



**Northumbria  
University**  
NEWCASTLE



**Anglia Ruskin  
University**



## **Maintaining Independence:**

A Study into the Health and Social Wellbeing  
of Older Limbless Veterans

A Summary of Key Findings



# Introduction

## Project Aims

The main aims of this study were:

- 1) To explore the physical, psychological and social wellbeing of older, limbless veterans across the life-course;
- 2) To ascertain the factors that contribute to the ability of limbless veterans to maintain their independence at various stages in their lives.

Ultimately, this research aimed to produce recommendations for health and social care policy around the requirements of an ageing veteran population, inform future service design, and shape the interface between NHS and third sector organisations with responsibility to care for limbless veterans.

## Methodology

The research used a peer-led approach to successfully identify and engage older limbless veterans. The research team conducted detailed life history interviews. The life histories of 32 limbless veterans, aged between 43 and 95 formed the data for the study. Each of the participants were involved in semi-structured life history interviews.

## Design

A multiple method convergent design was adopted for the study, encompassing Narrative Inquiry and Framework Analysis (Social Applied Policy Research). This enabled dual attention to 1) the narratives that shape how veterans reconstruct their lives and identities after limb-loss; and 2) policy and practice implications drawn from observations that some veterans may be more able to adjust and maintain independence than others

## Results

*Narrative Inquiry:* Narrative inquiry identified four different 'narrative types' which informed the stories of the participants. The four narrative types are: 'Struggling against Decline', 'Minimisation', 'Victimhood', and 'Life-as-Normal'.

*Framework Analysis:* Framework analysis identified three superordinate themes within the participant's life narratives. These three superordinate themes are, 'Barriers to Transition', 'Disparity of Care', and 'The Enduring Challenge of Limb-loss'.

*Convergent Analysis:* In order to gain a deeper understanding of the ways in which key themes contribute towards the construction of each narrative type, convergence between narrative inquiry and framework analysis was conducted.

This booklet provides a brief summary of the convergent findings and the subject expert lead discussion points which are included in full within the Maintaining Independence report.

## The 'Struggle against Decline' Narrative

Many participants' stories of aging and limb-loss hinged on a core tension: struggling against decline, while striving to maintain independence. The tone of the 'struggle against decline' narrative shifts between stories of 'struggling to adapt' and stories of 'adapting to struggle' according to the participants' perceived wellbeing, independence and quality of life. 'Adapting to struggle' may shift towards 'struggling to adapt' according to bodily deterioration, changes in health and mobility, and the emergence of social isolation.

Analysis of the key themes which contribute towards the construction of the 'struggle against decline' narrative type provided insights into the various challenges faced by limbless veterans throughout the course of their lives. Figure 1 provides a visual representation of the key themes which contribute towards the construction of this narrative type.



**Figure 1.** Visual representation of the key themes which contribute towards the construction of the 'Minimisation' narrative type.

### *Early Barriers to Health, Wellbeing and Independence*

**Limb Bereavement:** Veterans affected by limb-loss may experience an initial period of intense loss, grief and despair during early recovery from amputation as they mourn the loss of their limb and the subsequent loss of physical capabilities and military career.

**Delays in Prosthetic Provision:** Delays in the initial provision of prosthetic limbs may result in a prolonged period of immobility and limited physical activity, ultimately resulting in physical isolation and a heavy reliance upon others to meet basic needs.

**Poorly Adapted Living:** The experience of transition from the hospital, back into the home during early recovery from may be a significant challenge for veterans affected by limb-loss. Appropriate home adaptations are essential in order to allow limbless veterans to access their local community, ambulate around the home and maintain care needs independently.

**Difficulty Transitioning:** Veterans affected by limb-loss may experience significant challenges in transitioning from military life, back into civilian society. Civilian society may be perceived to be highly unfamiliar and lacking in structure, direction and discipline in comparison with military life.

## *Enduring Barriers to Health, Wellbeing and Independence*

---

**Pain and Discomfort:** Persistent pain and discomfort are common experiences for many veterans affected by limb-loss. Pain which is poorly managed may result in the inability to engage in physical activity or to utilise prosthetics comfortably. Pain may result in immobility, physical isolation within the home and a heavy reliance upon others to meet basic needs.

**Prosthetic Maintenance:** Ongoing issues with the fit and function of prosthetic limbs are likely to affect limbless veterans throughout the life-course. Issues such as poor socket fit may result in recurrent periods of heightened pain, reduced mobility and limited independence.

**Isolation:** An accumulation of physical deterioration, progressively worsening physical pain and increasing limitations in mobility during later life may result in physical and social isolation for older veterans affected by limb-loss.

---

## *Mediating Factors in the Health, Wellbeing and Independence*

---

**Continuity of Care:** The data suggests that poor continuity of care is a significant challenge for veterans affected by limb-loss. Participants described the negative physical impact of inconsistencies between services, ineffective inter-service communications, excessive waiting times between healthcare appointments and a paucity of long-term specialist support. Poor continuity of care was associated with increased pain and discomfort over time, resulting in limited mobility and reduced independence.

**Social Networks:** Building social networks within veteran associations may be a highly influential experience for veterans affected by limb-loss. Observing fellow veterans display self-confidence, engage in challenging physical activities and achieve personal goals may be associated with significant improvements in perceived self-efficacy, body image and independence.

**Employment:** Fulfilling post-injury employment may be associated with significant improvements in self-esteem, independence and quality of life amongst veterans affected by limb-loss. However, the data suggests that veterans who possess limited pre-military education, training and work experience may experience significant challenges in securing post-injury employment.

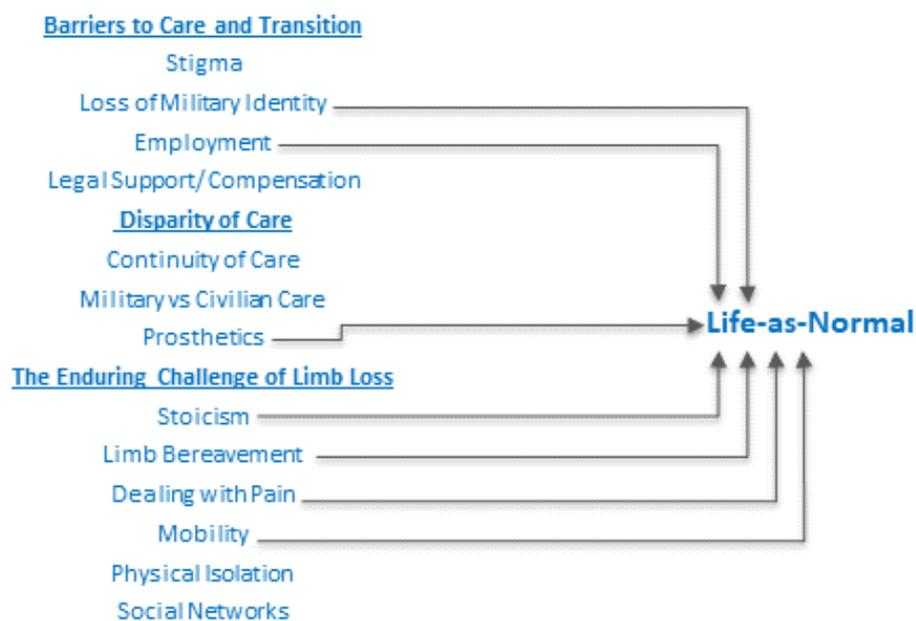
---



## The 'Life-As-Normal' Narrative

'Life-as-normal' narratives place a strong emphasis on being 'normal', however ongoing grief and anguish remain 'bottled up' inside the veteran. Limb-loss and its after-effects are not necessarily denied but remain somewhat hidden. Striving to be 'normal' in the aftermath of injury can be an important way for amputees to cope. However, this may also mask a great deal of enduring personal anguish.

Exploration of the themes which contribute to the construction of the 'life-as-normal' narrative type revealed a number of factors which may contribute towards the development and maintenance of unbaiting psychological distress amongst veterans affected by limb-loss. [Figure 2](#) provides a visual summary of the key themes which contribute towards the construction of this narrative type.



**Figure 2.** Visual representation of the key themes which contribute towards the construction of the 'Life-as-Normal' narrative type.

### *Potential Sources of Enduring Psychological Distress*

**Limb Bereavement:** Psychological distress associated with the physical loss of a limb and the subsequent loss of military identity may persist throughout the life-course.

### *Factors which Maintain Psychological Distress*

**Experiential Avoidance:** The excessively negative perception of undesirable internal events and a tendency to suppress, control or avoid negative emotions, cognitions and sensations may contribute to the maintenance of psychological distress by removing the opportunity for emotional learning, active problem solving and the disconfirmation of distressing cognitions.

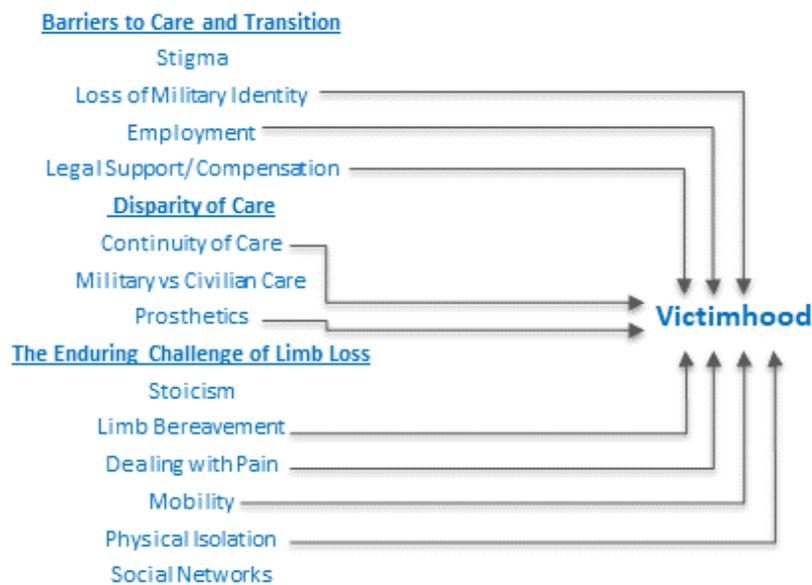
**Stoicism:** A tendency towards stoicism may contribute towards an avoidant coping style amongst veterans affected by limb-loss, resulting in a reluctance to engage in help seeking behaviour, limiting emotional expression and prolonging psychological distress.

**Social Stigma:** Veterans may perceive significant social stigma against those affected by disability. Perceived stigma may contribute towards an avoidant coping style amongst veterans affected by limb-loss, resulting in a reluctance to engage in help seeking behaviour, limiting emotional expression and prolonging psychological distress.

## The 'Victimhood' Narrative

The 'victimhood' narrative type was primarily characterised by expressions of suffering, anger and bitterness. Within stories of 'victimhood' the suffering manifested in physical, psychological, social, and occupational forms. Importantly, suffering was causally attributed to the actions or inactions of others, which compounds the anger and bitterness felt by the participant.

Exploration of the key themes which contribute to the construction of the 'victimhood' narrative type revealed a number of factors which may contribute towards the development and maintenance of unbaiting psychological distress amongst veterans affected by limb-loss. Figure 3 provides a visual summary of the key themes which contribute towards the construction of this narrative type.



**Figure 3.** Visual representation of the key themes which contribute towards the construction of the 'Victimhood' narrative type.

### *Potential Sources of Enduring Psychological Distress*

**Unsatisfactory Compensation:** Dissatisfaction with the level of compensation received in accordance with injury may result in unbaiting psychological distress, characterised by anger, bitterness and resentment towards the military.

**Unsatisfactory Care:** Dissatisfaction with the quality of care which has been provided since sustaining limb-loss may provoke anger and bitterness towards health and social care systems.

**Unemployment:** The inability to secure post-injury employment may have a negative long-term impact upon veterans' quality of life, resulting in the belief that a) the amputee is unattractive to potential employers and b) the amputee is likely to be subject to ongoing disability discrimination.

### *Factors which Maintain Psychological Distress*

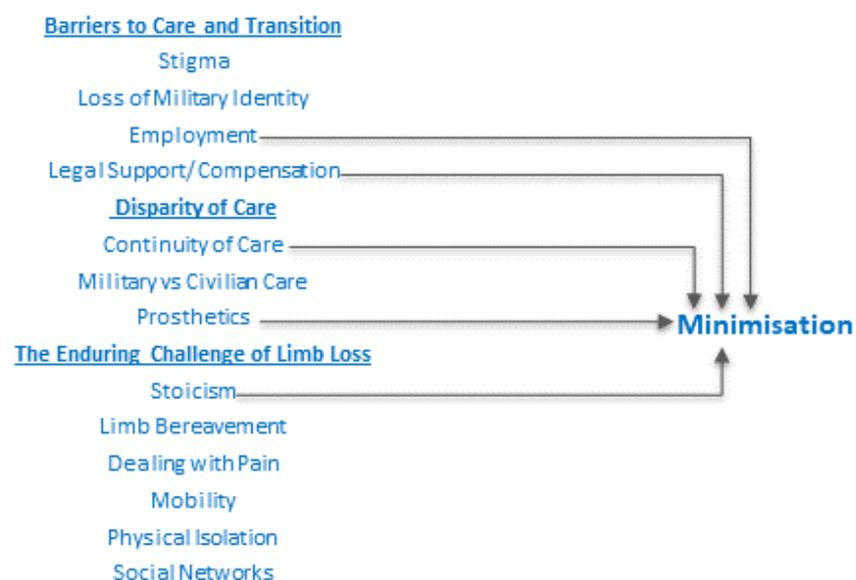
**Limb Bereavement:** Veterans affected by limb-loss may experience an initial period of intense loss, grief and despair during early recovery from amputation as they mourn the loss of their limb and the subsequent loss of physical capabilities and military career.

**Delays in Prosthetic Provision:** Delays in the initial provision of prosthetic limbs may result in a prolonged period of immobility and limited physical activity, ultimately resulting in physical isolation and a heavy reliance upon others to meet basic needs.

## The 'Minimisation' Narrative

Some participants told 'minimisation' stories, placing little emphasis on limb-loss in their stories. They spent more time during their interviews talking in detail about their careers and other achievements. It was clear that limb-loss occupied a much smaller place in their life-stories. There was a strong sense in which *work* – whether continuing in military service or civilian work – helped participants to 'normalise' their amputations and to minimise the impact of limb-loss.

Exploration of the key themes which contribute towards the construction of the 'minimisation' narrative type provides insights into factors which may 'minimise' the negative outcomes associated with limb-loss amongst veterans. Figure 4 provides a visual summary of the key themes which contribute towards the construction of this narrative type.



**Figure 4.** Visual representation of the key themes which contribute towards the construction of the 'Minimisation' narrative type.

### *Minimising Factors in Long-Term Negative Outcomes*

**Prosthetic Limbs:** Early rehabilitation which involved the use of prosthetic limbs may minimise the long-term impact of limb-loss amongst veterans by facilitating a return to previous physical capabilities.

**Continuity of Care:** Ongoing access to high quality healthcare throughout the life-course is essential in order to minimise the long-term health outcomes and barriers to independence associated limb-loss.

**Stoicism:** A stoic determination to cope and adapt may minimise the long-term impact of limb-loss amongst veterans by motivating them to achieve successful physical and psychological adjustment,

**Employment:** The capacity to secure fulfilling post-injury employment is essential in order to minimise the long-term impact of limb-loss on veterans' quality of life.

**Financial Compensation:** Satisfaction with the level of compensation received in accordance with injury may promote psychological adjustment to limb-loss and improve the quality of life by protecting veterans' financial security following limb-loss.

# Discussion Points

## Limb-Loss and Pain

Pain management and treatment, particularly for older veterans with limb-loss, is a complex process. Results from this study have shown that some of the complexities relate to stoicism, reluctance to report pain and fear of the side effects of medications. Given these complexities and the potential impact on limbless veterans' and their families' wellbeing, attention needs to be given to effective management of pain those affected by stump and phantom pain.

## Education and Post Limb-Loss Employment

The ability to maintain a fulfilling career forms a key factor in the ability of veterans to maintain their independence and sense of self-worth following limb-loss. Pre-military education and socio-economic position have been shown as an important risk indicators of the capacity of veterans to recover successfully following limb-loss. Findings point to the experience of cumulative inequality, whereby early disadvantage can become entrenched and perpetuated through subsequent life experiences and patterns of service provision. Support with re-gaining employment is highly important, particularly in cases where participants have limited education or training.

## Limb-Loss and Social Isolation

Older adults and veterans are both societal groups that are vulnerable to perceived loneliness and social isolation, and it is evident that limb loss also accentuates this. Both social isolation and loneliness were issues for participants, and this was due to factors including mobility issues, concerns about self-image, and feeling as though they do not relate to others.

## Limb-Loss, Independence and Activities of Daily Living

This study illustrates that veterans who are affected by limb-loss require timely access to high quality support and specialist healthcare services, starting from the time of amputation and extending throughout the life-course in order to maintain their capacity to engage in activities of daily living (ADL). Special attention must be paid to older veterans who suffered limb-loss prior to contemporary medical advances in prosthetic devices and prosthetic care. The present study demonstrates that such individuals may experience a number of barriers to ADL independence. Age-related physical decline and medical comorbidities may further impair older veterans' capacity to achieve ADL independence as they progress throughout later-life. A holistic, multifaceted approach to care and support which integrates a wide range of services and resources is essential in order to ensure that veterans affected by limb-loss receive the care and support they require to maintain ADL independence throughout the life-course.





