



**Northumbria  
University**  
NEWCASTLE



**Anglia Ruskin  
University**

## **Maintaining Independence:**

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

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## Foreword



Professor Jamie Hacker Hughes FAcSS FBPsS FRSM

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As a result of the many conflicts that the British Armed Forces have been involved in during and since World War II, many veterans have sustained traumatic limb-loss, either during combat or through other aspects of their military service. As a former head of healthcare psychology services for the Ministry of Defence for five years, I was greatly privileged to meet and work with many of this very impressive group of people at various stages on their road to recovery, which begins upon their return to the UK from theatre, first in Selly Oak Hospital or the Queen Elizabeth II hospital in Birmingham, then on to the Defence Medical Rehabilitation Centre at Headley Court, Surrey, before re-entering into the community. I was able to see most clearly that the impact of limb-loss clearly does not stop there, either for the service woman or man involved or for their partner or family.

The study that this research group from the Northern Hub for Military Veterans and Families Research at Northumbria University in collaboration with the Veterans and Families Institute at Anglia Ruskin University, have carried out is of fundamental importance. Beginning with a critical review of 21 studies which have looked at limb-loss in military veterans, it is clear that limb-loss is a progressive, degenerative, often very painful injury which can impact upon future physical and psychological well-being and quality of life and that how veterans cope with their injuries, as well as the social and political context in which injury and recovery occurs each have a substantial effect upon long term adjustment. The cost of healthcare provision for limbless veterans is, in addition, necessarily higher as this group may need additional support to their peers.

It is this aspect of the way in which physical, psychological and social well-being changes across the lifespan that this research group has examined, the results of their research being reported here. The group concentrated on older veterans (between the ages of 40 and nearly 100) who, between them, have served in all major conflicts including and since World War II. All had unilateral or bilateral amputations of upper or lower limbs. The research was based on the life histories of 32 veterans, collected over an eight-month period in 2016 and 2017, amassing a total of 10 hours of data for each participant, which were then thoroughly analysed using the latest innovative techniques and methods.

What makes this research study really special is that it has been carried out in conjunction with Blesma, The Limbless Veterans Charity, the country's leading charity for limbless veterans, whose members acted as researchers within the research team, contributing to design of the research proposal, the development of the research tools and coordinating recruitment into the study.

Unsurprisingly, this report makes numerous recommendations for local authorities, health and social care services, the Armed Forces and the government alike. It is hoped that the fruits of this study, contained in this report, and its recommendations will bring about a positive influence on the physical, psychological and social care of the United Kingdom's limbless veterans well into the future.





## **The Northern Hub for Veterans and Military Families Research**

**The Northern Hub for Veterans and Military Families Research at Northumbria University is a collective of academics, service providers and service users with an interest in improving the health and social wellbeing of veterans and their families across the lifespan.**

The Hub has evolved from the interests of Dr Mathew Kiernan Lieutenant Commander RN (Q) retired and Dr Mick Hill. It has established itself through an evolutionary process attracting and welcoming anyone with a genuine interest in its vision. We openly welcome visionary and innovative research that helps improve and understand the complexities that our veterans and their families experience across the whole lifespan. A fundamental principle of The Hub is collaboration in research for the benefit of others.



Anglia Ruskin  
University

**Veterans & Families Institute**

## **Veterans and Families Institute**

**The Veterans and Families Institute at Anglia Ruskin University carry out research, policy development and consultation on the impact of military service on veterans and their families.**

The Institute's academics work across disciplines including sociology, psychology, social policy, education, social work, nursing and ethics. Visiting Fellows provide additional expertise in psychiatry, clinical psychology and criminal justice. Since our inception, we have published reports and academic papers relating to both commissioned research and to areas of specific research interest.



## The Research Team



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The Northern Hub for Veterans and Military Families' Research and the Veterans and Families Institute would like to thank The Aged Veterans Fund for funding this project and the Royal British Legion for all their support in managing the Aged Veterans Fund Portfolio.

Most importantly we would like to thank all those who participated in the study. This project could not have been completed without the support of all the participants, who not only gave us their time, but most importantly, told us their stories.

We would like to extend our appreciation and thanks to the peer-researchers and Blesma, The Limbless Veterans Charity. This project could not have been completed without the participant recruitment from Blesma and the support of Helen and Bob.

Thank you to all those who participated in this project and especially Dr Barbara Harrington who worked with us for the first year and members of our steering group, Professor Jamie Hacker Hughes, Heather Betts (Blesma) and Bryan Elliot. Finally, thank you to Christine Scally-Morris for transcription of all data.

### The Aged Veterans Fund

This project is funded by The Aged Veterans Fund using LIBOR funding. The Aged Veterans Fund was established in 2015 to assist organisations across the UK to address the health, wellbeing, and social care needs of older veterans.



### The Royal British Legion

The Royal British Legion help members of the Royal Navy, British Army, Royal Air Force, Reservists, veterans and their families all year round. They also campaign to improve their lives, organise the Poppy Appeal and remember the fallen.

### Blesma, The Limbless Veterans

Blesma, The Limbless Veterans, is dedicated to assisting serving and ex-Service men and women who have suffered life-changing limb-loss or the use of a limb, an eye or loss of sight in the honourable service of our country.



## Abbreviations

<b>ADL</b>	Activities of daily living
<b>AK</b>	Above-knee
<b>ASSIA</b>	Applied Social Sciences Index and Abstracts
<b>BK</b>	Below-knee
<b>CINAHL</b>	Cumulative Index to Nursing and Allied Health Literature
<b>CTD</b>	Cumulative trauma disorder; overuse injuries resulting from reliance upon the intact limb
<b>DoD</b>	The US Department of Defence
<b>DVLA</b>	Driver & Vehicle Licensing Agency
<b>EMDR</b>	Eye movement desensitization and reprocessing
<b>GP</b>	General Practitioner
<b>HRQoL</b>	Health related quality of life
<b>JRRD</b>	Journal of Rehabilitation Research & Development
<b>MOD</b>	UK Ministry of Defence
<b>N</b>	Number
<b>NHS</b>	UK National Health Service
<b>OA</b>	Osteoarthritis
<b>OEF</b>	Operation Enduring Freedom (Afghanistan)
<b>OIF</b>	Operating Iraqi Freedom (Iraq)
<b>ORD</b>	Organization of Disabled Revolutionaries
<b>OT</b>	Occupational Therapist
<b>PTSD</b>	Post-traumatic stress disorder
<b>QoL</b>	Quality of life
<b>SSAFA</b>	Soldiers, Sailors, Airmen and Families Association
<b>SD</b>	Standard deviation
<b>USD</b>	US Dollars
<b>VA</b>	The US Department of Veteran Affairs
<b>WIS</b>	Wounded injured and sick

## Executive Summary

The impact of losing a limb extends well beyond initial recovery and rehabilitation, with long-term consequences and challenges requiring healthcare commitments across the life-course. A renewed interest in the long-term impact of limb-loss has been sparked by the social and political imperative to care for military veterans injured during the Iraq and Afghanistan conflicts. The starting point for this study was a sense that there are, perhaps, important lessons to be learned from older generations of veteran-amputees, and how their lives have played-out following the loss of a limb.

A review of existing literature emphasised that, whilst limbless veterans are generally able to achieve a good quality of life, limb-loss is still a progressive and degenerative injury, involving enduring experiences of pain, comorbidities, and sometimes mental health problems, which undermine veterans' health, well-being and quality of life. Veterans' approaches to coping and the way in which society views them, impacts upon their long-term adjustment to limb-loss. The literature highlights the substantial cost of caring for limbless veterans throughout the life-course and the financial commitments required to safeguard their long-term health and care needs.

Very few UK studies have considered the impact of limb-loss for military veterans across the life-course: fewer still have employed approaches where limbless veterans were given the opportunity to report how it was for them. Consequently, 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.

### Methodology

A multiple method convergent design was adopted for the study, encompassing Narrative Inquiry and 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.

*Narrative Inquiry:* This study adopts a dialogical narrative approach to explore the types of stories told by limbless veterans and how well served they are by these stories as they endeavour to age well and maintain their independence.

*Applied Policy Research:* Applied policy research concentrates on finding solutions to immediate practical problems. This approach played a key role in providing insight, explanations and theories of social behaviour for future policy recommendations.

*Convergence:* Finally, findings of narrative inquiry and applied policy research were integrated to provide greater understanding and insight into maintaining independence in older limbless veterans.

Peer-researchers purposefully sampled 32 participants to take part in this study (30 males, 2 females). Participants' ages ranged from 43 to 95 years (mean = 69.4, SD = 14.56) with representation from tri-services in the UK Armed Forces. The mechanism of participants' limb-loss (in-service attributable/non-attributable and post-service attributable/non-attributable) were varied in addition to the nature of limb-loss (single/bilateral, upper/lower limb). Some participants were also joined by family members/significant others.

Participants were involved in semi-structured life history interviews, conducted face-to-face at a location of the participants' choosing (usually their own home). With participants' permission, interviews were audio-recorded. Up to three interviews per participant were carried out, each lasting between 1.5-3 hours, in order to allow sufficient time for participants to share their full life story. One participant was interviewed via email on request. Full ethical approval was received from Northumbria University Ethics Committee.

All interviews were transcribed and then analysed using NVivo 11. Following the design of the study, narrative analysis (for narrative inquiry) and framework analysis (for applied policy research) were carried out before the final convergence analysis. The primary aim of analytical convergence was to identify the ways in which common themes contributed towards the construction of each narrative type.

## Results

*Narrative Analysis:* The analysis identified four different 'narrative types' which informed the stories of the participants. Narrative types are the broad 'story structures' – including themes and plot – which the participants used to put together their individual stories of ageing and limb-loss. Each narrative type may be thought of as the core thread common to the stories told by the participants. The four narrative types are 'struggling against decline', 'minimisation', 'victimhood', and 'life-as-normal'.

### Struggling Against Decline

Maintaining independence in old age was, generally speaking, a struggle for participants. The majority of the stories we heard centred on a struggle to maintain independence and to resist 'decline' in old age. Decline was expressed in terms of physical deterioration,

inactivity, and becoming increasingly dependent upon others. Unsurprisingly, participants were highly motivated to avoid slipping into such a state of decline. In other words, their stories emphasised their struggles to resist decline.

#### Minimisation

Some participants placed little emphasis on limb-loss in their stories. These participants spent more time in 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. In other words, limb-loss and its impact were 'minimised'.

#### Victimhood

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 compounded the anger and bitterness felt by the participant.

#### Life-as-Normal

Similar to 'minimisation', 'life-as-normal' narratives place a strong emphasis on being 'normal'. This narrative differs from minimisation, however, to the extent that ongoing grief and anguish related to limb-loss remain 'bottled up' inside the veteran. Limb-loss and its after-effects are not necessarily denied in the 'life-as-normal' narrative, but they remain somewhat hidden.

Studying participants' narrative biographies helps to place their struggles to resist decline and to maintain independence into context. It shows that the way in which participants respond to limb-loss has a lot to do with their experience of military life and allows us to identify factors which promote or inhibit independence in old age. The analysis reveals that maintaining independence in old age is a combination of physical, psychological, social, and narrative functions.

*Framework Analysis:* The analysis identified three superordinate themes within the participants' life narratives: 'Barriers to Transition', 'Disparity of Care', and 'The Enduring Challenge of Limb-loss'. These superordinate themes identify the significant challenges veterans face across the life-course from the point of limb-loss.

#### Barriers to Transition

The 'barriers to transition' theme highlighted the dissonance experienced by the participants, and the impact that limb-loss has had, not only at the point of loss, but the ongoing challenges to transition long after service. The data suggests that many

participants struggle with the loss of their military identity well into old age, and rarely view themselves as having a disability. This, however, would appear to change when aging impacts upon their mobility, which subsequently appears to lead to ever increasing social isolation. Employment and adequate compensation were crucial factors in helping veterans to maintain their independence post limb-loss, not only in the early years following loss, but also into old age. The greater the resource available would appear to support greater mobility and independence, even in much later life.

### Disparity of Care

The 'disparity of care' theme highlighted the perceived injustices in both accessing and entitlements to care. What was most significant was that geographical location appeared to determine both the availability, and standard of care received. The participants spoke of a postcode lottery and a two-tier system which discriminated between those who a) lost limbs during active service and b) lost limbs in service due to accidents, and those that lost limbs post service.

### The Enduring Challenge of Limb-Loss

The 'enduring challenge of limb-loss' theme, identified the everyday complications of ageing with of limb-loss. Although it would be very difficult to identify issues that were unique to the veteran's population in relation to aging with limb-loss, what was significant was the military mind-set, which remained very evident within the participant's accounts. Strong military identity remained, and this clearly shaped their personal opinions and preferences with regards the type of support they preferred to receive, most notable, support which had a strong connection to the military and veteran's communities.

*Convergence Analysis:* In order to gain a deeper understanding of the ways in which each prominent narrative style was constructed, convergence between narrative analysis and framework analysis was conducted.

### Struggling Against Decline

Analysis of the key themes which contribute towards the construction of the 'struggle against decline' narrative type, provides insight into the challenges faced by older limbless veterans throughout the course of their lives. As such, many of the findings, provide an understanding of the potential challenges faced by younger generations of limbless veterans as they age.

### Victimhood and Life-as-Normal

In many ways, the 'victimhood' narrative type and the 'life-as-normal' narrative type are highly opposing constructs. However, both narratives are characterised by unabating



psychological distress following limb-loss. Exploration of the key themes which contribute towards the construction of the 'victimhood' narrative type and 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.

### Minimisation

While 'minimisation' narratives may be less newsworthy than the 'dramatic overcoming' narrative which is popularised within the current social milieu, the minimisation narrative type powerfully demonstrates that limb-loss is not necessarily associated with significant long-term impacts upon health, wellbeing and quality of life. Exploration of the key themes which contribute towards the construction of the 'minimisation' narrative type provides insights into factors which may 'minimisation' the negative outcomes associated with limb-loss amongst veterans.

As a result of the convergence analysis, summary tables were created of the key findings and actionable recommendations related to physical health, social wellbeing, psychological wellbeing, physical isolation, employment and education and financial and social support (see page 106 ).

### **Discussion**

Following on from the convergence analysis, subject matter experts within the research team identified underlying points for discussion. These discussion points are integral to understanding the health and social wellbeing of older limbless veterans. Points for deeper discussion include 'limb-loss and pain', 'education and post limb-loss employment', 'limb-loss and social isolation' and 'limb-loss, independence and activities of daily living'.

*Limb-Loss and Pain:* The maintenance of independence was considered to be a fundamental aspect of successful ageing throughout the life-course. 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 upon limbless veterans' and their families' wellbeing, attention needs to be given to effective management of pain throughout the life-course for those affected by stump and phantom pain. Access to healthcare is a pre-requisite to obtaining quality of care and the issue of social unmet needs as a result of lack of mobility, needs further exploration. These issues have wider policy implications in relation to the integration of health and social care.

*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 to be 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. 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 (ADLs):* 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 ADL independence. 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 in order to maintain ADL independence. 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, due to the long-term use of poor quality prosthetic devices and limitations in early rehabilitation and prosthetic care. Age-related physical decline and medical comorbidities may further impair older veterans' capacity to achieve ADL independence as they progress throughout later-life. The capacity to engage in ADLs independently was a highly influential factor in the development veteran's personal life-stories, which determined their perceived wellbeing and quality of life and their confidence in their ability to successfully adapt to the challenges associated with limb-loss. As such, promoting ADL independence should be a key priority for organisations wishing to support veterans affected by limb-loss.



## Introduction and Existing Evidence



## Background

Limb-loss, as a consequence of military service has been thrust into the public consciousness and onto political agendas as a result of recent conflicts in Iraq and Afghanistan<sup>1</sup>. Between April 2006 and December 2011, (at least) 20 British military personnel suffered traumatic limb amputations in Iraq, and 237 in Afghanistan. UK traumatic limb amputation casualties in Afghanistan significantly increased from 2009 onwards with 55 sustained in 2009, 79 in 2010, and 53 in 2011. The number of multiple amputee casualties were reported to be 32 in 2009 - 2010 and 36 in 2010 – 2011.<sup>2</sup>The signature injuries produced by these conflicts have created a legacy that veterans and the societies they are part of, will need to deal with for many years to come<sup>3,4</sup>.

The lifelong impact of traumatic limb-loss is also particularly relevant for older (e.g. World War Two, Korean War, and Falklands War) veterans, whose health issues may be exacerbated by age-related changes and comorbidities, including the long-term psychological consequences of war<sup>3,5</sup>. Prior to the disseminating the primary research conducted by the research team, this report presents a critical review of the literature on ageing and limb-loss in military. The purpose of this was to a) comment on the current state of knowledge, b) explore avenues for developing research in this area, and c) highlight health and social care implications for older limbless veterans.

## Literature Review Methods

### Inclusion and Exclusion Criteria

**Participants:** the inclusion criteria for studies covered within this review included a sample population of older limbless military veterans. Excluded were studies of younger veterans from conflicts such as Iraq and Afghanistan. There were no restrictions on the type or cause of limb-loss, other than meeting the definition of 'major' limb-loss<sup>6</sup> and that the injury was sustained during the service person's military career.

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<sup>1</sup> Caddick, N., and Smith, B. (2014). The impact of sport and physical activity on the well-being of combat veterans: A systematic review. *Psychology of Sport and Exercise*, 15(1), 9-18.

<sup>2</sup> Wallace, D. (2012) Trends in traumatic limb amputation in Allied Forces in Iraq and Afghanistan, *Journal of Military and Veterans' Health*, 20 (2), 31-35.

<sup>3</sup> Geiling, J., Rosen, J., and Edwards, R. (2012). Medical Costs of War in 2035: Long-term care challenges for veterans of Iraq and Afghanistan. *Military Medicine*, 177(11), 1235-1244.

<sup>4</sup> Edwards, D., Phillip, R., Bosanquet, N., Bull, A., and Clasper, J. (2015). What is the magnitude and long-term economic cost of care of the British military Afghanistan amputee cohort? *Clinical Orthopaedics and Related Research*, 473(9), 2848-2855.

<sup>5</sup> Hunt, N., and Robbins, I. (2001). The long-term consequences of war: The experience of World War II. *Ageing and Mental Health*, 5(2), 183-190.

<sup>6</sup> Major limb-loss refers to any limb-loss which is above the level of the ankle or the wrist.

**Comparators:** where available, studies were included which drew explicit comparisons between ‘older’ (e.g., Korea/Vietnam-era) and ‘younger’ (e.g., Iraq/Afghanistan-era) veterans.

**Outcomes:** studies with outcome measures of the long-term impact of limb-loss, healthcare needs, and age-related complications or comorbidities associated with limb-loss were included within this review. Excluded were studies which focused solely on short-term rehabilitation.

**Study Design:** empirically-based studies of any study design were included within this review. Excluded were commentaries, reviews (*etc.*).

## Search Strategy

Guidelines for systematically searching and selecting papers for review were followed<sup>7</sup>. Key databases were searched, including: ASSIA, CINAHL, Cochrane Library, Medline, Web of Science, PsycArticles/PsychInfo, ProQuest Psychology and ProQuest Sociology Journals, and SPORTDiscus. The search terms included were as follows:

- "aging" OR "ageing" OR "older" OR "elder\*" OR "later life"
- "veteran" OR "veterans" OR "ex-military" OR "ex-service" OR "ex-force\*" OR "army"
- "limbloss" OR "limb loss" OR "limb-loss" OR "limbless" OR "amput\*" OR "prosth\*" OR "artificial limb"

Given the large range of potential outcomes of interest, outcomes were not included in the search strategy. Rather, the above three search strings were used to capture *all* potentially relevant papers on older limbless veterans, with key outcomes highlighted during the initial phase of searching. Citation scanning was conducted for all papers included at the final stage. A special issue in the *Journal of Rehabilitation Research and Development (JRRD)* – in which one of the searched-for articles was published – was searched, and the authors also searched their personal collections of articles.

## Selection of Studies, Data Extraction, Quality Assessment and Synthesis of Results

For screening, article titles and abstracts were scanned for relevance by one reviewer and checked against the inclusion criteria by five members of the review team. Any discrepancies were resolved by discussion. All relevant articles were subsequently read by three reviewers and a standardized data extraction form was used to record key findings from each study. This form was also used to capture details on the type of study, location, and sample characteristics

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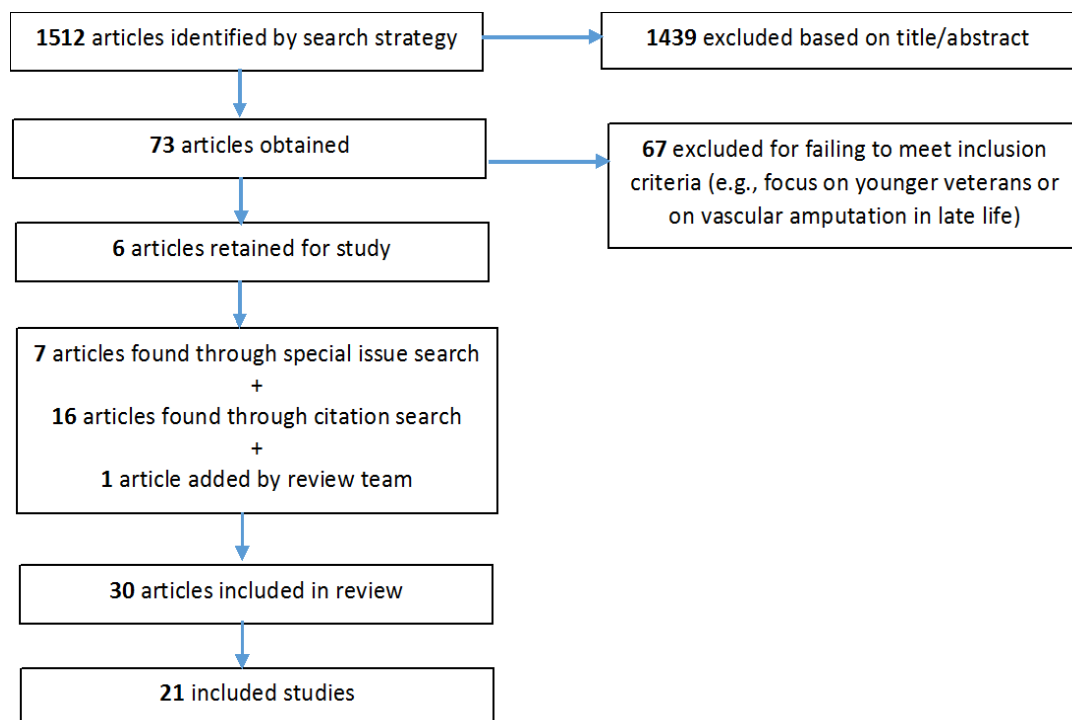
<sup>7</sup> Centre for Reviews and Dissemination (2009). *Systematic reviews: CRD's guidance for undertaking reviews in healthcare*. York: University of York.

including age, gender, type/cause of amputation, and (where relevant) conflict in which limb trauma originated.

## Literature Review Results

The search process yielded an initial 1,512 hits, which after screening resulted in a total of six articles relevant for inclusion (see Figure 1). Citation scanning resulted in an additional 16 articles. Given that many papers that were deemed relevant reported the age and ‘time since amputation’ of their samples, but did not refer to ‘ageing’, ‘older’, or ‘elderly’ veterans, a larger number of papers were identified through citation scanning than through the initial keyword search. Hand searching a special issue of *JRRD* led to the discovery of an additional seven articles.

Figure 1. Flow diagram of identification of eligible studies.



A total of 21 studies were identified, with one study – the Veterans Administration’s (2010) *Survey for Prosthetic Use*<sup>8</sup> – reported in ten separate articles (of which eight were published in a *JRRD* special issue). Nine out of the 21 studies were conducted in the U.S., with most of these (5/9) taking place within the VA healthcare system. Four studies were conducted in Iran,

<sup>8</sup> Reiber, G., McFarland, L., Hubbard, S., Maynard, C., Blough, D., Gambel, J., and Smith, D. (2010). Service members and veterans with major traumatic limb loss from Vietnam war and OIF/OEF conflicts: Survey methods, participants, and summary findings. *Journal of Rehabilitation Research and Development*, 47(4), 299-316.

one in Nicaragua and seven in the UK. Most studies (15/21) were surveys of various long-term physical and psychological outcomes, three used qualitative or mixed methods<sup>9,10,11</sup>, and three<sup>4,12,13</sup> used a form of economic modelling to estimate the long-term costs of caring for limbless veterans. The characteristics of all the studies are summarized in [Tables 1a](#) and [1b](#).

The literature was grouped into five topic areas covering: 'long-term health outcomes, prosthetics and quality of life', 'psycho-social adaptation and coping in older veterans', 'disability and identity', and 'estimating the long-term cost of prosthetic provision for limbless veterans'. Each will be discussed with a final discussion considering the quality of the literature on ageing and limb-loss in veterans.



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<sup>9</sup> Foote, C., Kinnon, J., Robbins, C., Pessagno, R., and Portner, M. (2015). Long-term health and quality of life experiences of Vietnam veterans with combat-related limb loss. *Quality of Life Research*, 24(12), 2853-2861.

<sup>10</sup> Machin, P., and Williams, A. (1998). Stiff upper lip: Coping strategies of World War II veterans with phantom limb pain. *The Clinical Journal of Pain*, 14(4), 290-294.

<sup>11</sup> Meyers, S. (2014). The social model of disability under the shadow of the revolution: Ex-combatants negotiating identity in Nicaragua. *Qualitative Sociology*, 37(4), 403-424.

<sup>12</sup> Blough, D., Hubbard, S., McFarland, L., Smith, D., Gambel, J., and Reiber, G. (2010). Prosthetic cost projections for service members with major limb loss from Vietnam and OIF/OEF. *Journal of Rehabilitation Research and Development*, 47(4), 387-402.

<sup>13</sup> Stewart, C., and Jain, A. (1999). An epidemiological study of war amputees and the cost to society. *Prosthetics and Orthotics International*, 23(2), 102-106.



**Table 1a. Summary of papers from the VA (2010) survey of prosthetic use study.**

Author(s)	Focus of article	Participants: age ( $M_{(age)}$ ), sex, aetiology of limb-loss and time since limb-loss ( $M_{(time)}$ )	Key findings
<b>1(i) Berke et al.</b>	Satisfaction with prosthetic care (sub-sample from VA cohort)	1. $N = 230$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs) 2. $N = 251$ OIF/OEF veterans with combat-related traumatic limb-loss (97% male, $M_{(age)} = 29$ yrs, $M_{(time)} = 3$ yrs)	Vietnam veterans reported lower care satisfaction and pain-free prosthetic use compared with OIF/OEF veterans. Prosthetic-fit issues common across both groups.
<b>1(ii) Blough et al.</b>	Economic modelling and long-term projection of prosthetic device costs.	1. $N = 298$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs). 2. $N = 283$ OIF/OEF veterans with combat-related traumatic limb-loss (97% male, $M_{(age)} = 29$ yrs, $M_{(time)} = 3$ yrs)	Average lifetime costs of prosthetic provision estimated up to 6.2-fold higher for OIF/OEF veterans compared to their older Vietnam counterparts.
<b>1(iii) Dougherty et al.</b>	Health outcomes and prosthetic use in multiple limb amputees (sub-sample)	1. $N = 73$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs) 2. $N = 61$ OIF/OEF veterans with combat-related traumatic limb-loss (95% male, $M_{(age)} = 28$ yrs, $M_{(time)} = 3$ yrs)	Significantly more age-related comorbidities in Vietnam compared to OIF/OEF group.
<b>1(iv) Epstein et al</b>	Factors associated with QoL.	1. $N = 298$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs). 2. $N = 283$ OIF/OEF veterans with combat-related traumatic limb-loss (97% male, $M_{(age)} = 29$ yrs, $M_{(time)} = 3$ yrs)	Vietnam cohort reported worse overall QoL compared with OIF/OEF cohort. Higher number of comorbidities associated with worse QoL in both groups.
<b>1(v) Gailey et al</b>	Prosthetic use and functional outcomes in unilateral lower-limb amputees (sub-sample)	1. $N = 178$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs). 2. $N = 172$ OIF/OEF veterans with combat-related traumatic limb-loss (98% male, $M_{(age)} = 29$ yrs, $M_{(time)} = 3$ yrs)	Compared with OIF/OEF veterans, Vietnam veterans had lower self-reported health, functional ability and QoL, used fewer prosthetics, and had a higher prevalence of arthritis and CTD.
<b>1(vi) Laferrier et al</b>	Factors influencing mobility and use of assistive technology (sub-sample)	1. $N = 245$ Vietnam veterans with combat-related traumatic lower limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs). 2. $N = 226$ OIF/OEF veterans with combat-related traumatic lower limb-loss (98% male, $M_{(age)} = 29$ yrs, $M_{(time)} = 3$ yrs)	Sole or supplementary use of wheelchair for mobility common in both groups, with more Vietnam veterans abandoning use of all prosthetics.
<b>1(vii) McFarland et al</b>	Satisfaction and prosthetic use in unilateral upper-limb amputees (sub-sample)	1. $N = 47$ Vietnam veterans with combat-related traumatic lower limb-loss (100% male, $M_{(age)} = 60$ yrs, $M_{(time)} = 39$ yrs). 2. $N = 50$ OIF/OEF veterans with combat-related traumatic lower limb-loss (98% male, $M_{(age)} = 30$ yrs, $M_{(time)} = 3$ yrs)	Higher prevalence of arthritis and CTD among Vietnam veterans compared with OIF/OEF veterans. Presence of comorbidities associated with reduced upper-limb activity in Vietnam veterans.

Key: AK = above-knee; BK = below-knee; CTD = Cumulative trauma disorder; OIF = Operating Iraqi Freedom (Iraq); OEF = Operation Enduring Freedom (Afghanistan); QoL = Quality of life.

Table 1a. Continued.

Author(s)	Focus of article	Participants: age ( $M_{(age)}$ ), sex, aetiology of limb-loss and time since limb-loss ( $M_{(time)}$ )	Key findings
1(ix) Dougherty <i>et al</i> (2012)	Health outcomes, QoL and prosthetic use in bilateral AK amputees (sub-sample)	1. $N = 23$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 60.4$ yrs, $M_{(time)} = 39$ yrs). 2. $N = 10$ OIF/OEF veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 27.2$ yrs, $M_{(time)} = 3$ yrs)	Self-reported health lower in Vietnam veterans compared to OIF/OEF veterans. QoL reportedly comparable between groups. Prosthetic use problematic, particularly in older veterans.
1(x) Dougherty <i>et al</i> (2014)	Health outcomes, QoL and prosthetic use in bilateral lower limb amputees (sub-sample; one AK and one BK).	1. $N = 13$ Vietnam veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 61$ yrs, $M_{(time)} = 39$ yrs) 2. $N = 11$ OIF/OEF veterans with combat-related traumatic limb-loss (95% male, $M_{(age)} = 28$ yrs, $M_{(time)} = 3$ yrs)	Vietnam veterans reported lower functioning and use of prosthetics. Both groups reported similar QoL and a moderate-to-strong impact of dual AK/BK amputation on their lives.

Key: AK = above-knee; BK = below-knee; CTD = Cumulative trauma disorder; OIF = Operating Iraqi Freedom (Iraq); OEF = Operation Enduring Freedom (Afghanistan); QoL = Quality of life.

**Table 1b.** Summary of remaining studies included in the systematic review.

Author, year and location of study	Design and focus of study	Participants: age ( $M_{(age)}$ ), sex, aetiology of limb-loss and time since limb-loss ( $M_{(time)}$ )	Key findings
<b>2 Desmond and MacLachlan (2006) UK</b>	Cross-sectional. Coping strategies and long-term psycho-social adaptation to lower limb-loss.	$N = 796$ members of Blesma with lower limb-loss (96% male, $M_{(age)} = 74$ yrs, $M_{(time)} = 42.6$ yrs). 82.8% of amputations reported as traumatic aetiology.	Problem solving, seeking social support, and increasing time since amputation were positively associated with positive adjustment to amputation.
<b>3 Desmond (2007) UK</b>	Cross-sectional. Coping strategies and long-term psycho-social adaptation to upper limb-loss.	$N = 138$ members of Blesma with combat-related traumatic upper limb-loss (100% male, $M_{(age)} = 75$ yrs, $M_{(time)} = 50$ yrs).	Avoidant coping strategies were associated with psychological distress and poorer adjustment.
<b>4 Dougherty (1999) USA</b>	Survey. Long-term outcomes for bilateral AK amputees from Vietnam War.	1. $N = 23$ Vietnam veterans with combat-related traumatic bilateral AK amputations (100% male, $M_{(age)} = 48$ yrs, $M_{(time)} = 28$ yrs). 2. $N = 145$ age and sex-matched controls	Comparatively decreased physical functioning noted among Vietnam amputees. The majority had been employed since injury, yet few were current prosthetic users.
<b>5 Dougherty (2001) USA</b>	Survey. Long-term outcomes for unilateral BK amputees from Vietnam War.	1. $N = 28$ Vietnam veterans with combat-related unilateral BK amputations 2. $N = 44$ Vietnam veterans with combat-related unilateral BK amputation plus $\geq 1$ other major injury (1 and 2; 100% male, $M_{(age)} = 48$ yrs, $M_{(time)} = 28$ yrs) 3. $N = 141$ age and sex-matched controls	Veterans with additional (secondary) injuries exhibited worse health outcomes and made greater use of psychological support services.
<b>6 Dougherty (2003) USA</b>	Survey. Long-term outcomes for unilateral AK amputees from Vietnam War.	1. $N = 18$ Vietnam veterans with combat-related unilateral AK amputations 2. $N = 28$ Vietnam veterans with combat-related unilateral AK amputation plus $\geq 1$ other major injury (1 and 2; 100% male, $M_{(age)} = 48$ yrs, $M_{(time)} = 28$ yrs) 3. $N = 141$ age and sex-matched controls	Both veteran groups had worse health outcomes than controls. Majority of veterans were currently employed and used prosthetics for on average 13.5h/day.
<b>7 Ebrahimzadeh and Fattahi (2009) Iran</b>	Survey. Long-term clinical outcomes in unilateral AK amputees.	$N = 31$ veterans of Iran-Iraq War with combat-related unilateral AK amputation (100% male, $M_{(age)} = 43$ yrs, $M_{(time)} = 17$ yrs)	High prevalence of pain and psychological symptoms including PTSD noted.
<b>8 Ebrahimzadeh and Hariri (2009) Iran</b>	Survey. Long-term clinical outcomes in unilateral BK amputees.	$N = 96$ veterans of Iran-Iraq War with combat-related unilateral BK amputation (100% male, $M_{(age)} = 43$ yrs, $M_{(time)} = 17$ yrs)	High prevalence of pain and psychological symptoms including PTSD noted.

Key: <sup>1</sup>Study took place at USA Veterans Administration (VA). AK = above-knee; BK = below-knee; Blesma = Blesma, The Limbless Veterans Charity; CTD = Cumulative trauma disorder; OA = Osteoarthritis; OIF = Operating Iraqi Freedom (Iraq); OEF = Operation Enduring Freedom (Afghanistan); PTSD = Post-traumatic stress disorder; QoL = Quality of life (Health-related = HRQoL)

Table 1b. Continued.

Author, year and location of study	Design and focus of study	Participants: age ( $M_{(age)}$ ), sex, aetiology of limb-loss and time since limb-loss ( $M_{(time)}$ )	Key findings
<b>9 Ebrahimzadeh et al. (2013) Iran</b>	Survey. Long-term clinical outcomes in veterans with hip disarticulation.	$N = 76$ veterans of Iran-Iraq war with combat-related hip disarticulation (96.1% male, $M_{(age)} = 44$ yrs, $M_{(time)} = 26.6$ yrs)	High prevalence of back pain, phantom pains and stump spasms noted. Lower QoL scores for pain and physical function compared to population norms. Sports participation associated with higher QoL.
<b>10 Edwards et al (2015) UK</b>	Economic modelling. Long-term cost of care for British veterans of Afghanistan.	$N = 265$ veterans of war in Afghanistan with combat-related traumatic limb-loss. Ages and time-since-injury not reported.	Long-term (40-year) cost of prosthetic provision for lower-limb amputee cohort estimated at £288 million (USD 444 million) in today's currency.
<b>11 Foote et al (2015) USA</b>	Survey and qualitative interviews. Long-term health and QoL among Vietnam veterans.	$N = 257$ Vietnam veterans with combat-related traumatic limb-loss. Age, sex, and time since amputation not reported. (Sub-sample of $n = 20$ for qualitative interviews)	High prevalence of pain and co-morbid arthritis. Interviews revealed that – even 40 years post-injury – mental health problems and ageing/pain-related comorbidities had a strong negative influence on QoL.
<b>12 Hoaglund et al (1983) USA<sup>1</sup></b>	Survey. Prosthetic problems and needs in veterans with lower-limb amputations.	1. $N = 133$ veterans with service-connected traumatic limb-loss (100% male, $M_{(age)} = 47$ yrs, $M_{(time)} = 21$ yrs). 2. $N = 42$ veterans with dysvascular disease-related limb-loss. (100% male, $M_{(age)} = 60$ yrs, $M_{(time)} = 2$ yrs).	High prevalence of 'moderate to severe intensity' residual limb pain, along with high prevalence of back pain, phantom pain, and prosthetic problems.
<b>13 Kulkarni et al (1998) UK</b>	Medical examination. Prevalence of osteoarthritis and osteopenia.	1. $N = 44$ World War Two veterans with combat-related unilateral lower limb-loss (100% male, $M_{(age)} = 73$ yrs, $M_{(time)} = 47$ yrs).	High prevalence of hip OA on both amputated and non-amputated sides. AK amputees had significantly more OA (and of greater severity) than BK amputees.
<b>14 Machin and Williams (1998) UK</b>	Survey and semi-structured interviews. Phantom pain and coping strategies.	1. $N = 26$ World War Two veterans and members of Blesma (100% male, $M_{(age)} = 76.8$ yrs, $M_{(time)} = \text{not reported}$ ). All injuries described as traumatic and either combat or service-related.	A dominant 'stiff upper lip' approach to coping with phantom pain was identified, with little recourse to social support or medical assistance.

Key: <sup>1</sup>Study took place at USA Veterans Administration (VA). AK = above-knee; BK = below-knee; Blesma = Blesma, The Limbless Veterans Charity; CTD = Cumulative trauma disorder; OA = Osteoarthritis; OIF = Operating Iraqi Freedom (Iraq); OEF = Operation Enduring Freedom (Afghanistan); PTSD = Post-traumatic stress disorder; QoL = Quality of life (Health-related = HRQoL).

Table 1b. Continued.

Author, year and location of study	Design and focus of study	Participants: age ( $M_{(age)}$ ), sex, aetiology of limb-loss and time since limb-loss ( $M_{(time)}$ )	Key findings
<b>15 Meyers (2014) Nicaragua</b>	Qualitative ethnographic. Disability and identity among veterans with limb-loss.	Participant numbers unstated. Participants described as male middle-aged veterans of Nicaraguan Civil War of 1980s with either combat-related amputations or loss of limb function.	Depending on social and political context, limbless veterans may identify as 'disabled' or as 'war wounded', and may distance themselves from, or alternatively align themselves with, 'other' disabled groups.
<b>16 Norvell et al (2005) USA<sup>1</sup></b>	Survey and retrospective cohort design. Prevalence of knee pain and osteoarthritis.	1. $N = 62$ veterans with traumatic lower limb-loss (100% male, $M_{(age)} = 63$ yrs, $M_{(time)} = 31$ yrs). 2. $N = 94$ veterans without amputation (100% male, $M_{(age)} = 65$ yrs).	Higher prevalence of knee pain and knee OA in amputees compared with non-amputees. Prevalence of knee pain also higher in AK amputees than BK amputees, linked to gait abnormalities.
<b>17 Sherman and Sherman (1983) USA<sup>1</sup></b>	Survey. Prevalence of phantom pain.	$N = 764$ veterans with combat or service-related amputations (100% male, $M_{(age)} = 51$ yrs, $M_{(time)} = 27$ yrs).	Persistence of phantom pain severe enough to cause at least occasional debilitation is the norm rather than exception for combat amputees. Veterans reported not being listened to when seeking treatment for phantom pains, and self-medicating with alcohol.
<b>18 Sherman et al (1984) USA<sup>1</sup></b>	Survey. Prevalence of phantom pain.	$N = 2694$ veterans with combat or service-related amputations (100% male, $M_{(age)} = 53$ yrs, $M_{(time)} = 28$ yrs).	Very high prevalence of moderately intense phantom pain. Many have given up on treatments and have had poor experiences with clinicians.
<b>19 Stewart and Jain (1999) UK</b>	Epidemiological survey. Analysis of prosthetic costs over 50 year period.	$N = 98$ veterans with combat-related traumatic limb-loss (100% male, $M_{(age)} = 74$ yrs, $M_{(time)} = 48$ yrs)	50-year costs of prosthetic limb provision estimated at £69 million.
<b>20 Taghipour et al (2009) Iran</b>	Survey. Long-term QoL outcomes in lower-limb amputees	$N = 141$ veterans of Iran-Iraq war with combat-related traumatic lower limb-loss (100% male, $M_{(age)} = 45.2$ yrs, $M_{(time)} = 21.6$ yrs)	Poorer mental and physical HRQoL among amputees compared to population norms. Low back pain most important contributor to poorer HRQoL.
<b>21 Wartin et al (1997) UK</b>	Survey. Prevalence of phantom and stump pain.	$N = 590$ members of Blesma with traumatic limb-loss (100% male, $M_{(age)} = 73$ yrs, $M_{(time)} = 50$ yrs)	High prevalence of phantom limb pain and stump pain. Intensity of phantom sensations a significant predictor for time-course duration of phantom pain.

Key: <sup>1</sup>Study took place at USA Veterans Administration (VA). AK = above-knee; BK = below-knee; Blesma = Blesma, The Limbless Veterans Charity; CTD = Cumulative trauma disorder; OA = Osteoarthritis; OIF = Operating Iraqi Freedom (Iraq); OEF = Operation Enduring Freedom (Afghanistan); PTSD = Post-traumatic stress disorder; QoL = Quality of life (Health-related = HRQoL).

### *Long-Term Health Outcomes, Prosthetics Use, and Quality of Life*

The largest collection of studies identified for review (16/21) focused broadly on assessing the long-term physical health outcomes (including pain and comorbidities) associated with limb-loss, levels of prosthetic use by older limbless veterans, and the impact of health outcomes and prosthetic use on quality of life. The largest of these studies was the VA's (2010) *Survey for Prosthetic Use*<sup>8</sup>. This was a national survey comparing health outcomes, quality of life, and prosthetics usage among 298 Vietnam veterans with combat-related traumatic limb-loss (mean age and time since amputation = 61 years and 39 years) and 283 of their younger Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF) counterparts (mean age and time since amputation = 29 years and 3 years). It was noted that using prosthetic devices can improve functional ability, enhance mobility and safety, facilitate higher levels of activity, and can also reduce the risk of secondary comorbidities and problems resulting from overuse of intact limbs among limbless veterans<sup>8,14</sup>. The survey aimed to document differences in health status and device use between older and younger veterans, and to forecast changes in prosthetic usage over time. It used a combination of validated and bespoke measurement tools, as well as analysis of medical records data.

Overall, findings from the survey revealed that health status (as measured on the SF-36 health questionnaire) was reported as 'good', 'very good', or 'excellent' among 70.7% of Vietnam veterans and 85.5% of OIF/OEF veterans<sup>8</sup>. Compared with OIF/OEF veterans, fewer of the older Vietnam veterans (90.5% vs. 78.2%, respectively) were current prosthetic users<sup>8</sup>. Findings on prosthetic use were further described with regard to the different types of amputation. Among lower-limb amputees, sole use of a wheelchair for mobility was more common in the Vietnam cohort compared with the OIF/OEF cohort, at 18% and 4%, respectively<sup>15</sup>. Seventeen percent of the Vietnam lower-limb amputees reported abandoning use of all prosthetic devices, rising to 33% among bilateral lower-limb amputees, and 30% among upper-limb amputees<sup>15,16</sup>. Vietnam veterans reported more problems with their

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<sup>14</sup> Gailey, R., McFarland, L., Cooper, R., Czerniecki, J., Gambel, J., Hubbard, S., Maynard, C., Smith, D., Raya, M., and Reiber, G. (2010). Unilateral lower-limb loss: Prosthetic device use and functional outcomes in servicemembers from Vietnam war and OIF/OEF conflicts. *Journal of Rehabilitation Research and Development*, 47(4), 317-332.

<sup>15</sup> Laferrier, J., McFarland, L., Boninger, M., Cooper, R., and Reiber, G. (2010). Wheeled mobility: Factors influencing mobility and assistive technology in veterans and servicemembers with major traumatic limb loss from Vietnam war and OIF/OEF conflicts. *Journal of Rehabilitation Research and Development*, 47(4), 349-360.

<sup>16</sup> McFarland, L., Hubbard-Winkler, S., Heinemann, A., and Jones, M. (2010). Unilateral upper-limb loss: Satisfaction and prosthetic-device use in veterans and servicemembers from Vietnam and OIF/OEF conflicts. *Journal of Rehabilitation Research and Development*, 47(4), 299-316.

prosthetics and more pain when using them compared to OIF/OEF veterans<sup>17</sup>. Other studies included in this review also revealed that prosthetic usage varied by type of amputation. For instance, a series of long-term follow-up studies of Vietnam veterans conducted by Dougherty<sup>18,19,20</sup> revealed that 87.5% of unilateral above-knee amputees were current prosthetic users (average of 13.5 h/day) compared with just 22% of bilateral above-knee amputees (average of 7.7 h/day), thereby highlighting the significant additional impact of multiple compared to single limb-loss.

A high prevalence of comorbidities and pain were identified across the studies in this review. Most studies which assessed arthritis revealed prevalence rates of between 54% and 71% among older limbless veterans<sup>8,9,14,21,22</sup>, with one study of unilateral lower-limb amputees reporting a lower prevalence of 16.1%<sup>23</sup>. This compared with around 15% of OIF/OEF veterans reporting arthritis<sup>24</sup>. Three papers<sup>14,17,24</sup>, reported a higher incidence of cumulative trauma disorder (CTD; overuse injuries resulting from reliance upon the intact limb) among Vietnam veterans, which compromised their ability to use prosthetics and reduced their prosthetic satisfaction levels relative to younger veterans. Coincident with the ageing process and the occurrence of comorbidities, some Vietnam veterans' prosthetics therefore became too heavy, uncomfortable and painful to use, resulting in greater levels of device abandonment.

Pain was reported to be so prevalent among limbless veterans that it was often under-evaluated<sup>17</sup>. The prevalence rates of numerous types of pain are described below in [Table 2](#). There was considerable variation in prevalence rates across the studies. It was suggested by

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<sup>17</sup> Berke, G., Ferguson, J., Milani, J., Hattings, J., McDowell, M., Nguyen, V., Reiber, G. (2010). Comparison of satisfaction with current prosthetic care in veterans and servicemembers from Vietnam and OIF/OEF conflicts with major traumatic limb loss. *Journal of Rehabilitation Research and Development*, 47(4), 361-372.

<sup>18</sup> Dougherty, P. (1999). Long-term follow-up study of bilateral above-the-knee amputees from the Vietnam War. *Journal of Bone and Joint Surgery*, 81(10), 1384-1390.

<sup>19</sup> Dougherty, P. (2001). Transtibial amputees from the Vietnam war: Twenty-eight-year follow-up. *Journal of Bone and Joint Surgery*, 83 (3), 383-389.

<sup>20</sup> Dougherty, P. (2003). Long-term follow-up of unilateral transfemoral amputees from the Vietnam war. *Journal of Trauma*, 54 (4,) 718-723.

<sup>21</sup> Dougherty, P., McFarland, L., Smith, D., and Reiber, G. (2014). Bilateral transfemoral/transtibial amputations due to battle injuries. *Clinical Orthopaedics and Related Research*, 472(10), 3010-3016.

<sup>22</sup> Kulkarni, J., Adams, J., Thomas, E., and Silman, A. (1998). Association between amputation, arthritis and osteopenia in British male war veterans with major lower limb amputations. *Clinical Rehabilitation*, 12(4), 348-352.

<sup>23</sup> Norvell, D., Czerniecki, J., Reiber, G., Maynard, C., Pecoraro, J., and Weiss, N. (2005). The prevalence of knee pain and symptomatic knee osteoarthritis among veteran traumatic amputees and nonamputees. *Archives of Physical and Medical Rehabilitation*, 86(3), 487-93.

<sup>24</sup> Dougherty, P., McFarland, L., Smith, D., Esquenazi, A., Blake, D., and Reiber, G. (2010). Multiple traumatic limb loss: A comparison of Vietnam veterans to OIF/OEF servicemembers. *Journal of Rehabilitation Research and Development*, 47(4), 333-348.

one study that phantom limb pain was often a persistent condition that stayed with the amputee for the remainder of their life<sup>25</sup>. Another study described back pain and pain in contra-lateral (non-amputated) limbs as “disabling and progressive problems of long-term surviving amputees” and argued that such problems were as great as phantom pains but were often overlooked<sup>26</sup>. Eight papers reported the prevalence of mental health comorbidities among older limbless veterans<sup>8,9,14,16,21,24,26,27</sup>. These studies reported rates of depression between 9.7% and 28% and PTSD between 15% and 46%.

**Table 2.** Prevalence of pain among older limbless veterans.

Type of pain	Average % pain prevalence identified in reviewed studies	Number of papers reporting prevalence statistics
Phantom limb pain	17 – 90.8	14
Residual limb pain	32 – 92.2	10
Chronic back pain	8 – 76.6	9
Pain in contra-lateral (non-amputated) knee (lower-limb amputees)	38 – 79.4	4
Prosthetic-related pain	33 – 51	3
Hip pain on ipsilateral (amputated) side in lower-limb amputees	14.8	1
Knee pain on ipsilateral (amputated) side in BK amputees	13	1

Despite the high prevalence of pain and comorbidities, Quality of life was reported as ‘good’, ‘very good’, or ‘excellent’ in 72.8% - 79.7% of older limbless veterans<sup>28,9</sup>. One reason for this may be that veterans tended to deal with pain via silent acceptance or a ‘stiff upper lip’ approach to coping<sup>10</sup>. One study<sup>29</sup> reported significantly poorer quality of life among limbless veterans in comparison with population norms. Among the factors related to poor quality of life, Epstein, Heinemann, and McFarland<sup>28</sup> revealed that poorer self-reported quality of life was significantly associated (in both Vietnam and OIF/OEF veterans) with the need for assistance with activities of daily living. Such assistance was required by one third of upper limb amputees

<sup>25</sup> Warton, S., Hamann, W., Wedley, J., and McColl, I. (1997). Phantom pain and sensation among British veteran amputees. *British Journal of Anaesthesia*, 78(6), 652-659.

<sup>26</sup> Ebrahimzadeh, M., and Fattahi, A. (2009). Long-term clinical outcomes of Iranian veterans with unilateral transfemoral amputation. *Disability and Rehabilitation*, 31 (22), 1873–1877.

<sup>27</sup> Ebrahimzadeh, M., and Hariri, S. (2009). Long-term outcomes of unilateral transtibial amputations. *Military Medicine*, 174(6), 593-597.

<sup>28</sup> Epstein, R., Heinemann, A., and McFarland, L. (2010). Quality of life for veterans and servicemembers with major traumatic limb loss from Vietnam and OIF/OEF conflicts. *Journal of Rehabilitation Research and Development*, 47(4), 373-386.

<sup>29</sup> Taghipour, H., Moharamzad, Y., Mafi, A. R., Amini, A., Naghizadeh, M. M., Soroush, M. R., & Namavari, A. (2009). Quality of life among veterans with war-related unilateral lower extremity amputation: a long-term survey in a prosthesis center in Iran. *Journal of orthopaedic trauma*, 23(7), 525-530.



in both older and younger veterans<sup>16</sup>. Among bilateral lower-limb amputees, Dougherty *et al.*<sup>24</sup> noted that 33% of Vietnam veterans (compared with just 6% of OIF/OEF veterans) could no longer walk. In addition, fewer Vietnam veterans were participating in ‘high impact’ activities such as skiing and basketball, compared with the younger cohort (see also, Reiber *et al.*<sup>8</sup>). In the only study to include qualitative analysis of older veterans’ quality of life experiences, Foote *et al.*<sup>9</sup> provided vivid descriptions of the effects of impairment and restrictions on activities caused by amputation and by not being able to walk long distances due to pain. Declining mobility with age was strongly linked to poorer quality of life in the narrative account of one veteran from Foote *et al.*’s<sup>9</sup> study.

Other factors related to poorer quality of life included a higher number of comorbidities, higher levels of pain, and mental health problems<sup>8,9,21,24,28,30</sup>. Several papers noted that the impact of age-related changes, pain and declining mobility on veterans’ quality of life<sup>9,19,24,26</sup> with mental health problems such as depression and PTSD – endured for many decades in some cases – described as among the primary reasons for poor quality of life among older limbless veterans<sup>9,26,28</sup>.

Finally, several papers considered the long-term impact of limb-loss on employment and personal relationships<sup>8,9,18,19,20,21,24</sup>. In a long-term follow-up of bilateral above-knee amputees from Vietnam, Dougherty<sup>18</sup> found that 70% of veterans were or had been employed outside of the home since their injury. Reiber *et al.*<sup>8</sup> similarly reported a 78.7% current employment rate among Vietnam veterans. The vast majority of veterans were also married and had children<sup>18,19,20,26,31</sup>. Accordingly, Dougherty<sup>18</sup> argued that Vietnam veterans had lived ‘relatively normal lives’ within the context of their physical limitations and that, contrary to media narratives, did not on the whole experience insurmountable emotional and physical scars. Indeed, Foote *et al.*<sup>9</sup> suggested that older Vietnam veterans with limb-loss had continued to make major life transitions and experienced positive quality of life, but that problems with pain, physical ailments exacerbated by ageing, and mental health problems could also adversely affect quality of life, thus underscoring the importance of ongoing care and rehabilitation.

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<sup>30</sup> Hoaglund, F., Jergesen, H., Wilson, L., Lamoreux, L., and Roberts, R. (1983). Evaluation of problems and needs of veteran lower-limb amputees in the San Francisco Bay Area during the period 1977-1980. *Journal of Rehabilitation Research and Development*, 20(1), 57-71.

<sup>31</sup> Ebrahimzadeh, M., Kachooei, A., Soroush, M., Hasankhani, E., Razi, S., and Birjandinejad, A. (2013). Long-term clinical outcomes of war-related hip disarticulation and transpelvic amputation. *Journal of Bone and Joint Surgery*, 95, e114, 1-6.

### *Psycho-Social Adaptation and Coping in Older Limbless Veterans*

Three studies<sup>10,32,33</sup> discussed coping and psycho-social adaptation among older limbless veterans. Desmond and MacLachlan<sup>33</sup> surveyed coping strategies and psycho-social adaptation with a sample of elderly lower-limb amputees (mean age = 74 years) who were members of Blesma, The Limbless Veterans Charity (Blesma). The term 'psycho-social adaptation' was not defined in this paper but was described in relation to an individual's ability to adapt to a range of challenges, including impairments in physical functioning, prosthesis use, pain, changes in occupation, and alterations in body image and self-concept. The authors reported that problem solving and seeking social support were coping strategies associated with fewer depressive symptoms and greater psycho-social adaptation among older veteran-amputees. Avoidant coping strategies (e.g., denial, alcohol use) were associated with poorer psycho-social adjustment, echoing wider findings about the maladaptive use of avoidant coping strategies in adaptation to disability. Greater time since amputation was also positively related to adjustment, with the average length of time being 42.6 years among the Blesma veterans.

In a later study, Desmond<sup>32</sup> went on to explore coping and adjustment among upper limb amputees from the Blesma cohort. In this study, psycho-social adjustment was conceptualized as "the absence of clinically elevated symptoms of anxiety and depression and evidence of positive adjustment to amputation and prosthesis use" (p. 17). Findings broadly mirrored those of the earlier study, although the associations between seeking social support and adjustment were not evident. As Desmond argued, the findings of this and the previous study hold relevance for the care of older veterans, in particular the importance of promoting adaptive, problem-orientated coping strategies designed to enhance long-term adjustment and quality of life.

Machin and Williams<sup>10</sup> also explored coping strategies in relation to phantom pains. They reported that veterans generally made little use of strategies such as problem solving or emotional support, preferring a 'stiff upper lip' approach to coping and a silent acceptance of pain. Many had also given up on medical assistance, making comments such as "I have had no success with treatments so far, so there is no point in even trying" (page 293).

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<sup>32</sup> Desmond, D. (2007). Coping, affective distress, and psychosocial adjustment among people with traumatic upper limb amputations. *Journal of Psychosomatic Research*, 62 (1), 15– 21.

<sup>33</sup> Desmond, D., and MacLachlan, M. (2006). Coping strategies as predictors of psychosocial adaptation in a sample of elderly veterans with acquired lower limb amputations. *Social Science and Medicine*, 62(1), 208-216.

### *Disability and Identity*

One study by Meyers<sup>11</sup> focused on the identity politics of disability and amputation amongst middle-aged veterans of Nicaragua's civil war of the 1980's. Meyers'<sup>11</sup> qualitative study drew upon interviews and participant observations conducted with opposing sides of the conflict in order to understand how each side positioned themselves with regard to the broader category of 'disability'. For the ex-Contra rebels (politically marginalized following their defeat by the Sandinista regime), adopting the social identity of 'disabled' became a means of arguing for equal rights and the protection of disability benefits. On the other hand, the Sandinistas under the 'Organization of Disabled Revolutionaries' (ORD) sought to distance themselves from 'other' disabled people, preferring to emphasise their privileged status as 'war heroes'. Their amputations were symbols of valor setting them apart from other disabled groups and protecting them from 'stigmatized' disabled identities. Sandinista veterans thereby adopted an ambiguous relationship with other disabled people: choosing to set themselves apart yet occasionally being compelled to identify with wider disability movements in order to gain access to benefits and resources.

Meyers'<sup>11</sup> findings showed that the political and military context in which veterans were injured was an important feature of their long-term adjustment to 'disability' and negotiations around personal and social identity. By highlighting matters of social identity, Meyers also situated the study of older veteran-amputees within the wider literature on critical disability studies (e.g., Meekosha & Shuttleworth, 2009<sup>34</sup>), which the literature on older veterans has otherwise yet to engage with. Indeed, one insight from Meyers' paper – mirroring the perspective of disability scholars more broadly<sup>34</sup> – was that disabled and amputee veterans were not a homogenous group in terms of their social identities and experiences of disability, and that various 'intersecting' identities (particularly in relation to age, gender, race, and combat-era) were important in understanding their lives.

### *Estimating the Long-Term Cost of Prosthetic Provision for Limbless Veterans*

In line with the aims of this systematic review to evaluate the long-term impact of limb-loss, three papers considered the long-term financial burden of prosthetic device provision required in order to meet veterans' mobility needs<sup>4,12,13</sup>. Using Markov model analysis, Blough *et al.*<sup>12</sup> projected the cost of prosthetic device provision for US veterans over 5 year, 10 year, 20 year and lifetime periods. Using the *Survey for Prosthetic Use* sample (see above), the authors contrasted the estimated lifetime cost of provision for Vietnam veterans compared with

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<sup>34</sup> Meekosha, H., and Shuttleworth, R. 2009. What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, 15(1) 47-76.

OIF/OEF veterans. Given the greater number – and greater technological advancement – of prosthetics used by OIF/OEF veterans, the cost of provision for the younger cohort was significantly higher than the Vietnam cohort. Costs were also compared by type of amputation, with unilateral upper, unilateral lower, bilateral upper, and multiple limb-loss forming separate categories for analysis. Given that lower-limb prostheses were typically more expensive and complex than upper-limbs, costs were also highest in the ‘multiple limb-loss’ category, such that the lifetime projected costs of provision for a single Vietnam and OIF/OEF multiple limb amputee were 750k and 3.4m US Dollars, respectively. This compared with lifetime costs for a unilateral upper limb amputee at 300k for Vietnam and 1.1m for OIF/OEF. Blough *et al.*<sup>12</sup> asserted that future costs of prosthetic provision could be manageable for the VA and for the Department of Defense (DoD), but that their estimates were ‘conservative’ because of potential outliers and the cost of future emerging technologies.

In a similar study with UK veterans, Edwards, Phillip, Bosanquet, Bull, and Clasper<sup>4</sup> argued for the imperative of long-term planning to meet the prosthetic and rehabilitative needs of Iraq and Afghanistan veterans. Using a simplified version of Blough *et al.*'s<sup>12</sup> Markov model, Edwards *et al.*<sup>4</sup> estimated that the long-term (40 year) cost of rehabilitation and prosthetic provision for the entire UK veteran cohort of Iraq and Afghanistan was £288 million (USD 444 million) in 2015 currency. Prior to the conflicts in Iraq and Afghanistan, Stewart and Jain<sup>13</sup> conducted a retrospective cohort study based on 98 British veteran-amputees from previous conflicts in order to produce an estimate of lifetime costs. Extrapolating from their sample to the rest of the UK population of war amputees, the figure they produced was £69 million, which did not account for any related, hidden, or future costs and, according to the authors, was likely to be a significant under-calculation.

None of the cost-estimate studies were, however, able to account for variations in the cost of care provision through chronic disease, age-related changes (e.g., in mobility), and comorbidities such as mental health problems that limbless veterans are likely to encounter ‘downstream’<sup>3</sup>. As Geiling Rosen and Edwards<sup>3</sup>, put it in their commentary on the ‘medical costs of war in 2035’, there was a need to consider the “secondary and tertiary consequences in middle age [which] might include decreased mobility, weight gain, coronary artery disease, and diabetes mellitus” (p. 1237). Accordingly, Geiling *et al.*<sup>3</sup> emphasised the need for early interventions – including prevention and treatment measures – to help mitigate the likely additional costs to society. Indeed, as Edwards *et al.*<sup>4</sup> also cautioned, their estimates should be considered merely as “the start of a challenge to develop sustained rehabilitation and recovery funding and provision” (p. 2854), and that ongoing assessment of injured soldiers and their care would be required as the population ages.

### *Quality of the Literature on Ageing and Limb-Loss In Veterans*

The literature as a whole is over-reliant upon the self-report survey method (17/21 studies). Whilst many of these were large, well designed surveys which included comparison groups, there are limitations associated with this dependence upon survey methodology. For instance, 11 studies discussed the potential representativeness of their samples, including questions over the presence of selection bias and differences between respondents and non-respondents. In particular, evidence that some veterans self-medicated with alcohol to deal with phantom pain<sup>35</sup> and avoided contact with clinicians when treatments were deemed ineffective<sup>10</sup> could indicate that non-respondents had potentially more severe problems with mental health or alcohol use. It could also be argued that the use of a single 5-point scale to assess quality of life within the VA survey for prosthetic use<sup>8</sup> was an overly simplistic measure for a complex, multi-faceted construct. While 11 studies used validated measurement instruments (12 also incorporated bespoke measurement tools), only one study<sup>22</sup> used medical assessments to determine the presence of comorbidities. There was also an absence of longitudinal follow-up studies which would have been able to determine the impact of limb-loss over time or throughout the life-course<sup>36</sup>.

Of the studies based in full or part on qualitative methods<sup>9,10,11</sup>, only one<sup>11</sup> provided sufficient information on data collection and analysis procedures for methodological rigor to be assessed. This study was classified as strong, based on the quality and extent of data collection, the well-documented relationship between researcher and participants, the clearly articulated findings and implications, and good grounding in theory. With the exception of this paper, however, the literature on older limbless veterans lacked theoretical depth and engagement with critical social issues such as ageing and disability, identity, and independence (e.g., Schwanen & Ziegler<sup>37</sup>). Overall, the quality of the literature on ageing and limb-loss in veterans may be categorized as weak-to-moderate. Despite an over-reliance on the self-report survey method, issues identified appear to be consistent across the literature (albeit with differing estimates of prevalence) (see [Tables 1a and 1b](#)), and the measures used possessed some face validity. Accordingly, the literature reviewed can be considered useful for drawing some conclusions regarding the long-term impact of limb-loss on veterans, whilst

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<sup>35</sup> Sherman, R. and Sherman, C. (1983). Prevalence and characteristics of chronic phantom limb pain among American veterans. *American Journal of Physical Medicine*, 62(5), 227-238.

<sup>36</sup> Murrison, A. 2011. *A better deal for military amputees*. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215338/dh\\_130827.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215338/dh_130827.pdf) [Accessed 02/03/17].

<sup>37</sup> Schwanen, T., and Ziegler, F. (2011). Wellbeing, independence and mobility: an introduction. *Ageing and Society*, 31(5), 719-733.

also recognizing the need for further well-designed research studies (both quantitative and qualitative), and prospective, longitudinal studies.

## Summary

The findings of this systematic review emphasise that, whilst limbless veterans are generally able to achieve a good quality of life, limb-loss is still a progressive and degenerative injury involving enduring experiences of pain, comorbidities, and sometimes mental health problems, which undermine veterans' health, well-being and quality of life. Furthermore, it is evident that approaches to coping, as well social and political context, exert an important influence on veterans' long-term adjustment and identity in relation to limb-loss. Finally, the literature highlights the substantial cost of caring for limbless veterans throughout the life-course and the financial commitments required to safeguard their long-term health and care needs.

The literature review identified older limbless veterans and the impact of ageing on maintaining independence as an area that needs further investigation. The aim of this study was therefore to capture the life-stories of limbless veterans over the age of 40. Understanding the experiences of older limbless veterans across their life-course will aid in the development of future policy with cross-generational benefits. A focus on the health and social wellbeing of the participants will also help to inform future policy makers of maintaining independence in limbless veterans as they age.



# Methodology





## Aims

By examining the multiple domains of wellbeing across the life-span, as portrayed through the individual biographies of older limbless veterans, this research sought to understand the holistic and life-long impact of limb-loss. 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.

We also explored the significance of stories for how participants attached meaning to their experiences and their lives post limb-loss. This included the potential role of stories for participants, for example, in bolstering self-esteem, celebrating success or demonstrating resilience in the face of adversity. The study draws on the experiences of veterans from military operations prior to those in Iraq and Afghanistan to contribute data on patterns of recovery. This includes levels of mobility and the impact of limb-loss on independence that will likely affect current and future generations of limbless veterans. Ultimately, the research aims 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 charities with responsibility to care for limbless veterans.

## Design

A multiple method convergent design (Figure 2) was adopted for the study, encompassing Narrative Inquiry<sup>38</sup> and Applied Policy Research<sup>39</sup>. 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.

In common with Naylor et al.<sup>40</sup>, a commitment to the active participation of veterans themselves was embedded throughout all stages of the research. This helped to ensure that the research reflected the experiences and priorities of service users and carers. Veterans worked with the research team to contribute to the design of the research proposal, the

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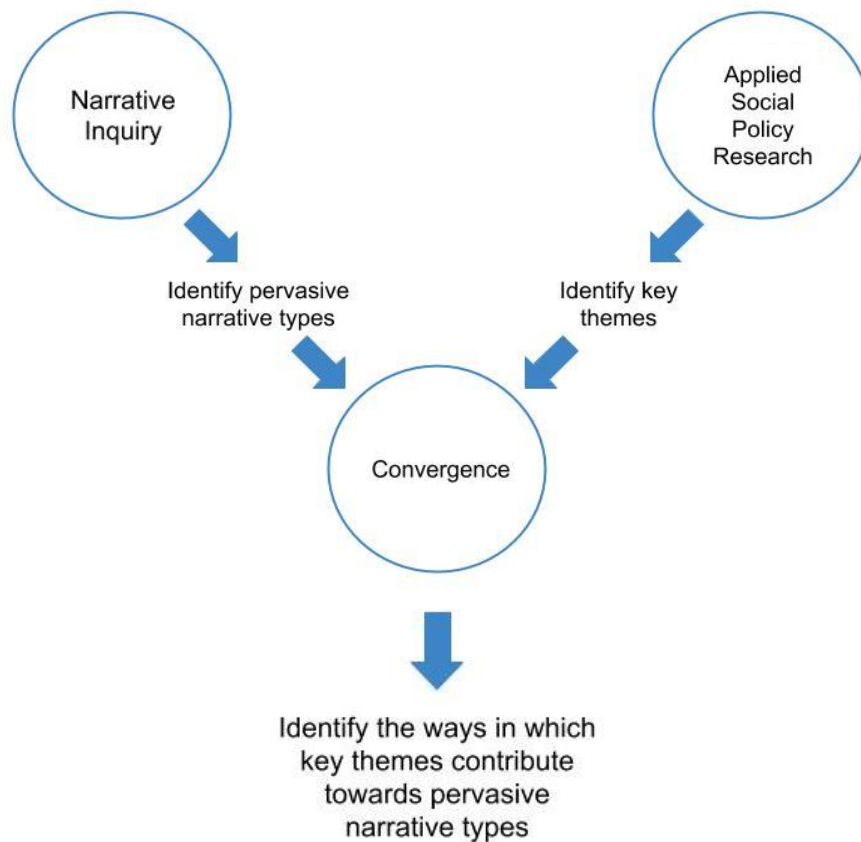
<sup>38</sup> Frank, A. (2012). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (eds.), *Varieties of narrative analysis* (pp. 33-52). Thousand Oaks, CA: Sage.

<sup>39</sup> Ritchie J & Spencer L (2002) Qualitative data analysis for applied policy research. *The qualitative researcher's companion*, 573(2002), 305-29.

<sup>40</sup> Naylor, C., Wallcraft, J., Samele, C., & Greatley, A. (2007). Research priorities for service user and carer-centred mental health services: Consultation report. *NCCSDO, London*.

development of the research tools and participant information resources. They also played a key role in the recruitment process.

**Figure 2.** Convergent design in practice



### *Narrative Inquiry*

Narrative inquiry is a term used to refer to diverse approaches, which share a concern with the ways which stories are used as a vehicle for organising and giving meaning to experiences<sup>41</sup>. The present study employed a form of narrative inquiry referred to as dialogical narrative analysis<sup>38,43</sup>. A dialogical approach does not treat stories as simply reflecting the actual state of affairs, or recounting how events actually happened, but understands stories themselves as active in affecting audiences and tellers. This includes a consideration of the role that these stories play in supporting people's concept of self-identity. The stories we tell are taken to be an important influence on how we think about and live out our lives, and the possibilities we see as open or closed to us<sup>42,44</sup>. The approach is termed 'dialogical' in

<sup>41</sup> Smith, B., & Sparkes, A. C. (2008). Contrasting perspectives on narrating selves and identities: an invitation to dialogue. *Qualitative Research*, 8(1), 5-35.

<sup>43</sup> Frank, A. (2010). *Letting stories breathe: A socio-narratology*. Chicago: University of Chicago Press.

<sup>44</sup> Phoenix, C., & Smith, B. (2011). Telling a (good?) counterstory of aging: Natural bodybuilding meets the narrative of decline. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(5), 628-639.

recognition that stories are not produced in isolation, but piece together scraps of stories previously heard and told and incorporate the voices of others<sup>38</sup>. Thus, this report therefore distinguish between 'narratives', which refer to the forms of narrative broadly available in society, and 'stories' which refer to the ways that participants draw on these available narratives to produce specific accounts of their own experiences. With regard to this study, a dialogical approach was used to explore the types of stories told by limbless veterans and how well served they are by these stories as they endeavour to age well and maintain their independence.

### *Applied Policy Research*

Applied policy research concentrates on finding solutions to immediate practical problems, and has a key role to play in providing insight, explanations and theories of social behaviour<sup>39</sup>. Framework analysis is an approach to qualitative analysis developed for the purpose of applied policy research. It has particular strengths in the systematic management of data, and in enhancing transparency and accountability with regards to the way in which recommendations are derived from the data<sup>45</sup>. In addition to its emphasis on responding to public and policy problems, framework analysis was favoured for the study due to its suitability for handling large data sets and the ability to balance consideration of individual circumstances with the production of overarching recommendations<sup>46,47</sup>.

### *Convergence*

The final stage of analysis employed a convergent parallel design, involving the integration of findings previously identified throughout the process of narrative inquiry and framework analysis. This mixed-method approach to research is referred to as analytical pluralism. Analytical pluralism is a growing practice within qualitative research. Scholars argue that in light of the multiplicity and complexity of social phenomena, the application of integrated

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<sup>45</sup> Ritchie, J., Lewis, J., McNaughton-Nicholls, C. and Ormston, R. (2013), *Qualitative Research Practice: A Guide for Social Science Students and Researchers, 2nd ed.*, SAGE Publications, Thousand Oaks, CA.

<sup>46</sup> Parkinson A, Eatough V, Holmes J, Stapley E, Midgley N. (2016) Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology*, 13 (2): 109-129.

<sup>47</sup> Gale NK, Heath G, Cameron E, Rashid S, Redwood S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 13: 117.

multiple methodologies have the potential to provide more comprehensive and meaningful insights into the subject of interest<sup>48,49,50,51,52</sup>.

## Participants

### *Recruitment*

Two peer-researchers co-ordinated the enrolment of participants to the study. These peer-researchers were veterans and members of Blesma, The Limbless Veterans Charity. Consequently, 33 participants were recruited from across the UK. A UK wide approach allowed for sufficient variation in the sample. Only data from 32 participants were included in the analysis. Please note, participant numbers were assigned at recruitment stage and therefore go up to 33.

### *Gender and Age*

The majority of participants were male (n = 30), there were two females. Ages ranged from 43 to 95 years old (mean = 69.4, SD = 14.56). It was acknowledged that there may be differences in experience depending on age. Only limbless veterans over the age of 40 were included in this study as it was expected that they would have significant limb-loss life experience. This would allow for the exploration of any continuing difficulties with mobility and/or services and the challenges that emerge over the life-course.

### *Military Service*

Participants served across all three services in the UK Armed Forces: Royal Navy/Royal Marines (n = 7), British Army (n = 19) and Royal Air Force (n = 5). Additionally, one participant was a Cadet. Recruiting participants across all three services of the UK Armed Forces, allowed for potential difference across services in terms of health and social care provision to be explored.

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<sup>48</sup> Creswell, J. (2003). *Research design: Qualitative, quantitative and mixed methods approaches (2nd ed.)*. Thousand Oaks, CA: SAGE Publications.

<sup>49</sup> Creswell, J., & Plano Clark, V. (2007). *Designing and Conducting Mixed Methods Research*. Thousand Oaks, CA: Sage.

<sup>50</sup> Kincheloe, J. (2001). Describing the bricolage: Conceptualizing a new rigor in qualitative research. *Qualitative Inquiry*, 7(6), 679-692.

<sup>51</sup> Kincheloe, J. (2005). On to the next level: Continuing the conceptualization of the bricolage. *Qualitative Inquiry*, 11(3), 323-350.

<sup>52</sup> Kincheloe J. & Berry, K. (2004). *Rigor and complexity in educational research: Conceptualizing the bricolage*. London: Open University Press.

Officers (Commissioned and Warrant) and other ranks were included in acknowledgement of potential differences this may give rise to in terms of economic constraints and employment opportunities post limb-loss.

Of 32 participants in the study, 59.4% (n = 19) had been deployed on operational duties during the course of their service, while 40.6% (n = 13) were never deployed. Reflecting the diversity of military service, participants who were deployed served in a range of conflicts: World War 2, Suez Crisis, Northern Ireland, Falklands and the Gulf War.

### *Limb-loss*

Whether limb-loss occurred during or outside military service was to be deemed important as this may have influenced the forms of support available to participants. Variation in the nature of limb-loss was recorded in order to illuminate potential differences in the challenges of adapting to limb-loss.

Consequently, 34.4% (n = 11) of participants had in-service attributable limb-loss, 6.2% (n = 2) had in-service non-attributable limb-loss and 3.1% (n = 1) had in-service limb-loss where the attributable cause was unclear. Of those that lost limbs post service, 28.2% (n=9) were due to accidents, 21.9% (n = 7) due to illness and 6.2% (n = 2) due to previous service and their limb-loss was reported as attributable. The nature of limb-loss (e.g. single/bilateral amputation; upper/lower limb) also varied across participants (see [Table 3](#)).

**Table 3.** Participant characteristics (N = 32).

<b>Age at interview (years)</b>	
<b>Mean (SD)</b>	<b>69.4 (14.56)</b>
<b>Range</b>	<b>43-95</b>
<b>Gender</b>	
<b>Male (%)</b>	30 (93.8)
<b>Female (%)</b>	2 (6.2)
<b>Service</b>	
Royal Navy/Royal Marines (%)	7 (21.9)
Army (%)	19 (59.4)
Royal Air Force (%)	5 (15.6)
Cadet (%)	1 (3.1)
<b>Operational service</b>	
Deployed (%)	19 (59.4)
No deployments (%)	13 (40.6)
<b>Mechanism of limb-loss</b>	
In-service attributable (%)	11 (34.4)
In-service non-attributable (%)	2 (6.2)
In-service unclear (%)	1 (3.1)
Post-service accident (%)	9 (28.2)
Post-service attributable (%)	2 (6.2)
Post-service illness (%)	7 (21.9)
<b>Nature of limb-loss</b>	
Above-knee (%)	14 (43.8)
Below-knee (%)	10 (31.3)
Through-knee (%)	1 (3.1)
Arm (%)	1 (3.1)
Double amputee (%)	4 (12.5)
Quadriplegic (%)	1 (3.1)
Monoplegic (%)	1 (3.1)

## Families

Participants were asked if they would like to include their immediate families/significant others (over 18 years and up to two people per primary interviewee). The aim of this was to aid in the holistic exploration of impact of limb-loss on families and to address gaps in the current understanding of the health and social care needs of families of older limbless veterans. The research team appreciated that the inclusion of family members/significant others may have potentially influenced the dynamics of the research interview insofar as;

- Participants may have tailored their narratives to the audience of listeners; and,
- Participants may have applied a greater degree of self-editing, perhaps limiting the candour of the interview;

However,

- The presence of a family member/significant other served as a means of obtaining multiple perspectives of the holistic significance of limb-loss; and,
- Family members/ significant others served as a means of on-the-spot member checking or validation of claims made.

In some circumstances, it was clear that the involvement of a family member/significant other served as a catalyst for conversations that had hitherto remained unsaid or suppressed for the duration of the post-limb-loss experience.

Overall, in line with recommendations for purposive sampling for qualitative studies<sup>53,54,55</sup>, the approach taken balanced a concern for accessing the range of responses according to above characteristics, with the ability to ascertain high quality, in-depth information.

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<sup>53</sup> Bryman, A. (2008). *Social research methods* (3rd ed. ed.). Oxford, New York: Oxford University Press.

<sup>54</sup> Barbour, R. S. (2014). *Introducing qualitative research: a student's guide* (Second edition. ed.). Los Angeles: SAGE.

<sup>55</sup> Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA.: Sage.

## Data Collection

Life histories were collected over a period of eight months from September 2016 to July 2017. Each of the participants were involved in semi-structured life history interviews, conducted face-to-face at a location of the participants' choosing (usually their own home). With participants' permission, interviews were audio-recorded. Up to three interviews per participant were carried out, each lasting between 1.5-3 hours, in order to allow sufficient time for participants to share their full life story. Consequently, there was close to 100 hours of rich, in-depth life narrative data collected. One participant was interviewed via email on request due to hearing difficulties.

## Data Analysis

Participant interviews were transcribed verbatim. To aid the analysis of textual data, Nvivo 11 server software was used across all three strands of the project. NVivo is a qualitative data analysis computer software package produced by QSR International. It has been designed for qualitative researchers working with rich text-based and/or multimedia information, where deep levels of analysis on small or large volumes of data are required. NVivo helps users organise and analyse non-numerical or unstructured data. The software allows users to classify, sort and arrange information; examine relationships in the data; and combine analysis with linking, shaping, searching and modelling. The researcher or analyst can test theories, identify trends and cross-examine information in a multitude of ways using its search engine and query functions. Researchers can make observations in the software and build a body of evidence to support their case or project.

### *Narrative Analysis*

In line with the narrative inquiry design, narrative analysis began with researchers immersing themselves in the data by reading the interview transcripts and field notes, as is common across approaches to qualitative analysis. This familiarisation process was also aided by the coding of participant interviews in NVivo according to significant issues and experiences that affected individual participants at different stages of their lives. This supported later stages of the analysis by facilitating the retrieval of data for participants. In accordance with a dialogical approach to narrative analysis, the researchers asked a series of questions of the data and participant's stories<sup>42</sup>. These included the following:

- How does the story shape people's sense of what is possible, what is permitted, and what is responsible or irresponsible?
- What kind of response does the story call for or seek to provoke from different listeners?



- What particular ideas about ageing limbless veterans do the stories seek to communicate?

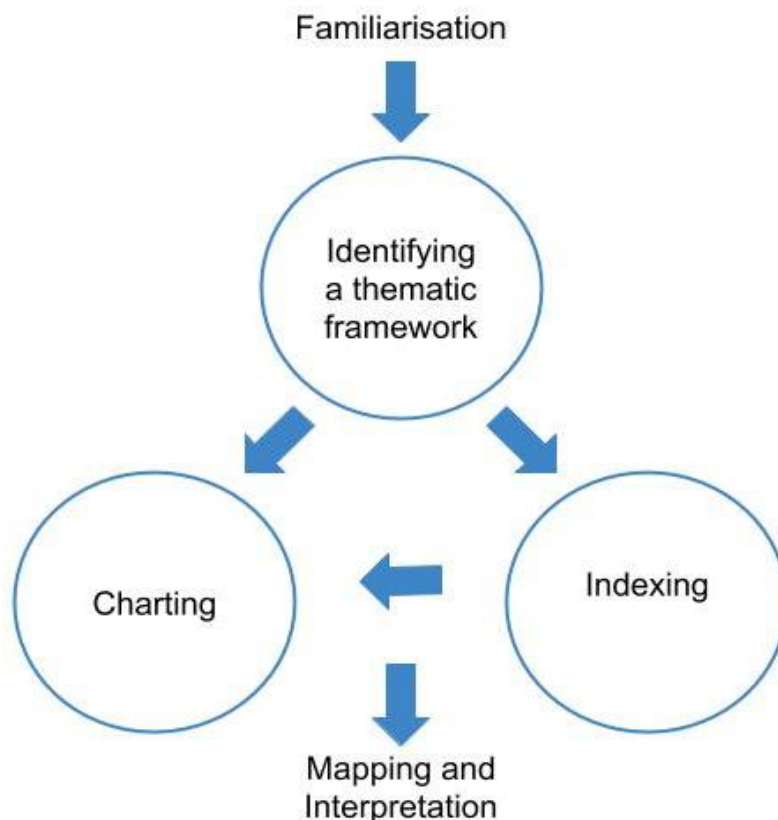
For each participant, a narrative summary was produced providing a synopsis of participant's life history, and the type of story(ies) or plot(s) they used to frame their experiences. Individual narrative summaries were then compared and contrasted with one another, in order to identify patterns in the forms of stories participants used when narrating their limb-loss.

### *Framework Analysis*

Applied policy research focuses on providing insights, explanations and theories of social behaviour and producing solutions for policy issues or questions<sup>39</sup>. Framework analysis of qualitative data sits at the heart of applied policy research methodology. Framework Analysis has been used to help achieve specified aims and outputs as well as to facilitate systematic thematic analysis of data<sup>39,45</sup>. This method was chosen for its capacity to handle data through a rigorous, transparent and logical process of thematic analysis.

The process consists of five phases (see also [Figure 3](#)):

**Figure 3.** Framework analysis in practice.



- 1) *Familiarisation*: The process of familiarisation involved immersion in a subset of the participant transcripts in order to begin to structure and make sense of the raw data.
- 2) *Identifying a thematic framework*: The next stage of analysis involved developing categories (or thematic framework) for the organisation of the data. This process was informed by the aims and objectives of the study, data driven themes, and interpretations developed during the familiarisation process<sup>56</sup>. The categories developed were then applied to, and refined using a selection of the data.
- 3) *Indexing*: Indexing refers to the process of systematically applying the thematic framework to the whole data set (Ritchie and Spencer 2002). In this study, the use of NVivo's automatic coding function was used in order to ensure that this stage was undertaken in a consistent manner. After automatic coding was undertaken, the data in each theme was reviewed by researchers manually in order to ensure that all material in each theme was relevant, remove any unrelated data and develop new themes where required.
- 4) *Charting*: Once all of the data was assigned to categories, the next phase involved grouping and re-organising categories in order to identify patterns in the data. Crucially, this technique enabled an interrogation of data according to research questions and objectives. Categories of data pertaining to each superordinate theme or hypothesis were arranged into matrices (using NVivo) to examine the extent to which interpretations were supported by the data, and to enable comparison between participants according to their particular attributes or circumstances. This method enabled a balance to be achieved between reducing and summarising data and remaining attuned to individual cases. Insights from matrices in turn enabled refinement of hypotheses and superordinate themes through a cyclical process. The ability to trace interpretations back to supporting data is a key strength of framework analysis, providing a clear audit trail of how conclusions were derived from the data.
- 5) *Mapping and interpretation*: This phase refers to the presentation of an overall picture of the data. It involved representing the key features of the data, mapping out how different aspects of data fit together, and drawing out explanations for patterns that have emerged<sup>45</sup>.

### *Convergence Analysis*

Due to the anticipated diversity of the target population of limbless veterans, it was expected that narrative analysis would yield a range of varied narrative typologies. The narrative

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<sup>56</sup> Pope C, Ziebland S, Mays N (2000) Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 320, 7227, 114-116

typologies identified stark contrasts with regards to veterans' health, wellbeing and independence following limb-loss. There is a clear challenge in demonstrating the diversity of the needs of limbless veterans, whilst ensuring that any resultant policy advice recognises the variety of complexities which exist within this community. By exploring the ways in which key themes contribute towards the construction of each narrative type, the research team aimed to provide more accurate conclusions about the needs and experiences of this diverse group.

1) *Dual-Phase Deductive Coding*: In order to converge the findings previously identified through narrative analysis and framework analysis, the data was subject to a dual-phase deductive coding process. The pervasive narrative types identified within the data-set during narrative inquiry provided the foundation for phase one of the convergent coding process. Based upon the narrative summaries composed during the narrative analysis, the distinctive characteristics of each narrative type were clearly defined. The data-set was then analysed in order to code data extracts according to a corresponding narrative type. This process was completed manually by members of the research team and involved re-reading the interview transcripts, identifying data extracts which conform to key characteristic features of an identified narrative type and utilising NVivo software to compile data extracts according to narrative type. [Figure 4a](#) provides a visual example of phase one of the coding process.

The pervasive subordinate themes which emerged within the data-set throughout the process of the framework analysis provided a scaffolding for phase two of the coding process. Using the previously identified themes, deductive coding was applied to the data extracts which were selected during phase one of the convergent coding process. In order to complete this process members of the research team first used the NVivo Query Wizard tool to identify instances of key subordinate themes within the selected data extracts, before scrutinising and interpreting the function of each theme within the context of the specific narrative type. [Figure 4b](#) provides a visual example of the phase two coding process.

2) *Interpretation and Critical Analysis*: The final stage of the convergence analysis involved the interpretation and critical analysis of the findings. To complete this process, the research team reviewed the findings in order to discuss the ways in which key themes contribute to the construction of each narrative type. Finally, members of the research team considered the findings of the convergence analysis as they relate to existing knowledge and previous research

Figure 4a. Visual representation of phase one of coding process using NVivo 11.

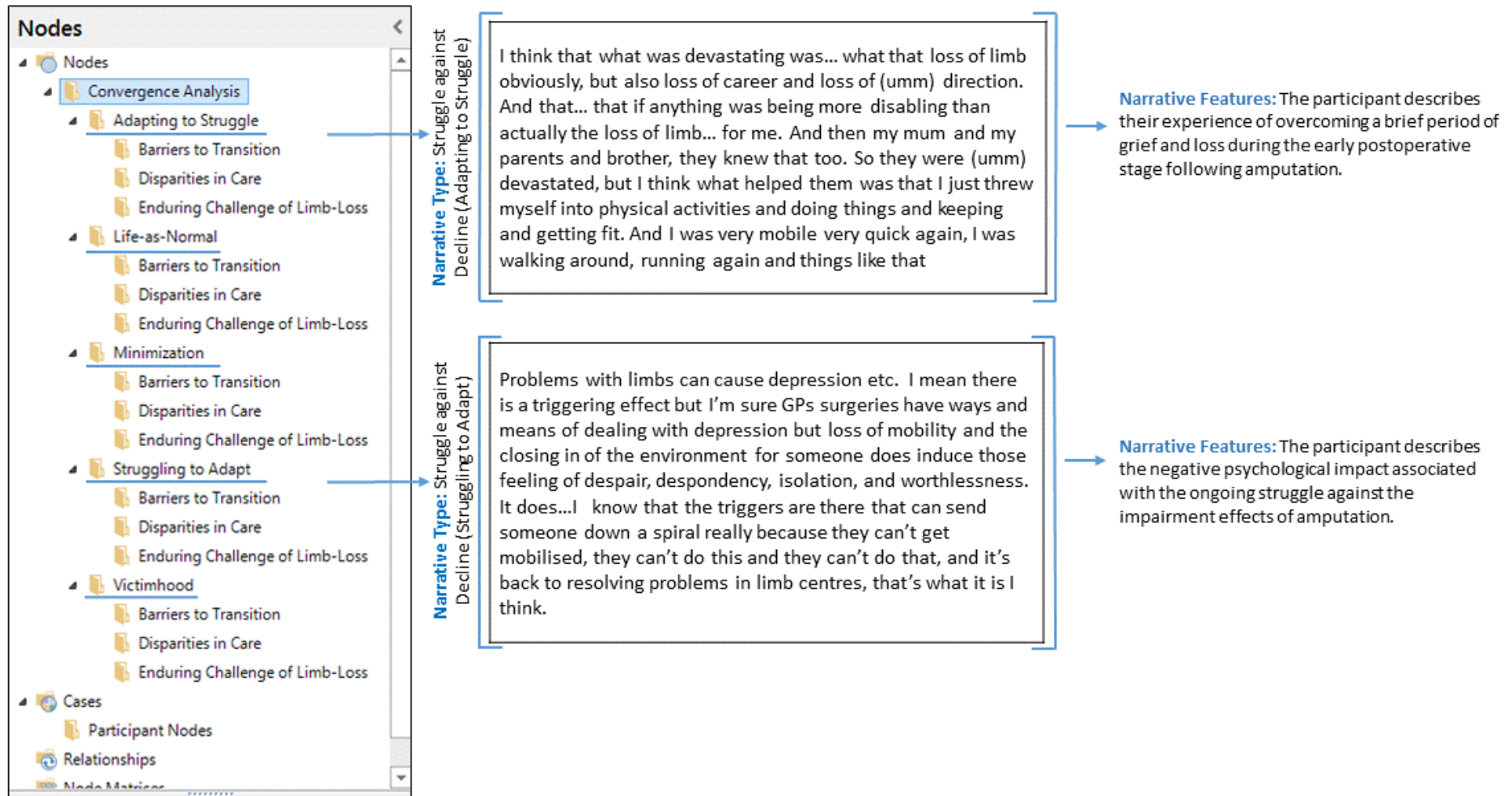
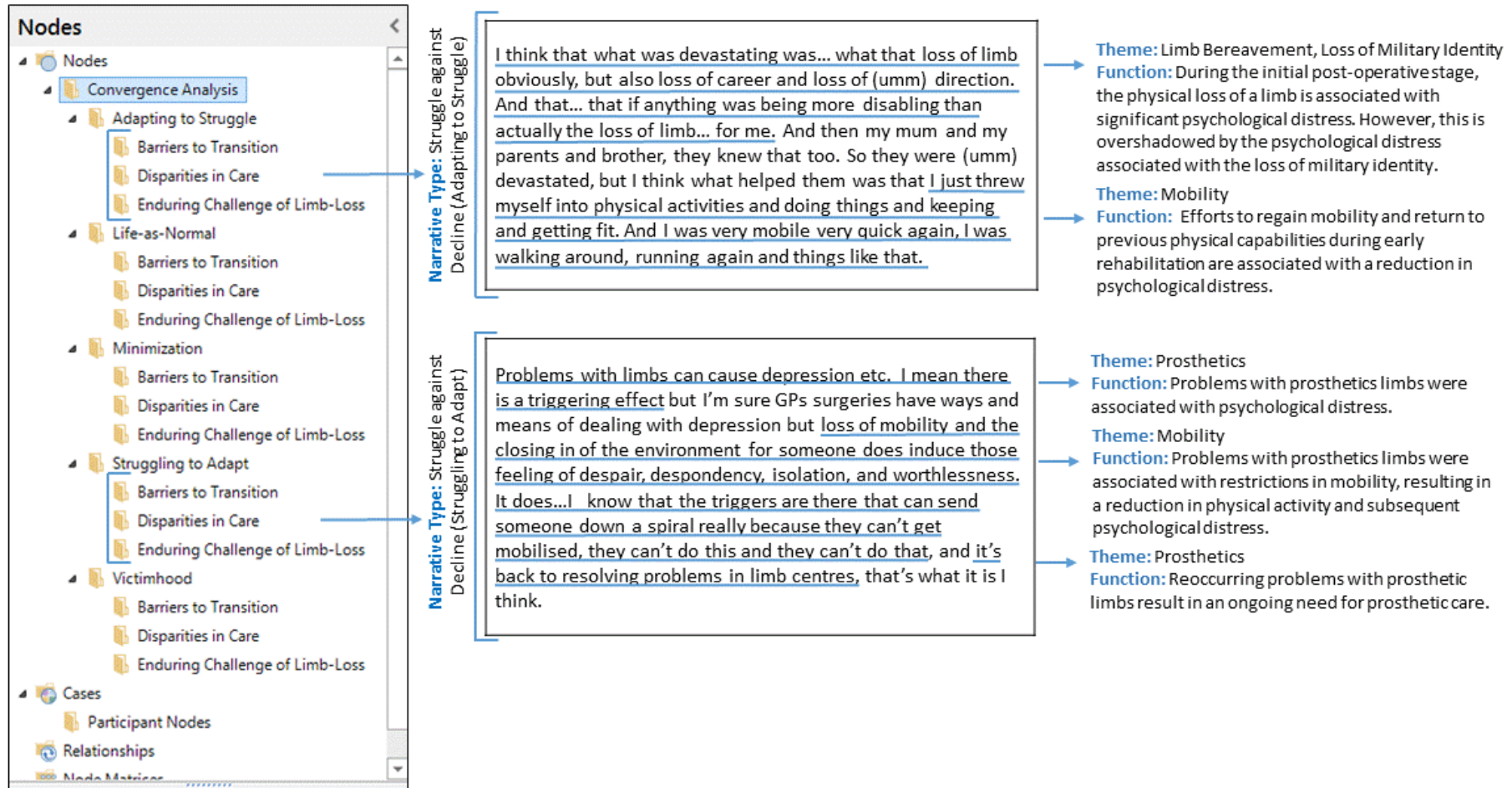


Figure 4b. Visual representation of phase two of coding process using NVivo 11.



## Ethics and Consent

All potential participants were issued with a study information sheet, which provided them with an overview of the research aims and procedures. Potential participants were informed that direct quotations from participants would be included within the publications which result from this research, however personal information which may compromise participants confidentiality, security or anonymity would be fully anonymised prior to inclusion. The information sheet also informed potential participants of their right to withdraw their participation at any time, without explanation and to have their data removed from the study. All potential participants were provided with an opportunity to ask questions about the research. Individuals who chose to participate in this research were required to sign a consent form, confirming that they understood the information provided to them and voluntarily chose to participate in the study.

Due to the sensitivity of limb-loss as a subject matter and the personal nature of narrative style interviews, it was important to minimise the potential psychological risks to the participants. All participants were known to Blesma and received a full risk assessment prior to taking part in the study. All interviews were conducted by highly experienced and skilled interviewers. At times during the interview process when participants became distressed, the interviewers provided support and reassurance and reminded the participant of their right to end the interview at any time. Participants received a full briefing and debriefing at the beginning and end of the interview process and were provided with a list of contacts from Blesma who they were able to contact if they required emotional or psychological support.

All data was stored in compliance with the Data Protection Act<sup>57</sup> and Northumbria University guidelines<sup>58</sup>. Interviews were digitally recorded, and transcribed. Both the audio recordings and the transcriptions were stored within a password-protected file, which was only accessible to the research team. All data will be stored for a period of five years prior to being destroyed.

Full ethical approval was received the from Northumbria University Ethics Committee.

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<sup>57</sup> Great Britain (1998) *Data Protection Act*. London: Stationery Office.

<sup>58</sup> *Northumbria University's research ethics and governance*: <https://www.northumbria.ac.uk/research/ethics-and-governance>.



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NOTE: WATER ONLY TO BE DRINKING MILK

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## Results: Narrative Analysis





Narrative analysis identified four different 'narrative types' which informed the stories of the participants. Narrative types are the broad 'story structures' – including themes and plot – which the veterans used to put together their individual stories of ageing and limb-loss. Each narrative type may be thought of as the core thread common to the stories told by the veterans who participated in this research. The four narrative types are 'struggling against decline', 'minimisation', 'victimhood', and 'life-as-normal'.

## Narrative Type 1: Struggling Against Decline

Maintaining independence in old age was, generally speaking, a struggle for participants. The majority of the stories told centred on a struggle to maintain independence and resist 'decline' in old age. Decline was expressed in terms of physical deterioration, inactivity, and becoming increasingly dependent upon others. Unsurprisingly, participants were highly motivated to avoid slipping into such a state of decline. In other words, their stories emphasised their struggles to *resist* decline.

Specific things which participants struggled with included restricted mobility (particularly walking), pain (including stump pain, pain in 'good' limbs, back pain, and phantom limb pains), and endeavouring to keep themselves active and 'engaged'. These struggles were often exaggerated by the ageing process:

*It's natural that you get weaker, your bones get worn out! And everybody does this, but as an amputee, it's emphasised, it's exaggerated more because you've got a difficult life, and it's made more difficult by ageing or trouble.* (Participant 5)

Whilst resisting decline and maintaining independence were described as a struggle, in most cases, this was a 'spirited' one rather than a gloomy or oppressive 'battle'. The following comments illustrate the typical manner in which participants described the struggle to maintain independence:

*Independence is everything. 100%. If I haven't got that independence I'm frustrated, I get niggly, bad tempered. [Spouse] nodding [their] head now! But I know it, but I just can't help myself. You know, if I try to do something and I can't do it, after a load of expletives I sort of say '[spouse], for God's sake, can you give me a hand?' Well, shoelaces! Shoelaces are the bane of your life really because I've only got one hand, trying to do up shoelaces is virtually bloody impossible! Zips! Zips ok, I can fumble and fumble and do it eventually. But if I go out, say I go for a meal, and I'm in a restaurant I can't stand in a restaurant*

*and fiddle about. So I've got to ask somebody to do it for me. Which is embarrassing for me.* (Participant 13)

*And you mention before about getting lazy. I was wondering what is the problem or the danger there if you start to get lazy and, you know, rely on other people?* (Interviewer)

*Oh the danger of being lazy is that you get stagnant and you just don't use your mind. You sit here watching that bloody thing, you know daytime television, God almighty! That's enough to drive anybody to bloody drink! No, laziness is a state of mind really. I don't like it, but it just creeps up on you. My biggest fear is if I sat here and got lazy I think I would deteriorate very, very quickly. Very quickly. I've got to have something to do.* (Participant 13)

The strong drive to maintain independence was typically a product of long-held personal values which were cultivated either before or during military service. As participant 13 continued to explain:

*You need to be strong because every time you have a posting, everybody on that ship is brand new to you. So if you show weakness, you don't know who's going to take advantage of that. So you don't show it at all. You know, you've got to be as hard as you can be. Otherwise you just get treated – well you get bullied, you get treated badly, you get all the rubbish and it's just a way that it manifests really. You learn that at a very, very early stage in your career. So you had to have your independence and I think that sort of – you know, I came out of the mob when I was forty and you still had to have your independence when you started work. So up to the age of fifty I – that's fifty years for independence to be installed in you. I think that's where it comes from.*  
(Participant 13)

Reflecting these and other comments, the first factor which emerged as helpful to maintaining independence was a resilient 'get on with it' attitude towards staying engaged and productive in life. This was an attitude towards life and limb-loss that was grounded in the participants' identities as ex-servicemen and women. It conveys an upbeat sense of resilience and resolve that had remained with these veterans throughout their careers and during their post-injury lives. Further brief examples include:

*I just get on with it, no use bellyaching.* (Participant 20)

*You look around and you think 'Oh, it ain't too bad really', and you get on with it.* (Participant 12)

Practically speaking, this meant that the participants sought enthusiastically to engage themselves in activities that helped to promote and protect their independence, for example walking, driving, doing the shopping, adapted physical activity, and fixing things around the home. Performing such tasks by themselves was important to participants' sense of themselves as 'independent'. This meant that they would often strive to carry out these tasks despite physical pain and discomfort caused by prosthetics and impaired mobility. Even so, engaging in productive activity seemed to be *self-reinforcing* for the participants' independence, i.e., these activities both provided evidence of continuing independence and helped to further sustain it.

#### *Factors promoting independence (#1)*

*A resilient 'get-on-with-it' attitude grounded in a strong military identity.*

Despite the mostly positive 'get-on-with-it' attitude toward struggling against decline, a distinction emerged between those who were 'adapting to struggle', and those who were 'struggling to adapt'. The difference was mainly observed in the participants' satisfaction with their quality of life, which was revealed in their narrative descriptions. In addition, the tone and structure of the stories differed, and accounts were less relentlessly positive among those who were 'struggling to adapt'.

'Adapting to struggle' meant that participants were relatively satisfied with their ability to overcome the limitations of pain and immobility, and that they felt engaged, active, and reasonably independent (i.e., they could perform the majority of tasks themselves and were satisfied with having some tasks carried out by significant others).

In contrast, 'struggling to adapt' meant that participants continually struggled to overcome the impairment effects<sup>61</sup> of their amputations. Impairment effects refer specifically to those restrictions upon bodily activity caused by the injuries participants had sustained earlier in their lives. For participants who were struggling to adapt in their old age, these impairment effects hampered their efforts to maintain independence and often led to feelings of vulnerability, frustration, and in some cases, isolation and loneliness. The following quotes/brief interview exchanges give a sense of participants 'struggling to adapt':

*So that's the pretty dull life that we have . . . I can't really see the situation changing a lot. I mean as long as the marbles are still working, we could just go on and on, you know, getting weaker and weaker!* (Participant 26)

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<sup>61</sup> Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas of disability studies and medical sociology*. Basingstoke: Palgrave.

*Yeah, I mean [they have not] got a lot of go in [them] these days, but [they] used to have. When we were first married [they would] have a go at pretty well anything. If [they] could have a go at it, [they would] do it. Whereas today [they are] not really . . .* (Spouse of Participant 33)

*Last two or three years I've lost the 'go' in me . . . I get annoyed when I'm trying to do things and I can't do what I want to do. So frustration takes over.*  
(Participant 33)

In light of these findings, one factor which emerged as crucial for ensuring that participants would 'adapt to struggle', rather than 'struggle to adapt', was support for overcoming impairment effects. This support came in many forms, such as the daily assistance provided by a partner or significant other, support from a competent prosthetist and limb-fitting service, or provision of social activities (including Blesma meetings and organised events) which helped to keep older participants active and engaged.

#### *Factors promoting independence (#2)*

*Support in overcoming the effects of amputation-related impairment.*

Even among participants whose stories suggested that they were 'struggling to adapt', the 'get-on-with-it' approach to coping with limb-loss was still prevalent. Despite their struggling, and despite feeling lonely and being socially isolated, some participants admitted that they were "*a bit too independent*" to ask for help or seek support.

#### *Factors inhibiting independence (#1)*

*Rigidly adhering to 'get-on-with-it' attitude in spite of mounting physical, psychological, and social difficulties.*

This was not the case with all of the participants. For example, several described attending Blesma meetings as a way of maintaining social connections. One participant also described becoming a 'befriender' for the military charity SSAFA, partly in response to their own feelings of loneliness. However, it became evident that the same strong-willed approach to coping which helped some participants to adapt could also become a burden that prevented them from seeking help from which they may have benefitted.

## **Narrative Type 2: Minimisation**

Some participants placed little emphasis on limb-loss in their stories. These participants spent more time in 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. In other words, limb-loss and its impact were ‘*minimised*’.

*Well to be honest with you I don't really think it [limb-loss] had any impact! You know, it never bothered me. Obviously it must have; but I mean probably wouldn't have bothered what I was going to do. But I can't honestly remember it being a big problem. I don't really know how to describe it . . . I've never felt all 'Why did this happen to me?' But I'd of felt the same way about anything that occurs. If it's you know something you wouldn't have wished, well you get on with and work around it. And that has been my way of accepting this and that I've lost my leg and I've got to get on with it and you've got no choice! And that that's my, well I suppose my attitude to life to be honest with you . . . To be quite frank, I don't even think about the fact I've got an amputation . . . as far as I'm concerned, it's been a nothing you know.* (Participant 4)

In most cases (though by no means all), participants who minimised the place of limb-loss in their stories had experienced less severe injuries (e.g., below-knee rather than above-knee amputation) than did others who struggled in their old age. It is possible, therefore, that lower-level amputations lend themselves to minimisation stories because veterans experience fewer restrictions on their capabilities as a result of their injuries.

*I've never shied away though from being an injured person in the sense of I don't go around wearing a badge, but some will say I do because I often wear shorts especially at this time of year. I don't wear a cosmetic on my leg; I don't need to. It is a false leg. I'm not going to hide the fact. But I just get on as normal. I mean I almost know no different now. And I've been like that from day one.* (Participant 29)

### Factors promoting independence (#3)

Lower level amputations with fewer associated ‘impairment effects’.

Participants who told minimisation stories often strongly emphasised their lives and bodies as simply ‘normal’, or no different to anybody else. Indeed, it was important to them to show that they were just as ‘able’ and capable of productive activity as their fully able-bodied peers. 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. Therefore, another factor that appeared crucially important in promoting independence was the ability to sustain a meaningful post-injury career:

*I'm lucky I've been able to move on in time and build a new career and have a nice family life, so that's why I'm so lucky really.* (Participant 29)

*I don't remember it [limb-loss] as being particularly difficult because you know, I wasn't out of work for a long time or anything like that.* (Participant 24)

#### Factors promoting independence (#4)

Maintaining a productive and fulfilling post-injury career.

Amongst participants who minimised limb-loss in their stories, well-fitting and functioning prosthetics were an important part of helping to live normal lives. These participants differed, however, in the extent to which prosthetics helped them to maintain a *social image* of normality. For example, participant 29 (quoted above) felt no self-consciousness about having their prosthetic limb “*on display*”. In contrast, much older participants tended not to want to “*advertise*” their prosthetic limbs, and therefore it was important for their prosthetics to appear unobtrusive and inconspicuous. Accordingly, there seemed to be a generational difference with World War II and post-war veterans preferring to keep their prosthetics hidden, and comparatively younger veterans feeling no discomfort with visible prosthetics. In both cases, prosthetics were important to the participants’ image of normality, but the perception of ‘normality’ with respect to prosthetics was different.

#### Factors promoting independence (#5)

Well-fitting and functioning prosthetic limbs.

Finally, ‘minimisation’ might also be considered as opposite to current narratives of ‘dramatic overcoming’, for example where limb-loss is dramatically and heroically overcome through sporting activity or other achievement such as in the Invictus Games. Narratives of ‘dramatic overcoming’ have become a dominant theme of recovery stories for injured veterans in recent years, with examples of veterans climbing Mount Everest, rowing across the Atlantic Ocean, and taking part in the Dakar Rally motor race. Yet whereas limb-loss is very much at the centre of these stories (i.e., as the source of adversity which is dramatically overcome through super-human effort and perseverance), ‘minimisation’ pushes limb-loss out of focus, declaring it as practically a non-issue. The ‘dramatic overcoming’ narrative was notably absent from the current findings. Instead of extreme ‘headline-grabbing’ physical challenges as a way of promoting ongoing recovery and independence, the participants described less intense forms of physical activity (e.g., going on a photography course, meeting up with other Blesma

members) as important in keeping them active, engaged, and mentally, physically and socially healthy.

#### Factors promoting independence (#6)

The availability of cultural narratives which allow for mundane 'hero narratives'.

#### Factors inhibiting independence (#2)

The pervasiveness of cultural narratives of 'dramatic overcoming', to which the majority of those affected by limb-loss cannot rise.

### Narrative Type 3: Victimhood

One participant interviewed told a story of 'victimhood' through which they expressed a great deal of anger and bitterness. This anger was directed towards numerous organisations, each perceived to have failed this participant in one way or another. These included surgeons who had repeatedly "*botched*" knee operations, the military for mishandling the participants discharge from service, a healthcare system which was unable to provide continuity of care, and the general public for a perceived sense of apathy or indifference towards personnel injured through non-combat means. As such, this story portrayed the participant as a victim of a) others' incompetence, b) an uncaring system, and c) a '*hierarchy of wounding*' which places combat injuries above injuries sustained in the course of 'regular duties'. Two extracts from participant two's interview illustrate the anger which they felt towards these various sources:

*I look into stuff, I try to find stuff out, I try to see is it just a set of situations that is just unique to me or is there a common theme to this and I ain't coming away with this as a common theme. I would like to know why are we being treated as second class military veterans to those that have actually been affected by conflict?* (Participant 2)

*I know from bitter experience of how the systems fall over and fail. I've seen it, it's happened to me numerous times in different establishments and it fails and it fails massively. I believe that we should have a system that gives continuity in care.* (Participant 2)

This participant described themselves as 'abandoned' and 'unwanted' by the military in the aftermath of their injury. This participants story suggests a lack of recognition, both for their service career and for the injuries they sustained as a result of service. The participant complained of being denied access to support through various charitable organisations who

reserved their resources for combat injured veterans, or veterans of particular conflicts. They also felt “discarded” as a result of media and public attention focusing on ‘combat heroes’ whilst those – like this participants – who lost limbs as a result of service but not during combat were forgotten about.

Other participants in this study deliberately distanced themselves from stories of victimhood, for example by rejecting others’ sympathy as a response to their amputations. This is perhaps because of the social stigma which can often be attached to people perceived as ‘victims’. Indeed, prior research (e.g., McGarry & Walklate<sup>62</sup>) suggests that veterans are generally uncomfortable being seen as ‘victims’ because victimhood is often associated with images of weakness and vulnerability which sit uneasily with the images of toughness and masculinity inherent to military identity.

Despite victimhood being stigmatised, however, it also enables people to express deeply held grievances. For one participant, adopting a story of victimhood may provide the advantage of legitimizing their anger and strengthening their case for extra support and recognition (see also McCartney<sup>63</sup>). Telling a story of victimhood could therefore act as a double-edged sword for older limbless veterans. On the one hand, this story legitimizes anger yet on the other hand, it traps the veteran in a ‘stigmatised’ identity.

### *Factors inhibiting independence (#3)*

*Adoption of a ‘victimhood’ narrative which traps the veteran in a stigmatised identity.*

One core aspect of the ‘victimhood’ narrative is the various forms of suffering endured by the participant. In participant two’s story, this suffering is manifested in physical, psychological, social, and occupational forms. Problems of pain and immobility also place particular limits on their independence. Importantly, each of these sufferings is causally attributed to the actions or inactions of others, which compounds the anger felt by the participant. In the participant’s own words, this situation is associated with a poor and demoralising quality of life:

*At the moment, how would you describe your quality of life?* (Interviewer)

*Poor to mediocre. Being left with in the situation that I am now at with not having a job is extremely demoralising. Being left with a leg that doesn’t work properly and does not give me the quality of life that I was told it would give me is*

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<sup>62</sup> McGarry, R., & Walklate, S. (2011). The soldier as victim: Peering through the looking glass. *British Journal of Criminology*, 51(6), 900–917.

<sup>63</sup> McCartney, H. (2011). Hero, victim or Villain? The public image of the British soldier and its implications for defense policy. *Defense & Security Analysis*, 27(1), 43-54.



*extremely demoralising. I have my girlfriend, we have our two dogs and if it hadn't been for my girlfriend and my two dogs I don't think I would be alive now. Because to me there is nothing worth living for personally from my own point of view. As I say no job, no quality of life, no health, being abandoned, it's extremely grim.* (Participant 2)

## Narrative Type 4: Life-as-Normal

Similar to 'minimisation', 'life-as-normal' narratives place a strong emphasis on being 'normal'<sup>64</sup>. This narrative differs from minimisation, however, to the extent that ongoing grief and anguish related to limb-loss remain 'bottled up' inside the veteran. Limb-loss and its after-effects are not necessarily denied in the 'life-as-normal' narrative, but they remain somewhat hidden.

One participant's story seemed to conform to the 'life-as-normal' narrative, whilst another described this as a 'past' story having later 'moved on' and begun telling a career-focused 'minimisation' story. For both of these participants, the initial grieving process following traumatic limb-loss seemed superficial at best:

*I grieved during that very short time of taking the bandages off [in hospital], see what I've got damaged and then moved on. It was a closing thing down, but the military training, military all the Northern Ireland stuff that I'd seen and done made everything easier. If I was a civilian I don't know if I would have coped. Being military, it was let's just move on and carry on.* (Participant 5, emphasis added)

Later in their interview, however, participant 5 revealed that they were still – over two decades post-amputation – suppressing anger and sadness about their injuries, the circumstances in which these injuries were caused, and the ongoing impact of multiple limb-loss on their life. These tensions would be released, "*like a blowhole*", only very infrequently:

*It's part and parcel of just being a victim of terrorism; me being you know, a sad story, most of the time, 99% of the time you know it doesn't come across, it doesn't worry at all. It's nearly the norm. I feel normal in a way.* (Participant 5)

One of the costs associated with telling a story of 'life-as-normal' therefore seemed to be the psychological burden of keeping one's struggles 'bottled up'. Further complications of a 'life-

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<sup>64</sup> Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.

as-normal' story are revealed in participant 5's comments about an unmet desire to pursue new romantic relationships:

*I don't want to feel desperate and I don't want to go on an internet site and the first thing I've got to put is that I'm in a wheelchair. But I don't want to be false so– it's like you know people say 'Go on the internet, you can find a girlfriend on the internet'. So you put a picture of your face and then you rely on somebody saying 'Oh [they] look cute!' But actually if I put a picture of my body in there, me sat on a chair without legs or in my wheelchair, then I just don't want to do that. I don't want to declare myself as a technically a severely disabled person. Because in your head you don't want to be that person, in your head you want to be normal.* (Participant 5)

Striving to appear – and to be – 'normal' in the aftermath of traumatic injuries can be an important way for amputees to cope and to move on in life<sup>65</sup>. Yet as these comments reveal, this can also mask a great deal of personal anguish that does not abate over time.

'Life-as-normal' can also be a story told for others' benefit, as the following comments demonstrate:

*They [family] were devastated, but I think what helped them was that I just threw myself into physical activities and doing things and keeping and getting fit. And I was very mobile very quick again, I was walking around, running again and things like that. So outwardly physically I was ok. I came to a lot of my troubles, my sadness about the whole thing, I kept it very internal for a long time. And because I didn't want to show it to them, I didn't, because I could see they were devastated for me anyway, they didn't need any more grief. So that was my way of protecting them. So that's how it was really for five years or so really and then I had a bit of a crash for that year. And then I got back on my feet again and carried on.* (Participant 29)

#### Factors inhibiting independence (#4)

*Narrating one's life "as normal" whilst holding back trauma and suffering internally.*

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<sup>65</sup> Jefferies, P., Gallagher, P., & Philbin, M. (2017). Being "just normal": a grounded theory of prosthesis use. *Disability & Rehabilitation*, 40(15), 1754-1763.

Attempting to live a 'life as normal' can be a way of protecting family members from the impact of traumatic limb-loss<sup>66</sup>. However, as described above, this comes at the cost of shouldering the burden of injury alone and not being honest (with oneself and others) about the true costs of traumatic limb-loss. For participant 29, telling a 'life-as-normal' story post-injury eventually led to a "crash", brought about by the realisation that *"I was in a bit of a turmoil because I was so lost with what I was going to do for the rest of my life."* This participant was later able to 'confront' and 'work through' the personal consequences of amputation – particularly the loss of their military career – and find productive new ways to live as a civilian. This eventually resulted in this participant telling a story about 'being normal' much more akin to 'minimisation' than maintaining the pretence of 'life-as-normal'. This is best summed up in the participant's own words: *"I'm an amputee; I don't go around wearing the label, I just get on with it."*

## Summary

Studying participants' narrative biographies helps to place their struggles to resist decline and to maintain independence into context. It shows that the way in which participants respond to limb-loss has a lot to do with their experience of military life and allows us to identify factors which promote or inhibit independence in old age. The analysis reveals that maintaining independence in old age is a combination of physical, psychological, social, and *narrative* functions. Accordingly, the focus of this chapter is on the multiple ways in which the *type of story* a veteran tells about coping with limb-loss and its many after-effects influences their experiences in both positive and potentially negative ways.

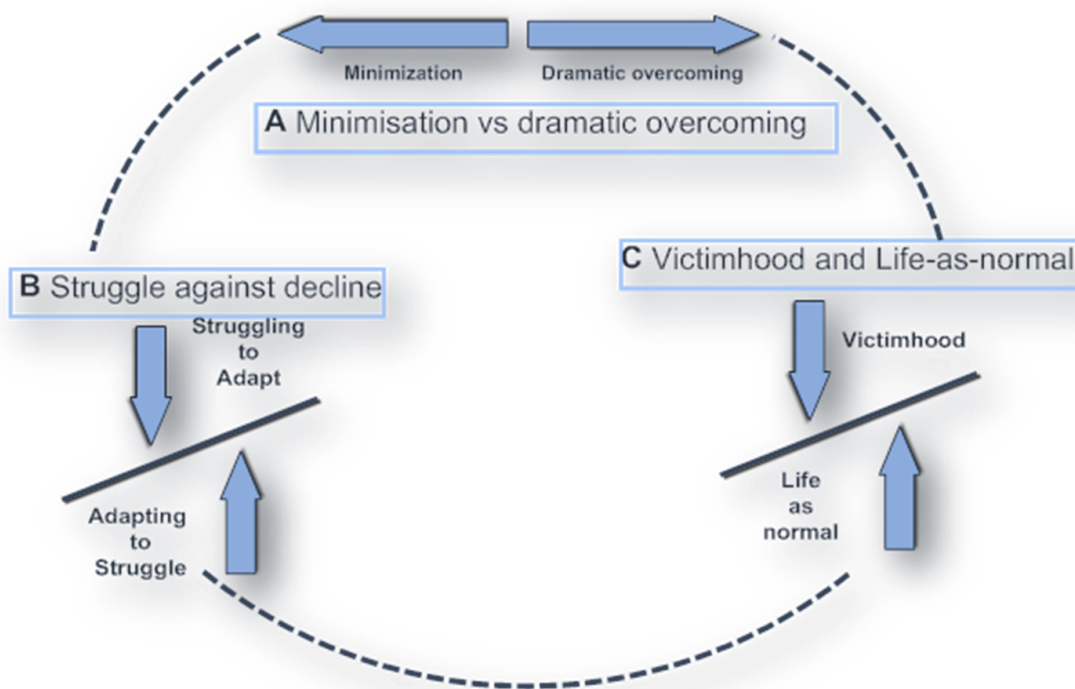
**Table 4.** Summary of factors promoting and inhibiting independence.

Factors promoting independence	Factors inhibiting independence
A resilient 'get-on-with-it' attitude grounded in a strong military identity	Rigidly adhering to 'get-on-with-it' attitude in spite of mounting physical, psychological, and social difficulties
Support in overcoming the effects of amputation-related impairment	Adoption of a 'victimhood' narrative which traps the veteran in a stigmatised identity
Lower level amputations with fewer associated 'impairment effects'	Narrating one's life 'as normal' whilst holding back trauma and distress internally
Maintaining a productive and fulfilling post-injury career	The pervasiveness of cultural narratives of 'dramatic overcoming', to which the majority of those affected by limb-loss cannot rise.
Well-fitting and functioning prosthetic limbs	
The availability of cultural narratives which allow for mundane 'hero narratives'	

<sup>66</sup> See forthcoming report from the Veterans and Families Institute on the impact of traumatic limb-loss on Blesma family members

The following conceptual model illustrates how each of the narrative types identified in this research are inter-related (each aspect of the conceptual model is discussed in further detail below):

**Figure 5.** Conceptual model of limbless veterans' ageing narratives.



**A Minimisation vs Dramatic Overcoming:** These are portrayed as opposing narrative types. Whilst the ‘dramatic overcoming’ narrative was not in evidence in the data collected here, this narrative is strongly present in the social milieu through events such as the Invictus Games. Whereas ‘minimisation’ narratives seek to avoid a focus on limb-loss and to downplay its relevance and impact upon the participant’s life, ‘dramatic overcoming’ narratives make limb-loss the focal point of the narrative – as the event which is heroically overcome, ‘beaten’ and battled back from via achievement and success.

**B The Struggle Against Decline:** The tone of the ‘struggle against decline’ narrative shifts according to the participant’s satisfaction with his or her ability to cope with pain and to overcome mobility restrictions. Quality of life appeared markedly better among those ‘adapting to struggle’. In contrast, those ‘struggling to adapt’ appeared closer to the ‘narrative of decline’ which traditionally portrays the ageing process<sup>67</sup>. Importantly, ‘adapting to struggle’ may shift

<sup>67</sup> Gullette, M. (2015). Aged by culture. In *Routledge handbook of cultural gerontology* (pp. 43-50). Routledge.

towards 'struggling to adapt' according to bodily deterioration, changes in health and mobility status, and the emergence of social isolation.

**C** *Victimhood and Life-As-Normal*: The dynamic relationship between 'victimhood' narratives and 'life-as-normal' narratives illustrate that 'life-as-normal' is one way of avoiding an oppressive and stigmatising 'victimhood' narrative. Elements of victimhood and suffering may remain in the 'life-as-normal' narrative, but these are covered up with the image of normality, which is sustained (and, perhaps, genuinely *felt*) as much as possible – for as long as possible.

Overall, this study of narrative biographies shows that positive stories of ageing with limb-loss are possible – likely, even. However, significant problems can also be experienced when veterans encounter increasing limitations on their mobility or capabilities, with decline and 'victimhood' unwelcome possibilities if difficulties are not addressed and overcome with appropriate and timely support.



## Results: Framework Analysis



In line with the framework analysis process, interview transcripts from four participants were analysed (see [Table 5a](#)). This generated an in-depth thematic framework which was then applied across the dataset using the auto-coding function of NVivo. This initial thematic framework was highly grounded in the specific details of participant accounts and provided a comprehensive index of themes, which then provided a foundation for further stages of analysis.

The next stage of analysis focused on interpreting and explaining the meaning and broader significance of sub-themes. Practically, this stage involved a reorganisation of sub-themes around the overarching themes developed, with decisions around the consolidation, amalgamation and reduction of themes driven by the extent to which these were supported across participant accounts. The result of this stage of the analysis is presented below in [Table 5b](#).

**Table 5a. Initial thematic framework.**

1.0 Physical	3.0 Social	4.0 Support
1.1 Ageing with limb-loss, co-morbidity	3.1 Access to services	4.1 Support from Blesma
1.2 Managing medication and pain	3.2 Awareness of support entitlements	4.2 Support from other military charities
1.3 Phantom pain	3.3 Care arrangements, responsibilities	4.3 Civilian vs. military rehabilitation/care
1.4 Physical fitness, mobility, daily activity	3.4 Education, training needs	4.4 Continuity of care
1.5 Prosthetics	3.5 Employment, career	4.5 Counselling, therapy
1.6 Rehabilitation	3.6 Family support and relationships	4.6 GP responses
1.7 Secondary complications	3.7 Financial circumstances	4.7 Job centre, welfare support
1.8 Socket pain	3.8 Friendship networks, social life	4.8 Legal support, processes
	3.9 Housing needs	4.9 Need to challenge healthcare staff
	3.10 Independence	4.10 Views of NHS
	3.11 Isolation	4.11 Peer support
	3.12 Press attention, media	4.12 Recognising non-conflict disability
	3.13 Quality of life	4.13 Recognising veteran-specific needs
	3.14 Social care	4.14 Self-funded or private care
	3.15 Spouse, relationships	4.15 Specialist care for limb-loss
	3.16 Transition into civilian life	4.16 Support from the military
		4.17 Veteran identity
2.0 Psychological		
2.1 Carrying on		
2.2 'Disabled' identity, stigma		
2.3 Mental health		
2.4 Motivation, self-belief, self-worth		



**Table 5b. Focussed thematic framework.**

1.0 Physical needs	3.0 Disparity of care	4.0 Stoicism
1.1 Ageing with limb-loss, co-morbidities	3.1 Access to services	4.1 'Disabled' identity and stigma
1.2 Managing medication and pain	3.2 Awareness of support/entitlement	4.2 Limb-bereavement (also 2.2; 4.5)
1.3 Phantom pain	3.3 Continuity of care/falling through the cracks	4.3 Veteran identity
1.4 Physical fitness, mobility, daily activity	3.4 Counselling/Therapy	
1.5 Prosthetics	3.5 GP responses	
1.6 Secondary complications	3.6 Lack of support (also 4.1; 4.2; 4.3; 4.5; 4.10)	
1.7 Socket pain	3.7 Need to challenge healthcare staff	
2.0 Social isolation	3.8 Views of NHS/lack of specialist care (also 4.15)	
2.1 Family support and relationships	3.9 Recognising non-conflict disability	
2.2 Friendships and social networks	3.10 Recognising veteran-specific needs	
2.3 Isolation	3.11 Military vs. civilian rehabilitation	
2.4 Peer support	3.12 Self-funded vs. private care	
2.5 Support from Blesma	3.13 Specialist care for limb-loss	
2.6 Support from other military charities	3.14 Transitioning to civilian life	
		5.0 Social care and welfare
		5.1 Care arrangements and responsibilities
		5.2 Education and training needs
		5.3 Employment/career
		5.4 Financial circumstances
		5.5 Housing needs
		5.6 Jobcentre and welfare support
		5.7 Legal support and processes
		5.8 Social care
		5.9 Support from the military

The final stage of analysis involved a process of further conceptualisation of themes. This was undertaken with a particular focus on the aims and objectives of the study, whilst considering the implications of the findings for policy provision. [Table 5c](#) shows the final thematic framework and associated subordinate themes. The numbers in brackets relate to the subordinate themes incorporated from the above table. Some of these were incorporated (and split) into more than one subordinate theme in the final table (therefore some numbers are shown twice). All subordinate themes in [Table 5b](#) were included in [Table 5c](#) (i.e. none were discarded between the second and third iterations of the thematic framework). This approach to analysis enabled us to work in an incremental process from themes grounded in the data, through to the more abstract interpretations of the wider significance and meaning of these themes.

**Table 5c. Final Thematic framework**

1. Barriers to transition	2. Disparity of care	
Employment (3.14, 5.2, 5.3, 5.6) Legal support, processes & disparity of compensation (5.4, 5.7, 5.9) Stigma (4.1) Loss of military identity (3.9, 4.3, 5.3)	Continuity of care (3.1; 3.2; 3.3; 3.4; 3.5; 3.12; 4.2) Military vs civilian care (3.6, 3.7, 3.8, 3.9, 3.10, 3.11) Prosthetics (1.5; 1.6; 3.13)	
<th style="background-color: #4F81BD; color: white;">3. The enduring challenge of limb-loss</th>		3. The enduring challenge of limb-loss
Dealing with pain (1.2; 1.3; 1.7) Mobility (1.1; 1.4) Physical isolation (2.3) Social networks (2.1; 2.2; 2.3; 2.5; 2.6) Stoicism (4.1; 4.2; 4.3)		

As shown in [Table 5c](#), this stage of analysis culminated in the generation of three superordinate themes which are discussed below in turn. These include: 1) the barriers participants experienced on transitioning out of military service and into civilian society; 2) the disparities in care experienced; and 3) the enduring challenges experienced by participants as they age with limb-loss.

## Barriers to transition

The data demonstrates that the loss of a limb represents a major disruption in participants' intended life-course, the extent to which social roles and relationships can be upheld, to self-identity, and to the ways one is viewed and treated by others. This theme reports on the far-reaching impact of limb-loss that participants reported.

### *Stigma*

The stigma attached to having lost a limb, or being 'disabled' had a significant effect on how the participants adjusted to their injury and transitioned back to civilian life. Participants described their difficulty in coming to terms with changes to their identity following limb-loss, suggesting that they struggled to accept being labelled as 'disabled', and stressed their efforts to project an image of 'normality' in everyday life:

*I don't want to declare myself as a technically (umm) a severely disabled person. Because in your head you don't want to be that person, in your head you want to be normal.* (Participant 5)

Participants suggested that they felt a sense of shame or embarrassment over their limb-loss when in public and many disguised their limb-loss by avoiding wearing shorts, opting for cosmetic prostheses, and practicing walking with a regular gait. A generational shift in attitudes to displaying prostheses was apparent however, with the participants in this study observing that the new generation of veterans with limb-loss appear more comfortable with displaying their prosthetic limbs than older veterans:

*I wanted to be (umm) you know accepted as normal. Actually I'm not really very (umm) much in favour of the way that the modern amputees look on their prosthesis because you know they don't care about the bits of leg sticking out.*  
(Participant 4)

The internalised stigma felt by participants was often reinforced by the attitudes and treatment of others encountered in daily life. Participants described a difficulty conversing with people without a disability, and expressed their frustration at being subjected to voyeuristic questions. Some reported patronising or derogatory remarks by both members of the public and professionals, which reinforced the perceived stigma:

*I was in a wheelchair for a while and there was a tendency to be talked down to. (umm) You know '[Do they] take sugar?' that sort of thing.* (Participant 6)

*I still didn't find it easy to talk to... normal... non-disabled people...I mean I thought well there's no empathy with you, I mean you're just... you're just asking me all these questions because you're nosey!...And you're prying.*  
(Participant 14)

The participants observed that there has been a marked change in attitudes towards veteran limb-loss over recent years and attributed this to the work of charitable organisations who have increased public awareness, as well as events such as the Invictus Games and the Paralympics.

*So yeah I think purely because of media exposure, people's attitudes have changed... there's more of an acceptance... I think it's purely based on the number of people being injured, people probably met many more injured ex... you know servicemen and women, (umm) there's... sporting... sporting events on (umm) Paralympics on TV, you know the London Paralympics. A lot of my friends were absolutely glued to it. (umm) There is a general acceptance of*

*disability and level of education to be brought is such that there's much greater acceptance.* (Participant 6)

### *Loss of Military Identity*

Participants described a sense of grief over the loss of their military career, networks and identity, which compounded feelings of social dislocation. Motivations for joining the military were often connected with participants' assessment of their educational ability and the life choices open to them. For those who did not see formal study as a career option, the military offered opportunities for learning and development, which participants had sometimes prepared for from an early age and anticipated to be life-long. While some participants were able to continue to serve in the military post limb-loss, most were not. Participants who described their early ambitions to join the military and envisioned serving for a full career, reported that they had devoted little consideration to what they might do if or when they had to leave service:

*I hadn't really give a lot of thought to well what will I do if I leave the army? What will I do if I got injured? You didn't think about that necessarily. (umm) Maybe one or two would, but I hadn't. I was so career-driven you know and faced on the army. I hadn't really thought about what if. So that was a big shock.*  
(Participant 29)

Participants in this position often reported that they found themselves particularly unprepared for transitioning back into civilian life, and described how, as a result, their shock on leaving the military was significant:

*I saw my career destroyed, I saw my... quality of life destroyed. I saw my physical fitness destroyed.* (Participant 2)  
*And it was the realisation it's the end! It's now a new life. Army over, military over, you're now a civvy. (umm) Scary!* (Participant 29)

However, even where it was possible to continue service, participants expressed their frustration that they would be unable to advance their careers as planned. Greater experience of civilian life prior to joining the military appeared to facilitate better adjustment during this transitional period. The following participant drew comparisons between their experience, and those who joined the military at a young age:

*I mean I knew a bit of it before I went in so I was basically more prepared to come out on Civvy Street than someone who got in when they were young, did*

*their service and then come out... oh!! I can't imagine it. You know it must have been really hard for some of them. That's why... a lot of them end up on the streets because they can't cope. It's all done for you.* (Participant 12)

Indeed, many participants described having satisfied ambitions by developing a career outside of the military, or in the military charitable sector. Nevertheless, findings point to the increased vulnerabilities of those who joined the military at a young age and who anticipate a life-long military career when transitioning back to civilian life.

### *Employment*

Finding alternative employment was crucial for participants in terms of re-forging a sense of purpose and maintaining independence when transitioning back to civilian life. The shock felt upon leaving the military, was exacerbated when participants had limited opportunities open to them for retraining and alternative employment. Education, skills and training developed through the military were not necessarily transferable to the civilian sector, with limitations imposed due to limb-loss further restricting options for a change in career:

*They'd advise you 'Well really looking at what you did in the army, I mean really your skillsets [name] are you know well maybe you can do bricklaying? Oh no you're an amputee now, you might struggle on sites and well really your bricklaying days are over! Can't do that, yeah. You were a diver in the army, mmm you can't do diving anymore, no one's going to insure you. You can't do that. Don't jump out of planes as a civvy, you can't do that. Mmm! Well we need to tap into your leadership skills and your (umm) blah, blah, blah'.* (Participant 29)

Limitations in personal financial resources, and a lack of grants available to support education, constrained opportunities for participants to undergo training or to attend university. Pressure to earn an income acted as a further barrier to engagement in education for some, although again, support in this area was described as having improved for current generations of limbless veterans:

*I think it's a good thing for the (umm) the latest... the latest veterans if you like or the injured (umm) the WIS community - wounded injured sick community. For them that they've benefited massively. (umm) I think if I had that sort of support (umm) in my early injured years than I would possibly be in a different place now in a sense of employment wise, I don't know. I probably would have gone to university. I could have myself, I could have gone, I could have applied, an access course and gone. But I just felt I had... I just felt I needed to get a job, I needed money. (umm) How was I going to sustain myself going to*

*university? You know who was going to pay the fees? I couldn't afford to pay it.* (Participant 29)

Many participants reported difficulties in obtaining employment after limb-loss. This was not only attributed to the impact of limb-loss upon physical capabilities and the limited availability of jobs, but also a perception that they were deemed to be unattractive to potential employers as a result of their disability. Where possible, many participants therefore preferred not to disclose their limb-loss to potential and actual employers in order to counter the risk that they be may discriminated against:

*I didn't want people to know I had one leg basically. You know they might have seen that limp and wondered what it was. (umm) So when I applied for a job I would never tell them I had a disability...I mean even now I will tell... apply for jobs I wouldn't tell people I have a disability, they need to find it out if they want to know.* (Participant 6)

The majority of participants articulated a preference to continue working after injury and the difficulty finding employment following limb-loss was described as highly detrimental to participants' self-worth and self-esteem:

*Being left with in the situation that I am now at with not having a job is extremely demoralising.* (Participant 2)

*So when I had a job I think that's... as soon as I got a job, you know my self-esteem was raised rather than just being some dribbly underdog.* (Participant 6)

The harmful effects of unemployment were connected with a reluctance to rely upon welfare support, which provided an additional layer of stigma for participants. This sometimes led participants to a decision not to apply for their benefit entitlements:

*I don't want to be seen as a charity. I want to know that I can go out there, earn the money in my own right and be able to pay for people to do this and not have to get it... get moneys from third parties to help me... That's why I won't apply for all the disability benefits because I don't want them. I don't want to be... I don't want the label to... for the country to label me as a scrounger and as a dole-dosser and that. I'm not a dole-dosser, I'm not a scrounger. I want a job.* (Participant 2)

*I mean they frighten the life out of you headlines on papers!.. You know the disabled are (umm) taking all this money and (umm) you know (umm) that we*

*haven't the rights to all of this, that and the other and I... I think I got a bit frightened.* (Participant 17)

While finding employment was extremely important to the majority of participants, the more pressing issue was the perceived lack of support around re-training and employment advice and assistance. Many participants suggested that they would have appreciated receiving greater support in this area. Participants were specifically critical of the military for a lack of advice and assistance around gaining post-service employment or re-training:

*I really cannot remember any specific employment support or any support from the military at all... I think it was pretty much non-existent, you're out of the military now.* (Participant 6)

However, some participants suggested that support from the military with regards employment and resettlement has since improved.

#### *Legal Support, Processes and Disparity of Compensation*

The data suggests that access to compensation and pension entitlements were a significant factor in the maintenance of independence among participants. Receipt of these financial entitlements was hugely important in signifying recognition of military contribution, providing a form of recompense in light of reduced earning power, and reducing reliance upon charitable support. There was variation in the level of compensation received by participants. Some described experiences of financial difficulty due to the amount of compensation that had been allocated to them, while others suggested that this had provided them with financial security:

*Yeah we haven't got a bad quality of life compared with a lot of older people. (umm) I've got a part-army pension, [name]'s got her private little pension. It stops us getting a lot of... help, money-wise...* (Participant 12)

Compensation was dependent upon factors such as whether limb-loss was sustained during or after service, or whether it was 'attributable'<sup>68</sup> or 'non-attributable'<sup>69</sup>. The participants highlighted a perceived inequality regarding the entitlements of those who lost a limb during service, and those injured during peacetime or outside of the military:

*So those that... that would be in my situation, but through conflict they get the best of the best. Those that have served Queen and Country by being injured through peacetime, they get nothing. Big discrepancy.* (Participant 2)

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<sup>68</sup> Attributable injuries are those sustained on operational duty, e.g. Korea, Northern Ireland, Falklands etc.

<sup>69</sup> Non-attributable injuries are those sustained whilst still serving, but usually from sporting accidents, road traffic collisions etc.

*I only got (umm) a lump sum compensation which was three years pay. That was it, no pension, nothing else. I don't get a disability pension in this country because I wasn't a member of Her Majesty's forces at the time.* (Participant 24)

One participant was particularly dissatisfied with their treatment, feeling that they had been unjustly dismissed from service rather than medically discharged so that the military could avoid the provision of compensation and a service pension. In addition, participant 5 felt that the veteran identity was being devalued by the volume of people applying for compensation, questioning their legitimacy to do so:

*I don't want to be part of it because in my personal view some people are jumping on the bandwagon and being an injured veteran is nearly becoming the norm now. It's a case of 'Oh I remember when we had trouble in [Northern Ireland] or (umm) you know I wonder if we could get some money out of this or whatever'. I've had my time and I'm very grateful to compensation schemes and war pension.* (Participant 5)

The process of applying for compensation for participants of this study was considered to be lengthy, impersonal and remote. Participants felt uninvolved in the compensation and war pensioning process and they felt unable to question the outcome:

*But then a blooming... an accountant person sits there on a machine and reduces your claim by 30%. And we have to accept it. We have to accept what the barristers and the lawyers and people say.* (Participant 5)

Some participants pointed to the inadequate legal representation received (through the military or otherwise), and difficulties affording legal advice. Indeed, many participants reported a lack of awareness of their financial rights, and received limited advice in this area. Given the difficulties navigating the compensation processes, and the potential for disempowerment when navigating these systems, participants relayed the importance of advocacy provided by veteran charities in enabling them to access their entitlements:

*And they [military] provided no advice on war pensions.* (Participant 6)

*Even through the process of applying for war disability pension, (umm) it has been a nightmare. Without the help and the support of the Veterans Agency, I doubt if I would have got anything now.* (Participant 2)

In summary, this theme identified a cluster of factors which may represent a barrier for limbless veterans in terms of their successful transition back into civilian life. The capacity to secure fulfilling post-injury employment was fundamental to participants' perception of successful



transition. However, analysis revealed a number of factors which may inhibit limbless veterans' capacity to secure employment. Participants who joined the military at a young age typically possessed limited pre-military education or civilian work experience. Not only did these participants report significant psychological difficulties in adjusting to the loss of their military career, but they also experienced challenges in securing post-injury employment as their skills were often deemed to be non-transferable to civilian roles of employment. The inability to engage in re-training or further education following limb-loss due to financial and practical constraints inhibited participants' capacity to improve the employment opportunities available to them.

Participants also highlighted a barrier to transition posed by perceived social stigma towards disabled individuals and the unwanted attention of others in public. This was associated with feelings of shame and embarrassment and a reluctance to disclose their disability. Finally, participants described financial barriers to successful transition. Compensation is dependent upon a range of factors related to the severity and context of the injury. As a result, some participants received compensation which provided them with financial security, while others experienced financial hardship. Participants felt that inadequate compensation hindered their capacity to transition successfully into civilian life. Participants felt alienated from the decision making process around their compensation entitlements and also felt unable to challenge the outcome of this decision making process due to the costs of legal representation.

## Disparity of care

Throughout the interviews, participants identified a number of dimensions of inequality with regards to the care they received following limb-loss. Some inequalities experienced were connected to being a veteran, namely the variation between military and NHS treatment, while others stemmed from more generic geographical or service related factors such as a lack of continuity in care, and the models of prosthetics available.

### *Continuity of Care*

Individuals reported a lack of continuity in their care, which had a detrimental impact upon their ability to recover from, and manage their limb-loss. Participants described variation in the quality of care between different centres, sometimes describing a '*postcode lottery*' with respect to access to care. As a result, some participants resorted to paying for private care, while others reported the need to travel long distances in order to access required services:

*The physio it was a... a fifty mile round trip, three times a week.* (Participant 8)

*There aren't any facilities that in [city] at all, (umm) so I have to go to [another city] every time.* (Participant 26)

Participants also discussed the impact of poor continuity of care between named healthcare professionals, with this increasing the time taken to receive prosthetics and resulting in conflicting advice being received:

*A mishmash of specialists intervening and giving you conflicting information.*  
(Participant 2)

The failure of health services to take responsibility for the provision of care, and a lack of co-ordination of treatment, was another aspect to a perceived poor experience of care, resulting in a feeling of not knowing where to turn to for support:

*The GP can do nothing. District nurse says it's not their business and (umm) OTs no, physios no. You need... what you need is somebody... who is looking after everything that you have that overarches all of these things and you go to them and they said 'Leave it with me and I will phone the appropriate body.*  
(Participant 25)

While the majority of the data highlighted participants' difficulties in the area of healthcare, there were also some issues identified around social support:

*So they... when I first came out of hospital they put me on full care, higher rate. Now two years later for some unexplained reason, they've put me back on the lower care because I was managing. 'Oh you're managing alright, you can...*  
(Participant 8)

### *Military vs Civilian Care*

Much of the discussion around care centred on the differences between military care, and care provided by the NHS, including the transition between the two healthcare services. Connected with the sense of loss over a military identity articulated above, participants typically favoured care provided by the military:

*I mean I enjoyed it, I enjoyed it at Headley Court.* (Participant 14)

Some preferred military-based care as they felt that the care provided by the NHS was substandard. This was sometimes suggested to be the result of a lack of available care, an unsatisfactory environment or extensive waiting times. In addition, many participants drew attention to a lack of specialist treatments available within the NHS in terms of both mental health, and particularly around the ability to fit and manage prosthetics:

*You've to wait a lot longer [in NHS hospitals].* (Participant 15)

*For many years of NHS. [PTSD] wasn't recognised.* (Participant 1)

*The NHS there is a massive lack of qualified prosthetists who can actually deal with the robotic legs.* (Participant 2)

However, military-based care was not only preferable due to the perceived inadequacies of the NHS. Participants also described the importance of the military environment in itself. In the context of feeling bereft of one's military identity and surroundings, military-based rehabilitation offered participants the opportunity to receive care within familiar surroundings, alongside those with whom they possess shared experiences (military service). Participants commented that the rigorous structure and intense forms of exercise and rehabilitation which are central to military approaches to rehabilitation, are reminiscent of military training. Rehabilitation within military systems was also valued for fostering peer relationships and providing a competitive yet supportive environment:

*Headley Court was great for the military mind. You were called by your rank and you call other people by your rank, so it got you back into the swing of things.* (Participant 5)

*The peers in... in the rehab centre, they're just people just like being in the unit. So it's not a matter of support, it's... you know having fun, getting on, making friends.* (Participant 6)

Despite the general preference of military care, to that of the NHS, some participants reported that the military did not provide them with sufficient follow-up care for their needs, and discussed their disappointment with the lack of support they received post-injury. As a result, a number of participants had resorted to funding their own care privately:

*I've had to go and get (umm) EMDR therapy off my own back. I've had to go and get psychiatric help off my own back. I've had to get counselling off my own back. I've had to pay for some of this. There's nothing through the military, there's no help and support. (umm) So yeah I'm a damaged person that is trying to rebuild himself and it's painful. It's painful, its... it hurts and it's also... leaves an extremely bitter taste in my mouth.* (Participant 2)

*There was no support [from the military]! [laughter] I got home and it was... I was like that... and it wasn't until somebody visited me (umm) a through care life officer.* (Participant 27)

Indeed, one participant recalled a change in the level of support they received after leaving the military, with this once again highlighting the risk that veterans may be left without support during the significant transitional period of early adjustment to limb-loss:

*While you're still in the military it's available, once you leave the military [switch noise] no Headley Court. Nothing.* (Participant 5)

Given the perceived lack of support provided by the military post-service, participants highlighted the importance of support provided by Blesma and other charitable organisations:

*Blesma really were very instrumental in my recovery, totally. More so than the army. (umm) The army's recovery was about physically recovering at Headley Court so getting a prosthetic limb, getting up a bit mobile. (umm) That was fine, that's probably as good as it could have been.* (Participant 19)

### *Prosthetics*

The participants highlighted an inequality in care in relation to the quality of prosthetics and fittings which veterans are able to access. Participants reflected in particular, on disparities experienced in relation to the provision of limbs, the process of rehabilitation, and experiences of unsatisfactory care. It is imperative to consider differences in the nature of limb-loss between the sample, as some participants' limb-loss was attributable to their service (either during or after service), whereas others lost their limb due to post-service accidents or illness. This fundamental difference impacts upon policy and services provision, as those with attributable limb-loss are eligible for MOD care, whereas others will have always been under the care of the NHS. Those with limb-loss in service, and/or attributable to service, gave examples of the multiple limbs they had received since amputation. Rather than preferring technically advanced limbs, fit and comfort were of paramount importance. In particular, individuals described the importance of socket fit and suggested that ill-fitting sockets were a major issue among amputees:

*Forget the fancy knee joints and technology below it, but the fit is the main thing.* (Participant 6)

*Most amputees in there are having trouble with the sockets.* (Participant 33)

That said, individuals with limb-loss in service, and/or attributable to service were also conscious of the cost of the limb itself, and once under NHS care, acknowledged how the affordability of limbs affected their care:

*The NHS have said full stop they can't afford to do it.* (Participant 2)

*A couple of us we managed to get the.... or get the government that's right to pay for them to make us a couple of legs and see how they went. And they were the best legs I've ever had.* (Participant 28)

Some participants highlighted the different regulations of acquiring limbs for younger amputees, and the higher quality prosthetics available to those injured during compared to outside of service as a further illustration of disparity in care:

*I mean look at them now, they get £50,000 legs and aftercare and everything. But before it was just a case of get on with it, you're a wimp.* (Participant 27)

*So basically if they wanted seventy grand all singing, all dancing knee (umm) foot, they can get it. So theirs were quite smart where mine looked like it'd been knocked up in my garden shed, my first one.* (Participant 30)

Interestingly, participant 27's limb-loss was attributable to service and they made a direct comparison to younger service personnel receiving the same care. In contrast, participant 30's amputation was a result of a post-service accident and care was provided through the NHS.

Rehabilitation was pivotal in the care process post-amputation, with participants highlighting the need to learn *"a new way to walk"* with their prostheses. However, while imperative in enabling participants to get on with their lives, participants highlighted the interruption of rehabilitation over everyday life, which therefore hindered their return to normality:

*Amputation I thought would... would end the hospital visits and also hopefully I could get back to normal life really. (umm) I didn't know anybody that... had a false leg.* (Participant 15)

Due to this continued and *"life-long"* rehabilitation, one participant referred to the prosthetist as the *"most important person in your life, next to your family"*. However, not all individuals experienced this level of rehabilitation, with some individuals (both those with limb-loss attributable to service and those with non-attributable limb-loss) describing non-existent services, or long waiting processes post-amputation:

*It were a month or so before I could get my first prosthetic limb [through the NHS] because obviously you're all angry, your stumps all angry and sore and sorting yourself out.* (Participant 30)

*[The NHS have] given you the leg, we've told you how to walk, off you go and you just get on with your life.* (Participant 2)

*I had no rehabilitation [from the MOD].* (Participant 14)

This theme demonstrates several facets to inequality in the care experienced by participants. Disparities highlighted here mark important aspects of experience which help to explain variation in the subsequent trajectories of participants' personal stories as they adapt to and re-build their lives following limb-loss.

## The enduring challenge of limb-loss

This theme deals with the everyday and enduring challenges associated with ageing as a limbless veteran which were identified by participants, and the ways in which they sought to deal with them. This includes: a consideration of pain management; the process of grieving over the lost limb; issues around mobility, physical isolation; social networks; and a stoic attitude to dealing with limb-loss.

### *Stoicism*

Participant attitudes to living with limb-loss were, for the most part, characterised by stoic acceptance, the majority of whom self-ascribed to a philosophy of 'getting on with it' or 'carrying on' in relation to managing and adapting to their limb-loss:

*you've got to have the right attitude to these things I think. But personally I'm the sort of bloke who says I don't care, it don't matter or it don't matter, I'll get over it. That's my attitude. And whatever happens in your life if... you've got to adapt to something different, you either adapt or you go under as far as I'm concerned* (Participant 12)

*so it was just carry on as normal really wasn't it* (Participant 15)

*you've got to get on with it, it's not going to change* (Participant 19)

In addition to displaying an attitude for 'getting on with it', many participants described their staunch independence and expressed a reluctance to rely upon others or to ask for help or assistance. While this potentially created a barrier to accessing formal and informal sources of support, this was not always the case, and participant 5 described an increased willingness to accept help as they aged:

*As long as you're not too proud to not ask for assistance. And I think there is something in that... I am so independent, it is difficult to actually go to them and actually say (umm) ' I need help' And what is more vital? Practical help, financial help, welfare assistance, you've got to just (umm) accept...* (Participant 5)

*you're on the street and you're struggling a bit with a bag or something and somebody comes up to help you, I get... I used to get a bit prickly about them because I... my thing was independence. Even if I was in absolute agony and somebody... my stump bleeding and all sorts of things, I would pretend I'm fine. I don't need any help. Thank you very much! I'm more inclined to accept help now. I mean now I'm a bit... no I don't get prickly, but (umm).* (Participant 6)

This attitude of carrying on despite adversity was attributed to a military mind-set and approach to coping with loss:

*If I was a civilian I don't know if I would have coped. Being a military, it was let's just move on and carry on.* (Participant 5)

*Because the army don't give you time to grieve, you just carry on and get on with it...it's time to get drinking and pissed up and then just forgetting about it.* (Participant 27)

### *Dealing with Pain*

Participants described enduring significant amounts of both generalised stump pain and phantom limb pain throughout their everyday lives. A considerable amount of pain was attributed to ill-fitting limb sockets. Participants reported pain levels which were largely uncontrolled, and described pain impacting upon sleep, their mood, and their mobility (either directly or by preventing them from using their prosthetics):

*I've got constant pain twenty-four hours a day, all the time.* (Participant 8)

*Phantom pain is also a bore. About once a month it comes on in my right stump which jumps around and prevents me walking or sleeping.* (Participant 7)

*I'm trying to work out what's phantom pain and what's proper pain and all this. If you know there is a difference* (Participant 33)

Furthermore, many participants suggested that clinicians struggled to manage their pain levels effectively and therefore resorted to prescribing high doses of strong painkillers. Participants described their difficulty functioning while taking such medications and expressed a concern that they were becoming medication-dependent:

*And that was part of the negligence, overdosing morphine.* (Participant 8)

*I've been in pain I've been to the pain clinic and they've tried every blinking thing on me, to no avail.* (Participant 11)

*they give you a carrier bagful of medication, Tramadol, Oramorp... and I obviously did... I got addicted to morphine.* (Participant 23)

In addition, data illustrated that prescribing high quantities of medication could constitute a risk to the safety of veterans with comorbid mental health issues:

*I'd stacked all the morphine and all the other tablets I had and I sat there with a pint glass and I emptied a blister of tablets into my mouth.* (Participant 2)

### *Mobility*

As a result of pain or ill-fitting limbs, many participants described mobility issues which impacted upon their ability to undertake everyday activities and which impinged upon their quality of life, their self-esteem, and their ability to maintain independence:

*It's crucial. Mobility is absolutely crucial. It would mean that I have a better quality of life, I'd have independence.* (Participant 2)

While some participants were able to stay active and maintain their engagement in fitness and leisure pursuits, others described their struggle to undertake more basic activities of daily living. Data suggests that changes in physical capability sometimes required psychological, as well as physical adjustment, potentially resulting in frustration, or where appropriate support was received, the capability to retain the ability to fulfil usual activities and social roles:

*I was always (umm) a very practical person. I've done everything in houses, I've built extensions (umm) and (umm) maintained cars and all that sort of thing throughout really. And of course you can't do these things now, not well enough to be satisfied with it.* (Participant 26)

*I picked [name] up on my shoulders and I walked there and I didn't feel like [they] were going to come tumbling down from six foot you know in the air. (umm) And they were... you know I could have filled up, I were filling up walking down the road with my daughter on my shoulders like any other parent! You know? Another big thing!* (Participant 30)

The ability to continue driving after amputation was extremely important for participants with regards to maintaining their quality of life:

*Once I got a prosthetic limb I was able to drive my car you see. I had to then have an automatic.* (Participant 11)

*the first thing I thought about was 'How am I going to drive my car?' And I thought well I can get an automatic, get it altered.* (Participant 12)



The age at which limb-loss occurred also affected the regaining of mobility, with younger veterans described as more able to become accustomed to walking with prosthetics. Likewise, participants described the complications that limb-loss posed to the usual ageing process due to the stress that walking with prosthetics imposed on the body, and the coexistence of limb-loss with other long-term conditions. Risk of falling when walking with prosthetics was also a common issue experienced by participants, with this also noted as more difficult to endure with age, and as potentially inhibiting mobility. In this respect, trips outside of the home or to unknown places were noted as particularly difficult by participants:

*And the deterioration side of things because of the accumulation of injuries and then the compounding effect of each against the other, means that maintaining mobility, independence is much more difficult than it was. (Participant 9)*

*I think the younger... the guys, the twenties and the thirties and what not that you know have a lot of years to go and were fitter and what not and could resist... make the falls without breaking things and what not. (umm) They were able to master this thing. (Participant 26)*

*Because I... I can't actually stand up. Yes it's... I've got to be very careful not to put any weight on that leg otherwise I'll go straight over (umm) and maybe break it and my hip as well. (Participant 17)*

Some participants pointed to differences in their ability to continue everyday activities depending upon the nature of limb-loss; this was typically described as being more difficult for those affected by upper limb or double limb amputation:

*this incident has completely changed your physical (umm) presence really. It's loss of legs, two legs, is completely different (Participant 5)*

*Never stopped us doing much to be truthful. I mean I say if it'd have been above-knee, it would have been a bit more... a bit more of a handicap I imagine. Can't bear thinking about it. (Participant 15)*

*Yeah independence is important. (umm) To be able to do things, you know lift, carry, paint, drive, pick up the kids, (umm) you know mow the lawn, all those sort of things where maybe above-knee guy or worse would maybe struggle with that. (Participant 29)*

Given their difficulties in keeping up with everyday activities, participants valued the financial assistance provided by Blesma or other charitable organisations to cover home adaptations and support with gardening.

### *Physical Isolation*

Connected with mobility issues and difficulty in forming social relationships, many participants described a sense of physical and social isolation following limb-loss. Some described how a difficulty getting out of the house had resulted in them feeling like a “prisoner” or “trapped” within their own home:

*Because it's amazing how many people around the... around the country, not just around here, who are in the same position as me and they're in their house and they feel trapped. (Participant 27)*

*I can't relax. So I don't go out socially anymore... So... so you do feel isolated. (Participant 8)*

*loss of mobility and the closing in of the environment for someone does induce those feeling of despair, despondency, isolation, and worthlessness. (Participant 10)*

This physical isolation resulted in feelings of loneliness among some participants. One participant described a particular vulnerability to loneliness at certain transition points in life, for instance, the death of their partner and when their children left home. Another described how the loneliness worsened during specific times of the year:

*I think personally it's the (umm) leaving the nest syndrome has hit me quite hard. (Participant 5)*

*It doesn't mean I don't get lonely. I do and I sometimes feel it badly. Times like Christmas are appalling for me. (Participant 9)*

Others pointed to more general trends such as the dissolution of social connections within local communities, as well as the shrinking of social circles with age, as factors further contributing to the experience of isolation and loneliness:

*There is very little interconnection between everybody in this street I would say. And (umm) so that ain't going to get any better. (Participant 26)*

*So you know these social acquaintances are getting smaller and smaller inevitably. (Participant 14)*

One participant suggested that there is a paucity of acknowledgement and support around issues of physical or social isolation and loneliness in comparison to that which is devoted to physical needs. The social activities provided by Blesma were therefore highly valued for combating isolation. However, geographical distance from where activities were commonly offered, as well as caring responsibilities for others, sometimes prevented participation.

Offering a greater number of social events within Blesma was therefore suggested as a potentially beneficial recommendation:

*We all talk about the... the physical problems with phantom pains and (umm) socket fittings as a physical painful side to limb-loss. But mentally, its... you know a terrible thing to be lonely and (umm) I think social events needs to be increased and the importance of social events in Blesma.* (Participant 5)

*I do feel a bit isolated up here because 95% of all the events that Blesma organise are [south of the border] and mainly [south of Birmingham].* (Participant 14)

### *Social Networks*

Some participants described how limb-loss had altered their ability to form and maintain relationships due to concerns around self-image, an inability to engage in similar activities to others, or other people's assumptions that limbless veterans and their families would become reliant upon them:

*It's very hard to make friends because you're not on the same level socially as people. You can't do the same things as couples.* (Participant 25)

As such, opportunities provided by third sector organisations were extremely important in helping participants to stay socially connected, facilitating connections among 'likeminded' people who shared the 'military mentality' and 'squaddies humour' and providing a sense of comradery:

*Like-minded people with limbs missing or the loss of use of limb. It's great banter, it's military, it's (umm) social and (umm) I you know I don't think I could do without it.* (Participant 5)

*you've got this comradery where you know where... it doesn't matter what unit you're in, whether your army, navy or air force, you just get together, you've been through similar things, you just get there and chat.* (Participant 27)

In addition, activities and events provided by third sector charities worked to inspire confidence and hope by instilling a sense of accomplishment and by demonstrating that it is possible to adapt to limb-loss and continue to live a fulfilling life. Participants described a reduced ability to engage with physical challenges offered as they aged, instead opting to engage in less intense activities such as photography.

*There are a lot of people out there who are much older and you tend to find that a lot of photographers are older (umm) who spend a lot of time at home on*

*their own. I think the photography thing has really opened up a world for people. Socially and culturally (umm) and has helped people develop including myself in fact because I love photography.* (Participant 6)

*Someone will look at you doing something and they'll say 'You can't do that' 'Watch me!' As soon as they say you can't do it, it's a challenge!* (Participant 1)

*It gives reassurance that they're at... at the end of all of this, there is light at the end of the tunnel. And that it can turn around.* (Participant 2)

Participants also noted the importance of social networks which are not military specific. User groups and peer support forums for those who have experienced amputation more generally were highly valued. These groups provided a forum for the sharing of practical tips for coping with limb-loss, using prosthetics and facilitating mobility. Those with access to user groups suggested that this had been integral to their ability to adjust, whereas those who had not received this form of support felt that this would have benefited them greatly, particularly during the period of early adjustment to limb-loss.

*That would have been a big help. People who've been in the same position as I... even if they've lost one leg or one arm, it's still... had that feedback from them, but I had nothing.* (Participant 10)

*They didn't give any guidance at all on this and we became aware later on that certain (umm) parts of the country had (umm) user, prosthetic user groups that met and discussed obviously you know things. That doesn't apply to this area at all. So you had to work it out for yourself... most of the information that I have has been gained from going to the clinic and meeting a lot of people that were there on the same day you know. And (umm) seeing what they've got fitted.* (Participant 26)

Another function of peer groups was to provide an opportunity for social comparisons amongst individuals experiencing limb-loss. Participants often suggested that reflecting upon the situations of those worse off than themselves helped them to accept their own injuries:

*Seeing somebody worse off than yourself is a big psychological lift really... amputees look at other people, fellow amputees, and gauge where they are. So I thought I'm better off than [name] and you know I'll get on with life.* (Participant 5)

Participant's not only benefited from receiving support from others within these forums, but readily provided advice and assistance to others in a similar position to themselves, with this also appearing to bolster their own self-esteem:

*Yeah because I think if you're helping other people ... moving onto them, they're helping you as well.* (Participant 33)

## Summary

The framework analysis identified three superordinate themes within the participant's life-stories. These three superordinate themes, *Barriers to Transition*, *Disparity of Care*, and *The Enduring Challenge of Limb-loss*, identify the significant challenges participants face across the life-course from the point of limb-loss. The findings within the *Barriers to Transition* theme highlighted the dissonance experienced by the participant, and the impact that limb-loss had, not only at the point of loss, but the ongoing challenges to transition long after service. The data suggests that many participants struggled with the loss of their military identity well into old age, and rarely viewed themselves as having a disability. This, however, appeared to change when ageing impacted their mobility, which subsequently lead to ever increasing social isolation. Employment and adequate compensation were crucial factors in helping participants to maintain their independence post limb-loss, not only in the early years following loss, but also into old age. Greater resources in this area would appear to support greater mobility and independence, even in much later life.

*Disparity of care* highlighted the perceived injustices in both accessing and entitlements to care. What was most significant was that geographical location appeared to determine both the availability, and standard of care received. The participants spoke of a postcode lottery and a two-tier system which discriminated between those who a) lost limbs during active service and b) lost limbs in service due to accidents, and those that lost limbs post service.

The third superordinate theme, *Enduring challenge of limb-loss*, identified the everyday complications of ageing with limb-loss. Although it would be very difficult to identify issues that were unique to the veteran's population in relation to ageing with limb-loss, what was significant was the military mind-set, which remained evident within the participants' accounts. Strong military identity remained, and this clearly shaped their personal opinions and preferences with regards the type of support they preferred to receive, most notably, support which had a strong connection to the military and veteran's communities.



**Results: Convergent Analysis – Combining the Results**

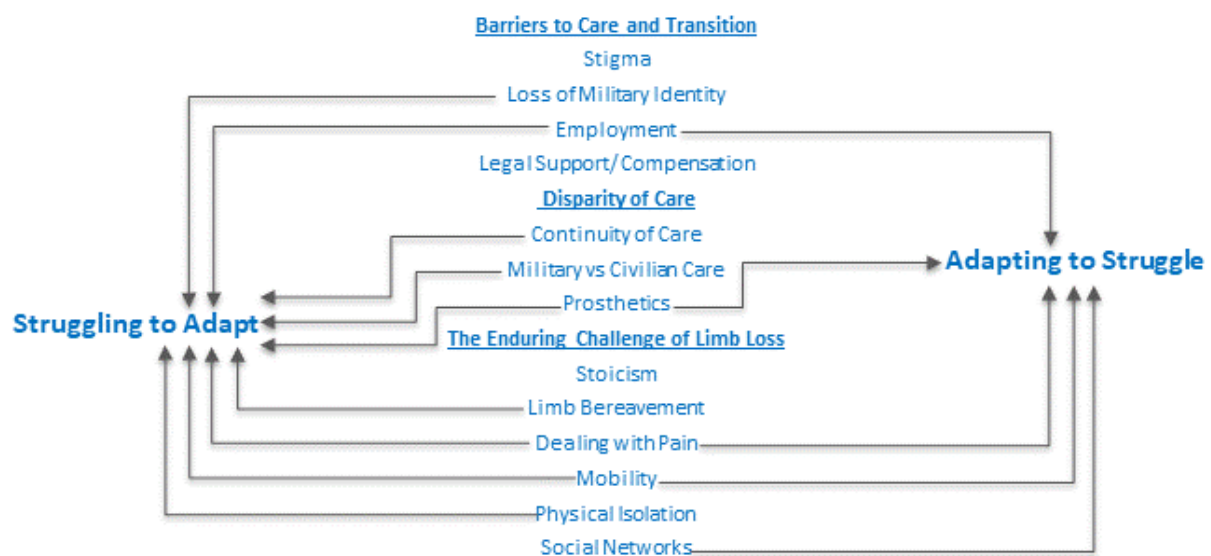


This chapter presents the results of the final stage of analysis within the project. In order to gain a deeper understanding of the ways in which each prominent narrative style was constructed, convergence between narrative analysis and framework analysis was conducted. The primary aim of analytical convergence was to identify the ways in which common themes contribute towards the construction of each narrative type.

## Struggling Against Decline

Analysis of the key themes which contribute towards the construction of the ‘struggle against decline’ narrative type, provides insight into the challenges faced by older limbless veterans throughout the course of their lives (see Table 6a). As such, many of the findings, provide an understanding of the potential challenges faced by younger generations of limbless veterans as they age. Encompassed within the ‘struggle against decline’ narrative type, is a clear distinction between participants who told stories of ‘struggling to adapt’, and participants who told stories of ‘adapting to struggle’. In order to explore the factors which promote or inhibit health, wellbeing and independence amongst veterans affected by limb-loss, the convergent findings compare and contrast key themes which contribute towards the construction of stories of ‘struggling to adapt’ and stories of ‘adapting to struggle’. Figure 6 provides a visual representation of the key themes, which contribute towards the construction of this narrative type. Arrows are indicative of the subordinate themes which emerged as recurrent or salient subject matter within data extracts which correspond to stories of ‘struggling to adapt’ and ‘stories of adapting to struggle’.

**Figure 6.** Visual representation of key the themes which contribute towards the ‘struggle against decline’ narrative type.





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

Analysis of stories of 'struggling to adapt' illustrates that early post-operative adjustment to limb-loss may be fraught with significant physical and psychological struggle. Participants described an early sense of hopelessness and despair associated with the loss of their limb and the subsequent loss of physical capabilities. This response is referred to as limb-bereavement, as research has long since identified a comparative psychological response to the loss of a limb and the loss of a loved one. Parkes<sup>70</sup> suggests that both limb-loss and the loss of a loved one are associated with a period of preoccupation and longing for the subject of loss. The grief associated with the loss of a loved one often abates with time, so too does the intensity of initial limb-bereavement. However, research also suggests that precautionary steps may reduce the negative psychological impact of limb-loss. For example, individuals who receive pre-surgery counselling demonstrate significantly lower levels of psychological distress following a range of surgical mutilations in comparison with individuals who do not receive pre-surgery counselling<sup>71,72</sup>.

Previous research suggests that grief and distress may intensify during early rehabilitation following limb-loss as the reality of limb-loss is fully realised<sup>73,74</sup>. However, the data in this study revealed a marked shift in participants' stories from the negative trajectory of 'struggling to adapt', to the positive trajectory of 'adapting to struggle' during this early rehabilitation stage. For many participants, adapting to the use of prosthetic limbs was a catalytic experience, which appeared to facilitate the development of stories of 'adapting to struggle'. The present study provides compelling evidence to suggest that the timely provision of prosthetic limbs during early recovery is essential in order to promote early psychological adjustment and reduce physical barriers to independence.

An additional challenge which may impair veterans' quality of life beyond the initial hospitalisation stage is the inability to ambulate independently within the home and to gain access to the local community. Analysis of 'struggling to adapt' type stories illustrates that living within a home with inadequate adaptations may significantly impair veterans' quality of life following limb-loss, impacting upon safety and independence and resulting in physical

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<sup>70</sup> Parkes, C.M. (1975). Psycho-social Transitions: Comparison between Reactions to Loss of Limb and Loss of a Spouse. *British Journal of Psychiatry*, 127, 204-210.

<sup>71</sup> Butler, D.J., Turkal, N.W., & Seidl, J.J. (1992). Amputation: preoperative psychological preparation. *The Journal of the American Board of Family Practice*, 5(1), 69-73.

<sup>72</sup> Maguire, P., Tait, A., Brooke, M., Thomas, C., & Sellwood, R. (1980). Effect of counselling on the psychiatric morbidity associated with mastectomy. *British Medical Journal*, 281(6253), 1454-1456.

<sup>73</sup> Randall, G. C., Ewalt, J. R., & Blair, H. (1945). *Psychiatric reaction to amputation*. *Journal of the American Medical Association*, 128(9), 645-652.

<sup>74</sup> MacBride, A., Rogers, J., Whyllie, B., & Freeman, S. J. (1980). Psychosocial factors in the rehabilitation of elderly amputees. *Psychosomatics*, 21(3), 258-265.

isolation within the home. For many participants receiving support from local authority housing organisations and third sector organisations in order to secure appropriate housing or to fund required home adaptations facilitated a shift in the trajectory of their stories from ‘struggling to adapt’, to ‘adapting to struggle’. The present analysis illustrates that suitable housing and appropriate home adaptations are essential in order to promote independence and maintain a good quality of life amongst veterans affected by limb-loss.

The present analysis provides compelling evidence to support the argument that education is a strong indicator of the ease with which a veteran-amputee is likely to secure employment and reintegrate into civilian life. Participants who join the military at a young age described their uncertainty, anxiety and apprehension regarding their prospects within civilian society, due to their limited pre-military education, training and work experience. For those participants, psychological adjustment following limb-loss was difficult in the civilian context –invariably perceived to be highly unfamiliar and lacking in structure, direction and discipline in comparison to military contexts.

**Table 6a.** Early barriers to health, wellbeing and independence.

<b>Early Barriers to Health, Wellbeing and Independence</b>	
<b>Limb-Bereavement</b>	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.
<b>Delays in Prosthetic Provision</b>	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.
<b>Poorly Adapted Living</b>	The experience of transition from the hospital setting, back into the home during early recovery from amputation, 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.
<b>Difficulty in Transitioning</b>	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.

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

For many participants, stump pain, phantom limb pain and prosthetic related skin irritation were recurrent issues throughout the life-course (see [Table 6b](#)). However, participants reported that physical deterioration and additional comorbidities exacerbated pain during later life. The findings of this study suggest that pain which is poorly managed may result in

immobility, reduced independence and physical isolation due to restrictions in physical activity and the inability to utilise prosthetic limbs comfortably. Furthermore, pain which is poorly managed with high doses of analgesic medication, may be associated with further impairments in quality of life due to unpleasant medication side effects.

Prosthetic limbs were a primary source of pain and discomfort throughout both ‘adapting to struggle’ type stories and ‘struggling to adapt’ type stories. Issues primarily centred around poor socket fit, which resulted in stump pain, skin irritation and skin abrasions.

Growing evidence suggests that amputees are also at an elevated risk of social and physical isolation<sup>75,76</sup>. As such, the risk of physical and social isolation amongst older limbless veterans is an important concern. Participants stories of ‘struggling to adapt’ demonstrate that an accumulation of physical deterioration, worsening pain and subsequent limitations in mobility may result in physical and social isolation during later life amongst veterans affected by limb-loss.

**Table 6b. Persistent barriers to health, wellbeing and independence.**

Persistent Barriers to Health, Wellbeing and Independence	
<b>Pain and Discomfort</b>	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.
<b>Prosthetic Maintenance</b>	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.
<b>Isolation</b>	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 Long-Term Outcomes associated with Limb-Loss*

Analysis of the key themes which contribute towards the construction of the ‘struggle against decline’ narrative type suggests that veterans affected by limb-loss commonly experience significant ongoing challenges throughout the life-course (see [Table 6c](#)). However, analysis

<sup>75</sup> Demet, K., Martinet, N., Guillemin, F., Paysant, J., & Andre, J. M. (2003). Health related quality of life and related factors in 539 persons with amputation of upper and lower limb. *Disability and Rehabilitation*, 25(9), 480-486.

<sup>76</sup> Pell JP, Donnan PT, Fowkes FGR, Ruckley CV. Quality of life following lower limb amputation for peripheral arterial disease. *European Journal of Vascular Surgery* 1993;7:448–451.

also revealed a number of key mediating factors which may influence the extent to which such challenges impact upon veterans' health, wellbeing and quality of life.

Taking into account the many enduring physical challenges associated with limb-loss, it is unsurprising that participants commonly expressed the need for ongoing healthcare, specifically tailored to amputees, throughout the life-course. The data suggests that ongoing high-quality care is essential in order to promote the positive trajectory of 'adapting to struggle' amongst veterans affected by limb-loss. The inability to gain timely access to effective care and support was associated with extended periods of increased pain, reduced physical activity and limitations in mobility. The repair, replacement and adjustment of prosthetic limbs emerged as the primary care need affecting participants throughout the life-course. The speed and quality of prosthetic care was a key factor in determining the trajectory of participants' stories. Participants who were unable to gain timely access to specialist prosthetic services, reported significantly greater challenges, which endured throughout the life-course. As such, the data suggests that continuity of care throughout the life-course is essential in order to promote health, wellbeing and independence amongst veterans affected by limb-loss.

The findings of this study suggest that social support from comrades within veteran associations may be associated with significant psychological benefits for veterans affected by limb-loss. Engaging with veteran associations such as Blesma and interacting with other veterans affected by limb-loss was an instrumental experience for many participants, which marked a transition within their story from 'struggling to adapt' to 'adapting to struggle'. Observing fellow amputees demonstrate confidence and engage in physically challenging activities was associated with dramatic improvements in psychological adjustment, characterised by enhanced self-esteem, body-image and perceived self-efficacy. As such, the data suggests that the opportunity to develop a social network of fellow veterans is highly influential in terms of veterans' perceived quality of life following limb-loss.

The capacity to secure fulfilling post-injury employment also emerged as a key mediating factor in determining the long-term impact of limb-loss on veteran's perceived quality of life. Participants who told stories of 'adapting to struggle' emphasised the importance of employment in terms of promoting self-esteem, perceived self-efficacy and independence. However, participants who joined the army at a young age frequently told stories of 'struggling to adapt', which featured significant challenges in securing post-injury employment. The inability to secure post-injury employment was often associated with poor pre-military education and limitations in pre-military training and work experience, resulting in a paucity of skills which are transferable to roles within civilian society. The Veterans' Transition Review<sup>77</sup>

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<sup>77</sup> Ashcroft, M. (2014). *The veterans' transition review*. Biteback Publishing.

asserted that the MOD has made efforts to maximise the accreditation of skills gained within the military. However, the review also claimed that the skills and qualifications gained throughout the course of a military career are often poorly understood by civilian employers and may not be directly transferable to civilian roles of employment. As a result, veterans may experience challenges in securing employment within civilian society. The present analysis illustrates that the inability to secure post-injury employment may have a significant long-term impact upon the quality of life of limbless veterans.

**Table 6c. Mediating factors in the long-term outcomes associated with limb-loss.**

<b>Mediating Factors in the Long-Term Outcomes Associated with Limb-Loss</b>	
<b>Continuity of Care</b>	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.
<b>Social Networks</b>	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.
<b>Employment</b>	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.

## Victimhood and Life-as-Normal

In many ways, the ‘victimhood’ narrative type and the ‘life-as-normal’ narrative type are highly opposing constructs. However, both narratives are characterised by unabating psychological distress following limb-loss. Participants who told stories which aligned closely with the ‘victimhood’ narrative type, openly discussed personal challenges and frequently expressed negative emotions such as anger and bitterness. Conversely, participants who told stories which aligned with the ‘life-as-normal’ narrative type, outwardly minimised personal challenges and denied any lasting psychological distress associated with limb-loss. [Figure 7](#) provides a visual representation of the key themes, which contribute towards the construction of both narrative types. Arrows are indicative of the subordinate themes which emerged as recurrent

or salient subject matter within data extracts which correspond to the 'life-as-normal' narrative type and the 'victimhood' narrative type'.

**Figure 7.** Visual representation of the key themes which contribute towards the 'life-as-normal' and 'victimhood' narrative types.



*Potential Sources of Enduring Psychological Distress*

Exploration of the key themes which contribute towards the construction of the 'victimhood' narrative type and the 'life-as-normal' narrative type, revealed a number of key experiences which may result in unabating psychological distress amongst veterans affected by limb-loss (see Table 7a)

Despite participants' determination to suppress and deny signs of ongoing psychological challenges associated with limb-loss, those who told stories which conformed to the 'life-as-normal' narrative type, were commonly overwhelmed by rare moments of profound psychological distress. Distress amongst participants who told stories which conformed to this narrative type was primarily associated with limb-bereavement and the subsequent loss of military identity. This study reveals that limb-bereavement may persist throughout the life-course, acting as a significant source of prolonged psychological distress amongst veterans affected by limb-loss.

The 'victimhood' narrative type is characterised by forthcoming discussions of personal challenges and the free outward expression of negative emotions. As such, analysis of this narrative type provided many rich insights into potential sources of prolonged psychological distress amongst veterans affected by limb-loss. While participants who told stories which

conformed to the 'victimhood' narrative type expressed some psychological distress associated with limb-bereavement, it was events which followed on from limb-loss that were the primary source of psychological distress. Participants expressed a deep dissatisfaction with the level of compensation and the service pension they have received in accordance with their injury. Disparities in the levels of compensation and service pension received by combat-injured veterans and non-combat injured veterans provoked deeply negative emotions such as anger, bitterness and resentment. The inability to challenge the decisions regarding compensation due to high legal costs and limited legal support also provoked similar expressions of psychological distress. As such, this study suggests that dissatisfaction with compensation and negative experiences of legal processes related to compensation, may result in prolonged psychological distress amongst veterans affected by limb-loss.

Dissatisfaction with the quality of care which was received following limb-loss was an additional source of psychological distress within the context of the 'victimhood' narrative type. Participants who told stories which aligned with this narrative type, expressed the view that discontinuous care and failures on behalf of healthcare professionals, often resulted in unnecessary pain and discomfort through their life-course, This lead to significant impairments in mobility, independence and overall quality of life. Participants expressed deeply seated anger, bitterness and resentment towards the military and the NHS for providing unsatisfactory care.

The inability to secure post-injury employment emerged as a key source of psychological distress amongst participants who told stories of 'victimhood'. Participants expressed the view that limb-loss has made them unattractive to potential employers and associated their inability to secure post-injury employment with disability discrimination. The findings of this study suggest that the inability to secure post-injury employment may impair psychological adjustment amongst veterans affected by limb-loss, resulting in prolonged psychological distress.

**Table 7a.** Potential sources of enduring psychological distress.

Potential Sources of Enduring Psychological Distress	
<b>Limb-bereavement</b>	Psychological distress associated with the physical loss of a limb and the subsequent loss of military identity, may persist throughout the life-course.
<b>Unsatisfactory Compensation</b>	Dissatisfaction with the level of compensation received in accordance with injury may result in unabating psychological distress, characterised by anger, bitterness and resentment towards the military.
<b>Unsatisfactory Care</b>	Dissatisfaction with the quality of care which has been provided since sustaining limb-loss may provoke anger, bitterness and resentment towards health and social care systems.
<b>Unemployment</b>	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 Maintaining Psychological Distress*

Analysis of the key themes which contribute towards the construction of the 'victimhood' narrative type and the 'life-as-normal' narrative type also revealed a number of factors which may maintain psychological distress amongst veterans affected by limb-loss (see Table 7b). A pervasive pattern of maladaptive coping emerged throughout themes which contributed towards the 'victimhood' narrative type. Participants typically demonstrated a defensive external locus of control<sup>78</sup> when describing negative experiences, undesirable circumstances and personal challenges. Negative life experiences were attributed to external failures within the military, within health and social care services and within society at large. The defensive external locus of control demonstrated within the context of the victimhood narrative type, may contribute towards participants' enduring psychological distress, by discouraging active problem solving and promoting a sense of helplessness<sup>79</sup>.

A strong tendency for rumination amongst participants who told stories of 'victimhood' also emerged throughout the analysis. Rumination refers to the repetitive contemplation and mental rehearsal of negative thoughts, emotions or events<sup>80</sup>. Participants who told stories which conformed with the victimhood narrative type devoted significant time to the process of

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<sup>78</sup> Locus of control is a concept first introduced by Rotter in 1954 which refers to an individual's beliefs regarding their own control and influence within their life. While individuals who possess a strong internal locus of control perceive their successes and failures to be the result of their own actions or inactions, those who possess a strong external locus of control attribute their successes and failures to external forces which are outside of their control.

<sup>79</sup> Lefcourt, H. M. (2014). *Locus of control: Current trends in theory and research (2nd ed.)*. New York: Psychology Press

<sup>80</sup> Alderman, B. L., Olson, R. L., Bates, M. E., Selby, E. A., Buckman, J. F., Brush, C. J., Panza, E. A., Kranzler, A., Eddie, D., & Shors, T. J. (2015). Rumination in major depressive disorder is associated with impaired neural activation during conflict monitoring. *Frontiers in human neuroscience*, 9, 269.



rumination throughout the course of the interviews. Participants discussed negative past experiences and emotions in great detail. Rumination is widely considered to be a maladaptive coping mechanism which maintains psychological distress by inhibiting effective problem solving. Furthermore, rumination is a common feature across both anxiety disorders and major depressive disorder<sup>80,81,82</sup>. This study illustrates the potential negative impact of rumination, as the data suggests that rumination may contribute towards psychological distress amongst veterans affected by limb-loss.

The data suggests a number of additional factors which may maintain psychological distress amongst veterans affected by limb-loss. During the analysis a pervasive pattern of experiential avoidance emerged throughout stories which conform to the 'life-as-normal' narrative type. The term 'experiential avoidance' broadly refers to the excessively negative evaluation of undesirable internal events, resulting in active attempts to suppress control or avoid unwanted cognitions, emotions and bodily sensations<sup>83,84,85</sup>. When telling stories which conformed to the 'life-as-normal' narrative type, it was evident that participants actively sought to suppress psychological distress and to avoid discussions of negative emotions, difficult experiences and personal challenges. Experiential avoidance is considered to be a highly maladaptive coping mechanism which may prolong psychological distress by removing the opportunity for emotional learning, active problem solving and the disconfirmation of distressing cognitions<sup>86,87</sup>. In line with previous research, this study suggests that experiential avoidance may be associated with prolonged psychological distress amongst veterans affected by limb-loss.

In direct contrast to maladaptive coping styles such as experiential avoidance and rumination, is problem-orientated coping (also referred to as active coping or engagement coping). Problem-orientated coping refers to active attempts to influence a situation through actions

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<sup>81</sup> Sarin, S., Abela, J., & Auerbach, R. (2005). The response styles theory of depression: A test of specificity and causal mediation. *Cognition & Emotion*, 19(5), 751-761.

<sup>82</sup> Olatunji, B. O., Naragon-Gainey, K., & Wolitzky-Taylor, K. B. (2013). Specificity of rumination in anxiety and depression: a multimodal meta-analysis. *Clinical Psychology: Science and Practice*, 20(3), 225-257.

<sup>83</sup> Hayes, S. C., Strosahl, K., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D. & Stewart, S. H. (2004). Measuring experiential avoidance: A preliminary test of a working model. *The psychological record*, 54(4), 553-578.

<sup>84</sup> Hayes, S. C., Wilson, K. G., Gifford, E. V., Follette, V. M., & Strosahl, K. (1996). Experiential avoidance and behavioral disorders: A functional dimensional approach to diagnosis and treatment. *Journal of consulting and clinical psychology*, 64(6), 1152.

<sup>85</sup> Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and commitment therapy: Understanding and treating human suffering*. New York: Guilford.

<sup>86</sup> Newman, M. G., & Llera, S. J. (2011). A novel theory of experiential avoidance in generalized anxiety disorder: A review and synthesis of research supporting a contrast avoidance model of worry. *Clinical psychology review*, 31(3), 371-382.

<sup>87</sup> Dugas, M. J., Gagnon, F., Ladouceur, R., & Freeston, M. H. (1998). Generalized anxiety disorder: A preliminary test of a conceptual model. *Behaviour research and therapy*, 36(2), 215-226.

such as problem solving, emotional expression or emotional regulation<sup>88,89,90</sup>. In comparison with other coping styles, problem-orientated coping has been associated with enhanced psychological wellbeing and improvements in physical health status<sup>89</sup>. The data suggests a number of factors which may discourage problem-orientated coping amongst veterans affected by limb-loss. The data suggests that a stoic attitude may prevent problem-orientated coping by discouraging emotional expression. When telling stories, which closely aligned with the 'life-as-normal' narrative type, participants commonly, expressed a resolute attitude or a 'stiff upper lip', suppressing signs of psychological distress when possible and denying the extent of personal challenges. Participants discussed their determination to 'get on with it' regardless of their disability. There was an emphasis on the importance of independence, and an expression of deep reluctance to rely upon external sources of care and support. This suggests that stoicism may prevent problem-orientated coping by limiting help-seeking behaviours.

The data also suggests that social stigma associated with disability may discourage emotional expression and inhibit help-seeking behaviour amongst veterans affected by limb-loss. Previous research suggests that perceived social stigma may result in a reluctance to disclose personal information which has the potential to cause judgment or discrimination<sup>91</sup>. Participants who told stories which aligned with the 'life-as-normal' narrative type, devoted considerable time during the course of their interviews to the discussion of negative perceptions of disability within society and their desire to distance themselves from the identity of victimhood imposed upon them by others.

The impact of social stigma was evident when analysing the ways in which themes such as prosthetics and employment, contribute towards the construction of the 'life-as-normal' narrative type. Within the context of this narrative type, prosthetic limbs provided participants with a means through which to conceal their disability and to distance to themselves from an identity of victimhood. For participants who told stories which conformed to the 'life-as-normal' narrative type, the capacity to conceal their disability was particularly important within professional settings. They emphasised the importance of post-injury employment as

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<sup>88</sup> Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H., & Wadsworth, M. E. (2001). Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. *Psychological bulletin*, 127(1), 87.

<sup>89</sup> Connor-Smith, J. K., & Compas, B. E. (2004). Coping as a moderator of relations between reactivity to interpersonal stress, health status, and internalizing problems. *Cognitive Therapy and Research*, 28(3), 347-368.

<sup>90</sup> Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: a review and critique of category systems for classifying ways of coping. *Psychological bulletin*, 129(2), 216.

<sup>91</sup> Beals, K. P. (2004). *Stigma management and well-being: The role of social support, cognitive processing, and suppression* (Doctoral dissertation, ProQuest Information & Learning).

a self-affirming ‘normalising’ experience, but also described their reluctance to disclose their disability to prospective employers or to request adjustment within the workplace for fear of judgment and discrimination. As such, the findings from this study suggest perceived social stigma may prevent problem orientated coping, ultimately resulting in prolonged psychological distress amongst veterans affected by limb-loss (see Table 7b).

**Table 7b.** Factors maintaining psychological distress.

Factors Maintaining Psychological Distress	
<b>External Locus of Control</b>	The belief that personal outcomes are primarily influenced by external sources, may contribute to the maintenance of psychological distress through the belief that negative circumstances have always been and will continue to be beyond control.
<b>Rumination</b>	A tendency to repetitively contemplate or mentally rehearse negative past events and emotions may inhibit effective problem solving, ultimately contributing towards the maintenance of psychological distress.
<b>Experiential Avoidance</b>	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.
<b>Stoicism</b>	A tendency towards stoicism may contribute towards an avoidant coping style amongst veterans affected by limb-loss. This may result in a reluctance to engage in help-seeking behaviour, limiting emotional expression and prolonging psychological distress.
<b>Social Stigma</b>	Veterans may be influenced by the perceived social stigma attached to those with disabilities. 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.

## Minimisation

While the ‘minimisation’ narrative type is not as newsworthy, nor as popularised within the current social milieu as the ‘dramatic overcoming’ narrative type, this type powerfully demonstrates that limb-loss is not necessarily associated with significant long-term impacts upon health and quality of life. To gain a deeper understanding of the factors which may facilitate the development and maintenance of ‘minimisation’ narratives, it is highly pertinent to explore the key themes which contribute towards the construction of this narrative type. Figure 8 provides a visual representation of the key themes which contribute towards the construction of this narrative type. Arrows are indicative of the subordinate themes which emerged as recurrent or salient subject matter within data extracts which correspond to the ‘minimisation’ narrative type.

**Figure 8.** Visual representation of key themes which contribute towards the ‘minimisation’ narrative type.



#### *Factors Which may ‘Minimise’ the Long-Term Impact of Limb-Loss*

Analysis of the key themes which contribute towards the construction of the ‘minimisation’ narrative type, suggests the experience of early rehabilitation involving the use of prosthetic limbs may act as a foundation for ‘minimisation’ stories amongst veterans affected by limb-loss (see Table 8). Given the importance of prosthetics to participants’ ‘minimisation’ stories, it is unsurprising that prosthetic care emerged as the primary care need for participants who told stories which conformed to this narrative type. Problems with prosthetic limbs which required maintenance, repair or replacement, were a primary cause for experiences of struggle which interrupted ‘minimisation’ stories. However, interruptions were brief, as timely access to specialist prosthetic care, ensured participants who told stories of ‘minimisation’ spent limited time struggling with defective or ill-fitting prosthetics. They reported a general satisfaction of ongoing care and support they received since sustaining their limb-loss and expressed confidence in their capacity to gain timely access to appropriate care and support when required. In contrast to the majority of the participants, some who told stories of ‘minimisation’ also reported limited experiences of pain, reduced physical activity or immobility as a result of limb-loss and prosthetic use. As such, findings illustrate potential benefits of effective ongoing care and support for limbless veterans with regards to minimising pain and discomfort, promoting independence and wellbeing and reducing limitations in physical activity and mobility.

The data suggests that the capacity to secure fulfilling post-injury employment is also fundamental to the development of the 'minimisation' narrative type. Participants who told stories which conformed to this narrative type, devoted the majority of the time during their interviews to the discussion of post-injury employment. The data therefore provides compelling evidence to support the argument that post-injury employment is highly beneficial for veterans affected by limb-loss. It is possible that participants' educational and vocational pre-military background may have facilitated their capacity to secure post-injury employment. Participants who told stories which conformed to the 'minimisation' narrative type typically possessed strong educational backgrounds or work experience outside of the military.

In line with research which suggests that stoicism is associated with impairments in quality of life,<sup>92,93</sup> analysis of the 'victimhood' narrative type illustrated that stoicism may impede psychological adjustment following limb-loss, acting as a significant barrier to emotional expression and preventing help-seeking behaviour. However, there is evidence to suggest that stoicism may be a beneficial trait, associated with psychological resilience in the face of adversity<sup>94</sup>. This study provides compelling evidence to support the argument that stoicism contributes significantly towards the development of the 'minimisation' narrative type amongst veterans affected by limb-loss.

Interestingly, satisfaction regarding the legal support and compensation received following injury was common across all stories of 'minimisation'. There is some debate amongst scholars regarding the potential impact of financial compensation on the health, wellbeing and quality of life of disabled individuals. While some argue that financial compensation may have a negative impact upon quality of life, discouraging successful rehabilitation and psychologically reinforcing behaviours which demonstrate disability<sup>95,96</sup>, others assert that the financial security afforded to individuals who receive compensation reduces the risk of anxiety and depression which may result from an acquired disability<sup>97</sup>. The findings of this study

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<sup>92</sup> Murray, G., Judd, F., Jackson, H., Fraser, C., Komiti, A., Pattison, P. & Robins, G. (2008). Big boys don't cry: An investigation of stoicism and its mental health outcomes. *Personality and Individual Differences*, 44(6), 1369-1381.

<sup>93</sup> Moore, A., Grime, J., Campbell, P., & Richardson, J. (2013). Troubling stoicism: Sociocultural influences and applications to health and illness behaviour. *Health*, 17(2), 159-173.

<sup>94</sup> Spiers, J. (2006). Expressing and responding to pain and stoicism in home-care nurse-patient interactions. *Scandinavian Journal of Caring Sciences*, 20(3), 293-301.

<sup>95</sup> Guest, G. H., & Drummond, P. D. (1992). Effect of compensation on emotional state and disability in chronic back pain. *Pain*, 48(2), 125-130.

<sup>96</sup> Fordyce, W. E. (1985). Back pain, compensation, and public policy. *Prevention in health psychology*, 15, 391-400.

<sup>97</sup> Mendelson, G. (1983). Not 'cured by a verdict.' Effect of legal settlement on compensation claimants. *Pain*, 16(2), 219.

support the notion that satisfactory financial compensation is associated with positive outcomes for veterans affected by limb-loss.

**Table 8.** Factors which may ‘minimise’ the long-term impact of limb-loss.

Factors which may ‘minimise’ the long-term impact of limb-loss	
<b>Prosthetic Limbs</b>	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.
<b>Continuity of Care</b>	Ongoing access to high quality healthcare throughout the life-course is essential to minimise the long-term health outcomes and barriers to independence associated with limb-loss.
<b>Stoicism</b>	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.
<b>Employment</b>	The capacity to secure fulfilling post-injury employment is essential to minimise the long-term impact of limb-loss on veterans’ quality of life.
<b>Financial Compensation</b>	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.

## Summary: Key Findings and Actionable Recommendations

Framework analysis identified key superordinate and subordinate themes from across the data. However, narrative analysis identified four distinct narrative types which shape the way in which veterans reconstruct their lives and identities following limb-loss. The identified narrative types encompassed both similarities and stark contrasts in terms of veterans health, wellbeing and independence. By exploring the ways in which the key themes identified through framework analysis contribute towards the construction of each of the narrative types identified through narrative analysis, this research aimed to provide a more comprehensive and accurate understanding of the health and social care needs of this diverse community. The findings, which resulted from this convergent analysis and subsequent actionable recommendations are summarised in [Tables 9a-f](#).

**Table 9a. Key findings and actionable recommendations - physical health.**

Maintaining Independence		
Physical Health	Key Findings	Actionable Recommendations
<b>Continuity of Care</b>	<p>Taking into account the many enduring physical challenges associated with limb-loss, it is unsurprising that participants commonly expressed the need for ongoing healthcare for amputees throughout the life-course. However, many participants reported a lack of continuity in their care, which had a detrimental impact upon their ability to recover from and manage their limb-loss.</p> <p>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.</p>	<p>It is essential that veterans affected by limb-loss have timely access to high quality healthcare services, starting from the time of amputation and extending throughout the life-course. Healthcare providers and policy makers must ensure that all limbless veterans are able to access services when required and should aim to standardise the quality of care across services.</p>
<b>Specialist Care</b>	<p>Participants highlighted a paucity of specialist healthcare support for amputees, particularly with regards to prosthetic limb care. The inability to access specialist healthcare services resulted in extended periods of increased pain, reduced physical activity and limitations in mobility. Some participants described a ‘postcode lottery’ with respect to access to care. In order to address the gap in mainstream services, some participants resorted to paying for private care, while others reported the need to travel long distances in order to access required services.</p>	<p>Specialist healthcare services are fundamental to the health and wellbeing of limbless veterans, particularly with regards to the maintenance of prosthetic limbs. Accordingly, access to specialist services must be improved nationwide, in order to reduce health inequalities and promote seamless high-quality care for veterans affected by limb-loss.</p>
<b>Pain Management</b>	<p>Participants described enduring significant amounts of generalised stump pain and phantom limb pain throughout the course of their lives. Participants described pain impacting upon their sleep, mood, and mobility (either directly or by preventing them from using their prosthetics). Many participants suggested that clinicians struggled to manage their pain effectively and therefore resorted to prescribing high doses of pain medication. Such high doses of powerful medications were not only associated with undesirable side effects, but also constitute a risk to the safety of veterans with comorbid mental health issues.</p>	<p>It is evident that there are significant challenges with regards to the management of pain amongst amputees. The development of clear research-based treatment recommendations is essential in order to improve the management of stump pain and phantom limb-pain amongst limbless veterans.</p>

Table 9a. Continued.

Maintaining Independence		
Physical Health	Key Findings	Actionable Recommendations
<b>Age-Related Decline</b>	This report highlights the growing care needs of limbless veterans as they progress throughout later life. Participants described the impact of age-related physical decline and musculoskeletal conditions such as arthritis and the way in which they compound the challenges associated with limb-loss. Due to reduced strength and heightened pain and discomfort, many participants reported reductions in mobility and in their capacity to engage in physical activities. As a result, participants frequently reported increasing physical and social isolation during later life.	Health and social care providers must be aware of the increased vulnerability of limbless veterans as they age. In order to ensure that limbless veterans are able to maintain their health, wellbeing and independence for as long as possible, special attention must be taken to ensure that older limbless veterans receive sufficient care and support to manage their healthcare needs.



**Table 9b. Key findings and actionable recommendations - social wellbeing.**

Maintaining Independence		
Social Wellbeing	Key Findings	Actionable Recommendations
<b>The Military Charity Sector</b>	<p>Some participants described how limb-loss has altered their ability to form and maintain relationships due to concerns around their self-image, their physical limitations and the negative preconceptions of others. The social activities provided by Blesma were therefore highly valued for combating isolation. As such, opportunities provided by third sector organisations were extremely important in helping participants to stay socially connected, facilitating connections among 'likeminded' people who share the 'military mentality' and 'squaddies humour' and providing a sense of comradeship. Events for limbless veterans also worked to inspire confidence and hope by instilling a sense of accomplishment and by demonstrating that it is possible to adapt to limb-loss. Participants described a reduced ability to engage in physical challenges as they aged, instead opting to engage in less intense activities such as photography. It is important to note that geographical distance from available activities, as well as caring responsibilities for others sometimes prevented participation in events.</p>	<p>The work of the military charity sector is highly valued amongst veterans affected by limb-loss. It is important that limbless veterans are able to continue their engagement with military charities such as Blesma as they progress throughout later life. As such, the military charity sector should continue to provide a diverse range of activities and events which are accessible to all limbless veterans, regardless of their physical capabilities. Additionally, the sector should aim to provide opportunities for veterans across the whole of the UK, ensuring that veterans from all geographical locations are able to benefit from their services.</p>
<b>Non-Military Peer-Support</b>	<p>Non-military specific user groups and peer support forums for those who have experienced amputation more generally, were highly valued. Such groups provided a forum for sharing practical tips for coping with limb-loss, using prosthetics and facilitating mobility. Those with access to user groups suggested this had been integral to their ability to adjust, whereas those who had not received this form of support felt it would have benefited them greatly.. Another function of peer groups was to provide an opportunity for social comparisons with others experiencing limb-loss. Reflecting upon the situations of those worse off than themselves helped participants to accept their injuries. Participants also provided advice and assistance to others in a similar position to themselves, with this too appearing to bolster self-esteem.</p>	<p>Access to user groups and peer support forums is associated with significant physical and psychological benefits for veterans affected by limb-loss. In order to promote psychological adjustment and physical rehabilitation, all limbless veterans should be offered access to non-military specific forms of peer-support. Provision of this form of support may be particularly important during the early stages of adjustment following limb-loss.</p>

**Table 9c. Key findings and actionable recommendations - psychological wellbeing.**

<b>Maintaining Independence</b>		
<b>Psychological Wellbeing</b>	<b>Key Findings</b>	<b>Actionable Recommendations</b>
<b>Limb-Bereavement and the Loss of Military Career</b>	Feelings of grief associated with the physical loss of a limb and the subsequent loss of ones' military career may persist throughout the life-course, acting as a significant source of prolonged psychological distress amongst veterans affected by limb-loss.	Veterans affected by limb-loss must have access to support which is able to assist them in coming to terms with the loss of their limb and the subsequent loss of their military career. The time which has elapsed since injury should not impact upon the availability of services, as limb-bereavement and grief regarding the loss of a military career may continue to affect limbless veterans well into later-life.
<b>Stoicism</b>	Participant attitudes towards living with limb-loss were largely characterised by stoic acceptance. This attitude of 'carrying on' despite adversity was attributed to a mind-set and approach to coping with loss. The data suggests that a stoic attitude may prevent adaptive problem-orientated coping by discouraging emotional expression and inhibiting help-seeking behaviours. However, 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.	While stoicism may be associated with self-motivation which promotes positive psychological adjustment following limb-loss, stoicism may also discourage emotional expression and inhibit help-seeking behaviours. Those who provide care and support to veterans affected by limb-loss should be aware of the tendency for stoicism which is typical of this population, and strive to encourage active help-seeking and emotional expression.
<b>Maladaptive Coping</b>	The data identified a number of maladaptive coping strategies which may prolong psychological distress amongst veterans affected by limb-loss. Maladaptive coping strategies described by participants included rumination (the repetitive contemplation and mental rehearsal of negative thoughts, emotions or events), a defensive external locus of control (the belief that personal outcomes are primarily influenced by the actions of others) and experiential avoidance (the excessively negative perception of negative internal events and tendency to suppress control or avoid undesirable emotions, cognitions and sensations).	Maladaptive coping strategies maintain harmful behaviours and psychological distress and have been associated with a wide range of psychopathologies, including anxiety disorders and major depressive disorder. Taking into account the psychological distress associated with limb-loss, it is imperative that limbless veterans are able to develop adaptive forms of coping, which allow for emotional expression, active problem solving and appropriate help-seeking behaviour. Organisations who aim to support veterans affected by limb-loss should therefore strive to encourage problem-orientated coping.

**Table 9d.** Key findings and actionable recommendations - physical isolation.

<b>Maintaining Independence</b>		
<b>Physical Isolation</b>	<b>Key Findings</b>	<b>Actionable Recommendations</b>
<b>Driving</b>	Participants emphasised the importance of driving in terms of their mobility, quality of life and independence. A number of participants discussed the ways in which age-related physical decline has resulted in an inability to continue driving during later life. Participants perceived the inability to drive as a significant threat to independence, resulting in restrictions in mobility and a need to rely upon others in order to engage in regular daily activities.	It is clear that driving is often fundamental to mobility and independence amongst limbless veterans. As such, this study suggests that veterans who find that they are no longer able to drive a car may require additional support in order to maintain their independence and social engagement during later life.
<b>Housing and Home Adaptations</b>	The inability to ambulate independently within the home or to gain access to the local community may greatly impair limbless veterans' quality of life, impacting upon safety and independence and resulting in physical isolation within the home. For many participants receiving support from local authority organisations and third sector charity organisations, in order to secure appropriate housing or to fund required home adaptations, facilitated their capacity to adapt to life following limb-loss.	The Armed Forces Covenant asserts that when appropriate, veterans should receive special treatment above and beyond that which may be expected by a civilian. For those injured during their service, this should include preferential access to appropriate housing schemes and additional assistance with required home adaptations. The present report explicitly illustrates the value of this form of housing support for veterans affected by limb-loss. Local authorities and third sector organisations should work to ensure that all limbless veterans are able to benefit from appropriate housing and home adaptations.

**Table 9e.** Key findings and actionable recommendations - employment and education.

Maintaining Independence		
Employment and Education	Key Findings	Actionable Recommendations
<b>Employment</b>	The capacity to secure fulfilling post-injury employment emerged as a key factor in determining the long-term impact of limb-loss upon participants' perceived quality of life. Employment was crucial for participants in terms of re-forging a sense of purpose and maintaining independence when transitioning back to civilian life. Despite this, many participants experienced significant challenges in securing post-injury employment.	In a time when the media and the current social milieu are dominated by the notion of rehabilitation through sporting competition and expedition style activities, it is crucial for society to recognise the importance of fulfilling employment for limbless veterans. In order to promote a successful transition back into civilian life and maintain independence amongst limbless veterans, all limbless veterans should have access to support and advice around post-injury employment and where possible measures should be taken to reduce existing barriers to employment.
<b>Education and Re-training</b>	Participants who joined the military at a young age reported significant difficulties in securing post-injury employment and associated this with poor pre-military education and a lack of pre-military training and work experience. While the MOD has made efforts to maximise the accreditation of skills gained within the military, the present report suggests that these skills are still poorly understood by civilian employers. The inability to engage in re-training or further education following limb-loss due to limited availability or financial and practical constraints, inhibited participants' capacity to improve the employment opportunities available to them.	This report suggests that veterans who join the military at a young age may be at a significant disadvantage in terms of securing employment after leaving the military. This is a particularly pressing issue for limbless veterans who may have left service abruptly and without preparation following injury. Efforts to improve the accreditation of skills gained within the military should continue. Additionally, care should be taken to ensure that all limbless veterans receive the support and advice they require in order to access education and training opportunities following limb-loss.
<b>Disability Discrimination</b>	Many participants felt that their disability made them an unattractive candidate to prospective employers. Participants described their reluctance to disclose their disability to prospective or current employers or to request adjustment within the workplace for fear of judgment and discrimination.	Within the UK, it is illegal for any employer to discriminate against a job candidate or employee on the basis of a physical or psychological disability. It is clear that further steps must be taken to address professional discrimination against limbless veterans, in order to ensure that they are treated with fairness and respect by prospective or current employers and to assure them with the confidence to request adjustment in the workplace when required.

**Table 9f. Key findings and actionable recommendations - financial and social support**

Maintaining Independence		
Financial and Social Support	Key Findings	Actionable Recommendations
<b>Compensation</b>	The data suggests that access to compensation and pension entitlements were significant factors in the maintenance of independence. Receipt of these financial entitlements was extremely important in signifying recognition of military contribution, providing a form of recompense in light of reduced earning power, and reducing reliance upon charitable support. However, there was variation in the levels of compensation. While some described financial difficulties, others suggested that compensation provided them with financial security. Unfortunately, participants felt alienated from the decisions regarding compensation entitlements and felt unable to challenge the outcome of this decision making process due to the costs of legal representation.	Decisions around compensation entitlements impact upon limbless veterans' financial circumstances and quality of life for the duration of their lives following limb-loss. It is therefore important that veterans do not feel alienated from this decision making process and efforts should be made to improve the experience of injured veterans throughout. Additionally, steps must be taken to improve access to legal representation for veterans who wish to challenge decisions around their compensation entitlements.
<b>'Hierarchy of Wounding'</b>	Participants highlighted a ' <i>hierarchy of wounding</i> ' which places combat injuries above injuries sustained within peacetime operations or during civilian activities. This hierarchical differentiation appears to be both sanctioned and sustained by, not least, the military charity sector, and some charities appear to use the mechanism of injury as the basis for discriminating their provision of support. As compensation, entitlements are also dependent upon whether limb-loss was sustained during or after service, or is considered to be 'attributable or 'non-attributable', the 'hierarchy of wounding' disproportionately affects those who are likely to require the greatest levels of financial support.	It is important to recognise that veterans who lose a limb as a result of peacetime operations or during civilian activities, may be at a significant disadvantage with regards to the level of financial and practical support available to them following their injury. Third sector organisations who aim to support limbless veterans should aim to eradicate this 'hierarchy of wounding', in order to ensure that all limbless veterans are able to benefit equally from their services and support.
<b>Welfare Entitlements</b>	As is the case within the wider population, reliance upon welfare support served as a source of embarrassment and social stigma amongst limbless veterans. As a result, a number of participants reported a reluctance to claim welfare support, regardless of their entitlements.	Local authorities and other organisations responsible for providing social support to limbless veterans must be aware of the reluctance to claim welfare support. Efforts should be made to reduce the stigma around welfare support and action should be taken to ensure that all limbless veterans are in receipt of the appropriate welfare entitlements.



## Discussion of Key Findings and Potential Policy Implications



Following on from the convergence analysis, subject matter experts within the research team identified underlying points for discussion. These discussion points are integral to understanding the health and social wellbeing of older limbless veterans. Points for deeper discussion include: 'limb-loss and pain', 'education and post limb-loss employment', 'limb-loss and social isolation' and 'limb-loss, independence and activities of daily living'.

## Limb-Loss and Pain

The experience of ongoing pain following amputation is complex. It is often described as a mixture of acute post-operative pain; pain of the stump and phantom limb pain caused indirectly by amputation of the limb<sup>98</sup>. The complexity of pain associated with amputation is difficult to manage and has a significant bearing upon daily living and the maintenance of independence for those with limb-loss. Participants in this study shared experiences of their own personal complex relationship with post-amputation pain. These highlighted endeavours to remain independent despite increasing levels of pain associated with ill-fitting or otherwise uncomfortable limbs, mobility issues, and under-diagnosed and poorly treated pain. Participants' responses to limb-loss were also intimately connected to their experience of serving in the Armed Forces and loss of military career.

The topic of pain was prevalent across participants' post limb-loss life-stories and it was evident that the ongoing pain experienced was often highly damaging to quality of life. Participants spoke of the challenges of dealing with pain day-to-day as well as the side-effects of painkillers. Pain was also described as an issue that impacted on family and friends. Family members and significant others described concern about the effects of largely uncontrolled levels of pain and the subsequent loss of ability to carry out day to day tasks:

*I think pain is one of the most debilitating things ... the painkillers just make him on a different planet. So if we want to go places, we want to do stuff and there's lots of jobs, simple jobs around the house that again [spouse] knows [they] could do if [they] could concentrate on those and not the chronic pain (umm) You know there was stuff that [spouse] was doing before (umm) that [they] can't do anymore ... and it worries me an awful lot that you know neither of us can really afford for [their] disability to get any worse. Otherwise we lose what little bit of independence that we have. (Spouse of Participant 2).*

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<sup>98</sup> Kulkarni J., Grady K. (2009) Post Amputation Chronic Pain Profile and Management. In: Murray C. (Ed.) Amputation, Prosthesis Use, and Phantom Limb Pain. New York: Springer.



Maintaining mobility was often referenced as being central to maintaining independence in general, and specifically active ageing, allowing participants to lead independent lives. Ineffective or inappropriately prescribed prostheses were seen as restricting mobility, rehabilitation and limiting independence. As a result of ill-fitting limbs, many participants described mobility issues which impacted on their quality of life, self-esteem and ability to maintain independence. Problems related to pain were often described as decreasing functional ability, preventing or disturbing sleep, impairing social activities and increasing social and physical isolation.

*Cycling particularly ... it's basically ripped my stumps to bits ... and knocked all the skin off, it bleeds, gets infected. I had to stop training ...so its big time held me back from cycling ... if you have discomfort, you can't walk any distance, difficult to go ... even just to go out to the shops or something like that.*

(Participant 6).

The pervasiveness of pain and comorbidities such as arthritis and residual limb pain also appeared to negatively complicate the process of growing older, often leaving participants in the current study 'struggling to adapt'. Pain management in the years after amputation was seen as increasingly challenging when adapting to old age. Many participants demonstrated a nuanced understanding of their pain (and its management) and the complex interaction between socket pain and phantom pain. The failure to initially control acute pain following limb-loss impacted on daily functioning and socialising and, for some participants, has led to chronic stump and phantom pain. It was evident from participants' accounts that the burden of pain after amputation is considerable. Severe post-amputation pains from phantom limbs have been recorded in survivors from World War II, some 50 years after the loss of a limb<sup>99</sup>. The phrase 'phantom pain' is used to define the illusion of presence of a limb after it has been amputated.

Previous research has identified the persistence of phantom pain that is severe enough to cause at least occasional debilitation as the norm rather than the exception. Sherman & Sherman<sup>100</sup> surveyed US veterans (N = 764) with combat or service-related amputations and reported that veterans believed that they were not being listened to when seeking treatment for phantom pains, and were consequently self-medicating with alcohol. Participants in this study described their own experiences of phantom pain in a limb and/or limbs which were

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<sup>99</sup> Neil, M.J.E. (2016) *Pain after Amputation*; *BJA Education*, 16 (3), 107–112.

<sup>100</sup> Sherman, R., and Sherman, C. (1983) Prevalence and characteristics of chronic phantom limb pain among American veterans. *American Journal of Physical Medicine*, 62, 5, 227-238.

removed and provided accounts of various types of persistent phantom sensations, distinct from stump pain, which were described as being felt in the residual body part:

*... my biggest problems weren't that ... my stump although it were tightening and being itchy that were quite (umm) quite bad. It were (umm) phantom pains. I suffered absolutely horrendous phantom pains.* (Participant 30).

*Phantom pain is also a bore. About once a month, it comes on in my right stump which jumps around and prevents me walking.* (Participant 7).

Seeking help for the pain and discomfort associated with phantom pain was described by participants as problematic, both in terms of being able to describe the pain adequately to health professionals and in terms of obtaining effective treatment.

*Well you try and explain it, but they just can't understand it. They don't know how I'm getting pain there when I haven't got an ankle there...And then I have to explain it that its nerve ends that come to here on your stump and you can't... you know it must be the brain doesn't know you haven't got that bit of leg.* (Participant 19).

*Because a lot of what I get is phantom pain. When you say that to a doctor they just look at you...* (Participant 8).

*... I was still in a lot of pain I must admit...there was still a lot of pain (umm) and at that stage the phantom pain was outright...outrageous. So I was on ... and I was on morphine tablets.* (Participant 14).

*Every hour on the hour for about five minutes your leg, [spouse] was trying to stop the pains. You know and ... [name] is on tablets constantly for phantom pains because we know that if [spouse] stops them [spouse] gets it really bad.* (Spouse of Participant 13).

The issue of phantom pain within the limbless veteran population has been acknowledged as a major problem and subject to academic discussion. Medically, phantom pain is viewed as 'difficult to treat' as the exact basis of pain mechanism is still unknown. Opioids are commonly used as a first-line treatment, with dose determined by effect and no defined ceiling dose<sup>101</sup>.

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<sup>101</sup> Kumar, V. Garg, R. Bharati, S.J. Gupta, N. Bhatnagar, S. Mishra, S. & Balhara, Y.P.S (2015) Long-Term High-dose Oral Morphine in Phantom Limb Pain with No Addiction Risk, Indian Journal of Palliative Care, 21 (1), 85 – 87.

Others have suggested that, although phantom pain is often classified as neuropathic pain, few of the large-scale trials of treatments for neuropathic pain have included sufficient numbers of phantom pain sufferers to have confidence that they effectively provide an evidential base for treatment of this condition<sup>102</sup>. In the updated version of the Cochrane Review on phantom limb pain<sup>103</sup>, it is noted that there is still uncertainty in relation to the most effective pharmacological management of symptoms. For participants in this study, it appeared that medications currently prescribed, appeared to provide limited benefits in terms of pain relief or quality of life more generally.

Stump pain presents a further well-known problem following amputation and is an ongoing issue throughout life<sup>104</sup>. Some participants reported that they were unable to routinely wear their prosthesis due to poorly fitting sockets. Adequate care (or rather, lack of such) around prosthetics was often the focus of participants' accounts, with significant emphasis placed on the importance of how the prosthetic 'sits' on the socket. It is noteworthy that comfort of the socket and stump pain are the most common symptoms referred to prosthetics clinics<sup>105</sup> and this was reflected in the experiences of study participants:

*It were a month or so before I could get my first prosthetic limb because obviously you're all angry, your stumps are all angry and sore and sorting yourself out.* (Participant 9).

*Because of my socket pain, I was bodily tense and compressing my spine.*  
(Participant 7).

*I've had to keep going back saying 'You've got to do something about this leg because it's making it sore'.* (Participant 4).

It is also well understood that there is a strong correlation between socket pain and phantom pain. In the UK, Warton and colleagues<sup>106</sup> carried out a survey on the prevalence of phantom pain and stump pain (N = 590 members of Blesma with traumatic limb-loss) and reported a high prevalence of phantom limb pain and stump pain. The intensity of phantom sensations

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<sup>102</sup> Richardson, C. & Kulkarni, J. (2017) A review of the management of phantom limb pain: challenges and solutions, *Journal of Pain Research*, 2017 (10), 1861–1870.

<sup>103</sup> Alviar, M.J.M. Hale, T. & Dungca, M. (2016) Pharmacologic interventions for treating phantom limb pain (Review), *Cochrane Database of Systematic Reviews*, 10.

<sup>104</sup> Ahmed, A, Bhatnagar, S. Mishra, S. Khurana, D. Joshi, S. & Ahmad, S.M. (2017) Prevalence of phantom limb pain, stump pain, and phantom limb sensation among the amputated cancer patients in India: A prospective, observational study, *Indian Journal of Palliative Care*, 23 (1), 24-35.

<sup>105</sup> Hanspal, R.S. Fisher, K. & Nieveen, R. (2003) Prosthetic socket fit comfort score. *Disability and Rehabilitation*, 25 (22), 1278-1280.

<sup>106</sup> Warton, S.W. Hamann, W. Wedley, J.R. & McColl, I. (1997) Phantom pain and sensation among British veteran amputees. *British Journal of Anaesthesia*, 78 (6), 652-659.

was seen as a significant predictor for time-course duration of phantom pain. Of the 149 amputees who reported phantom pain to their family doctor, 49 were told there was no treatment available.

Given the complex interaction between phantom and stump pain, it is unsurprising that concerns around pain management was a consistent issue for many participants: issues typically included a (perceived) inadequate response from care providers as well as a (perceived) lack of choice or options. For instance:

*... [Spouse] been let down time and time again. And this is a [person] who doesn't want to sit on [their] backside and do nothing, but [their] pain is huge! But then on the flipside [spouse] doesn't want to live a life on painkillers. So if we could get the socket sorted, the pain would go ... the pain wouldn't go necessarily, but it would be at a manageable level.* (Spouse of Participant 2).

*I have nerve pain in the stump ... don't mean a thing but the pain is inside and I tried to explain it to these people but [er] it's like I come from space. I've been in pain. I've been to pain clinic and they've tried every blinking thing on me to no avail on the nerve to make it go away.* (Participant 11).

Concern about the prescription and use of opioids was a salient feature of several participants' narratives:

*And I was in so much pain and that's what I said the morphine, it was so upsetting sometimes because I'd come in in tears ... I just didn't know where I was ... they give you a carrier bagful of medication, Tramadol, Oramorph... and I obviously did... I got addicted to morphine ...* (Participant 23)

*I was on so many different versions of morphine, I didn't know whether I was coming or going.* (Participant 2).

The effective treatment of pain requires specialist knowledge and training in pain management and is vital in terms of maintaining independence in the context of both limb-loss and ageing<sup>107</sup>. In the current study, it was clear from participants that pain was not, and should not be treated, as an isolated problem. The substantial health and social problems resulting from persistent pain contribute to greater responsibility, cost and resources for healthcare services<sup>108</sup>.

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<sup>107</sup> Schofield, P. Sofaer-Bennett, B. Hadjistavropoulos, T. Zwakhalen, S. Brown, C. Westerling, D. Weissbrod, D. Škvarč, N.K. & Wright, S. (2012) A collaborative expert literature review of pain education, assessment and management, *Ageing Health*, 8(1).

<sup>108</sup> Cairncross, L. Magee, H. & Askham, J. (2007) *A Hidden Problem: Pain in Older People*. Oxford: Picker Institute Europe.

Furthermore, the failure to assess pain appropriately and an underestimation of amputees levels of pain by healthcare providers contribute to chronic suffering<sup>109</sup> as reported by some participants in the current study. Conversely, 'life-as-normal' narratives highlighted a heightened sense of stoicism and a reluctance to 'make a fuss' and to [honestly] report levels of pain.

Families played a key role in the support networks of participants, the support and encouragement given by family was not only relied upon by participants but recognised as an essential element of their rehabilitation. In line with themes identified from participants, families identified apparent inadequacies in services provided to them for the treatment of pain and the help available was not felt appropriate.

### *Summary*

The maintenance of independence was seen as a fundamental aspect of successful ageing throughout the life-course. 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, fear of the side effects of medications. Given these complexities and the potential impact on limbless veterans' and their families' wellbeing, attention must be given to effective management of pain throughout the life-course for those affected by stump and phantom pain. Access to healthcare is a prerequisite to obtaining quality of care and the issue of social unmet needs as a result of lack of mobility, requires further exploration. These issues have wider policy implications in relation to the integration of health and social care.

## **Education and Post Limb-Loss Employment**

Education, training and social backgrounds of participants prior to joining the military were varied. Some participants self-identified as 'not academic' and drawn to the military as an applied career to further their skills and education, whereas others, entered the military with greater levels of education and training. The pre-service social backgrounds of the participants had an important influence on the employment opportunities available to them following limb-loss.

Participants often struggled to transfer the skills gained in the military to civilian roles and those with limited pre-military experience of civilian employment, training and education (as a result of joining at a young age) found it particularly challenging to secure alternative employment.

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<sup>109</sup> Melding P. (2002), Can we improve pain management in nursing homes? Medical Journal of Australia, 177, 5–6.

These findings are mirrored by existing work, highlighting poorer employment and transitional outcomes for those entering the military early on in life, from disadvantaged backgrounds and with low levels of education<sup>110</sup>. Furthermore, research on veterans with lower-limb amputation found increased years of education as a predictor of health-related quality of life<sup>111</sup>. It is important to acknowledge the relevance of this for all participants, regardless of when they lost their limb(s).

For those who experienced in-service limb-loss, premature discharge resulted in the inability to develop skills, qualifications, or education to the level that initially anticipated. Previous observations have pointed to a particular risk of poor transition among those who exit the military prematurely<sup>77</sup>. A lack of support around employment and training during transition out of the military was a common experience for many participants. Although many of the participants noted the (now) increased range of opportunities for further study that are open to current cohorts of veterans, recent work also points to the low and delayed uptake of education and training opportunities post-service such as standard or enhanced learning credits<sup>77</sup>. Support was found here for suggestions that this low uptake was as a result of low consideration given to careers after service.

Previous literature (not specific to, but including the experiences of military veterans) found that the severity of amputation has a variable impact upon employment rates after limb-loss<sup>112</sup>. Participants with lower level amputations (e.g. below-knee) perceived that they faced fewer barriers to employment post-limb-loss in comparison to those with above-elbow or above-knee amputations. This was attributed to lower levels of physical restrictions, as well as the attitudes and practices of employers. The availability of appropriate and well-fitting prosthetics was also essential to the ability to continue to fulfil work roles.

Opportunities such as re-training or studying at university were sometimes closed-off to participants due to pragmatic issues of affordability (e.g. a lack of personal resource or financial support to cover the up-front costs of training) and the need to seek an immediate source of income. Participants' appraisal of opportunities for re-training were also affected by 'breadwinner anxiety'; a term used to describe the pressure participants felt to provide for, and

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<sup>110</sup> Forces in Mind. (2013). *The mental health of serving and ex-Service personnel review*. London: The Forces in Mind.

<sup>111</sup> Christensen J., Ipsen, T., Doherty, P., & Langberg, H. (2016) Physical and social factors determining quality of life for veterans with lower-limb amputation(s): a systematic review. *Disability and Rehabilitation*, 38:24, 2345-2353.

<sup>112</sup> Darter, B. J., Hawley, C. E., Armstrong, A. J., Avellone, L., & Wehman, P. (2018). Factors Influencing Functional Outcomes and Return-to-Work After Amputation: A Review of the Literature. *Journal of occupational rehabilitation*, 1-10.

avoid becoming a burden upon their families. This was exemplified when one participant suggested:

*I feel obligated that I should pay the bills. A bit old-fashioned like that I suppose*  
(Participant 13).

Participant 13 relayed the considerable anxiety and depression which they had previously experienced during a period of unemployment following injury, culminating in alcohol use in an attempt to address these feelings. Such concerns appeared to connect with notions of masculinity and what constituted a 'good husband', this extended to the performance of duties outside of paid employment. One participant described how prior to injury they did '*anything like what a husband would be doing*', including home repairs, driving, shopping, undertaking activities with the children and escorting them to and from school. This conveyed some loss to an identity as a 'husband' or 'father'.

A wife of a participant described how forming relationships with other couples after limb-loss was difficult as other women often assumed that she wanted to borrow their husbands for home repairs or other forms of domestic work. An inability to fulfil paid and domestic work responsibilities, or in some cases, to maintain traditional gender roles, was attached to a more general stigma of being out of work in society and/or to receiving benefits. This adds to the understanding of the pressure participants experienced with regards to finding re-employment, and the experience of low self-esteem where they are unable to do so. The significance of employment can be encapsulated in one participant's suggestion that on gaining employment they no longer felt like a "*dribbly underdog*" and another's description of a 9-month period of unemployment as "*my worst nine months in my life*".

A reticence to undertake further education, and the experience of breadwinner anxiety was connected with class identity. Even where participants possessed the capability, they perceived university as a route that was unavailable to them. In the words of one participant:

*I think for me in the 60s, mid-60s, uni was for rich kids. That was the realm of the rich, not the working people... The realm of the rich kids! The upper class, noses up the air jobs!* (Participant 1).

When describing how nobody in their family had previously attended university, participant 5 commented:

*I didn't get any encouragement so I wasn't sat down saying you know come on you need to revise! Because with two A Levels you could go to university. Or actually, now having had a military career, I knew that really I should have studied a bit harder and could have gone to Sandhurst.* (Participant 5)

Findings suggest multiple factors impacted post limb-loss employment including, participants' attitudes to education, class identity in education, personal assessment of learning capabilities, pressures to generate an income and 'breadwinner anxiety'. The physical side of education and training was also cited as problematic. One participant described how difficulty sitting for extended periods of time, combined with a lower perceived worth of education and old age produced a prohibitive effect upon their engagement in formal training.

Distinct challenges in the forms of employment available to the participants were also identified. Research not specific to veterans showed that only a small proportion of amputees return to their former role of employment, and that those who do so tend to be employed in an office rather than a manual occupation<sup>112</sup>. Greater levels of education have also been associated with access to more flexible forms of employment among amputees<sup>112</sup>. The majority of those leaving the forces find new employment in skilled trades and occupations (20%), associate professional and technical roles (17%), and elementary occupations (15%)<sup>77</sup>. Thus, a considerable proportion of those jobs typically taken up by ex-service personnel involve manual labour. However, the physical restrictions due to limb-loss, and in some cases the unavailability of prosthetics which can withstand the intensity of this work, means that limbless veterans are often unable to take up manual forms of employment. Taken together with a lack of opportunities to re-train for alternative occupations, limbless veterans are therefore at a particular disadvantage in finding employment. The limitations in the support available to veterans around finding employment further exacerbates this issue. As such, advice encouraging veterans to seek employment similar to their role in the military<sup>110</sup> is unlikely to apply to limbless veterans. Likewise, support that is predominantly oriented towards ensuring that ex-military personnel return to employment as soon as possible<sup>110</sup> may, in the case of limbless veterans, actually reinforce the sense of 'breadwinner anxiety' felt by participants.

The ability to continue with paid employment was not only beneficial for participants' self-worth, but also for ensuring a sense of financial security. Participants and families with less material and financial resources experienced a greater sense of precarity as they sought to cope with their injury. This was particularly so given that limb-loss often increased everyday financial outlay (e.g. due to the requirements to buy or hire equipment, make adaptations to the home, or pay for prescriptions and transport), and caring arrangements often reduced household income. In addition, many participants suggested that they self-funded aspects of their care to supplement or overcome gaps in mainstream health and social care provision. As not all veterans are able to afford to do so, this scenario risks widening health and social



inequalities. Drawn-out legal processes and long waiting times for the receipt of compensation disproportionately affected those most vulnerable and therefore exacerbated these inequities.

The transition review<sup>77</sup> posits that the 'most important factor in a successful transition is the attitude and preparation of the individual'. Findings highlight the extension of this to transition in general post limb-loss. Significant structural barriers were identified for participants including potential discrimination from employers and inequalities in access to care and prosthetics available. The transition review<sup>77</sup> recognises the influence of stereotyping and discrimination by employers towards veterans, such as preconceptions that they are institutionalised or aggressive. Limbless veterans are therefore likely to experience double jeopardy due to constrained employment opportunities, assumptions based on their disabilities.

### *Summary*

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 to be 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. This study points to the distinct and clustering challenges around employment and transition experienced by limbless veterans.

Those who struggled with post limb-loss employment were often unable to engage in further education or training, had preconceived perceptions of education, were unable to sustain previous career due to its physical nature or their employer's attitudes and experienced pressures to maintain their pre limb-loss identity. Forms of employment support offered to such groups must accommodate these challenges, particularly by ensuring that meaningful support for career change is provided where appropriate.

## Limb-Loss and Social Isolation

There are two primary narratives which shape the ways in which people experience older age – these are the ‘narrative of decline’ and narratives of ‘successful ageing’, both of which were reflected in the stories told by participants of this study. Despite ‘successful ageing’ narratives offering a much more positive vision of old age, they too have been criticised for creating unrealistic expectations for older people to live up to, and for creating a category of ‘unsuccessful agers’ who are by default labelled as ‘burdens’<sup>113</sup>. The ‘narrative of decline’ is the culturally pervasive perspective on ageing within Western societies<sup>67</sup>. In this narrative, an ever-ageing population is seen as a social problem as individuals become increasingly dependent on health and welfare services. The ‘narrative of decline’ is a highly negative depiction of ageing. Participants in this study were keen to distance themselves from this narrative.

By describing the ways in which they fought to stay independent, the participants clearly sought to align themselves with narratives of ‘successful ageing’, rather than the ‘narrative of decline’. For the most part, participants’ efforts in this regard were positive, highlighting their resilient ‘get-on-with-it’ approach to staying independent. However, analysis also revealed how this approach can work to the detriment of veterans’ health and well-being, such as being stoic, by ‘doggedly’ striving to complete various physical tasks despite increasing levels of pain and damage to joints, or through being ‘too independent’ to seek help to address care needs or social isolation. Understanding and identifying the point at which veterans’ efforts to stay independent (i.e., to age ‘successfully’) start to become detrimental to health and well-being is therefore an important challenge for ensuring that support is accessed where it is needed. Age was often perceived as ‘exaggerating’ the impact of limb-loss; namely upon, mobility, social isolation and loneliness.

Social isolation and loneliness are different concepts, despite often being misunderstood as one. Whereas social isolation is more objective and considers the social environment, such as the frequency of social relations and social networks<sup>114</sup>, loneliness is a subjective social and emotional experience of the discrepancy between the social relationships an individual has and the social relationships they wish to have<sup>115</sup>. It is now understood that loneliness and social isolation are linked to multiple health related risk factors, such as an increased risk of

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<sup>113</sup> Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of aging studies*, 29, 41-52.

<sup>114</sup> Victor, C., Scambler, S., Bond, J., & Bowling, A. (2000). Being alone in later life: loneliness, social isolation and living alone. *Reviews in Clinical Gerontology*, 10(4), 407-417.

<sup>115</sup> Walton, C. G., Shultz, C. M., Beck, C. M., & Walls, R. C. (1991). Psychological correlates of loneliness in the older adult. *Archives of Psychiatric Nursing*, 5(3), 165-170.

high blood pressure<sup>116</sup>, cognitive decline<sup>117</sup>, depression<sup>118</sup>, and mortality<sup>119,120</sup>. Its importance and impact is coming to the forefront of public attention with the founding of charities in the wider population, such as the Campaign to End Loneliness<sup>121</sup>, and the Jo Cox Commission<sup>122</sup> seeking to address these challenges.

Evidence from UK military charities suggests that both loneliness and social isolation are prevalent issues for veterans of all ages<sup>123,124</sup>, and with the majority of available evidence, and public attention, currently focusing on increased age as a risk factor for loneliness<sup>125</sup>, it is imperative to consider the potential impact on aged veterans. Older adults are particularly vulnerable to feelings of social isolation and loneliness due to illness and disability<sup>126</sup> as well as social and geographical mobility issues<sup>127</sup>. Whereas veterans can feel lonely or socially isolated due to military-specific factors including PTSD and trauma<sup>128,129,130,131</sup>.

Within this study, social isolation and loneliness were openly discussed by participants, and were considered to be the result of, increased physical limitations, bereavement or family changes. These factors led to decreased social networks, and are also important factors of

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<sup>116</sup> Hawkey L. C, Masi C. M, Berry J. D, Cacioppo J. T. (2006) Loneliness is a unique predictor of age-related differences in systolic blood pressure. *Psychology and aging*, **21**(1), 152.

<sup>117</sup> James BD, Wilson RS, Barnes LL, Bennett DA. (2011) Late-life social activity and cognitive decline in old age. *Journal of the International Neuropsychological Society*, **17**(6), 998-1005.

<sup>118</sup> Cacioppo J. T, Hughes M. E, Waite L. J, Hawkey L. C, Thisted R. A. (2006). Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. *Psychology and aging*, **21**(1), 140.

<sup>119</sup> Steptoe A, Shankar A, Demakakos P, Wardle J. (2013). Social isolation, loneliness, and all-cause mortality in older men and women. *Proceedings of the National Academy of Sciences*, **110**(15), 797-801.

<sup>120</sup> Holt-Lunstad J, Smith T. B, Layton J. B. (2010). Social relationships and mortality risk: a meta-analytic review. *PLoS medicine*, **7**(7).

<sup>121</sup> <https://www.campaigntoendloneliness.org>

<sup>122</sup> <https://www.jocoxloneliness.org>

<sup>123</sup> Royal British Legion. (2014). *A UK household survey of the ex-service community*. London: The Royal British Legion.

<sup>124</sup> SSAFA. (2017, 23.10.17). Retrieved from <https://www.ssafa.org.uk/latest/41-veterans-have-felt-isolated-research-reveals>

<sup>125</sup> Kuwert, P., Knaevelsrud, C., & Pietrzak, R. H. (2014). Loneliness Among Older Veterans in the United States: Results from the National Health and Resilience in Veterans Study. *American Journal of Geriatric Psychiatry*, **22**(6), 564-569.

<sup>126</sup> Goll, J. C., Charlesworth, G., Scior, K., & Stott, J. (2015). Barriers to social participation among lonely older adults: the influence of social fears and identity. *PLoS one*, **10**(2).

<sup>127</sup> Valtorta, N., & Hanratty, B. (2012). Loneliness, isolation and the health of older adults: do we need a new research agenda?. *Journal of the Royal Society of Medicine*, **105**(12), 518-522.

<sup>128</sup> Itzhaky, L., Stein, J. Y., Levin, Y., & Solomon, Z. (2017). Posttraumatic stress symptoms and marital adjustment among Israeli combat veterans: The role of loneliness and attachment. *Psychological Trauma: Theory, Research, Practice, and Policy*, **9**(6), 655.

<sup>129</sup> Solomon, Z., Bensimon, M., Greene, T., Horesh, D., & Ein-Dor, T. (2015). Loneliness trajectories: The role of posttraumatic symptoms and social support. *Journal of Loss and Trauma*, **20**(1), 1-21.

<sup>130</sup> Stein, J. Y., & Tuval-Mashiach, R. (2015). Loneliness and isolation in life-stories of Israeli veterans of combat and captivity. *Psychological trauma: theory, research, practice, and policy*, **7**(2), 122.

<sup>131</sup> Celeste Carr, D., Ureña, S., & Taylor, M. G. (2017). Adjustment to Widowhood and Loneliness Among Older Men: The Influence of Military Service. *The Gerontologist*.

social isolation and loneliness within both the veteran<sup>132,133,134</sup> and ageing population<sup>126</sup> literature. However, it is important to note that limb-loss further exacerbated participants' vulnerability to social isolation and loneliness in older age.

Limb-loss affected perceived loneliness and social isolation; either due to mobility issues and not being able to partake in regular activities, concerns about self-image, and not relating to others. Individuals generally understood their decreased mobility (due to their limb-loss and ageing) as having an impact on their independence, completion of daily activities, and quality of life; specifically their ability to participate socially outside of the home. It is understood that loneliness and social isolation experienced by veterans can be the result of 'alienation'<sup>130</sup>, and in this study, this seemed heightened due to limb-loss. Previous literature suggests that group interventions targeting specific groups are most effective in reducing social isolation<sup>135</sup>. In line with this, participants identified peer-support groups, both military and amputee-specific, as highly valuable. Research also found the reactions of others towards limb-loss reinforced the stigma participants felt and their concerns about body image<sup>136</sup>. In light of these issues, many participants, particularly older veterans, opted to hide their limb-loss or prostheses. This was described as a strategy for impression management, and avoiding stigmatisation. Peer-support, including support provided by limb-loss specific charities such as Blesma and non-military charities, was considered to be crucial in terms of providing social networks of like-minded people, with similar experiences and a sense of camaraderie. Being connected to others through shared stories, shared understandings and shared challenges unsurprisingly appeared to be imperative to participants' social participation.

### Summary

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 unable to relate to others.

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<sup>132</sup> Carr, D., Ureña, S., & Taylor, M. G. (2017). Adjustment to Widowhood and Loneliness Among Older Men: The Influence of Military Service. *The Gerontologist*, *gnx110*.

<sup>133</sup> Gould, C. E., Shah, S., Brunskill, S. R., Brown, K., Oliva, N. L., Hosseini, C., Bauer, E., Huh, J. W. T. (2017). RESOLV: Development of a telephone-based program designed to increase socialization in older veterans. *Educational Gerontology*, *43*(8), 379-392.

<sup>134</sup> Monin, J. K., Mota, N., Levy, B., Pachankis, J., & Pietrzak, R. H. (2017). Older Age Associated with Mental Health Resiliency in Sexual Minority US Veterans. *American Journal of Geriatric Psychiatry*, *25*(1), 81-90.

<sup>135</sup> Cattan, M., White, M., Bond, J., & Learmouth, A. (2005). Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions. *Ageing & Society*, *25*(1), 41-67.

<sup>136</sup> Murray, C. D., & Fox, J. (2002). Body image and prosthesis satisfaction in the lower limb amputee. *Disability and Rehabilitation*, *24*(17), 925-931.

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

Within health research, the phrase ‘Activities of Daily Living<sup>137</sup>’ (ADLs) is commonly used to refer to the fundamental skills, capacities and resources required to maintain basic care needs and engagement in regular day-to-day living. ADLs are categorised as basic ADLs or instrumental ADLs. Basic ADLs are essential self-care activities commonly mastered throughout the course of early childhood. There are five domains which are typically included: personal hygiene and grooming, dressing, toileting and continence, mobility and ambulation and eating. Instrumental ADLs include the more complex, higher-order functions which are required in order to maintain independence and quality of life, typically mastered during adolescence or early adulthood. These domains include financial self-management, management of one’s health and medications, housekeeping, shopping, food preparation, travelling by car or by public transport and using the telephone.

Previous research has identified limb-loss as a significant cause of disability which may result in heavy ADL dependency. Upper-limb amputees may experience ADL dependency in areas such as dressing or food preparation<sup>138</sup>, while individuals with lower-limb amputations commonly experience ADL dependency in areas such as bathing and home ambulation<sup>139</sup>. Level of amputation is correlated with level of functional impairment amongst upper and lower limb amputees. In both cases, bilateral amputees reported significantly greater levels of functional impairments and ADL dependency than unilateral amputees<sup>139,140,141</sup>. Amongst upper extremity amputees, above-elbow amputees reported significantly greater levels of impairment than below-elbow amputees<sup>142,143</sup>. Similarly, among lower extremity amputees, above-knee amputees reported significantly greater levels of impairments and dependency than below-knee amputees<sup>139,140,144</sup>.

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<sup>137</sup> Roper, N. (2000). *The Roper-Logan-Tierney model of nursing: based on activities of living*. Edinburgh: Churchill Livingstone.

<sup>138</sup> Jang, C. H., Yang, H. S., Yang, H. E., Lee, S. Y., Kwon, J. W., Yun, B. D., . . . Jeong, H. W. (2011). A survey on activities of daily living and occupations of upper extremity amputees. *Ann Rehabil Med*, 35(6), 907-921.

<sup>139</sup> Narang, I. C., Mathur, B. P., Singh, P., & Jape, V. S. (1984). Functional capabilities of lower limb amputees. *Prosthet Orthot Int*, 8(1), 43-51.

<sup>140</sup> Helm, P., Engel, T., Holm, A., Kristiansen, V. B., & Rosendahl, S. (1986). Function after lower limb amputation. *Acta Orthop Scand*, 57(2), 154-157.

<sup>141</sup> Østlie, K., Franklin, R. J., Skjeldal, O. H., Skrondal, A., & Magnus, P. (2011). Assessing physical function in adult acquired major upper-limb amputees by combining the Disabilities of the Arm, Shoulder and Hand (DASH) Outcome Questionnaire and clinical examination. *Arch Phys Med Rehabil*, 92(10), 1636-1645.

<sup>142</sup> McFarland, L. V., Choppa, A. J., Betz, K., Pruden, J. D., & Reiber, G. E. (2010). Resources for wounded warriors with major traumatic limb loss. *Journal of Rehabilitation Research and Development*, 47(4), 1.

<sup>143</sup> Ovadia, S. A., & Askari, M. (2015). Upper extremity amputations and prosthetics. *Semin Plast Surg*, 29(1), 55-61.

<sup>144</sup> Vogel, T. R., Petroski, G. F., & Kruse, R. L. (2014). Impact of amputation level and comorbidities on functional status of nursing home residents after lower extremity amputation. *J Vasc Surg*, 59(5), 1323-1330

Existing research exploring the impact of limb-loss upon ADL independence has typically adopted a quantitative cross-sectional design. As such, there is a paucity of research which aims to explore the real-life impact of limb-loss upon veterans' ADLs throughout the life-course. The present study represents the only qualitative inquiry to date, which has attempted to explore veterans' lived experiences of the immediate, short-term and long-term functional impairments associated with limb-loss.

ADLs featured heavily throughout participants' personal stories, spanning ubiquitously across superordinate themes and narrative types. The capacity to achieve ADL independence emerged as a highly influential factor in determining the trajectory of participants' personal stories at different times throughout their lives. The data suggests that ADL independence is central to participants' perceived quality of life and their confidence in their ability to overcome and adapt to the challenges associated with limb-loss. Furthermore, this study illustrates the many ways in which the physical challenges associated with limb-loss, may impact upon veterans' capacity to achieve ADL independence throughout the life-course.

Findings suggest that the capacity to achieve ADL independence may be significantly impaired during the early stages of limb-loss, as veterans await the initial provision of prosthetic limbs. For many participants, the early post-operative phase was characterised by significant restrictions in mobility and physical functioning, resulting in ADL dependence and heightened psychological distress. Participants frequently reported that psychological distress experienced during the early post-operative phase did not abate until physical rehabilitation began. Contemporary research suggests that pre-prosthetic rehabilitation during the early post-operative stage may promote the rehabilitation of physical functioning and reduce long-term ADL dependency<sup>145</sup>. Pre-prosthetic rehabilitation typically involves strength training, residual limb shaping and non-prosthetic mobility training<sup>146,147</sup>. In addition to promoting physical recovery, the findings of this study suggest that pre-prosthetic rehabilitation may be associated with additional psychological benefits for veterans affected by limb-loss. Interventions which improve mobility and ADL independence during the pre-prosthetic phase, may be associated with reductions in early psychological distress.

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<sup>145</sup> De-Rosende Celeiro, I., Simon Sanjuan, L., & Santos-Del-Riego, S. (2017). Activities of daily living in people with lower limb amputation: outcomes of an intervention to reduce dependence in pre-prosthetic phase. *Disabil Rehabil*, 39(18).

<sup>146</sup> Esquenazi, A., & DiGiacomo, R. (2001). Rehabilitation after amputation. *Journal of the American Podiatric Medical Association*, 91(1), 13-22.

<sup>147</sup> Geertzen, J., van der Linde, H., Rosenbrand, K., Conradi, M., Deckers, J., Koning, J., . . . Voesten, H. (2015). Dutch evidence-based guidelines for amputation and prosthetics of the lower extremity: Rehabilitation process and prosthetics. Part 2. *Prosthet Orthot Int*, 39(5).

This study also demonstrates that appropriate housing and required home adaptations are essential to maintain ADL independence amongst veterans affected by limb-loss. For a number of participants, receiving support from local authorities in order to secure appropriate housing or receiving aid from local authorities and third sector organisations to fund required home adaptations, facilitated a shift in their stories from 'struggling to adapt', to 'adapting to struggle'. This was characterised by reduced ADL dependency and an enhanced quality of life.

Since 1990, UK law has required that local housing authorities provide financial aid to disabled individuals in order to fund required home adaptations<sup>148</sup>. More recently, the Care Act of 2014 has reinforced this statutory obligation, explicitly outlining the importance of suitable living arrangements and appropriate home adaptations. The UK government recognises additional responsibilities to veterans who have acquired a disability or illness due to their military service. The Armed Forces Covenant represents an informal understanding between the government, the nation and the Armed Forces, that those who serve or have served will be treated with fairness, respect and gratitude. This study explicitly illustrates the value of such understanding for support for veterans affected by limb-loss in terms of promoting ADL independence, and maintaining a good quality of life across the whole life-course.

Previous research has identified significant maintenance issues with prosthetic limbs, which require regular adjustment, repairs and replacements in order maintain proper fit and full functionality over time. For example, Nair, Hanspal, Zahedi, Saif and Fisher<sup>149</sup> analysed the provision and maintenance of prostheses amongst 173 above-knee and below-knee amputees over a 10 year period (1993-2002). Above-knee amputees required an average of 0.96 new prosthesis, 2.31 major repairs, 21.85 minor repairs, 3.27 new sockets and 3.36 component changes, while below-knee amputees required an average of 1.44 new prostheses, 3.16 major repairs, 14.19 minor repairs and 2.89 new sockets. Problems with prosthetics may result in significant pain, discomfort and functional impairments for amputees. Other research reported 40% of veterans had experienced medical problems as a result of prosthesis use and 82% reported a limiting capacity to engage in physical activities due to issues related to prosthetics<sup>150</sup>.

This study suggests that problems with prosthetics may significantly impact upon limbless veterans' capacity to engage in ADLs throughout the life-course. Participants reported

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<sup>148</sup> House of Commons (1990) *The National Health Service and Community Care Act*. London: HMSO.

<sup>149</sup> Nair, A., Hanspal, R. S., Zahedi, M. S., Saif, M., & Fisher, K. (2008). Analyses of prosthetic episodes in lower limb amputees. *Prosthet Orthot Int*, 32(1), 42-49.

<sup>150</sup> Sherman, R. A. (1999). Utilization of prostheses among US veterans with traumatic amputation: a pilot survey. *Journal of Rehabilitation Research and Development*, 36(2), 100.

persistent problems with prosthetics, resulting in limitations in mobility and restrictions in physical activities. They emphasised the importance of ongoing high-quality prosthesis care in terms of maintaining independence and quality of life. Therefore, it is suggested that high quality prosthetic limbs and timely access to specialist prosthesis care, is essential in order to maintain ADL independence amongst veterans affected by limb-loss.

ADL dependency is a growing concern as limbless veterans progress throughout later life. Previous research suggests that there is a negative correlation between age and ADL independence amongst amputees, with elderly amputees reporting significantly greater levels of impairment than younger amputees<sup>151,152,153</sup>. In line with previous research, this study suggests that age-related factors may compound the physical challenges associated with limb-loss, resulting in greater levels of ADL dependency during later life. Participants described the impact of age-related physical decline and musculoskeletal conditions such as arthritis. Due to reduced strength and heightened pain and discomfort, many participants reported reductions in their capacity to engage in ADLs independently.

An additional factor which must be considered as limbless veterans progress throughout later-life is their capacity to drive a car. Many participants emphasised the importance of driving in terms of their overall quality of life and ADL independence. However, within the UK, a Group One licence is only valid until the time that the holder reaches 70 years of age. At this time, and every three years thereafter, the holder is required by law to renew their licence by submitting a medical questionnaire to the Driver & Vehicle Licensing Agency (DVLA). Individuals with a medical condition which may impair their capacity to drive may also require a driving assessment or a medical examination. A number of participants in the present study discussed the ways in which age-related physical decline has resulted in an inability to continue driving during later life. Participants perceived the inability to drive as a significant threat to independence, resulting in restrictions in mobility and a need to rely upon others to engage in regular daily activities. It is clear that driving is considered to be fundamental to ADL independence amongst this population. As such, this study suggests that during later life, veterans who are affected by limb-loss may require additional support in order to maintain ADL independence if they find that they are no longer able to drive a car.

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<sup>151</sup> De-Rosende Celeiro, I. D.-R., Santos-del-Riego, S., & García, J. M. (2017). Homebound status among middle-aged and older adults with disabilities in ADLs and its associations with clinical, functional, and environmental factors. *Disability and health journal*, *10*(1), 145-151.

<sup>152</sup> Schoppen, T., Boonstra, A., Groothoff, J. W., de Vries, J., Goeken, L. N., & Eisma, W. H. (2003). Physical, mental, and social predictors of functional outcome in unilateral lower-limb amputees. *Arch Phys Med Rehabil*, *84*(6), 803-811.

<sup>153</sup> Shin, J. C., Kim, E. J., Park, C. I., Park, E. S., & Shin, K. H. (2006). Clinical features and outcomes following bilateral lower limb amputation in Korea. *Prosthet Orthot Int*, *30*(2), 155-164.



### *Summary*

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 ADL independence. 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. 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, due to the long-term use of poor quality prosthetic devices and limitations in early rehabilitation and prosthetic care. Age-related physical decline and medical comorbidities may further impair older veterans' capacity to achieve ADL independence as they progress throughout later-life. The capacity to engage in ADLs independently was a highly influential factor in the trajectory of participant's personal life-stories, which determined their perceived wellbeing and quality of life and confidence in their ability to successfully adapt to the challenges associated with limb-loss. As such, promoting ADL independence should be a key priority for organisations wishing to support veterans affected by limb-loss.



