

Non-medical Services for Caregivers of Children Experiencing Amputation

Thesis

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Abstract

Children who experience amputation and their families often need extra support services because amputation is a traumatic event. While children who have experienced amputation and their families typically receive extensive medical care with regards to amputation, non-medical care may be less available. This research is exploratory in nature and is intended to assess the non-medical needs and services received by families of children experiencing amputation. Parents and/or caregivers of children who have experienced amputation were asked to fill out an online questionnaire assessing the non-medical services the children were offered after amputation, the services they received, and any barriers they encountered in getting the services. Follow up telephone interviews were also conducted for participants who indicated their willingness to be interviewed on the questionnaire. The recruitment method only yielded a total of two responses from caregivers. Both caregivers reported that their child acquired amputation through accidental means. Each caregiver reports being offered different services and information after their child experienced amputation. The only service both were offered was that of mental health services for the family. Both families indicated that they were unable to utilize offered services after hospitalization due to the distance from their home residence to the services. It is difficult to draw meaningful conclusions as the response rate was limited; however the following conclusions may be made: Amputations due to disease or cancer appear to be on the decline due to medical advancements; there appears to be a lack of follow up support in rural areas and services may need to be embedded in already existing ones to meet the needs of children and their families; communication among medical and non-medical care providers needs to be improved to offer the best recommendations for these children and their families.

Dedication

I dedicate this thesis to my fiancé, Gregg Swint, who has provided me the love, strength, and support that I needed to pursue my dreams and goals.

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This project would not have been possible without the assistance and encouragement from numerous individuals. First and foremost, I would like to thank Dr. Denise Bronson. Without Dr. Bronson, completing this thesis would have been nearly impossible. She provided me with clear guidance and support throughout my journey and for that I am ever grateful. Secondly, from the OSU College of Social Work I would like to thank Jennie Babcock and Andrea Severson for their endless encouragement and interest in my education. Thirdly, I would like to extend my thanks to the National Amputee Coalition for their willingness to advertise my survey in their online magazine and on their website. Next I would like to thank several social workers at Nationwide Children's Hospital in Columbus, Jeanette Foster and Avalon Espinoza, for their insight and willingness to assist with my research. Finally I would like to extend my thanks to family, without you I would have never been inspired to undertake this project. Thank you all!

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Chapter 1: Statement of Research Topic

Introduction

Children who experience amputation and their families often need extra support services because amputation is a traumatic event. While children who have experienced amputation and their families typically receive extensive medical care with regards to amputation, non-medical care may be less available. This research is exploratory in nature and is intended to assess the non-medical needs and services received by families of children experiencing amputation. The aim of this study is to determine whether families are receiving non-medical resources to assist them with post-amputation adjustment.

Currently, amputation or limb loss among children is a condition that does not receive much attention in the public media. This may be due to overall decline in the number of amputees, especially among those under the age of 18. Rates among children have been shown to be dropping for cancer-related and trauma-related amputations (National Limb Loss Information Center: Fact Sheet, 2008) due to advances in limb-salvage technology, re-implantation of extremities, and neoadjuvant chemotherapy (Dillingham, Pezzin, & MacKenzie, 2002; Ng & Berlet, 2010). It has been reported that surgeons are using more aggressive limb sparing strategies especially in cases involving the cancer osteosarcoma (Dillingham et al., 2002). Even though overall rates of amputation have been declining for cancer and trauma victims, rates are actually increasing in cases of dysvascular amputation.

Dysvascular amputations occur due to issues with blood vessels and are often related to persons with diabetes (National Limb Loss Information Center: Fact Sheet, 2008; Ng & Berlet, 2010). Ng and Berlet's 2010 study estimated that in 2005 there were 623,000 Americans living with limb loss and that almost 80% of those were the result of dysvascular reasons. In the United

States there are approximately 215,000 children living with diabetes. Estimates report that almost 19,000 children are newly diagnosed with diabetes each year (Centers for Disease Control and Prevention, 2011). Each one of these children is at risk for developing dysvascular issues that may lead to amputation. Dysvascular amputations occurring during childhood do happen, although they are rare (Krajbich, 1998). Even so, the percentage of amputations due to diabetes/dysvascular disease is likely to grow even more as the population with diabetes is expected to double by 2030 (Ziegler-Graham, MacKenzie, Ephraim, Trivison, & Brookmeyer, 2008). Another study (Dillingham et al., 2002) showed that in 1996, rates of dysvascular amputation was eight times that of trauma-related amputations, the second leading cause for amputation.

Statement of the Problem

Despite the overall declining number of persons with amputations, there are almost 1.7 million people in the United States who are currently living with limb loss (National Limb Loss Information Center: Fact Sheet, 2008). While the majority of these individuals are the elderly, there are also 70,000 children living with limb loss (National Limb Loss Information Center: Fact Sheet, 2008). Children may experience amputation due to trauma, cancer, or congenital deficiencies.

Traumatic amputations represent a major cause of morbidity in children. It is reported that in 2003 approximately 956 children were hospitalized for traumatic amputations in the United States (Conner, McKenzie, Xiang, & Smith, 2010). Many forms of traumatic amputation exist; however the most prevalent cause of traumatic amputations is due to lawn mower accidents (Conner et al., 2010; Loder, 2004; Trautwein, Smith, & Rivara, 1996). Amputations due to lawn mowers have been shown to account for 14-29% of traumatic amputations in

children (Conner et al., 2010; Loder, 2004; Trautwein et al., 1996). Motor-vehicle accidents represent another large percentage of traumatic pediatric amputations, accounting for between nine and 15% of amputation. Farming related injuries can also lead to limb loss in children and have been estimated to represent 15% amputations as well. The examples listed above are not the only reasons leading to traumatic amputation, but represent the most common causes. Train injuries, other machine injuries, explosive devices, burns, and pinching extremities between objects all represent alternative ways in which children may suffer the loss of a limb (Conner et al., 2010; Loder, 2004; Trautwein et al., 1996).

Amputations may also occur in the pediatric population due to cancer, specifically a cancer called osteosarcoma. Osteosarcoma is a type of cancer that typically yields amputation and most often affects adolescents; between 500 and 900 cases are newly diagnosed each year (Bryant, & Pandian, 2001; Kim, Chalmers, & Morris, 2010). Amputation is just one of the treatment options for osteosarcoma and until recently it was the most popular. New advances in chemotherapy and cancer treatment have decreased the amount of amputations due to this cancer (Kim et al., 2010).

Pediatric amputation also encompasses congenital limb deficiencies. By definition a congenital limb deficiency is a condition which exists at birth (Smith, 2006) and is very different from a traumatic amputation which is typically acquired accidentally after a child has been born. According to one article (Smith, 2006) the congenital limb deficiency rate is one per 1000 live births. Another study (Dillingham et al., 2002) reports that in 1996 congenital limb deficiencies accounted for 0.8% of all limb loss. Congenital limb loss is often considered the largest form of amputation among the pediatric population (Krajbich, 1998).

There is limited literature specifically dealing with limb loss among the pediatric population; this is especially true in regards to issues surrounding mental health and support services (Conner et al., 2010). A study by Andrews, Williams, and VandeCreek (2010) focused on the pediatric population, and assessed the parents' experience with the services and physicians. They found that 78% of parents in the study thought information was being withheld from them about their child's potential resources. Parents believed that health care providers withheld information from them about the origin of their child's limb loss as well as the child's future developmental outcomes. Others reported a general feeling of withholding information about useful services for the child and family. The study revealed that parents were satisfied in referrals for physical therapy, occupational therapy, or prosthesis fitting; however, only 18% of parents were referred to mental health providers. This study brings into question what non-medical resources might be needed for these children and their families, and why only a small percentage of families are being offered counseling to help them adjust to the changes following an amputation. It also suggests that families may not receive non-medical services to help their child and family successfully adjust to the child's amputation.

Purpose of the Study

The long term goal of this study is to assess whether families are receiving non-medical resources to assist them with post-amputation adjustment. The study has several specific aims: (1) To assess the non-medical services that were offered and received by children who have experienced pediatric amputation and their families; (2) To identify the non-medical services that these children and families found they needed for promoting positive recovery from the trauma associated with pediatric amputation; and, (3) To identify strategies that might help lessen the gap between what was needed and what was received in terms of non-medical services. The

specific research questions for the proposed study are as follows: (a) Are the needs for non-medical services among children who have undergone amputation and their families being met?; (b) What barriers, if any, stand in the way of these children and their families obtaining these services?; and (c) What can be done to improve accessing help to benefit these children and their families?

Chapter 2: Literature Review

Pediatric Amputation

Children and adults both experience amputation; however a child's small skeletal mass and skeletal immaturity permits children to be at a greater risk of experiencing a traumatic amputation with complications (Conner et al., 2010). Even though amputation may affect all ages, a pediatric amputation has additional considerations that do not apply to an adult amputation because the child is still growing. When a child undergoes a surgical amputation, special attention must be paid to preserving growth plates (Ng & Berlet, 2010). Additionally, bone overgrowth at the end of the stump is common and this complication is virtually unseen in adults. One final consideration is prosthesis fitting. Children continuously need to be re-fitted for prosthetic devices to maintain maximum functionality (Krajbich, 1998). All of the reasons listed above show why a child amputation poses challenges that an adult amputation may not.

Another factor that affects children and not adults in regards to limb loss is congenital limb deficiency. In fact, children experience congenital limb deficiencies twice as often as acquired amputations (Bryant & Pandian, 2001). Reasons are not wholly conclusive on why congenital limb deficiencies occur. One explanation for congenital limb deficiencies is due to genetics (Evans, Thakker, & Donnai, 1991; Smith, 2006). There are three types of single-gene disorders that have been linked to limb deficiency in children: autosomal dominant, autosomal recessive, and x-linked recessive (Evans et al., 1991). Autosomal dominant disorders can be passed down from either parent and can affect both male and female children. The disorder is often transmitted to about half of a couples' offspring. Autosomal recessive disorders occur in about 25% of parent's offspring as the parents both carry the gene on their recessive alleles. In order for a child to have the disorder they need to receive both of the parent's recessive gene for

the disorder. Finally x-linked recessive genes are carried by females; however they do not actually have the disorder, the disorder can only be present in their male children (Evans et al., 1991). In each of these types only one affected gene causes the limb deficiency and the affected gene can be traced back through family history. Limb deficiencies may also be the result of chromosomal disorders where an extra chromosome is present (Evans et al., 1991; McGuirk, Westgate, & Holmes, 2001). Examples of such disorders are: trisomy 18, also known as Edward's Syndrome; and trisomy 13, also known as Patau's Syndrome. Environmental agents represent another common explanation for congenital limb differences (Evans et al., 1991; McGuirk et al., 2001; Smith, 2006). This refers to teratogenic agents such as infections, chemicals, or medications that the mother may be exposed to during pregnancy when the legs and arms of the child are developing. Examples of environmental agents include thalidomide, aminopterin, and alcohol.

Amputations are classified as either congenital or acquired according to why the amputation was needed. Acquired amputations consist of those that result from an accident or disease. The most common types of traumatic amputations that children experience are accidents from lawn mowers, farm machinery, motor vehicles or other types of mechanical equipment. Traumatic amputations also include pinching between two objects and amputation due to power tools (Conner et al., 2010). Loder (2004) identified children who experienced an amputation due to gunshot wounds. Other reasons for acquired amputations include amputation due to cancers such as osteosarcoma, amputations due to severe infections, amputations due to abnormal blood vessels, and amputations due to nerve problems (Smith, 2006).

Services for Children Experiencing Amputation

Pediatric amputation obviously requires medical services such as physical therapy, occupational therapy, prosthesis fitting, and pain management. Research suggests that caregivers are typically offered these types of services for their child after amputation (Andrews et al., 2010). Andrews and colleagues surveyed 50 parents of children with amputations due to congenital limb deficiencies. In their study, 64% of parents said their child was referred for physical therapy, 48% of parents were referred for occupational therapy, 57% were referred for a prosthetic and 36% were referred for surgery. Due to the fact that children are always growing, prosthesis fitting is always reoccurring in the life of the child (Smith, 2006). However, these are not the only services that children and their family need to have an overall successful outcome to the amputation. For example, families may need financial assistance, counseling, and social supports; or in other words, non-medical services (Gallagher & MacLachlan, 2001; Horgan & MacLachlan, 2004; Unwin, Kacpersek, & Clarke, 2009; Weir, Ephraim, & MacKenzie, 2010; Williams, Ehde, Smith, Czernieck, Hoffman, & Robinson, 2004).

Financial Assistance

Pediatric amputation is a condition that incurs high costs. One study by Hostetler, Schwartz, Shields, Xiang, & Smith (2005) reports that traumatic amputations cost roughly \$23,465 for hospital expenses alone. This estimate does not take into account follow up appointments for monitoring and rehabilitation. Weir and colleagues (2010) surveyed 123 children and families and discovered that around 82% of these families paid out-of-pocket for services that were not wholly covered by their private insurance. In the same study 26% of the households were reported to be below the federal poverty line, indicating that these families likely need extra financial assistance to help reach a positive outcome.

Mental Health Services

Counseling, or mental health services are another form of non-medical assistance that children who have undergone amputation and their families may need to foster positive adjustment. There are a plethora of research articles addressing the psychological adjustment of amputees (Hanley, Jensen, Ehde, Hoffman, Patterson, & Robinson, 2004; Horgan & MacLachlan, 2004; Varni, Rubinfeld, Talbot, & Setoguchi, 1988, 1989, 1992; Varni & Setoguchi, 1991). Depression and anxiety have been found to be elevated immediately after an amputation (Hanley et al., 2004; Horgan & MacLachlan, 2004). This indicates that mental health services should be offered to the child shortly after the amputation and should not be put off until the depressive or anxious symptoms are visible. While mental health services for the child who has experienced the amputation seems understandable, the child's siblings and caregivers may also need these services. One study (Gallagher & MacLachlan, 2001) reports that amputees definitely believed the experience of limb loss was harder on their family members than it was on them. Research shows that children who have a sibling with a disability are more likely to develop psychological adjustment problems than their peers (Lobato & Kao, 2002). Also many parents experience stress from the amputation, along with disruption of work routines and financial difficulties (Giallo & Gavidia-Payne, 2006; Weir et al., 2010). The above examples represent reasons why children and their families may need to receive mental health services for positive adjustment to the child's amputation.

Social Support

Social support is another vital service that research shows is important to promote positive adjustment for amputees. A qualitative study (Gallagher & MacLachlan, 2001) of several amputees indicates that the participants expressed the importance of a peer group, or

speaking to someone who has been through a situation similar to their own. Many studies (Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser 1995; Rybarczyk, Nyenhuis, Nicholas, Schulz, Alioto, & Blair, 1992; Thompson & Haran, 1984; Williamson, 1995; Williamson, Schulz, Bridges, & Behan, 1994) have shown a link between perceived social support and quality of life and depressive symptoms. The studies indicate that individuals who perceive more social support report greater quality of life and less depressive symptoms.

Anticipated Benefits of the Study

Organizations, systems and companies who deal with pediatric amputation may see benefit as a result of this research. If a gap is identified between services needed and received while also determining the barriers to services, then strategies can be developed to help overcome this gap and provide clients with adequate resources. These strategies and even knowing the gap exists will provide a vehicle for change among the way organizations offer their services. Therefore, it can be inferred that individuals of the study's target population may also personally benefit from these changes. Specifically agencies may be able to begin to develop assessment tools that help to discover gaps in a child's care, or work on implementing programs to help combat the barriers to the services. Organizations may be able to raise awareness of the issue to service providers who will then make every effort to eliminate the gaps in the child and family's services.

Chapter 3: Methodology

Research Design

This research employs a cross-sectional design to examine the extent to which children that have experienced amputation and their families are receiving non-medical services following the amputation. Information was gathered through a quantitative survey and/or qualitative interview.

The purpose of this exploratory study was to gather descriptive information about children who have experienced amputation and about the non-medical services they receive. This data was collected in order to determine if adequate services are being provided to the child and family so they may have a successful adjustment to the child's amputation.

Sample

Participants for the study were recruited through convenience sampling. Convenience sampling is a form of non-probability sampling that relies on subjects in the population that are convenient to the researcher (Rubin & Babbie, 2011). An advertisement was placed in The Amputee Coalition's online magazine *inMotion* and a link to the online survey placed on their webpage. The Amputee Coalition is a national organization that provides support, references and information to individuals who have undergone amputation and their families. After exposure to the advertisement or webpage individuals could participate if they chose to do so. Criteria for participating were as follows:

- Participants must be at least 18 years of age
- Participants must be a parent/caregiver of a child who has experienced an amputation
- Participants' child must have experienced the amputation within the last 10 years.

Data Collection

Data were collected using an online survey developed through the internet program SurveyGizmo, and through telephone interviews. Participants were made aware of and provided the link to the survey through the Amputee Coalition's webpage and online magazine *inMotion*. Once potential participants proceeded to the link for the survey, they were directed to a webpage that gave information on the study, confidentiality, and time commitment. At the bottom of this page individuals could either consent or decline to participate in the study. If they agreed to participate they were directed to the survey. Upon completion of the survey individuals were asked if they would be willing to provide contact information for a follow up telephone interview. Those who provided contact information gave their consent to be contacted. Follow up interviews examined the participants' responses more closely and asked for more explanation and detail. Interviews also asked participants to share more about their overall experience in dealing with their child's amputation.

The online survey consisted of several parts beginning with demographic information about the child who required an amputation. The questions included things such as age, gender, and race as well as the type of amputation the child required and which part of the body was amputated. The remaining sections were broken up into categories revolving around the types of non-medical services these children and their families may have been offered or received following amputation. Categories included: mental health services, support services, financial assistance, education, transportation, and other. Wrap up questions focused on whether the family made contact with a social worker and if they were generally satisfied with the amount of services they were offered post-amputation. A copy of the survey is included in Appendix A.

Caregivers who participated in the follow up telephone interview were asked more in depth questions revolving around the responses made in their online survey. For example, “On your survey, you indicated that you were unable to participate in some of the offered services to you, can you elaborate more why?” Questions also referred to caregivers’ satisfaction of collaborating with the social worker and if the social worker was helpful. To see the interview question guide in its entirety please see Appendix B.

Data Analysis

The original plan for analyzing this research was to download the raw data from SurveyGizmo into an excel sheet, code and then analyze the quantitative responses to the survey. However, only two responses were acquired as a result of sampling methods for this study. Therefore a qualitative comparison of the two cases was completed noting the similarities and differences among the two responses.

Additionally, both individuals who participated in the survey provided their contact information and indicated that they would be interested in participating in a follow up interview via telephone. Questions asked in the follow up interview were based off participants’ responses in the survey. Responses to the follow up questions will be synthesized and analyzed to identify recurring themes presented by the subjects.

Chapter 4: Findings

As this study only yielded two responses, these responses will be compared over different areas to discuss the findings. The information is provided below.

Demographic Characteristics

The demographic information for both cases is very similar. Each survey and follow up interview was completed by the child's mother. One child was three years old at the time of amputation and is now six years old; the responses provided by this child's mother will be referred to as participant one. The second child was 10 at the age of amputation is currently 12 years old; this participant mother and her responses will be referred to as participant two. Both participants' children were Caucasian, male, and acquired their amputation through accidental means. Each of the children's accidents involved a lawnmower accident and ended in the loss of their left foot. Participant two shared that her child required amputation at the ankle whereas participant one shared that her child required it at mid-foot. Both mothers assure that their children utilize a prosthetic device on a daily basis.

Mental Health

In regards to mental health services, both participants report being offered mental health services for the family. However, only participant two utilized the mental health services. Participant one did not utilize the mental health services because the services were located too far away from their residence. Participant two, reported that mental health services were only offered for the child at first but later the counselor allowed the rest of the family to attend. Even though participant two and her family was offered and did utilize mental health services, she relates that they were only able to utilize the services on three different occasions. After these occasions it was too hard to keep seeing the counselor as the counselor was located two hours

away from their place of residence. The participant reported that the child is currently seeing the school psychiatrist when needed, but wished that their child could have received services from a pediatric psychiatrist, however there was not one in the area in which they live.

Support Groups

Participant one reported being offered support group services. The support group offered was a family support group. Even though it was offered the family was unable to participate in the support group as it was located too far away from their residence. Participant one also reported in the telephone interview that the hospital staff where their child received medical attention only looked in the area near the hospital for existing support groups. They believe that the hospital neglected to look into support group options that were closer to their residence. In the telephone interview this participant said they would have likely used support groups if they were made aware of any closer to where they reside. Participant two reported no support groups were offered and was disappointed because she would have utilized the support if it was available.

Education

After these children experienced their amputation, participant one was the only participant who reported receiving educational information surrounding the amputation process. Education was only offered for the caregivers as the child who experienced the amputation was still rather young. The caregivers believe that having this education was helpful and increased their understanding of what was going on around them and what was happening with their child. Participant two indicated on the survey that she and her family did not received education; however upon further conversation in the telephone interview both mothers reported that some education was provided but it was rather limited. Participant two said that she and her husband

were only informed about one type of amputation that their child could undergo and that this type of amputation would greatly increase their child's chances of mobility. After agreeing to this type of amputation and after the child had gone through surgery, she said that doctors told her and the father that this type of amputation has limited prosthetic options. Participant two reported that had she known the limitations of prosthetic options she and her family may have chosen to go with a different type of amputation for the child. She also reports that after the amputation occurred no one in the hospital informed any family member of a prosthesis doctor to contact; the parents had to go out and seek the prosthesis doctor in the hospital. Follow-up treatment information was not provided to participant two or her husband.

Financial Assistance

Participant one reported receiving additional financial assistance outside the realm of their health insurance. She and her husband received \$300 to help pay for the gas to get to follow up appointments and for hospital visits. This money came from the caregiver's home town, not from the location of the hospital in which the child was receiving medical care. No additional finances were offered for the child or family.

Transportation

Neither of the participant caregivers received transportation aid during the time their child was hospitalized nor for the time after which includes follow-up appointments. As stated in the previous section, participant one was provided with \$300 cash to help pay for gas, but that money was not closely monitored.

Other Services

On the survey, neither of the participants reported that they received additional types of services not mentioned on the survey. During the telephone interview participant one retracted

that statement and reported she and her husband were offered the Ronald McDonald house near the hospital. Ronald McDonald house provided them with a place to sleep while their child was hospitalized as they did not live close enough to the hospital in which their child was receiving care.

Wrap up Questions and Information

Participant one sought assistance from an agency called the Bureau for Children with Medical Handicaps (BCMh). She reported that this agency was found without the assistance of the hospital support staff where their child was receiving medical care. BCMh provides financial assistance to parents and families of children with medical handicaps. The participant did not specify exactly the kind of help they received from this agency, but did report finding the agency to be helpful. Participant two stated that education or guidance on submitting insurance claims would have been helpful. She also mentioned that assistance on selecting a prosthesis doctor would have been extremely helpful because she felt lost on where to go, and would have liked information on prosthesis doctors closer to her child's home.

Both caregivers who completed this survey report that they believe their family was offered an adequate amount of services that was consistent with the severity of their child's amputation. Participant one reported being "totally satisfied" and participant two reported to be "satisfied". However, both also reported being disappointed with the services that they actually could utilize.

Only participant one remembered speaking with a social worker during the time her child was in the hospital and she had to seek out the social worker on her own. The social worker visited only after being asked for by the family. Participant one said that the social worker did not really facilitate linkages with any services near the hospital or in the area of the family's

home. Participant one said that the nurse who normally provided medical care to the child was more helpful and provided more service suggestions than the hospital social worker.

Participant two does not remember being assigned a social worker during their child's hospital stay. She reports that one checked in with them, but only once and did not offer any advice or suggestions. Participant two reported that the child and family had more contact with the hospital psychologist during and after the child's discharge than with the social worker.

Chapter 5: Discussion & Conclusion

It is necessary to look at the research questions posed to see if any conclusions can be drawn from the study. First, is the need for non-medical services in children who have undergone amputation being met? It is hard to answer this question accurately as only two caregivers responded to the survey. Both mothers reported that they were satisfied with the amount of services they and their children were offered, but they also expressed a desire to be able to utilize more services. Further research needs to be undertaken in order to better answer this question. Second, are there barriers that stand in the way of children and their families obtaining these non-medical services? Based on the survey and interview responses received for this study several barriers present: limited resources in rural areas, families living in rural areas with no transportation assistance, and no concrete assistance from social worker or other service professional. Again, more research needs to be completed to validate these barriers as well as to identify additional barriers to this population. Finally, what can be done to improve assessing help to benefit these children and their families? The findings from this study are unable to identify concrete ways to improve assessing need for these children; only suggestions may be made based on the respondents' comments. For example, ensuring that doctors and nurses, as well as other professionals who will definitely have contact with the child and family facilitate linkages to a social worker. This will enable social workers to identify service needs within and outside the hospital that may be of assistance to the child and family in order to promote successful outcomes. Overall, more rigorous research needs to be completed in order to provide a more comprehensive assessment of the service needs for families experiencing a childhood amputation.

Limitations

There were several limitations associated with this study. First, the methodology employed a convenience sampling method. The convenience sampling method provided a very low response rate of only two responses. Due to the low response rate, the results of the study are unable to be generalized to the population of children with amputation. A more thorough random sampling method utilizing hospital records may have produced more responses to the survey. Although the Amputee Coalition is a national organization it may be utilized more by adults with amputations than children or parents of children who have experienced amputation. Additionally this type of sampling method introduces bias into the study as those who responded were only those who felt comfortable sharing the experiences of their child's amputation. A second limitation of the methodology is that it utilizes a cross-sectional design. The survey only focuses on the time of amputation for the child and immediately after their hospital release. Therefore this method does not allow conclusions to be made about changes in receipt of services over time for the child and their family. Finally, limitations arise for those individuals whose child experienced amputation several years or a decade ago. Information they provide may not be holistic in nature as details surrounding the experience may be forgotten due to the time lapse.

Implications for Practice

While conclusive findings cannot be drawn and generalized for all populations, there are still relevant implications for social work practice. For instance, the results suggest that many services to promote positive adjustment after amputation are not being offered for children and their families. The survey indicated a lack of financial assistance, educational information, support groups or help with transportation. Social workers and other professionals should strive

to offer the necessary services to these children and their families so that successful outcomes of positive adjustment are more easily reached. Better communication among medical providers, social workers, and other professionals of the hospital staff can help to assure that all potentially beneficial services are offered to patients. This is especially true in regards to educating families on next steps and follow-up appointments for the child. It is crucial for the child to make contact with prosthetic doctors and even physical/occupational therapists after recovery from the amputation. Families should not have to seek out these individuals on their own; recommendations should at least be made on who to contact for follow-up in certain areas and for next steps.

Both participants reported working with a social worker only minimally. Doctors and other hospital staff need to recommendation social worker services and once recommendations are made it may be better for social worker to seek out the child and family rather than the reverse. Hospital situations can make for a scary atmosphere for families and often families do not know where to specifically go to make contact with a social worker. By increasing the awareness to doctors and other medical staff on the importance of referring to social worker for recommendations may increase the likelihood that these children are seen by social workers.

Additionally, both participants report that their children acquired amputations due to lawn mower injuries. This may seem surprising; however several studies (Conner et al., 2010; Loder, 2004; Trautwen et al., 1996) suggest that in regards to traumatic amputation the most prevalent cause is due to lawn mower incidents. Another study estimates that 658 amputations in children each year are the result of a lawn mower accident (Loder, Dikos, & Taylor 2004). Injuries such as amputation occur either because the child was riding/driving the lawn mower, or the child was

not seen by the driver. Often times it is reported that children are on the lap of the driver when accidents occur (Hammig & Jones, 2010). Both participants of our sample report their children were male; this is not surprising as lawn mower injuries, especially amputation, occur more frequently with males (Hammig & Jones, 2010). Prevention is the preferable method of dealing with these types of injuries (Hammig & Jones, 2010; Loder et al., 2004). It is difficult for social workers and medical professionals in a hospital setting to utilize prevention techniques as they typically deal with reactive issues to an injury. However, these professionals should educate the children and families that they are providing for and utilize them to spread the word to other individuals about prevention.

Social workers who are employed in a hospital setting are often very busy and may not have enough time to devote to all clients equally. However children of amputation and their families may benefit from more linkages from the social worker on helpful services post treatment. If the child and family do not live in the immediate area of the hospital, social worker should do a search for similar services that are located closer to the child's residence. This is a tricky task as children from rural areas may not have any services located near them. Lack of services in the child's area of residence was an issue that both participants of this study reported. This implies that maybe rural areas need to have more services that can help child and their families adjust to amputation. While it does not make sense to create whole new services, services that are already established could benefit from embedding pediatric amputation services into them such as mental health child psychologists, or prosthetic doctors who specialize in child amputation, etc.

The biggest implication from this research is that amputations due to disease, cancer, or for congenital reasons are on the decline. This is supported with the fact that there have been

advancements in limb-salvage technology, re-implantation of extremities, and neoadjuvant (which simply means preoperative) chemotherapy. Each of these offers alternatives to amputation in children that are more aggressive yet allow the children to keep their limbs (Dillingham et al., 2002). Limb salvage refers to surgery that is performed on bones in order to prevent amputation. This is often seen when dealing with bone tumors or sarcomas. It is often coupled with neo-adjuvant chemotherapy which is described below. While individuals typically prefer this surgery to amputation there are complications that result (Nagarajan, Neglia, Denis, Clohisy, & Robison, 2002; Weissten, Goldsby, & O'Donnell, 2005). Limb re-implantation or replantation refers to restoring a body part to its original area. Research shows us that this provides a better outcome for patients than undergoing amputation and a later prosthetic fitting. Additionally patients would often rather have a limb or body part that does not work to its full potential rather than losing it completely for aesthetic reasons (Atzei, Pignatti, Baldrighi, & Maranzano, 2005; Graham, Adkins, Tsai, Firrel, & Breidenbach, 1998; Sorensen & Allison, 2009). Even with advances in replantation, children and families should understand that recovery often lasts longer and multiple surgeries afterward may need to be completed (Glasse, 1999; Sorensen & Allison, 2009). Neo-adjuvant chemotherapy is a relatively successful way to shrink the child's tumor due to osteosarcoma. With the help of this new therapy to shrink tumors, limb salvage techniques can be utilized instead of amputation. Sometimes no limb salvage techniques are even necessary after administered chemotherapy (Kim et al., 2010). Workers should be aware for reasons of decline, but also still aware of what procedures and services are beneficial when amputation does result. Just because other advancements instead of amputation are being made it does not justify eliminating knowledge or services for amputation.

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Appendix A: Online Survey Non-medical Services for Caregivers of Children Who Have Experienced Amputation

Summary

This is a research study that uses a survey to ask questions about the non-medical services (i.e. therapy, financial support, social support) that you and your family received after your child experienced amputation. It also asks about the types of services that you wished you had received after the amputation. During the research process if the participants learn of a new service or resource that they did not know of before, they may be able to use this newly recognized resource to better the recovery process for the child who has undergone amputation. An additional benefit is that the information from participants in this research will improve the system of care given to children with limb loss. The questions on the following pages will address these two topics and the entire survey will take about 15 minutes to complete.

It is important to know that your participation is completely voluntary. You may refuse to participate or withdraw from the survey at any time; there are no penalties, or loss of benefits to which you are otherwise entitled, for doing so. You must be 18 or over and the parent or legal guardian of a child who has experienced limb loss.

The information collected in the survey will be completely anonymous. However, at the end of the survey you will be asked if you are willing to participate in a short (15-20 minute) phone interview about your family's experiences with the non-medical services you received. If you indicated an interest in being interviewed we will ask for your name, phone number, email address, and times that would be convenient for the interview. If you agree to a follow-up interview and provide contact information, this information will be stored separately from the online survey responses. After the interviews all identifiers will be removed from the data and permanently destroyed. At no time will your identity be associated with the online survey responses or the telephone interviews. This identifying information will be destroyed after the interview and will never be connected in any way to the answers you provide on the questionnaire or interview. We will work to make sure that no one sees your survey responses

without approval. But, there is a small possibility that an unauthorized person could access your online responses. In some cases, this information could be used to identify you. Your data will be encrypted to reduce the risk that unauthorized persons can view the information.

For questions about the research, complaints or if you feel you have been harmed by participation, you may contact Denise Bronson at 614-292-1867. For questions about your rights as a research participant, or to speak with someone who is not a member of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Thank you for your participation.

Sincerely,

**Denise E. Bronson, Associate Dean & MSW Program Director
Katie Eickholt, BSSW student**

1) I have read the description of this study and consent to participate.*

- Yes, I consent to participating in this research study.
- No, I decline consent to participate in this study.

Demographics

2) Gender of Child who experienced amputation:

- Male
- Female

3) Child's age when amputation occurred:

4) Current age of child:

5) Child's Race:

- Asian
- Black/African-American
- White/Caucasian
- Hispanic
- Native American/Alaska Native
- Native Hawaiian or Pacific Islander
- From multiple races
- Other:: _____

Type of Amputation

6) Was the cause for amputation...?*

- Congenital - meaning the condition exists at or dates to birth
- Acquired - meaning the amputation occurred because of a condition that developed after birth
- Accidental - referring to events or situations that are non-medical in nature that lead to amputation

Acquired

7) You indicated the amputation was acquired, please check below what lead to the amputation

- Diabetes
 - Infection
 - Vascular Disease
 - Cancer
 - Other:: _____
-

Accidental

8) You indicated the amputation occurred due to accidental circumstances, please check below what type of accident lead to the amputation

- Car Accident
 - Burns
 - Farm/Mower accident
 - Body part pinched in door/car/other items
 - Other Trauma:: _____
-

Area of body amputated

9) Please indicate the part/area of body child had amputated:*

Note: If child has multiple amputations, please select the most severe.

- Finger(s)
- Toe(s)
- Leg

- Arm
- Hand
- Foot

10) Please indicate if the area amputated was on the Right or Left of the child's body:

- Right
 - Left
-

Fingers

11) Please indicate the severity of the finger loss:

- Loss at top knuckle
 - Loss at middle knuckle
 - Loss at bottom knuckle
-

Toes

12) Please indicate the severity of toe loss:

- Loss of part of toe(s)
 - Complete loss of toe(s)
-

Leg

13) Please indicate the severity of leg loss:

- Loss at thigh (whole)
 - Loss at knee
 - Loss at middle calf
-

Arm

14) Please indicate the severity of arm loss:

- Loss at shoulder (whole)
 - Loss at elbow
 - Loss at forearm
-

Hand

15) Please indicate the severity of hand loss:

- Loss at wrist
 - Loss at mid-hand
-

Foot

16) Please indicate the severity of foot loss:

- Loss at heel
 - Loss at ankle
 - Loss at mid-foot
-

Prosthesis

17) Does child currently utilize a prosthetic?

- Yes
- No

18) If not, why? (check all that apply)

- Discomfort
 - Cost of prosthetic device
 - Problems with insurance
 - Broken
 - Doesn't function well, or promote good functioning
 - Lack of service to support continued/regular use
 - Other:
-

Mental Health Services

"Mental Health Services" refers to things such as therapy or counseling.

19) Were you **OFFERED** Mental Health Services after the amputation occurred?

Yes

No

Mental Health Services (cont.)

20) For whom were the *mental health services* **OFFERED**?
(check all that apply)

Family

Child

Parents/Caregivers

Siblings

21) Did you **RECEIVE** or **USE** any mental health services?

Yes

No

22) Who **UTILIZED** the *mental health services*?

Family

Child

Parents/Caregivers

Siblings

None

23)

If you were offered *mental health services* in which you were unable to participate, what/why were the reasons for your non-participation? (check all that apply)

- Family/Child didn't meet eligibility requirements
 - No transportation available
 - Service located too far away
 - No financial support
 - Services were un-helpful
 - Personal Choice (e.g. did not want to partake in service)
 - Other:
-

Support Groups

Support Groups refer to groups led by individuals who are in similar situations; support groups may be just for the child, for the family, for the parents, or for siblings.

24) Were you OFFERED Support Groups after the amputation occurred?

- Yes
 - No
-

Support Groups (cont.)

25) For whom were the *support groups* OFFERED?

- (check all that apply)
- Family

- Child
- Parents/Caregivers
- Siblings

26) Did you RECEIVE or USE any support groups?

- Yes
- No

27) Who UTILIZED the support groups?

- Family
- Child
- Parents/Caregivers
- Siblings
- None

28)

If you were offered *support* and were unable to participate, what/why were the reasons for your non-participation? (check all that apply)

- Family/Child didn't meet eligibility requirements
 - No transportation available
 - Services located too far away
 - No financial support
 - Services were un-helpful
 - Personal Choice (e.g. did not want to partake in service)
 - Other:
-

Education

Education can include any classes, meetings, or even brochures/handouts that are offered to help educate the family on what to expect after amputation has occurred.

29) Were you **OFFERED** education after the amputation occurred?

Yes

No

Education (cont.)

30) For whom was the *education* **OFFERED**?

(check all that apply)

Family

Child

Parents/Caregivers

Siblings

31) Did you **RECIEVE or USE** any education?

Yes

No

32) Who **UTILIZED** the education?

Family

- Child
- Parents/Caregivers
- Siblings
- None

33)

If you were offered *education* but were unable to participate, what/why were the reasons for your non-participation? (check all that apply)

- Family/Child didn't meet eligibility requirements
- No transportation available
- Service located too far away
- No financial support
- Services were un-helpful
- Personal Choice (e.g. did not want to partake in service)
- Other:

Financial Assistance/Aid

Financial Assistance may take many forms but some examples are: welfare programs, social security, and insurance.

34) Were you **OFFERED** financial assistance/aid after the amputation occurred?

- Yes
- No

Financial Assistance/Aid (cont.)

35) For whom was the *financial assistance* OFFERED?

(check all that apply)

- Family
- Child
- Parents/Caregivers
- Siblings

36) Did you RECIEVE or USE any financial assistance?

- Yes
- No

37) Who UTILIZED the financial assistance?

- Family
- Child
- Parents/Caregivers
- Siblings
- None

38)

If you were offered *financial assistance* and were unable to participate, what/why were the reasons for your non-participation? (check all that apply)

- Family/Child didn't meet eligibility requirements
- No transportation available
- Services located too far away
- No financial support

- Services were un-helpful
 - Personal Choice (e.g. did not want to partake in service)
 - Other:
-

Transportation

Transportation may include buses/bus passes, shuttles, taxis, or services that help individuals get to doctor appointments, meetings, or other services.

39) Were you OFFERED transportation after the amputation occurred?

- Yes
 - No
-

Transportation (cont.)

40) For whom was the *transportation* OFFERED?

- Family
- Child
- Parents/Caregivers
- Siblings

41) Did you RECIEVE or USE any transportation?

- Yes

No

42) Who UTILIZED the transportation?

- Family
- Child
- Parents/Caregivers
- Siblings
- None

43)

If you were offered *transportation services* but were unable to participate, what/why were the reasons for your non-participation? (check all that apply)

- Family/Child didn't meet eligibility requirements
- Service located too far away
- No financial support
- Services were unhelpful
- Personal Choice (e.g. did not want to partake in service)
- Other:

Other Services

44) Were you OFFERED other services (not mentioned previously) after the amputation occurred?

- Yes
- No

Other Services cont.

45) What was the additional service you were OFFERED?

46) For whom was the service OFFERED?

- Family
- Child
- Parents/Caregivers
- Siblings

47) Did you RECEIVE or USE this service?

- Yes
- No

48) Who UTILIZED the additional service?

- Family
- Child
- Parents/Caregivers
- Siblings
- None

49) If you were offered services in which you were unable to participate, why/what were the reasons for your non-participation? (Check all that apply)

- Family/Child didn't meet eligibility requirements
- No transportation available

- Service located too far away
 - No financial support
 - Services were unhelpful
 - Personal Choice (e.g. didn't want to participate)
 - Other:
-

Other Services cont.

50) Were you OFFERED any other additional services (not mentioned previously) after the amputation occurred?

- Yes
 - No
-

Other Services cont.

51) What was the additional service you were OFFERED?

52) For whom was the service OFFERED?

- Family
- Child
- Parents/Caregivers
- Siblings

53) Did you RECEIVE or USE this service?

- Yes
- No

54) Who UTILIZED the additional service?

- Family
- Child
- Parents/Caregivers
- Siblings
- None

55)

If you were offered services in which you were unable to participate, what/why were the reasons for your non-participation? (check all that apply)

- Family/Child didn't meet eligibility requirements
- No transportation available
- Service located too far away
- No financial support
- Services were un-helpful
- Personal Choice
- Other:

Wrap-up Questions

56) Were there other services, NOT LISTED on this survey that you found helpful (i.e. services you sought out on your own without the help of a social worker)?

57) Are there services your family was NOT OFFERED that you believe would have been beneficial?

58) Did your family receive an adequate amount of services corresponding to the severity of the child's amputation?

Yes

No

59) Were you satisfied with the services your family received given the severity of the amputation?

Totally Satisfied

Satisfied

Dissatisfied

Totally Dissatisfied

60) Did you have a social worker/case worker who helped refer or arrange for non-medical services for the child and family?

Yes

No

I don't know

61) Is there any additional information regarding your child's non-medical services that you wish to share?

62) Would you be interested in participating further in an interview via telephone?

Yes

No

Thank You!

Thank you for taking our survey. Your responses, time, and effort are very important to us!

Appendix B: Phone Interview Question Guide

Note: Only respondents who indicate a willingness to be interviewed and provide contact information on the online survey will be interviewed by phone.

INTERVIEW QUESTIONS

- 1) On your survey, you indicated that you were unable to participate in some of the offered services to you, can you elaborate more why?
- 2) You indicated that there were services that you were NOT offered that you believe would have been beneficial to helping the child and family adjust more successfully. Tell me why you believe the service(s) you indicated would have helped promote positive adjustment for your family.

3) Why do you believe you inadequately received or were inadequately offered services to help your child and family post-amputation? What do you believe were the reasons for this?

4) Do you believe that if you had a social worker/case worker in the hospital, obtaining resources would have been more helpful?

- Do you wish a social worker kept contact with your family and provided links to additional resources after the child was discharged from the hospital?

5) Did you find the social worker/case worker helpful? Or did you like having the social worker's help?