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Pediatric Acquired Amputation: A Personal and Professional Viewpoint

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Abstract

Life care planning for individuals with amputation can be challenging due, in part, to the many variables affecting outcome including, age of onset, cause, level of amputation, prosthetic needs and medical complications. This paper explores pediatric acquired amputation through the eyes of the author who has lived with below knee amputation for over a half-century. This uniquely personal perspective provides a basis for examining how the physical and emotional needs of an individual living with amputation change across the lifespan. The issues related to outcome are explored, notably access to medical and rehabilitative resources, the impact of social and spiritual connections and, most notably, what it truly feels like to be a child facing amputation. A literature review undertaken as part of this project showed a dearth of research concerning outcomes of middle age to older individuals who sustained amputation in childhood. It is hoped that by sharing this personal experience, professionals will have a deeper understanding of what constitutes a desired outcome and a broader view of what is essential for achieving such an outcome. Future studies may address the long-term physical and psychosocial effects of amputation acquired in childhood.

"I fell under a lawn mower when I was 3 ½ years old." These were the words my mother taught me to say when anyone asked the question— what happened to your leg? By the time I entered public school, I knew the response well. Knowing that I would have to face this question alone, my mother prepared me to answer simply, directly and politely, because in my southern home, being different was no excuse for being impolite. No further information or explanation was required on my part. The question was not to be regarded as rude, for people have a natural curiosity about the obvious. Children are quite approachable, even by complete strangers and it was a fairly frequent question whenever I met someone new. Frankly, I became somewhat weary of it, but I did not fear the question because I was prepared. I learned to be patient, answer the question and then move on to other—at least to me—more interesting topics. In her own way, my mother was teaching me not to run from difficulty, or attack others because of it, but to face it, with grace and dignity. That is why I became a vocational rehabilitation counselor.

The focus of this article is pediatric acquired traumatic amputation, from the perspective of someone who has both lived with unilateral below-knee amputation for over a half-century and has worked as a rehabilitation professional for over thirty years. My hope is to provide the reader with some personal examples of life as an amputee, while addressing needs assessment and recommendations that may improve functional and emotional outcomes for those living with amputations.

Onset and Early Years

Among children with amputation, 40% are acquired and 60% are congenital (Tooms, 2008). What happened that day in 1960 in my parents' front yard was by any definition a crisis. It was totally unexpected, involved significant loss and wildly disrupted the normal routine. The most recent evidence shows that despite prevention efforts, lawn mowers account for 12.1% of all amputations, with 75% involving the lower extremity, and 56.6% of those occurring in children age 5 years or younger (Borne, Porter, Recicar, Maxson & Montgomery, 2017). Living in a rural area of Tennessee and 40 minutes from the nearest hospital, an aunt drove us while my father used his hand as a tourniquet until they met the ambulance mid-trip.

There is nothing more difficult in life than watching someone you love suffer and it is worse when you feel that you contributed to that suffering in some way. It seems too hard, too devastating to face, and too impossible to understand. When the crisis touches a child, the pain is particularly exquisite. While the most intense emotional reactions are those experienced by people who were involved in the trauma or who witnessed it firsthand, crises such as these are never individual -- they happen in the context of family and community.

As one who has worked in the field of rehabilitation for many years, I have spent countless hours reading the medical records of those who have been catastrophically injured or who are dealing with chronic illness. As I read my own records from so long ago, I was immediately astonished by the lack of documentation. The entire hospital record consisted of three pages. The small-town general surgeon and limited hospital staff managed to see to the surgical and recovery needs of a child with a catastrophic injury. I sustained no infection and no complications and had, by all appearances, a quiet stay at the hospital. The return of veterans with injuries from the WWII and Korean War contributed to major strides in the development of prosthetics. Not only would I live a projected normal lifespan, but I would walk again. This is the new normal for parents of a child with a catastrophic injury.

Conversely, the large pile of cards and letters sent to my family during this time testify that much more was going on. Those who knew us, as well as those who did not, reacted with the whole gamut of human emotions—grief, shock, fear, shame, guilt, confusion and even anger. There were words of encouragement, kindness and love, with repeated references to our family's faith. People sent toys, flowers and at the urging of the local newspaper editor, money. The community and large extended family were clearly grieving, while at the same time breathing grace into the tragedy.

If the accident were to happen today, I would be airlifted to nearby Vanderbilt University Medical Center, a Level 1 Trauma Center with cutting edge treatments. An army of experts would be involved in my care and additional surgical procedures would likely be performed or considered, with an emphasis on limb length conservation without compromising prosthetic use. Particularly in the case of lawn mower injury and burns, surgeons use procedures such as skin grafts, traction and soft tissue shifting plastic surgery to preserve limb length (Tooms, 2008).

But at that time, care was very different, post-hospitalization there was no physical therapy, occupational therapy, home health or rehabilitative services. My parents attended one visit with a psychologist at the request of the surgeon. The closest prosthetic service was almost two hours away from our home. Our first visit for prosthetic care is notable. The prosthetist was an upper extremity amputee and wore a prosthesis, which frightened me to tears. An effort was made to get me to participate anyway, but my father had seen enough. He quickly explained to the staff that we would be seeking treatment elsewhere. He told me years later that he did not want me to be forced to engage in this important and ongoing process with such fear and trepidation. Sometimes, only a parent knows what a child needs, or does not, in a particular situation. I must say that, aside from this experience, I never met a prosthetist I did not like. As a rehabilitation professional and as a patient, I have found the people in this profession to be knowledgeable, compassionate, patient and encouraging. It is truly a marriage of medicine, engineering, art and craftsmanship and it is no wonder the patient's relationship with the prosthetist is a special one.

With no medical training or assistance, my mother assumed the role of physical/occupational therapist. Initially, I rejected wearing the prosthesis, but my mother would not take no for an answer. She insisted that I gradually increase my time in the device. There are, of course, individual differences concerning use of a prosthesis, but I am very glad that she persevered. Either she, my father, or both made frequent trips to the prosthetist for adjustments during my formative years. It could not have been easy or convenient for my parents. I recall little of that experience, but I distinctly remember that there was typically a visit to a local amusement park or ice cream. Today, I doff/don my prosthesis automatically and without thought, like putting on a shoe for most people. As professionals, we will do well to remember that research notes that parental support is critical for the child to become a functional prosthetic user (Collier, Nguyen & Hillebrand, 2018).

I was fortunate to grow up in a time of general freedom for children. I had almost free rein of our 200+ acre cattle and tobacco farm. My father worked in a large manufacturing plant by night and farmed by day; my mother was a stay-at-home mom. Without fanfare, and with no preconceived notions of what I could or could not do, my parents allowed me to test and find my own physical limits. Of course, the fun things to do on a farm involve physical activity. With my sister or cousins close by, I managed to climb trees, swim creeks, ride horses, swing on ropes or grapevines over large sinkholes, and generally engage in somewhat hazardous, but wonderful activities. Moreover, I was expected to, as much as possible, participate in feeding the cattle, cutting tobacco, and hoeing the garden. Sweat, abrasions, muscle pain, spasms, and prosthetic adjustments were dealt with and in my young mind were simply an inconvenience with the allimportant goal of getting me back outside. While everyone is different. I have no recollection of not being an amputee. I recall having muscle pain. It is noted in the research that phantom limb pain is typically lost rapidly in children under the age of 10 (Collier, 2018).

Social Interaction

The prosthesis that I wore consisted primarily of wood and leather, with a SACH (solid ankle cushioned heel) foot. The lower part of the prosthesis was primarily wood and the above knee portion was made of leather, which also covered braces on either side for support. It laced up like a shoe, from the top of the knee to mid-thigh. The child who becomes an amputee at an early age is forced at an emotional level to face some very adult issues. Physical pain, time consuming medical and rehabilitation care, inconvenience, and extra precautions to name a few. Add to that ridicule, rejection and even contempt of the thoughtless or cruel words and actions of others and you have yourself a pot that can easily boil over. Stares are uncomfortable at best and threatening at their worst. I experienced this and more. None of this was easy, but in the end, the words, actions and attitudes of my parents, whom I trusted completely, took precedence over anyone else's.

Children adopt their parents view of them. By the time I got on the school bus for the first time, even at the tender age of five, I knew some things. I knew that my parents thought I was the cutest thing ever and that I was valued and loved. I was connected with a place and people who delighted in me, put limits on me and disciplined me. This had nothing to do with the way I walked or the appearance of my prosthesis. It had everything to do with the fact that I was their child. I was taught at an early age that I should feel sorry for anyone who made fun of me because such remarks showed ignorance and lack of understanding. They were to

be pitied, but never hated. All of this was not so much articulated but lived. It still hurt, but I believe that absorbing this perspective provided a boundary that served to protect me from internalizing the bad while not closing me off from the good in life. I could not control what others said or did, but I was beginning to learn to control my responses, which was a powerful experience.

However, there are limits to pity and understanding. On one occasion, while on the playground, I kicked a boy with my prosthesis because he said something particularly unkind. He did not get up for a long while. The teacher gave me this incredulous look, but in an age of something a little more thoughtful than zero tolerance, he did not say a word. There were no lasting physical injuries and no repercussions for anyone. The boy didn't say he was sorry, and I didn't have any desire to apologize, but he never bothered me again! This little story may be humorous, but it is certainly not the best example of conflict resolution. Prevention is paramount. Today, there is much practical information for parents, teachers and fellow students to make the road easier and to prevent and/or stop bullying.

I had many friends at school, a large and engaged extended family, as well as a busy church and social life. I had an assortment of pets, cousins and friends. I enjoyed birthday parties and sleepovers, I went on long horseback rides, took piano lessons and learned to ride a bicycle. Later on, I dated, skipped school once, wrecked a car, and occasionally stayed out too late. Still, aside from my prosthetist, I was the only amputee I knew. For a long time, I silently assumed I was the only one. Contact with other amputees, particularly those of the same age group, would have been very helpful. Participating in retreats, sports and outdoor activities in a safe and accepting environment for individuals affected by disability and their families offer an opportunity physical fitness, support and encouragement. The National Center on Health, Physical Activity and Disability (NCHPAD) serves those with physical, sensory and cognitive disabilities across the lifespan and is an excellent resource for information for those seeking all types of physical and social activities.

Surgical Revision

When I was about twelve years old, I began experiencing severe pain at the end of the residual limb. The prosthetist gave my parents and me the news that due to my physical growth, the bone of the residual limb was interfering with the use of the prosthesis. I needed surgery to remove part of the bone and make the limb more compatible for use of a prosthesis. When the three of us were left alone in the little examining room, I began to cry. Immediately, my father urged me not to cry. But my mother looked directly at him and in a voice that left no room for argument said firmly, "It's okay if she cries—she can cry if she *wants* to." This minor conflict between my parents amused me. I smiled. Almost chuckled. Immediately my anxiety was lowered. It was going to be ok. I was safe.

Having only one revision during my formative years is unusual, as terminal overgrowth is the most common complication of amputation surgery in children. Stump revision at 2-3 year intervals are commonly the case. Other complications associated with the pediatric amputee include adventitious bursae, bone spurs, extensive stump scarring, neuromas and phantom limb pain (Tooms, 2008). At the very least, those facing multiple medical procedures need a good support system, but may also require counseling or psychotherapy to address multiple issues such as grief, depression, adjustment issues and relational/spiritual issues.

Vocational Rehabilitation

One day while in high school, I was pulled out of class to talk with a vocational rehabilitation counselor. Apparently, the State of Tennessee wanted to pay my way through undergraduate school. During our discussion, it became apparent that my parents did not really "need" someone to pay for college tuition, as, they had long since assumed the financial responsibility for that endeavor. Nevertheless, the counselor insisted that these benefits were available and he said something I will never forget. He said that regardless of the family's ability to pay "we want to help because society *owes* you a debt". I had never heard of such an idea. At the time, I could see his point. The cruel remarks, the stares, the rejection and ridicule. After much persuasion, I convinced my independent and proud father to accept the help and I became a client of the State of Tennessee's Vocational Rehabilitation Service (VRS). I am grateful for those services and the financial assistance was helpful for a family on a modest income. I am even more grateful for the "aha" moment in my counselors' office concerning my career direction.

Today I see many clients who are chronically frozen in anger, fear or depression at least partially because they believe someone—an employer, the driver of the other vehicle, a physician--- someone owes them something. True enough. Sometimes someone needs to pay. After all, the accurate assessment of needs and the cost of those needs is what my life care plans are all about. But just speaking for myself, if society owes me a debt, it is a debt that they cannot pay. Sometimes, only forgiveness will do, and when we live that out the pain does not win.

Present Day

Today, my husband and I live on a small farm on the outskirts of Birmingham, Alabama. I showed Arabian horses for twenty years and developed a private rehabilitation practice. I still deal with the inconveniences, occasional disruptions and need for increasing accommodations. Complications for me have involved another revision due to bony overgrowth of the fibula, low back pain, arthritis in the unaffected lower extremity, and skin issues. There is an increasing focus on my general health, weight control,

nutrition, flexibility and strength, I want to hold on to my K-4 level (the ability to exceed ambulation and exhibiting high impact, stress or energy levels) as long as possible.

My current treatment team includes a physiatrist, orthopedic surgeon, physical therapist, dermatologist, podiatrist and a prosthetist. Today, the prosthesis I use is a pro-flex LP align with a stored energy foot. However, as I get older, it seems that what is newest is not always what is best. The same person has fashioned my prosthetics for over 20 years. He is a below the knee amputee himself. He knows the anomalies of my residual limb, the potential problem areas and understands my activity level. The cost of follow-up for me is nothing.

As one might expect, I have experienced many improvements in prosthetic wear over the years. Some of the changes that were most significant for me were improvements in socket development, push-button heel height adjustability, the advent of "skin" and gel liners and sleeves. I have experienced significant reduction in abrasions, improvement in gait and appearance and increased ease of use with these developments. I have quite the collection of prosthetics—one for wearing around the house, one for swimming/kayaking and one for work, shopping, etc. I wear an external silicone sleeve for walking, bicycle riding and other exercise.

Costs and insurance coverage impact care. At one point, my insurance carrier refused to pay for "skin" for a new prosthesis which they regarded at the time as purely cosmetic. I was able to negotiate successfully this matter, and this has not been a problem since. They provide two gel liners twice yearly, which is absolutely not enough for an individual with my activity level. I purchase at least two additional liners per year.

Closing Thoughts

The challenging aspect of being an amputee is that it is sometimes the first thing noticed about you. The opportunity of being an amputee is that people remember you. These days, I am rarely asked "what happened to your knee/leg" by total strangers. When it occurs, my response is based on the time, place and manner in which the question is asked. I always make time for children. Many times, I simply say (taken from an old Ann Landers column) "It's an old injury. Thank you for your concern, but I'm fine. How are you?". As a professional rehabilitation consultant, my response is essentially the same, while firmly and pleasantly adding "We are here to discuss your case".

So, what made the difference for me? When people ask me this question, they are really asking multiple questions: How did you and your family overcome this catastrophe? Why did you not give in to despair and desperation? When and how did you come to a place where you not only thrived, but could give back to others? As a response, I will echo the words I hear again and again from those in support groups, peer training, counseling sessions and even from total strangers. *What made the difference was faith, family and friends*.

When assessing the loss of others, I have often caught myself focusing on improving the physical function of people with amputations while minimizing the psychosocial factors related to such events. The physical work of rehabilitation and living with a disability requires emotional endurance, stamina and motivation on the part of the child and family. In my professional experience, I have observed that some psychological factors may need to be addressed before real progress can be made on physical needs. If we can address these psychosocial issues on a deeper level as part of the assessment, will it not result in better outcomes? Every interview/contact is an opportunity to come to a deeper understanding of the child and family.

I have also found myself focusing on the problems and obstacles, with little regard for the assets. We live in a world where a person with a physical or mental impairment must focus on what they do not have in order to obtain what they need. In fact, our tendency as human beings is to focus on the negative. Conversely, a study led by Donald S. Bae, pediatric orthopedic surgeon, found that some children with upper limb amputation have more positive emotional well-being when compared to a non-injured peer group (Ertz, 2018). I have to remind myself to ask questions that dig deep to find untapped resources within the individual and family, on which to base care plans.

Recommendations

As I look back on my own family's experience, I would like to suggest two overarching needs in the lives of the catastrophically injured for your consideration:

When facing loss, good patient information will only take you so far. *What you really need is comfort* and real comfort comes through genuine connection. Even when there is no time for comfort, people can receive it in even brief interactions with others.

For many, faith answers the questions of comfort, purpose and meaning. Making provisions for people to work this out with a skilled listener of a like-faith should not be overlooked. In addition, the close-knit community and nearby extended family of my upbringing are seen much less frequently today. Some people are so isolated pre-injury that they have no genuine connections. Everyone who is in pain reaches for something or someone. What or who does this individual reach for in times of stress and how are faith, family and friends impacting that reach? Premorbid personality, coping patterns, family roles, cultural differences, and general outlook are all impacted by connections. I encourage you to seek intentional ways to assess and understand the nature and quality of the family's connections and how that may impact the life care plan and ultimate psychosocial adjustment to a traumatic amputation. Skilled interviewers can evaluate such connections without imposition or offense.

Secondly, *you need to make some sense of it*. A life care plan is an amazing living document. I love the logic of it. It is comprehensive, yet individual. It addresses the big picture of medical and rehabilitation needs, but is detailed in how the needs will be met. It projects the expected, but is adaptable for the unexpected. It looks far into the future, but can be used to help in the present day. In short, it brings order to what is inherently very complex and messy. The sharing and application of such a document with the families of children will do much to reduce anxiety and stress. The case manager is in a unique and powerful position to come along beside the family and help guide them through the physical and emotional journey.

As rehabilitation professionals, we can provide people with the opportunity to live with disability in ways that promote dignity, wholeness and a sense of well-being. We are far too realistic to view those with significant disability through rose-colored glasses. We know and have seen too much. But because we are bound to do what is in the best interest of those we serve, we must never stop looking at them through the lens of hope.

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