Caring and Coping: The family experience of living with loss of limb use

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"I'm dealing with the lack of use of limb, which is why I am in Blesma, but actually it's a whole lot of other stuff that's not directly linked to lack of use of limb, but it's all part of the whole issue. That's quite challenging at times."

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Table of contents

Appendix

Executive Summary

This research examines how veterans and their families adapt to living with acquired loss of limb use. It is difficult to estimate the number of UK veterans who are living with acquired loss of limb use. We do know, however, that 401 are beneficiaries of Blesma (November 2024). On looking at the wider literature (see Appendix 1), it became apparent that there needs to be more focus on the experiences of families. Most research tends to focus on loss of use in specific conditions, such as spinal cord injury, with the emphasis placed on the negative experiences of being an informal carer. While this research is helpful, it does not align with findings from our previous research Caring and Coping: The Family Experience of Living with Loss of Limb(s) (CC1), which indicate that the family does not necessarily consider themselves an informal carer for the veteran or consider their supporting role negative. Therefore, this research aimed to learn from veterans and their families about their everyday experiences living with acquired loss of limb use, to inform what support might be needed. To do this, we invited Blesma members with loss of limb use and their families to tell us about their experiences (84 in total).

It is important to mention that this research has a positive outlook on learning from veterans and their families who are dealing with their loss of limb use. In doing so, this report identifies the diverse spectrum of needs associated with loss of use of limb that do not fit neatly into one category, details that individual and family needs shift and change, and importantly, that no-one talks about how current and future needs can be identified and potentially mitigated. Importantly, the report reveals the hidden parts of living with loss of limb use, and what people do to manage this in their daily lives, and in doing so, the participants told us that the central problem they are managing is the uncertainty that can accompany loss of limb use.

Uncertainty refers to a state of being unsure about one's everyday wellbeing, which can often change and fluctuate. Change can be short-term, such as having a bad cold, or long-term, such as limb deterioration, emotional/mental wellbeing, chronic pain, or changes in bowel/bladder functioning. It is uncertainty that ripples across the family, potentially causing disruption to their everyday living. Thus, managing uncertainty becomes a crucial concern for the family. This research documents four types of uncertainties experienced and describes how these challenges affect the family and impact their everyday lives in areas such as employment and schooling and bring accompanying worries about finance and long-term housing needs. As a result of this, an Understanding Uncertainty protocol has been developed, with the aim to help people identify what types of uncertainty impacts them, and how it might be better managed and to think forward about how to actively manage possibles in the future.

Alongside, the research details how difficult it is to talk about their worries and because of this, individuals are not planning the process of ageing with loss of limb use, and the potential challenges this can bring. As a direct result of this finding, two Safe Conversation protocols have been developed to help people have safe conversations to start to plan for their future.

Importantly, this research identifies that families do not necessarily require more support; rather, it details the need for wider society to develop responsive and flexible structures that recognise the demands uncertainty brings to family life. Central within this is the need

to enable families to feel safe to have difficult conversations about actual and possible uncertainties within the family itself, with wider health and support services, employers, and educational organisations.

This research presents the unique and complex context of the family living with loss of limb use. Importantly, this research details that adapting to living with loss of limb use in the family is a lifelong and continual process. There is no blueprint, and the process is therefore unique to each family, and to everyone within the family. Because there is no single predictable linear support pathway, support needs to be nuanced to the individual's context.

However, for this support to be useful, the role that uncertainty plays needs to be centralised. Uncertainty itself can rarely be predicted; this means that possibles can be foreseen over the life course, but how the individual's health plays out on any one day cannot. It is living with uncertainty in the everyday that needs to be acknowledged by the individual, the family and wider society. To summarise the findings a short animation has been made that explains the research findings.

https://www.youtube.com/watch?v=jzwEumvtLlk

Practical application of research findings

This research explores living with loss of limb use from the veterans' and families' perspectives. Whilst formed on data from veterans and their families, the findings are intended to be transferable to all persons with loss of limb use, the families that care and support that person, and service provider organisations. The findings are explained as follows, and alongside a short animation has been made, which can be found here:
https://www.youtube.com/watch?v=jzwEumvtLlk

Learning to adapt to loss of limb use requires intentional planning of daily routines. This helps establish stability in the family's daily lives, but these change as the individual and family age. Learning to adapt, therefore, is a lifelong and changing process that differs for all and has no linear trajectory.

Learning to adapt requires developing routines. Developing routines however takes time, requires patience and also recognition that there will set backs. Accepting adaptations into the home and family life, are integral.

Many factors can destabilise everyday routines, such as feelings of anxiety, chronic pain, and bladder and bowel problems. Such problems are often hidden within the family and can be disruptive to the everyday routines of the family. These hidden and often unknown disruptions bring uncertainty, which can destabilise the family's everyday norm, sometimes for unknown lengths of time. It is uncertainty, therefore, that is most difficult for families to manage.

Uncertainty is challenging for people to cope with, and people in the family cope differently with the challenges that uncertainty brings. The characteristics of coping are presented in Table 2. This is especially so as uncertainty is often hidden inside the family home, and individuals might not want to share their worries with others. This is why individuals in the family need to be asked separately from one another how they are coping, with support offered in relation to their individual needs.

TYPE OF UNCERTAINTY	EXAMPLES	IMPACT ON FAMILY CARERS
Known and certain	– Planned surgery, for example, hip/shoulder replacement/cataract extraction – Pulling a muscle temporarily reduces self-care/mobilisation – Cold/flu symptoms, reducing ability to self-care – Feelings of anxiety/stress on key dates of injury/diagnosis	– Family caregivers may need to provide additional care/support – This may require short term absence from employment/family activity, with anticipation that normal patterns will be resumed upon recovery
Unknown and uncertain	– Fall/overuse of residual limb(s) which may require surgery to stabilise with uncertainty re future capacity to self-care/mobilise as before – Sudden deterioration of chronic illness, reducing capacity to self-care/mobilisation	– Family caregivers need to provide additional care/support at short notice, with little certainty of duration or what the new norm may be like
Unknown, uncertain and unseen	– Episodes of mental health illness reducing capacity to self-care – Feelings of fatigue, tiredness and frustration. – Acute or chronic pain, reducing ability to self-care	– Family may need to adjust childcare/employment, with little certainty of what the new norm may be like – Family may feel unbelieved because the uncertainty is hidden – Family may not disclose the reasons for requiring time away from their normal lives, as they may feel unbelieved
Known and uncertain	– General ageing reduces strength in residual limb(s), reducing self-care capacity – Deterioration of symptoms of chronic illness – Deterioration of mental health illness	– Predicted changes due to ageing – May require significant changes in care support needs – Wider family may need to assist and may need time away from work/family to assist – The main carer may have care support needs of their own – Financial assistance may be required to introduce formal care support for both

Table 1: Recognising different types of uncertainty

COPING LEVEL	PERSON WITH LOSS OF LIMB USE	FAMILY
LOW	– Reliance on others to maintain Activities of Daily Living (ADLs) – Reluctance to mobilise within abilities – Not managing own health conditions – Reluctance to socialise/isolation – Not admitting to needing additional help/support – Not recognising that physical and emotional wellbeing can change – Not talking to their partner about their immediate and future worries/concerns – Not feeling able to adequately explain their needs to health and social care support services	– Constant monitoring of the other physical needs – Constant worry about what could happen – Reluctance to socialise – Not admitting they need health to support each other – Not managing own health conditions – Not seeking health support when worried about own health – Not admitting to needing additional help/support – Feeling anxious about daily changes in other health and wellbeing – Not recognising that some changes in their partner's wellbeing are short term – Not talking to their partner about their immediate and future worries/concerns – Not feeling able to adequately explain their needs to health and social care support services
MID	– Managing own ADLs – Mobilising within capacity independently – Managing own health conditions – Acceptance that the physical and emotional wellbeing needs of the other can change daily and can be short term – Feeling able to approach difficult topics with significant others to discuss current/future concerns – Feeling able to plan – Liaising with health and social care support services – Socialising independently and with others	– Intervening in ADLs only when needed – Acceptance that the physical and emotional wellbeing needs of the other can change daily and can be short term – Feeling able to approach difficult topics with significant others to discuss current/future concerns – Feeling able to plan – Seeking out support for themselves as felt needed – Managing own health conditions
HIGH	– Managing own ADLs – Reducing current activity if likely to be detrimental to future health needs – Understanding uncertainty in health needs, and putting in mitigations to plan for possible changes – Talking about and acting on decisions from conversations about what to plan for next – Proactively seeking help and support for current and possible future health/social care needs – Proactively talking about and planning for future health, social and housing needs	– Proactively talking about, and planning, for own and partner's health needs – Understanding uncertainty in health of the other and planning mitigations accordingly – Proactively talking and planning future financial and housing needs – Being realistic about what the future might hold and recognising possible barriers

Table 2: Characteristics of coping

Talking about coping means talking about uncertainty, especially potential future uncertainties. Talking about uncertainty is challenging for families. As a result, conversations are often avoided. This means that potential future problems are not actively planned for. Therefore, it is important to have conversations about uncertainty in safe ways within the family. Importantly, these conversation must feel safe for both people. Table 3 presents a Safe Conversation guide, as suggested by partcipants in this research. The questions can be changed to meet your needs, but it is advised the structure of the conversation stays the same, as this provides a safe begiinning, middle and end to the conversation.

What do we need to understand?	Conversation prompts
– What do we know and expect about the loss of limb use? – How do we understand the cause/condition?	– Do we understand the condition? – What do we understand about possible associated health and support needs?
– How might we understand more about the cause/condition?	– Do we need to understand more? – If you did get more unwell again, what do you think about changing where we live? – I am worried that at some point that you will … – I am worried that when you go (insert activity) it might cause you more harm…
– What matters to us now and in the future	– What things are important to us that we should be open about? – Where do we see ourselves? – I am scared that … – I worry about … – Who else do we need to include in these conversations? Should we speak with other families of veterans with loss of limb use or friends?
– What do we think would help? – What are the options and plans for the future?	– What has happened in the past that might help us predict? – How prepared are we to respond quickly to unseen change? – What would be the best ways for us to stay at home? – Can we talk about how we might cope with not knowing quite what will happen or when? – It is a good idea to talk about what we can do and how to get help if you get more unwell … – When do think we should next talk about this?

Table 3: Supporting safe conversations in the family

Similarly, coping and uncertainty is difficult to talk about with health and support professionals. This is often because people do not feel in control of important conversations with health professionals. This is compounded by feeling that professionals are not listening to their needs and assumptions about what those needs are. Because of this, a Safe Conversation guide with health and support professionals has been developed, which can be adapted by the individual/family to support conversations that are more likely to result in appropriate actions that are relevant to the individual and family.

Stages of conversation	Person with health needs: What is needed for you to prepare have a safe conversation?
Pre-conversation/meeting	– Prepare a summary ready of what the problem is that you want to discuss. – Be clear about what it is you want to find ways of managing/understanding/treating
Starting the conversation/meeting	– Ask for names of all people who are in the conversation – Check the time you must have the conversation – Check if anyone else could be involved in the conversation
Setting the purpose of the conversation/meeting	– Be clear about the purpose of your conversation
Talking about the purpose	– Discuss what is most important and/or problematic for you – Give examples to describe and explain your purpose
Thinking about workable solutions	– Have an idea of how you would like to see your problem(s) considered – Be open to differing solutions/compromise – your preferred way might not be available
Closing the conversation/meeting	– Take notes of what is being agreed, what will happen next, and by whom

Table 4: Supporting safe conversations with health/support professionals

Uncertainty ripples outside the family and can affect employment. Family members will take sick days/annual leave from employment to support the person with loss of limb use in times of uncertainty. Employers therefore need to develop flexible working practices that values the role caring plays in society and to accommodate the demands that uncertainty may require. It is similarly recommended that schools and universities are inclusive and proactive in responding to how sudden changes may affect their students. This research presents a framework that maps wider support to different types of uncertainty. This can be adapted for individuals/families, and helpful to support people to plan ahead.

COPING AND UNCERTAINTY IN FAMILIES: THE WIDER PICTURE

Types of uncertainty	Family actions	Organisational support	Education and employment
Known: Short-term extra support Return to individual normal expected	– Talking together about what support might be needed – Finding out what support might be needed – Inform support organisations if more help is needed – Help with childcare readied, just in case	– Awareness of procedure – Awareness of family context to activate support as asked – Flex in support provision to respond to support needs quickly/at short notice – Signposting immediate care service support, e.g., GP, mobility support services, provision of/loan of adaptive aids – Regular check-ins for return to everyday normal – Individual and family assessments are used to support and address health needs, such as poor mental health, and refer them appropriately – Encouraging safe conversations about uncertainty	– Employment: Employer understands that employee home needs can change/fluctuate – Disability and carer-friendly policies and practices – Valuing the positive role of caring in society. – Opportunity to access flexible employment practices: • Job sharing/flexible hours • Opportunity to work remotely – Education: awareness of family context/possibility in changes of childcare provision – Awareness of school nursing services of children/young people's family context – Provisions to support children, young people, and the family's school routine
Known and uncertain: Change is predicted with a return to new and unknown norms	**As above.** – Revisiting conversations about uncertainty. – Knowing how/who to contact for more support.	**– As above, plus:** – Prompting update safe conversations about current changes and likely future uncertainties – Being clear about what type of support can be offered short term/with speed – Flex to respond quickly/at short notice to family needs – Helping in setting different/relevant/achievable goals for PwLLU/family/carer – Updating moving/handling support for PwLLU and family carers	**– As above, plus:** **Employer awareness:** – A compassionate work environment that believes in the sudden need to change working hours – Leave sharing practices – Protected leave **Education:** – Awareness of family context/possibility in changes of childcare provision – Check-ins with individual students/provision of talking service support for students – Support in maintaining educational routine.

Table 5: Planning ahead with uncertainty (Continues over page)

COPING AND UNCERTAINTY IN FAMILIES: THE WIDER PICTURE

Types of uncertainty	Family actions	Organisational support	Education and employment
Unknown and uncertain and unseen: Unforeseen changes in health/ability that might or might not level off to a different norm	– Adjustment in family norms to manage uncertainty – Knowing what/who to contact in support organisations – Having wider support available to step in, e.g. to aid with childcare – Rechecking conversations about future uncertainty – Planning for changes	**As above, plus:** – Referrals to caregiver support groups & services for both and each of main caregivers & person with uncertainty. – Independent assessment of current coping levels of PwLL and family carers. – Prompting safe conversations about the potentially changing nature of care needs and support for the family. – Provision/signposting to disease-specific resources. – Pain management information giving/support, e.g., pain Q & A crib sheet*, ways to describe pain and types of questions to ask health professionals to help manage pain. – Checking comorbidities (if any) are being managed in both PwLLU/carer.	**As above, plus:** – Financial support: Support/carer benefits.
Unseen and uncertain: Changes in bladder/bowel care Feelings of anxiety	**As mentioned above, plus:** – Family carers witnessing changes might not know when to intervene/ask for external support – Family carers may not feel able to disclose changes because they are unseen and may not feel believed – Family carers may not know who to approach to ask for support – Rechecking conversations about future uncertainty – Planning in accordance with changes	**As above, plus:** – 24x7 response to sudden crises – of main carer and/ or person with uncertainty – Quick response to additional adaptive equipment & supplies to respond to uncertainty requirements – Signposting/resources to inform decisions as to how to manage unseen uncertainty – Access to talking services – Instigating safe conversations about current and future uncertainty	**As above, plus:** **Financial planning:** – Support to manage change in family income – Scenario planning considering altered lifespan projections and/or change in needs – Changes in housing/adaptations to housing
Known and certain: Ageing	– May require significant changes in care support needs for both PwLLU and family carer – May need to change the living environment to support changing needs – Wider family may need to assist and may need time away from work/family to help – Main family carer may need specific care support needs – Financial help may be needed to introduce formal care support for both	– Independent assessment of coping levels of PWLLU and family/carer – Signposting for the long term: pensions/finance etc – Information about alternative safe housing/living/ financial support directed to PWLL, carer, family unit as relevant – Where necessary, helping in family conversations re long term future care and support needs of the PwLLU/ family carers – Prompting safe conversations and providing resources re support should PwLLU pass	**As above, plus:** – Access to advanced care planning – Hospice care – Advanced pain management **For wider family:** – Protected leave – Other employment services that protect employment to support end of life care – Funeral planning/legal assistance/wills

Recommendations

The recommendations have been derived from an in-depth and robust analysis of data collected from 84 participants over 18 months and have been carefully considered by the academic team, Blesma staff and members, to ensure that they are both practicable and actionable whilst adhering to the evidence base from which they emerged.

It is important to note that throughout this research, it has become apparent that whilst significant success can be achieved improving the individual and family experience, there are more significant structural and societal challenges that need to be addressed. These may seem insurmountable, but it is important that they are raised here, as they have a tangible and sometimes damaging impact on the lives of the people we interviewed for this research. Consequently, alongside arranging the recommendations across four broad categories, the reader will see that findings highlight that broader societal changes are needed.

A potential corollary of this unique research is the translation of the findings across the wider health and social care sector. As such, the following recommendations are generic to all organisations that provide support and care for individuals and families that live with limb loss. Previous research with Blesma (REF CC1) has resulted in changes beyond that organisation, and the impact has been recognised as 'World-leading' (REF UoA 20 ICS).

These recommendations fall broadly into four categories.

1 Changes to the way that families can be empowered to provide enhanced support and care:

1.1 Understanding adapting over the life course

Adjusting to loss of limb use is a complex, multi-faceted process that requires ongoing adjustments and mental readiness. This process is often non-linear and changes over time. Adjustments over time are significant and are often not visible to those outside the home. It is recommended this is recognised by healthcare providers, to support individuals within the family to sustain coping. Individuals and families need to be prepared for adaptation to occur over the life course.

1.2 Recognising routines

Families develop complex daily routines to support everyday living with loss of limb use. However, routines, especially the level of detail, are often under-recognised, yet are essential if unexpected change occurs in the wellbeing of the person with loss of limb use. It is recommended routines are revisited regularly, so they can be reimplemented should the need arise. A Key Tips for Individuals and Families Living with Loss Limb Use is presented in the Resources.

1.3 Understanding uncertainty in the family

Uncertainty is a factor in all lives; however, when living with loss of limb use, uncertainty creates added complexity. This research identified four different types of uncertainty. The different types of uncertainty are detailed in table 1, which can be adapted to individuals and their partners' unique contexts.

Family-specific uncertainty: Families should be supported to think ahead and talk about uncertainty in relation to themselves. A Safe Conversation guide has been developed to support this and can be found in this report.

1.4 Understanding coping and uncertainty in the family

Whilst considering potential uncertainty in the family, there is a need to understand the coping levels of each member of the family. This research details characteristics across low, medium and high levels of coping. Understanding coping and uncertainty is presented in table 2. It is recommended that coping levels of each family member are assessed separately by health and support professionals.

1.5 The family witnessing change

Witnessing change is emotionally challenging for families, involving both large and small aspects of daily life. This needs further understanding and it is recommended further work is undertaken specific to families, to explore how witnessing presents and manifests over the life course. The impact of witnessing change in significant others is rarely discussed but can be an important factor in how people cope. It is recommended that opportunities are available for individuals to talk about their concerns separately from one another and without fear of causing distress to others. This aspect could be incorporated into the Safe Conversation guides presented in this report.

1.6 Adapting can be masked and/or involve overcompensation.

It is recommended that intense focus on matters outside the family, such on sport or voluntary work, be recognised as a possible indication of low coping, It is recommended this aspect be discussed further to identify if this is problematic for the family, whilst supporting the veteran's aims and ambitions.

1.7 Understanding the impact caring has on individuals within the family

Caring is complex and demanding and for many reasons, and often, individuals do not discuss their own wellbeing. It is recommended that the opportunity to discuss individual wellbeing be provided. Helpful resources provided by the Carers Trust can help *www.carers.org*. It is important that use of such resources be done in the individual's own time and space, reducing the concern that using such resources might worry others. It is important that such resources are signposted to families, but not imposed upon them.

1.8 Recognising the hidden aspects of loss of limb use.

In this research, the hardest aspects to manage were those that are not seen socially, for example bladder and bowel care, management of the chronic pain, and feelings of anxiety. To support individuals/family members in managing these, it is recommended that resources for support, information/guidance are accessed, for example, *Bladder & Bowel UK (www.bbuk.org.uk) and Bladder & Bowel Community (www.bladderandbowel.org)*

2 Improvements in the way that support staff and healthcare providers approach working with loss of limb use

2.1 Health and support professionals need to be aware of the vital role routines have when living with loss of limb use. It is recommended that health and support staff provide consistency in routine care delivery because inconsistency may have implications that destabilises the daily routines that sustain independence and wellbeing.

2.2 It is recommended that healthcare support providers are upskilled to understand the concept of uncertainty when living with loss of limb use. It is recommended that the Safe Conversation with Health Professionals in table 4 is used to support conversations that are meaningful to the individual's unique context, and not led by assumptions of the health/support professional.

2.3 The hidden aspects of adaptation to loss of limb use are significant and often not visible to those outside the home. It is recommended health and support providers are upskilled in bowel and bladder care and recognising anxiety and depression. Learning resources can be accessed via *RCN Learn | Royal College of Nursing and Spinal Injuries Association (www.spinal.co.uk)*

2.4 Experiences of pain may not always be fully admitted to because it is difficult to describe or explain pain as experienced. Similarly, health professionals may not be versed in understanding the impact of chronic pain in those with loss of limb function. It is recommended that a help sheet with questions to ask health professionals be developed, to help individuals describe pain and/or ask relevant questions to explain/assess pain, to assist in the appropriate management of pain associated with loss of limb use. It is recommended that health professionals have additional education about the management of pain associated with loss of limb use.

3 Wider societal changes in the recognition of the challenges faced by both patients and their families, especially when engaging in work and other meaningful activities

3.1 Supporting uncertainty in society

Supporting families with loss of limb use living with uncertainty needs to extend beyond the family unit. A barrier to family wellbeing is often a lack of flexibility in employment working practices and the demands of education upon families. It is recommended that employees offer opportunities for those with care responsibilities be able to work flexibly at short notice. It is recommended that employers follow recommendations set by Carers UK, particularly relating to recognising the range of skills that carers gain through their caring role and consider adopting the Carer's UK Carer Confident benchmark, run by Employers for Carers, to move towards becoming a carer friendly employer.

Education organisations need to understand the demands that care support for a parent may encompass. It is recommended that schools/colleges/universities provide inclusive environments where young carers and their families feel comfortable and safe to tell staff about their caring role and access support. Useful resources to guide educational organisations can be found via The Carers Trust and Barnardo's. *(www.barnados.org.uk)*

3.2 Organisational signposting of support and resources

A key feature in the findings is that individuals do not talk about their worries with each other for fear of causing greater worry. It is recommended that organisations support individuals by prominently signposting resources for information and support. *(www.nhs.uk)* and *(www.gov.uk)*

4 Addressing significant gaps in the knowledge base, where much more work is needed to make sure that interventions, training and processes have a robust evidence base

4.1 Seeing diverse types of disabilities

It is recommended that diverse types of loss of limb use are made visible across public facing and organisational communications. This includes (but is not exclusive to) people who are wheelchair users, people with loss of use of one arm, with partial mobility, with limb deformity and dysphagia.

Managing bladder and bowel function can have implications for the veteran's everyday routines. However, its significance was generally not found to be understood across health and support provision. There is an urgent need to develop current information/advice/guidance resources and to normalise conversations about bladder and bowel care within society. Further research is needed to understand how individuals manage bladder and bowel care and its potential impact on family life.

4.2 Further research is needed to understand how chronic pain is experienced and managed in the family context. Additional research is needed to understand how health professionals understand and manage the individual's lived experience of their chronic pain, and resource guides are needed that will support conversations about chronic pain, recognising the unique impact chronic pain has within the family.

Caring and Coping: The family experience of living with loss of limb use

Main Report

Chapter 1

Purpose of research

The purpose of this research is to provide an in-depth understanding of veterans with loss of limb use and their family's everyday living experiences. The research objectives are to:

- Provide in-depth insight into how veterans and their family's experience everyday living with loss of limb use.
- Understand the everyday barriers experienced by veterans with loss of limb use and their family overcomes barriers.
- Inform strategic planning for services that support individuals and the family living with loss of limb use.

Note to the reader

Before we explain how we did the research and what we found, it is important to define the term 'family.' In this research, the term 'veteran family' refers to a unit of people that includes at least one person who has served in the Armed Forces. The family includes individuals who play a significant role in supporting a veteran who has lost the use of their limb(s), without financial compensation. This may include individuals not biologically or legally related to the veteran; such as friends.

Ethical approval

The research received ethical approval from the ethics panel of the Anglia Ruskin University Faculty of Health, Social Care and Education under the reference number ESC-SREP-20-011.

How we did the research

To explore the experiences of veterans and families living with loss of limb use, we used a methodology called Grounded Theory. This way of doing research is helpful because it starts from the perspectives of the people it is interested in, so they can explain what matters to them, what has been difficult, and how they have overcome difficulties and barriers. This way of doing research worked well in its predecessor Caring and Coping: the family experience living with loss of limb/s. To do this, we used different ways to find out what it is like living with loss of limb use.

This report presents the findings across these differing methods.

Invitations to take part

To ensure that the most appropriate individuals in Blesma were invited to take part, the following inclusion criteria were used:

- Individuals whose injuries are service attributable/diagnosed with a condition that resulted in loss of use of limb/s in service (351 beneficiaries)

- Individuals who have lost use of limb/s for reasons unrelated to service (50 beneficiairies)

Invitations to participate in interviews were sent out to all relevant members of the Blesma community and were also promoted through Blesma's general communications, such as the Blesma Magazine. Those who were interested in participating contacted the research team directly, and the team then sent them participant information and consent forms. For those who expressed interest in participating, a research team member held a telephone conversation with them to discuss the purpose of the research, the interviews, how their interviews would be used, and to answer any further questions they may have had. As a result, Blesma is unaware of who participated in the research.

The surveys were implemented by BristolOnLine Surveys to all relevant beneficiairies in Blesma. To take part, letters and emails were sent, by Blesma, to relelvant beneficiaries. Paper copies, with stamped return envelopes were sent to those who requested. Two different surveys were distributed: one for the veteran, and one for their family members. For those who requested assistance to complete the surveys (either online of paper), a Blesma Support Officer was available. Consent to partcipate was indicated via completed returns.

To take part in structured question interviews, invitations were forwarded to relevant beneficiaires via Blesma communications. Interest to take part was indicated to the research team.

Who took part in the research

In total, 70 hours of interview data were collected with 37 individuals. Thirty-two survey responses were received, and 15 individuals took part in closed answer telephone interviews (See Appendix 2). A summary of the biographical sample is presented in Table 1, with further biographical details in Appendix 3.

TYPE OF INFORMATION	WHO TOOK PART
Unstructured interviews with individuals with loss of use of limb(s)limb(s) and family carers	N = 38 (70 hours interview data) • 25 veterans with loss of limb use • 5 partners • 3 parents • 2 sons • 3 women veterans with loss of limb use
Surveys of veterans with loss of limb use and families	N = 32: • WHO-QOL-BREF: n = 23 • From 16: n = 9
Telephone structured interviews	N = 15 (5 hours of interview data) • 10 Veterans with loss of limb use • 5 family members

Table 6: Summary of sample

Note about the sample

The participants reflected on their experiences, with some living with their conditions for over 20 years and others more recently. As a result, the experiences shared in this report span different age ranges, and detail how people adjusted to their loss of limb use, both past and present.

It is important to note that the causes of loss of limb use vary. They can range from sudden physical or biological trauma, for example, spinal cord injury or cerebral vascular accidents, or chronic illness resulting in long-term limb degeneration. As a result, there are different mobility issues, ranging from those who rely on wheelchairs to those with limited use of limbs but still have some mobility range, with wider issues including dysphagia, reduced bladder and bowel control, and chronic pain. In this report, we aim to present overall patterns of the experiences of individuals managing their conditions and learn from their experiences. Therefore, we do not focus on the cause of loss of limb use but rather on how individuals manage their everyday living with their loss of limb use. Consequently, we rarely refer to the aetiology of the loss of limb use.

Analysis

Analysis in grounded theory occurs throughout the data collecting phases and uses coding and constant comparison as the data collection continues. This starts by initially identifying similarities and differences across what participants share during interviews, and as more information is collected from participants, more questions are asked by the researchers to understand further. This starts to build a picture of what is often experienced, and importantly, how they seek to, or have, overcome problems. Doing the research this way means that we learn from people's experiences and sharing these means they can help others, who might, in the future, experience similar aspects.

As grounded theory is practical in its purpose, its findings and conclusions should be able applicable directly to the context of the research and, importantly, readers who have knowledge about the research context should recognise familiarity when reading the findings. It should therefore be expected that readers will be able to see the findings as directly relevant and applicable to the context, that is, there should be a sense of intelligibility in the findings, and this acts as the main tenet of credibility to a grounded theory research study.

Chapter 2

Findings

The following details patterns across the interviews and surveys, and uses quotations from individual participants to exemplify what was important and challenging to them. This does not infer that there is any one way of learning to live with loss of use of limb(s), or any linear way of doing so. Rather, findings detail no single way of doing so but do reveal several factors that all the participants went through at some point, to enable them to live their current lives. The key here is that people are continually adapting; there is no stable endpoint, but rather learning to adapt is continuous in relation to the uncertainties being experienced at any one time. Because of this, the findings start from the perspective of continually adapting.

Continually adapting

Learning to adapt to loss of limb use requires intentional planning of daily routines. This helps to establish stability in the family's daily lives, but routines change as the individual and family age. Learning to adapt, therefore, is a lifelong changing process, that differs for all and has no linear trajectory.

Realising the need to adapt

A clear finding was that the continual adapting was needed, but this had become so routine, they had forgotten how they did it:

> *"I'm sure there's much more to say, but it becomes every day, that you stop noticing."* (Veteran)
>
> *"But when I really thought about it, and if I saw a camera of myself every day, there would be hundreds of things that I do in different ways. But you do forget."* (Veteran)

It was in reflecting on their actions, the decisions made and behavioural changes over years, that participants remembered how much they had done to learn to adapt and to keep adapting. Adapting is therefore continual because adaptation never actually occurs and there is no fixed end. Rather, abilities always fluctuate. As a result, learning to live with their loss of use of limb was an ongoing process of adapting to an unknown and often uncertain tomorrow.

It was through these reflections that participants detailed what they had done to get them to that point in time. These are as follows:

Doing things differently

Learning to adapt starts from realising a need to relearn everyday actions. These everyday actions are things previously been taken for granted.

> *"You're having to relearn everything, every single little thing about life, you're having to relearn how you do everything, that's from day-to-day routine, from being a dad, how do I change my son's nappy, how do I get dressed. So literally, every single aspect of life you*

> *have to relearn."* (Veteran)
>
> *"It's everything. You can never really know until it happens, but the amount of detail that goes into every tiny action. You just don't know it. And then when you can't do it, it's huge. It's actually incomprehensible. And somehow you have to remember what you did, and then re-learn it differently. And that in itself, is mammoth'* (Veteran)

Alongside this, the re-learning is never linear,

> *"Things are not linear; they go round circles. It's how they all interact; how do I move forward with [redacted]?"* (Veteran)
>
> *"When I think back, it was such a muddle, nothing made sense, everything shifted and changed, gradually."* (Veteran)
>
> *"You make a small improvement, and the next day, bang, it's like it never happened, and you just can't think how you did it. Why did it seem to work yesterday and today it's impossible. Then tomorrow, who knows, I might be able to do it even better. But then, something else happens in my knackered body that wasn't expected, and it shifts again. There's nothing you can plan in this. And that is really hard to live with"* (Veteran)

Alongside these realisations, is accepting a constant state of flux, where one day you feel capable, and the following day you might not. It is this flux that creates challenges to everyday living.

> *"You will hit a hurdle, and it will bounce you back. For definite."* (Veteran)
>
> *"The two steps back, is the time that hits you hard."* (Veteran)

This means there is no blueprint to follow; adapting is a uniquely individual process. Key to starting to learn to adapt was the realisation of the *"need to do things differently"*. This did not come easily and took time, and in retrospect, participants realised that had they realised this sooner, they might have adapted to their loss of limb use more quickly.

> *"I can tell you this stuff now, and it sounds easy, but at the time, it was hard, really hard. It was difficult, I was difficult. I refused to believe both that I couldn't use my [redacted] and that I had to change to make my life to be liveable again. I don't know how long it took me, but it was a long time."* (Veteran)
>
> *"I was horrible. I didn't know it then. I was going to function, come what may. I listened to no one. In my head, I was going to overcome this. And people who said anything, tried to give me advice? Nope. It was my way only. It took a long time to realise I couldn't do this on my own"* (Veteran)
>
> *"It was learning to live with the body, the new body, as it is. For that first three and a half, four years it was just getting used to being."* (Veteran)
>
> *"He was ridiculously stubborn. He'd argue anything. And I didn't know anything. Nobody told*

> *us. Nobody said 'this is gunna be hard, but do this, it might just help. But actually, until he's got his head in the right place, it wouldn't have mattered what I did, cos I was always going to be wrong at that time."* (Partner)

However, participants were able to describe various realisations and barriers they experienced over their life of learning to adapt. These included:

- It is nonlinear and constantly changing
- Finding the right headspace
- There will be plateaus
- Realising you need to do things differently
- Realising everything takes longer
- Realising everything must be in the right place
- Learning to think ahead
- Becoming aware of slight changes in the body
- The difference between feeling tired and fatigue
- The need to slow down
- Feeling oversensitive
- Downtime is important

Adapting therefore is challenging, nonlinear and uncertain. Central to learning to adapt is forming habits and maintaining regular routines:

Forming habits and routines

> *"We wake up at 6am. I get up and go see him. Help him sit up, bring him a coffee, make sure everything is laid out in the right way for him. I get myself ready and go to work. The carers come in then to help him bath, dress, take medications. When he's up and ready, then he can pretty much manage, but everything has to be ready, in its place. Like lunch has to be ready. If it's not, then he can't, and he gets frustrated and grumpy, and that filters over to when I'm back from work. So yeah, it's just habit now. It's a routine, it works mostly, I get to do my everyday life, and he does his."* (Partner).
>
> *"It's knowing routines….and alternatives, like of alternate days they [district nurses] come in at eight o'clock to administer the new medication that will stimulate your bowel, and then they come back an hour later to clean up and everything. But if nothing's happened, what's next? It can through your whole routine out."* (Veteran).

Establishing a routine that requires everything to be in its proper place can be challenging. To develop a routine, it is important to acknowledge that everyday life requires a different approach, and this involves making deliberate efforts. To achieve this, a mental readiness or preparedness to begin to adapt is needed. This was called finding the *'right headspace'*.

Finding the right headspace

> *"I don't believe that people move forward until they got their mental mind sorted, preparation, they're in the right headspace. Once you've got the right headspace, I'm not saying it's going*

> *to be easy. But then you can start moving forward."* (Veteran)

This in turn requires the individual to be prepared to be in the right headspace. This is challenging, because it requires recognition that life has changed from the way it was before:

> *"I just didn't want to face it, cos that meant it was never going to change, or get better."* (Veteran)

> *"Everything I had, my future, it was there, it was exciting. Boom. Gone. In a flash. No. There was no way to prepared for that. It took me a hell of a long time to realise I could only move on, but differently. Don't get me wrong, it's still raw, all these years, but once I realised things, things seemed to change."* (Veteran)

Being prepared to be in the right headspace therefore is important, but getting to that point is difficult, and often avoided:

> *"I didn't know where I was. I had just started my journey, so I was looking for something else. I didn't know what I was looking for. Everyone I think reacts in a different sort of way, and a different timeline. I was looking in the wrong place for a long time, it took me ages to work that out."* (Veteran)

> *"That's mental preparation. In order to understand and reach acceptance, that was really difficult. I don't think I could have move forward until I got to accept."* (Veteran)

> *"Facing your fears is one of the hardest things you've ever done. Mental preparation is harder than physical."* (Veteran)

Part of finding the right headspace was realising that adapting means accepting adaptations into your life:

> *"I use the ceiling track hoist to get in and out of bed, and then when I'm in bed the carers slide sheets to turn me or move me around. Put me on my side or wherever I need to be. I have a shower trolley, so I get transferred from my bedroom to shower."* (Veteran)

> *"Well, in my bedroom? I've got an electric profile in bed, so the head moves, and the feet move, plus It's got a bed lifter, so I can just lift it right up of the morning and just slide off it."* (Veteran)

> *"I've got the bed rail. There are grab rails within reach everywhere, I use the grab rails in most rooms. I've got me a taller toilet, and I've got a frame around that, and I've got grab handles. Ah, it's like an old person's bathroom. There's a nice, lovely seat which folds up and then grab the handle on the on the wall, so I can stand up again. So, I've had the conservatory put on, so my wheelchair doesn't have to stay in the bedroom, although it's there at the moment, because in the hot season, it was too hot in the conservatory for it. There's grabbers and remote controls everywhere. If I want to put my lights on that's over there. Turn the telly on. Everything's remote control to the plug sockets, because I just can't reach them to turn them on and off."* (Veteran).

The need to continually reevaluate the space within which people live, and the adaptations of that space, was recognised as continual. This is because living with loss of limb use constantly changes and is rarely static:

> *"I'm currently waiting for a fully adaptive kitchen to be put in. I can't use my oven. I can't bend down to use it. I've not used my oven for six years since I've been here. The cupboards, I haven't a clue what's in the bottom cupboards. I can't get in and out of them, most stuff is just left out on the side. The kitchen looks like an untidy hoarder lives there because everything is on the side. Everything below that level is almost useless to you unless I open the cupboard, and it's right there in the front. And now, with the shoulders the top ones are out of reach as well. I can't manage them"* (Veteran).

> *"I'm, we're Ok for now. But I know how the house looks will have to change because I know I'm going to need more. It's like you get yourself established, which is in itself exhausting, and then you realise it has to change again. It is never static"* (Veteran)

Integral in learning to adapt therefore is developing the 'headspace', which in turn requires understanding that current and the future needs are constantly shifting and never known. Part of this shift towards being in the right headspace was also linked to gaining a different type of resilience, and this was particularly noticed by the wider family:

> *"Something switched in him. I can't really place it, but he found he could do things differently. I think, once he got that, then I did, we moved forward. But we'd been a bit stuck before, although if you looked in from the outside, you'd have seen us doing normal family things, which was in itself, at that time, chaos."* (Partner)

> *"I can't really remember, but somehow, it changed. I think it started with a hand bike. Yes, I got him one from [redacted] and after much pushing, a lot of pushing, cos he refused, he went out on it with another veteran who uses a hand bike. That gave him the nudge over. Once he found that freedom, it filtered into other parts of life."* (Partner)

Central to being prepared to be in a different headspace was the family, who were described as an anchor that secures the individual whilst they are in the turmoil of learning to adapt.

The family as anchor

Learning to adapt included recognising the family as plural:

> *"The first one is realising it's not my illness, it's our illness."* (Veteran)

> *"It's not I, it's we, because the effect on the family, arguably, was more difficult than it was on me."* (Veteran)

Family members described the signs they look out for that indicates the headspace of the veteran. This was a lifelong process, with various red flags along the way. Importantly, these were remembered retrospectively, from the perspective of *"if I'd known then what to look out for"* (Partner)

Red flags, masking and the military identity

Participants described their *"red flags"*. Red flags were described as activity that appears as positive because they suggest the individual is coping.

> *"He was overcompensating [for injury]. Definitely. We've seen it, whether it was on the TV or it was a chat with [redacted] or something. I thought "that's what you do, you overcompensate, definitely.* (Partner)
>
> *"I can write the script "you do too much, you get yourself stressed" and then he becomes miserable, and he would take it out on me. I'm not being snapped at, and he's terrible for doing things and I will say "you are just not listening to anything that I say." I could write the book on it."* (Partner)

The red flags described included:

- Singular focus on physical rehabilitation
- Singular focus on competitive sport
- Challenging travel/extreme adventure holidays
- Employment
- Giving back to others as part of civic duty
- Negative behaviours e.g. alcohol misuse

A strong military legacy informed and influenced how individuals adapted; however, it also informed red flags and masking. For some, this included going over and above what was required, especially in relation to giving back to society and helping others:

> *"He's using his experience through the military to try and make something better in the world. That comes in the form of him working on a committee that deals with [redacted] and support for veterans. He's also volunteered in a support capacity for [redacted]. He's always been proactive and trying to help [redacted] be the best it can be and support veterans as best they can. He feels passionate about doing that because he wants to make the world a better place and to help people that need it. It's what he did, what he signed up for, and it'll never leave him."* (Partner)

Fulfilling the ideal of the military identity could, however, be difficult for the family:

> *"He never stops. Literally never. He's on this, on that, doing this, doing that, getting involved here and there. Before, it was his bike and being competitive, but now his shoulders are knackered. It drives me nuts cos he's never around to help me with the kids, cos he's always helping others. But how can I tell him off about that?"* (Partner)
>
> *"That frustrates [redacted], she thinks there should be a time for work and a time for family. She's right absolutely, but this is what's instilled in me from the [service redacted]."* (Veteran)

Often realising overcompensating as avoidance often took many years:

> *"She said, "you are not dealing with this at all, you are just completely projecting everything on to me." It was only about a year later after she said this that I started to accept the feelings of loss and grief. I didn't cope well."* (Veteran)

> *"Yes, in [year removed] I had a big meltdown in relation to being disabled for 15 years. Thinking "what did you do on the ten year anniversary? Or five years? Oh shit, I did run away", This is all falling into place now, yes, I run away on big anniversaries."* (Veteran)

The military identity therefore presents as positive and negative factors. Positive factors entail the transference of the 'military mindset' to learn to adapt, and negatively as *'not talking about,' 'getting on with,' 'not admitting to' and 'not asking for help.'*

> *"As a proud '[redacted], that I find that really hard to get my head round. I was defensive. I'd do absolutely anything other than accept."* (Veteran)

> *"If somebody throws down the gauntlet, I will go out of my way to prove the bugger's wrong. So, I've had two motorbikes since my accident, and I rode them with one hand because I was told I couldn't do so. I was told by a surgeon I would never ride again. So, I went to one appointment on a motorbike."* (Veteran)

A barrier to adapting therefore is a complex interplay between overcompensating and avoidance that can last many years. This means that veterans can look like they are coping, because they look like they are achieving. However, it could also be that appearances of achieving are masking, or hiding, lower coping. Learning to adapt, therefore can be hidden from those outside the home. The hidden aspects of loss use of limb(s) were a dominant theme through the interviews.

Chapter 3

Hidden life with loss of limb use

Alongside the visible physical differences, participants discussed many hidden aspects. By hidden, we mean aspects not seen by others outside the home context. This includes the loss of privacy needing helps requires, and aspects that carries social taboo, such as bowel and bladder care, and chronic pain.

Loss of privacy

> *"Being on my own is the biggest thing because you could never ever have any. Even now you know, for the last 20 years, you never have any privacy. Everything you do has got to be arranged by somebody, or somebody who's got to be there. Or if I wanna send a text message. They've always got access to my iPad, to my phone, to my laptop. You know, you're never really on your own. Truly."* (Veteran)

> *"I used to love being on my own. I used to read, lie on my bed, with the sun, and read. Now, I can't do that. I need help to do that. Someone has to help me. Never being alone is so hard"* (Veteran)

> *"Friends come to visit, but you've all still got to have somebody in another room."* (Veteran)

> *"But even if I drive to see friends. I have to take [carers] with me. And so, they're always there."* (Veteran)

> *"Carers are in and out the whole time. I need them, but it can be hard. It's taken me a long time to accept this"* (Veteran)

Alongside a sense of loss of privacy were feelings of loneliness:

> *"No, nothing sat here on my own. Totally, I think that's the difference is also I'd say, don't be on your own. It's the isolation that is almost as bad as the physical pain."* (Veteran)

A key finding are feelings of loss of privacy and loneliness are often under-recognised and as such, not often discussed. A recommendation from this research is that these aspects need to be better considered when supporting individuals with loss of limb use.

Bladder and bowel care

Loss of bowel and bladder function was problematic.

> *"My bladder doesn't work at all, officially it's got 4% functioning, but on a practical level, that means I have to use a catheter every time I urinate. I can feel my bladder filling up. When I get the urge to go, I should go quickly it can bet tricky when out and about, and I've had a few accidents.""* (Veteran)

> *"I was stuck at my desk and had an accident with my bowels. I was self-conscious of the other people. I just tried to crack on with it. I got back to the car, dragged my chair, I felt as if I was going to die, to be honest. I got back home I wanted to go to bed, got in the shower, clean myself off. But how I felt then? It was hard, it is hard'."* (Veteran)

> *"It's hard, it's embarrassing, but you got to think at the end of the day your skin's is gonna break down. You're gonna get pressure sores. It can knock your schedule for the day, sometimes the week"* (Veteran)

.

From the women participants, managing bowel and bladder care trumped that of menstruation:

> *"Well, menstruation is the least of your problems really. It's nothing compared to that (bowel). It's insignificant you just have to shower, put a pad in and get on with it. It's not as bad as if you have had bowel care and it didn't work. That can really knock you out."*

Managing bowel care was part of routines, but managing those routines, was difficult:

> *It's knowing routines … .and alternatives, like on alternate days they [district nurses] come in at eight o'clock to administer the new medication that will stimulate your bowel, and then they come back an hour later to clean up and everything. But if nothing's happened… what's next? It can throw your whole routine out."* (Veteran).

The overall long-term management of bowel and bladder care was experienced as exhausting and a factor that contributed to feelings of stress and anxiety:

> *"Bladder, it's been an ongoing problem, its run me down a little bit. It's not an excuse. It's a contributing factor to some of my frustrations, some of my anxieties."*

> *"My ability to deal with stress now post-injury is much, much worse than it was pre-injury. On a medical level, but also on emotional one. I struggle with that sometimes. Particularly when I consider going back into the workplace after my injury. I hold my stress in my stomach and the amount of times I peed or pooed myself. Pre-injury I would have found that slightly amusing. Post-injury, it's a reflection upon how I process stress. I feel sad that I don't feel as able to go into all of the situations that I would like to go into."* (Veteran)

Participants identified the invisibility of bowel/bladder management as a taboo in society, but also when conversing with health professionals, for example:

> *'I was going into huge detail of pee and poo. The doctor then took about 20 seconds, "I'm terribly sorry if this is too impolite or too personal a question. But can I ask you some questions about your private procedures?" I was disappointed, they were coming into that philosophy of "this is something that we shouldn't be talking about. They absolutely should because it causes so much distress and stress for me and others around me as well."* (Veteran).

Participants therefore identified a need to openly discuss bladder and bowel management:

> *"I absolutely love when talking to people about it. I describe my injury to someone who hasn't got a medical background, that I'm paralysed from the knees down, with a host of other issues related to my bladder, bowel and sexual functioning. Very rarely do people follow up on any of those last three categories. I like to put it out there because it should be known. My legs and wobbliness I can manage and don't need to talk about. But this is a different ball game and needs to be recognised."* (Veteran)

A key finding from this research therefore is that living with loss of limb use may also mean living with limited bowel and bladder function, which is often under-recognised and misunderstood. A recommendation from this research therefore is that resources are needed to support individuals in managing their continence needs.

Living with chronic pain

Managing chronic pain caused significant distress across the participants:

> *"It's not a sensation of having use of the limb, it's just the pain that comes with like the nerve pain. You constantly feel sort of numb and pins and needles and kind of crushing feeling all at the same time. It's constant. It tends to be better in the summer than it is in the winter when it's cold and when I'm cold. It's a lot worse."* (Veteran)

> *"The pain is really hard' and 'I've been awake since four o'clock this morning because my shoulder was in agony, and nobody knows that. I had to wake up at four o'clock in the morning, take some pain medication and you don't then fall back to sleep, because you can't get comfy. That's a regular occurrence, but that's how I live my life."* (Veteran)

> *"Pretty much pain all day, which is mitigated by pain meds. There's some school of thought that the pain meds are causing pain and I need to get off them. The strongest pain med I was on was oxycodone, I took oxycodone for 12 months full dose, then lower dose for six months, and during that time I wanted to shoot my arm off, the pain was that bad."* (Veteran)

Chronic pain experienced was described in differing ways:

> *"There's always some sort of sensation going on in my legs, 24/7, whether that be pains, pins and needles, numbness, lack of sensation - there's always something going on. Sometimes you get all of them."* (Veteran)

> *"Spasms can be so strong that I cannot physically move from what I'm doing, I find it difficult to breathe. If I miss a dose, I feel withdrawal symptoms after three hours and that is really painful."* (Veteran)

> *"Depends on the day, sometimes it can be linked to the weather, sometimes it can be stress-related. There is pain there all the time, a dull, nerve-throbbing type. That's always there. That then expands to stronger electric shocks running up and down the arm."* (Veteran)

> *"And then, when it gets really bad, I envisage it like clenching a fist. And if you keep clenching, the arm gets tighter and tighter and then eventually all of the muscles contracting, and it starts curling right in. And there have been times, where I'm curled up on the floor, although that arm isn't moving, my brain is telling me that fists clenched so much and it bends me double. But that arm hasn't moved an inch. It's trying to work out how to release that clenched fist, even though the fist isn't clenched. In my mind that's the best way I've been able to describe it in the others."* (Veteran)

Managing chronic pain was a problem identified in CC1; however, different in this sample was the public perception that pain cannot be felt in limbs with reduced functionality:

> *"I had to wake up at four o'clock in the morning, take some pain medication and you don't then fall back to sleep, because you can't get comfy. That's a regular occurrence, but that's how I live my life. It's not normal day-to-day life of two legs. But few people want to hear that. They see my limb as not used, therefore, there can be no pain."* (Veteran).

Participants explained that chronic pain in relation to loss of limb use was not understood to be different to other types of pain, for example, phantom pain:

> *"But it's not phantom limb, because I still have the limb. But the arm doesn't work, I don't have a feeling in the arm, but I have pain on the inside of it. So, I have electric shocks running up and down my arm all day, every day. But massaging the arm doesn't do anything. The only benefit I have right now is that I can physically get hold of my arm and massage it. Mentally this gives me one step up from an amputee, but not by much. So, there is, there's a definite difference between an amputee living with pain and a loss of use of limb."* (Veteran).

Participants described how living with pain impacted regular daily living: *"some days where I don't want to talk to people, I don't want to deal with things." (Veteran) and how painful episodes were managed varied: "Drugs, tears, and in the past, alcohol" and "'I just have to allow for the pain to reduce, move away from what I'm doing, go and sit down, and try to relax the body" (Veteran). For others, the need for strong analgesia was controlling: "And I know that now I am addicted to it. I won't be able to stop it."* (Veteran)

The experience of living with chronic pain was described as exhausting:

> *"I've got a life of pain, and I am tired."*
>
> *"It just so wears me out, you're exhausted."*
>
> *"Everything wears me. Everything is so tiring; I am so tired. The effort just to sit here and watch telly at times, when I get into bed, I'm wide awake. Four o'clock in the morning, I might go to bed. Sometimes I don't go to bed."*
>
> *"I don't do early, because mornings just don't exist for me. The pain when I've been in bed, the pain to get out of bed, and to get moving, clean my teeth, and to get dressed, and to do the breakfast, and to feed her [assistance dog], and to take a ton of tablets, and to get yourself out. It takes me all morning to do what people would do in half an hour."*

Participants were asked if other people understand the pain experienced and responses varied:

> *"Some do, some don't. Fortunately, at the moment, I have a pretty good GP. Again, the issue with constantly moving around the country, you meet different doctors that do different things."* (Veteran)

> *"As much as anyone can do, because sometimes it's hard for me to understand the pain, so how can I expect somebody else to understand it?"* (Veteran)

> *"He said, I think you suffer an awful lot more than you let on, and you just hide it all. And that was it. I just totally broke down. Somebody had seen through it. Somebody had seen through my oh, so just a bit [redated], and he saw through it, and he said, No, it's not just a bit of [redacted]."* (Veteran)

A dominant theme was how others close to the veteran witnessed their pain, an aspect that caused distress across the family:

> *"The pain. The pain is really hard."* (Partner)

> *"But he's in so much pain all the time."* (Partner)

> *"Pain has been a constant thing from the beginning. They tried lots of things, he's been in pain clinics back and forth, and I think he is also on the highest doses of special nerve painkillers that he can get."* (Partner)

The impact of witnessing another in pain cannot be underestimated:

> *"I don't know if it's more about the loss of use of limb as it is living with someone who is in constant pain and the limits that it places. He is restricted, but I find by far the most upsetting aspect is this constant pain, hearing somebody who's in pain so much of the time it's quite distressing. I haven't got used to it after four years. He's on massive painkillers and special stuff for the nerves because of the damage to the nerves. All the time he is bent over in pain or shouting in pain and waiting for him to stop, because the pain takes over completely. And then it's the worry, "I'm gonna bump out". I can't get used to it, I have to leave the room, walk away, I feel bad because he's not doing it on purpose. That emotional side of it, is the hardest. I'm feeling, I wish I could fix this and him to shut up. I can't keep listening to somebody in pain and not be able to do anything about it. It's almost like you hear a crying baby, it evokes a reaction. Sorry, I didn't expect to get upset. It's really, really frustrating, I feel like my head's gonna explode."* (Partner)

Recounting her experiences of witnessing pain was emotional and the interview was paused. The interview restarted when she felt ready, and with her permission, we continued to talk about the pain she was witnessing:

> I: *"Do you think he knows how hard it is for you to see him in pain?"*

> P: *"I don't know. I walk out of the room, and I pretend I put the kettle on. You are just trying to keep everybody going, is your default position, just to keep going, that's what it's become. I think I've been on this default position right from the beginning of his injury. I'm looking for him to have less pain so, then I wouldn't have to deal with it. But there may be a different way for me to deal with it, I suppose."* (Partner)

Witnessing pain was recounted by siblings:

> *"In the evenings for him is painful, but back in the day, we would all sit together and watch a scary movie. He would jump out to scare us. He doesn't do that anymore. We used to do family games, spend hours at the table. Now he can't sit there for a long time, his arm hurts him. Can't do much of that anymore."* (Son)

Similar to CC1, there is need to understand how it is to live with chronic pain, from both the individuals and families' perspectives.

From this study, the women veterans reflected similar themes to their male peers in the wider sample. Differences that could be presumed to be difficult, such as menstruation and sanitary care, were insignificant when compared with other problems to be managed such as bladder and bowel care, managing chronic pain and exhaustion. However, alongside the family witnessing the veteran in chronic pain, the family also had to witness their partner change as a consequence of their injury.

Chapter 4

The family witnessing change

The family described a constant witnessing of the veteran which was mostly hidden. *"It's been difficult watching"* (Partner). Witnessing explained by participants a includes a complex interplay between fears, *"I always had this fear, nightmares", and optimism "you've got to show a positive, optimistic front".* Types of witnessing experienced are detailed here:

- Loss of resilience
- Loss of hope
- Loss of military identity
- Loss of military family
- Setbacks and frustrations
- Early ageing

However, it is important to realise that family witnessing begins at the outset of injury/diagnosis, characterised by feelings of helplessness:

> *"The nurse said: "just go." She told me exactly where to go, says the hot chocolate in there is to die for "You just go in, you have a hot chocolate, and we'll ring you when he's out to surgery." We're talking about seven or eight hours in surgery, so I went with it, did exactly as I was told, got the hot chocolate. In the middle of some cafe, I sat and sobbed my heart out. I didn't know if he was coming out from there again."* (Parent)

> (cries) *"It was my child and I wanted to make it better and I couldn't. I felt helpless. I put the face on every time I spoke to him "oh don't worry, it's absolutely fine, never mind." (Parent)*

> *"I wanted to protect him from that, which I couldn't. So, it was difficult."* (Parent)

Central was witnessing the progression and changes of the other, with hope, seeing change and setbacks over the life course. Inherent within this, was the loss of small, but important, aspects of everyday life between partners. One aspect that carried emotional reflection was the simplicity of making cups of tea:

> *"He can't do really small things for me. Like, he can't get me a tea. Just tea. Or a biscuit. To have him make me a tea would be such a treat. I'd give anything to have that. You know, sit outside in the garden, and him bring me a tea."* (Partner)

> *"I get up, make [redacted] a tea, take it up to him, get myself ready for work, make him another tea. He'll have 'it in bed until the carers come in to help get up. I'll go to work. (Participant starts to cry, pauses to get a tissue,). I'm sorry, it's just hit me that."* (Partner).

> *"You know, people say it must be hard to not have holidays n such like. But it's not those things. I'd love for him to bring me tea, or for him to make me a tea whilst we're watching TV. I'd give anything for that."* (Partner)

> *"I think mum would just like him to make her a tea. He can't, and she doesn't say anything. But that's just what you do for each other, isn't it?"* (Son)

The significance of what 'small things', such as a cup of tea, might mean to the partner was rarely discussed:

> *"No, I'd sound a bit ungrateful if I moan about tea when he's in so much pain. No, I keep it in. In fact, I didn't really realise 'til now how important it must be for me."* (Partner)

Within this, witnessing change itself, was recognised as difficult to address:

> *"Thing is, 'cos you're getting on with it, everything's in its place, it all looks OK, but really, every day is different. You never quite know. So, everything can be in place, but then something changes in him, and it's all out the window. I've planned to do something, and on paper, I should. But then, something happens, and I can't."* (Partner)
>
> *"We used to plan to do loads. But it's changed cos he keeps changing, so we've kinda given up planning anything cos he might not be able to do it. And that makes things worse, cos he feels bad, I feel bad, mum feels bad. Its continual change. All you know is it'll change, but as to what that might be? Who knows."* (Son)

A second central aspect of witnessing change revolves around the constant uncertainty that accompanies loss of limb use over the life course.

Chapter 5

Uncertainty

So far, the findings have detailed how participants learnt to adapt to living with loss of limb use. Inherent within this is the changing nature of the health of the individual with loss of limb use, which can fluctuate, sometimes with little notice and sometimes in ways that are unseen outside the home context.

> *"I'm dealing with the lack of use of limb, which is why I am in Blesma, but actually, it's a whole lot of other stuff. It's not directly linked to lack of use of limb, but it's all part of the whole issue. That's quite challenging at times, it's all down to the uncertainty"'* (Veteran)

The crux of concern of the participants was that the uncertainty of health changes ripples through the family, which, in turn, can destabilise the daily norms of the family. Family life, therefore, revolved around maintaining stability (through routines) and managing unknowns and corresponding uncertainty.

It is also important to note that the corollary to uncertainty is certainty. Here, certainty refers to health changes that might be predictable and likely to happen; however, it is uncertain exactly when. An example of this is a hip or shoulder replacement. Most people will be likely to need one, however, it is not known when, nor what the person's health might be like at that time. This was particularly prevalent for those who used wheelchairs and/or canes, who are reliant on their arms to self-mobilise.

> *"He never stopped. In his chair. If he wasn't helping others, he was rolling in some competition of other. It's difficult, 'cos both those things helped him and us. At the same time, he was ruining what parts of him were working. So, when he had to have his first shoulder replacement, it was horrific. We weren't prepared for it. We were a bit more so for his second replacement. But that first knocked us."* (Partner)

> *"If there's one thing the youngsters need to know, is, save your joints. You think they'll go on for ever. But like everyone else, they wear out, and faster, 'because we use what we have working a lot more and differently. Your joints are forever, not just now."* (Veteran)

Similarly, we know we will have health challenges due to the ageing process; however, we do not necessarily know what these may be – they are certain (ageing) and uncertain at the same time. In between, there are other unknowns we cannot predict or foresee. It is these types of unknowns and their corresponding uncertainties that were problematic to the participants, what they may be like, but also, how they ripple across the family.

Types of uncertainty

Participants described four types of uncertainty. These are:

1. Known and certain (like a shoulder replacement)
2. Unknown but uncertain (like changes in limb mobility over time/managing bowel and bladder/exacerbation of other long-term conditions conditions)
3. Unknown, uncertain, and often unseen (like new diagnosis of health conditions/ bowel and bladder changes/mental health struggles)
4. Known and certain (changes that will occur due to natural ageing)

The greatest challenges are numbers 2 and 3 because these are the least predictable, which in turn presents the most difficulty for the family. This is because the support needs of the individual with loss of use of limb(s) can fluctuate from better to worse and back to better, while others may progress to a stage involving more intensive caregiving. Such changes ripple into family norms, and as such will change. The nature and extent of family care thus circles around the person with loss of use of limb(s) and the uncertainty about their future. For families supporting a veteran with loss of limb use, uncertainty means daily life can change from day to day, with care and support actions cited as including:

- Providing additional personal care and emotional support
- Increased assistance with mobilisation
- Helping with medical treatments
- Managing episodes of acute/chronic pain
- Scheduling and coordinating appointments
- Coordinating formal service providers
- Providing transportation
- Increased housework, house maintenance and outdoor work
- Managing finances
- Coordinating childcare/increased help with childcare
- Managing employment commitments

Examples of uncertainty for the veteran with loss of use of limb and the family are presented in Table 1.

TYPE OF UNCERTAINTY	EXAMPLES	IMPACT ON FAMILY CARERS
Known and certain	– Planned surgery, for example, hip/shoulder replacement/cataract extraction – Pulling a muscle temporarily reduces self-care/mobilisation – Cold/flu symptoms, reducing ability to self-care – Feelings of anxiety/stress on key dates of injury/diagnosis	– Family caregivers may need to provide additional care/support – This may require short term absence from employment/family activity, with anticipation that normal patterns will be resumed upon recovery
Unknown and uncertain	– Fall/overuse of residual limb(s) which may require surgery to stabilise with uncertainty re future capacity to self-care/mobilise as before – Sudden deterioration of chronic illness, reducing capacity to self-care/mobilisation	– Family caregivers need to provide additional care/support at short notice, with little certainty of duration or what the new norm may be like
Unknown, uncertain and unseen	– Episodes of mental health illness reducing capacity to self-care – Feelings of fatigue, tiredness and frustration. – Acute or chronic pain, reducing ability to self-care	– Family may need to adjust childcare/employment, with little certainty of what the new norm may be like – Family may feel unbelieved because the uncertainty is hidden – Family may not disclose the reasons for requiring time away from their normal lives, as they may feel unbelieved
Known and certain	– General ageing reduces strength in residual limb(s), reducing self-care capacity – Deterioration of symptoms of chronic illness – Deterioration of mental health illness	– Predicted changes due to ageing – May require significant changes in care support needs – Wider family may need to assist and may need time away from work/family to assist – The main carer may have care support needs of their own – Financial assistance may be required to introduce formal care support for both

Table 1: Recognising different types of uncertainty

Whilst managing uncertainty was described as a feature of family life, the uncertainty itself was experienced differently across the family, and how individuals coped with uncertainty changed and fluctuated.

Chapter 6

Coping and uncertainty

Coping refers to how well people actively manage their everyday lives. This makes coping a subjective experience that can fluctuate and change often, depending on what is happening at that time. Therefore, coping is always subjective and changing.

> *"My way of coping, I don't know if it's been specific to his injury, it's the way I've always coped and carried on. Coping is like full steam ahead. I'll probably pay for it somewhere down the line. That's what mums do"'* (Parent)

These changes were managed as part of getting on with it. However, because some changes were unseen outside the home environment, the family balanced how much they told others, which meant they did not ask for help. This was particularly relevant in relation to maintaining employment and educational responsibilities.

> *"Sometimes, I'll need to take an impromptu leave day (from work) when he's wobbly. I don't really talk about home at work, so no-one really knows."* (Partner)

> *"I have taken sick time off before to help out here. I'd rather do that than tell people." (Partner)*

> *"I go to work as regular life. I love my job, so it's no hardship. But I don't want to be defined at work as a carer cos I don't think I am. I think once people do that to you, it changes. So, sick days. If needed, annual leave."* (Partner)

Reasons for not disclosing any support challenges were also because the family wanted wider society to see the veteran as the individual they are, rather than the limitations loss of limb use might bring:

> *"People see him, and yes, he's a bit lopsided and what, but he's so able and capable. He's seen at the school gate. But no-one knows that a urinary tract infection can knock him flat, which changes how I work. But I don't want others to view him in any other than he is at his best."* (Partner)

Similarly, it was unclear how schools understood the home context:

> *"I struggled through school. Obviously, I wouldn't tell anyone, although my mum informed teachers and they knew, so they give me space or time out of class that I was just feeling down. When it happened, I just went to school the next day, as if it never happened. And then my head teacher called me in his office and said he knew what was happening. He contacted all my teachers, so I felt much more reassured, so I didn't have to tell them myself."* (Son)

> *"A bit more school support, someone checking on every now and then, like a guidance teacher. It helped for me, but it didn't do as much as it could. Maybe do it once a day, like every morning go out and they see how you're feeling, just keep checking up on you. That's the main thing, school support. You have to do your work, but your mind is not 100% focused, it was on my dad."* (Son)

> *"I'm not really sure, it was a whirlwind. I was trying to keep afloat, and the kids did too. I told the school, and then, well, we got on with it. I suppose the more you do that, the less you realise because it becomes normal."* (Partner)

Additionally, worries can include planning finances and where to live in current and future years, housing and retirement. However, these were rarely discussed.

> *"The future. Nope. Not being discussed. He's a micro planner. For me, nope."* (Partner)

One aspect identified in this research is the difficulty in having conversations about how individuals are coping with managing uncertainty, especially in relation to the future.

Talking about coping and uncertainty

Talking about coping and the future is difficult:

> *"Neither of us are talking about it. We're okay, secure, which means we don't need to as yet."* (Partner)

> *"Clueless. I know we should. But where to start? How?"* (Partner)

How the family was coping was often not considered:

> I: *"Has anyone ever asked you how you manage it?"*

> P: *"No. Maybe, that's why I get so upset talking about it because I never really had done it. I don't like talking to [redacted] about it. Because I don't feel like I have the right to be upset when he's lost so much. I don't feel like I protected him. I couldn't make it better. As his mum that is my job. I could only be at the other end of the phone and talking through whatever is the problem at the time. I can never put myself in his situation because I don't know how he's coped."* (Parent of Veteran)

For most, the emotional impact of living with the loss of limb use was not discussed by the family: 'I don't talk to anyone about it' (Partner). Reasons why family carers may choose not to discuss their feelings with others were linked to uncertainty:

> *"It was the uncertainty, I just didn't know where to go to, who to speak with. I still don't. I don't think that's ever changed"'* (Partner)

> *"Who do I tell? What do I say? I didn't, still don't, really know what to expect. It can all change so fast. How do you tell that? It's like, this might happen, but it might not, and nothing might happen. I don't know, it's difficult to get your head round, so you crack on."* (Partner)

> *"Did people recognise that something was wrong? There was, are, a couple of close people in my network who knew what's going on, but I didn't really want to tell, no-one ever does."* (Partner)

Like CC1, participants described characteristics that suggested differing levels of coping, as shown in Table 2.

This table describes characteristics that individuals might show in relation to how they are coping. It is designed for individuals to refer to check their own coping levels, and to use to think about what they might need to cope more effectively in the future.

It can also be used by support workers to check for characteristics that might suggest lower levels of coping. It is suggested that conversations about coping with the person with the loss of limb use and their family members be held separately so individuals can say how they are feeling, or what their worries are, without upsetting one another.

COPING LEVEL	PERSON WITH LOSS OF LIMB USE	FAMILY
LOW	– Reliance on others to maintain Activities of Daily Living (ADLs) – Reluctance to mobilise within abilities – Not managing own health conditions – Reluctance to socialise/isolation – Not admitting to needing additional help/support – Not recognising that physical and emotional wellbeing can change – Not talking to their partner about their immediate and future worries/concerns – Not feeling able to adequately explain their needs to health and social care support services	– Constant monitoring of the other physical needs – Constant worry about what could happen – Reluctance to socialise – Not admitting they need health to support each other – Not managing own health conditions – Not seeking health support when worried about own health – Not admitting to needing additional help/support – Feeling anxious about daily changes in other health and wellbeing – Not recognising that some changes in their partner's wellbeing are short term – Not talking to their partner about their immediate and future worries/concerns – Not feeling able to adequately explain their needs to health and social care support services
MID	– Managing own ADLs – Mobilising within capacity independently – Managing own health conditions – Acceptance that the physical and emotional wellbeing needs of the other can change daily and can be short term – Feeling able to approach difficult topics with significant others to discuss current/future concerns – Feeling able to plan – Liaising with health and social care support services – Socialising independently and with others	– Intervening in ADLs only when needed – Acceptance that the physical and emotional wellbeing needs of the other can change daily and can be short term – Feeling able to approach difficult topics with significant others to discuss current/future concerns – Feeling able to plan – Seeking out support for themselves as felt needed – Managing own health conditions
HIGH	– Managing own ADLs – Reducing current activity if likely to be detrimental to future health needs – Understanding uncertainty in health needs, and putting in mitigations to plan for possible changes – Talking about and acting on decisions from conversations about what to plan for next – Proactively seeking help and support for current and possible future health/social care needs – Proactively talking about and planning for future health, social and housing needs	– Proactively talking about, and planning, for own and partner's health needs – Understanding uncertainty in health of the other and planning mitigations accordingly – Proactively talking and planning future financial and housing needs – Being realistic about what the future might hold and recognising possible barriers

Table 2: Characteristics of coping

Again, like the findings from CC1, few family members in this sample spoke openly about how they were feeling or coping and, if asked, would say they were coping. This means that the family might look as if they are coping but might be feeling they are struggling to cope (unseen). This is exemplified in Diagram 1 below.

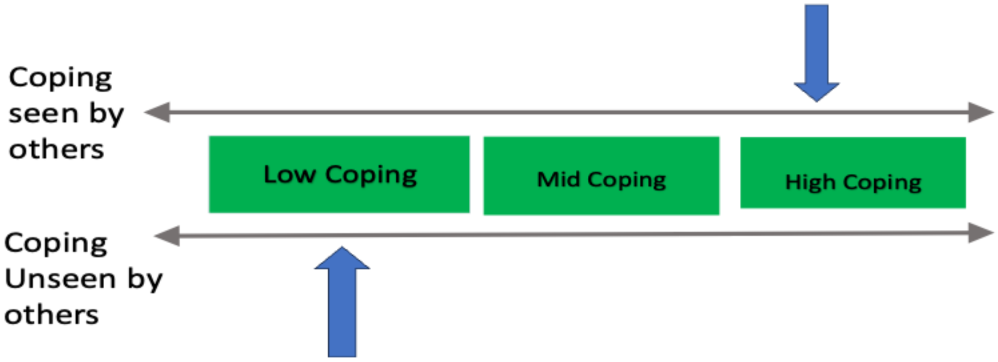

Diagram 1: Seeing hidden coping

Despite this, the participants were clear about what was needed to help them talk safely. This next section focuses on how to have safe conversations about uncertainty.

Safe conversations about uncertainty

Talking about coping and uncertainty was identified as needed yet avoided:

> *"We should. We're not."* (Partner)
>
> *"We should. No idea how."* (Veteran)

Reasons for not feeling able to talk about their worries were often because previous conversations had not gone well and had made them feel unsafe. From this, participants were able to be clear as to why conversations had not gone well and made them feel unsafe. These included:

- The conversation not being at the right time
- The conversation not being in the right place
- Not feeling believed
- The purpose of the conversation was not clear
- There was not enough time set aside for the conversation
- Continual retelling of the reason for the loss of limb use
- Being told what to do rather than helping the individuals work out what they need to do in ways that work for them
- Others thinking they know what's best for individuals
- Being talked over
- Lack of clear objectives about what to will happen next
- Lack of clear outcomes about what is more likely/least likely to happen
- Lack of clarity as to who is taking the next steps
- Difficulty in how to close a difficult conversation

These factors acted as a barrier to opening future conversations, and would therefore be avoided:

> *"What is the point? If you know from the outset you're going to get upset, why bother? I know even before the conversation happens that I'll be on edge, often unreasonable. Best avoided."* (Veteran)
>
> *"He's narky even before. So, if I want to try to bring something up… we just shut down on each other and carry on as if there's nothing there."* (Partner)

However, it was also recognised that episodes of uncertainty provided an opportunity to have conversations in an appropriate and safe way. Central to this was the need to feel safe: 'That's when it comes back to that safe space. Recognition, applying empathy, that human touch. So, they feel they, they can talk about whatever.' Participants were clear as to what was needed to feel safe and be heard:

> *"Facial expressions say a lot, watching the eyes. That's why I much prefer doing a Zoom call than a phone call, otherwise you have no idea what they're doing. Here on Zoom, it feels like I'm speaking to you. And you're listening and I'm talking. There's an interaction between us. Some people I've spoken to, you know "you're not there, you're not really listening", you can just see it in their face and their demeanour."* (Veteran)
>
> *"If I'm taking the time to talk about something that's really quite personal, then I want whoever is on the other side to be listening and say, "here's some thoughts, here's some ideas.'"* (Veteran)

From these barriers, participants were asked what safe conversations would be like, from which two Safe Conversation protocols were developed, in collaboration with participants, as a guide. It is recommended these are used as a resource to enable individuals to have difficult conversations, safely. These are shown as follows:

Having safe conversations in the family

The following resource has been designed to support people to have safe conversations in the family. It is designed to be adapted by individuals to be relelvant to their contexts.

What do we need to understand?	Conversation prompts
– What do we know and expect about the loss of limb use? – How do we understand the cause/condition?	– Do we understand the condition? – What do we understand about possible associated health and support needs?
– How might we understand more about the cause/ condition?	– Do we need to understand more? – If you did get more unwell again, what do you think about changing where we live? – I am worried that at some point that you will … – I am worried that when you go (insert activity) it might cause you more harm…
– What matters to us now and in the future	– What things are important to us that we should be open about? – Where do we see ourselves? – I am scared that … – I worry about … – Who else do we need to include in these conversations? Should we speak with other families of veterans with loss of limb use or friends?
– What do we think would help? – What are the options and plans for the future?	– What has happened in the past that might help us predict? – How prepared are we to respond quickly to unseen change? – What would be the best ways for us to stay at home? – Can we talk about how we might cope with not knowing quite what will happen or when? – It is a good idea to talk about what we can do and how to get help if you get more unwell … – When do think we should next talk about this?

Table 3: Supporting safe conversations in the family

Having safe conversations with support professionals

The following resource has been designed to assist people to have safe conversations with support professionals. Please adapt this to be relevant to your needs. You may wish to share this with support professionals, so they have a clear idea of what your needs might be and use it to help you lead Safe Conversations to manage health concerns together.

Stages of conversation	Person with health needs: What is needed for you to prepare have a safe conversation?
Pre-conversation/meeting	– Prepare a summary ready of what the problem is that you want to discuss. – Be clear about what it is you want to find ways of managing/understanding/treating
Starting the conversation/meeting	– Ask for names of all people who are in the conversation – Check the time you must have the conversation – Check if anyone else could be involved in the conversation
Setting the purpose of the conversation/meeting	– Be clear about the purpose of your conversation
Talking about the purpose	– Discuss what is most important and/or problematic for you – Give examples to describe and explain your purpose
Thinking about workable solutions	– Have an idea of how you would like to see your problem(s) considered – Be open to differing solutions/compromise – your preferred way might not be available
Closing the conversation/meeting	– Take notes of what is being agreed, what will happen next, and by whom

Table 4: Supporting safe conversations with health professionals

Chapter 7

Wider organisational support for the family

The benefits of organisational support for individuals with loss of limb use and their family was clear: 'It's been the absolute making of him, he really fits with Blesma, it's made a huge difference to him' (Partner). Whilst the population in this research were reflecting on support from veteran organisations, the following points were seen to be generic to support organisations across the health and social care sectors.

The diversity across types of loss of limb use needs raising generally across the support sectors. Specifically, loss of limb use that did not require permanent adaptive mobility aids generally felt less represented/visible across support literatures:

> *"His injury is a little unusual in that he is so able and he's a walker. There's still lots of shared issues with people in wheelchairs and with people with similar injuries, but it is a different bracket. It would be good for them to be seen."* (Partner)
>
> *"I know I hide mine from others, but it would still be good to see others similar out there. I know they are there, but I never see them, let alone meet one."* (Veteran)
>
> *"I think it's so complex and confusing. I think possibly not in place, but generally out there. There's been such a narrow vision. It's the wheelchair, people in a wheelchair, and then they stand up, you think. Oh, they're fake. Yes, and that's why this bit that not all disabilities are visible. I use a wheelchair and yes, I stand up and walk away from it. Doesn't mean, I don't need it."* (Veteran)
>
> *"It makes it hard for others, and I get fed up trying to explain, yes I might be able to do this now, but tomorrow? Who knows?"* (Veteran)

Learning from more experienced individuals with loss of limb use helps less experienced people, especially in relation to recognising barriers and pitfalls over the life course:

> *"We do look at things very differently and we can guide. We can't solve but we can help them work things out for themselves."* (Veteran)

Having a mentor was identified as important in the initial stages of adapting to living with loss of limb use: '[redacted] had a mentee from the[redacted], chatting to him about personal things, toileting, and just generally his wealth of information. This was emphasised as how learning from experience offers nuanced insight into the hidden aspects of loss of limb use:

> *"It's important to have that information of what is needed…. another guy, who was paralysed had to do the same, he needed to go to the toilet, he had to do a manual bowel evacuation. I said, "we'll get out of our room early and while we go to breakfast, have the key, go in and do what you need to do," and he was "oh God, brilliant!". Just because you know those things, and nobody else needed to know."* (Partner)

Learning from others who have raised a family with loss of limb use was identified as being as useful:

> *"I certainly would be interested to hear from other families who are a little ahead of us with having kids in terms of their coping strategies, mechanisms or how they've worked through those early years with having kids. I'd to chat to another mum who has navigated that period. More about how to raise children more than anything else,"* (Partner)
>
> *"Sometimes the thing that you need to talk about is kids, as opposed to the injury," (Partner)*
>
> *"It's about life and people and where people are at that point in time, it's not necessarily focused on the ability, or loss of limb use, of the injured veteran,"* (Partner)
>
> *"If their family had someone like my dad, it would have been good to chat to them, so they can reassure as well. It's good to get reassurance that yes, it happens, but turns out OK. They'll get better, maybe not 100 % of what they were. It will take time, there may be a couple of years of that, but it will get much better and they'll get more use of their arm, and they'll go back to their usual self."* (Son)

Specific to this veteran sample was an awareness of how veterans communicate. This was exemplified by the role of banter for the veteran as means of connecting with other veterans, and the experience of it from the non-veteran:

> *"Still in his head in every part of him, he is still [service] through and through…. The diving trips and different weekends …they don't pull any punches. "Are you carrying your legs with you today?" "Are you taking the long legs with you today?" Everybody's so upfront, and I think that's what he needs, and I'm assuming that's the kind of conversations that that he missed so much from being in the Armed Forces. He has always been absolutely military, through and through, and obviously always will be."* (Parent)
>
> *"A big part for [veterans] at events is the camaraderie and sharing experiences, and for partners that may not be such a significant bit."* (Veteran)

A balance is needed between providing sufficient space for veterans to connect with one another and space for families to communicate.

Understanding uncertainty in wider society

Uncertainty ripples far wider than the family into the wider social context, impacting employment and schooling. From the findings, wider organisational support is needed to enable individuals to sustain indpendendance and wellbeing. The following table summarises action points that could suport families living with loss of use of limb/s, and can be udpated to suit the family's needs.

Chapter 8

Surveys of Blesma population living with loss of limb(s) use

Introduction

The surveys sought to explore the impact that loss of use of limb may have on the veteran and the family. For this, we used the WHOQOL-BREF (Abbreviated World Health Organisation Quality of Life) and the FROM-16 (Family Reported Outcome Measure) quality of life assessment.

The surveys were disseminated between April and May 2022, with the support of the Blesma communications team who promoted it amongst veterans with loss of limb use. The platform used to deliver these questionnaires was JISC Online Surveys. Paper copies were also circulated, and where needed, Blesma Support Officers supported the veteran/family with completion by reading and scribing answers. The following paragraphs will discuss the surveys and findings.

Survey for Blesma veterans with loss of limb use

Instrument: The WHOQOL-BREF

The WHOQOL-BREF is a 26-item questionnaire which measures the impact of an illness on a patient's quality of life (QoL) and is suitable for measuring the impact of a loss of use of limb condition. Participants are assessed across four domains: Physical Health (seven questions), Psychological (six questions), Social Relationships (three questions) and Environment (eight questions). Additionally, there are two initial questions regarding overall perception of QoL and health satisfaction. Each question has a five-point Likert interval scale where patients rate their response from 'Not at all' or 'Very dissatisfied' (one point) to 'An extreme amount' or 'Very satisfied' (five points). Using a calculating formula (domain mean score is multiplied by a factor of 4, then 4 is deducted and then result is multiplied by a factor of 6.25), each of the four domains are assigned scores between 0 and 100, where a lower score indicates a poorer QoL.

All completed questionnaires were analysed, and where one or two questions were skipped, an average score for the question was added based on the responses of the other participants, as per the recommendations of the official WHOQOL-BREF survey.

Survey responses from Blesma veterans with loss of limb use

A total of 23 veterans have responded to the survey. Assuming the Blesma loss of limb use population is circa 315 veterans with loss of limb use, then this equates to a response rate of about 7%. While other Blesma surveys receive a completion rate of 3-4%, the current completion rate allows for a confidence level of 85% and an error margin of 15%. A higher number of responses would have provided a higher confidence level and lower error margin. The mean age of the Blesma participants was 56 (min 33, max 81), with the majority aged between 45 and 64. A breakdown by age groups is found in the table below.

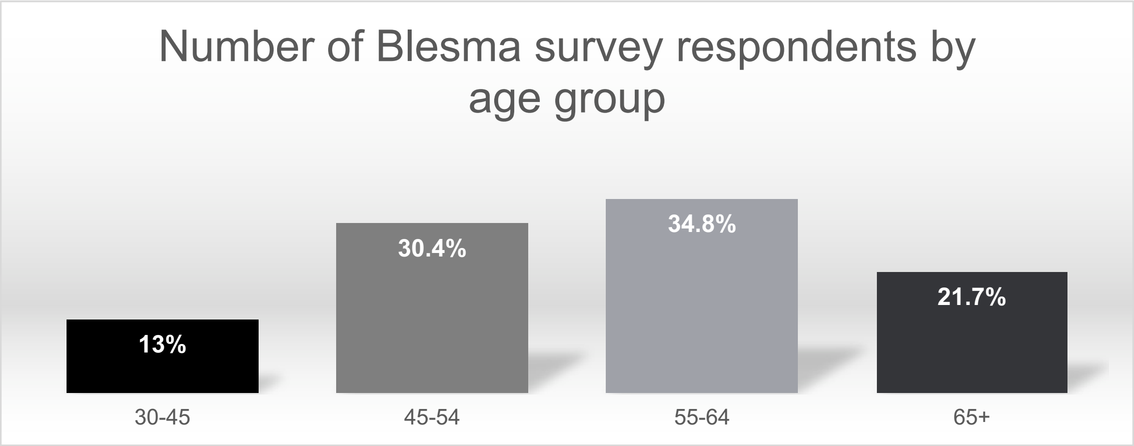

Table 5. Number of Blesma survey respondents by age group

The breakdown by gender was 22 male respondents (95.7%) and one woman (4.3%).

The following table presents the results of the self-assessed QoL amongst the Blesma survey respondents. 52.2% of the Blesma participants report that their quality of life is either good or very good; yet the remaining 47.8% should be the focus for Blesma and other support organisation. What this lower quality of life means will be itemised in the following tables that consider different aspects related to the quality of life.

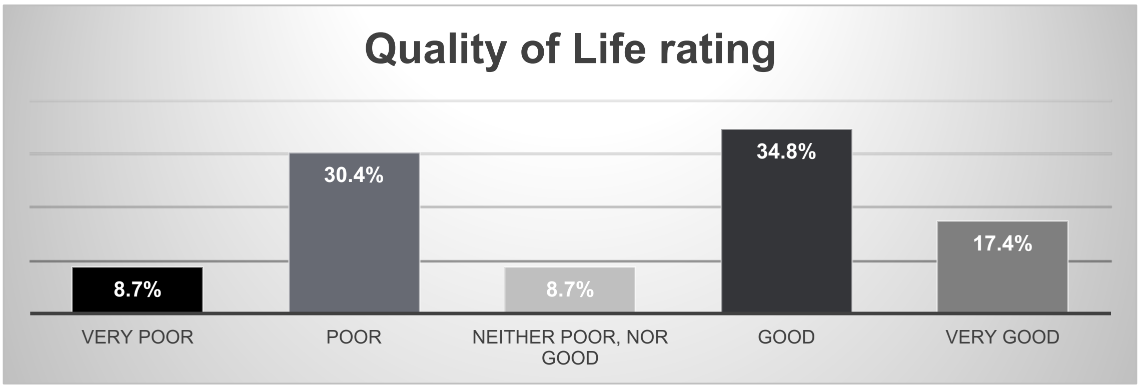

Table 6. Self-assessed quality of life amongst Blesma loss of limb use veterans

The health rating of Blesma veterans with loss of limb use closely follows the normal distribution in the population ("the bell curve"). However, when only 30% of the respondents consider their health to be either "good" or "very good", this is a relatively low rating when compared to the rating of quality of life. Interviews have shown that veterans often have multiple conditions such as an underlying loss of limb use, comorbidities linked to the loss of limb use (e.g. bladder or chest infections), and/or conditions which can be traced back to the military experience (e.g. PTSD).

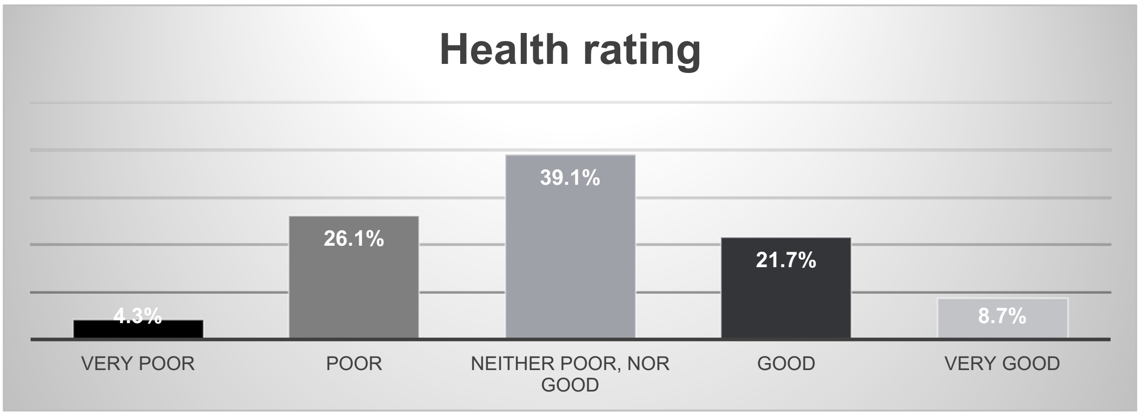

Table 7. Self-assessed physical health rating amongst Blesma loss of limb use veterans

The overall health conditions and physical abilities of veterans with loss of limb use is reflected in the capacity to perform daily activities. This category has received the lowest scores of all 26 measures of QoL in the survey, contributing to the lower generalised score of the "Physical Health" domain. Please note there is no result for the 'very satisfied' category because no respondent chose this option.

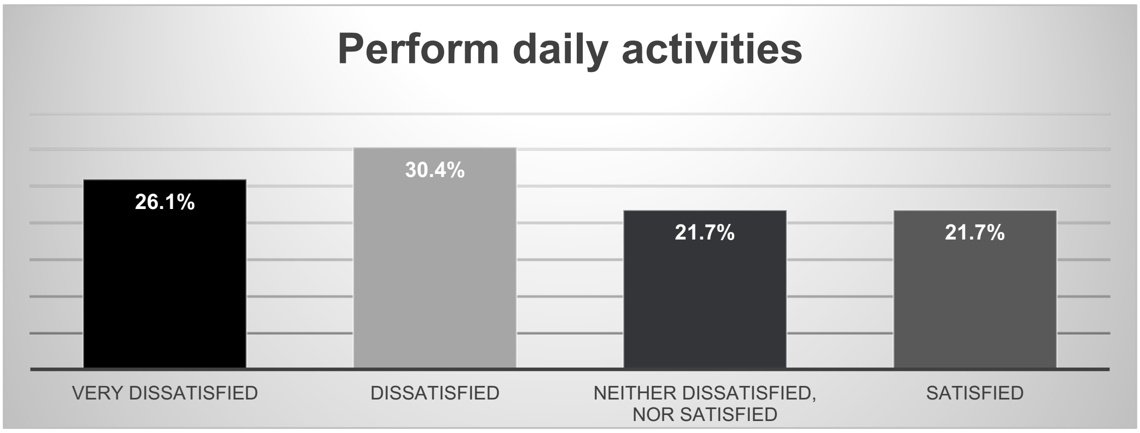

Table 8. Self-assessed capacity to perform daily activities amongst Blesma loss of limb use veterans

The second lowest score of the 26 items of the survey was satisfaction with sleep. This matter has been often flagged in interviews, related to limb pain, moving in bed, and PTSD-related nightmares. It impacts on the 'ability to perform daily activities' presented above. Please note there is also no result for the 'very satisfied' category because no respondent chose this option.

Table 9. Sleep satisfaction amongst Blesma loss of limb use veterans

Nearly 70% of the respondents are either satisfied or very satisfied with their living place, making it an area of less concern. Interview participants tended to be more satisfied if they owned their house or rented a place long term, where suitable adjustments could be made. They tended to be less satisfied if they found themselves in social housing, as it can take years for housing providers to assess and make adaptability adjustments, or to reaccommodate tenants.

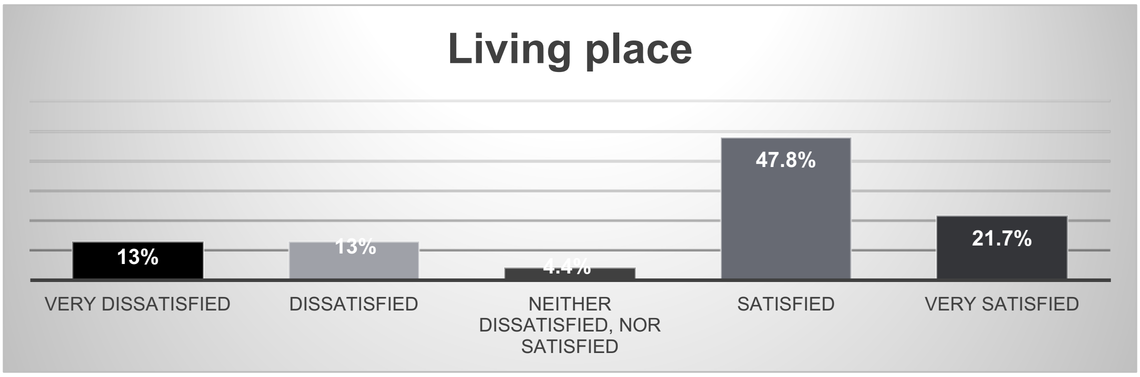

Table 10. Satisfaction with their living space amongst Blesma loss of limb use veterans

Satisfaction with opportunities for leisure activities for those with loss of use of limb is the area with the fourth lowest score (above capacity for work, sleep satisfaction, and satisfaction with sex life). This is an area where Blesma activities can make a more immediate difference for the quality of life of veterans with loss of limb use. In our interview conversations with participants, some have flagged up the fact that organising event days with veterans with loss of limb and veterans with loss of use of limb can put the latter group at a disadvantage. For example, they have mentioned activities which required moving off the chair, which they were not physically able to perform. Additionally, some veterans with loss of limb use attach a degree of stigma to their condition, as they may not feel entitled to attend such events because the cause of their condition is not related to the battlefield or service in the Armed Forces (see "hierarchies of wounding," Caddick et al, 2020).

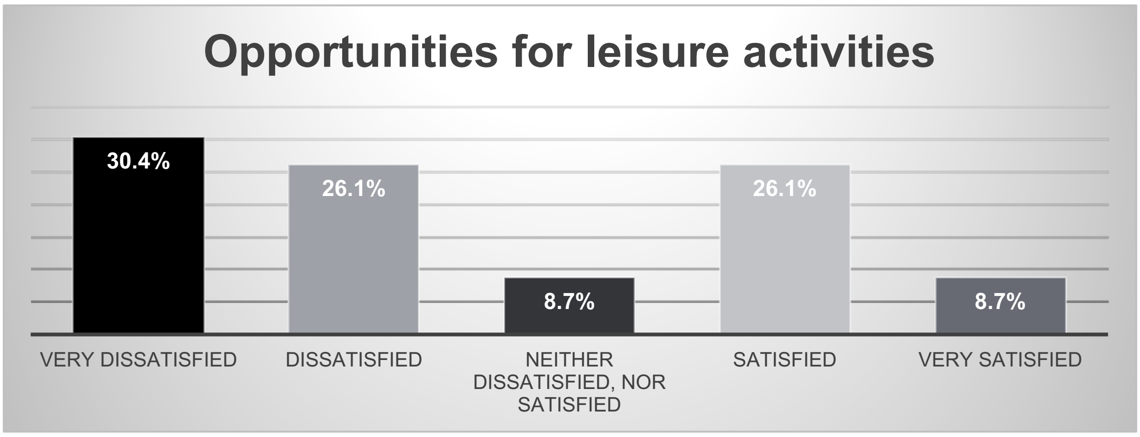

Table 11. Satisfaction with opportunities for leisure activities amongst Blesma loss of limb use veterans

Availability of information did not get any "very satisfied" ratings amongst the survey participants. Yet this is an area of medium concern for the veterans, partially related to the difficulties of navigating the medical, social care, and military-specific support available to them. Most veterans with loss of limb use that we have spoken with, however, were very satisfied with the information and support that they have received from the Blesma organisation at a one-to-one level.

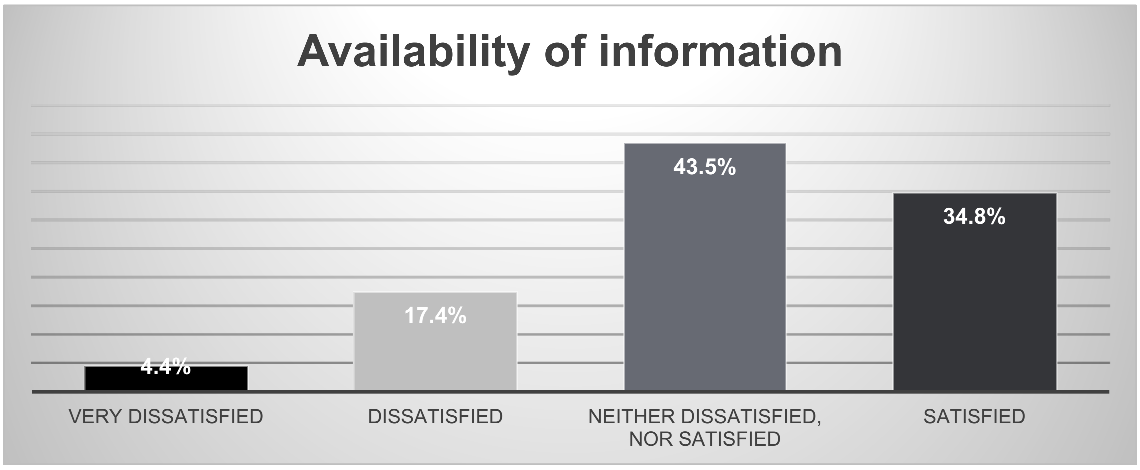

Table 12. Satisfaction with the information available to Blesma loss of limb use veterans

Overall, the satisfaction with personal relationships is relatively high, with around 60% of the respondents being "satisfied" or "very satisfied". This is on a par with "satisfaction with transport," the area of highest satisfaction amongst veterans with loss of limb use. It needs to be mentioned that such scores tend to refer primarily to the support received from the very close network and immediate family of veterans with loss of limb use, rather than the extended network. For that reason, "satisfaction with support from friends" received a markedly lower overall rating.

Another point to make here is that satisfaction with sex life is amongst the lowest three areas of satisfaction amongst the veterans. This is a matter that has also been brought up in interviews and is particularly relevant for those veterans with loss of limb use who are paralysed from the neck, shoulders, or waist down. It can also impact on the ability of the younger veterans with loss of limb use to become parents. Yet despite the physical limitations, veterans with loss of limb use have found ways to build or maintain strong bonds with their partners.

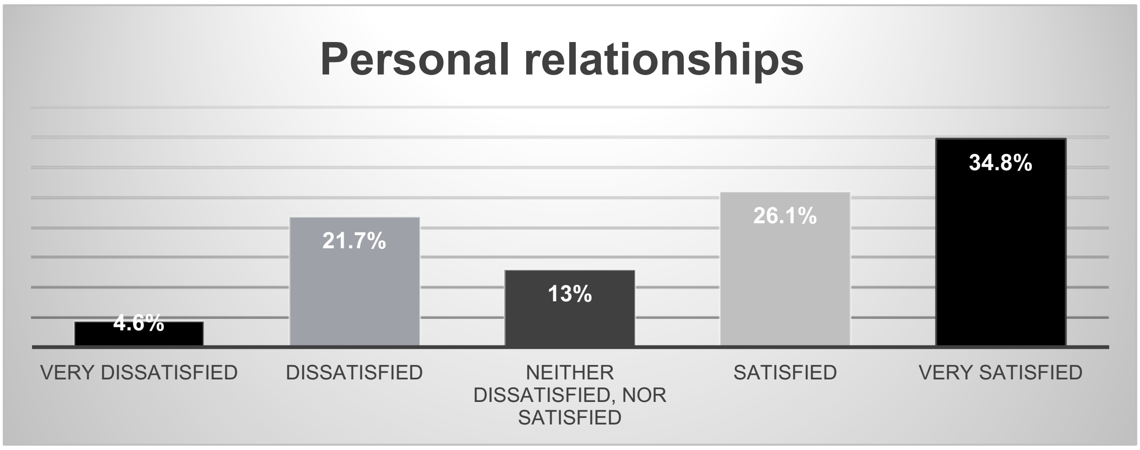

Table 13. Satisfaction with the personal relationships of Blesma loss of limb use veterans

All surveyed veterans with loss of limb use have at least occasional spells of low mood. As per the table below, there is no results in the "Never" category because no respondent chose this option. From our observations in the interviews, the categories at risk of generalised low mood are those with a PTSD diagnosis, veterans with loss of limb use who live alone, and those who have multiple physical and mental co-morbidities. We recommend that these veterans with loss of limb use are targeted for individualised support and more frequent check-ins.

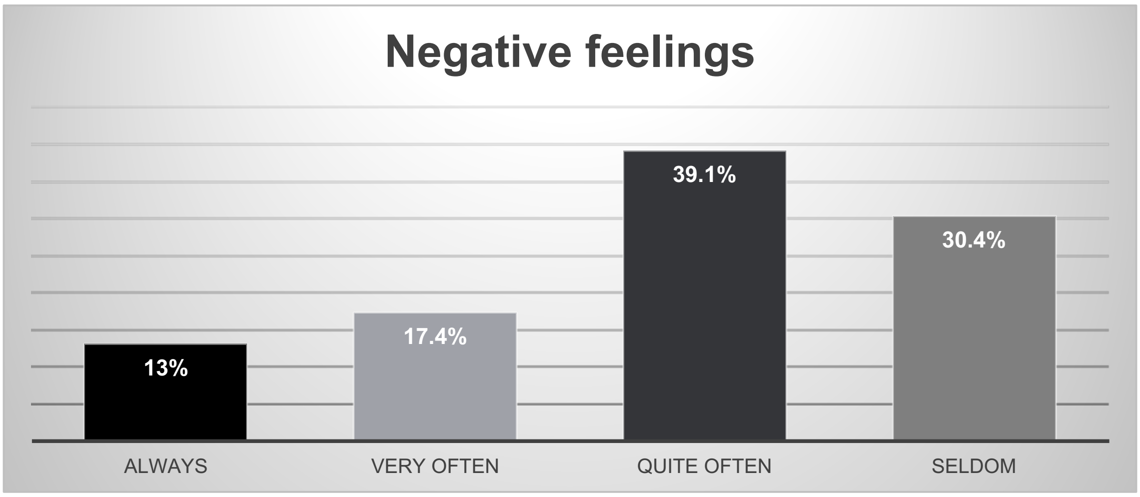

Table 14. Prevalence of low mood amongst Blesma loss of limb use veterans

We have now seen the itemised results of some of the most essential elements in the survey related to the quality of life for veterans with loss of limb use. As a reminder, the WHOQOL-BREF contains four domains, each with several itemised questions. The aggregated results of the four domains of the quality-of-life survey for veterans are presented in the table below.

WHOQOL-BREF Domain	Mean score	Standard Deviation	Minimum score	Maximum score	Median score
Physical Health	39.4	19.6	3.6	78.6	45.8
Psychological	51.6	24.3	8.3	95.8	54.2
Social Relationships	51	24.3	8.3	91.7	50
Environment	52.2	22.4	3.6	85.7	53.6

Table 15: Scores for Blesma veterans with loss of limb use for the four domains of the WHOQOL-BREF survey

For comparison, a study by Brittain et al (2021) on patients with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) used the WHOQOL-BREF survey for patients and the FROM-16 for family Veteran with loss of limb use. The study found the following mean scores: for Physical Health= 21.8, Physiological= 40.9, Social relationship= 40.8, and Environment= 54.7. Interestingly, the Blesma veterans with loss of limb use have a higher quality of life in all domains except Environment when compared to the ME/CFS patients.

As it stands, physical health is the area in which participants had the lowest quality of life. The psychological domain was the area with the highest median and maximum score, showing that despite the bodily changes that loss of use of limb conditions brings, a positive mindset can increase the quality of life of the veterans. In fact, the association between quality of life and psychological wellbeing is the strongest of all the associations tested with this survey data. As such, there is a significant positive relationship between the two using a Spearman rank order correlation (rs = 0.9043, p (2-tailed) = 0), meaning the variations between one element can account for 90% of the variation of the other.

Age is not an important determinant for the quality of life for veterans with loss of limb use. A Pearson correlation test indicated that there is a non-significant, very small negative relationship between the two (r (21) = .0727, p = .742), meaning quality of life may slightly decrease as veterans age.

Large positive correlations have been found between quality of life and the other three domains of the WHOQOL-BREF survey: Physical Health, Social Relationship and Environment.

Quality of life & WHOQOL-BREF Domain	R score	p (2-tailed)
Physical Health	0.66	0.00051
Psychological	0.90	0
Social Relationships	0.69	0.00021
Environment	0.76	0

Table 16: Correlations between QoL and its component elements (Spearman rank correlation coefficient)

The aggregated scores of the four domains presented above reveal that the mental wellbeing of the veteran is the most essential element. This is followed by a good living environment in and outside of the house, including via public services, and through the ability to move around. The next factor in scale of importance is good social relationships, primarily with the close family. Physical health is the least important contributor to the wellbeing of the surveyed veterans. This suggests that Blesma veterans with loss of limb use have been able to detach their physical limitations from the idea of a meaningful, fulfilling life.

The review of the survey data results for veterans with loss of limb use ends with the table on the next pages, which presents the correlations between quality of life and all elements which may relate to it. These elements are presented in decreasing order of the Spearman rank-order correlations, meaning the first elements are more strongly correlated with quality of life. In other words, enjoying life, satisfaction with oneself, and bodily appearance are the top three elements indicative of wellbeing. The least important elements for the quality of life are the amount of medical treatment a veteran need, the support from their extended network (rather than close family), or the amount of money to which they have access. This indicates that it is the ability to create a meaningful life despite the circumstances that can influence wellbeing, more so than the supportiveness of the wider network or monies received.

Quality of Life Correlations with WHOQOL-BREF Elements	Spearman R Score	P(2-Tailed)
Enjoying life	0.87	0
Satisfaction with oneself	0.8	0
Satisfaction with bodily appearance	0.78	0
Safety	0.76	0
Meaningful life	0.75	0
Ability to perform daily activities	0.74	0
Ability to get around	0.73	0
Good living environment	0.73	0
Energy levels	0.68	0.0003
Leisure opportunities	0.67	0.00049
Fewer negative feelings	0.57	0.00412
Sex life	0.56	0.00519
Info available	0.54	0.00786
Capacity for work	0.51	0.0123
Access to health services	0.5	0.01428
Ability to concentrate	0.49	0.01899
More money	0.43	0.04056
Friends' support	0.42	0.04886
Less medical treatment	0.41	0.04983

Table 17. Correlations between QoL and its itemised elements (Spearman rank correlation coefficient)

Survey for families of veterans with loss of limb use

Instruments: The FROM-16

The Family Reported Outcome Measure (FROM-16) is a 16-item questionnaire which measures the impact that a patient's illness has on the quality of life of their close family. It was produced by the University of Cardiff (Salek et al, 2012), based on extensive interviews with 140 families of veterans with loss of limb use across 26 different medical specialties. Since 2012, it has gained worldwide traction and has been validated and used in other studies in conjunction with the WHOQOL-26 survey. Therefore, it is a suitable instrument for measuring the impact of a loss of use of limb condition on a veteran's partner and family.

The questionnaire consists of two domains: Emotional (Part 1) and Personal & Social Life (Part 2). Each answer is graded on three-point scale ratings consisting of 'Not at all' (score 0), 'A little' (score 1) and 'A lot' (score 2). While the questionnaire has 16 items, we have removed one item related to sexual health, following consultation with BSOs. Thus, the maximum possible score

is 30, and a higher score indicates a greater impact on the family's QoL.
Just like for the WHOQOL-BREF survey, the research team tested survey responses for internal reliability, to gauge the ability of the FROM-16 instrument as a consistent measure of quality of life amongst veterans' families. We used a Cronbach's alpha coefficient, and the test result was a Cronbach Alpha coefficient of 0.81. This is identical to the coefficient obtained separately for the WHOQOL-BREF survey and provides a very good level of reliability, without being high enough (near 1) to indicate redundancy.

Survey responses from families of Blesma veterans with loss of use of limb

The research team received nine paper and online responses to the survey. This is not a sample large enough to allow extrapolations to the entire population of families of veterans with loss of use of limb.

A small sample size also increases the likelihood of a Type II error, by confirming initial hypothesis when an alternative hypothesis may be true. In this case, the null hypothesis is that the family of a veteran with loss of limb use is not affected by the loss of use of limb of someone close, and we will present the results of a few correlations tested below, which could not refute the null hypothesis. For this reason, most of the statistics presented in relation to this survey will be descriptive, rather than inferential.

The mean age of the family members who responded to the survey was 50 years (min 35, max 73). The breakdown by gender was seven women (77.8%) and two men (22.2%).

The breakdown of the ratings received (0, 1, or 2), where 0 is the most positive outcome and 2 the most negative, is presented in the table below. Most ratings (40%) were using the maximum negative score of 2. Only 24% of the itemised responses said the conditions of the veteran with loss of limb use do not affect them in a certain way (e.g., "My travel is affected", score 0, "not at all").

FROM-16 score	Frequency	Percentage from total
0	32	24%
1	49	36%
2	54	40%

Table 18. Frequencies of the FROM-16

	Score	Median score	Minimum score	Maximum score
Part 1: Emotional	6.77	8	0	12
Part 2: Personal & Social Life	10.66	11	5	15
Total score	17.44	17	5	27

Table 19. Mean scores of the FROM-16 survey

These scores are comparable to the average scores obtained in other studies. For example, Brittain et al (2021) found average scores for families of veterans with loss of limb use tend to be between 18 and 20. The mean score for families in this survey is 17.44, noting that one question has been excluded, thus the scores will be slightly lower than those obtained in other studies using the original survey.

The area where the survey takers had the lowest quality of life was difficulty in going on holidays (total score of 15 out of maximum possible 18). Next with scores of 13 were lack of satisfaction with family activities, inability to work at full capacity, insufficient budget, and insufficient sleep. While going on holiday is the area of the most difficulties, this has less of an effect on the ability of the survey respondents to travel on their own (total score of 8, second lowest).

The area where the quality of life of families is least affected (score of 2 out of 18 possible) is family network. This is represented by the question "I can have good relationships with other families of veterans with loss of limb use." The result is somehow surprising when considering the relatively high score regarding the ability to talk with others about their own thoughts, presented below. This may suggest that family networks allow for assistance, but without intruding into the intimate thoughts and matters of the close family of the veteran.

Of the six questions in Part 1 (Emotional), the highest score received was for the statement "I feel worried" (score of 12), followed closely by the statements "I feel frustrated" and "It is difficult to find someone to talk to about my thoughts" (scores of 11 each).

The two domains of the survey, Emotional (Part 1) and Personal & Social life (Part 2), have been checked for association. Due to the small number of responses, the research team could not find a correlation between the respondents' feelings on one side, and their personal and social life on the other. The results of the Spearman rank correlation coefficient (rs) were 0.64539, p (2-tailed) = 0.06048. By normal standards, the association between the two variables would not be considered statistically significant.

A relation between the age of the family respondent and their total score showing their quality of life has been tested. The Pearson test found the value of R is -0.261. Although technically a negative correlation, meaning the quality of life of the family decreases with age, the relationship between these variables is only weak, as it is closer to 0 than to 1.

The relationship between the quality-of-life scores obtained by the veterans and the scores obtained by their families have been tested. In the WHOQOL-BREF test a higher score means a higher quality of life, while in the FROM-16 a higher score denotes a lower quality of life. As such, the null hypothesis is that the scores are unrelated. A Pearson correlation test indicated that there is a non-significant, small negative relationship between WHOQOL-BREF and FROM-16 score (r (7) = .358, p = .344), therefore the null hypothesis cannot be refuted.

Other correlations tested were between the quality of sleep of the veterans and of their family. A Pearson rank-order test found no statistically significant associations (rs = 0.13887, p (2-tailed) = 0.7216). Equally, the research team could not find an association between the physical health of the veterans, which is the area of lowest quality of life amongst Blesma loss of limb use veterans, on one side, and the total FROM-16 quality of life score amongst their families on the other (rs = 0.37553, p (2-tailed) = 0.31927).

Conclusions from surveys

The survey sought to understand quality of life (QoL) across the families of Blesma veterans with loss of limb use. Quality of life has been defined by the World Health Organisation as the individual's perception of their position in life, in the context of culture and value systems in which they live and relation to their goals, expectations, standards, and concerns (WHO, 1993). This definition provides an important concept related to the veteran population: The military has its own culture and therefore those who are/have been in the military, may have different responses to adapting to acquired loss of limb use. The purpose of understanding QoL in this research therefore is to identify participants' insight into their QoL, to be analysed alongside the interview data, and not intended for comparison purposes.

There are many scales that can be used to assess the QoL of populations, spanning multiple disciplines, in part driven by people living longer, the increase in chronic conditions and rising costs of healthcare delivery. This has resulted in many assessment instruments, most of which are linked to specific aetiologies/disease processes. To assess the most relevant generic scales to use with both the individuals with loss of use of limb(s) and their family experiences, a scoping review was conducted, and from this the validated WHO QOL-Bref and the From16 were identified as being most useful. A full report is presented in Appendix 2 and the findings summarised below.

Recruitment for the surveys was via promotion via Blesma literature, with links to online portals for completion and anonymised return. Paper copies were also forwarded for completion, with assistance from BSOs as requested by individuals.

WHO Qual-Bref; A total of 23 veterans responded to the survey. Assuming the Blesma veterans with loss of limb use population is circa 315, then this equates to a response rate of about 7%. While other Blesma surveys receive a completion rate of 3-4%, the current completion rate allows for a confidence level of 85%.

Analysis found 30% of the respondents reported their health to be either "good" or "very good" with lower scores relating to physical health and poor sleep. The psychological domain had the highest median with maximum scores, suggesting links between quality of life and psychological wellbeing. The aggregated scores of four domains (Physical, Psychological, Social Relationships and Environment) similarly indicates the mental wellbeing of the veteran as the most important aspect, followed by a good living environment in and outside of the house, including via public services and the ability to move around with ease. The next factor in importance was good social relationships, primarily with close family. The least important was physical health. These findings were reiterated within the interview data, where managing physical wellbeing was least discussed, and emotional adaptation to loss of use of limbs was of higher priority.

FROM -16; Nine paper and online responses were received. As we cannot predict the number of family members to the beneficiary, we cannot ascertain a confidence level. Responses indicate the lowest quality of life was difficulty going on holidays, family activities, inability to work at full capacity, insufficient budget, and insufficient sleep. The QoL least affected was family network. The highest score received was for the statement “I feel worried”, followed closely by the statements “I feel frustrated” and “It is difficult to find someone to talk to about my thoughts”. This suggests that family networks support practical aspects of care, but less so in relation to the individual’s intimate thoughts and feelings. This finding was identified in the interview data, where families identified feelings of satisfaction with general support, whilst also feeling unable to talk about difficult topics with their veteran partner and others.

Chapter 9

Telephone interviews findings

To check that the findings were relevant to veterans and families, we implemented a closed questionnaire interview with veterans and family members. The closed questions were developed from analysis to see if the findings were meaningful and useful. The questions were as follows and were accompanied by a short narrative of the findings, including diagrams:

- Veterans/their families told us that learning to adapt to a change in limb use was difficult but could be done. Looking at Diagram 1, do the things that people said sound familiar to you? Yes/No
  – If no, why not?
- Veterans/their families told us that living with loss of limb use brings with it uncertainty. Looking at Diagram 2, does this feel familiar to you? Yes/No
  – If no, why not?
- Veterans/their families told us that coping with loss of limb use is experienced differently within the family. Looking at Diagram 3, does this seem familiar to you? Yes/No
  – If no, why not?
- Veterans/their families told us that that it is hard to talk about uncertainty. Do you agree/disagree?
  – If you disagree, why?
- From what the veterans/their families told us, er developed two safe conversation protocols that can be used to help people have safe conversations. Looking at the protocols, do you think they will be useful? Why/why not?

Ten veterans with loss of limb use and five family members were interviewed (two hours), the results of which were transcribed, coded, and integrated into the overall findings.

Findings from closed questions

Overall, the participants agreed with the findings, often adding emphasis on certain parts and thinking through how the findings may have been useful to them in their previous life experiences of living with loss of use of limb. The conversation protocols were identified as helpful because reliving the cause/impact of their loss of use of limb(s) was experienced as difficult. Individuals also identified that there is a need to have conversations that look forward to unknown futures, but also that it can be difficult to have such discussions.

Chapter 10

Report summary

The purpose of this research was to learn how families live with loss of limb use. Participants in this research were generous with their time, sharing their experiences and thoughts, and importantly how to make things easier for others. Central across all aspects was acknowledging that uncertainty is ever present and complex. This includes recognising:

- The injury/diagnosis remains central as it affects the resultant abilities.
- People learn to adapt to living with loss of limb use, but there is no blueprint or linear way to do so; it is highly unique and individual.
- A means to learning to adapt is to find the right headspace. The right headspace refers to the emotional and mental preparation needed before a person can work towards long term adaption. Recognising this, and consideration of their emotional and mental wellbeing, may indicate that an individual is coping well. However, this might not be visible to others, and as such may not be an outward sign of coping.
- Uncertainty brings health changes that are often unpredictable and unseen, and are rarely linear.
- Witnessing uncertainty and change is difficult, and this is rarely discussed.
- People cope with uncertainty in different ways. Often, people might not admit to feeling unable to cope, especially in front of one another. Coping is difficult to discuss.
- Assessing coping levels is important. However, certain behaviours might mask the coping level of the individual. For example, a focus on sport/employment/civic good could look to others like coping. It may, however, be masking low coping, because the individual is avoiding accepting their loss of use of limb by keeping busy.
- Masking is a behaviour that conceals avoidance of finding the right headspace. Masking can include an overfocus on rehabilitation, competitive sport, adventure holidays, employment, doing good for others. This is important to note because such activities are often viewed as evidence that a person is coping. This research, however, highlights that such activity could indicate low coping.
- There is a need to better understand the balance between fulfilling a military identity of service and wanting to do good and the avoidance of adapting to current personal circumstances.
- Support processes recognise that people may take many years to start to adapt to their loss of limb use, and assumptions ought not to be made about the longevity of acquired loss of limb use and the acceptance process.
- Uncertainty is difficult to talk about because it can be upsetting.
  Safe conversations are needed to talk about uncertainty. Safe Conversation guides may be useful tool to enable Safe Conversations both within the family and with health professionals.
- Uncertainty ripples wider than the family home, possibly impacting educationand employment. This needs to be thought through in the family, and a guide on the impact of living with loss of limb use and the wider context has been developed to help people think about, and plan ahead to living with loss of limb use, uncertainty and the wider context.

Limitations of research

This research reports original and unique findings that add to our understanding of living with loss of use of limb(s) in the veteran community and is intended to have transference to the civilian community. However, some limitations should be noted. The interview sample was self-selected, articulate, had adapted to living with loss of use of limb(s), with financial security. As such, some aspects may not be directly transferable to the wider Blesma veterans with loss of limb use population. Similarly, the survey responses may have limitations, for example, responders may over- or understate their responses, those who have issues to address may be more motivated to respond, and only those who are well educated or have access to secure resources, or who are highly satisfied or extremely unsatisfied may respond or overrepresented. Further work is therefore needed to identify those across socioeconomic, cultural groups and diverse types of family and friendship groups. Families of veterans with loss of limb use talked about their lives revolving around the veteran, rather than about their feelings in relation to the changes in abilities post injury/diagnosis. How to encourage individuals to discuss their thoughts and feelings as independent from the veteran with loss of limb use is recognised as being difficult. Further work is needed to identify how families may talk more about their experience, as separate from the veteran. It must also be noted that not all families will identify as caregivers, nor have social network ties to support organisations. Further work is needed how to communicate with families who do not use Blesma as a resource for finding support and information.

Conclusion

From the outset of this research, it has been important to celebrate the key role of the support provided by the Blesma Support Officers and Outreach workers, especially in relation to the significant impact that their input has on the wellbeing of the veterans they support. This project collected information from 84 Blesma members and/or their families who live with, or alongside, loss of limb use. The central message was clear: adapting to loss of limb use takes a lifetime, and uncertainty is the most stable aspect. Alongside, participants were clear in how what helped over time and what their barriers were, physically, intellectually, emotionally, and socially. The clear message is that uncertainty can be managed by routines, careful forward planning and a ‘getting on with it’ and ‘can-do’ perspective. It was also clear that the central problems of these families’ lives are like those of most people; talking about worries and uncertainties is difficult to do, whether it be between partners, families or healthcare and support providers. Because of this, key resources about having safe conversations have been developed, directly informed by what participants told us. It is hoped these will form protocols for individuals to adapt to their own needs and situation. It is also hoped that these could be of use to the wider population, irrespective of their health and wellbeing situations. Alongside, this research identifies that families do not necessarily require more support; rather, it details the need for wider society to develop responsive and flexible structures that recognise the demands uncertainty brings to family life. Central within this is the need to enable families to feel safe to have difficult conversations about actual and uncertainties within the family itself, with wider health and support services, employers, and educational organisations. Alongside, these findings and recommendations will continue to cement Blesma’s leadership as a provider organisation that engages in research and then uses evidence-based findings to improve the quality of their service provision, leading to improved outcomes for their members and families.

Appendix 1

Initial literature review: the family perspective of living with loss of limb use

1 To conduct the literature review, a scoping methodology was adopted, as it suited the broad aim of examining the literature and gaps in research pertaining to loss of limb function. We included peer-reviewed published literature of qualitative methodology, originating from any location. We have employed the five-stage framework method by Arksey and O'Malley (2005) due to its comprehensiveness, as outlined below.

This review was updated in 2022 by Miltali Sarkharkar, an undergraudate medical student from from Boston University student, whilst gaining research experience in the UK.

Identifying a research question: This should include the study population, any outcomes, exposure, or intervention. This scoping review's question is to understand what the experiences of families that care for loss of limb functionality are, in the civilian, military and veteran contexts. It includes national, international, and cross disciplinary perspectives over a period of approximately 20 years (published in 2000 or after).

2 Identifying relevant studies: The following databases were searched:

- EBSCO (including PsychInfo, PsychARTICLES, MedLine, CINAHL Plus; behavioural sciences collections)
- ProQuest Central (including ProQuest Military Collection, ProQuest Psychology Database, ProQuest Social Sciences Database, ProQuest social science premium collection, Assia)
- Science Direct
- JSTOR
- Wiley Online library
- Web of Science
- Scopus
- PubMed

Search terms and Boolean phrases used are outlined in Table 1 and centred on variations of the key words 'loss use limb', 'spinal cord injury' and 'family' and 'caring'.

KEY WORD	SEARCH STRINGS
Loss use limb(s)	physical loss of limb use, limb impairment, paraplegia, tetraplegia, quadriplegia, tetraparesis, limb ischemia, loss of function of limb(s), spinal cord injury, SCI, acquired injury
Family	Family carers/ing, family care give*, informal care/ing, unpaid care/ing, living with, experience of, veteran family, civilian family, adult

Table 1. Search terms used to identify relevant studies.

3 Study selection: The initial database search returned 156 papers. Following exclusion of all papers other than peer-reviewed journal articles, 151 papers remained. We reviewed the titles and abstracts of the papers based on the inclusion and exclusion criteria outlined in Table 2.

Inclusion criteria

- Family caring for acquired physical loss of limb functionality in the military, veteran and civilian populations
- Sampled populations with injuries acquired over 12 months ago and which are likely to last for the rest of the life of the person affected, and which impact daily activities
- English only, peer reviewed research
- Within 20 years of publication
- No geographical limitations
- Original research using qualitative methodology.

Exclusion criteria

- Impairment that is primarily because of loss of limb/amputation
- Impairment that is mental or cognitive in origin
- Impairment under 12 months of duration
- Review papers that do not include original research (although these were used to check all research papers had been captured)
- Grey literature that has not been peer-reviewed (this was decided as the peer-review process ensures that the research identified is of a sufficient quality)

Inclusion was based on the paper having a substantive focus on caring for people with acquired loss of limb functionality, resulting in loss of limb use. Following a review of the titles and abstracts, 118 full text papers remained and were reviewed independently by the two researchers. We read the full versions of each paper and categorised them as relevant, potentially relevant, or not relevant. Those deemed to be not relevant included papers that did not meet the full inclusion criteria. Those in the potentially relevant category included papers that mentioned acquired physical injury resulting in loss of limb use, but did not have a substantive focus on family carers (for example, quality of life of disabled people). In total 14 papers met the full inclusion criteria. Figure 1 shows the full scoping review process.

The rigorousness of the research findings and methodologies applied is an important aspect when producing synthesis studies, including scoping reviews. Caroll, Booth and Lloyd-Jones (2012) recommend that inadequately reported qualitative studies should be omitted from reviews, because studies are likely to repeat the findings of correctly reported studies, while carrying the risk of inappropriate data collection and analysis. For this reason, we are using the Reporting Assessment Checklist by Caroll et al. (fig. 2) to review the quality of the papers included in this study. This includes four criteria of assessment: mentions of the study's question and study design; description of the selection of participants, details on data collection methods, and details on how data analysis was produced. Following this process, fourteen of the studies reviewed fulfilled all four of the Reporting Assessment Checklist criteria.

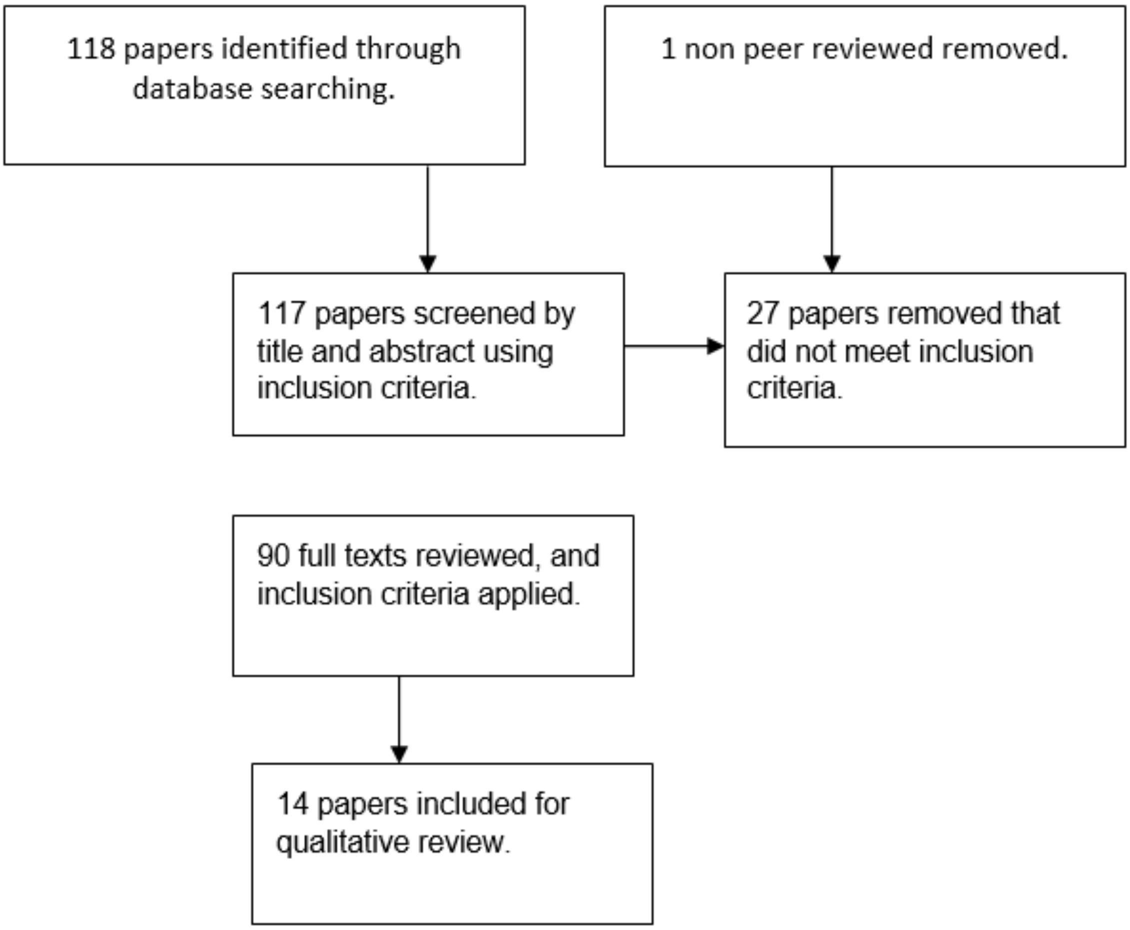

Figure 1: Study selection process

4 Charting the data: The data from selected papers was extracted and collated in a spreadsheet (Table 1): title, author, year, journal, location of research participants, study aim or objective, methodology type, research techniques sample size, ethical approval, main results and findings, recommendations.

5 Collating, summarising, and reporting the results: The articles were read by both researchers and data were summarised. Certain themes emerged across the 14 papers, and the charted data is shown in Table 2. A summarised analysis of the research papers is shown in the results section below.

Findings

All studies are primary research, where most participants have been injured for more than 12 months. Six of the studies focus solely on the experiences of carers, while the rest feature the 'carer-person cared for' dyad as the focus, with mentions of the role of formal carers and extended support network. An overarching theme of the papers is the burden for family carers and the strategies that the relatives are using to adapt and overcome the difficulties. Juguera Rodriguez et al. (2018) observe that loss of limb use leads to family caregivers experiencing changes in every sphere of their lives, with women representing most family carers within heterosexual couples only. The research populations are located across Canada (four studies), Iran (two studies), US (two studies) and Taiwan, UK, Spain and Australia (one study each).

General themes focus on informal care for people with loss of limb functionality including isolation, loneliness, depression, change in health status, role overload, and changes in family structure. We have grouped these themes into six categories of interest:

1. Changing relationship dynamics: conflict, boundaries, protective behaviour, control, independence, and interdependence. Frequency of this theme is 11 articles
2. Carer's emotional responses: emotional strain, improved self-awareness, privacy awareness, appreciation, resilience, feeling it is a rewarding labour, faith. Frequency of this theme is 11 articles
3. Family: keeping it cohesive/dissolution, adapting to the new normal, taking care of children, feelings of love not changing, physical intimacy and leisure changing. Frequency of this theme is 10 articles
4. External support: kinship and friends, information, and readiness for caring at home (or lack of), support from larger community, working with formal carers, alternative medicine. Frequency of this theme is 8 articles
5. Carer's self-care: secondary complications, fatigue, lack of sleep. Frequency of this theme is 7 articles
6. Material support: assistive technology, unsuitable housing, financial problems, unemployment. Frequency of this theme is 7 articles

The concept of burden was dominant, identifying the ability to adapt to the new physical limitations of the partner and the need for physical and emotional support, as well as the carer's own mental resilience to adapt and transform the household dynamics to the new limiting circumstances. Findings identified adaptation to the new circumstances afforded by the loss of limb functionality as a gradual process occurring in the months or years after the moment injury/disease is confirmed (Chen and Boore, 2008; Jevathevan et al, 2019; Lucke, 2013; Pullin, 2020). Sometimes the result is not adaptation, but manifests as family breakdown due to the insurmountable pressure (Chen and Boore, 2008). Where adaptation does occur, open, honest communication is essential in negotiating and adapting to the new ways of living (Beauregrad). While external factors can support or impede the efforts of the carer, data presented in the papers is focused mainly on the carers' perceived negative impacts (Charliefue). An overview of these negative themes includes: lack of proper training and support from medical personnel, lack of financial support, stigma and unsuitable housing and public infrastructure. Loss of limb functionality has an impact on the ability of the spouse/partner to fulfil their domestic tasks, which is more poignant if the loss happened during the relationship rather than before. While feelings of love are reported to remain unchanged after loss of limb functionality, it is the physical barriers that negatively impact on intimacy (Jeyathevan et al., 2019). Working together as a couple (or as a 'dyad" often used in literature), as well as with medical rehabilitation and formal carers, is key to preventing feelings of strain and loneliness among carers. 13 out of the 14 papers selected include recommendations for health practitioners and rehabilitation teams to consider the educational, emotional, financial, peer support, employment, own ageing, and health concerns of the carers. Three articles also emphasise the need for culturally appropriate support interventions for carers, which take into consideration their system of belief regarding disease management and the moral obligation of support.

Limitations

The conduct of this scoping review has revealed gaps in the available literature and knowledge about loss of limb functionality. The articles reviewed are significantly geared towards the burden of women carers, who represent most of the informal carers. There are no mentions in the literature about non-heterosexual couples, or non-cis gender carers or patients with loss of limb functionality. Informal carers are usually from the same nuclear family, but the scoping review has not been limited to a strict definition of who can act as primary carer for someone with loss of limb functionality. Still, the literature reviewed describes the role of carers within the spouse/partner, or child-parent dyad. Six of the 14 studies (Chen; Dickson; Manns; Munce, 2016; Nikbakht-Nasrabadi, Pullin) include data from other family members acting as main carers, such as siblings and aunts.

Acknowledgement

This review was updated in 2022 by Miltali Sarkharkar, an undergraudate medical student from from Boston University student, whilst gaining research experience in the UK.

Beauregard et al 2010: relationship changes, limits leisure ability, difficulties domestic tasks and young kids, problems for physical intimacy
Charliefue et al 2016: few positive themes: changes in identity: awareness, enhanced family cohesiveness and feeling appreciated. Negative themes included physical and emotional strain, dissatisfaction with hired carers and strain on family relationships. Health-related themes included fatigue and lack of sleep. Sources of strength for carers: faith and support from friends and co-workers
Chen et al 2008: catastrophic event: anxiety financial problems, role change, conflict; carer burden, resilience, or breakdown
Dickson et al 2018: assistive technology: negotiating boundaries, independence and control, privacy for carers, acceptance, lack of training, rewarding nature of caring, stigma
Jeyathevan et al 2019: 1) disintegration of relationship: protective behaviours, asymmetrical dependency, loss of sex and intimacy, and difficulty adapting; 2) Re-building/maintaining the relationship: interdependence, shifting commonalities, adding creativity into routine, and creating a new normal
Juguera Rodriguez et al 2018: external support, financial support, information, adaptation
Labbe et al 2017: house: size, ambiance, unsuitable for needs
Lucke et al 2013: family: faith, fear for the future, love, sadness for loss, overcoming difficulties
Manns et al 2017: readiness, community health care, information pathway, health promotion, contextual factors
Munce et al 2016: wellness awareness, monitoring for secondary complications, independence-dependence conflict, directing someone else to provide care
Munce et al 2014: physical support, maintaining independence, caregiver giving emotional support, burnout
Nikbakht et al 2019 1) physical rehabilitation by various methods; 2) tendency towards the use of alternative medical methods; and 3) making effort for self-reliance
Pullin et al 2020: protective caring, self-care, negotiated caring, surreptitious care, strategic caring
Shabany et al 2020: 1) disruption in the existential integrity of the individual: emotional reactions, isolation, family structure change; 2) constructive life recovery: physical limitations, social relationships, spirituality, hope, self-reliance, alternative medicine, assistive devices; 3) inhibitors of family-centred empowerment: dependence, lack of training or medical support, money, social facilities or employment; 4) facilitators of family-centred empowerment: personal characteristics, social support and; 5) back on track: family and marriage

Table 3. Summary of themes across papers.

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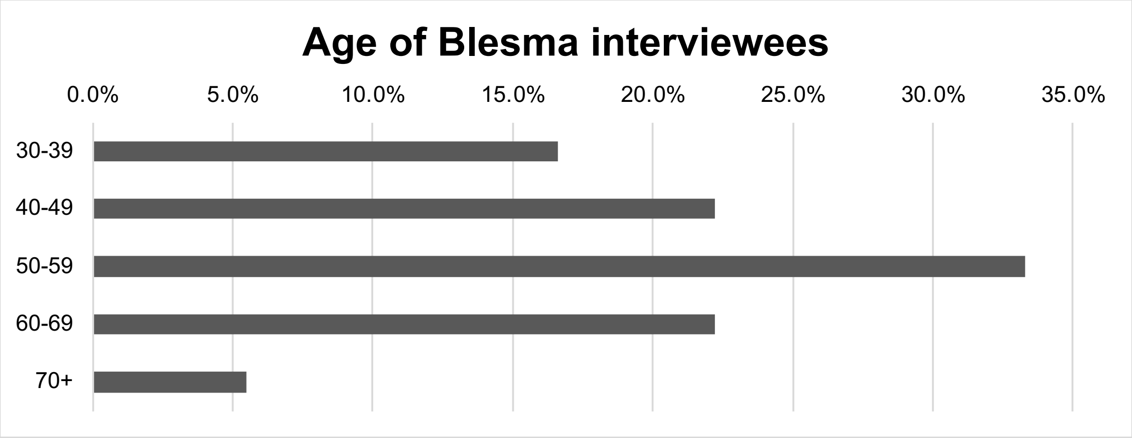
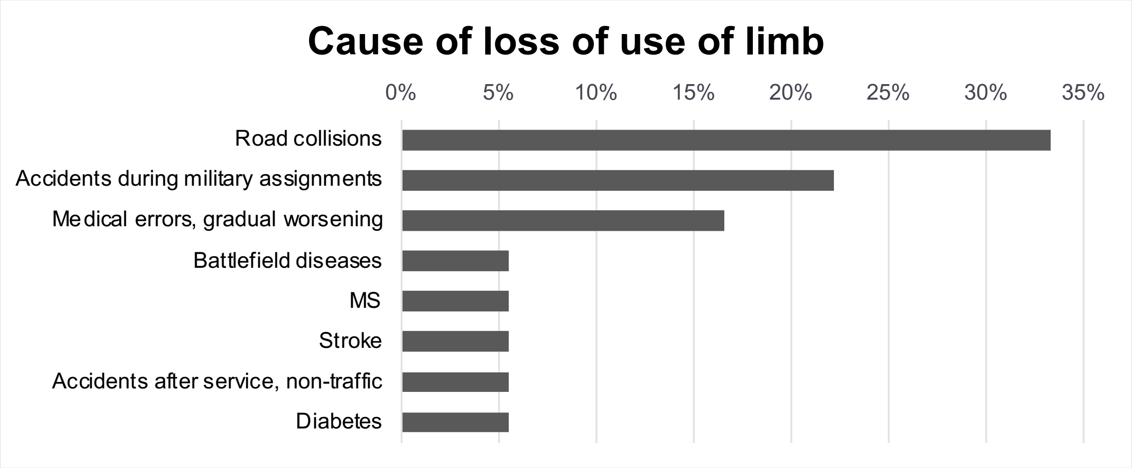
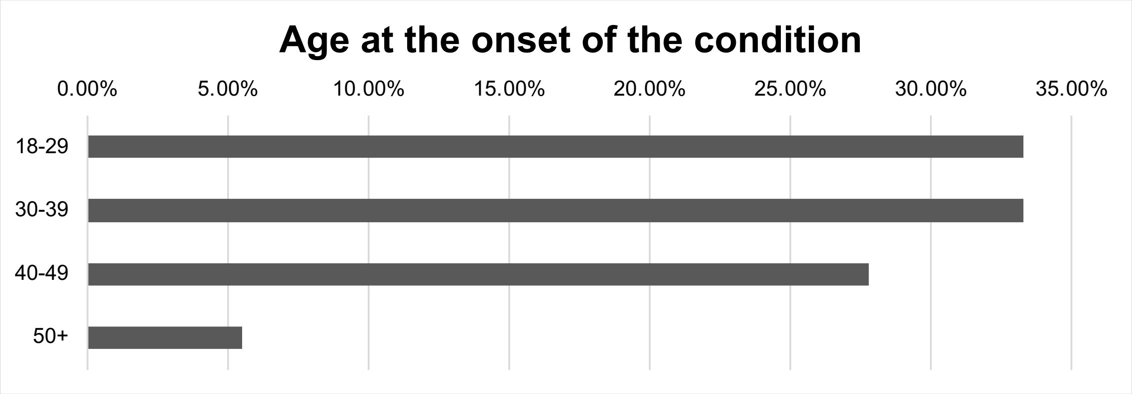
Appendix 2

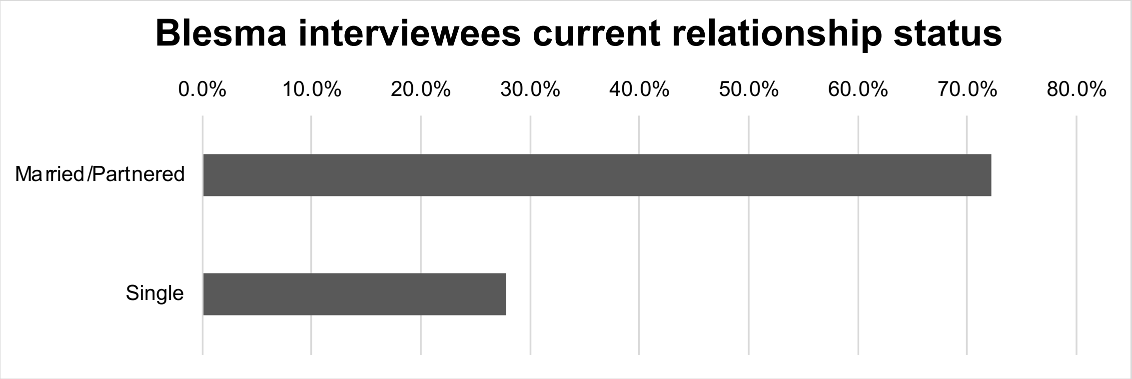
Biography of interview sample

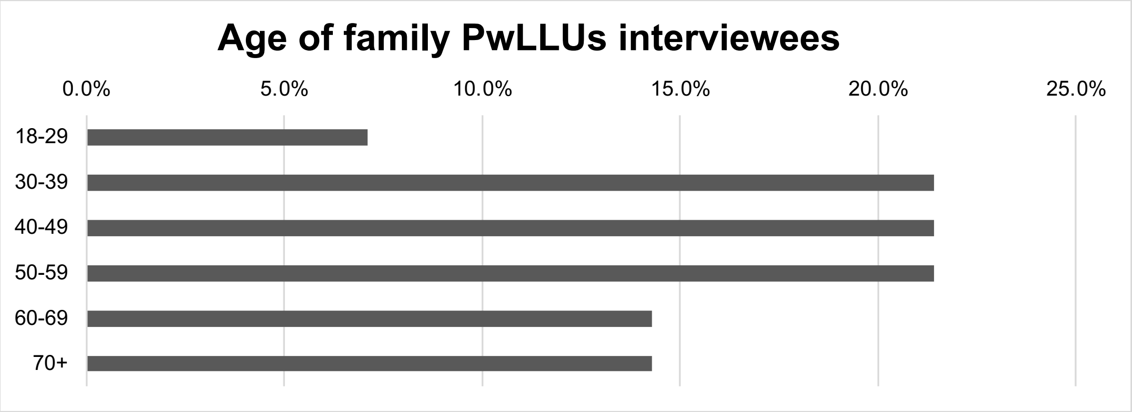
The following is an overview of the sample recruited for each phase of the study:








Blesma interviewees current relationship status
0.0%
10.0%
20.0%
30.0%
40.0%
50.0%
60.0%
70.0%
80.0%
Married/Partnered
Single


Age of family PwLLUs interviewees
0.0%
5.0%
10.0%
15.0%
20.0%
25.0%
18-29
30-39
40-49
50-59
60-69
70+