Traumatic Limb Loss and the Needs of the Family

Current Research: Policy and Practice Implications

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Foreword

Blesma has always attended to the families of its Members (the limbless veterans). We appreciate the benefits of a holistic approach to support and the value of family cohesion. However, while attentive to obvious distress and always practical in approach, we have gathered little hard evidence on the deeper needs of the family as a whole and how our support might be more effective, especially in the longer term; Blesma is there for life not only while a case file is open.

This is why we commissioned the Veterans and Families Institute at Anglia Ruskin University to undertake an extensive review of the literature to consider what research and evidence has been undertaken into the impacts of traumatic limb loss on the family. This review concludes that no one else in the UK has been deliberately accruing evidence either. The most recent report of the House of Commons Defence Committee expresses a similar opinion. We aim for this valuable piece of work to be a catalyst for Government and the Service charities to collaboratively improve understanding of the family needs surrounding those severely injured in the service of their country.

Barry Le Grys
Chief Executive
Blesma, The Limbless Veterans
Introduction

For nearly 100 years, Blesma, The Limbless Veterans, has directly supported Service men and women who have lost limbs and the use of limbs or the loss of eyesight in the service of our country, and also those veterans who have lost limbs as a result of accidents or medical conditions\textsuperscript{1,2}.

Although severe and life-changing injury as a result of conflict is as old as war itself, the recent protracted conflicts in Iraq and Afghanistan have focused public attention on the needs of injured Service personnel and veterans.

The expansion of new media such as the internet and 24-hour news coverage has undoubtedly had an impact on public perceptions of injured Service personnel and their needs. Over the past few years there has been a proliferation of charities offering help and support to veterans, and there appears to be no shortage of public support to donate. Whether or not this situation continues following the withdrawal from Afghanistan is a matter of great interest.

Although there has been an unprecedented growth in the number of charities providing support for ex-Service personnel, there is a growing concern about the effectiveness of the services that are provided or the efficacy of therapeutic interventions\textsuperscript{3-5}. 
Background

Although not new, improvised explosive devices (IEDs) have become the weapon of choice in Afghanistan. Since the beginning of operations in Afghanistan there has been a change from traditional battlefield warfare to counter insurgency with asymmetric warfare and this, in turn, has led to a rise in the use of IEDs and the associated blast injuries. Recent improvements in body armour, front line medicine trauma techniques, and speed of medical evacuation have meant that far more personnel are surviving catastrophic blast injuries that until very recently would have been fatal.

From the onset of recent UK military operations in the Middle East, 16 and 275 personnel have suffered traumatic limb loss in Iraq and Afghanistan respectively, with 105 of the Afghanistan casualties suffering significant multiple amputations (SMAs). A further 62 Service personnel have suffered amputations as a result of injuries sustained in other locations6. Since 2001, 353 UK military personnel have lost limbs in the course of their service. Over a similar period 1,558 US military personnel had suffered battle-injury major limb amputations in both theatres of conflict7.

As the leading provider of long-term support of limbless ex-Service personnel, Blesma are concerned to ensure that their beneficiaries receive the best approaches to care and support. It is a strategic ambition of the charity to promote evidence-based practice and to encourage investigation and research to inform service delivery and innovation.

Blesma have identified that there is a lack of knowledge organisationally about the impact of traumatic limb loss on families and on what measures the charity can take to improve the rehabilitative outcomes of its recipients through working with families.

Blesma have commissioned a brief review of the literature to consider the following questions:

– What evidence is available on the emotional and psychological impact of traumatic limb loss on families and Service families in particular?

– What coping strategies have been adopted by the families?

– What interventions have been shown to be effective?
Methodology

Narrative Literature Review

A narrative reviews approach was used, as opposed to a systematic review which addresses a very specific question. Narrative reviews are commonly broad in scope, making them more appropriate for integrating a wider range of issues on a given topic, identifying existing gaps in the literature, and generating new areas for further research and inquiry.

Because understanding the needs of families of Service personnel who have suffered limb loss is a new area of research that lacks evidence, a narrative review was deemed to be the most appropriate.

Studies or review articles included in this narrative review considered the support needs of families, the impact of the limb loss on families and their coping strategies. The literature was searched in a three-stage process. First, we used the following databases: ASSIA, Social Care Online, Web of Science, PubMed, and Ebsco (including AMED, Cinahl Plus, Medline, PsychARTICLES, Psychology and Behavioural Sciences Collection, PsychINFO, Child Development and Adolescent Studies) and ProQuest dissertations. The searched keywords were “traumatic limb loss”, “traumatic amputation”, “dismember$”, “famil$”, “spouse$”, “child$”, “coping”, “impact”, “military”, “armed services”, “army”, “navy”, “marine$”, “air force”. The Boolean connecters “and” and “or” were used to combine keywords and to search for multiple topics simultaneously.

The second stage included a search using the ProQuest family of databases. We used related search terms not included in the original agreed search parameters, but including the more prominent contemporary nomenclature used in the US literature. We focused especially on “poly-trauma” and support for the family. The limitations inherent within this search are discussed later in the text.

The third stage of the search used a “snowball” approach whereby after reviewing citations from key articles retrieved in the first stage, additional articles on the impact of traumatic limb loss on families were identified. Abstracts from these additional studies were reviewed and full-length articles were retrieved.

Inclusion criteria were very broad and all material published since the establishment of Blesma in 1932 was considered, including academic theses and grey literature as well as papers published in peer reviewed journals. The exclusion criterion was papers not written in English.
Results

The results of searching the named databases identified using the search parameters identified above are shown in Table 1: Search Results. As this illustrates, we were only able to identify six research papers that contained the search terms defined in our methodology. Table 2 presents a list of the articles that were reviewed and the brief discussion considers whether the three questions posed:

– What evidence is available on the emotional and psychological impact of traumatic limb loss on families and Service families in particular?

– What coping strategies have been adopted by the families?

– What interventions have been shown to be effective?

are considered and answered within the scope of the papers identified in the review.

Table 1: Search Results

<table>
<thead>
<tr>
<th>SEARCH STRINGS</th>
<th>Results of combined search of all databases (*following abstract checks for relevance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>traumatic limb loss OR</td>
<td>796</td>
</tr>
<tr>
<td>traumatic amput$ OR</td>
<td></td>
</tr>
<tr>
<td>dismember$</td>
<td></td>
</tr>
<tr>
<td>AND Famil$ OR Spouse$ OR</td>
<td>54</td>
</tr>
<tr>
<td>child$</td>
<td></td>
</tr>
<tr>
<td>AND coping OR impact</td>
<td>10*</td>
</tr>
<tr>
<td>AND military OR Armed Service$ OR Army</td>
<td>6*</td>
</tr>
</tbody>
</table>
Table 2: Impact of Traumatic Limb Loss on Families

<table>
<thead>
<tr>
<th>Reference</th>
<th>Type of Study</th>
<th>Population and Condition</th>
<th>Method</th>
<th>Evidence of impact on families</th>
<th>Coping strategies</th>
<th>Intervention types</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ferguson, Richie and Gomez (2004)</td>
<td>Qualitative</td>
<td>n=85 37 (30 male, 7 female) survivors of traumatic limb loss due to land mines 10 family members 7 service providers from 6 conflict areas (Bosnia, El Salvador, Eritrea, Ethiopia, Jordan, Mozambique) and 31 (19 male, 12 female) USA amputees (theatre of trauma not reported)</td>
<td>Semi-structured interviews conducted by US trained social workers. Data analysis was completed using grounded theory analytic strategies</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Afshar and Afshar, (2007)</td>
<td>Descriptive</td>
<td>Iranian study n=7 (all male) Bilateral hand amputations due to handling land mines Age range 9-40</td>
<td>Medical examination, history taking and assessment using the FAM</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Friedemann-Sanchez, Sayer and Pickett (2008)</td>
<td>Qualitative</td>
<td>US study n=56 providers of VA polytrauma rehabilitation</td>
<td>RAP methodology – provider self-report including: polytrauma patient characteristics; family member involvement in rehabilitation; impact of polytrauma on providers</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Ebrahimzadeh and Rajabi (2007)</td>
<td>Descriptive</td>
<td>Iranian study Post amputation follow up (ave. 17.4 years) n=27 Iranian soldiers who had suffered amputations of foot and ankle</td>
<td>Medical examination and history taking</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Ebrahimzadeh and Hariri (2009)</td>
<td>Descriptive</td>
<td>Iranian study Post amputation follow up (ave. 17.5 years) Follow-up study considering functional, psychological and social outcomes n=200</td>
<td>Medical examination and history taking</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Using the search terms identified in the methodology we were only able to identify six papers of some relevance.

Three of these studies followed up traumatic limb-loss victims in Iran\textsuperscript{10, 12, 13}. All of these descriptive studies used medical examinations and history taking to elicit the physical and psychosocial impacts of traumatic amputation. Afshar and Afshar (2007)\textsuperscript{10} considered the long term follow-up needs of seven Iranian male bilateral hand amputees who had lost their limbs as a result of land mines. The authors considered the psychological and economic impacts of bilateral hand loss on the participants and noted that this catastrophic injury had little impact on marriage or relationships. The sample size was (thankfully) small and it is difficult to establish if the sample is representative. Similar results on social functioning were reported by Ebrahimzadeh and colleagues in studies of other amputations with larger sample sizes \textsuperscript{12, 13}. In all of these studies family members were not interviewed and the authors did not consider the impact of the injuries on the wider family or how the families were involved in rehabilitation.

In an international study of the impact of traumatic limb loss on land mine survivors, Ferguson et al (2004)\textsuperscript{9} identified a dynamic relationship model between economic opportunities, social integration and physical and psychological health. Although families and family dynamics are identified as important in an ideal rehabilitative pathway, the impact on the family, or indeed their contribution to rehabilitation, is not explored, even though 10 family members were interviewed in the course of the study. This qualitative study was quite extensive, with 85 participants, but its international scope and exploration of impact across a vast range of cultural and socio-economic differences need to be taken into consideration.

In a cross-sectional survey by Dougharty et al (2014), Vietnam era amputees were compared with those injured in current operations. The authors found no significant differences in measures of quality of life between the two groups\textsuperscript{14}. This survey looked exclusively at the amputee and did not consider the objective experiences of family members.

In the most informative of the papers, Friedmann-Sanchez et al (2008)\textsuperscript{11} used a Rapid Assessment Process (RAP) methodology to obtain in-depth qualitative information. The perspectives of USA VA rehabilitation providers on the involvement of polytrauma patients’ families in rehabilitation were assessed. The authors acknowledged that there is very little comparable literature, but noted that compared to other VA rehabilitation services, families of polytrauma patients were much more involved in rehabilitation and needed much more intensive support themselves – although the nature of this support was not discussed.
None of the papers identified in the review of the literature looked directly at the experiences of families, although social functioning and relationships were an important element for the participants in the research. As we were unable to identify any literature of note specifically relating to traumatic limb loss and family impact, the authors extended the search terms to incorporate “polytrauma”. The meaning of the term polytrauma is discussed in more detail below. Even though the term has an American aetiology and refers to multiple injury (and is not strictly related to traumatic limb loss), it was felt that any literature relating to the impact of polytrauma on families may be of interest.

We used the ProQuest family of 24 health and social care databases, and searched using the following string: “polytrauma” AND “family” AND “support”. We identified 384 articles, 14 from peer-reviewed journals. A brief abstract review of the 14 articles identified six for further consideration; these are detailed in Table 3 Impact of Polytrauma on Families. Of the six, three of the papers were more focused on the impacts of traumatic brain injury (TBI) as the primary presenting condition.\(^{15-17}\)

The review findings using both the original search terms and the new “polytrauma” string were augmented using a snowball approach where we considered key citations in articles of interest. The outcomes of this expansion of the search criteria are considered in the discussion section below.

There is much that is not understood about the impact of caring for severely injured personnel on the family. In a comprehensive review of the literature Griffin et al (2009)\(^{18}\) have identified seven keys areas where there is a paucity of research and more needs to be understood to inform the research policy agenda and practice delivery. They identified specific staff training in delivering polytrauma care and communicating important information as requiring further investment, an issue discussed at some length by Friedemann-Sánchez and colleagues (2008)\(^{15}\), who conclude that polytrauma providers require much more information about what families need to know, and where, when and how to deliver this without having a deleterious impact.

Griffin et al (2009) found that little is understood about the long-term impact on the families of care giving, whether this is financial or psychological. They also identified that very little is known about the impact of family attitudes towards polytrauma recovery, something that has been well documented in other health conditions and even less is known about the psycho-social adjustment of family members to some of the unique traumatic injuries associated with combat.
Griffin et al (2009) also found that negotiating the system of care is particularly problematic. Even though this research was mainly based on US studies the myriad of different charities that are present in the UK make informed decision making difficult for families. Whom should they trust to deliver evidence based interventions?

Schaaf and colleagues (2013)\(^{19}\) looked at perceived needs and whether these had been met amongst a sample of 44 military families in a polytrauma setting. They identified that most of the civilian research had focused on the needs of carers of patients with TBI and had used the Family Needs Questionnaire (FNQ), a tool specifically designed for families of patients with a brain injury.

Civilian studies using the FNQ have identified that family members consider health information as one of the most important needs\(^{20-25}\) and that emotional and instrumental support are more often cited as being less important and indeed less likely to be met\(^{21-24}\). Schaaf et al (2013) found that the findings amongst their military population were consistent with civilian findings.

With the exception of a small study, carried out in Northumbria by Moules and Chandler (1999)\(^{22}\), most of the research into family experiences has been conducted in the USA. It is likely that the structural and systemic differences between the US and UK system of care may impact on family needs and perceptions, and their access to different statutory and voluntary sector services.

The Schaaf et al (2013) study was cross-sectional, that is considered the issues at one point in time. There has been very little longitudinal research considering the impact on families over an extended period of time. Griffin and colleagues (2012)\(^{16}\) studies a comparatively large sample of family caregivers for injured US Service personnel and veterans (n=564). They found that interested parents rather than spouses tended to be the main providers of care. This is an important finding as when we consider the more conservative definition of family used by the UK MOD, where parents may be excluded in decision making, even though the US evidence suggests that they may have a more important role than thought.

Griffin et al (2012) also found that within the post-injury range (<1 to >7 years) of the families they interviewed, the intensity of the care giving did not alter. Very little is known about caregiving patterns and even where there is a more considerable research base, such as with TBI research, no literature considers issues beyond five years post-injury. There is little clarity about what the long-term needs of severely injured US Service personnel may be, especially the impacts on the family and the caring relationships.
Collins and Kennedy (2008) argue the importance of the family in polytrauma care and rehabilitation, however in their case review paper the focus of discussion is towards traumatic brain injury as the principal polytrauma injury. In the US, the Veterans Administration has taken steps to try to standardise the care and support that families of injured Service personnel receive. Hall et al (2010) evaluated the changes associated with this “Family Care Collaborative” approach and found a cultural shift towards a more family-centred care delivery model. The greater numbers of injured US Service men, the geographical spread of services and the systemic differences, compared to the UK make comparisons difficult, however the product of the collaborative approach of closer family working may have longer term social and clinical benefits.
## Table 3 Impact of Polytrauma on Families

<table>
<thead>
<tr>
<th>Reference</th>
<th>Type of Study</th>
<th>Population and Condition</th>
<th>Method</th>
<th>Evidence of impact on families</th>
<th>Coping strategies</th>
<th>Intervention types</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schaaf et al (2013)19</td>
<td>Quantitative</td>
<td>N=44 Carers of US service polytrauma cases</td>
<td>Cross-sectional study using the Family Needs Questionnaire (FNQ)</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Griffin et al (2012)16</td>
<td>Quantitative</td>
<td>N=564 Carers of US service polytrauma cases</td>
<td>Cross-sectional survey</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Hall et al (2010)26</td>
<td>Cross-site Mixed method</td>
<td>N=226 rehabilitation staff working in 4 US Polytrauma Rehabilitation Centres (PRCs)</td>
<td>Provider survey of family care</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Perceived competence with working with families</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Specific site practice changes</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Provider and facilitator perceptions</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Validated measure of success for family interventions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Griffin et al (2009)18</td>
<td>Discursive</td>
<td>Considering the research and literature around the coping mechanisms of families of patients with polytrauma</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Collins and Kennedy (2008)17</td>
<td>Discursive with case study</td>
<td>Considering the emotional impact of polytrauma on families</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Friedemann-Sánchez et al (2008)15</td>
<td>Literature review</td>
<td>Information needs of carers of polytrauma patients</td>
<td>Narrative review</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Discussion

The literature review failed to identify any UK research looking predominantly at the impact of traumatic limb loss on the family. This was the case for both military and civilian cohorts. However, a number of interesting questions have been raised in particular whether the findings of the US research are translatable or replicable in the context of the UK health and social care system.

There are also a number of definitional issues that require further discussion to ensure clarity when trying to understand the findings presented in the US literature.

Families

Understanding the impact of families and family relationships on recovery from physical illness is a relatively recent phenomenon. During the late 1950s, the field of psychiatry began to recognise the role that the family plays in the mental health of individual family members. What emerged from this was a canon of literature that considered the importance of the family in the emotional as well as physical health of the family27. The involvement of family caregivers has been shown to be important for the success of patients’ rehabilitation28, 29 and research has shown that families of patients with polytraumatic injuries need appropriate communication and support in caring for their loved one, as well as help dealing with their own stress and anxiety15.

The definition of family is not as straightforward as could be expected. Different organisations adopt different definitions and this has material importance when collecting information, planning services or making strategic or policy decisions. What then is meant by family? The historical notion of extended family and the nuclear family common in the 1940s and 50s, although still present, are no longer the predominant family structures in contemporary society30.

The term nuclear family can be defined simply as a wife/mother, a husband/father, and their children, although there is a degree of ambiguity. An extended family is a vertical extension of a core nuclear family to include a third (e.g. grandparents) or even fourth generation.

Of course, family is quite a fluid notion and is influenced by the dominant societal ideologies of what a family should look like31. Recent sociological definitions of family do not rely on legal or biological relationships, but rather on ties of experience and commonality. “Families comprise persons who have a shared history and a shared future.”32. This systemic definition is also useful in the context of the military where an institutional reliance on unit cohesion, whether that is ship, regiment or squadron, is paramount for military effectiveness.
Generally, the nature of the family is not defined in the research literature we considered, but it is implicit that family falls into the traditional view of a nuclear family or of caregiver. This distinction is not as pedantic as it at first appears. What little we know about the needs and experiences of UK military families33 is driven by a very conservative interpretation of the family unit which fails to include many meaningful relationships.

The type of support offered by families has been divided by Cohen and Syme34 into different categories. Instrumental support such as the provision of direct services (such as a transporting a family member for appointments) or care giving (e.g. helping with personal care, dressings, injections etc.); Informational support such as giving advice about whether to seek assistance or helping to find and qualifying information online; emotional support, providing empathy or a listening ear; and a sense of belonging, a feeling that the person is a member of a family or a group that cares. There are overlapping relationships between these four categories but researchers have suggested that emotional support has the most important impact on health outcomes35 and Campbell36 argues that it would not be possible to replace family support with services that only provide instrumental or informational support. In other words, it is families themselves that are imperative to getting the best rounded and effective support and the most important psychological component cannot be replicated by agencies external to the family.

The importance of the family is illustrated in a number of studies that have considered the significant health benefits of being in a close relationship. Even after controlling for other factors, marital status affects overall mortality, disease-specific mortality (e.g. cancer and heart disease) and morbidity35, 37. Married people are healthier than the widowed, who are in turn healthier than divorced or never married people. Of course, the quality of the married relationship is also important and it has been shown that, for sufferers of congestive heart failure, marital quality was a strong predictor of death as the severity of the coronary artery disease in the first place38. Overall, enhanced family and individual life satisfaction for survivors of injury has been shown to be associated with greater social integration39.

The corollary of good family relationships on health outcomes is unfortunately that critical hostile or negative relationships have a much stronger impact on health outcomes. In health terms, being unpleasant or nasty is worse than simply adopting a neutral position and just not being nice36. Living in families that are overly critical has been shown to be a strong predictor of mental illness relapse40-42, and has a negative impact on smoking cessation43, weight management44, blood pressure45 and diabetes control46.
Failure in rehabilitation may be the result of disordered family dynamics, alienation, or the collapse of a concerned but overwhelmed family. Even stable families may be disrupted by the stresses involved in caring for a disabled or chronically sick member\textsuperscript{47}.

We know very little about the long term impact of deployment and its associated stressors on military families\textsuperscript{48} but there is a growing body of compelling US literature arguing the importance of identifying mechanisms for therapeutic work with military families\textsuperscript{17, 49-54} and the deleterious impact of deployment and Service-related injury or death on children\textsuperscript{55-57}. Recent US research has also confirmed Verluys\textsuperscript{47} hypothesis about the impact of family disruption caused by care giving and has emphasised the importance of supporting families and caregivers with the ongoing tasks of providing support for injured Service personnel\textsuperscript{16}, and this view is supported by Cozza and colleagues, with a strong emphasis on family support:

“Combat injury can weaken interpersonal relationships, disrupt day-to-day schedules and activities, undermine the parental and interpersonal functions that support children’s health and wellbeing, and disconnect families from military resources. Treatment of combat-injured Service members must therefore include a family centred strategy that lessens risk by promoting positive family adaption to on-going stressors.”p.311\textsuperscript{58}

The US policy push is to enable families to support active Service personnel more effectively\textsuperscript{59, 60} although there is little emphasis on the wellbeing of the families themselves or the long-term effect of caring for a family member who has been severely injured on operations. Even the most recently published reports considering the psychological needs of US Service families do not specifically consider the impact of traumatic limb loss or more broadly polytrauma on the overall psychological health of the family or the provision of services for this unique group\textsuperscript{53, 54}.

In the UK, the policy position is to ensure that there is no disadvantage due to military service and, where required, to give special consideration to those who have been bereaved or wounded as a result of service\textsuperscript{61}. Recent policy has focused on the physical needs of those who have suffered a traumatic amputation\textsuperscript{62} or who have been injured more generally\textsuperscript{63} but, as the Royal British Legion point out: “There is still much more to be done on creating a care pathway for amputee veterans and their families that addresses their health and social care needs holistically.”\textsuperscript{64} There is a dearth in research on the needs of the families of military and ex-Service (veteran) personnel. The provision of interventions is patchy and the quality of provision is inconsistent\textsuperscript{65}.
Polytrauma

When looking at military traumatic limb loss, the prevailing research literature is broadly dominated by polytrauma, as illustrated in Figure 1 - Polytrauma. Although this is not a new term, its adoption by the military is a recent phenomenon, driven predominantly by the large numbers of (mainly US) Service personnel with devastating blast injuries acquired during the recent conflicts in Iraq and Afghanistan.

Figure 1 - Polytrauma

In civilian medicine the term "polytrauma" is generally used to describe blunt trauma patients whose injuries involve multiple body regions, compromise the patient's physiology and potentially cause dysfunction of uninjured organs: although there remains a wide degree of divergence in the definition across disciplines. The US Military offers a definition using a biopsychosocial description... two or more injuries to physical regions or organ systems, one of which may be life threatening, resulting in physical, cognitive, psychological, or psychosocial impairments and functional disability.

When considering the impact of military polytrauma on families there is emphasis in the research literature on traumatic brain injury (TBI). Friedemann Sánchez, Griffin speculate that this is because the process of rehabilitation tends to be driven by the TBI needs of the polytrauma patient.
Little research has been undertaken on understanding the needs of families caring for a patient with polytrauma and whether their experiences are comparable to carers of patients with TBI or other long term conditions. In one of the few examples where research has been undertaken in this area, Schaaf, Kreutzer administered the Family Needs Questionnaire (FNQ) to 44 families of Service personnel at one of the five Polytrauma Rehabilitation Centers (PRC) operating in the USA. This cross-sectional study concluded that although families felt that they were getting high quality informational support from the specialist PRC, the FNQ results indicated that family members are likely to be struggling with day-to-day caregiving outside the hospital environment and may lack a supportive and understanding community of friends and family who can relate to their experiences (i.e. the instrumental and emotional support needs identified by Cohen and Syme).

Where a UK study has been conducted looking at the long term outcomes of recent conflict British combat amputees, the authors have considered and measured functional outcomes for the amputee, but have not looked at broader outcomes in the context of the family.

Care Delivery for Traumatic Limb Loss

The research in the small number of published papers and grey literature that we identified was mainly undertaken in the USA, predominantly within the US Department of Defense Polytrauma Rehabilitation Centers (PRCs). Although there are many lessons that can be learnt from this American research, it is also worthwhile considering some of the more obvious differences between the US and UK systems of care for wounded Service personnel and their families. These variances may be important when considering whether the research findings are replicable in the UK context.

What are the differences between the two systems for delivering support that might impact on replicability? We have identified a number of areas that may have a potential impact and should be considered when assessing whether the findings of the US research are directly applicable to the UK.

General provision of health and social care: In the UK all military personnel have their health and social care needs met by the Defence Medical Services, this includes the rehabilitative functions of DMRC (Defence Medical Rehabilitation Centre) Headley Court and the recovery functions offered by the Personnel Recovery Units and the charity-funded Personnel Recovery Centres. The healthcare and social needs of families and veterans are met by statutory services, i.e. the NHS and Local Authorities. All healthcare provision is free at the point of access and priority is determined by clinical need. In the USA, health care is provided by private hospitals and clinics. Most citizens have medical insurance. This is usually provided by the individual's employer.
and extends to his or her immediate family. However, for Service personnel injured in the line of duty the costs of healthcare are met by the VA and, in some cases, the healthcare benefits for the most severely wounded are extended to their families. There is considerable concern about the ongoing affordability of treating veterans in the US system and this is coupled with recent waiting list scandals and a Sisyphean backlog of veterans who are effectively lost to the system 70.

Number of casualties: as already reported since 2001, 353 UK and 1,558 US Service personnel have lost limbs. We have been unable to find any information relating to polytrauma or complexity within these cohorts, other than the UK figures showing that 105 of the recorded casualties had lost more than one limb. If one compares the relative sizes of the two fighting forces (including all branches), the casualty ratios for traumatic limb loss are approximately 7:10,000 and 9:10,000 for the US and UK respectively. Of course, there are many compounding variables that may impact on casualty figures: location; frequency and severity of contacts; speed and quality of medical attention; quality of body armour; training and unit cohesion etc. These are rather crude figures and, on balance, non-comparable, however they may have value when considering the wider impacts of delivering ongoing and long-term care.

Signature Injury: it has been argued, particularly in the American literature, that traumatic brain injury (TBI) and mild traumatic brain injury (mTBI) are the signature injuries of the Afghanistan conflict 71, 72 with reported rates among returning veterans varying between 12%-23% 73, 74. This is reflected in the emphasis of the research which we have considered in this report. Most studies looking at the impact of traumatic injury on families have focused on polytrauma (q.v.) and more specifically on the challenges associated with the management of TBI. This is not necessarily reflected in practice or custom in the UK. Although the rehabilitation processes within the DMS and NHS manage the needs of veterans with TBI, there are no UK military charities that have a remit to consider this area and associated service provision gaps may be filled by providers with little or no experience of working with this particular cohort.

Extrinsic factors and families: The geography and demographic profiles of the UK and US make comparisons about service delivery challenging. To accommodate the large numbers of US military casualties (51,809 as of January 10, 2014) 7 and the complexity of their injuries, the U.S. Department of Veterans Affairs established the Polytrauma System of Care (PSC). This national system of care balances access and expertise to provide specialized life-long care to the combat injured and comprises: four specialised regional rehabilitation centres; 21 specialised outpatient and sub-acute rehabilitation programs; designated polytrauma teams at smaller, more remote VA facilities; and a point of contact at all other VA facilities 75, 76. In the PSC, working with families is integral to their model of care and the importance of this approach is documented 15-18, 52. However, although there are four geographically spread centres
with family provision, accommodation and access to travel reimbursements, a combination of very large distances to travel, poverty (economic and psychosocial), and the long periods of time required to facilitate rehabilitation, all act to preclude some families from meaningful engagement in therapeutic activity.

Conversely, in the UK absolute casualty numbers are smaller and the facilities for trauma treatment, rehabilitation and recovery offered by the DMS, NHS and Charity Sector are more geographically accessible to families than those in the USA. Limited accommodation for families is provided at the RCDM trauma and orthopaedic centre at the Queen Elizabeth Hospital Birmingham (Fisher House) and at the DMS rehabilitation facility at Headley Court. The Personnel Recovery Centres (PRCs) (MOD-led initiatives, in partnership with Help for Heroes and The Royal British Legion), also provide family rooms for their users. Although accommodation is provided there is very limited access to family therapies both within the DMS and, for veterans, through the NHS.

There is a cultural and practice gap between the USA and UK in the engagement and inclusion of the family in psychical and psychological recovery of wounded Service personnel, and this is reflected in the dearth of UK research literature in this area.
Conclusions

Implications for research, policy and practice

The authors have been unable to identify any published UK research literature concerning the impact of traumatic limb loss on families, either within the military or civilian populations. This does not mean that traumatic amputations do not have an impact on families or that families should not be integral to rehabilitation. In fact, the opposite is likely to be the case.

Some UK research, sponsored by the MOD, is looking at the services available for families of wounded, injured or sick (WIS) Service personnel and this is due to report towards the end of 2014. Hopefully, this will help to inform the debate and raise the profile of family needs as we strive to provide the best possible care for our injured Service personnel.

As we have briefly discussed, most of the literature concerning families and military casualties has been generated by the USA. In the USA there is much more emphasis on the use of psychotherapy (in general) and the importance of family-focused work in the rehabilitation of injured Service personnel.

In the UK, the provision of mental health care has, historically, been dominated by services for those patients with very severe illnesses such as schizophrenia or bipolar disorder. In recent years there has been both a policy and practice shift to refocus the mental health debate around the provision of services in primary care, delivered through investment in the Improving Access to Psychological Therapies (IAPT) programme. Although the IAPT programme has been in operation for over 4 years, there are significant capacity issues, especially in the provision of services for veterans and military families. There are a few notable exceptions such as the Military and Veterans Services in Catterick, North Essex, the North West and North East, Pennine Health Care, London and in the devolved administrations. The IAPT or general NHS provision of family therapies for civilians or military families alike does not have a specific military focus and tends to concentrate on referrals via Family Consultation Services for families with very severe needs.

The focus of research in the area of traumatic limb loss and families is dominated by work undertaken in the USA on poly trauma. The complex nature of poly trauma presentations has led to dominance in the literature on the foremost presenting condition, which in the US is traumatic brain injury (TBI), and the impact on families. Even where this is the case, very little research has been undertaken to explore the effects on the family and the importance of the family in rehabilitation and recovery. The dynamic between the family and health has been explored for a number of other
conditions such as cancer, heart disease and diabetes where there is compelling evidence that good relationships have a positive impact on rehabilitation and health outcomes.

We do not fully understand the impact of traumatic limb loss on families on a number of levels and these areas are worthy of further investigation:

- What are the implications for the family of traumatic limb loss: psychological; wellbeing; practical; financial etc?
- What are the short, medium and long-term outcomes for family cohesion and health?
- What is the impact of the family dynamic on recovery and resilience to civilian transition?
- What interventions would families find helpful, and, importantly, which interventions have an evidence base for efficacy?
- Is it possible to develop services based on the limited evidence base available from the US literature or are the cultural and systemic barriers too large?

In the UK, we are able to offer world-class services to our injured Service personnel thanks to the skills and dedication of staff within both the Defence Medical Services and the National Health Service. Although we are able to manage the medical and rehabilitative needs of very severely injured personnel, the UK system of care is not one built on an holistic model of biopsychosocial provision, where the needs and experiences of the family are integral.

The key questions must therefore be:

- Does traumatic limb loss have a deleterious impact on the family?
- In turn, does this impact on rehabilitation, effective transition and the maintenance of a productive and successful civilian life?
- How can the military charity sector help to support the families of their members to improve the overall quality of life for all?
- How can military charities that have a specific remit to support our injured veterans align their activity to understand and meet the needs of families?
Recommendations

Given the evidence that has been identified within the few international studies discussed in this paper, and the general paucity of research into the impact of traumatic limb loss on the families of UK Service personnel, our recommendations are intended to help frame and inform better service provision and outcomes.

We strongly believe that the maintenance of cultural change is required in order to ensure that the needs of the family are considered throughout both the shorter-term rehabilitative processes and the longer-term transitions that those severely injured will face. Consequently, the recommendations are aimed at both policy makers and service deliverers.

Recommendations for policy makers

a. When considering policy that impacts on the holistic needs of Service personnel who have been severely injured or lost limbs, ensure that the needs of the family are also taken into consideration;

b. Use policy to encourage a cultural shift towards family-centred care and rehabilitation;

c. Commission and fund high quality research into the long-term impact of polytrauma (and especially traumatic limb loss) on families, ensuring that policy-making and strategic decision-making are evidence-based;

d. Commission and fund high quality research to consider the relationship between the wellbeing of the family and rehabilitation and recovery outcomes. This should also include the potential long term economic impacts of delivering a whole-family approach.

Recommendations for service providers

a. For providers to commission or undertake a scheme of comprehensive research to understand how families’ health and functioning impact on the recovery process for injured personnel, this will better inform clinical and social outcomes;

b. To routinely monitor and evaluate the impacts of traumatic limb loss on families themselves. These could include the impact of secondary trauma; coping strategies and family wellbeing; and, family coping and cohesion. These should be considered throughout the recovery process including the transition from DMS support to that of the NHS, Local Authorities and the Military Charity Sector;
c. Be cognisant of the needs of families, and help carers to request a full statutory assessment of needs under the Care Act 2014, ensuring that families have access to any available statutory support and provision, and assistance with budgets and finances;

d. Petition and work with commissioners and providers of mental health services to ensure that the needs of military and veterans families are met. This should include the provision of appropriate family support in primary care; and,

e. Where the evidence supports the approach, encourage family engagement in rehabilitation and recovery, and ensure that families are supported throughout.

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