

**RUNNING HEAD: Psychological support following amputation**

**TITLE: Experiences of Receiving Formal Psychological Support following Lower Limb Amputation: A Qualitative Study**

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### **TITLE: Experiences of Receiving Formal Psychological Support following Lower Limb Amputation: A Qualitative Study**

#### **ARTICLE CATEGORY: Research paper**

#### **Abstract**

**Purpose:** This study sought to explore the experiences of receiving formal psychological support following non-vascular-related lower limb amputation.

**Materials and Methods:** Semi-structured interviews were conducted with five individuals (3 males, 2 females, aged 38-56) with lower limb loss. Two had unilateral above knee amputations, one a unilateral below knee amputation, one a unilateral through-knee amputation, and one had bilateral above knee amputations. Four had trauma-related amputations, one had an amputation due to cancer. All had received formal psychological support related to their amputation. Interpretative phenomenological analysis was used for the analysis of the data.

**Results:** Four themes were developed: 1) The need for psychological intervention - denial and acceptance; 2) 'Safe space' - being valued, heard, and validated; 3) The importance of focus, transparency, and specialist knowledge; and 4) The most helpful techniques and approaches. Findings highlighted aspects of psychological support that were helpful and unhelpful.

**Conclusions:** The findings provide insights into how psychological support for people with lower limb amputation can be delivered or improved. These include: the importance of psychological support throughout rehabilitation; the benefit of transparency and collaborative goal setting in sessions; and participants' preference that those providing formal psychological support have limb loss specific knowledge.

**Key words:** amputation; interpretative phenomenological analysis, limb loss, psychological support.

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### **Experiences of Receiving Formal Psychological Support following Lower Limb Amputation: A Qualitative Study**

#### **Introduction**

The psychosocial difficulties experienced due to lower limb amputation (LLA) have been well documented [1]. Depression is often experienced during the early stages following LLA and for up to 2 years, with depressive symptomatology decreasing between 2 and 10 years after the limb removal surgery, matching the depression rates experienced in the general population [1]. Suicidal ideation can also be experienced by some individuals with LLA [2]. Anxiety has been reported to affect over half of the population with LLA especially during hospitalisation and the early stages of recovery [1].

Body image disturbance is a common psychological difficulty following LLA [1]. Those affected often report dissatisfaction, and at times repulsion with the way their bodies look after surgery [3], something that has been found to affect their self-esteem and impact the formation and maintenance of romantic relationships [4]. Dissatisfaction with a new body image following LLA has been found to exacerbate depression and anxiety and affect the perception of one's quality of life, whilst people report experiencing stigma for their 'different' appearance [1].

Changes in identity and self-perceptions present challenges to the person with LLA as they transition from an able-bodied identity to one of 'disability' that may evoke feelings of inferiority [5]. Returning to work might be challenging and some individuals have to change jobs or modify their workplace [6].

To effectively support individuals following LLA, rehabilitation offered needs to be coordinated by multidisciplinary teams (MDTs) that can support the management of the

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variety of challenges experienced and aid physical and psychological adjustment [7-9]. One review concluded that challenges in the care provision include lack of clear communication that leaves individuals unprepared before the operation, ‘nonchalance’ by health care providers and ‘losing sight of the psychological aspect of patients who undergo this procedure’, and limited support upon discharge [10; p.130]. To combat these challenges, it has been recommended that consultation by mental health professionals needs to be offered throughout the pre- and post-amputation phases [10].

Early intervention and psychological support can help commence the adjustment process earlier, mitigating long-term challenges [11]. Self-management programmes for people with limb loss have previously been developed. Typically, these have involved people with limb loss as trainers or leaders in session and content delivery within peer support groups [12, 13]. Peer support can improve outcomes for individuals following amputation [14] and can provide a sense of belonging, hope and resilience [15]. However, peer-mentors report challenges related to uncertainty and doubt about their mentoring abilities and with developing and maintaining resilience in the role [15].

Working as a psychologist in an MDT that supports the rehabilitation of people with LLA focuses on increasing psychologically informed thinking within the team, and on the effective completion of assessments, formulations (a term used in clinical psychology to refer to a summary of a person’s difficulties and the possible causes of these), and interventions [16]. In regard to therapy and interventions, Cognitive Behavioural Therapy (CBT) has been found to reduce anxiety, low mood and pain, and improve self-esteem and sleep [17] for people with LLA. CBT has also been found to increase positive outcomes when used in inpatient settings with older LLA populations [18] as well as when specialised versions of it are used for the management of chronic pain caused by amputation [19]. In addition, guided imagery

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[20] and Eye Movement Desensitisation and Reprocessing (EMDR) [21] have been found to help in the management of phantom limb pain experiences. Solution-focused Therapy, a goal-oriented approach, and Motivational Enhancement Therapy, that encourages the development of motivation for change, are approaches shown to aid adjustment during the early stages of the LLA rehabilitation process [22]. Additional therapy models that have been suggested for their potential to decrease depressive symptomatology and distress related to LLA include Interpersonal Psychotherapy, an approach that supports individuals with relationship difficulties [16], and Acceptance and Commitment Therapy, that uses mindfulness and the individual's personal values to improve the quality of day-to-day life [22].

It has been suggested that counselling can be helpful as an early intervention, during the first few weeks following limb loss surgery, to support individuals with practical difficulties, such as completing tasks, employment, and housing, but the effectiveness of the approach has not been determined for psychological problems arising at later stages in the recovery process [23]. Research published on work-related amputation recommends that rehabilitation counsellors can support return to work through providing psychoeducation and interventions based on CBT, exposure therapy, assertiveness, and social skills training [24].

Whilst the above-mentioned recommendations and guidance offer valuable insight into mental health approaches for supporting people following LLA, no research has been conducted to understand the experience of receiving formal psychological support from the perspective of those with lower limb amputation. Getting an in-depth understanding of how psychological input is experienced and what aspects of the support provided are helpful or unhelpful can lead to further developments to future support provided. Thus, the current study sought to address the research question 'What are the experiences of people who had

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received formal psychological support following lower limb amputation?’ and to make recommendations for improving this.

### **Method**

#### ***Design***

This study was concerned with prioritising the first-person perspectives and experiences of people with lower limb amputation (LLA) who had received psychological support for this, therefore a qualitative approach to data collection and analysis was adopted. Semi-structured interviews were conducted, and the data was analysed using interpretative phenomenological analysis (IPA) [25]. IPA is a research methodology based on the philosophical principles of phenomenology (the study of lived experience), hermeneutics (the interpretation of the experience), and idiography (the detailed analysis of individual accounts) [25]. Therefore, IPA was chosen as it facilitates the exploration of participants’ meaning-making regarding their experiences.

#### ***Ethical Approval***

Ethical approval was granted by the Lancaster University Faculty of Health and Medicine ethics committee (reference number FHM-2022-0645-RECR-2). All procedures described herein were part of this approval, including verbal consent (in place of written consent) and the videorecording of interviews.

#### ***Sampling and Participants***

IPA uses small, homogeneous samples that allow for the identification of convergent and divergent accounts within and across well-defined samples [26, 27]. Small sample sizes

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allow for an in-depth analysis of data, so that the detail of each individual case can be explored and interpreted [27].

Inclusion criteria for the study were individuals above 18 years of age who had experienced amputation of a lower limb and had received formal psychological support (that is, from a professional psychology practitioner). Individuals not fluent in English, or who had experienced cognitive impairment impacting their ability to consent, or who were still receiving psychological support, were excluded from the study. The last criterion was put in place to safeguard the therapeutic alliance between participants and their therapists [28]. At the time the study was developed and conducted (the ethics application was submitted in December 2021), the impact of the COVID 19 pandemic and government restrictions meant the usual clinical (the NHS in the UK) and charitable sector recruitment strategies were depleted or absent. Therefore, to ensure adequate recruitment, the study was made open to geographically dispersed participants rather than focussing on the United Kingdom (where the research team was based).

Thirteen individuals completed the 'expression of interest' form of which 8 were excluded (3 did not respond to the interview invitation, 2 were still receiving psychological support and 3 had not received psychological support). In total 5 participants (3 males, 2 females) met the inclusion criteria and completed the interviews. Participants were all white, aged between 38 and 56 years old (mean=46) and had received formal psychological support between less than one month and seven years prior to the interview (four of these received support from a psychologist and one from a counsellor). Two participants had unilateral above knee amputations, one had a unilateral below knee amputation, one had a unilateral through-knee amputation (Gordon, one year following limb reconstruction surgery), and one had bilateral above knee amputations. Four of these amputations related to trauma, one

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participant had an amputation due to cancer. The sample is considered homogenous as all participants had experienced lower limb amputation and all had received psychological support for it. Participant information can be found in table 1.

[INSERT TABLE 1 HERE]

### ***Procedure***

The study was advertised on social media (amputation-focussed Facebook and Reddit groups and via an X, formerly Twitter, account dedicated to the research project). Several amputation charities were approached but did not respond. The advertisement comprised of a poster explaining the purpose of the study, an electronic participant information sheet and an 'expression of interest' form that included demographics and other questions to ensure adherence to the inclusion criteria. Participants were contacted via email to arrange a suitable time and date for the interview. Interviews were conducted remotely between September 2022 and March 2023 via Microsoft Teams and recorded. The limitations that Covid restrictions made in conducting face-to-face interviews, and the targeting of an international sample, made the use of video conferencing software suited for the project. As the interviewer was very familiar with using Microsoft Teams for clinical sessions from the beginning of the Covid-19 pandemic, she felt aware of the advantages and disadvantages of trying to engage people through a screen, and able to use her experience to facilitate safe and meaningful conversations. In place of written consent, verbal consent was requested and videorecorded prior to the commencement of the interview. Interviews were videorecorded using the Teams record and transcription features. Participants had the option to turn their camera off if they preferred. One participant (Daisy) requested this. After the completion of



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interviews participants were emailed a 'debrief sheet' containing information on resources and charities that could be contacted in case of need.

### ***Data collection***

An interview schedule was developed by the first author (RM, a clinical psychologist working in physical health, with no prior experience of conducting qualitative research interviews or working with people who have experienced limb loss) in collaboration with the second and third authors (respectively, LB, a clinical psychologist working within a prosthetic and amputee rehabilitation centre, and CM, an academic health psychologist with specialist knowledge in limb loss and qualitative research methods). Published interview schedules on limb loss were also taken into consideration [e.g., 29, 30]. The aim was to capture participants' meaning making of their experiences of psychological support which was possible through questions such as: 'What aspects of the support you received helped you the most?'. All interviews were conducted by the first author (RM) and lasted between 67 and 98 minutes (mean=83 minutes). The interview schedule is provided in Appendix A.

### ***Data Analysis***

Verbatim interview transcripts were produced using the Teams transcription feature. These were imported into Word documents and manually edited by the first author (RM) to correct errors and formatting, and to take out any identifiers to preserve participants' anonymity. This produced 154 double-spaced pages, or approximately 50,000 words. Participants were given pseudonyms to maintain confidentiality. As described by Smith [31; p.38] analysis aims to 'understand the content and complexity of [...] meanings rather than measure their frequency'; to achieve this, and to provide a fully auditable analysis, the IPA analysis steps described by Murray and Wilde [26] were followed. This involved reading each transcript multiple times, keeping the research question in mind and developing initial

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codes for each transcript. For the first transcript, the first author (RM) and third author (CM) compared independent coding. This facilitated discussion of what and how segments of the interview were interpreted. As a result, modifications were made to the titling of codes. Next, RM grouped these codes into clusters (individual themes) and a narrative summary with a title was written for each. CM then reviewed these narrative summaries and made suggestions for changes to their titling, phrasing and interpretative content. RM then repeated this process for the four remaining interviews. After the process was completed for all transcripts, RM and CM met to identify convergent and divergent information, and to merge the themes identified for each participant into final themes that accommodated the whole sample. These were then reviewed by LB, who made suggestions for changes to phrasing. Excerpts from at least half of the participants that were representative of the interpreted experience were used to evidence each theme, following IPA guidance published by Rose et al. [32]. A detailed audit trail was developed for each transcript. These are available on request. By doing this, Yardley's [33] guidance to committing to transparency, rigour, and sensitivity to context to produce qualitative research of high standard was followed.

### ***Reflexivity***

IPA is a method that employs 'double hermeneutics' as it explores how participants interpret their experiences whilst also acknowledging the role of the researcher in making sense of what participants communicate [34]. It is therefore crucial for the researcher's beliefs, assumptions, and own experiences to be 'bracketed' and for a reflexive position to be adopted so that the influence of these on the analysis remains limited [27]. The first author used a reflective journal throughout the interview and analysis of data stages. To illustrate how reflexivity was engaged in during the project, the following is a distilled synthesis of the first author's (RM, who conducted the interviews and led on the analysis) self-reflexive knowledge generated throughout the research.

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My first contact with the subject of limb difference and rehabilitation was during my training to be a clinical psychologist. Prior to designing the research project in collaboration with a health and clinical psychologist who, respectively, researched and worked clinically with this population, I conducted an (unpublished) literature review (over a 7-month period) on the psychological difficulties experienced following limb loss to familiarise myself with the topic area. Even though I was aware that conducting the review could by no means 'teach me' all I needed to know about limb loss, it made me feel like I had progressed on to a good stage of knowledge and understanding to proceed with my thesis and contact with participants.

After the first interview I came to the realisation that many of the topics participants would refer to were completely unknown to me. For example, some participants started talking about the type of prosthesis they would use, or limb salvage processes they had experienced, areas I was not knowledgeable about. Participants appeared to be aware of this, possibly as my title of 'Trainee' was reflective of the stage I was at in my career as a psychologist, and they would usually elaborate further on matters, such as the time when one of the participants explained that having a through knee amputation meant that the socket used on the prosthesis would be shorter and they would not require a supportive belt. This highlighted further how privileged I felt to be allowed to explore this topic with participants and made me even more passionate about publishing evidence that could be used by myself and other professionals in future clinical practice.

Even though I had not used IPA to analyse data before, I felt a familiarity with the process of interpretation that I believe stemmed from my experiences of using psychological assessment and formulation in clinical settings, processes that also require interpretation and in-depth understanding of others' experiences. Drawing more parallels between IPA and

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clinical practice, as important as it is to be aware of countertransference, the process during which the therapists' own feelings and experiences can influence the therapeutic processes and responses to clients, it is equally important to adopt a reflexive approach whilst using IPA, including attempts to 'bracket' my experiences and assumptions. This activity was aided through the audit processes of analyses described above, which involved the second and third authors discussing my coding and production of themes from the data obtained.

### **Results**

The analysis of the data produced four themes: 1) The need for psychological intervention - denial and acceptance; 2) 'Safe space' - being valued, heard, and validated; 3) The importance of focus, transparency, and specialist knowledge; and 4) The most helpful techniques and approaches.

#### ***Theme 1. The need for psychological intervention - denial and acceptance.***

Under consideration here are the different emotional reactions participants had to lower limb amputation (LLA) and their decisions to seek help. Four participants (all except Melissa) contributed to this theme. For some, their need for psychological support was not obvious to them to begin with and specific circumstances led them to the realisation that they needed help. Jack was involved in a car crash and was in a coma for six weeks. He only learnt that his parents had made the choice to allow for his legs to be amputated a few days after regaining consciousness. A long period of experiencing unexplained physical symptoms of food poisoning led him to the decision to visit a psychologist (participants used the terms

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‘therapist’ and ‘psychologist’ interchangeably) and it was through this that he realised that the trauma of his LLA had not been processed and was now physically manifested:

I then went to see a therapist at that point. And that was when I came to understand how much of the trauma, I had just locked away inside and never addressed and never dealt with, and that through finding that way to live each day and be OK with it... I was just locking away all of that stuff. (Jack)

In Jack’s case, not being aware of his trauma could be attributed to an unconscious decision to ‘push it all away’ in an effort to fight suicidal thoughts that he experienced upon learning that both his legs had been amputated:

So, I made this decision in the hospital very early on that I was going to commit suicide as soon as I was discharged... There was this feeling as if, though I had not died... that person did, if that makes any sense? And that everything that I had done in my life up until that point had been a waste.  
(Jack)

The decision to take his life changed when he found out how many people had been involved in saving him the day of the car crash, something that possibly led him to fight suicidal thoughts and suppress any negative feelings, ‘converting’ his emotions to feelings of gratitude to those who saved him:

But then, when I learned how I was rescued and what went into keeping my life, preserving my life, I realized that suicide was not an option. (Jack)

The need for psychological support to deal with the trauma of limb loss was also initially not consciously experienced by Gordon, who described how filling in a questionnaire for the litigation taking place for his limb loss triggered the initial feelings of grief as he

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realised that he had not physically progressed since his accident. Gordon, maintaining an identity of strength and resilience, having served in the US Air Force for 21 years, was not prepared for the emotional impact of limb loss. The lack of communication by his health care professionals about psychological difficulties exacerbated the grieving period even further:

And as I was answering all these questions, I realized that I wasn't any further than I was two years before... and that's what kicked it off... as I was feeling that in those few moments... just hurled me into that long period of grieving.  
(Gordon)

“Hey, I know you’re feeling great, but let's just... keep in touch because what's common is people have this cycle of coming to realization of your... you know... the lasting impact of your trauma”. That would’ve probably been pretty good. (Gordon)

Arguably, participants were experiencing denial around what was happening at the time, which at the very beginning served as a protective mechanism. For Daisy, whose LLA came after falling off the last step of a restaurant escalator, initial feelings of denial about a potential amputation meant that she rejected the support initially offered:

...they come in pretty soon after your surgery to kind of give you a pep talk... about how your life is gonna change... And I remember whenever they came in for the first time, I was just like “Get out. I don't wanna talk to you. Get out”. And that's totally not like me. Like, I don't think I've ever told anyone to get out, like in my whole life. But I just remember I was like, “I just don't accept it”. (Daisy)

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Despite this, feelings of hopelessness and the realisation that her life had changed forever, eventually led her to seeking help:

And just all of those negative feelings, like worthlessness, depression, it was just getting to where like it was too hard, and I just knew that if I didn't reach out and do something that I was just gonna be stuck like that forever... So that's what drove me to speak to someone. (Daisy)

Contrary to the experiences described above, Robert, initially felt that he was not in need of psychological support. Being shot in the leg and having low chances of survival led to him feeling gratitude for being alive, something that was responsible to his quick adjustment to a new normal:

I was mainly just relieved to be alive. I was... really cutting corners there. I mean, it was less than a minute from bleeding out, so quite happy... and I knew how serious it was when it happened as well. I mean, you could see that, or could tell it hit my femoral artery and I know how bad that is... Properly waking up after surgery and everything... mostly felt relief. (Robert)

In addition to this, through Robert's narrative it became apparent that the feeling of not needing psychological support was also stemming from his effort to defend an able-bodied identity. For him, accepting that psychological support would be needed could potentially reinforce perceptions of being vulnerable or a "victim", which he did not want to be portrayed as:

You're seen more as a victim of something bad that has happened to you... And I didn't really enjoy that very much. That sucked. (Robert)

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The complexity of feelings that can arise when deciding to accept psychological help is very evident through Robert's narrative as the doubt of his quick adjustment being 'the right way' eventually led him to the decision to speak to a psychologist:

I felt like "I feel OK"... I mean... "I don't feel any real pressing need to do it, but is that true? Am I fooling myself here? Should I just give this a chance? And maybe I get a change to perspective, or both in a positive or a negative way? Or just am I missing out on something?" So, I thought, "Yeah, sure, I should give this a try just to see what it is". (Robert)

### ***Theme 2. 'Safe space' - being valued, heard, and validated.***

The importance of a 'safe space' in therapy was highlighted by three participants (Robert, Daisy, Melissa). Whilst definitions of what felt 'safe' were different, all participants appeared to value having someone to listen to their difficulties. For Daisy and Melissa, their psychologist and counsellor were able to offer a 'listening ear' to difficulties that were not shared with family and friends. Redirecting conversations when needed was also raised as a helpful technique as intense emotions would at times lead participants to "spiral" down in thoughts and emotions about things not directly related to the impact of limb loss:

So, for example if you say certain things to members of your family, they will try and make you feel better or they will not wanna hear it, so you might not wanna mention it. (Melissa)

...the first thing that I appreciated working with her was that she let me have that space to just literally say "this sucks". I had the space to just whine about it and just talk about how hard it is and just kind of the things that you don't



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really let your friends and family know because you wanna stay positive...

So, it was really nice to be able to kind of get those negative feelings off my chest. (Daisy)

...being able to interject herself into my stream of thought when she could tell that I was kind of almost being manic or just kind of like I said before, like spiralling. So... she was really good at redirecting me and taking back control of the session while also... just making me feel heard. (Daisy)

For Robert, who attended three sessions with his psychologist in total, receiving the validation that his quick adjustment and the lack of need for long-term input were 'normal' provided a sense of relief:

...like "I don't really see this as fruitful, and I have a pretty positive, well positive, or neutral outlook on the whole thing. This feels like a new normal"... And he confirmed that... "That's a very valid opinion, but again, we're here if you need"...Relief, simply... (Robert)

A sense of flexibility, safety and of lack of pressure is evident through Robert's narrative as his psychologist offered the validation he needed, but also remained available for future help. Not being pressured to 'fit in a box' and hit specific targets was also shared by Melissa who experienced a hard time during group physiotherapy when having to 'compete' with others who experienced different types of limb loss. A sense of lack of safety is apparent from Melissa's description of what was happening in the physiotherapy sessions as the pressure to progress at the same speed as others was put on her, giving her no control over the pace of her progress. Having this counteracted by the way she worked with her counsellor meant that Melissa was able to build a therapeutic relationship with them that was not possible with other members of her healthcare team:

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And I remember thinking, “that's ridiculous”. Like, “we're all completely different. Some of us have had cancer... some people have had burns and accidents”. And also, there are a lot of, I don't want to call them... kind of loud, confident guys that had lost their limbs through car accidents or motorbike accidents and I think for some people that would have been great, that kind of camaraderie that, you know, all egging people on. But I was a relatively like quiet... I was kind of like “I don't want you to egg me on. I just want to learn how to do this”. (Melissa)

It felt very safe. That's what I'd say they did. They made it feel very safe and they took the pressure off. So, a lot of rehab is pressure. “You should be doing this... You need to walk faster”. So, in lots of ways, she made me feel under less pressure. She gave me that space to be able to just say, “Oh, God, this is going on”. And I don't necessarily think I have said some of the stuff to the physios or the OT that I would have said to her. (Melissa)

The strength of the therapeutic alliance and safety in the sessions was also raised by Daisy but through a different process, a more personal one. When missing sessions and not rearranging, Daisy's psychologist would call her, something that was interpreted by her as genuine concern and care:

If there were times when she hadn't heard from me in a little while, like say I had cancelled our appointment, but I didn't follow up to make another appointment, she would proactively reach out to me, and I didn't feel like it was in a way that a doctor would, to gain business. It wasn't like the sales kind of a thing... I felt that she was genuinely concerned and wanted to hear back from me. (Daisy)

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Reaching out to her when she had not made contact meant that Daisy, who had been struggling with feeling like a burden on others, was able to reclaim her value as an individual and feel “wanted” when possibly other relationships around her had left her feeling like she was managing her limb loss “alone”:

And like a problem that I struggle with is, I feel like I'm the burden sometimes, especially now that I do need more help with stuff... I feel like I'm a burden and that even applies to like medical providers. So, it was nice to hear from her that I was, like, wanted and she cared for me as a professional... The advantages are that you're not suffering alone. (Daisy)

### ***Theme 3 - The importance of focus, transparency, and specialist knowledge.***

Four participants (Jack, Gordon, Melissa, Daisy) contributed to this theme, in which the importance of the focus of sessions, transparent communication and specialist knowledge of the mental health professionals was stressed. Gordon and Daisy both shared a feeling of disappointment with the lack of focus in their sessions. Not having collaboratively decided on a goal and not setting agendas at the beginning of sessions left participants feeling unsure regarding the purpose of the sessions and ultimately led to disengagement:

The focus was just not focused at all. It was kind of all over the place from different things to different needs that seem to arise during that time.

(Gordon)

Yeah, I guess the areas of treatment... If you wanna say... that I was a little disappointed in, is that we never came up with a treatment goal or at least that wasn't something that we came up with together. She may have had one for

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me, but I just wasn't aware of what it was. And that was part of the reason why things just kind of like tapered off other than the fact that I was feeling better, but I didn't kind of see where we were going at that point. (Daisy)

Whilst it can be argued that the specific psychologists had neglected the important step of agenda setting and collaborative therapy planning, further conversations with participants revealed that possibly a lack of transparency and open communication was the actual problem. This is evident from the following data excerpt in which Daisy describes engaging in an assessment process. However, this was not explained to her. Because of this, she felt that the questions asked at the initial stages of therapy were “basic” and not “directly related” to the amputation:

So, our first couple of sessions weren't, I felt, directly related to my amputation, but some of the questions that she was asking were, I just wanna say pretty basic questions not to skip over, but were pretty basic. So just, “How do you feel now?”. (Daisy)

The lack of transparency was brought up again by Melissa, who started questioning the reasons behind why she was seen by a counsellor and not another professional. Despite the counselling being offered by the same service where she was attending her physiotherapy sessions, the reasons behind the choice of the professional were not explained and this contributed to her starting to lose trust in the service she was offered as a whole. Whilst it is possible that there was no other choice for support since it was counsellors that were employed by the service, it would have been important to offer Melissa the option to be supported by other professionals through other providers, giving her more control over the care she received:

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Like thinking about this out loud, why is counselling offered and not for example, CBT or [a] clinical psychologist... like who has decided that counselling is what's required when you lose a limb? (Melissa)

And I even now I don't know how transparent it is, so if you don't access counselling, would you get certain limbs if you do... so in in some ways I felt like it was non-judgmental and confidential, but I actually don't know if it was. (Melissa)

Trusting the mental health professionals who offer psychological support is extremely important and that trust can either be built or broken by multiple factors, one of which is how much specialist knowledge and understanding of the problem they have. This is evident through Jack's narrative who after completing EMDR therapy for limb loss was referred to a social worker for support with other difficulties. He felt this professional had no understanding of the impact LLA had on all aspects of his life, irrespective of the fact that their sessions focused on other problems:

...if you don't have the right therapist, I believe that there is potential harm that can happen to oneself, one's relationships. So, it's very important to make certain that the therapist that you were seeing has an understanding of what your needs are...And I went to this person that, you know, didn't really have any understanding of limb loss and how that was informing everything. (Jack)

The expertise of the professional was also brought up by Gordon, who felt disappointed with the lack of a clear therapeutic approach, which for him meant that his clinical psychologist was not equipped enough to help him efficiently. Since they started their work together during the litigation process, he expected that he would have been warned

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about the potential “grieving” that could arise later on, but it seemed like his psychologist did not have that knowledge or understanding:

It was actually more like a sort of a counselling session, which I would not expect from a clinical psychologist. I'd expect them to maybe do some therapy which I know is different but... Yeah, it was just kind of weird... You know, “Open up some CBT”... “Do whatever you know”. I mean that could have been helpful anyway, but... Yeah, just didn't... (Gordon)

I guess you can't just say “every single person will hit to your mark and that will happen, but it's very typical, you see”. So, to have a clinical psychologist that understood that, and everything, would have been really great. (Gordon)

Contrary to those experiences, Melissa felt that her therapist was “tuned in” and had the knowledge and skills to understand what the priorities were for her, ultimately making her sessions person-centred:

I think counselling helped me to think, “Well, what is it that's important to me?” And I don't care whether I'm using a crutch or a stick... So I think it was what I needed, and she was very sensitive and sort of tuned into my needs. (Melissa)

Having the right professional with the right experience and knowledge came hand in hand with receiving support at the right time, which for participants was as early as possible. Receiving support early would potentially mean better adjustment and preparation for the psychological difficulties that would follow:

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I would've definitely got her on board sooner and we would have talked about the potential for that sudden feeling of loss and that was what would have been dealt with before it hit. (Gordon)

Yeah, going all the way back to the beginning, I wish that had been something that was just mandatory before I even left the hospital. I feel like there was a huge mistake made there and that that my adjustment would have been a lot more effective in those early days. (Jack)

### ***Theme 4 - The most helpful techniques and approaches***

Three of the participants (Daisy, Jack, Melissa) spoke about specific techniques and approaches they found helpful in therapy. For Daisy and Jack, the decision on which approach would be the most beneficial to them entailed a deeper understanding of the underlying emotions that led to them experiencing difficulties in adjusting to limb loss. Whilst participants were not openly told that this was part of the formulation (a summary of a person's difficulties and the possible causes of these), they both were very aware of the triggering emotions they were experiencing. For Daisy, a sense of guilt at the thought that she was responsible for her accident led to her psychologist encouraging self-compassion, whilst for Jack, determining that the underlying cause was anxiety led to the choice of EMDR:

Because one thing I struggled with is that my amputation and the accident was like 100% my fault... I struggled with a lot of guilt... because I ruined my own life... And if I was feeling sad or if I wasn't able to do something, whatever it is, I just always thought that it's because I didn't measure up, like I wasn't good enough. And so, she really instilled that I need to be

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kinder to myself and treat myself like I would anybody else. And so that was one thing that she would have me do especially is talk to like younger [name]. As silly as that sounds. But she would say, you know, "Talk to your younger self, you're automatically gonna be more kind". (Daisy)

...initially the goal was to find out... to try to diagnose why I was having those physical symptoms that we couldn't find a physically medical diagnosis for, so that was the initial goal and then the EMDR treatment was once we determined that it was an anxiety-based issue. (Jack)

Both approaches were very helpful to participants as they felt that this type of work succeeded in reducing the behaviours and feelings that were precipitating their difficulties. An additional gain aside from the relief they both experienced was an understanding of the reasons behind their difficulties, something that is evident by the way they were both able to articulate in detail the benefits and understanding they gained:

And so, the way that we addressed that was through a process called EMDR which led to me understanding and basically unlocking that very first traumatic memory in my life, which stems all the way back to when I was very young and suffered food poisoning... Now anytime my anxiety reached that point where it was boiling over, those symptoms were coming all the way back from when I was five years old and, so it was through doing that in the MDR process that we were able to finally treat that. And I would love to say that it was 100% successful, it was absolutely successful. (Jack)

Biggest change is the fact that she was able to help to change my pattern of thought. She has made me a lot more aware of how I'm speaking to myself. My internal dialogue wasn't positive and so the biggest take away is that I've learned



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to recognize whenever I'm having like that moment of negative self-talk and then I'm able to turn it around by realistically kind of praising myself for the things that I have done and accomplishments that mean thanks to me personally, so that would be the biggest difference. (Daisy)

From the participants' narratives in the previous theme, it became apparent that the complexity of difficulties experienced require a mental health professional who is very skilled and knowledgeable around limb loss. This was extended further in this theme through Daisy's account which highlighted the importance of a psychologist knowing that the help they can provide can be useful but also acknowledging the contribution of experts by experience that can aid normalisation following limb loss. Signposting Daisy to resources and encouraging her to contact with other people with limb loss, from whom she could learn things she wouldn't be able to learn in sessions, led to her feeling more supported and gave her a new community to belong to:

One of the things that I don't know if this is a therapy technique, but she encouraged me to reach out to other people like through support groups online or in person to make me feel more normalized and to see that I'm not the only person like struggling with my issue or my amputation... That was beneficial because I felt like, you know, I got a lot of my questions answered and then I was also able to help other people in small ways by answering like their questions. So that was beneficial...I feel as weird as this sounds... I have a new kind of community to fit in, and that community is of disabled people, and so a strange feeling that I get is whenever I see other people that have prosthetics especially... I wanna wave to them and talk to them about their experience. So that's kind of something new that I have in my life. (Daisy).

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A contemporary topic, the way of attending sessions, was raised by Melissa as an important issue that can support individuals with LLA, given their physical limitations. Attending counselling in person meant long commute hours for Melissa and was something that appears to have impacted on her engagement. Given the rupture in trust between her and the rehabilitation service, it is likely that Melissa was not able to share these difficulties with her provider and explore the possibility of attending sessions remotely:

So, this was face to face and there wasn't an option to have telephone or video counselling. So, I think now it might have carried on for longer if that was an option because I went back to work that was exhausting for an amputee anyway. So, I would have had to travel an hour and a half to see her, and it was highly unlikely... And I definitely think if there would have been an opportunity to continue virtually at that time I would have done, so I think I would have carried on. (Melissa)

## **Discussion**

The aim of the study was to explore and understand the experiences of receiving formal psychological support following lower limb amputation (LLA), addressing a present gap in research literature.

The first theme highlighted the complexity of realising the need for psychological support, with some participants experiencing denial of the psychological impact of LLA and others accepting what had happened but questioning whether their reaction was “valid”. This echoes a review by Kortte and Wegener [35; p.187] on denial of illness in medical rehabilitation populations, in which they argue that ‘although denial may serve a

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psychologically protective function, it may also impede participation in rehabilitation activities.’ The current findings support the comparison made between limb loss and the loss of a loved one [36] and the Five Stages of Grief theory as experiencing denial is usually the first response to a loss, and acceptance the final one [37]. Based on the theory, not all individuals will experience all of them necessarily and this was confirmed in the study as one of the participants described that being grateful to be alive led to the instant acceptance of limb loss. This can be further understood through consideration of theory regarding transitions and processes for persons with chronic illness and disability (CID), where this has focussed on psychosocial adaptation [38]. For example, Livneh’s [39] model of psychosocial adaptation to CID posits a diverse set of antecedents, processes and outcomes that incorporate biological, psychological, sociocultural and environmental factors. The importance of these facets can be seen in participants’ accounts in the present study, relating to their individual responses to the physical changes brought by amputation.

Where there was a period between the antecedents of limb loss and the amputation, not being prepared for the psychological impact of LLA caused additional difficulties in the already challenging process of experienced grief. As one of the participants (Gordon) shared, he would have wanted to be told by the professionals around him that this was something that he could experience. Even when the amputation was sudden, a lack of early psychological intervention was mourned (as in Jack’s case). The importance of pre-operative preparedness has been stressed for some time [11]. However, it appears that neither this, nor early psychological intervention for immediate traumatic amputations, always happen in all services.

The second theme highlighted the importance of therapeutic alliance in therapy, which was experienced by participants through feeling heard, valued, and validated, whilst the third

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theme captured participants' needs for focus, transparency, and specialist knowledge. These findings accord with the Common Factors theory [40, 41] which suggests different psychological approaches have common elements that support psychological progress. Therapeutic alliance, reassurance, therapist's expertise, trust, warmth, genuineness, and structure are common factors that have been found to be vital for successful outcomes in therapy [42].

The significance of a therapist who offers the space for clients to be heard but is also able to redirect conversations (theme 2) can also be found in the list of most helpful processes in psychotherapy devised by Levitt et al. [43]. In their list, one of the most helpful therapist characteristics included someone that is sufficiently caring but who also can support the client to remain focused in the topic discussed.

As shared by participants in theme 3, the lack of transparency about what stages therapy entailed, and of an end goal and measurable progress, led to disengagement. The importance of openly talking about therapy goals and expectations, as well as measuring progress towards short-term and long-term goals, have been highlighted in published literature as important strategies that prevent premature termination [44]. Goal setting is an important part of self-management programmes in rehabilitation following limb loss. Coffey and colleagues [45, 46] have highlighted the role of tenacious goal pursuit (TGP), or striving towards goals, following amputation in speeding up progress in the attainment of valued goals and the experience of positive affect. They also suggest that when goals cannot be achieved through a strategy of TGP, then being able to disengage from or adjust one's goals (flexible goal attainment, or FGA) is likely to buffer against negative affect that might otherwise ensue from disruptions in goal attainment. This leads to a recommendation that those with limb loss should be encouraged to strive "towards attainable goals" and be

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provided with support "in adjusting or dissolving commitment to goals no longer feasible [45].

The current study extends the importance of goal-related strategies by showcasing that lack of them not only impacts engagement with therapy, but can affect the overall trust and therapeutic relationship with other aspects of care provided. Since a holistic approach is required for the support of people with limb loss [8], adopting a transparent and goal led approach in psychotherapy can potentially influence the progress and effectiveness of other treatments received with a rehabilitation programme.

The final theme presented the clinical approaches and techniques that were found to be the most helpful to participants. Participants spoke about the therapy approaches that helped them manage emotional difficulties, stressing the importance of formulation (a summary of a person's difficulties and the possible causes of these) driven interventions. For one participant, work with their psychologist included self-compassion to fight against guilt and guidance to contact experts by experience to aid normalisation. Self-compassion training has been found to improve quality of life for men with amputations as the result of land-mine explosions [47], and peer support, both on a one-to-one and group level, has been shown to be beneficial for individuals with limb loss [48]. For another participant, EMDR was considered the right approach to address a physical manifestation of anxiety, the effectiveness of which has already been shown when it comes to management and reduction of phantom limb pain [21].

The current study has provided novel evidence regarding the importance of offering remote access to therapy for those with LLA. As shared by one participant, lack of access to online therapy meant that termination of sessions was the only option as travelling to a rehabilitation centre, whilst facing mobility difficulties was extremely difficult.

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### ***Clinical Implications***

Five areas of important clinical implications have been identified through the results of the current study. These include: 1) the availability of psychological support throughout rehabilitation; 2) the benefit of transparency and collaborative goal setting in sessions; 3) the importance of specific knowledge and psychologists' expertise in the field of limb loss; 4) formulation driven treatment; and 5) remote access to therapy.

As proposed by Butler et al. [11] supporting individuals with planned amputations psychologically before the limb removal takes place is an essential step that can support with psychological adjustment following surgery. Their recommendation that this can be done by the family physician is reflective of the way health care was provided in the past. With the current evidence about the importance of MDT approaches for the support of people with limb loss [7, 8], pre-operative and post-operative support can be provided by qualified psychologist, who can enhance psychological preparation and adjustment to all facets of LLA.

The Pluralistic Framework [49] is an approach that recommends integrated goal setting, irrespective of the therapeutic approach used, as a vital part of psychotherapy and counselling. Goal-focused sessions, reflective of the needs and wants of clients, during which progress is regularly monitored, is the proposed way to increasing positive therapeutic outcomes. Especially for individuals with limb loss, clear psychological goal setting can be very useful when other competing goals for physical rehabilitation may be prioritised by other health professionals for the overall improvement of quality of life [45, 46]. In addition to this, transparency regarding the therapy stages, decisions made, and models used can help clients de-mystify the process and increase their trust in mental health professionals [50].

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Psychological expertise is a concept that has been debated, and different parameters, such as the skill of the therapist and the years of experience and credentials, amongst others, can be used as defining competency criteria [51]. The current study highlights the importance of knowledge around the psychological impact of limb loss by supporting professionals, something that could be achieved within clinical psychology training or through the continuing professional development curriculum that covers topics of physical disability.

The use of formulation for the understanding of psychological difficulties is an approach that has been used in recent years instead of psychiatric diagnosis [52]. Using the knowledge that comes from understanding the deeper meanings and processes that cause and maintain psychological distress, can lead to the selection of the most appropriate psychological approaches [53], which in this case can be best suited to relieving distress caused by limb loss. As stated by participants, different individuals needed different approaches and future practice needs to incorporate formulation driven interventions that will best support individual needs.

Remote access to therapy has increased since the COVID-19 pandemic and evidence suggests that its efficacy is comparable to in-person treatment [54]. For one participant in this study, only having the option of in person therapy contributed to disengagement. As current technological advances make remote access possible, the option to attend to psychotherapy remotely needs to be offered to clients, especially since the population to be supported experiences mobility difficulties making access to in person therapy more challenging.

### ***Strengths and Limitations***

This is the first study to explore the experiences of receiving psychological support for people with lower limb amputation (LLA). It identifies important helpful and hindering aspects of the support received and from these recommendations have been made on how to

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improve psychological support that is offered to this population. One limitation of the study is that in obtaining a sample of 5 participants from 3 different countries, a specific focus on service provision and potential improvements, which may be impacted considerably by a country's healthcare system, was not possible. It is also acknowledged that not all participants had the same causes of amputation and different amounts of time had passed for participants since their limb loss at the time of interview, which limit sample homogeneity. In addition, while the present study concentrates on the experiences of participants with LLA due to trauma, and in one case cancer, the findings cannot be extrapolated with certainty to other limb loss populations (such as those with upper limb loss or who have lost a limb to complications from diabetes or peripheral arterial disease). Finally, the manner in which the study was advertised and allowed people to participate arguably biased the sample towards having a level of technological knowledge of computers and software which may mean those who took part may also differ in other ways to those without this knowledge.

### ***Future Research***

As indicated above, further research on the experiences of receiving psychological support following limb loss for participants with different types of amputations and underlying causes would be beneficial. For example, most amputations in the West occur in older people as the result of complications from vascular diseases. Therefore, achieving a better understanding of how to address psychological difficulties for this group would be advantageous.

In the present study, all participants were white and resided in developed countries. Although generalisation of results is not an IPA aim for a single study, having studies using alternative samples, such as different limb loss types and causes, other ethnic groups and those from different cultural backgrounds, would help identify the strength of, and variation



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in, the findings presented here in different contexts and allow for more understanding of how to improve psychological support for all people with limb loss. Future research could also adopt a longitudinal approach to investigate where positive results remain over time or whether psychological input is required for a longer period.

The study highlighted the importance of specialist knowledge and understanding of psychologists and other mental health professionals when supporting individuals with lower limb amputation (LLA). Future research could focus on the experiences of providing psychological support to individuals with limb loss by mental health professionals, something that could inform training needs.

### ***Conclusion***

The present study identified novel findings regarding the experiences of formal psychological support for people with lower limb amputation (LLA). The exploration and interpretation of participants' experiences and meaning-making has identified what people with LLA find helpful and unhelpful, which has been used here to make recommendations regarding future psychological support for this population. It is hoped that the clinical implications of the current research will be used to improve the psychological care provided to people with limb loss, through the work of psychologists, other allied mental health professionals and non-mental health professionals involved in the general rehabilitation process. Recommendations for future research have also been made, including extending investigation of the same topic to other limb loss populations and examining the delivery of formal psychological support to people with limb loss have. Such work has the potential to increase the knowledge base surrounding the provision of psychological care following amputation and lead to better rehabilitation outcomes.

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### **Disclosure of interest**

The authors declare that there are no interests to declare.

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### **References**

1. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: A review. *Disabil Rehabil*, 2004; 26(14-15): 837-850.
2. Turner, A.P., Meites TM, Williams RM, et al. Suicidal ideation among individuals with dysvascular lower extremity amputation. *Arch Phys Med Rehabil*, 2015; 96(8): 1404-1410.
3. Ward Khan, Y, O'Keeffe F, Nolan M, et al. "Not a whole woman": an interpretative phenomenological analysis of the lived experience of women's body image and sexuality following amputation. *Disabil Rehabil*, 2021; 43(2): 251-261.
4. Mathias, Z, Harcourt, D. Dating and intimate relationships of women with below-knee amputation: an exploratory study. *Disabil Rehabil*, 2014; 36(5): 395-402.
5. Senra H, Oliveira RA, Leal I, et al. Beyond the body image: a qualitative study on how adults experience lower limb amputation. *Clin Rehabil*, 2012; 26(2): 180-191.
6. Burger H, Marinček Č. Return to work after lower limb amputation. *Disabil Rehabil*, 2007; 29(17): 1323-1329.
7. Del Piero, LB, Williams RM, Mamiya K, et al. The role of interprofessional teams in the biopsychosocial management of limb loss. *Curr Phys Med Rehabil Rep*, 2020; 8(4): 396-404.
8. Keszler, MS, Wright KS, Miranda A, et al. Multidisciplinary amputation team management of individuals with limb loss. *Curr Phys Med Rehabil Rep*, 2020; 8(3): 118-126.
9. British Society of Rehabilitation Medicine [Internet]. Amputee and Prosthetic Rehabilitation - Standards and Guidelines; 3rd Edition 2018 [cited 07 May 2023]. Available from: <https://www.bsrn.org.uk/downloads/prosthetic-amputeerehabilitation-standards-guidelines-3rdedition-webversion.pdf>
10. Bennett J. Limb loss: The unspoken psychological aspect. *J Vasc Nurs*, 2016; 34(4): 128-130.

## **RUNNING HEAD: Psychological support following amputation**

11. Butler DJ, Turkal NW, Seidl JJ. Amputation: preoperative psychological preparation. *J Am Board Fam Pract*, 1992; 5(1): 69-73.
12. Wegener ST, Mackenzie EJ, Ephraim P, et al. Self-management improves outcomes in persons with limb loss. *Arch Phys Med Rehabil*. 2009;90(3):373–380.
13. Turner AP, Wegener ST, Williams RM. Vetpals Study Group, et al. Self-management to improve function after amputation: a randomized controlled trial of the VETPALS intervention. *Arch Phys Med Rehabil*. 2021;102(7):1274–1282.
14. Cain JJ, Ignaszewski D, Blymire C. Living well after amputation: lessons in innovation, peer support, and health policy. *Tech Orthop*. 2021;36(4):360–366.
15. Richardson LJ, Molyneaux V, Murray CD. Being a peer support mentor for individuals who have had a lower limb amputation: an interpretative phenomenological analysis. *Disabil Rehabil*, 2020; 42(26): 3850-3857.
16. Desmond DM, Coffey L, Gallagher P, et al. Limb amputation. In *The Oxford Handbook of Rehabilitation Psychology*. 2012, Oxford University Press.
17. Sharma R, Singh D, Sharma S. Efficacy of cognitive behaviour therapy and quality of life in the amputees. *International Journal of Indian Psychology*, 2016; 3(3): 151-166.
18. Alavi M, Molavi, H, Molavi R. The impact of cognitive behavioral therapy on self-esteem and quality of life of hospitalized amputee elderly patients. *Nursing and Midwifery Studies*, 2017; 6(4) 162-167.
19. Pereira L, Noronha D, Bishop A. Cognitive behavioral therapy for postamputation chronic pain: a case report. *Cognitive and Behavioral practice*, 2023; 30(1): 160-168.
20. Moura VL, Faurot KR, Gaylord SA, et al. Mind-body interventions for treatment of phantom limb pain in persons with amputation. *Am J Phys Med Rehabil*, 2012; 91(8): 701-
21. Schneider J, Hofmann A, Rost C, et al. EMDR in the treatment of chronic phantom limb pain. *Pain Med*, 2008; 9(1): 76-82.

## **RUNNING HEAD: Psychological support following amputation**

22. Jo, SH, Kang SH, Seo WS, et al. Psychiatric understanding and treatment of patients with amputations. *Yeungnam University Journal of Medicine*, 2021; 38(3): 194-201.
23. Price E, Fisher K. How does counseling help people with amputation? *Journal of Prosthetics and Orthotics*, 2002; 14: 102-106.
24. Wald J, Alvaro R. Psychological factors in work-related amputation: considerations for rehabilitation counselors. *The Journal of Rehabilitation*, 2004; 70(4): 6-15.
25. Smith JA, Fieldsend M. Interpretative phenomenological analysis. In PM Camic (Ed.), *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design* 2nd ed. 2021, American Psychological Association: Washington, DC, US. p. 147-166.
26. Murray CD, Wilde DJ. Thinking about, doing and writing up research using interpretative phenomenological analysis. In C Walshe, S Brearley (Eds.) *Handbook of Theory and Methods in Applied Health Research*. 2020. Edward Elgar Publishing: Chichester. p. 140-166.
27. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. 2nd edition. Core new edition. ed. 2022, Thousand Oaks.
28. Guxholli A, Voutilainen L, Peräkylä A. Safeguarding the therapeutic alliance: managing disaffiliation in the course of work with psychotherapeutic projects. *Front. Psychol.* 11:596972.
29. Murray CD. The social meanings of prosthesis use. *Journal of Health Psychology*, 2005; 10(3), 425-441.
30. Murray, CD. Being like everybody else: the personal meanings of being a prosthesis user. *Disabil Rehabil*, 2009; 31(7): 573-581.
31. Smith JA. *Qualitative Psychology: A Practical Guide to Research Methods*. 3rd edition. 2015. Sage: London.

## **RUNNING HEAD: Psychological support following amputation**

32. Rose J, Malik K, Hirata E, et al. Is it possible to use interpretative phenomenological analysis in research with people who have intellectual disabilities? *Journal of Applied Research in Intellectual Disabilities*, 2019; 32(5), 1007-1017.
33. Yardley L. Dilemmas in qualitative health research. *Psychology & Health*, 2000; 15(2): 215-228.
34. Larkin M, Watts S, Clifton E. Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 2006; 3(2): 102-120.
35. Kortte KB, Wegener ST. Denial of illness in medical rehabilitation populations: theory, research, and definition. *Rehabilitation Psychology*, 2004; 49(3): 187-199.
36. Parkes, CM. Psycho-social transitions: comparison between reactions to loss of a limb and loss of a spouse. *Br J Psychiatry*, 1975; 127(3): 204-210.
37. Kübler-Ross E, Kessler D. The five stages of grief. In *Library of Congress Catalog in Publication Data (Ed.), On grief and grieving*. 2009. (pp. 7-30).
38. Bishop MM. Quality of life and psychosocial adaptation to chronic illness and disability: preliminary analysis of a conceptual and theoretical analysis. *Rehabil Counsel Bullet*. 2005;48(4):219–231
39. Livneh H. Psychosocial adaptation to chronic illness and disability: an updated and expanded conceptual framework. *Rehabil Counsel Bullet*. 2022;65(3):171–184.
40. Rosenzweig S. Some implicit common factors in diverse methods of psychotherapy. *Journal of Psychotherapy Integration*, 2002; 12(1): 5-9.
41. Wampold BE, Imel ZE. *The Great Psychotherapy Debate: The Evidence for What Makes Psychotherapy Work*. 2015. New York, NY: Taylor & Francis.
42. Bergin AE, Garfield SL. *Handbook of Psychotherapy and Behavior Change*. 4th ed. ed. 1994. New York: J. Wiley.

## **RUNNING HEAD: Psychological support following amputation**

43. Levitt H, Butler M, Hill T. What clients find helpful in psychotherapy: developing principles for facilitating moment-to-moment change. *Journal of Counseling Psychology*, 2006; 53: 314-324.
44. Swift JK, Greenberg RP, Whipple JL, et al. Practice recommendations for reducing premature termination in therapy. *Professional Psychology: Research and Practice*, 2012; 43(4), 379-387.
45. Coffey L, Gallagher P, Desmond D. Goal pursuit and goal adjustment as predictors of disability and quality of life among individuals with a lower limb amputation: a prospective study. *Arch Phys Med Rehabil*. 2014;95(2):244–252.
46. Coffey L, Gallagher P, Desmond D, et al. Goal pursuit, goal adjustment, and affective well-being following lower limb amputation. *Br J Health Psychol*. 2014;19(2):409–424.
47. Ghazanfari F, Shafiei M. Effectiveness of self-compassion training on dysfunctional attitudes and quality of life in mine explosion amputees. *Iranian Journal of War & Public Health*, 2017; 9(1):41-46.
48. Reichmann JP, Bartman KR. An integrative review of peer support for patients undergoing major limb amputation. *Journal of Vascular Nursing*, 2018; 36(1): 34-39.
49. Cooper M, McLeod J. A pluralistic framework for counselling and psychotherapy: Implications for research. *Counselling and Psychotherapy Research*, 2007; 7(3): 135-143.
50. Turns B, Springer PR, Sibley DS. Removing the “mystery” in therapy: transparency as a continuous intervention in family psychotherapy. *Journal of Family Psychotherapy*, 2019; 30(1): 1-19.
51. Hill CE, Spiegel SB, Hoffman MA, et al. Therapist expertise in psychotherapy revisited. *The Counseling Psychologist*, 2017; 45(1), 7-53.
52. Johnstone L. psychological formulation as an alternative to psychiatric diagnosis. *The Journal of Humanistic Psychology*, 2018; 58(1): 30-46.

## **RUNNING HEAD: Psychological support following amputation**

53. Dawson DL, Moghaddam NG. Formulation in action : applying psychological theory to clinical practice. 2015, Warsaw, Poland: De Gruyter Open Poland.

54. Stefan R, Mantl G, Höfner C, et al. Remote psychotherapy during the COVID-19 pandemic. Experiences with the transition and the therapeutic relationship. A longitudinal mixed-methods study. *Frontiers in Psychology*; 12: 743430.



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**Table 1.** Participant characteristics.

Pseudonym	Age in years	Country of residence	Limb loss type	Limb loss cause	Time since psychological input	Input received	Type of professional
Robert	39	Sweden	Right leg, above knee	Gun shot wound	3 years	3 sessions over 6 weeks	Psychologist
Gordon	56	UK	Right leg, through knee	Bone infection	<1 month	Every two weeks for 18 months	Psychologist
Daisy	38	US	Right leg, below knee	Blood clot after a fall	3 months	Every two weeks for 14 months	Psychologist
Melissa	48	UK	Left leg, above knee	Bone cancer	5 years	Every two weeks for 5 months	Counsellor
Jack	47	US	Bilateral, above knee	Car accident	7 years	Every two weeks for 6 months, then once per	Psychologist

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month for a  
year

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### **Appendix A: Interview Schedule**

#### ***Current situation***

Before commencing the interview, could you briefly tell me a bit about yourself?

Could you please describe the nature of your limb loss?

#### ***Experiences of limb loss***

How long ago did you have this experience?

What were your initial feelings around it?

What is it like for you to live with limb loss now?

Could you please describe what help and support have you received for your limb loss so far?

#### ***Psychological support***

What kind of psychological support have you received?

How long ago was that?

How long did you receive psychological support for / how many sessions have you had?

What led you to seeking psychological support following limb loss?

#### ***Experience of receiving psychological support***

Do you think that the psychological support you received helped you?

What aspects of the support you received helped you the most?

What aspects of the support you received did you find the least helpful?

What aspects of the psychological support you received do you wish were different?

Was there any point you wanted to stop receiving psychological support? If yes, why?

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What do you think were the advantages and disadvantages of receiving psychological support?

Would you recommend it to other people who have experienced limb loss?

Does the psychological support you received still have a positive effect after X amount of time  
/ years?

### **Other**

Is there anything else you would like to share about your experience of receiving psychological support that has not been covered in the questions?

Are there any comments / thoughts you would like to share regarding taking part in this study?