

Resilience in Survivors of Traumatic Limb Loss

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Abstract

Landmine Survivors Network (LSN) is a global network of survivors helping mine victims heal, recover, and reclaim lives. LSN conducts research to determine what creates a 'successful' survivor that is, one who overcomes trauma and experiences physical and psychological health. Throughout the life course, the means to achieve this success differs. LSN studied the impact of environmental risk factors, coping strategies, and resilience characteristics of limb loss survivors in six landmine-affected countries and the United States. In depth interviews of 89 participants, including people with limb loss, their family members and service providers, were analyzed using grounded theory strategies (Strauss and Corbin, 1990). A dynamic six factor model of recovery emerged and indicated significant variation depending on life stage. Programs intended to facilitate recovery need to be comprehensive and address the individual's stage specific physical, psychological, economic and social needs within the context of family, community, and the socio cultural environment at large.

Introduction

Landmine injuries are one of the leading causes of limb amputations in post conflict countries. Landmine Survivors Network (LSN) empowers individual survivors, families and communities affected by landmines to recover from trauma, fulfill their rights, and reclaim their lives. To assist in these goals, LSN conducted a study to help determine what creates a 'successful' survivor that is, one who overcomes trauma and is psychologically healthy. This exploratory interview study examined the impact of environmental risk factors, coping strategies, and resilience characteristics of limb loss survivors across differing cultural, societal and economic backgrounds.

Tens of millions of people with disabilities around the world are systematically denied access to adequate health care, housing, education, social contact, or the means to earn an income. This situation has little to do with the physical limitations of an amputation or other disability, and has everything to do with poor health care, societal barriers, negative attitudes, and avoidance reactions to difference. The social, political, and personal dimensions of an individual's life constitute the social psychological factors that affect recovery processes during and after medical treatment. Social-psychological factors '...underlie the way disability as a value loss is perceived and reacted to by other people, as well as by the self' (Wright, 1983, p6).

Landmine survivors who have lost limbs cope with their injuries in myriad ways. Certainly, the psychological factors that influence recovery are significant, and have important implications for acceptance or non acceptance of the disability itself. However, the environmental factors (e.g., societal access, societal perception/attitudes) also play a significant role in the recovery process. In our study we found there are several factors that cause a trauma survivor to be more resilient, including:

Aspects of the Individual, including resilient attitudes, beliefs and personality;
Adequate first aid and on going medical Treatment;
Emotional, physical, and material support from Family;
Social Support from friends, other amputees and community members;
An Economic Situation where basic subsistence needs are met; and
A Society where attitudes toward people with disabilities are inclusive.

LSN's research indicates that the impact of these factors, positive or negative, varies throughout an individual survivor's life.

Methodology

Trained interviewers queried 89 participants from seven countries (Bosnia, Ethiopia, Eritrea, Jordan, El Salvador, Mozambique, and the United States). An open ended interview format was used in the six landmine affected countries, and a semi-structured protocol was used in the United States. Of the 89 participants, 68 were people with limb loss, 12 were immediate family members of people with limb loss, and nine were experienced service providers (two of whom were also people with limb loss). Participants ranged in age, gender, socio economic status, urban rural location, ethnicity, time since injury, and degree of rehabilitation at the time of interview.

Indigenous LSN social workers conducted interviews outside the United States and USA trained psychologists and one peer counselor conducted the USA interviews. LSN Network staff identified potential participants in order to obtain a diverse sample in each mine affected country. The USA sample was drawn from participants at a national amputee conference and from amputee support groups. Questions were open ended to ensure the maximum range of responses. The use of local interviewers in all countries ensured both the requisite cultural knowledge and language fluency necessary for producing in depth interviews.

Participants in mine affected countries were asked three specific questions as prompts: a) Please tell me the story of your landmine accident/limb loss/amputation; b) What has been helpful in your recovery? c) What has not been helpful in your recovery? The USA sample was asked similar questions as well as specific questions on their coping strategies, social support, body image, and personality. The study utilized grounded theory analytic strategies (Glaser and Strauss, 1967; Strauss and Corbin, 1990). This approach allowed access to greater depth and diversity of participants' perspectives, as they were allowed to describe their experiences in their own words. Interviews were transcribed and translated into English text (where the interview was not conducted in English) for analysis. Transcripts were then coded, and a second researcher checked each code. This process of pairs of researchers checking each other's coding and construct generation was repeated at all levels of analysis to ensure that categories reflected participants' narratives. Data were analyzed to develop an emergent theory with specific country based factors that lead to recovery. After each country was analyzed, data were collapsed to examine common denominators across all the countries. In this paper, we examine the significance of generational and life course factors.

Results and discussion

A six factor model of recovery in limb loss survivors emerged from the participants' narratives. The six factors that have an impact on an individual's experience of disability are:

Individual: attitudes, beliefs, and personality

Treatment: first aid and on going medical treatment

Family: material, emotional and physical support

Social Support: emotional support from friends, other amputees, and community

Economic Situation: basic individual economic necessities, and

Society: socio cultural and political context.

As the following discussion shows, these recovery factors interact with the various developmental challenges normally faced at different life stages (cf. Erikson's 1964 life span model; McAdams, 2000) to produce different recovery needs and outcomes.

Individual through the life course

The first factor, the Individual, represents the person's physical being, their personality and their attitudes and emotions. The most important aspects of this factor for the survivors in our sample are how their core personality, their reactions to the traumatic injury and their response to the physical changes that accompany the limb loss interact as they adjust to and eventually learn to accept the physical and psychological changes accompanying limb loss.

In our sample, a broad range of strong emotions accompanied the initial trauma and the realization of the physical loss of the limb. These included denial, anger, depression, disconnection, disempowerment, and vulnerability. How the individual processes these emotions is crucial to his or her successful recovery and re integration into society. There has to be a psychological shift to incorporate the body change and recognize that life will be different. We call this level of acceptance of the limb loss pragmatic acceptance.

People who recover psychologically from the traumatic accident move from pragmatic acceptance to what we call acceptance with resilience. They accept the limb loss, and express a desire to live and to make what happened to them into something good, to derive meaning from the traumatic event. They often have the perspective that things could have been worse. They do not define themselves by their amputation; it is a part of who they are, but not all. They perceive and describe themselves as 'normal' (despite the negative messages they get from society about their disability), and they often describe an identity shift so they now feel they benefit from the support of, and feel connected to, other amputees. Often they describe the amputation as the start of a new life and that they feel a desire to be altruistic. This generally happens due to good physical health, psychological well being, and social and economic integration.

In contrast, people who do not recover psychologically from the traumatic accident move from pragmatic acceptance to what we term acceptance with resignation. They are resigned to the limb loss; feel depressed and bad about themselves. They have a negative outlook on life, and describe themselves as feeling abnormal due to the limb loss, disconnected from friends and family, and unsettled. Depending on the immediate family context, the amputee could remain isolated, and have delayed social and economic integration. This generally happens due to a lack of social support, the poor physical condition of the individual and/or poverty.

The participants vary in how they accept the limb loss, and some have experienced all of the different kinds of acceptance. Type of acceptance interacts with the individual's age and their current

developmental stage, tasks, and responsibilities. At different life stages the means through which a person reaches acceptance and recovery also vary.

In childhood, some of the issues the individual needs to resolve include trust, independence, and competence. A landmine injury can impact a child's ability to trust and feel secure in a context that includes the possibility of re injury. Some of the family members interviewed describe how difficult it is to watch their child struggle to regain their independence after the injury, but it is clear that the family needs to allow the child to develop independence and to take initiative, to allow for a full recovery. In adolescence, the individuals face the developmental task of figuring out their identity, their role in the world, particularly how to fit into the adult world. Paradoxically, for one American survivor who was 19 at the time of her accident, the injury had a positive impact on her view of herself and her identity. Her parents lived far away from the hospital so she dealt with much of the medical care and legal issues herself. This gave her a feeling of control, she felt that she was really an adult, and it became a defining moment for her developmentally. She went on to help others with limb loss and has a positive outlook on life, clearly someone who has reached acceptance with resilience.

In young adulthood, the psychosocial issue to address is whether you will form intimate relationships or whether you will become isolated. This is particularly at issue for our sample, as the question of whether they will find love and marriage and have the opportunity to have children is paramount for many. This appeared a more significant issue for the young women in our sample than for the young men. Many of the women are resigned to being 'unmarriageable' as a result of the injury, which has a significant effect on their ability to accept the limb loss positively, and to recover.

When people have left young adulthood, have made their decisions regarding family and intimate relationships, they enter mature adulthood, where the main issue or task they face is whether they will be productive or generative. Will they create something worthwhile and leave something behind them when they are gone? This stage is associated with building and providing for families, having productive work, altruism to make the world a better place, and a change in perspective on one's place in society. Many of our survivors describe their need to be productive in order to feel 'normal' and a contributing member of their family and community. Those who are able to fulfill the life roles they have hoped for themselves are more likely to accept limb loss in a positive way.

In old age, the individual is focused on looking back at his/her life, gleaning the wisdom that comes with age and sharing that wisdom with family and community. When societal attitudes toward people with disabilities prevent that opportunity, it is significantly more difficult for older people with acquired disabilities to accept those disabilities with resilience.

Treatment through the life course

The second recovery factor, Treatment, refers to medical and rehabilitative care. This includes professional support, that is, the psychological and emotional support provided by healthcare providers. It also includes emergency and on going medical care (whether or not it was provided by a professional), physical rehabilitation, and the access to and use of prostheses or other mobility equipment. In most of the countries treatment is neither coordinated nor comprehensive. This means that survivors are provided with few of the basic treatments and procedures essential for health and day to day functioning. For many, having a good-fitting prosthesis is of utmost importance, since it increases their mobility and therefore self sufficiency, and allows them to compete better for jobs. However, good prosthetic care and adjustments are not the norm in our sample and when survivors get prostheses that do not fit, this leads to further physical problems such as curvature of the spine or gait difficulties.

For children, appropriate mobility equipment is a particular issue since children need more frequent care and prosthetic change as they grow. This issue continues for adolescents, but the additional concern in this population is the cost of medical care and appropriate mobility equipment. Many adolescents at the time of injury are very concerned about the financial impact their injury may have on their family. For many adult survivors, concerns about their sexual functioning and mobility are paramount as they focus on romantic relationships and the ability to participate in productive work. Among the older participants, the normal physical decline of aging complicates the medical picture for those who must adjust to a newly acquired disability.

Family through the life course

The third recovery factor, Family, includes immediate or extended family and in a number of countries this also includes clan or village. Survivors in every country speak about the central role of family support. Family support at times provides basic economic necessities, mobility, care giving, and ameliorates negative social attitudes by offering encouragement and treating the survivor as a capable human being. If hospitals do not provide adequate care, family members often take on added responsibilities, such as cooking or providing blood for transfusions.

The larger community functions as the family in some countries. For example, in Eritrea and Ethiopia the survivors describe a very strong sense of community where individuals in the community act as the family normally would. Community support in these two countries includes material and physical help such as farming, harvesting, the teaching of a vocation; as well as the provision of food and entertainment. There is also emotional and psychological help, including moral support, comfort, encouragement, the provision of counsel, and the feeling of love and belonging in a community.

For children and usually for adolescents, the family is crucially important for providing basic economic necessities, adequate medical care, social support, and the lens through which society's attitudes toward people with disabilities are transmitted or understood by the survivor. Whether or not a child has a full recovery is dependent upon the family's ability to provide physically and emotionally. In Jordan, the father of a Palestinian girl, who was 10 when she lost her lower leg, explains that her family's encouragement to continue making friends and their active advocacy in her school was pivotal to her recovery. As a result, she goes to school, has friends, and is actively involved in her community. In her case, her parents provide her with all the necessary ingredients for a full, successful recovery. As an adolescent and young adult, the impact of the injury on one's ability to have romantic relationships is of particular concern. An American survivor, who was 16 at the time of injury, describes her experience:

I remember when I first woke up wondering if guys would date me...you don't sit and ponder, 'Am I going to get married and have a family?' But it's something that's kind of on the back shelf... Well maybe that can't be.

Throughout our sample, but particularly among more mature adults, it is clear that family can have both positive and negative impacts on recovery. On the positive side, family provides support (both financial and emotional) and dependents (both elders and children) provide the motivation for many people to live, as expressed by a Bosnian survivor:

I once again start thinking of suicide as an option, wondering whether I should kill myself and put an end to my suffering...I got a burst of energy, strength, and courage, because I began to think of everyone who depended on me, my son, who was two and a half, my wife, my family, only then did I get some more energy.

On the negative side, our participants worry most about the potentially harmful impact of the limb loss on their families; with their biggest fear that of becoming a burden.

Elders face a decline in status in the family. Elder parents expect their children to take care of them, but because their dependency is so high, offspring cannot address all their needs while taking care of their own families. Spouses often reject the elder amputees, creating an isolated, desperate social situation. For example, elders in Jordan feel depressed, angry and hopeless. Cultural expectations would be that family would take care of the elders, but one older Jordanian woman felt her children and husband ignored her, which led to a decline in her mental health including isolation and depression.

Social support through the life course

The fourth factor, Social Support, includes peer support from other amputees, and the presence of emotional support outside the family, including friends, neighbors, and other community members (in those countries where community and family are distinguished from one another). There are cases of survivors with few social relationships, causing isolation, psychological distress, and depression. Staying connected to others is important to our healthier participants. More specifically, our survivors talk about the importance of peer support, of the role models that other rehabilitated amputees can play. 'If they can, so can I' is a very powerful motivator. The turning point in recovery for many is seeing other amputees leading productive, fulfilling lives.

One survivor, from Eritrea, who was six at the time of injury, describes the importance of social support, which, in childhood, comes primarily from family and friends:

Being alone can demoralize one's spirit. Friends gave me a lot of moral support. They contributed in a major way. If I were alone, I would have been distressed about my artificial limb being fitted and I would have felt disabled and tense. But they came to play with me regularly, and I felt like a normal child.... They saw to it that no harm came to me. They advised me well and told me to continue my further studies. My parents, friends and neighbors made a great contribution by counseling me.

The focus on body image and peer acceptance among adolescents means that social support from same age peers is particularly important as well as mobility equipment that allows the amputee to participate in age appropriate social activities.

Those caring for young amputees need to focus on social relations, and helping the survivor acquire a positive self-image. A service provider in Jordan suggests that adolescents prefer a very good looking, well fitting prosthesis to avoid peer discrimination. This is particularly the case in teenage years, when the primary concerns are social acceptance and body image. Among adults, connection to community through a job or other groups, and the social support of a spouse or romantic partner are particularly important. Those survivors who have positive social relationships are better able to weather the emotional difficulties of limb loss. Among older adults, problems with mobility make maintaining or establishing social relationships more difficult.

Economic situation through the life course

The fifth factor, Economic Situation, represents the tangible realities of an individual's life, including economic security, employability, level of vocational training and education, and the possibility of accessing health care. Economics greatly affect a survivor's physical and psychological health, and negative economic situations make socio economic reintegration very difficult. The major deterrents to recovery for resilient survivors with strong family and peer support are lack of economic and employment opportunities and lack of access to health care. One survivor from El Salvador describes his economic situation:

I could not have a real job, like a normal person who has his two feet... these are my difficulties, really... what I consider an obstacle is that I cannot work in a normal job.

This economic situation is also influenced by whether the survivor is a war veteran or a civilian. In each country, war veterans normally get better treatment than civilians, due to institutional medical, economic and social support systems.

For child survivors, family is the main source for economic necessities. For recovering adolescent survivors, family again is significant in ensuring basic economic necessities in the present, but one's identity at this age includes one's role in the working world, so the ability to provide for oneself and become a productive member of society is a particular concern for adolescents with limb loss. In young adulthood, there is a shift from family providing for basic economic needs to the individual needing to become more responsible for his or her own economic situation and often for a spouse or new family. The precursor to work is a good fitting prosthesis. The precursor to a prosthesis is health insurance or other financial means.

For the mature adults in our sample, the idea of being 'productive' and contributing to the world at large is paramount, and access to productive endeavors (in or outside of the paid workforce) becomes an important focus. "To be constantly and consistently denied the opportunity to work, to make a material contribution to the well being of society is to be positioned as not being fully human, indeed in my view, is the root cause of us being labeled as "other" (Oliver, 1999).

One survivor in Ethiopia describes his feeling about losing a limb during what should be his most productive period:

I was herding the cattle. ...But now, after I became disabled, it is impossible to go there ... there can never be any work for me ... it was better to die than to sit idle.

In contrast, an American survivor describes his experience of recognizing he could still be productive after a war injury. Still on crutches and unable to walk he is told by a General:

'Let me know when you're ready, there's still a lot to do, I've got a big job for you.' He turned on his heel and walked away. And, that makes a big difference, you know, that kind of, what do we call it, instant rehabilitation.

Clearly the economic situation of the individual, the number of dependents s/he has, the social support available to him/her, the availability of appropriate mobility equipment, and societal attitudes toward disability all contribute to the ability to be productive during this life stage, as well as in old age when people are often increasingly dependent on their family for basic economic necessities, mobility and medical care.

Society through the life course

The final factor, Society, represents the socio political, cultural and economic context of the country where the person lives. This includes the current socio political situation, (such as whether the country is at war), as well as government policies related to disability, and general public awareness and attitudes toward people with disabilities. While on the one hand survivors have to be resilient and determined to integrate, when society fails to encourage their social or economic integration, prospects for recovery are slim. We found that even if a person has psychological health and physical wellness, s/he may not experience socio economic integration due to external societal circumstances.

For children, being a productive member of society means the opportunity to play with friends and not be

seen as a burden. Perhaps most interestingly, the family appears to be the lens through which survivors view societal attitudes toward people with limb loss. Survivors whose family (and to a lesser extent, friends), treat them as 'normal' children, without a debilitating attitude toward people with disabilities, have a sense of self which remains largely unchanged and they are more likely to accept the limb loss with a resilient, connected sense of self. One survivor, from Eritrea, who was six at the time of injury, describes the importance of hiding his disability.

I have never lived as a disabled person. I walk as a normal person and like others I can do any work. This was made possible by the artificial limb.

One El Salvadoran survivor was 11 at the time of his injury, but when given treatment in the United States was warned by a doctor that his adolescent years would be difficult for him since women would not be interested in him romantically. Here, in a fascinating interaction of societal attitudes and medical treatment, the survivor was provided with excellent medical care, rehabilitation and adequate mobility equipment, but at the same time his fundamental identity of potential romantic partner was challenged, causing him to question whether he would be able to fulfill the role of husband and father. For adolescents, negative societal attitudes are particularly damaging when they have an impact on peer acceptance. Those who have adequate social support are very grateful for the opportunity to be with people (family or friends) who treat them 'normally.'

Among the young adults in our sample, the issue of marriage is paramount. According to the Jordanian service provider, women with limb loss tend to foreclose traditional expectations of marriage and children more than men. Probably due to societal attitudes, amputee women tend to see themselves as abnormal and unmarriageable.

Men, on the other hand, do not necessarily lose the expectation that they will marry. One Jordanian survivor, who was a 20 year old unmarried man at the time of our interview, describes Jordanian societal expectations that any young non-disabled male be productive, marry, and have a family, but there are no such expectations for a man with a disability. However, this survivor still hopes to work, find a wife, and have children. His fear is that society's discrimination will render him unemployable, which will make him a poor candidate for marriage, since no one will want to marry a man who cannot provide for his family. At the time of the interview, the survivor was actively fighting against this social discrimination. He was not going to accept society's view of disability. He was seeking a prosthesis, which would assist him in finding work. With work, he was confident he could offer a woman a secure home.

When society discounts the contribution of wisdom from an older person with a disability despite their cultural role as an elder in the community, he or she can experience bitter despair. The opportunity to be a productive member of society is based almost entirely on maintaining status in the community as an elder. For people with disabilities this status of age may be discounted due to negative societal attitudes toward disability, virtually eliminating the opportunity to contribute to family or community.

Summary and conclusions

The recovery experiences of limb loss survivors vary greatly based on their stage in the life course. As a result, programs intended to facilitate recovery need to be comprehensive and address the individual's stage specific physical, psychological, economic and social needs within the context of family, community, and the socio cultural environment at large.

As people develop throughout the lifespan, they go from being economically, physically, and emotionally dependent on parents to becoming self reliant and independent, then becoming increasingly dependent on

their adult children. If this cycle is allowed to continue for the survivor without significant, long-term interruption, the survivor has a chance to make social and economic integration possible. Physical and psychological health are precursors to developing intimate relationships, finding work, maintaining or establishing social relationships, and the ability to integrate into society regardless of public attitudes toward disability.

The opportunity to be a productive member of society also varies at different life stages. As a child and adolescent your task is to prepare to be a fully functioning adult. As a young or mature adult your tasks are to have a family and to provide for them. As an elder your tasks are to provide wisdom to family and community. At each stage, the six recovery factors interact to make it more or less possible for a survivor to be productive and contribute to the family, community and society.

Attitudes toward people with disabilities also impact recovery at all ages. Family appears to function as a buffer against negative societal attitudes for children with disabilities. As survivors move through adolescence and young adulthood the existence or lack of intimate relationships can reflect societal and cultural attitudes toward disability. In adulthood, societal attitudes can impact the ability to find employment and provide for one's family. In old age, societal attitudes appear to have a negative impact on the elders' status in the community, affecting the mental health of older amputees.

Research is needed to investigate further the interrelationships between current life stage, age at the time of limb loss, and recovery factors. In addition, studying societal attitudes toward disability and the impact of limb loss on becoming a productive member of society will enhance the development of age appropriate, integrated, and survivor centered rehabilitation and trauma recovery programs.

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