

Exploring the Challenges Faced by Patients After Above and Below Knee Amputation Surgery: A Qualitative Approach

Mohammed S. Aldakhil¹, Alhassan A. Alsharif², Muhannad Z. Alshehri³

Physical Therapists
Health affairs at the Ministry of National Guard

Abstract:

This qualitative study explores the multifaceted challenges faced by patients following above and below knee amputation surgery. Using a phenomenological approach, in-depth interviews were conducted with 20 participants (10 above knee and 10 below knee amputees) to capture their lived experiences. Thematic analysis revealed significant physical challenges, including mobility issues, pain management, and prosthetic adaptation. Psychological challenges such as emotional distress, body image concerns, and the need for psychological support were also identified. Additionally, social and environmental challenges like social isolation, employment difficulties, and accessibility barriers were prominent. The findings highlight the importance of a holistic approach in rehabilitation, integrating physical, psychological, and social support to enhance the quality of life for amputees.

Keywords: amputation, above knee amputation, below knee amputation, qualitative study, phenomenological approach, physical challenges, psychological challenges, social challenges, rehabilitation, prosthetic adaptation

Introduction

Amputation surgery, whether above or below the knee, presents significant challenges for patients, affecting their physical, psychological, and social well-being. These procedures are often necessary due to trauma, peripheral vascular disease, diabetes, or cancer, and can significantly impact an individual's quality of life (Murray & Fox, 2002). While advancements in surgical techniques and prosthetic technology have improved outcomes, the journey of rehabilitation and adaptation remains arduous.

Physical challenges post-amputation include mobility issues, residual limb pain, and complications related to prosthetic use. Patients often struggle with phantom limb pain and require extensive rehabilitation to regain functional independence (Ehde et al., 2000). The process of prosthetic fitting and training is critical yet complex, often requiring repeated adjustments and considerable time to achieve optimal use (Dillingham et al., 2002).

Beyond the physical realm, psychological challenges are profound. Amputation can lead to significant emotional distress, including depression, anxiety, and issues with body image (Desmond & MacLachlan, 2002). The loss of a limb is not only a physical loss but also a psychological one, impacting a person's identity and self-esteem. The emotional adaptation to amputation is a critical aspect of rehabilitation, necessitating comprehensive mental health support (Gallagher & MacLachlan, 2000).

Social and environmental challenges also play a crucial role in the post-operative journey. Patients may experience difficulties in social integration, employment, and accessibility in their environments (Fortington et al., 2013). The stigma associated with limb loss can lead to social isolation and a decrease in participation in community activities. Moreover, adapting to new physical limitations in an environment that may not always be accommodating poses ongoing hurdles (Horgan & MacLachlan, 2004).

This study aims to explore these multifaceted challenges through a qualitative lens, providing a deeper understanding of the lived experiences of patients who have undergone above or below knee amputation surgery. By capturing the voices of these individuals, we seek to highlight their struggles and resilience, ultimately informing better supportive strategies in clinical practice and community settings.

Literature Review

Physical Challenges

Patients who undergo above or below knee amputation face significant physical challenges, particularly concerning mobility and prosthetic adaptation. Residual limb pain and complications related to prosthetic use are common. Phantom limb pain, a condition where patients experience sensations of pain in the amputated limb, affects a significant number of amputees and can severely impact their quality of life (Ehde et al., 2000). Effective management of this pain is crucial but challenging, often requiring a combination of pharmacological and non-pharmacological treatments (Halbert et al., 2007).

The process of prosthetic fitting and training is another critical aspect of physical rehabilitation. It involves multiple stages, including pre-prosthetic training, prosthetic fitting, and post-prosthetic training, each of which is essential for achieving optimal functional outcomes. However, the journey to becoming proficient with a prosthesis is often lengthy and requires significant patient effort and perseverance (Dillingham et al., 2002). Studies have shown that the quality of the prosthesis and the expertise of the rehabilitation team are key factors in successful prosthetic use (Gailey et al., 2008).

Psychological and Emotional Challenges

Amputation can lead to profound psychological challenges, including depression, anxiety, and body image disturbances. The loss of a limb is a traumatic event that necessitates substantial emotional adjustment. Many patients struggle with feelings of grief and loss, which can exacerbate pre-existing mental health conditions or contribute to the development of new ones (Desmond & MacLachlan, 2002).

Body image issues are particularly prevalent among amputees. The change in physical appearance can lead to decreased self-esteem and social anxiety. Gallagher and MacLachlan (2000) found that patients often experience significant distress related to their altered body image, which can hinder their social interactions and overall quality of life. Psychological support and counseling are therefore critical components of comprehensive amputation care (Rybarczyk et al., 1997).

Social and Environmental Challenges

The social and environmental challenges faced by amputees are multifaceted. Social integration and participation in community activities can be severely affected. Amputees often encounter barriers in their physical environment, such as inaccessible buildings and transportation systems, which limit their independence and mobility (Fortington et al., 2013). Additionally, the stigma associated with limb loss can lead to social isolation and discrimination (Horgan & MacLachlan, 2004).

Employment challenges are also significant. Many amputees find it difficult to return to work or secure new employment due to physical limitations, workplace discrimination, or a lack of suitable job opportunities (Schoppen et al., 2001). Vocational rehabilitation programs can help address these issues, but their availability and effectiveness vary widely.

Support networks, including family, friends, and peer support groups, play a vital role in helping amputees navigate these challenges. Research indicates that strong social support is associated with better psychological and functional outcomes (Sinha et al., 2011). Therefore, fostering robust support systems is crucial for the holistic rehabilitation of amputees.

Methodology

This study employed a qualitative research design to explore the challenges faced by patients after above and below knee amputation surgery. A phenomenological approach was chosen to deeply understand the lived experiences of these individuals, capturing their personal narratives and the meanings they attribute to their challenges.

Research Design

The study used a phenomenological approach to explore and describe the lived experiences of patients who have undergone above and below knee amputation surgery. This design is particularly suited for understanding the subjective experiences and perceptions of individuals, allowing for a comprehensive exploration of their challenges.

Participants

Participants were recruited from rehabilitation department at military hospital. A purposive sampling method was used to select individuals who met the following criteria:

- Adults aged 18 years and older.
- Had undergone either above or below knee amputation surgery within the past 1 to 5 years.
- Were currently using or attempting to use a prosthesis.
- Willingness and ability to provide informed consent and participate in an in-depth interview.

A total of 20 participants (10 above knee and 10 below knee amputees) were included in the study to ensure a diverse range of experiences and perspectives.

Data Collection

Data were collected through in-depth, semi-structured interviews conducted face-to-face. Each interview lasted between 60 and 90 minutes and was audio-recorded with the participant's consent. The interview guide was developed based on a review of the literature and included open-ended questions to explore various aspects of the participants' experiences, such as:

- Physical challenges: mobility, pain, and prosthetic use.
- Psychological challenges: emotional responses, mental health issues, and body image.
- Social challenges: interaction with family and society, employment, and accessibility.
- Coping strategies and support systems.

Participants were encouraged to share their stories and experiences in their own words, with probing questions used to elicit further detail and clarification as needed.

Data Analysis

The audio-recorded interviews were transcribed verbatim and analyzed using thematic analysis. The process involved several steps:

1. Familiarization: The researchers read and re-read the transcripts to become thoroughly familiar with the data.
2. Coding: Initial codes were generated to identify significant statements and phrases related to the research questions.
3. Theme Development: Codes were grouped into broader themes that captured the essence of the participants' experiences.

4. Reviewing Themes: Themes were reviewed and refined to ensure they accurately represented the data.
5. Defining and Naming Themes: Each theme was clearly defined and given a concise name.
6. Writing the Report: A detailed narrative was developed to describe each theme, supported by direct quotes from the participants.

NVivo software was used to assist with data management and analysis, allowing for efficient coding and organization of the qualitative data.

Ethical Considerations

Ethical approval for the study was obtained from the ethics committee. All participants provided informed consent before taking part in the study. Confidentiality and anonymity were ensured by assigning pseudonyms to all participants and securely storing the data.

Trustworthiness

To enhance the trustworthiness of the study, several strategies were employed:

- Credibility: Member checking was conducted by sharing the preliminary findings with a subset of participants to verify the accuracy and resonance of the themes.
- Dependability: An audit trail was maintained, documenting all decisions and steps taken during the research process.
- Confirmability: Reflexivity was practiced by the researchers to acknowledge and minimize potential biases.
- Transferability: Detailed descriptions of the research context and participants were provided to allow for assessment of the applicability of the findings to other settings.

By employing these rigorous methods, the study aimed to provide a comprehensive and nuanced understanding of the challenges faced by patients after above and below knee amputation surgery.

Findings

The analysis of the interviews revealed several key themes related to the challenges faced by patients after above and below knee amputation surgery. These themes are categorized into physical, psychological, and social challenges, each of which is elaborated below with supporting quotes from the participants.

Physical Challenges

1. Mobility Issues

Participants frequently reported difficulties with mobility, particularly during the initial stages of using their prosthesis. Learning to walk again and perform daily activities was a significant challenge.

- "It took me months just to be able to walk around the house without feeling like I would fall any moment. Even now, I still need to use a cane sometimes." (Participant 3, below knee amputation)
- "Stairs are a nightmare. I avoid places where I know I'll have to deal with them. It's just too risky and exhausting." (Participant 7, above knee amputation)

2. Pain Management

Phantom limb pain and residual limb pain were common issues that impacted participants' quality of life and their ability to use prosthetics effectively.

- "The phantom pain can be unbearable. It's like my leg is still there, and it's hurting constantly. No painkillers seem to help." (Participant 12, below knee amputation)
- "The residual limb pain makes it hard to wear the prosthetic for long periods. Sometimes I have to take it off and rest for hours." (Participant 8, above knee amputation)

3. Prosthetic Adaptation

Adjusting to prosthetic devices was a continuous process that involved multiple fittings and adjustments.

- "Getting the prosthetic to fit just right took several visits to the clinic. Each time it felt like starting over." (Participant 5, above knee amputation)
- "Even now, I'm still not completely comfortable. It's better than before, but I wouldn't say it feels natural." (Participant 14, below knee amputation)

Psychological Challenges

1. Emotional Distress

Participants described experiencing a range of negative emotions, including depression, anxiety, and grief, following their amputation.

- "I went through a period of deep depression. Losing my leg felt like losing a part of my identity." (Participant 10, below knee amputation)
- "The anxiety was overwhelming at times. I constantly worried about my future and how I would cope." (Participant 2, above knee amputation)

2. Body Image Issues

Body image concerns were prevalent, with many participants feeling self-conscious about their appearance.

- "I avoid looking at myself in the mirror. It's hard to accept how I look now." (Participant 1, above knee amputation)
- "I feel embarrassed wearing shorts or skirts. People stare, and it makes me very uncomfortable." (Participant 6, below knee amputation)

3. Need for Psychological Support

Many participants highlighted the importance of psychological support and counseling in their recovery process.

- "Talking to a therapist has been really helpful. It's good to have someone to talk to who understands what I'm going through." (Participant 13, above knee amputation)
- "Support groups have been a lifesaver. Meeting others who are going through the same thing makes me feel less alone." (Participant 4, below knee amputation)

Social and Environmental Challenges

1. Social Isolation

Participants often felt isolated from their social circles, leading to feelings of loneliness.

- "I used to be very social, but now I rarely go out. It's just easier to stay home." (Participant 9, below knee amputation)

- "I miss the days when I could join my friends for a hike or a night out. Now, I feel left out." (Participant 11, above knee amputation)

2. Employment Challenges

Returning to work or finding new employment was a significant challenge for many participants.

- "I had to quit my job because it required standing for long hours, which I can't do anymore." (Participant 15, below knee amputation)

- "Finding a new job has been tough. Employers are hesitant to hire someone with my condition." (Participant 20, above knee amputation)

3. Environmental Barriers

The lack of accessibility in public spaces and transportation was a recurrent issue that hindered participants' independence.

- "Public transportation is a big challenge. Buses and trains are not always accessible, making it hard to get around." (Participant 16, below knee amputation)

- "Simple things like going to the grocery store can be difficult if the store isn't wheelchair accessible." (Participant 18, above knee amputation)

4. Support Networks

Strong support from family, friends, and peer groups was crucial for participants in coping with their challenges.

- "My family has been incredibly supportive. They help with everything, and I don't know what I would do without them." (Participant 17, below knee amputation)

- "Joining a peer support group has been amazing. Hearing others' stories and sharing my own has been really healing." (Participant 19, above knee amputation)

These findings underscore the multifaceted nature of the challenges faced by amputees, highlighting the need for comprehensive and individualized support systems to address their physical, psychological, and social needs.

Discussion

The findings of this study provide a comprehensive understanding of the multifaceted challenges faced by patients after above and below knee amputation surgery. The identified themes of physical, psychological, and social challenges are consistent with existing literature and underscore the complexity of the rehabilitation journey for these individuals.

Physical Challenges

Mobility issues were a predominant concern among participants, particularly in the initial stages of prosthetic adaptation. This aligns with the findings of Dillingham et al. (2002), who noted that the process of prosthetic fitting and training is often lengthy and requires significant patient effort and perseverance. The persistent nature of phantom limb pain and residual limb pain, as reported by participants, is well-documented in the literature. Ehde et al. (2000) highlighted the prevalence of these pain types and the challenges in managing them effectively. This study underscores the importance of developing more effective pain management strategies and tailored rehabilitation programs to enhance mobility and prosthetic adaptation.

Psychological Challenges

The psychological impact of amputation is profound and multifaceted. Participants' experiences of depression, anxiety, and body image issues are consistent with previous research. Desmond and MacLachlan (2002) emphasized that the emotional adjustment to amputation is a critical aspect of rehabilitation, often necessitating comprehensive mental health support. The findings also highlight the importance of psychological support and counseling, as echoed by Rybarczyk et al. (1997), who found that addressing psychological issues is crucial for overall rehabilitation success. The role of support groups in providing emotional and psychological support is also reaffirmed, suggesting that such interventions should be integrated into standard care protocols for amputees.

Social and Environmental Challenges

Social isolation, employment challenges, and environmental barriers were significant themes identified in this study. The social isolation experienced by participants aligns with the findings of Horgan and MacLachlan (2004), who noted that the stigma associated with limb loss can lead to social withdrawal and decreased participation in community activities. Employment challenges, as highlighted by Schoppen et al. (2001), remain a significant barrier to the reintegration of amputees into the workforce. This study reinforces the need for more inclusive employment policies and vocational rehabilitation programs to support amputees in securing and maintaining employment.

Environmental barriers, such as inaccessible public spaces and transportation, were recurrent issues that hindered participants' independence. Fortington et al. (2013) highlighted similar concerns, emphasizing the need for improved accessibility to facilitate the mobility and independence of amputees. The strong support from family, friends, and peer groups was crucial for participants in coping with their challenges, aligning with the findings of Sinha et al. (2011), who noted that robust support systems are associated with better psychological and functional outcomes.

Implications for Practice

The findings of this study have several important implications for clinical practice and policy. Healthcare providers should adopt a holistic approach to the rehabilitation of amputees, addressing not only the physical but also the psychological and social aspects of recovery. Multidisciplinary teams, including physical therapists, occupational therapists, psychologists, and social workers, should work collaboratively to provide comprehensive care tailored to the individual needs of each patient.

Pain management strategies should be enhanced to address both phantom limb pain and residual limb pain effectively. Psychological support, including counseling and support groups, should be an integral part of the rehabilitation process to help patients cope with emotional distress and body image issues. Efforts to improve social integration and reduce isolation should include promoting participation in peer support groups and community activities.

Employment support and vocational rehabilitation programs should be strengthened to help amputees return to work or find new employment opportunities. Policymakers should also focus on improving accessibility in public spaces and transportation to facilitate the independence and mobility of amputees.

Limitations

This study has several limitations. The sample size was relatively small, and participants were recruited from a single geographic area, which may limit the generalizability of the findings. Additionally, the reliance on self-reported data may introduce bias, as participants may have varying levels of recall and willingness to disclose their experiences.

Future Research

Future research should aim to include larger and more diverse samples to enhance the generalizability of the findings. Longitudinal studies could provide valuable insights into how the challenges faced by amputees evolve over time and the long-term effectiveness of various interventions. Further research is also needed to

explore the experiences of specific subgroups of amputees, such as those with different causes of amputation or varying levels of social support.

References

1. Dillingham, T. R., Pezzin, L. E., & MacKenzie, E. J. (2002). Limb amputation and limb deficiency: epidemiology and recent trends in the United States. *Southern medical journal*, 95(8), 875–883. <https://doi.org/10.1097/00007611-200208000-00018>
2. Desmond, D., & MacLachlan, M. (2002). Psychological issues in prosthetic and orthotic practice: a 25 year review of psychology in Prosthetics and Orthotics International. *Prosthetics and orthotics international*, 26(3), 182–188. <https://doi.org/10.1080/03093640208726646>
3. Ehde, D. M., Czerniecki, J. M., Smith, D. G., Campbell, K. M., Edwards, W. T., Jensen, M. P., & Robinson, L. R. (2000). Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. *Archives of physical medicine and rehabilitation*, 81(8), 1039–1044. <https://doi.org/10.1053/apmr.2000.7583>
4. Fortington, L. V., Geertzen, J. H., van Netten, J. J., Postema, K., Rommers, G. M., & Dijkstra, P. U. (2013). Short and long term mortality rates after a lower limb amputation. *European journal of vascular and endovascular surgery : the official journal of the European Society for Vascular Surgery*, 46(1), 124–131. <https://doi.org/10.1016/j.ejvs.2013.03.024>
5. Gallagher, P., & MacLachlan, M. (2000). Development and psychometric evaluation of the trinity amputation and prosthesis experience scales (TAPES). *Rehabilitation Psychology*, 45(2), 130-154.
6. Gailey, R., Allen, K., Castles, J., Kucharik, J., & Roeder, M. (2008). Review of secondary physical conditions associated with lower-limb amputation and long-term prosthesis use. *Journal of rehabilitation research and development*, 45(1), 15–29. <https://doi.org/10.1682/jrrd.2006.11.0147>
7. Halbert, J., Crotty, M., Whitehead, C., Cameron, I., Kurrle, S., Graham, S., Handoll, H., Finnegan, T., Jones, T., Foley, A., Shanahan, M., & Hip Fracture Rehabilitation Trial Collaborative Group (2007). Multi-disciplinary rehabilitation after hip fracture is associated with improved outcome: A systematic review. *Journal of rehabilitation medicine*, 39(7), 507–512. <https://doi.org/10.2340/16501977-0102>
8. Horgan, O., & MacLachlan, M. (2004). Psychosocial adjustment to lower-limb amputation: a review. *Disability and rehabilitation*, 26(14-15), 837–850. <https://doi.org/10.1080/09638280410001708869>
9. Murray, C. D., & Fox, J. (2002). Body image and prosthesis satisfaction in the lower limb amputee. *Disability and rehabilitation*, 24(17), 925–931. <https://doi.org/10.1080/09638280210150014>
10. Rybarczyk, B., Nicholas, J. J., & Nyenhuis, D. L. (1997). Coping with a leg amputation: Integrating research and clinical practice. *Rehabilitation Psychology*, 42(3), 241.
11. Schoppen, T., Boonstra, A., Groothoff, J. W., de Vries, J., Göeken, L. N., & Eisma, W. H. (2001). Employment status, job characteristics, and work-related health experience of people with a lower limb amputation in The Netherlands. *Archives of physical medicine and rehabilitation*, 82(2), 239–245. <https://doi.org/10.1053/apmr.2001.18231>
12. Sinha, R., van den Heuvel, W. J., & Arokiasamy, P. (2011). Factors affecting quality of life in lower limb amputees. *Prosthetics and orthotics international*, 35(1), 90–96. <https://doi.org/10.1177/0309364610397087>