

Patient Experiences of Life Years After Severe Civilian Lower Extremity Trauma With Vascular Injury

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WHAT THIS PAPER ADDS

This study contributes to a deeper understanding of life with a reconstructed or amputated limb resulting from severe lower extremity trauma with major arterial injury. To the authors' knowledge, this has not previously been investigated. The results may help to improve clinical practice aiming to guide this group of patients and their relatives through a traumatic life changing situation. The study shows that patients are satisfied with the surgical treatment, but they describe the need for continuous interpersonal psychological support. The results could give guidance to healthcare professionals on support for patients in their transition back to "normal life."

Objective: Severe lower limb trauma with arterial injury is often devastating for the individual. Many studies describe how to manage these injuries when they occur. Short-term functional outcome is quite well described, but the patients are often young, and their suffering is physical, mental, and social from a lifelong perspective. The aim of this study was to report patient experiences of their lives several years after their accidents, and to explore mechanisms of how to improve management.

Method: The Swedvasc registry was searched for participants from 1987 to 2011, living in the region of Uppsala, Sweden. Some amputated participants were added from the Walking Rehabilitation Center. There were five reconstructed patients with an intact limb, and three with amputations. In depth interviews were conducted and systematically analyzed, using A Giorgi's descriptive phenomenological method.

Results: Eight patients participated, five with reconstructed and three with amputated limbs. Life affecting functional impairments were described by all patients. The patients undergoing amputation had received more structured follow up and support through the Walking Rehabilitation Center. The satisfaction with the cosmetic result was poorer than expected. All patients had developed strategies of how to cope with their impairments and stated they now lived "normal lives."

Conclusions: Despite substantial physical, psychological, and cosmetic impairments years after severe lower limb trauma, the participants described life as "normal" and mainly satisfactory. Transition to the new situation could have been facilitated by more frequent and continuous follow up after discharge from hospital, in particular among the non-amputated patients who tend to be lost to follow up. Findings also indicate that family members have to be acknowledged, strengthened, and supported.

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INTRODUCTION

Clinical advances in modern medicine have greatly improved the possibilities of saving and reconstructing a mangled extremity. Microsurgery with free flaps, modern fracture treatment, and advanced vascular surgery have contributed to these advances.^{1,2} Many studies describe the dilemma of

saving or amputating a mangled extremity, attempting to find evidence for the best choice. Opinions diverge regarding which treatment leads to the best outcome for the patients with respect to function and quality of life.^{3–6} The actual number of traumatic amputations or limb reconstructions for severe trauma with major vessel injury in Sweden is low. Tampe et al. concluded, in a Swedish nationwide population based study of open tibial fractures, that the amputation rate was between 2% and 10%.⁷ There were 125 amputations in 1998–2010, approximately 10 per year, or one per million inhabitants/year.⁷ It may be expected that injuries with concomitant vascular injury have an even higher amputation

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rate. Many studies conclude that there is no significant physical difference between reconstructed and amputated patients at long-term follow up (after 2–7 years).^{8–10} Even though a number of studies try to estimate quality of life with different scores, and describe poor physical and psychological outcomes,^{11,12} it is not known how the patients themselves experience their life after a mangled extremity accident. Most studies are quantitative, measuring functional and health related outcomes with questionnaires.¹³ However, are the right questions asked? Is this group of patients treated in the best way? Only two previous studies have been identified in the literature in which patients themselves state their situation.^{14,15} Knowing more about these patients' own experiences could highlight potential improvements for management, to achieve a better long-term outcome.

A concept that must be addressed in this context is transition: the way people respond to change over time, how people adapt or cope with life changes.¹³ Whether this transition can be facilitated has been debated.¹⁶

The aim of this study was to give in depth descriptions of how patients experience life years after severe lower extremity trauma with vascular injury.

PATIENTS AND METHODS

Patients who experienced trauma including vascular injury to one or both lower limbs were identified by searching the Swedvasc registry from 1987 until 2011.¹⁷ Additional patients were identified through the patient records of the Walking Rehabilitation Center in a university hospital. The Walking Rehabilitation Centre is a daycare center for patients with a prosthesis following amputation. It is staffed by orthopedic technicians, orthopedic consultants, and physiotherapists, who all follow a strict rehabilitation protocol.

The inclusion criteria were that 4 years or more should have passed since the trauma and that the accident had taken place in a civilian setting. The inclusion threshold of 4 years is arbitrary, but was based on clinical experience of the time it usually takes to adapt to new circumstances. Sixteen potential subjects were selected and contacted by mail. Nine of them accepted participation in the study. One of these was later excluded as the arterial injury was associated with previous trauma. Three declined to participate, and four did not answer despite repeated letters. A final letter was sent to these seven to try to identify the reasons for non-participation, unfortunately only one of them responded that because of psychological fatigue he was unable to participate.

The method used was descriptive phenomenological modified by A. Giorgi,^{18,19} based on the phenomenological philosophy of Edmund Husserl^{20–22} (For details see [Appendix S1](#),²³ Supplementary material). Semi-structured interviews were recorded and transcribed verbatim (See [Appendix S2](#), Supplementary material). All interviews were conducted by the first author (KB) and took place either in the homes of the participants ($n = 4$) or in a small conference room at the university hospital ($n = 4$). A four stage analytic procedure was performed (see [Appendix S1](#)). The analysis was

performed independently by two researchers (KB and EJ). The findings were then discussed among the whole research team, and consensus was reached.

Ethical considerations

This investigation was approved by the ethical committee of the Uppsala/Örebro region. The interviewees may recall negative memories, creating negative emotional reactions, but the voluntary participation was emphasized in the written information and consent. The investigation took place several years after the injury and the risk of severe psychological reactions was estimated to be small.

RESULTS

Eight patients were included in the study. Median time from accident was 12 years (4–17). The case records could be retrieved in all cases. The median age at the time of the injury was 35.5 years (range 17–55). Participants characteristic are described in [Table 1](#). The interviews varied in length from 35 to 67 min.

The essence of life after the trauma was described as “A life changing event that foiled existence, daily life, and plans, but where disability was finally integrated as part of normal life.” The descriptions that constitute the interviewees' experience resulted in three themes which are presented below, illustrated by direct quotes from the interviews.

An everlasting reminder of physical and cosmetic impairments in daily life with a changed perception of self

All patients experienced some functional impairment, the reconstructed more than the amputated. Those who had had a reconstruction done described an everlasting reminder of pain, numbness, stiffness, and altered sensory function in the extremity. The pain was worsened by cold weather. Physical and psychological fatigue was commonly described, with greatest capacity in the morning hours and decreasing during the day. This affected, for example, working hours and daily activities at home. The interviewees described how functional impairments had afflicted their working situation or choice of profession.

“Then it really hurts, I'm tired, I don't have the energy for anything, I'm in resting mode; that's what I got to do and it usually lasts until it's time to go to bed. I take my medication again and try to sleep. It isn't easy – my legs feel prickly and achy.” (Participant 4)

Impaired balance was also a common topic for both reconstructed and amputated patients. Walking on uneven terrain, snow, gravel, and on slippery winter roads was described as fearful with risk of falling. Also riding a bike or walking up or down stairs was connected with feelings of unease.

“I tried to ride my bike when I was in a town with my daughter. We were going to ride to a beach and she had an old bike, but it didn't work. I got so shaky there was just no way ... that's hard, too, because I'd really like to do that sort of thing. I used to do it a lot.” (Participant 2)

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