words/or ask follow up question regarding these:

Bathing, showering; toileting, toilet hygiene; dressing; personal
devise care; personal hygiene and grooming)

-Does her SD help you at all during mealtimes? (Eating and Feeding)

-How does her SD help you move around or move things? (Functional

Mobility: moving objects, moving in bed, moving things in way of w/c)

-Does the SD play a part in your sleep routine? (Rest and Sleep: Rest,
sleep, sleep preparation, sleep participation)

What chores or responsibilities do you have at home or at school?

Do you ever have a hard time doing any of them?

Do you use your SD to help you with any of this?

Do you have to help take care of your SD?

-What do you have to do?

What are some things that your service dog help you with that you haven't told me about?

-What exactly does she do?

-Can you show me?

What is your favorite thing the SD can do?

Is there anything she can do that you don't use her for?

Where does your SD go with you outside of your home?

-What is it like out in the community with SD?

-School?

-Shopping?

Tell me about school.

-Friends?

-Schoolwork?

-PE? Activities?

-What is your favorite thing at school? What is the hardest thing at school to do?

-What does your SD do at school?

How do you feel when you meet someone new?

How do you feel about being in a w/c?

How do you feel when your dog is with you?

How do you feel about being in a w/c?

How do you feel about owning a SD?

What do you do when you feel frustrated about things?

How does your SD make you feel?

-Does your dog ever do things that make you happy or feel better?

-feel mad or Feel worse?

How do others seem to act around your SD?

-Do you feel you are approached more b/c of the SD? Less?

-How was it when you first got your SD?

-Is it different now?

Do you get therapy anywhere?

-Have you ever received therapy?

-Does your SD ever go with you?

How does your SD get a long with the rest of your family?

-Who all do you live with?

-How do they feel about your SD?

-How do they interact with her?

-Do you have any other animals?

-How does your SD like them?

Do you know of anyone else that has an SD?

-Do they have SMA?

Do you think other teenagers with SMA would benefit from a SD?

-Why? Why not?

-What about children?

Is there anything else you want me to know or you want to add?

How does owning a service dog make you feel?

Leisure/play

What does SD do when you are doing this?

Acknowledgments

I would like to thank Kari Tanta, PhD, OTR/L, FAOTA and Lucretia Berg, MS, OTR/L for their constructive advice, careful reading, guidance, and encouragement. I would also like to thank George Tomlin, PhD, OTR/L for his assistance in earlier versions of this research paper. Lastly, I would like to thank the participants of this study for openly sharing their experiences with me. This research was completed in partial fulfillment of requirements for a Master of Science in Occupational Therapy degree at the University of Puget Sound. It was supported in part by a research grant from the University Enrichment Committee at the University of Puget Sound.