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Doctoral Thesis

Experiences of Limb Difference: Psychological entailments and support

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Thesis Abstract

The current thesis consists of a literature review, an empirical paper, and a critical appraisal of the process undertaken.

The systematic literature review presented thematically the specific areas of limb difference and rehabilitation that have been studied through interpretative phenomenological analysis (IPA). The process followed was similar to that of thematic analysis and four themes were identified: 1) The process of learning, supporting, and alternative ways to receiving help; 2) Physical and psychological adjustment to limb difference; 3) Experiences of using prosthetics; and 4) Experiences of romantic relationships and sexuality. The adherence of the presented studies to IPA guidelines was assessed using a qualitative tool specifically designed for the quality appraisal of IPA studies and studies were given an overall score of ‘Poor’, ‘Acceptable’ or ‘Good’. The findings highlight the experiences of living with limb difference, the support available and the psychological entailments around adjustment, prosthesis use and relationships. Clinical Implications are discussed in the context of improving the rehabilitation offered by psychologists and other professionals. The appraisal of IPA adherence paves the way to completing IPA research of high standard.

The empirical paper explored the experiences of receiving psychological support following limb loss. Semi-structured interviews were conducted with five participants and data was analysed using IPA. Four themes were generated by the data analysis: 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. Clinical implications focused on the ways psychological support is provided.

Finally, the critical appraisal offered an overview of practical, methodological, ethical, and personal reflections on the research process undertaken. The importance of reflexivity and the intricate relationship between being a clinician and a researcher were considered.

Declaration

This thesis comprises research undertaken for the Doctorate in Clinical Psychology at the Division of Health Research University between September 2020 and June 2023. The research presented is my own, except where due reference is made. The research has not been submitted for any other academic award.

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Frist and most importantly, I would like to thank everyone who took part in my study as without their contribution, reflection, openness, and engagement this research would have been an impossible task to complete. It was a privilege to be able to hear the experiences shared and I hope the findings and presentation of the contributions made are able to support others with similar experiences.

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Chapter 1 : Literature Review

The use of interpretative phenomenological analysis in the study of limb difference and rehabilitation: A systematic review and quality appraisal

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Abstract

Purpose: Interpretative phenomenological analysis (IPA), a qualitative research methodology, focuses on the understanding and interpretation of lived experience. The current review had three aims. As a growth in studies using IPA to study disability, such as amputation, has been noted the past few decades, the first aim of the review is to set out the features of IPA that make it suited for the study of limb difference and rehabilitation. Second, to review systematically the available literature on these topics that have used IPA. Third, to identify, for researchers interested in applying IPA to the study of limb difference and rehabilitation, or for evaluating such research, the features of high-quality IPA that they should inculcate in this endeavour.

Materials and methods: A systematic search of four databases identified 26 papers for inclusion. A thematic summary of study findings was conducted, and the quality of the papers was assessed using a previously developed tool for the appraisal of IPA studies.

Results: The analysis produced four themes: 1) The process of learning, supporting and alternative ways to receiving help; 2) Physical and psychological adjustment to limb difference; 3) Experiences of using prosthetics; 4) Experiences of romantic relationships and sexuality. The quality appraisal of the study assessed 12 papers as ‘Poor’, 8 papers as ‘Acceptable’ and 6 papers as ‘Good’.

Conclusion: Familiarisation with the published IPA literature on limb loss and rehabilitation can inform the clinical practice by psychologists and other rehabilitation professionals. Following the quality appraisal process can help in the identification and production of IPA research of high standard.

Key words: interpretative phenomenological analysis, limb loss, amputation, rehabilitation

Introduction

Many people live with acquired limb loss or congenital limb difference and require the support of rehabilitation professionals and services [1,2]. Limb loss, or amputation, refers to the partial or entire surgical removal of an extremity [3], whilst congenital limb difference refers to being born with absent or not fully formed limbs [4]. Causes for amputation vary, with different aetiologies across various regions in the world. In countries such as Canada [5], the United Kingdom (UK) [6], Germany [7] and Bahrain [8] the leading causes of amputation are diabetes and vascular disease. Conversely, trauma is the main reason in countries such as Iran [9] and Nigeria [10]. It is estimated that around 2250 babies are born with congenital limb differences in the US every year, sometimes undetected before birth, that can be caused, amongst other reasons, by specific medication and vascular disruption [11].

Limb loss can result in a variety of physical and psychosocial challenges with significant impact on the day-to-day lives of individuals [12]. Physical difficulties include residual limb and phantom limb pain [13,14], musculoskeletal problems [15], reduced mobility [16] and increased risk of mortality [17,18]. On a social level, limb loss can affect people's ability to return to work [19,20] cause changes in relationships and intimacy [21-23] and increase perceived social stigma [22]. In addition, psychological impact includes depression, anxiety and suicidal ideation [24-27], anger and resentment [28] as well as body image disturbance [24]. Children born with limb difference have also been shown to experience functional limitations to varying degrees and dependence on parents [29]. Some children face stigma, difficulties with school performance and challenging relationships with peers and siblings [29,30].

According to the National Institute for Health and Care Excellence (NICE) [31], a rehabilitation assessment and consultation needs to be provided before limb removal surgeries and rehabilitation including strengthening exercises, pain management, and prosthesis fitting needs to begin promptly after surgery. Following the guidance from the British Society of Rehabilitation Medicine (BSRM) [1], PARCs need to be equipped with multidisciplinary teams including, amongst others, medical consultants, prosthetists, physiotherapists, occupational therapists, psychologists, and podiatrists.

Quantitative research has been used to study many of the aforementioned challenges and to inform the health services involved in the rehabilitation of people with limb difference [32]. From identifying risk factors [33,34] and the different roles they play in male and female populations [35], to learning about self-reported health outcomes [36], and the prevalence of experienced pain [37], quantitative research has offered valuable insights regarding measurable aspects of limb difference. However, quantitative research is limited in providing an understanding of the personal interpretation of the impact of limb difference by the people experiencing it and those around them. This limitation has been addressed, particularly over the last two decades, with a growth in qualitative research which aims to foreground participants' perspectives, experiences and meaning making of living with limb difference [38].

A variety of qualitative research methods have been employed to study limb difference. Thematic analysis has aided an understanding of adjustment to using prosthetics [39], the day-to-day experience of people with an amputation [12], and the psychosocial impact of being born limb different [29]. Similarly, grounded theory has revealed the main concern of prosthesis users to feel 'normal' [40] and has explored the impact of limb difference on the family [41]. Ethnography has focused on the study of physical rehabilitation following

amputation and the process of re-establishing an able-bodied identity [42], as well as the different dimensions of the rehabilitation process that need to be combined for successful outcomes [43].

Another approach, that is widely used in the health and rehabilitation sciences, is interpretative phenomenological analysis (IPA) [44]. This qualitative method is one that is argued here to have particular utility for the study of limb difference and rehabilitation because of its ability to provide a detailed understanding of the motivations, responses, and behaviours of individuals. A recent rise in number of IPA studies in the field has been noted and previous reviews have focused on collating evidence from studies using a broad array of qualitative methodologies regarding the experience of amputation and rehabilitation [38,45]. There are certain features and utility of IPA work (outlined below) in relation to the field of limb difference and rehabilitation that can be better elucidated by reviewing the body of available literature. Based on this, the present review has three main aims: First, to set out the features of IPA that make it suited for this purpose. Second, to review systematically the available literature on these topics that have used IPA. Third, to identify, for researchers interested in applying IPA to the study of limb difference and rehabilitation, or for evaluating such research, the features of high-quality IPA that they should inculcate in this endeavour.

What is interpretative phenomenological analysis?

IPA is a qualitative research method, developed originally in the field of health psychology by Jonathan Smith, that studies the way people interpret and give meaning to their life experiences [44]. It is a methodology that has been used in published studies for over three decades and has mainly focused on studying the experience of illness [46]. Within

the field of health psychology IPA has allowed for a move away from strict biomedical approaches using quantitative methods of research, bringing to light the importance of interpretations people have regarding their subjective bodily experiences, coping and adjustment [47]. It has three main theoretical strands: phenomenology, hermeneutics and idiography. Phenomenology is an approach that focuses on examining and understanding lived experience [44], whilst hermeneutics refer to the attempt to uncover the meaning and intentions of the person regarding their shared experiences [48]. Although the IPA researcher is interested in identifying patterns in experiences and meaning for particular phenomena (such as limb difference), an idiographic focus in IPA means that the differences between participants, or the nuances of individuals' experiences and meaning making, are of equal analytical concern [49].

The sample in IPA is purposive, small, and homogenous [44]. The researcher looks to investigate a particular experience for which participants can offer their own individual perspective, something that can be done successfully in smaller samples that allow for in-depth analysis. Particular importance is also paid to the homogeneity of the sample, where participants might share common socio-demographic or other characteristics of research concern, allowing for the variability of the phenomenon studied to become known.

Due to the ability to probe, through soliciting more detail in response to answers provided, and clarify understanding in real-time, the primary, most economical method used by the majority of IPA studies to collect data have been one-to-one, in person, semi-structured interviews [44]. However, other methods also used include online forum discussions, focus groups, personal diaries and interviews carried out via email [49].

During the process of narrating their experiences in an interview, participants share their attempts to make sense of those experiences on a personal and social level. This constitutes a hermeneutic process, a process of interpretation, which is further interpreted by

the researcher. Consequently, analysis in IPA involves a ‘double hermeneutic’ approach where meaning is derived by combining the phenomenological narrative of participants’ personal interpretations, with the interpretations of those accounts made by the researcher [50,51]. Therefore, IPA recognises that the interpretative capacities of the researcher can be both a resource (researchers’ understanding are necessary to make sense of what participants say) and a potential problem (there is a need to identify, ‘bracket’ and keep in abeyance one’s own potential biases so as to privilege the meaning-making of participants) [44].

Given its idiographic nature that focuses on the individual experience and patterns for small, well-defined, and homogenous groups, IPA does not claim to be able to generalise findings to the wider population from individual studies. Although such generalisations may be possible as individual study findings are repeated with other groups in different contexts, IPA studies tend to draw out the implications for populations that share the characteristics (e.g., type of amputation, ages, and genders) and contexts (e.g., social, service, cultural) of those who took part [44,52].

The above features of IPA make it well suited for studying many areas of amputation and rehabilitation that can help inform service delivery surrounding the care of the limb difference community.

Review focus

Having outlined the particular features of IPA, attention is now given to demonstrating IPA’s versatility in researching a variety of topics related to limb difference and rehabilitation. First, the empirical, peer-reviewed research published in these areas is reviewed systematically. Next, quality criteria specific to IPA research are applied to this body of work to help researchers interested in conducting or evaluating IPA research on these topics.

Method

The current systematic review adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist guidelines [53] in conjunction with the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines [54].

Search strategy

The review sought to identify peer-reviewed journal papers relevant to limb difference and rehabilitation. The search strategy employed was discussed by the research team (a trainee clinical psychologist, a health psychologist with research expertise in IPA and limb difference, and a clinical psychologist working in a UK prosthetic and amputee rehabilitation centre) and one of the Lancaster University library specialists.

Relevant studies were identified through a systematic search of the following databases: PsychInfo, MEDLINE, CINAHL and Web of Science. The search was initially completed in August 2022, including all publication years up to 31st August 2022. Through this, 24 research papers were identified. The search was updated in February 2023 and two additional papers were found, bringing the total number of studies included in the review to 26.

A combination of subject headings and free text search terms was utilised, and searches focused on open field search, titles, and abstracts. The Boolean operator ‘OR’ was used to search for terms within the concepts of limb difference and rehabilitation and within IPA terms, and the Boolean operator ‘AND’ was used between the two concepts. In order to guarantee that all relevant papers were included, the reference lists of the identified papers

were checked on Google Scholar using the ‘cited by’ function, but no additional papers were identified. The detailed presentation of the search terms and strategy utilised to identify articles on each database is included in table 1.

[INSERT TABLE 1 HERE]

Inclusion and Exclusion criteria

Papers were included where it could be determined that: 1) a sample who had experienced limb difference, or professional prosthetists and orthotists working directly with or studying the field of limb difference, had been used; 2) IPA was the method of qualitative analysis; 3) papers were published in a peer reviewed journal; and 4) papers were published in English or Greek, as the first author is fluent in both languages. No exclusion criteria were applied.

Selection strategy

PRISMA guidelines [53] were used to summarise the screening process of identified literature, which is shown in figure 1.

[INSERT FIGURE 1 HERE]

An independent reviewer was given the list of inclusion criteria and based on this reviewed 20% (n=12) of titles and abstracts of the identified studies. The first author and reviewer were 100% in agreement. The detailed characteristics of each identified study are shown in table 2.

[INSERT TABLE 2 HERE]

Thematic Summary

The process followed was very similar to that of thematic analysis [55] and followed the steps as outlined by Finlay [56]. Data findings (that is, all text from the themes as presented in the findings of each paper) were extracted and the first author read them multiple times. Familiarization with this content allowed for the development of small summaries for each study, including a descriptive label of the essence of the content. The next step involved reading the summaries and labels created and grouping them together to form different thematic categories, which were then given a name representative of the essence of each theme. By doing this, articles that had focused on the study of similar topics were grouped together (e.g. all articles where prosthesis was identified as the main topic through the summary and label were allocated in the same group). This process was followed to identify a set of descriptive themes that incorporated findings from all relevant papers regarding limb difference and rehabilitation (The grouping process can be found in Appendix 1-C). Through this process four themes were identified: 1) The process of learning, supporting and alternative ways to receiving help; 2) Physical and psychological adjustment to limb difference; 3) Experiences of using prosthetics; and 4) Experiences of romantic relationships and sexuality. One study [57] that was suitable for two themes has been included in both.

Quality Appraisal of Selected Studies

Attempts have been made in the past for the creation of tools suitable to appraise the quality of qualitative studies [58-60]. However, the particular theoretical underpinnings and method of conducting and reporting analysis in IPA results in a set of more specific criteria

that researchers have argued should be specifically considered in the quality assessment of IPA studies [46,61,62]. For example, recently four quality criteria have been published by Nizza et al. [63] which they consider to be indicator of high-quality IPA papers. These include: ‘constructing a compelling, unfolding narrative’, ‘developing a vigorous experiential and/or existential account’, ‘close analytic reading of participants’ words’ and ‘attending to convergence and divergence’. For these reasons, use of specialised IPA tools is advocated. Such a tool was initially created by Smith [46], who invited the reviewer to score IPA papers as ‘Acceptable’, ‘Unacceptable’ and ‘Good’ based on specific IPA criteria such as the adherence of the study to the three IPA theoretical underpinnings, the number of excerpts presented and the prevalence of themes in the analysis. This IPA guide was further developed by Rose et al. [62] who combined the original guide with recommendations on what constitutes a ‘good enough’ IPA paper made by Larkin and Tompson [61], and a quality checklist for qualitative research developed by Yardley [64].

For the current study the Rose et al. [62] IPA quality guide has been chosen to critically appraise the adherence of the included studies to IPA standards due to its guidance in and utility in differentiating between different levels of quality for IPA studies. The guide focuses on six important aspects within each study: Theory, Informants, Transparency, Coherence of Analysis, Focus and Trustworthiness. The authors invite the reviewer to score each of those areas as ‘Good’, ‘Acceptable’ or ‘Poor’ and provide guidance on how to decide on the scores. An overall score of ‘Good’, ‘Acceptable’ or ‘Poor’ is then assigned to each paper indicating its adherence to IPA guidelines. The guide developed by Rose et al. [62] can be found in table 3.

[INSERT TABLE 3 HERE]

Rose et al's [62] guide is used in this review to appraise the IPA quality of the papers that are thematically presented. Its use is not intended to exclude any papers from the review, but to highlight examples where IPA methodology principles have been followed appropriately, and where further improvement is needed.

The process of quality assessment of the papers was completed by the first author following a thorough conversation with the research supervisor that aimed to clarify details of the assessment process (e.g., how could audit, triangulation and credibility checks appear in papers). After completion of the quality assessment the research supervisor audited the process completed for 31% of studies (n=8) to ensure that the criteria for appraising the studies were followed appropriately. The first author and research supervisor were in full agreement of the scores given.

Results

Thematic Presentation

Theme 1: The process of learning, supporting and alternative ways to receiving help.

Schoenberg and Shiloh [65] explored the experiences of receiving psychological support in an orthopaedic rehabilitation ward whilst participants (with unilateral and bilateral amputations) were still inpatients. The authors found that experiencing intense mental distress, receiving psychological support at no extra cost, viewing hospitalisation as a 'legitimate' reason to accept help, and believing in the link between physical and mental distress led people to accepting psychological support. On the other hand, embarrassment,

stigma, the emotive nature of sessions and a fear of dependence on the psychologist deterred people.

The concept of support was also explored by Richardson et al. [66] but from the perspective of mentors who had experienced limb loss and were supporting peers with the same experience. The authors offered an in-depth account of positive experiences and challenges faced by mentors, including the creation of hope, fighting against uncertainty, and the personal vulnerability that this process exacerbates. The results of the study are suggested to be useful in informing peer mentor training and support the creation of guidelines around the responsibilities and safeguarding of peer mentors.

Alternative ways of providing support during rehabilitation have also been explored through IPA. Cooper et al. [67] studied the experience of people who used a virtual reality training programme that allowed them to interact with peers online and engage in rehabilitation via using avatars. The study found that participants identified with their able-bodied avatars and felt ‘like a whole person’. The prospect of virtual reality being a helpful tool to rehabilitation was formerly presented by Moraal et al. [68] who studied the experience of a veteran who lost his leg during a military mission and was subsequently offered 24 virtual rehabilitation sessions that aided with his prosthesis use. The authors were interested in understanding the transitioning experience from seeing the prosthesis as an object, to embodying it, where the prosthesis becomes an incorporated part of one’s body image and body perception. This process was supported by engaging in virtual reality training as the participant started to trust the machine supporting him in the virtual world and gained confidence in using his prosthesis in day-to-day life.

Hill [69] used IPA with prosthetics and orthotics students and their lecturers. The study aimed to determine which concepts in the learning experience were troublesome (difficult to

learn) and which concepts were threshold (knowledge that facilitates new understanding that was previously inaccessible). The author compares all themes identified through the IPA process against criteria of what constitutes threshold knowledge. The implications of the study to the learning process of students in prosthetics and orthotics is not discussed. More light into this is shed through the author's previous publication of the same study in 2017 [70] where educational implications are mentioned. The author argued that understanding threshold concepts can facilitate an understanding of how students learn, something that has the potential to improve the curriculum design.

Theme 2: Physical and Psychological adjustment to limb difference.

Hamill et al. [71] explored the experiences that influence adjustment to limb loss 18 months following surgery. They found that important issues included the responses of others to the amputation, the non-acceptance of a 'disabled' identity, social support and comparison, but more importantly, the control participants had over the decision to amputate. Adjusting to amputation was found to be a process that began before surgery. The way participants' physical and mental ability was perceived by others, and the way they were treated, had a bigger impact on them feeling disabled than the actual amputation did. Made to feel disabled affected participants gender roles as women felt less 'feminine' and men less 'masculine'. Adjustment was also influenced by whether participants were experiencing social isolation post-surgery, which would exacerbate feelings of despair and could lead to consideration of suicide. Negative social interactions with others could pre-empt future relationships negatively and increase the likelihood of participants withdrawing and avoiding social contact. Conversely, meeting individuals who inspired them to persevere within

rehabilitation, or comparing with those in worse situations, were social mechanisms that aided adjustment.

Adjustment to amputation at an earlier stage (4-8 months following surgery) was studied by Roșca et al. [72]. They found that experiencing anxiety, anger and guilt, role limitations, isolation, social withdrawal, and phantom limb pain could impact participants' ability to adjust.

Lopez et al. [73] explored the experiences of adjustment to amputation of older people using a wheelchair. Using self-reflection, being in control and feeling able to be more independent whilst using a wheelchair, as described by one participant, were presented as the main strategies reinforcing adjustment following amputation. The majority of participants in the study spoke about the importance of being given options of different treatment methods for pain, including medication and amputation, and being able to choose the best for them.

McDonald et al. [74] explored the experiences of individuals with congenital and acquired upper limb absence (ULA), some of whom used prosthesis. They found that participants' independence and ability were experienced positively through adopting 'can-do' attitudes towards challenges and using prosthesis. Using prosthesis, especially for participants with congenital limb difference, was useful but only if introduced early enough, before personal mobility mechanisms developed. Participants did not feel 'disabled' and for those with acquired losses, a prosthesis aided in maintaining activities and relationships that were important before the amputation. The aesthetic appearance of the prosthesis and technological improvements also reinforced the development and maintenance of individuals' identities, sense of ability, and aided social integration and acceptance.

Stutts et al. [75] focused on the adjustment and post-traumatic growth of women with amputations, collecting data through a 'free-response' questionnaire (analysed through IPA) and the Post-traumatic Growth Inventory (PTGI). Their results showed that women with an

amputation felt they could better adjust when they had social support, positive attitudes towards themselves, and self-acceptance. Some women though, reported experiencing various difficulties, such as discrimination, lack of acceptance, understanding and support by others, and body image and motherhood challenges that hindered the adjustment process.

Katsanou et al. [76] studied the adjustment of paralympic athletes to limb loss. They found that engaging in sports aided in adjustment despite initial difficulties with prosthesis use due to pain and long hours of training for its use. Participants described the generation of a new identity that moved from seeing oneself as disabled and fearing for the future, to feeling they could fight for a better life and overcoming what they previously considered as insurmountable obstacles. What helped them in this transition and adjustment to a new reality was participating in paralympic sports, where they felt they were no longer seen as different, discovered new physical possibilities, and were inspired by people with similar physical conditions. For some, participation in sports completely changed their life as they underwent a cognitive transformation to seeing life and amputation through a positive lens, that was not centred around regaining their past way of living, but in creating a new normal.

The experiences of motivation around being active during leisure time, was explored by Olsen et al. [77]. Results focused on how pride, shame, goal setting, relating to others and being part of a limb loss community can influence individual's motivation to be active. Participants highlighted the importance of the embodied experience during activity that was expressed through muscle memory and detachment from sensory stimuli, such as pain, during activity.

Washington and Williams [78] explored the experiences of people with diabetes and peripheral vascular disease following amputation. They interviewed their sample twice, with interviews completed four months apart during a period relatively close to the occurrence of

their amputation (2-16 months). They found that having time to prepare for the amputation, allowed for better adjustment especially when combined with positive attitudes and humour.

Further consideration of diabetes and limb loss was given by Zhu et al. [20]. Their study sheds light to the struggles of regaining ‘normality’ that are exacerbated by physical constraints, wound healing challenges, the fear of further amputations, loss of independence, the psychological impact of not being able-bodied, and the social stigma attached to it. The study presents the challenging experiences of people as they fight to regain a ‘normal’ identity, by concealing limb loss, ‘refusal of being abnormal’, remaining positive and using self-motivation to maintain parts of their old lives, make plans for the future, and reinstate their identities within familial and societal roles.

Kragh Nielsen et al. [79], explored the thoughts of individuals with diabetic foot ulcers in relation to potential amputation. Participants shared thoughts regarding the predicted physical, mental, and social impact of amputation. The results revealed that amputation is seen as a taboo topic and people at risk might avoid talking about it. Participants expressed worries about strangers’ attitudes towards their possible amputations and shared their plans on using prosthetics to conceal limb loss. Given the difficulties participants had already encountered with diabetic ulcers and fearing the limitations limb loss could cause, maintaining independence and physical ability after a potential amputation featured in the analysis as an extremely important topic.

Theme 3: Experiences of using prosthetics.

Murray [80] explored the experiences of embodiment of artificial limbs. This study shed light into the experiences of achieving a deeper level of integration of prosthesis within body image, transforming artificial limbs into corporeal structures. For some of the

participants who experienced prosthesis embodiment, the use of their artificial limb provided the physical component of the mental representation of their missing limb that was present through phantom limb sensations. This allowed for an intertwinement between the prosthetic limb and the phantom one which provided a sense of completeness. Whilst some of the participants did not share this experience and their use of a prosthesis remained purely practical, others reached a level of embodiment that allowed them to sense the environment around using the prosthesis. The author suggests that continuous prosthesis use can increase the possibility of experiencing embodiment by the wearers.

The concept of prosthesis embodiment was also considered by Saradjian et al. [81]. Prosthesis was found to help participants feel and display a ‘normal’ appearance through improved function and an able-bodied form which reinstated their body image, whilst it decreased feelings of difference and aided in social integration. For some, the prosthesis became such an integral part of their body image that they experienced prosthetic embodiment as described by Murray [80].

Middleton and Ortiz-Catalan [82] explored the experiences of using upper limb bionic prosthesis. Bionic prosthesis was preferred over other types of prosthesis as it did not impact on other parts of the body that would have been used to compensate whilst mobilising. Improved control over the prosthesis was experienced when electrodes were implanted and using their bionic arms daily felt like a ‘natural’ process despite the sensations feeling ‘electric’ or ‘numb’. The use of bionic prosthesis enabled participants to complete various tasks of daily life such as cooking and skiing, decreased or even eliminated phantom limb pain and improved participants’ self-esteem, self-image, and social relations.

van Heijningen and Underhill [83] studied the experiences of individuals using digital prosthesis. They found that its use enabled participants to continue day-to-day tasks and regain their independence by experiencing improved grip, something that improved their

confidence and self-esteem. The authors argue that digital prosthesis was important for participants both functionally and in terms of their body image.

Murray [57] explored the social meanings of prosthesis use for individuals with limb difference. Prosthesis enabled participants to be an active part of social activities whilst preserving an independent adult identity. Wearing it was found to yield mixed responses from strangers, with people often being offensive and avoiding social contact, and others being curious and intrusive. Social interactions with friends and family were also mixed as some individuals experienced loved ones who could not stand seeing them without their prosthesis and others who were ‘fine’ with it. Wearing a prosthesis in public appeared to influence the way a person was treated, and it was often used as a means of keeping a ‘secret identity’ of able-bodiedness. Concealment could end up being ‘pleasant’ when others would eventually find out as it proved its success in hiding limb loss, or it could make things more challenging when individuals would eventually have to share their story with others. At other times, concealment helped relationships to be built by seeing the ‘true person’ and not the disability but led to individuals not being perceived as ‘real’ amputees by others in the limb loss community.

The author further explored the personal meanings of prosthesis use, via the same sample in a separate study [84]. Through using prosthesis participants felt that ‘recovery was possible’, they could be ‘like everyone else’ and were able to ‘get their lives back’. Whilst for some of the participants the realistic appearance of the prosthesis was important, for others functionality and a commitment to raising disability awareness by showing the artificial limb to the world was prioritised. Using their prosthesis allowed participants to regain parts of their social and personal identity as they were able to work, be independent and achieve personal goals.

Whilst all the above-mentioned studies focused on adult populations, Oliver et al. [85] explored the experiences of parents whose children used a prosthesis. Within the sample most children had congenital limb difference, something that challenged parents' pre-existing expectations of having a child. Whilst parents shared that coming to the realisation that their child had a limb difference was difficult, they were able to build resources and tackle challenges and would adopt protective behaviours when they felt that their children were discriminated against. Parents felt that using lower limb prostheses enabled their children to attend to activities they would not be able to do otherwise, and this contributed to feeling 'normal'. On the other hand, parents of children with an upper limb prosthesis felt that the prosthesis did not improve functionality, further highlighting their child's difference.

Theme 4: Experiences of romantic relationships and sexuality.

In Murray's [57] study on the social meanings of prosthesis, single participants shared concerns regarding whether they would be seen as attractive and be able to find romantic partners who would accept their physical difference. Others in relationships at the time of limb loss shared experiences of being rejected and abandoned because of it. The visibility of a prosthesis was seen as a barrier to forming relationships for some. However, even when concealing limb difference was possible, some participants experienced anxiety when been approached by romantically interested others in social events.

Mathias and Harcourt [86] studied the dating and intimate relationship experiences of women who had undergone below-knee amputation. Participants highlighted challenges with intimacy and shared that the portrayal of the 'perfect woman' through the media made them feel unattractive. Revealing their limb loss and prosthesis use early on during dating reduced participants' anxiety of finding the right time to share it with their dates. Early disclosure also

acted as a facilitator for participants to make judgments around the suitability of a partner as, based on their date's reactions, they could determine their intentions, and acceptance attitudes. Using the prosthesis as a 'tool' to accept or reject someone as a potential partner empowered women to reject others before being rejected first.

The sexuality and body image of women with lower limb amputations was also explored by Ward Khan et al. [23]. Participants felt that using prosthetics was not aesthetically pleasing, making them experience intense feelings of dislike, to the point of avoiding looking at their own bodies. Previous insecurities about appearance were exacerbated and many women felt the need to use appearance enhancers, such as expensive make up, to counteract the 'ugliness' of their bodies. Due to the amputation affecting lower limbs, participants were unable to dress as they wanted, something that further impacted on their self-esteem. Feeling different from the norm, ruminating about what their partners' feelings towards them were, and facing practical difficulties, such as weight gain, led to loss of sexual desire. Participants felt that for romantic relationships to be formed and maintained a higher level of trust was required than before the amputation.

On the other hand, men's experiences were explored by Keeling and Sharratt [22], who interviewed military men with limb loss and scaring. Their study found that participants' intimate relationships were impacted upon due to physical restraints and appearance changes. Being part of the army meant that some men held strong ideals about masculinity. Not fitting within societal standards of a masculine appearance and having their masculinity challenged by limb loss impacted negatively on their self-esteem. Most of the participants expressed worries around intimacy and faced the uncertainty of whether their partners found them physically attractive. Some of the participants' relationships ended following their amputation and others' grew stronger through the trauma. For people who engaged in new relationships the fear of rejection led to uncertainty of the best timing to disclose amputation.

A common worry between participants focused on the intentions of potential partners and disclosing their limb loss early during dating served as a way to determine their motives.

Having presented an array of issues that researchers have investigated using IPA, the attention is now turned to applying a tailored critique to how these studies utilised IPA. Together, these sections, allow the reader to see the versatility of IPA in investigating issues related to limb difference and rehabilitation, along with the particular strengths and limitations of these studies in how they apply IPA.

Quality appraisal

The guide developed by Rose et al. [62] was used to appraise the adherence of the above presented studies to IPA guidelines. Based on the guide, 12 papers were scored as ‘Poor’, 8 papers were found to be ‘Acceptable’, and 6 papers were ‘Good’. As clarified by the authors, assigning an overall score of ‘Poor’ is not indicative of a study with no merit, rather a study that does not adhere sufficiently to IPA guidelines but whose contribution can still be valuable. A detailed presentation of the appraisal is provided in table 4.

[INSERT TABLE 4 HERE]

Poor

Papers were rated ‘Poor’ overall if they had scored ‘Poor’ on Theory or Coherence of Analysis (CoA), or both. The decision to give an overall marking of ‘Poor’, despite the guide not clarifying any assessed area as more important than the other, came as it was felt that theory and analysis are integral parts of IPA which when not understood and presented properly can jeopardise the quality of the overall quality of an IPA study.

The papers rated as poor in regards to Theory did not make clear reference to IPA's theoretical underpinnings (phenomenology, hermeneutics, idiography) and were not clear in their rationale around the reasons why IPA was the most suitable approach to study the given topic. For example, Stutts et al. [75] did not provide sufficient detail of IPA theory, and similarly, in both papers by Hill [69,70] no reference is made to IPA theory and why this methodology would aid in the investigation of threshold concepts and troublesome knowledge. Similarly, while Lopez et al. [73] explain that IPA is interested in the experiences of participants and refer to the idiographic approach, they do not present the theory sufficiently. Similar problems with limited explanation of theory and rationale were present in the studies completed by Kragh Nielsen et al. [79] and Washington and Williams [78].

Within CoA, it is expected that the appraisal should focus on the implementation of theory into practice. Studies should present themes with excerpts from at least half of the participants. Emphasis is given to providing a good balance between commentary and interpretation. Most papers that scored 'Poor' in CoA lacked interpretation, relied mainly on paraphrasing excerpts, or did not provide enough excerpts to support the arguments made. For example, McDonald et al. [74], did not present enough participant excerpts and did not include participant identifiers, making it impossible to determine the prevalence of each participant's contributions. Examples of lack a hermeneutic approach include Stutt's et al. [75] who offered minimal commentary on the results and no interpretation, and Kragh Nielsen [79] who presented the results explaining what participants shared rather than interpreting it. Lopez et al. [73] included the comments of a participant's wife to 'add to the context', an opportunity not given to other participants and an addition which jeopardized the homogeneity of the sample and the in-depth understanding of the experience by the wheelchair users themselves.

Three of the papers were assessed as ‘Poor’ on CoA as they were influenced in the generation of themes by various models and theories, entering the process of analysis pre-determining the theme content rather than inductively and hermeneutically developing it from the data. These include the studies by Schoenberg and Shiloh [65] who used the Kushner-Sher conflict model [87], Rosca et al. [72] who used the self-psychology model [88] and Olsen et al. [77] who used Self-Determination theory [89] and embodied phenomenology [90].

About half of the ‘Poor’ papers were assessed as ‘Poor’ in Trustworthiness and Focus as they failed to provide evidence of audit, triangulation or credibility checks and lacked a clearly focused approach. For example, Hill [69] presents data of debatable significance to participants given that no direct implications of the research were presented, and Washington and Williams [78] did not reference audit completed by other members of the research team.

Whilst the majority of the papers that scored ‘Poor’ had scored ‘Poor’ for more than half the assessment criteria, some papers had ‘Good’ and ‘Acceptable’ ratings on the individual criteria but were given a ‘Poor’ total score. One example is Cooper et al. [67], which was assessed as ‘Good’ on Theory, Informants and Focus, but ‘Poor’ on CoA, as they presented 14 themes, some of which were not evidenced by any data excerpts. Similarly, Olsen et al. [77] was assessed as ‘Good’ on Transparency, Focus and Trustworthiness, but ‘Poor’ on CoA as not enough participant excerpts were presented, one theme was not evidenced at all, and theme generation was influenced by theories, as explained above.

Acceptable

An overall score of ‘Acceptable’ was given to papers where Theory, CoA and other assessed fields were considered to pass the ‘Acceptable’ criteria. Six out of 8 papers assessed as ‘Acceptable’ overall received an ‘Acceptable’ score on Theory and CoA, providing

appropriate evidence for arguments made through excerpts, sufficient levels of interpretation, and reference to the theoretical principals of IPA. Those were the studies by Richardson et al. [66], Murray [57,80,84], Saradjian et al. [81] and Zhu et al. [20].

The guide stresses the importance of participants comprising a homogenous sample. The homogeneity of the sample is assessed under Informants, alongside the information on participant selection. Five out of 8 papers were assessed as ‘Acceptable’ for Informants as they provided sufficient participant selection and relatively homogenous samples [57,68,80,83,84]. For example, the study by Moraal et al. [68], scored ‘Acceptable’ on Informants as only 1 participant was included in the study, but they provided sufficient and appropriate data to answer the research question. Three of the studies, Richardson et al. [66], Saradjian et al. [81] and Zhu et al. [20] were assessed as ‘Good’ on Informants despite being assessed as ‘Acceptable’ overall as they presented homogenous samples that allowed them to address the research question and presented detailed information on participant selection. In the ‘Acceptable’ category were also papers that scored ‘Good’ on Transparency, Focus and Trustworthiness, such as the ones by Murray [57,80], Saradjian et al. [81] and Zhu et al. [20], as they provided evidence of audit and triangulation, a strong study focus that explored topics of importance to participants, and a clear outline of all stages of research undertaken. The overall scores remained ‘Acceptable’ for the above-mentioned studies as IPA Theory and CoA were assessed as ‘Acceptable’.

Again, whilst Rose et al. [62] do not consider any area to be of higher importance than the others when deciding on an overall score, assessing all 26 studies, and gaining experience on drawing out the fine details of assessing IPA quality has led to the conclusion that Theory and CoA are of particular importance. This does not intend to decrease the significance of the other assessed areas, but an argument could be made that a clear Focus and robust

Trustworthiness could be expected from any qualitative research regardless of its methodological approach [91].

Good

Six studies were given an overall score of 'Good' as they were assessed as 'Good' on most areas including Theory or CoA, or both. Keeling and Sharratt [22] and Ward Khan et al. [23], scored 'Good' on Theory and CoA as they demonstrated appropriate depth of detail in the presentation of the theoretical underpinnings of IPA, in-depth interpretation of the data presented and detailed participant excerpts. The other three papers in the 'Good' category, Oliver et al. [85], Katsanou et al. [76] and Mathias and Harcourt [86], scored 'Acceptable' in either Theory or CoA as some details were missing such explanation of one of the IPA theories, but still were given an overall score of Good as they presented great detail in the adherence to IPA standards. The paper by Hamill [71] was the only paper included in the review that scored 'Good' on all assessed fields. The study demonstrated exceptional detail on all assessed areas. The extended version of IPA scores can be found in Appendix 1-D.

Discussion

The aims of this review were to thematically present the areas of limb difference and rehabilitation that have been explored through IPA and to appraise the adherence of the identified studies to IPA principles. In doing this, the intention was to demonstrate the versatility of using IPA for informing service provision and rehabilitation in the field of amputation and prosthetics and to aid researchers in the field in evaluating and conducting IPA research.

The review found that IPA has been used to study the process of learning about and supporting people with limb loss. Efforts have been made to understand alternative ways of providing rehabilitation such as offering virtual reality prostheses, and to gain an understanding of the ways others can support people with limb difference either through their training or through mentoring. The results also revealed that adjustment to limb difference can differ from person to person and a lot of factors can play a part in the adjustment process such as the support from others, others' reactions to limb difference and 'can-do' attitudes. The reviewed research indicates that prosthesis use can go beyond the use of an artificial limb for functional and mobility purposes and that individuals can reach a level of embodiment, where the prosthesis almost becomes part of the body. Through IPA, the impact of limb loss on romantic relationships and intimacy was also elaborated, as well as the need for additional support to be provided to those who want to share and receive help with difficulties in relationships.

Focusing on studies that have used IPA, topics that have been explored using other qualitative methodologies are further enriched, by the presentation of personal experiences that are interpreted by the individuals and the researchers. For example, understanding the daily lives of people with amputations that has been studied through thematic analysis was further elaborated on through IPA studies that revealed the processes of adjustment to limb loss that individuals undergo [71,73]. Similarly, the concern of prosthesis user's to feel 'normal', studied through grounded theory, was further enriched with IPA studies focusing on the embodiment of artificial limbs [80] and the social and personal meanings of using prosthesis [57,84].

IPA is a complex methodological approach that requires careful application of its theoretical principals. Reviewing the adherence of the presented literature on limb difference and rehabilitation against IPA quality assessment criteria enabled the identification of strong

and weaker characteristics in the methodology and reporting of these studies. This in turn can help researchers consider how best to design their own IPA studies on these topics, and how to evaluate research that uses IPA. The Rose et al. [62] guide allowed for a detailed assessment of the presented literature and highlighted the importance of adhering to the theoretical principals of phenomenology, hermeneutics and idiography throughout the collection and analysis of data.

Despite this, as a methodological approach, IPA presents with specific weaknesses. IPA findings are not generalisable as data derives from single studies, including small numbers of self-selecting participants who cannot be representative of the population they are drawn from. As an approach, it can be considered subjective and overly reliant on the researcher's interpretation [92]. IPA criticisms also focus on the lack of standardisation of IPA steps making the process more descriptive than interpretative [93]. Researchers endeavouring in the application of IPA would benefit from adherence to published guidance on the process that needs to be undertaken and from careful consideration of the ways in which they can appraise their work [62,63].

Clinical Implications

The above-mentioned findings of the literature review and the quality assessment process completed are important on three levels. First, the areas of limb difference and rehabilitation that IPA has explored can support mental health professionals, such as psychologists and counsellors, in their direct work with clients who have experienced limb difference [1,2]. This includes understanding the factors that facilitate accepting psychological support [65], and the ways in which others' responses, social support and

control can aid adjustment [71]. In addition, the understanding how limb loss can affect relationships, the processes of disclosure to interested others, and its impact on sexuality, body image, self-esteem, and identity [23,57,86] can inform the psychological support that can be provided to people with limb difference.

Second, rehabilitation health professionals such as prosthetists, orthotists, and physiotherapists [1] can benefit from the information collated to further inform and improve existing practices. This can be achieved through directly accessing the research published or by being supported by psychologists, to access published knowledge on the topic and to work in psychologically-informed ways. Examples include understanding the importance of the aesthetics and functionality of a prosthesis and the impact of limb difference to feeling ‘feminine’ or ‘masculine’ [71,74] the potential of embodiment through regular prosthesis use [80], and the benefits of exercise and belonging in a community [76].

Lastly, based on the outcomes and recommendations made regarding adherence to IPA principles, this review serves as a guide for researchers interested in evaluating published IPA research or using IPA in the future. This in turn has crucial clinical implications as adhering to IPA guidelines has the potential to produce valuable research which consequently informs clinical practice on populations with limb difference.

Limitations and Future Research

The lack of a second, independent reviewer presents a limitation of this study, as valuable contributions and support could have been provided in selecting the included studies, constructing themes and applying the quality criteria.

Most of the reported studies related to samples comprising of people with amputations, and comparatively fewer studies addressed congenital limb differences. Further research using IPA with such samples would therefore be valuable. Moreover, the identified

studies mainly used western, white, and heterosexual populations. Research with more diverse population, and in different geographical regions could offer more inclusive and diverse findings. The experiences of professional groups working with people with limb difference (e.g., prosthetists and psychologists) were also largely absent in the available literature, as were the experiences of family members and partners who are often involved in supporting people with limb difference through their rehabilitation journey. Further research with such groups would be useful in gaining a polyvocal and integrated understanding of limb difference rehabilitation.

Using the Rose et al [62] quality appraisal tool facilitated the uniform evaluation of the included studies to IPA guidelines across 6 criteria (Theory, Informants, Transparency, Coherence of Analysis, Focus, Trustworthiness). However, more recent guidance by Nizza et al [63] has emphasised the priority of high-quality analysis in determining the overall quality of an IPA paper that are much more stringent than ‘coherence of analysis’ as used in Rose et al [62]. They argue that a good analysis should demonstrate the construction of a compelling, unfolding narrative; develop a vigorous experiential and/or existential account; evidence close analytic reading of participants' words; and attend to convergence and divergence. Although these authors do not present a tool to differentiate between different levels of attainment with regards to these quality criteria, the importance of this for high quality IPA indicate that future IPA specific quality appraisal tools would benefit from incorporating these observations.

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Table 1. Search terms used in the research databases.

| Database | Phenomenon of Interest | Methodology |
|---------------|---|--|
| APA PsychInfo | <p>DE "Phantom Limbs" OR DE "Prosthesis" OR DE "Amputation"</p> <p>OR</p> <p>TI amput* OR limb loss OR limb difference OR congenital limb OR limb deficiency OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR prosthe* OR podiatr* OR below knee OR above knee OR above elbow OR below elbow OR disarticulation OR transhumeral OR transradial OR hemicorporectomy OR hemipelvectomy OR hindquarter OR disarticulation OR transfemoral OR Symes</p> <p>OR</p> <p>AB amput* OR limb loss OR limb difference OR congenital limb OR limb deficiency OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR prosthe* OR podiatr* OR below knee OR above knee OR above elbow OR below elbow OR disarticulation OR transhumeral OR transradial OR hemicorporectomy OR hemipelvectomy OR hindquarter OR disarticulation OR transfemoral OR Symes</p> | <p>DE "Interpretative Phenomenological Analysis"</p> <p>OR</p> <p>TI "Interp* phenomenological analysis"</p> <p>OR</p> <p>AB "Interp* phenomenological analysis"</p> |

| | | |
|---------|--|--|
| MEDLINE | MH "Phantom Limb" OR MH "Artificial Limbs" OR MH "Prostheses and Implants" | MH 'Interpretative phenomenological analysis' OR TI "Interp* phenomenological analysis" |
| | OR | OR |
| | TI <i>amput*</i> OR <i>limb loss</i> OR <i>limb difference</i> OR <i>congenital limb</i> OR <i>limb deficiency</i> OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR <i>prosthe*</i> OR <i>podiatr*</i> OR <i>below knee</i> OR <i>above knee</i> OR <i>above elbow</i> OR <i>below elbow</i> OR <i>disarticulation</i> OR <i>transhumeral</i> OR <i>transradial</i> OR <i>hemicorporectomy</i> OR <i>hemipelvectomy</i> OR <i>hindquarter</i> OR <i>disarticulation</i> OR <i>transfemoral</i> OR <i>Sympes</i> | AB "Interp* phenomenological analysis" |
| | OR | |
| | <i>amput*</i> OR <i>limb loss</i> <i>limb difference</i> OR <i>congenital limb</i> OR <i>limb deficiency</i> OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR <i>prosthe*</i> OR <i>podiatr*</i> OR <i>below knee</i> OR <i>above knee</i> OR <i>above elbow</i> OR <i>below elbow</i> OR <i>disarticulation</i> OR <i>transhumeral</i> OR <i>transradial</i> OR <i>hemicorporectomy</i> OR <i>hemipelvectomy</i> OR <i>hindquarter</i> OR <i>disarticulation</i> OR <i>transfemoral</i> OR <i>Sympes</i> | |

| | | |
|--------|---|---|
| CINAHL | ((MH "Amputation") OR "amputation" OR (MH "Above-Knee Amputation") OR (MH "Amputation, Traumatic") OR (MH "Amputation Care (Iowa NIC)") OR (MH "Below-Knee Amputation") OR (MH "Amputation Stumps")) | DE "Interpretative Phenomenological Analysis" OR TI ("Interp* phenomenological analysis") OR AB ("Interp* phenomenological analysis") |
| | OR <i>TI amput* OR limb loss OR limb difference OR congenital limb OR limb deficiency OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR prosthe* OR podiatr* OR below knee OR above knee OR above elbow OR below elbow OR disarticulation OR transhumeral OR transradial OR hemicorporectomy OR hemipelvectomy OR hindquarter OR disarticulation OR transfemoral OR Symes</i> | |
| | OR <i>AB amput* OR limb loss OR limb difference OR congenital limb OR limb deficiency OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR prosthe* OR podiatr* OR below knee OR above knee OR above elbow OR below elbow OR disarticulation OR transhumeral OR transradial OR hemicorporectomy OR hemipelvectomy OR hindquarter OR disarticulation OR transfemoral OR Symes</i> | |

| | | |
|----------------|--|--|
| Web of Science | <p>amputation OR limb loss OR Prostheses (All Fields)</p> <p>OR</p> <p>amput* OR limb loss OR limb difference OR congenital limb OR limb deficiency OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR prosthe* OR podiatr* OR below knee OR above knee OR above elbow OR below elbow OR disarticulation OR transhumeral OR transradial OR hemicorporectomy OR hemipelvectomy OR hindquarter OR disarticulation OR transfemoral OR Symes (Title)</p> <p>OR</p> <p>amput* OR limb loss OR limb difference OR congenital limb OR limb deficiency OR ((phantom OR loss OR false OR artificial OR fake) N3 (limb* OR extremit* OR arm* OR leg* OR finger* OR hand* OR toe*)) OR prosthe* OR podiatr* OR below knee OR above knee OR above elbow OR below elbow OR disarticulation OR transhumeral OR transradial OR hemicorporectomy OR hemipelvectomy OR hindquarter OR disarticulation OR transfemoral OR Symes (Abstract)</p> | <p>Interpretative Phenomenological Analysis (All Fields)</p> <p>OR</p> <p>Interp* phenomenological analysis (Title)</p> <p>OR</p> <p>Interp* phenomenological analysis" (Abstract)</p> |
|----------------|--|--|

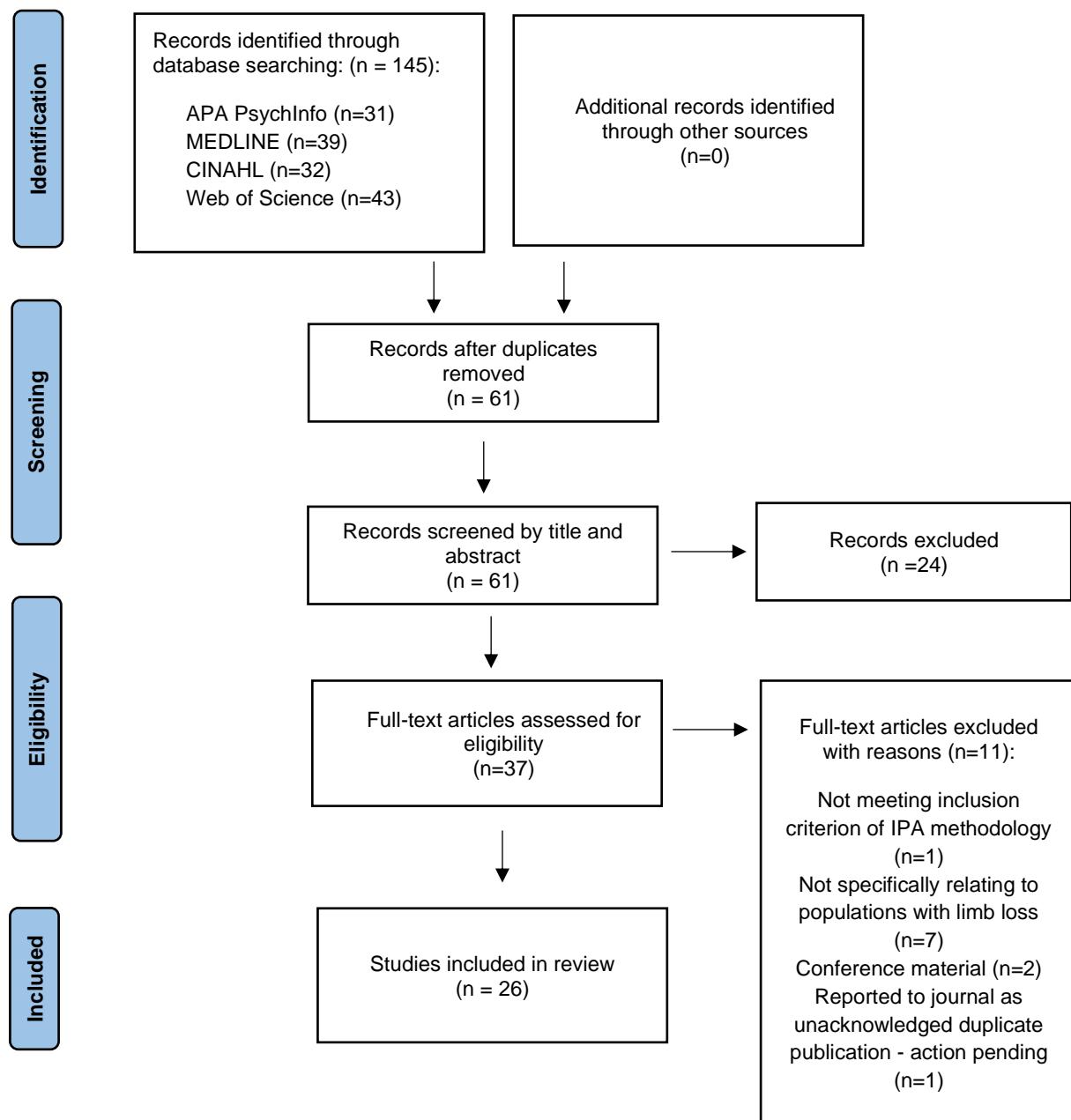
Figure 1. PRISMA flow diagram of the systematic search.

Table 2. Characteristics of studies included in the review.

| Author & year of publication | Country | Research question | Participants | | | Participant recruitment | Amputation type & time since amputation | Design and data collection | Theme |
|-----------------------------------|---------|--|------------------------|----------------------|---------------------------------------|--|--|---|--|
| | | | Number of Participants | Gender | Age range & mean | | | | |
| Schoenberg and Shiloh (2002) [66] | Israel | To explore the experience of hospitalised patients of receiving psychological support in an orthopaedic rehabilitation ward. | 10 | 6 males 4 females | 38-62 years old Mean age = 49 | Participants recruited at an orthopaedic rehabilitation centre. | 8 unilateral and bilateral amputations. 2 significant bone fractures. | Semi-structured interviews carried out in patient's rooms. Interview duration was 1h. | Theme 1: The process of learning, supporting and alternative ways to receiving help. |
| Richardson et al. (2020) [68] | UK | To explore the experience of peer mentors who offer support to individuals with lower limb amputations. | 8 | 3 males 5 females | 57-64 years old Mean not provided. | Participants were peer mentors who worked for and were recruited from an advocacy charity. | 4 below knee 3 above knee 1 through hip 7-48 years following | Semi-structured interviews. 7 interviews completed over the phone. 1 interview completed at | Theme 1: The process of learning, supporting and alternative ways to receiving help. |

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|---------------------------|-----|--|----|---------------------|--|--|--|---|--|
| | | | | | | | amputation and prosthesis | participant's home. | |
| Cooper et al. (2018) [69] | USA | To explore the experiences of people with limb loss using a virtual self-management programme. | 20 | 14 male 6 female | Age range not provided. Mean age = 54.3 | People who experienced limb loss were randomly allocated to two self-managements trainings, one in the form of e-learning and one in a virtual world. All people participating in the study were interviewed. It is not clear where the sample was found and how it was recruited. | Unilateral and bilateral upper and lower limb amputations. 14 participants experienced limb loss 0-5 years prior to the study. 5 participants, 11 - 20 years prior to the study. | Semi-structured interviews completed virtually using text chat. No information provided regarding duration of interviews. | Average duration of interviews 62 min. Theme 1: The process of learning, supporting and alternative ways to receiving help. |

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|------------------------------|-----------------|--|--|---------------|---------------|--|---|---|--|
| Moraal et al. (2013) [70] | The Netherlands | To explore the experience of an individual receiving virtual rehabilitation following lower limb amputation. | 1 (interviewed twice) | 1 male | 36 years old | Participant experienced limb loss during a military mission and engaged in virtual rehabilitation in a military rehabilitation centre. Unclear how the authors identified the participants and made contact. | Lower right extremity amputation. Interviews completed within the first year following limb loss. | Semi-structured interviews conducted at a military rehabilitation centre. No information provided regarding duration of interviews. | Theme 1: The process of learning, supporting and alternative ways to receiving help. |
| Hill (2017) [72] | UK | To explore threshold concepts within prosthetist's education. | 26 18 students 8 lecturers | Not provided. | Not provided. | Participants recruited from an undergraduate prosthetics and orthotics programme. | Not applicable. All interviews were conducted in the participant's work / study place except for fourth year students who responded to questions via | Semi-structured interviews and questionnaires. | Theme 1: The process of learning, supporting and alternative ways to receiving help. |

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| Hill (2020) [71] | UK | To explore the difference between troublesome knowledge and threshold concepts. | 26 18 students 8 lecturers | Not provided. | Not provided. | Participants recruited from an undergraduate prosthetics and orthotics programme. | Not applicable. | Semi-structured interviews and questionnaires. Some interviews conducted via email. Unclear where the rest of the interviews took place. No information provided regarding duration of interviews. | Theme 1: The process of learning, supporting and alternative ways to receiving help. |
| Hamill (2010) [73] | Northern Ireland | To explore the experience of psychological adjustment within 18 | 8 | 5 males 3 females | All participants aged 18 and above. No | Sample found through the patient list of an | 7 unilateral lower extremity amputations (3) | Semi-structured interviews lasting 1h | Theme 2: Physical and Psychological adjustment to |

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|--------------------------|-------------|---|---|-------------------------|---|--|--|--|
| | | months following amputation. | | specific ages provided. | NHS prosthetic service. | above knee, 4 below knee). 1 unilateral upper extremity (above elbow) amputation. | carried out at the prosthetic clinic. | limb difference. |
| | | | | No mean provided. | | | Time since amputation not provided. | |
| Roşca et al. (2021) [74] | Romania | To explore the psychological impact of amputation. | 7 | Not provided. | 41 - 75 years old Mean not provided. | Participants recruited through a traumatology hospital in Bucharest. | 1 Upper limb 6 Lower limb amputations. 4-8 months following amputation. | Semi-structured interviews lasting 1h completed at the hospital or at the participant's homes. Theme 2: Physical and Psychological adjustment to limb difference. |
| Lopez et al. (2017) [76] | New Zealand | To explore the experience of older adults' adjustment to lower limb amputation when wheelchairs are used long term. | 4 | 4 males | Over 65 years old - No specific ages provided. Mean age = 84 | Participants were found through a health database. | Unilateral and bilateral below and above knee amputations. 3-12 years following amputation. | Semi-structured interviews lasting 14-51 minutes completed in the participant's homes. Theme 2: Physical and Psychological adjustment to limb difference. |

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| McDonald et al. (2020) [77] | USA | To explore the experiences of people with upper limb amputations in regards to ability, quality of life and prosthesis use. | 14 | 7 males 7 females | 18-71 years old Mean age = 41.4 | Participants recruited through prosthetics clinics through emails sent to clinicians and an online prosthesis community who contacted adults who had previously received a prosthesis from them. | Unilateral and Bilateral upper limb loss 10 of them congenital and 4 as a result of amputations. Of the participants, 8 did not use upper limb prosthesis. | Semi-structured interviews | Theme 2: Physical and Psychological adjustment to limb difference. |
| Stutts et al. (2015) [78] | USA | To explore the experiences of women who have had limb loss in terms of their coping and post-traumatic growth. | 30 | 30 females | 23 - 81 years old Mean age = 50 | Participants recruited through online support forums, regional groups, and amputation foundations. | 14 Below knee 11 Above knee 2 Upper limb 2 bilateral arm amputations 1 bilateral above knee amputation. | Data was collected through a 'free response questionnaire' created by the authors. Additional data was collected through the Post-traumatic | Theme 2: Physical and Psychological adjustment to limb difference. |

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| | | | | | | | | Growth Inventory. |
| Katsanou et al. (2020) [79] | Greece | To explore the experiences of athletes using prosthetics and the effect of paralympic sports on their adjustment to amputation. | 8 | 7 males 1 female | All participants above 18 years old - No specific ages provided. Mean not provided. | Participants recruited through the Greek Paralympic Committee. Initial contact with interested participants completed through the phone in order to ensure inclusion criteria were met. | 4 Below knee. 1 Above knee. 3 Hip. 6 Unilateral. 2 Bilateral. Over 4 years following amputation. | Semi-structured interviews completed at locations chosen by participants. Duration ranged between 30min and 1h 30 min. |
| Olsen et al. (2023) [80] | USA | To explore the experiences of motivation to engage with physical activity. | 6 | 1 male 5 females | 37 - 62 years old. Mean not provided. | Participants identified through charities and individuals with access to limb loss communities. | 6 Lower Limb 4 - 21 years since amputation. | Semi-structured interviews completed with participants twice via Zoom. Photo diaries used to employ 'photo-elicitation' in |

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| | | | | | | | | | the interviews. Interviews lasted 45-75 minutes. |
| Washington and Williams (2016) [83] | UK | To explore the experiences of people living with a chronic condition (diabetes and/or peripheral vascular disease) and who have experienced amputation and the impact of those experiences on their psychological well-being. | 6 | 4 males 2 females | Age range not provided. Mean age males = 64.8 Mean age females = 69 | Participants recruited through the Manchester Disablement Services Centre. | 6 unilateral lower limb amputations. 3 Above knee 3 Below knee 14 months following amputation | Semi-structured interviews completed twice (4 months apart) with each participant, each lasting about 1h, completed at the centre | Theme 2: Physical and Psychological adjustment to limb difference. |
| Zhu et al. (2020) [21] | Singapore | To explore the experiences of adjustment of patients with diabetic lower extremity amputations and | 9 | 6 males 3 females | 37 - 72 years old Mean not provided. | Participants were patients in a primary healthcare setting and were screened by wound care | 9 Lower Extremity Amputations Interviews completed | Semi-structured interviews lasting 45-60 minutes conducted in a room where patients were | Theme 2: Physical and Psychological adjustment to limb difference. |

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| | | post-amputation wounds in primary care. | | nurses for eligibility to participate in the study. | within a year of amputation. | attending wound treatment. | |
| Kragh Nielsen et al. (2022) [84] | Denmark | To explore the thoughts that individuals with diabetic foot ulcers had in regards to leg amputation. | 5 | 4 males 1 females Mean not provided. | 40-80 years old. Participants were receiving care at an outpatient wound clinic and were identified by wound nurses. | Participants had diabetic foot ulcers and no scheduled amputation but could need one in the future. | Semi-structured interviews completed at the participants' homes, lasting 32-80 minutes. Theme 2: Physical and Psychological adjustment to limb difference. |
| Murray (2004) [85] | UK | To explore the experience of embodiment of artificial limbs. | 35 | 16 males 19 females Mean not provided. | 16 - 75 years old. Data gathered via 3 sources: 14 participants identified through an NHS service provider and were | 24 Lower limb 3 Upper limb 8 congenital limb absences (4 lower limb; 4 upper limb). | Semi-structured interviews that took place in person at a space agreed between the author and the participants, lasting Theme 3: Experiences of using prosthetics. |

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| Saradjian et al. (2008) | UK | To explore the experience of men who have been using | 11 | 11 males | 31-64 years old. | Participants identified through a rehabilitation centre. | 5 Below elbow 4 Above elbow 1 Shoulder disarticulation 1 Wrist disarticulation | approximately 1h. Semi-structured interviews completed via email during a span of 2-6 months. 5-60 (15 average) emails were exchanged with each participant. Online discussion group posts that were generated within 2 years prior to the study commencing. |

| | | upper extremity prosthesis. | | Mean not provided. | | 7-48 years since amputation | service lasting around 45 minutes. | |
|------------------------------------|------------------------|---|---|--|--|--|--|--|
| Middleton and Ortiz-Catalan (2020) | Sweden | To explore the experiences of using bionic prosthesis in day-to-day life. | 3 | 3 males 43 - 46 years old. Mean not provided. | No information around how participants were found or contacted provided. | 3 Upper Limb. Participants were using prosthesis for 2-6 years at the time of interviews. | Semi-structured interviews completed lasting 40 - 75 minutes. Place of interviews not specified. | Theme 3: Experiences of using prosthetics. |
| van Heijningen & Underhill (2022) | The Netherlands and UK | To explore the experience of individuals using digital prosthesis in day-to-day life. | 4 | 2 males 40 - 58 years old. 2 females Mean not provided. | Participants identified through a rehabilitation centre by using the electronic patient record to determine whether they fit the inclusion criteria. | 3 thumbs 1 person with index and middle finger amputation | Semi-structured interviews completed at a rehabilitation service lasting 45-60 minutes. | Theme 3: Experiences of using prosthetics. |

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|-----------------------|----|--|----|------------------------|--|--|--|--|--|
| Murray (2005) [58] | UK | To explore the meaning of prosthesis in the context of social occasions and relationships. | 35 | 16 males 19 females | 16 - 75 years old. Mean not provided. | Data gathered via 3 sources: 14 participants identified through an NHS service provider and were interviewed in person. | 24 Lower limb 3 Upper limb 8 congenital limb absences (4 lower limb; 4 upper limb). Time since amputation not provided. | Semi-structured interviews that took place in person at a space agreed between the author and the participants, lasting approximately 1h. | Theme 3: Experiences of using prosthetics. & Theme 4: Experiences of romantic relationships and sexuality. |
| | | | | | | 21 participants identified through an email discussion group and were interviewed via email. | Posts made on an online discussion group during the 2 years before the | Semi-structured interviews completed via email during a span of 2-6 months. 5-60 (15 average) emails were exchanged with each participant. | |

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| | | | | | | study commenced. | | Online discussion group posts that were generated within 2 years prior to the study commencing. |
| Murray (2009) [89] | UK | To explore the experience of prostheses use for people with limb loss and congenital limb deficiency in regards to its personal meanings. | 35 | 16 males 19 females | 16 - 75 years old. Mean not provided. | Data gathered via 3 sources: 14 participants identified through an NHS service provider and were interviewed in person. | 24 Lower limb 3 Upper limb 8 congenital limb absences (4 limb; 4 upper limb). Time since amputation not provided. | Semi-structured interviews that took place in person at a space agreed between the author and the participants, lasting approximately 1h. |
| | | | | | | 21 participants identified through an open invitation to an email discussion group and were interviewed via email. | | Semi-structured interviews completed via email during a span of 2-6 months. 5-60 (15 average) emails were |

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| | | | | | Posts made on an online discussion group during the 2 years before the study commenced. | | | exchanged with each participant. | |
| | | | | | | Online discussion group posts that were generated within 2 years prior to the study commencing. | | | |
| Oliver et al. (2020) [90] | UK | To explore the experiences of parents of children with limb difference who use prosthesis. | 7 | Not provided. | Parents of children with limb difference aged 5-16 years old. Mean not provided. | Participants identified through the social media pages of online charities supporting adults and children who experience limb difference. | 2 Upper Limb 5 Lower Limb 6 Congenital 1 Acquired Time since amputation not provided. | Semi-structured interviews completed over the phone and in person lasting 47-66 minutes with an average of 57 minutes. | Theme 3: Experiences of using prosthetics. |
| Mathias and Harcourt (2013) [91] | UK | To explore the dating and intimate | 4 | 4 females | 18 - 23 years old. | Participants recruited through | 4 Below knee amputations. | Semi-structured interviews completed | Theme 4: Experiences of romantic |

| | | relationships experiences of women with below knee amputations. | Mean not provided. | amputee Facebook groups. | Over 4 years following amputation. | through an online messaging platform (MSN) lasting about 1h. | relationships and sexuality. | |
|--------------------------------|---------|---|-----------------------|---|---|--|--|--|
| Ward Khan et al. (2021) [24] | Ireland | To explore women's experiences of body image and sexuality following lower limb amputation. | 9 | 9 females 35-62 years old. Mean not provided. | Participants identified through a rehabilitation service. | Single high level pelvic amputation. 8 Single below knee amputation. | Semi-structured interviews taking place at locations most convenient for the participants, lasting 1-2h. | Theme 4: Experiences of romantic relationships and sexuality. |
| Keeling & Sharratt (2022) [23] | UK | To explore the experiences of romantic relations of military personnel who have | 4 | 4 males 33-42 years old. Mean not provided. | Participants were identified through a previous study completed by one of the authors, social media, and veteran charities. | Amputation occurred minimum a year before the interviews took place. 2 participants with scaring. 1 above knee amputation, missing digits and scaring. | Semi-structured interviews lasting 60-78 minutes. No location specified. | Theme 4: Experiences of romantic relationships and sexuality. |

experienced
limb loss.

1 Below knee
amputation and
scaring.

Time since
amputation not
provided.

Table 3. IPA quality appraisal guide developed by Rose et al. [64]

| 1. THEORY: | Good | Acceptable | Poor |
|---|--|---|------|
| Good: Clearly subscribes to all of the theoretical principles of IPA in a coherent fashion: it is phenomenological, hermeneutic, and idiographic. | | | |
| Acceptable: Attempts to subscribe to the theoretical principles of IPA but some areas are not clear. Some evidence of the research being phenomenological, hermeneutic, and idiographic. | | | |
| Poor: Not consistent with theoretical principles of IPA. | | | |
| Phenomenological: is the study sufficiently grounded at looking at what the experience is like for the person? Or does it simply look at what happened. Is the question more than “what people talked about”. Are the researchers looking at the meaning? | Hermeneutic: How does the participant make sense of their experience? How does the researcher make sense of the participant making sense of their experience? Is there sufficient interpretation of meaning? | Idiographic: concerned with the particular depth of analysis. How has an experience been understood from particular people in a particular context? Does it link to theory? | |
| 2. INFORMANTS: | Good | Acceptable | Poor |
| Good: Appropriate data from a homogenous sample of participants relevant to the research question | | | |
| Acceptable: Appropriate data from participants which has enabled the researchers to make some attempts to answer the research questions. | | | |
| Poor: Inconsistencies in data collection and lack of information on participant selection, unable to conclude if the participants are a homogenous sample. | | | |
| Notes: Make references to the homogeneity of sample. | | | |
| 3. TRANSPARENCY: | Good | Acceptable | Poor |
| Good: Sufficiently transparent so that the reader can see all the stages of the research process. | | | |
| Acceptable: Appropriately transparent, lacks detail in some areas of research methodology. | | | |
| Poor: It is unclear what stages were undertaken; the majority of information is missing. | | | |

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|---------------------------|------|------------|------|
| 4. COHERENCE OF ANALYSIS: | Good | Acceptable | Poor |
|---------------------------|------|------------|------|

Good: Sufficient sampling from the corpus. There are appropriate extracts from at least half the participants for each of the themes presented.

Acceptable: Appropriate sampling from corpus to show density. Most of themes have extracts from at least half of the sample.

Poor: The themes are not evidenced well. Mostly large number of themes which may be superficial from a large number of participants. Analysis lacks interpretation and there is little or no commentary.

| | | | |
|-----------|------|------------|------|
| 5. FOCUS: | Good | Acceptable | Poor |
|-----------|------|------------|------|

Good: The paper has a specific focus. The research question is interested in something that is of significance to the participant's life and is answered by the research.

Acceptable: The paper has some focus, but it is not specific. The research question has some significance to the participant's life but is not specifically important.

Poor: The paper lacks a strong focus. It is questionable as to whether the research topic is of interest to the participant. Findings not related to question asked.

| | | | |
|---------------------|------|------------|------|
| 6. TRUSTWORTHINESS: | Good | Acceptable | Poor |
|---------------------|------|------------|------|

Good: Appropriate use of triangulation or audit and/or credibility-checking to achieve trustworthiness.

Acceptable: Some attempt of using triangulation, audit, or credibility.

Poor: No use of triangulation, audit, or credibility checks.

Table 4. Individual and overall study scores using Rose et al. [64] guide.

| Cooper et al. (2018) [69] | | | |
|---------------------------|------------------|---------------|---|
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Good | Poor | Sample appears homogenous. |
| Informants | Good | | |
| Transparency | Acceptable | | |
| Coherence of Analysis | Poor | | |
| Focus | Good | | |
| Trustworthiness | Poor | | |
| Hill (2017) [72] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Poor | Sample relatively homogenous based on research question. Both lecturers and students able to reflect on learning difficulties within the course but different perspectives expected given difference of experience. |
| Informants | Acceptable | | |
| Transparency | Good | | |
| Coherence of Analysis | Poor | | |
| Focus | Acceptable | | |
| Trustworthiness | Poor | | |
| Hill (2020) [71] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Poor | Sample appears to be homogenous. |
| Informants | Acceptable | | |
| Transparency | Acceptable | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Poor | | |
| Trustworthiness | Poor | | |
| Lopez et al. (2017) [76] | | | |

| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
|------------------------------------|------------------|---------------|---|
| Theory | Poor | Poor | Comments made by the wife of one participants were included. |
| Informants | Poor | | Sample not homogenous. |
| Transparency | Good | | |
| Coherence of Analysis | Poor | | |
| Focus | Poor | | |
| Trustworthiness | Acceptable | | |
| McDonald et al. (2020) [77] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Poor | Sample is not homogenous. Most participants had congenital limb absence, and some acquired limb loss. That means that their perception of ability will be influence by different factors and even though they present themes that theoretically were derived from all participants. |
| Informants | Poor | | |
| Transparency | Good | | |
| Coherence of Analysis | Poor | | |
| Focus | Acceptable | | |
| Trustworthiness | Acceptable | | |
| Middleton and Ortiz-Catalan (2020) | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Poor | Homogenous sample. |
| Informants | Acceptable | | |
| Transparency | Poor | | |
| Coherence of Analysis | Poor | | |
| Focus | Good | | |
| Trustworthiness | Acceptable | | |
| Kragh Nielsen et al. (2022) [84] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Poor | Sample appears to be homogenous. |

| Informants | Good | | |
|---|------------------|---------------|---|
| Transparency | Good | | |
| Coherence of Analysis | Poor | | |
| Focus | Good | | |
| Trustworthiness | Acceptable | | |
| <hr/> Olsen et al. (2023) [80] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Poor | Sample is not homogenous. |
| Informants | Acceptable | | |
| Transparency | Good | | |
| Coherence of Analysis | Poor | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Roșca et al. (2021) [74] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Poor | Unable to conclude if the sample is homogenous as no data provided around gender, time since amputation, living situation. Big age range. |
| Informants | Poor | | |
| Transparency | Acceptable | | |
| Coherence of Analysis | Poor | | |
| Focus | Acceptable | | |
| Trustworthiness | Poor | | |
| <hr/> Schoenberg and Shiloh (2002) [66] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Poor | Sample is not homogenous - 8 participants had amputations and 2 had bone fractures and had a big age range (38-62yo). |
| Informants | Poor | | |
| Transparency | Acceptable | | |

| Coherence of Analysis | Poor | | |
|-------------------------------------|------------------|---------------|--|
| Focus | Poor | | |
| Trustworthiness | Poor | | |
| Stutts et al. (2015) [78] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Poor | Massive time range since amputation (0-41 years), women with different levels and types of amputation. Looks at post-traumatic growth but this can differ significantly for someone who just had it and someone who had it for 41 years. Sample is not homogenous. |
| Informants | Acceptable | | |
| Transparency | Acceptable | | |
| Coherence of Analysis | Poor | | |
| Focus | Acceptable | | |
| Trustworthiness | Acceptable | | |
| Washington and Williams (2016) [83] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Poor | Sample appears to be homogenous. |
| Informants | Acceptable | | |
| Transparency | Acceptable | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Poor | | |
| Trustworthiness | Poor | | |
| Moraal et al. (2013) [70] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Acceptable | Only 1 participant so no argument about homogeneity can be made. |
| Informants | Acceptable | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |

| | | | |
|-------------------------------------|------------------|---------------|--|
| Trustworthiness | Acceptable | | |
| <hr/> Murray (2004) [85] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Acceptable | Sample is homogenous given all participants were using prosthesis. |
| Informants | Acceptable | | An argument can be made that the embodiment experience for ULP, and LLP might be different as well as there might be a completely different experience for people with acquired limb loss and congenital limb absence. |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Murray (2005) [58] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Acceptable | Sample relatively homogenous. |
| Informants | Acceptable | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Murray (2009) [89] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Acceptable | Sample not entirely homogenous. |
| Informants | Acceptable | | Big age range and sample constitutes of both limb loss and congenital limb difference and both upper and lower limb amputations and difference for which the personal meanings of using prosthesis may vary a lot. |
| Transparency | Acceptable | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Richardson et al. (2020) [68] | | | |

| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
|-----------------------------------|------------------|---------------|---|
| Theory | Acceptable | Acceptable | Homogenous sample. |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| Saradjian et al. (2008) | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Acceptable | Sample is homogenous - authors seem to have purposely excluded women with the argument that majority of ULA happens to men. |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| van Heijningen & Underhill (2022) | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Poor | Acceptable | Homogenous sample for the most part. |
| Informants | Acceptable | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Poor | | |
| Zhu et al. (2020) [21] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Acceptable | |

| Informants | Good | | |
|--------------------------------------|------------------|---------------|---|
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Hamill (2010) [73] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Good | Good | They studied adjustment within 18 months of amputation, so all participants were amputated within that timeframe. 1 participant was still at rehab, 7 were at home. Sample is largely homogenous. |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Good | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Katsanou et al. (2020) [79] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Good | Good | Homogenous sample - All participants adults with amputations who were part of an Olympic team and had all had amputation 3 years prior (at least) of the interviews. |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| <hr/> Keeling & Sharratt (2022) [23] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Good | Good | Homogenous sample. |
| Informants | Good | | |
| Transparency | Good | | |

| Coherence of Analysis | Good | | |
|----------------------------------|------------------|---------------|--|
| Focus | Good | | |
| Trustworthiness | Acceptable | | |
| Mathias and Harcourt (2013) [91] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Acceptable | Good | Homogenous sample. |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Good | | |
| Focus | Good | | |
| Trustworthiness | Good | | |
| Oliver et al. (2020) [90] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Good | Good | Sample mostly homogenous (congenital and acquired could have a different experience, and the location of the limb difference could also play a part, but all participants were parents and age range was good to provide specific enough information). |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Acceptable | | |
| Focus | Good | | |
| Trustworthiness | Acceptable | | |
| Ward Khan et al. (2021) [24] | | | |
| Assessed area | Individual score | Overall score | Comments about homogeneity of sample. |
| Theory | Good | Good | Homogenous sample relevant to research question. |
| Informants | Good | | |
| Transparency | Good | | |
| Coherence of Analysis | Good | | |

| | |
|-----------------|------------|
| Focus | Good |
| Trustworthiness | Acceptable |

Appendix 1-A: Instructions for authors.

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Disability and Rehabilitation is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

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- Observational studies - [STROBE](#)
- Randomized controlled trial - [CONSORT](#)
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Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
 - People with MS have complex reasons for choosing to exercise or not.
 - Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.
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Updated 12-11-2021

Appendix 1-B. Implications for Rehabilitation**Implications for Rehabilitation**

- Interpretative phenomenological analysis (IPA) provides a robust, qualitative method for a range of health professionals in understanding and facilitating rehabilitation for people with limb difference.
- The evidence base gathered by IPA relating to limb difference and rehabilitation indicates the importance of providing and receiving support, physical and psychological adjustment to limb difference, experience of prosthesis use, and the impact of limb difference on romantic relationships and sexuality.
- The review provides a detailed guide of how to evaluate, design and report IPA research in relation to limb difference and rehabilitation.

Appendix 1-C. Grouping process.

| Author & year of publication | Summary | Label | Final Theme title |
|-----------------------------------|---|----------|--|
| Schoenberg and Shiloh (2002) [66] | Receiving psychological support for limb loss when in hospital. Focus on the elements that facilitate and inhibit engagement with psychological support offered. | Support. | |
| Richardson et al. (2020) [68] | The study focuses on the experiences of peer mentors for people with limb loss. Participants spoke about the value of supporting others with limb loss and the importance of having a shared experience. Difficulties in peer mentoring were also explored. | Support | Theme 1: The process of learning, supporting and alternative ways to receiving help. |

| | | |
|---------------------------|---|-------------------------------------|
| Cooper et al. (2018) [69] | Using a virtual reality programme for rehabilitation. Participants were part of the virtual world as avatars. The authors explained how this helped them gain a sense of being “whole”. | Alternative ways to provide support |
| Moraal et al. (2013) [70] | Virtual reality for rehabilitation. The participant was a veteran with limb loss. The authors explored the experience of using a virtual environment to support with prosthesis use. | Alternative ways to support. |
| Hill (2017) [72] | The author explains threshold and non-threshold concepts. Interviews were completed with undergraduate students studying prosthetics and their lecturers with the goal to establish which parts of the knowledge acquired are threshold concepts. | Leaning. |

| | | |
|--------------------------|--|-------------|
| Hill (2020) [71] | Republished study. Same summary | Leaning. |
| Hamill (2010) [73] | Focus on adjustment a year and a half after limb loss. Participants highlighted the importance of being in control regarding the decisions they would make. Social parameters affecting adjustment were discussed (gender, relationships with others around them). | Adjustment. |
| Roșca et al. (2021) [74] | The study focuses on the understanding of adjustment following limb loss. Strong focus on the factors that make adjustment more challenging such as isolation and physical limitations. | Adjustment. |
| Lopez et al. (2017) [76] | Exploration of the experiences of older people with amputations when using wheelchairs. Talks about aspects that help adjustment with a | Adjustment. |

| | | |
|-----------------------------|--|---|
| | specific focus on being given different options of treatment to choose from. | |
| McDonald et al. (2020) [77] | Sample included both people with congenital and acquired limb loss. The study focuses on the adjustment and the development of a new identity with the support of social communities around. | Adjustment. Theme 2: Physical and Psychological adjustment to limb difference. |
| Stutts et al. (2015) [78] | The study focuses on adjustment and post-traumatic growth of women with limb loss. Helpful and inhibiting factors impacting on adjustment were discussed. | Adjustment. |
| Katsanou et al. (2020) [79] | Adjustment of athletes engaging in paralympic sports following limb loss. Processes that aided adjustment were discussed. | Adjustment. |

| | | |
|-------------------------------------|---|-------------|
| Olsen et al. (2023) [80] | Focus on adjustment and motivation to be active during leisure time and how this is linked with embodiment. Factors that influence motivation and their greater impact discussed as well. | Adjustment. |
| Washington and Williams (2016) [83] | Participants had experienced limb loss and also had diabetes and vascular disease. Helpful and unhelpful processes that aid or inhibit adjustment were discussed. | Adjustment. |
| Zhu et al. (2020) [21] | Participants had diabetes and had experienced limb loss. Difficulties of leading a “normal” life explored with participants talking about the fear of being amputated but trying to remain positive by keeping parts of their day-to-day lives before amputation alive. | Adjustment. |

| | | |
|----------------------------------|--|-------------|
| Kragh Nielsen et al. (2022) [84] | Participants did not experience amputation before the interviews but could be at risk of it. The predicted outcomes of amputation were discussed including the potential use of prosthetics. Focused both on the physical and psychosocial adjustment. | Adjustment. |
| Murray (2004) [85] | Understanding the experience of embodiment of prosthesis. The link between the phantom limb and the prosthesis played a part in the process of embodiment - the prosthesis felt like the missing limb. | Prosthesis. |
| Saradjian et al. (2008) | Participants used upper limb prosthesis. The study explores the impact of limb loss and the use of prosthesis by participants. Prosthesis helped participants maintain the appearance they had pre- | Prosthesis. |

Theme 3: Experiences of using prosthetics.

| | | |
|------------------------------------|--|---|
| | limb loss and facilitated social engagement. | |
| Middleton and Ortiz-Catalan (2020) | Bionic limb prosthesis. Through the interviews the benefits of using this type of prosthesis were explored. The concept of embodiment was brought up by participants as well. | Prosthesis. |
| van Heijningen & Underhill (2022) | The authors explored the experiences of using digital prosthesis. Participants spoke about the help prosthesis offered in completing tasks of daily living and being independent. | Prosthesis. |
| Murray (2005) [58] | Prosthesis use understood through the lens of social interactions. Participants spoke about how others see them in social environments and the importance of using prosthesis to hide limb loss. Romantic and sexual | Prosthesis. Relationships. Theme 3: Experiences of using prosthetics. & Theme 4: Experiences of romantic relationships and sexuality. |

| | | | |
|----------------------------------|--|-------------------------|--|
| | relationships also discussed. | | |
| Murray (2009) [89] | Prosthesis use explored through understanding its personal meaning to participants. Appearance and functionality discussed as well as independence that can be achieved through prosthesis use. | Prosthesis. | |
| Oliver et al. (2020) [90] | Participants were parents of children with congenital limb difference. Understanding of the use of prosthesis for children through the perspective of the parents. Lower and upper limb prosthesis discussed. | Prosthesis. | Theme 3: Experiences of using prosthetics. |
| Mathias and Harcourt (2013) [91] | The study focused on the understanding of romantic relationships of women with limb loss. The topic of disclosure was central | Romantic relationships. | |

for women to judge the suitability of partners.

| | | | |
|-----------------------------------|--|------------------------------------|---|
| Ward Khan et al. (2021) [24] | The study focuses on the experiences of women with limb loss. Worries around changes in appearance were explored in the context of sexual interest and romantic relationships. | Romantic relationships. | Theme 4: Experiences of romantic relationships and sexuality. |
| Keeling & Sharratt (2022) [23] | Participants were military men who had experienced limb loss. The changes in intimate relationships following limb loss and the worries around intimacy were explored. | Intimacy and sexual relationships. | |

Appendix 1-D. Extended version of IPA scores.

| Cooper et al. (2018) [69] | | | | | |
|---------------------------|------|------------|------|---------------|---|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | X | | | Poor | Theory - Clear explanation of all IPA underpinnings. Clearly stated why this method is suitable for this specific topic. |
| Informants | X | | | | Informants - Sample appears homogenous. Enough data to answer question. |
| Transparency | | X | | | Transparency - All stages clear but given the fact that it is part of a bigger study, some more information could have been given. |
| Coherence of Analysis | | | X | | Coherence of analysis - Not enough excerpts, massive number of themes. |
| Focus | X | | | | Focus - Clear focus, great results presented but not in an IPA way. |
| Trustworthiness | | | X | | Trustworthiness - No mention of audit, triangulation, or credibility checks |
| Hill (2017) [72] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory - No mention of IPA theory, reasons for using IPA not set out. |
| Informants | | X | | | Informants - Sample relatively homogenous based on research question. Both lecturers and students able to reflect on learning difficulties within the course but different perspectives expected given difference of experience. This is not discussed in the study. Data from participants is enough to answer research question. |
| Transparency | X | | | | |
| Coherence of Analysis | | | X | | |

| Focus | | X | | | Transparency - All stages of research sufficiently transparent. Coherence of analysis - Not enough extracts in most themes. No interpretation of extracts presented. Experience looked into and individual accounts presented. Focus - Topic of some interest to the participants. Trustworthiness - Triangulation - data gathered from 2 groups (students and lecturers) but no explicit explanation given on differences in accounts or overlapping data. No use of audit or credibility checks. |
|-----------------------|------|------------|------|---------------|---|
| Trustworthiness | | | X | | |
| Hill (2020) [71] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory: They used a theoretical approach of troublesome knowledge and threshold concepts from the outset and then they organised their themes based on how it fit to those theories. No mention of why IPA is appropriate for the research question. IPA theoretical underpinnings not presented. |
| Informants | | X | | | Informants - Sample relatively homogenous based on research question. Both lecturers and students able to reflect on learning difficulties within the course but different perspectives expected given difference of experience. This is not discussed in the study. |
| Transparency | | X | | | Coherence of analysis: Not enough extracts provided and no measure of prevalence of themes even though they mention 'Frequency of occurrence and the variation within the emergent themes were also considered'. Description of data, lack of interpretation. |
| Coherence of Analysis | | | X | | Focus: Debatable significance to participants since no implications of research discussed. |
| Focus | | | X | | |
| Trustworthiness | | | X | | |

| | | | | | |
|--------------------------|------|------------|------|---------------|--|
| | | | | | Trustworthiness: Analysis completed by one person, no mention of triangulation, audit, or credibility checks. |
| Lopez et al. (2017) [76] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory - Limited explanation of IPA underpinnings in Design. Explanation of why it is the best method to study experiences of adjustment when using a wheelchair long-term attempted but not fully clear. |
| Informants | | | X | | Informants - Sample is not homogenous as participants' wife's comments included but only for 1 participant- all participants used wheelchairs daily which was central to the research question. Sample selection is clear, but extracts do not answer the research question. |
| Transparency | X | | | | Transparency - All stages of research process clear. |
| Coherence of Analysis | | | X | | Coherence of analysis - Themes present enough extracts but it is not clear which comments were made by a participant's wife and which comments were the participant's comments. One interview stopped at 15 minutes, so richness of data cannot be determined. |
| Focus | | | X | | Focus - Data from participants not fully relevant to research aim. Aim was to understand adjustment to limb loss when using a wheelchair long term and reader expects to understand the role of long-term wheelchair use in aiding or inhibiting adjustment. Extracts not relevant to this - instead they provide an account of general adjustment experiences not linked with wheelchair use. Findings are not directly relevant with research question. Research question remains unanswered. |
| Trustworthiness | | X | | | Trustworthiness - Audit described. |

| McDonald et al. (2020) [77] | | | | | |
|------------------------------------|------|------------|------|---------------|--|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Poor | Theory - Theoretical underpinning explained. Idiography and interpretation could have been explained more clearly. |
| Informants | | | X | | Informants - Sample is not homogenous. Most participants had congenital limb absence, and some acquired limb loss. That means that their perception of ability will be influenced by different factors and even though they present themes that theoretically were derived from all participants, it would be more robust if the sample was homogenous. |
| Transparency | X | | | | Scoring poor even though there is enough info on participant selection. |
| Coherence of Analysis | | | X | | Transparency - All stages clear. |
| Focus | | X | | | Coherence of analysis - There are interpretations and commentary but not enough extracts. Not even half of the participants' extracts present. Some participants' data were never quoted (there are names in their table that are not mentioned in the analysis). |
| Trustworthiness | | X | | | Focus - Focus of the paper could be more specific. Trustworthiness - Audit process explained. |
| Middleton and Ortiz-Catalan (2020) | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Poor | Theory - Through the intro the authors show an in depth understanding of what IPA is and what it is designed to study. The phenomenological |
| Informants | | X | | | |
| Transparency | | | X | | |

| Coherence of Analysis | | | X | | element and idiography are described but not named. Hermeneutics openly stated. Informants - Sample is homogenous - all had bionic limbs and had been using them for over 2 years. Not enough information on participant selection. Transparency - It is not entirely clear how participants were recruited. Coherence of analysis - The authors presented categories in which they included identified themes. It is unclear whether they used the word category instead of theme or they did not follow the exact IPA guidance on theme generation. More like 3 case studies where description of experience is given through quotes. Minimal interpretation. Focus - Significant to participants. Trustworthiness - Audit mentioned but no details given. |
|----------------------------------|------|------------|------|---------------|--|
| Focus | X | | | | |
| Trustworthiness | | X | | | |
| Kragh Nielsen et al. (2022) [84] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory - IPA underpinnings mentioned some in Design and some in Data generation. Not a concise clear account of what IPA does. Appropriateness of using IPA to answer the research question not explained. |
| Informants | X | | | | Informants - Sample seems to be homogenous in addressing the research question. All participants had diabetic foot ulcers but no planned amputations. Sufficient information on participant selection. |
| Transparency | X | | | | Transparency - Stages of research process clear. |
| Coherence of Analysis | | | X | | |
| Focus | X | | | | |

| Trustworthiness | | X | | | Coherence of analysis - Not enough extracts provided. No interpretation present in discussion and not enough commentary in the results section. Extracts are described rather than interpreted. Looks into experience and gives attention to individual accounts. Focus - Clear focus and usefulness of research. Trustworthiness - Audited by senior researchers, not much detail provided on the process though. Reflexivity also discussed. |
|--------------------------|------|------------|------|---------------|---|
| Olsen et al. (2023) [80] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory - Theoretical underpinnings of IPA not clearly stated. Hermeneutics referred to as reflection. No mention of idiography. Informants - Enough information provided on participant selection. Authors tried to recruit a sample with similar characteristics but due to the big age range and years after amputation it is apparent that the sample is not homogenous. Transparency - Clear stages of research. Coherence of analysis - There is interpretation present but not enough excerpts from participants. There is a theme that has no excerpts at all. The themes are not generated based on what participants spoke about around their motivation to exercise but were based on the Self-Determination theory and Maurice Merleau-Ponty's concepts of embodied phenomenology. Whilst the findings are interesting and useful for limb loss communities, this is not standard IPA. Focus - Study of great significance to participants. Trustworthiness - Auditing completed by 7 'peer debriefers'. Participants were invited in a type of 'reflective' triangulation. |
| Informants | | X | | | |
| Transparency | X | | | | |
| Coherence of Analysis | | | X | | |
| Focus | X | | | | |
| Trustworthiness | X | | | | |

| Roșca et al. (2021) [74] | | | | | |
|-----------------------------------|------|------------|------|---------------|---|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Poor | Theory - Theoretical underpinning of IPA mentioned but lack detail. |
| Informants | | | X | | Informants - Unable to conclude if the sample is homogenous as no data provided like gender, time since amputation, living situation. Age range is big. Not enough info provided on selection of participants. No inclusion or exclusion criteria. |
| Transparency | | X | | | Transparency - Stage of participant selection not clear. Rest of areas transparent enough. |
| Coherence of Analysis | | | X | | Coherence of analysis - Extracts from at least half of participants. |
| Focus | | X | | | Interpretation present but authors use self-psychology theory to generate results instead of immersing in the data to identify themes as they emerge through the narratives which could then confirm or contradict existing theory. |
| Trustworthiness | | | X | | Focus - Focus is clear but could be clearer with a homogenous sample and clear inclusion and exclusion criteria. Trustworthiness - No audit, triangulation, or credibility checks. |
| Schoenberg and Shiloh (2002) [66] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Poor | Theory - Talks about method used being IPA in abstract - no direct explanation of why this is the best approach in Methods but in the last paragraph in the intro it explains the importance of looking into |
| Informants | | | X | | |
| Transparency | | X | | | |

| | | | | | |
|-----------------------|--|--|---|--|--|
| Coherence of Analysis | | | X | | participant's experiences. It is not linked with the IPA theoretical presentation, but a reference is made to it. |
| Focus | | | X | | Informants - More info could be given on participants selection. Sample is not homogenous - 8 participants had amputations and 2 had bone fractures and had big age range (38-62yo). Authors try to look into inhibiting and facilitating forces to attending psychology whilst being an inpatient but the differences in conditions (amputation vs bone fracture) and big age range could mean that the sample is not similar enough to answer the question. Research question is answered based on data provided from participants but uncertain whether results would be the same if the sample was homogenous. |
| Trustworthiness | | | X | | Transparency - No information given on inclusion and exclusion criteria. Seems like anyone who accepted to be interviewed was included in the study. Coherence of analysis - Analysis is influenced by the Approach - Avoidance model - authors seem to present the data that is fitting this model rather than the themes that occur through the analysis of the data. Unable to say which participants said what given lack of anonymised identifiers. There is some interpretation of data present. Focus - Even though findings shed some light to the research question, they are heavily influenced by the Approach - Avoidance model which weakens the focus of the study which was to explore the experiences of hospitalised patients of receiving psychological support. Trustworthiness - No audit, triangulation, or credibility checks. Also, participants known to researcher as they were working there which can affect the results as some people might answer in specific ways as they think their care will be affected. |

| Stutts et al. (2015) [78] | | | | | |
|-------------------------------------|------|------------|------|---------------|---|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory - No explanation of IPA theory. Argument made for why a qualitative approach was necessary, but not why IPA was the best approach for it. |
| Informants | | X | | | Informants - Massive time range since amputation (0-41 years), women with different levels and types of amputation. Looks at post-traumatic growth but this can differ significantly for someone who just had it and someone who had it for 41 years. Sample is not homogenous. Enough info on selection presented and data to answer the research question. |
| Transparency | | X | | | Transparency - Stages transparent enough but info missing on inclusion and exclusion criteria. |
| Coherence of Analysis | | | X | | Coherence of analysis - No commentary, no interpretations, not enough excerpts. |
| Focus | | X | | | Focus - Clear focus but as the sample is so varied it might not be beneficial and of the same interest to all. |
| Trustworthiness | | X | | | Trustworthiness - Mentions audit. More detail on audit process could have been provided. |
| Washington and Williams (2016) [83] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Poor | Theory - They state they use interpretivistic phenomenology. IPA as a term not used. Underpinnings of IPA not explained. Smith cited but no elaboration on the method used. |
| Informants | | X | | | |
| Transparency | | X | | | |

| Coherence of Analysis | | X | | | Informants - Sample appears to be homogenous - this allowed authors to make an attempt to answer the research question. Transparency - Transparent enough to understand stages of research. Lacks detail in IPA explanation - confusion about use of IPA to analyse transcripts. Coherence of analysis - Some interpretation present. Some themes have less than half participants' excerpts. Focus - Focus appears clear initially but conclusions are not clear enough and claims from authors are not always backed. Trustworthiness - No mention of any audit, triangulation or credibility checks. |
|---------------------------|------|------------|------|---------------|--|
| Focus | | | X | | |
| Trustworthiness | | | X | | |
| Moraal et al. (2013) [70] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Acceptable | Theory - No explanation as to why they needed IPA. Phenomenology made reference to but no reference to hermen and Idiogr. Informants - Only 1 participant so sample is homogenous. Data from participant attempted to answer the research question. This is more of a case study and would be best seen as such rather than IPA. Transparency - All stages of research clear. Coherence of analysis - There is interpretation and clear evidence but seems more like a case study in general than IPA. Focus - Clear focus and of significance to participant. Trustworthiness - Credibility checks. Some audit also present. |
| Informants | | X | | | |
| Transparency | X | | | | |
| Coherence of Analysis | | X | | | |
| Focus | X | | | | |
| Trustworthiness | | X | | | |
| Murray (2004) [85] | | | | | |

| | Good | Acceptable | Poor | Overall score | Comments |
|-----------------------|------|------------|------|---------------|--|
| Theory | | X | | Acceptable | Theory - Explanation of why IPA needed presented. Phenomenology explained but no mention of interpretation or idiography in the description of the approach. Interpretation mentioned in Reliability and Validity section but made no reference to within explanation of IPA theory. |
| Informants | | X | | | Informants - Sample is relatively homogenous given all participants were using prosthesis. An argument can be made that the embodiment experience for ULP, and LLP might be different as well as there might be a completely different experience for people with acquired limb loss and congenital limb absence. Information on participant selection clear. |
| Transparency | X | | | | Transparency - Stages of research very clear. |
| Coherence of Analysis | | X | | | Coherence of analysis - Very high number of participants - half of participants' extracts included criterion not met. There is interpretation present but not all participants' extracts could be included. |
| Focus | X | | | | Focus - Paper has strong focus and explores a topic very important to participants. |
| Trustworthiness | X | | | | Trustworthiness - Triangulation (used interviews & discussion group material). |
| Murray (2005) [58] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Acceptable | Theory - Clear explanation of why IPA is needed. Explanation of phenomenology. Interpretation and idiography not fully clearly stated. |
| Informants | | X | | | Informants - Sample relatively homogenous. All participants used prosthesis so conclusion about its social meaning can be drawn. Sample |
| Transparency | X | | | | |

| Coherence of Analysis | | X | | | | not fully homogenous though given that people with congenital limb absence may have different experiences since experiencing limb loss from birth. Transparency - All stages of study clear. Coherence of analysis - Themes well evidenced, interpretations presented. But not all themes have at least half the participants' extracts included. Sample very large. Focus - Clear focus of study. Trustworthiness - Triangulation - data from different sources presented. |
|-----------------------|------|------------|------|---------------|---|---|
| Focus | X | | | | | |
| Trustworthiness | X | | | | | |
| Murray (2009) [89] | | | | | | |
| | Good | Acceptable | Poor | Overall score | | Comments |
| Theory | | X | | Acceptable | Theory - Reasons why IPA is suitable explained. Phenomenology explained. Idiography and hermeneutics not made reference to. | |
| Informants | | X | | | Informants - Sample not entirely homogenous. Big age range and sample constitutes of both limb loss and congenital limb difference and both upper and lower limb amputations and difference for which the personal meanings of using prosthesis may vary a lot. Data enough to answer research question. | |
| Transparency | | X | | | Transparency - No information provided on inclusion and exclusion criteria. All other stages very clear. | |
| Coherence of Analysis | | X | | | Coherence of analysis - Very big sample (35) - not half of participant excerpts provided. Great detail into interpretation. | |
| Focus | X | | | | Focus - Very clear focus. | |
| Trustworthiness | X | | | | Trustworthiness - Triangulation (used interviews & discussion group material). | |

| Richardson et al. (2020) [68] | | | | | |
|-------------------------------|------|------------|------|---------------|---|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Acceptable | Theory - Theoretical underpinnings clearly outlined. No reference made as to why IPA is the best method to study this. |
| Informants | X | | | | Informants - Homogenous sample. Clear info on participant selection. |
| Transparency | X | | | | Transparency - Clear stages of study. |
| Coherence of Analysis | | X | | | Coherence of analysis - At least half participants' quotes included in themes. Some interpretations present. |
| Focus | X | | | | Focus - Clear focus of study of interest to participants. |
| Trustworthiness | X | | | | Trustworthiness - Audit process explained in detail. Also, great reflexivity section. |
| Saradjian et al. (2008) | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Acceptable | Theory - Great explanation of IPA theory in methods but idiographic aspect not mentioned. Clear explanation of why it is suitable to answer the research question. |
| Informants | X | | | | Informants - Sample is homogenous - authors seem to have purposely excluded women with the argument that majority of ULA happens to men. |
| Transparency | X | | | | Transparency - All stages of research clearly presented. |
| Coherence of Analysis | | X | | | Coherence of analysis - Enough extracts from participants. There are points where interpretation is present but could have been more detailed. |
| Focus | X | | | | Has details of individual experience. Author's presentation of relationship between themes and overarching themes (awareness of physical difference |
| Trustworthiness | X | | | | |

| | | | | | <p>and ability) and outcome (pride in positive coping) is initially confusing. Too many subthemes.</p> <p>Focus - Clear focus of study and interesting findings that enrich knowledge on studied area.</p> <p>Trustworthiness - Audit and credibility checks.</p> |
|--------------------------------|------|------------|------|---------------|--|
| van Heijnen & Underhill (2022) | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | | X | Acceptable | <p>Theory - Only mention of phenomenology. Hermeneutics and Idiography not mentioned at all. No explanation of why IPA is the best method to study this topic.</p> |
| Informants | | X | | | <p>Informants - Homogenous sample for the most part. Despite that, a participant had known the author before - not sure how credible the data can be. One of the participant did not meet the inclusion criteria which was to be using prosthesis. Authors did not specify how long this participant had not used prosthesis for.</p> |
| Transparency | X | | | | <p>Transparency - All stages clear. Tables with IPA analysis steps and inclusion and exclusion criteria table great additions.</p> |
| Coherence of Analysis | | X | | | <p>Coherence of analysis - At least half of participants' extracts presented. Enough commentary and some interpretation. Excerpts could be more detailed to prove the interpretations.</p> |
| Focus | X | | | | <p>Focus - Clear focus and significant to participants even though arguments made in discussion not fully supported from results.</p> |
| Trustworthiness | | | X | | <p>Trustworthiness - One participant was known by the researcher and was asked to act as if they didn't know each other (?). Author suggests summaries and transcribed material was crosschecked with the participant for validity but not the analysis.</p> |

| Zhu et al. (2020) [21] | | | | | |
|------------------------|------|------------|------|---------------|---|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Acceptable | Theory - Some IPA theory explained in the methods section. No justification provided on why it is the best method to study the research question. Some more IPA theory provided in the data analysis section but still no justification as to why it is the best method for the specific question. |
| Informants | X | | | | Informants - Sample is homogenous as all participants had amputations and had undergone wound care. All participants had experienced amputation within the last year but for some participants it was not their first amputation. |
| Transparency | X | | | | Transparency - All stages of research are transparent. |
| Coherence of Analysis | | X | | | Coherence of analysis - All themes but one have extracts from at least half of the participants. Interpretation of extracts present. Looks into the experiences of participants and focuses on the individual account. |
| Focus | X | | | | Focus - Clear focus of study - useful for participants with amputation and wound care needs. |
| Trustworthiness | X | | | | Trustworthiness - Audit and credibility checks process presented. |
| Hamill (2010) [73] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | X | | | Good | Theory - They set out characteristics of IPA and why it is appropriate for their research question. |
| Informants | X | | | | Informants - They studied adjustment within 18 months of amputation, so all participants were amputated within that timeframe. 1 participant was |
| Transparency | X | | | | |

| Coherence of Analysis | X | | | | still at rehab, 7 were at home. Sample is largely homogenous. Data from participants answers research question sufficiently. Transparency - All stages of research process are clear. Coherence of analysis - Extracts from more than half of participants for each theme, looks at experience, it gives attention to individuals and the groups, interpretation present at various parts. Focus - Clear focus, topic significant to participants and results answer the research question. Trustworthiness - Audit and Credibility checks. |
|--------------------------------|------|------------|------|---------------|---|
| Focus | X | | | | |
| Trustworthiness | X | | | | |
| Katsanou et al. (2020) [79] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | X | | | Good | Theory - All theoretical IPA underpinnings explained - reason for choosing IPA explained too. Informants - Homogenous sample - All participants adults with amputations who were part of an Olympic team and had all had amputation 4 years prior (at least) of the interviews. Inclusion criteria stated in detail. Transparency - All stages of research are clear. Coherence of analysis - Enough extracts from participants and interpretation. Authors do not include pseudonyms or numbers as identifier for the reader to see which participants said what. Focus - Very clear focus of the study. Trustworthiness - Audit present. |
| Informants | X | | | | |
| Transparency | X | | | | |
| Coherence of Analysis | | X | | | |
| Focus | X | | | | |
| Trustworthiness | X | | | | |
| Keeling & Sharratt (2022) [23] | | | | | |

| | Good | Acceptable | Poor | Overall score | Comments |
|----------------------------------|------|------------|------|---------------|--|
| Theory | X | | | Good | Theory - All theoretical underpinnings of IPA clearly explained in Design - Method. |
| Informants | X | | | | Informants - Homogenous sample. Detailed info on participant selection. |
| Transparency | X | | | | Transparency - All stages very transparent and clear. Great explanation of why 2 participant interviews were excluded. |
| Coherence of Analysis | X | | | | Coherence of analysis - Extracts from at least half of the participants presented. Interpretations present. |
| Focus | X | | | | Focus - Clear focus of study. |
| Trustworthiness | | X | | | Trustworthiness - Some attempt of using audit. |
| Mathias and Harcourt (2013) [91] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | | X | | Good | Theory - No mention of the idiographic aspect of IPA. Talks about experience and interpretation and explains why it is suited to address the research question. |
| Informants | X | | | | Informants - Homogenous sample - appropriate data that allows research question to be answered. |
| Transparency | X | | | | Transparency - Clear stages of research. |
| Coherence of Analysis | X | | | | Coherence of analysis - Extracts enough - interpretation present, links individual experience and group experience. |
| Focus | X | | | | Focus - Clear focus. |
| Trustworthiness | X | | | | Trustworthiness - Audited by other researcher since first author had experienced limb loss. |

| Oliver et al. (2020) [90] | | | | | |
|------------------------------|------|------------|------|---------------|--|
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | X | | | Good | Theory - Clear explanation of theoretical underpinnings of IPA & explanation of why it is needed to study the current matter. |
| Informants | X | | | | Informants - Sample mostly homogenous (congenital and acquired could have a different experience, and the location of the limb difference could also play a part but all participants were parents and age range was good to provide specific enough information). Detailed explanation of participant selection. |
| Transparency | X | | | | Transparency - All stages very clear. |
| Coherence of Analysis | | X | | | Coherence of analysis - Themes are well evidenced but some of the quotes are very short. Interpretation and commentary present. Fantastic summaries at the end of each theme encapsulating the results. |
| Focus | X | | | | Focus - Clear focus and of interest to the participants. |
| Trustworthiness | | X | | | Trustworthiness - Reference to audit made but no details provided. |
| Ward Khan et al. (2021) [24] | | | | | |
| | Good | Acceptable | Poor | Overall score | Comments |
| Theory | X | | | Good | Theory - Theoretical underpinnings of IPA stated. |
| Informants | X | | | | Informants - Homogenous sample relevant to research question. Info on participant selection available. |
| Transparency | X | | | | Transparency - All stages of research are transparent. |

| | | | | | |
|-----------------------|---|--|--|--|---|
| Coherence of Analysis | X | | | | Coherence of analysis - Extracts from at least half of the participants are present. Interpretation fantastic, looks at individual experience and gives info for the entirety of participants. |
| Focus | X | | | | Focus - Clear focus and issue significant to participants. Trustworthiness - Some audit present. |

Chapter 2 : Empirical Paper

Experiences of Receiving Psychological Support following Limb Loss

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Prepared for submission to Disability and Rehabilitation (please see Appendix 2-D for author guidelines and 2-E for Implications for Rehabilitation)

Abstract

Purpose: This study sought to explore the experiences of receiving psychological support following limb loss.

Materials and Methods: Semi-structured interviews were conducted with five individuals who had experienced limb loss and had received psychological support for it. 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 limb loss can be delivered or improved. These include: 1) the importance of psychological preparation before planned amputations and 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.

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

Introduction

The psychosocial difficulties experienced due to limb loss have been well documented in literature [1]. Depression is often experienced during the early stages following amputation 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]. Between 21-63% of people with traumatic limb loss experience depression [2], with young people with amputations being affected more than older ones [3]. Anxiety has been reported to affect over half of the population with limb loss especially during hospitalisation and the early stages of recovery [1], with people sharing experiences of despair, rumination, helplessness, and insomnia [4].

Body image disturbance is a common psychological difficulty [1]. People with limb loss often report dissatisfaction, and at times repulsion with the way their bodies look after surgery [5], something that has been found to affect their self-esteem and impact on the formation and maintenance of romantic relationships [6,7].

Changes in identity and self-perceptions present challenges to the person with limb loss as they transition from an able-bodied identity to one of ‘disability’ that may evoke feelings of inferiority [8]. Returning to work might be challenging and some individuals have to change jobs or modify their workplace [9].

In order to effectively support individuals following limb loss, rehabilitation offered needs to be coordinated by multidisciplinary teams (MDTs) that are able to support the management of the variety of challenges experienced and aid physical and psychological adjustment [10-13]. Challenges in the care provided include lack of clear communication that

leaves individuals unprepared before the operation, limited support upon discharge, professional neglect in identifying psychological support needs and lack of empathy [14]. In order to combat that, it has been recommended that consultation by mental health professionals needs to be offered throughout the pre- and post-amputation phases [14,15].

Offering an MDT approach addressing the holistic, biopsychosocial needs of individuals with limb loss has been found to improve physical ability and general health [11]. Working as a psychologist in an MDT that supports the rehabilitation of people with limb loss focuses on increasing psychologically informed thinking within the team, and on the effective completion of assessments, formulations, and interventions [16]. Aside the regular process of assessing someone's psychological difficulties [17], specific assessment tools have been developed such as the Trinity Amputation and Prosthesis Experiences Scales (TAPES) [18] and the e-Questionnaire for Persons with a Transfemoral Amputation (Q-TFA) [19] that measure psychosocial adjustment and prosthesis satisfaction. In regards to therapy and interventions, Cognitive Behavioural Therapy (CBT) has been found to enhance quality of life for people with limb loss, as well as reduce anxiety, low mood and pain, and improve self-esteem and sleep [20]. CBT has also been found to increase positive outcomes when used in inpatient settings with older populations [21] as well as when specialised versions of it are used for the management of chronic pain caused by amputation [22]. In addition, guided imagery [23] and Eye Movement Desensitisation and Reprocessing (EMDR) [24] have been found to help in the management of phantom limb pain experiences. Solution-focused Therapy and Motivational Enhancement Therapy are approaches shown to aid adjustment during the early stages of the rehabilitation process [25].

It has been suggested that counselling can be helpful as an early intervention, during the first few weeks following 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 [26].

Whilst the above-mentioned recommendations and guidance offer valuable insight into mental health approaches for supporting people following amputation, no research has been done to understand the experience of receiving formal psychological support from the perspective of those with limb loss. 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 aimed to explore the experiences of people who had received psychological support following limb loss in order to make recommendations for improving this.

Method

Design

This study was concerned with prioritising the first-person perspectives and experiences and sense-making of people with limb loss 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)[27]. IPA has a set of theoretical assumptions and philosophical underpinnings that align closely with the aims of the research. These include an ontological and epistemological adoption of aspects of philosophical phenomenology (the study of lived experience as it appears in consciousness), hermeneutics (the interpretation, or

making sense of, experience), idiography (the detailed examination of individual accounts alongside the identification of shared experience/understandings for a well-defined, small, homogenous group) [27]. This contrasts with other frequently used methods for studying experiences of phenomena, such as reflexive thematic analysis [27,28]. Unlike IPA, RTA is not wedded to a single set of theoretical or philosophical assumptions, so these need to be made explicit. As the influential proponents of RTA, Braun and Clarke [28], note, IPA is a methodology that provides an entire framework for those conducting research. Contrarily to that, TA is resembling “bespoke furniture” that someone can design and build independently. In ‘building it yourself’, therefore, it is possible to draw on similar frameworks to design an RTA study that do something similar to IPA, but these do not offer an obvious way that improves it.

Ethical Approval

Ethical approval was granted by the Lancaster University Faculty of Health and Medicine ethics committee (reference number FHM-2022-0645-RECR-2). The application submitted, and approval can be found in Chapter 4.

Recruitment

The plan for recruiting participants included two stages. Stage 1 focussed on obtaining participants who received psychological support for their limb loss by mental health professionals. In case it was not possible to recruit enough participants with these experiences, a second stage of recruitment was planned, broadening the type of professionals that had offered psychological support to include any other health care professionals. Enough

participants were recruited through stage 1, and the second stage of recruitment was not needed.

Sampling and Participants

IPA uses small, homogeneous samples that allow for the identification of convergent and divergent accounts within and across well-defined samples [27,29]. Small sample sizes allow for an in-depth analysis of data, so that the detail of each individual case can be explored and interpreted [30]. For that reason, the current study aimed to recruit between 6 to 10 participants.

Inclusion criteria for the study were individuals above 18 years old who had experienced amputation of an upper or lower extremity and had received psychological support. 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 in order to safeguard the therapeutic alliance between participants and their therapists [31].

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 met the inclusion criteria and completed the interviews (table 1). Participants were aged between 38 and 56 years old (mean=45.6) and had received psychological support between three months to seven years prior to the interview.

Despite the diverse background of participants (different countries of origins), majority of participants had experienced traumatic amputations. More specifically, one of the participants was shot in the leg during a trip to another country, another participant had an amputation due to cancer, another due to a fall from an escalator, and two others due to road

traffic accidents. Even though the leading cause of limb loss in developed countries is diabetes [32,33], no participants with amputations caused by diabetes expressed interest in participating in the study. Reasons behind this could include the fact that older adults who experience limb loss due to diabetes [34] are not accessing and using social media, where the study was advertised, as much as younger counterparts [35].

[INSERT TABLE 1 HERE]

Difficulties with finding people who had received psychological support prolonged recruitment, that lasted for 7 months. Although this is a lower number than originally sought, recommendations for professional doctorates indicate a range of 4 to 10 participants is preferable [36].

Procedure

The study was advertised on social media (Facebook, Reddit and Twitter). The advertisement comprised of a poster explaining the purpose of the study, an electronic participant information sheet and an ‘expression of interest’ form (Chapter 4, Appendix 4-J) 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 via Microsoft Teams. Verbal consent was requested and videorecorded prior to the commencement of the interview. After the completion of 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 (Chapter 4, Appendix 4-I) was developed by the lead researcher in collaboration with the research team. As a first step the lead author familiarised herself with published IPA interview schedules [37,38], and following this developed questions with the aim to capture the meaning making of participants regarding their experience of receiving psychological support. Both the second author (a clinical psychologist working directly with people with limb loss in a prosthetic and rehabilitation centre) and third author (a health psychologist with an extensive publication record with limb loss populations using IPA) provided feedback on the questions. This process led to improvement of the schedule, which included questions such as: ‘What aspects of the support you received helped you the most?’. Questions were used as a guide throughout the interview and the lead researcher was able to use them flexibly to promote understanding of the experiences and meaning-making of participants. All interviews were conducted by the lead researcher and lasted between 67 and 98 minutes (mean=83 minutes).

Data Analysis

Interview transcripts were produced, and participants were given pseudonyms to maintain confidentiality. As described by Smith [36,p.38] analysis aims to ‘understand the content and complexity of [...] meanings rather than measure their frequency’. In order to achieve that and to provide a fully auditable analysis, the IPA analysis steps described by Murray and Wilde [29] were followed (Step-by-step guide available in Appendix 2-B). This involved reading each transcript multiple times, keeping the research question in mind and developing initial codes for each transcript (Coding example in Appendix 2-A). The initial

codes of each transcript were grouped into clusters (individual themes) and a narrative summary was written for each. After the process was completed for all transcripts, through identifying convergent and divergent information, the clusters were merged into final themes. 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. [39].

Credibility

A detailed audit trail (example available in Appendix 2-C) was developed for each transcript. By doing this, Yardley's [40] guidance to committing to transparency, rigour, and sensitivity to context in order to produce qualitative research of high standard was followed. The audit trails of each interview and the final themes generated were shared with the research team who were able to provide feedback on the work completed. Through this process, clusters were reviewed and updated, and the titles given to final themes amended.

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 [41,42]. 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 influence on the analysis remains limited [27]. The lead researcher used a reflective journal throughout the interview and analysis of data stages (excerpts from the reflective journal can be found in Chapter 3).

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. The contribution that each participant's data and analysis made to these final group themes are provided in table 2.

[INSERT TABLE 2 HERE]

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

Under consideration here are the different emotional reactions participants had to limb loss 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

‘therapist’ and ‘psychologist’ interchangeably) and it was through this that he realised that the trauma of his limb loss 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)

The losses and significant transformations Jack experienced are evident through his narrative. He had not been given the time to process his limb loss and that led to him experiencing trauma that was “locked away”. 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)

Jack felt that none of his accomplishments, actions and relationships mattered any more as losing his legs felt like losing his life. This led to the decision to take his life as in his mind his old self had already died. Witnessing how others valued his life by trying to save him on the day of the accident, led to a cognitive shift for Jack, a shift towards valuing his own life. Fighting suicidal thoughts and suppressing any negative feelings, ‘converted’ 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 that filling in a questionnaire for the litigation taking place for his limb loss, following a road traffic accident, triggered the initial feelings of grief as he 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 limb loss 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)

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 for his quick adjustment to a new normal. Having no time to process what was happening to him but realising that the shot could lead to him to dying posed a severe existential threat to him:

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 seeing more as a victim of something bad that has happened to you...

And I didn't really enjoy that very much. That sucked. (Robert)

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 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 (limb loss due to cancer) 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. Her therapist provided a space for her where she could be who she truly was without having to compete or prove herself and her progress to others:

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)

Reaching out to her when she had not made contact meant that Daisy, who had been struggling with feeling like a burden to others, was able to reclaim her value as an individual and feel "wanted" when possibly other relationships around her had left her feel like she was managing her limb loss "alone". Daisy's experience of needing more help made her feel like a burden to others and having a professional that is approachable and allowed for a safe therapeutic relationship to develop was very helpful for her:

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 on 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 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 excerpt from Daisy's interview where she was engaging in the assessment process but that was not explained to her, making her feel that the questions asked at the initial stages of therapy were "basic" and not "directly related" to the amputation. This confusion and lack of understanding of what was going on during therapy made Daisy feel that her session were now irrelevant with her problem, a sense that could pre-empt the rest of her therapy negatively:

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 that she was attending her physiotherapy sessions at, 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 on the care she receives:

Like thinking about this out loud, why is counseling offered and not for example, CBT or [a] clinical psychologist... like who has decided that counseling 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 limb loss 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 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:

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, they both were very

aware of the triggering emotions they were experiencing. For Daisy, a sense of guilt in 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 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. For Jack experiencing EMDR as successful brought up a sense of relief and opened up the way to living his life in a different way becoming aware of what his five year old self had experienced:

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)

Bigest 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 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. Through reaching to others and sharing her experiences

with them Daisy developed a new identity, one that gave her a sense of belonging a new community:

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).

A contemporary topic, the way of attending sessions, was raised by Melissa as an important issue that can support individuals with limb loss, given the physical restraints. 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 psychological support following limb loss, 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 limb loss and others accepting what had happened but questioning whether their reaction was “valid”. The emotional reactions experienced by participants are discussed in theories published on the psychological adaptation of people with chronic illness and disability [43,44]. Based on those theories, the psychological reactions experienced after traumatic events are “raw” and representative of the emotional state of the people in the moment but also a natural outcome of their experience. Following the initial reactions, a reduction in the intensity of experience is noted as adaptation to the traumatic event begins, a process that can be influenced by personality and social support available.

Not being warned about the psychological impact of limb loss caused additional difficulties in the already challenging process of experienced grief. As one of the participants shared, he would have wanted to be told by the professionals around him that this was something that he could experience. The importance of pre-operative preparedness has been stressed for some time [45]. Despite this, it appears that it may not be common practice amongst some 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 theme captured participants' needs for focus, transparency, and specialist knowledge. These findings accord with the Common Factors theory [46,47] that 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 [48].

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. [49]. 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 [50]. The current study extends the importance of those 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.

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 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 has been found to support resilience in other populations with disabilities, such as those with spina bifida [51], and peer support has been shown to be beneficial for individuals with limb loss [52]. 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 [24].

Clinical Implications

Five areas of important clinical implications have been identified through the results of the current study. These include: 1) the importance of psychological preparation before planned amputations and 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. [45] supporting individuals with planned amputations psychologically before limb removal is an essential step that can support with psychological adjustment following surgery. With the current evidence about the importance of MDT approaches for the support of people with limb loss [10,11,13], pre-operative and post-operative support can be provided by qualified psychologist, who can enhance psychological preparation and adjustment to all facets of limb loss.

The Pluralistic Framework [53] 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 [53]. 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 [54].

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 [55]. 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 has been used in recent years instead of psychiatric diagnosis . 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 [56], 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 [57]. 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.

Limitations

Whilst the study makes important contributions for the improvement of future psychological work and rehabilitation, the study did not include a diverse sample. All participants were white, and all resided in developing countries. Even though generalisation of results is not an IPA aim, having a larger sample with more diverse participants would have allowed for more understanding of how to improve psychological support that is not Eurocentric. The lack of participants who had experienced diabetes also meant that large portion of people with limb loss was not represented in the sample.

Whilst the development of the interview schedule included input from all members of the research team, it lacked input from experts by experiences who could have provided a different perspective on the development of specific questions. Moreover, recruiting participants online meant that people with no access to social media were not aware of the study, and therefore were unable to participate. Whilst the sample is considered homogenous in regards to the features of research concern, 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, issues that compromise part of the demographic homogeneity of the sample.

Further limitations include, that the analysis was primarily conducted by one researcher with discussions and modifications following consultation with other team members. Although this can help increase the fidelity and depth of analysis, there are always additional details and emphases that could be given prominence with the involvement of additional researchers. This reflects a limitation of all qualitative analysis in that the final outcomes are to some degree reliant on the interpretative capacities of those engaged in research [27].

Future Research

Future research could focus on exploring the experiences of receiving psychological support of a more varied sample and the study could adopt a longitudinal approach to investigate where positive results remain over time or whether psychological input is required for a longer period of time.

The study highlighted the importance of specialist knowledge and understanding of psychologists and other mental health professionals when supporting individuals with limb loss. 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 used IPA to explore the experiences of receiving psychological support following limb loss. The findings have revealed supportive and hindering aspects in therapy that has led to recommendations on how to improve future psychological support provided.

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Table 1. Participants' demographics and information on psychological support.

| Pseudonym | Age in years | Country of residence | Limb loss type | Time since psychological | Type of professional input |
|-----------|--------------|----------------------|---------------------------|--------------------------|----------------------------|
| Robert | 39 | Sweden | Right leg Above knee | 3 years ago | Psychologist |
| Gordon | 56 | UK | Right leg Through knee | Less than a year ago | Psychologist |
| Daisy | 38 | US | Right leg Below knee | 3 months ago | Psychologist |
| Melissa | 48 | UK | Left leg Above knee | 5 years ago | Counsellor |
| Jack | 47 | US | Bilateral Above knee | 7 years ago | Psychologist |

Table 2. Individual themes' (clusters) contribution to the final themes.

| Participant | Theme 1 - The need for psychological intervention - denial and acceptance. | Theme 2 - 'Safe space' - being valued, heard, and validated. | Theme 3 - The importance of focus, transparency, and specialist knowledge | Theme 4 - The most helpful techniques and approaches |
|-------------|---|---|---|--|
| Robert | <ul style="list-style-type: none"> • Quick adjustment to a new normal. • Defending an able-bodied identity. | <ul style="list-style-type: none"> • It's OK to feel OK. • Normalisation of feelings from psychologist and the knowledge that help is available are the biggest help. | | |
| Gordon | <ul style="list-style-type: none"> • Not warned about the grieving process. | | <ul style="list-style-type: none"> • Lack of focus in therapy, identification of needs and specific approach made sessions unhelpful. • Timing and the need for a psychologist who knows about the emotional impact of limb loss. | |
| Daisy | <ul style="list-style-type: none"> • Limb loss changing life for ever. | <ul style="list-style-type: none"> • Creating a safe space to share difficulties and being genuinely concerned. | <ul style="list-style-type: none"> • Need for transparency, agenda setting and therapy planning. | <ul style="list-style-type: none"> • Self-compassion supported a new perspective. • Signposting and encouraging contact with |

experts by experience can aid normalisation.

Melissa

- Safe space and the lack of pressure
- Person centred care in therapy - ‘tuning into’ individual needs.
- Remote access to support
- Need for transparency and open communication

Jack

- Locked away trauma - not realising the emotional impact of limb loss.
- Finding our own way through it is not the same as professional treatment.
- The success of EMDR
- The dangers of working with the wrong therapist

Appendix 2-A. Example of coding.

| Initial Codes | Transcript |
|--|--|
| Psychologist made her feel heard but was good at redirecting her. | So, the... what I felt was most effective with her is that in terms of interacting with me, is that she gave me the time and space, if you will, to fully express myself and be heard. But she was also good at redirecting me or kind of 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, it was she was really good at redirecting me and taking back control of the session while also like I said, just making me feel heard. So that was a that was a really good method. Another thing that she did for me is that 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 like, I felt that she was genuinely concerned and wanted to hear back from me. And like a problem that that I struggle with is, I feel like I'm the burden sometimes, especially now that I do need more help with stuff. I, you know, 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. 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. So, that was good. 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 |
| Psychologist genuinely concerned. | |
| Feeling wanted and cared for by the psychologist. | |
| Psychologist encouraged her to reach out to experts by experience and through that normalisation was possible. | |

Encouragement by
psychologist to be kinder
to self - self compassion.

beneficial. She just encouraged me this was a big thing that she spoke on is just encouraged me to be kind to myself because I was under the impression and still kind of am, that if you just work hard enough, if you just practice enough, if you just walk enough, if you just anything enough, then you'll get the desired result. 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 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. But then, in a way like, it helps you kind of work out like past issues. You know those kind of like Daddy issue kind of thing you know so that was a big one. It's just being kind to myself.

Appendix 2-B. Murray and Wilde [35] - IPA Methodology.

1. Choose a transcript and format it for analysis.
2. Read the transcript with the research questions in mind and make notations on the transcript.
3. Copy notations to Post-it notes.
4. Group Post-it notes into clusters.
5. Write extended narratives for each cluster.
6. Produce a table for each cluster, with original notations and narratives. Supporting quotes from the transcript can be added into a third column.
7. Title the cluster.
8. Repeat steps 1-7 for subsequent transcripts.
9. Merge analysis across transcripts.

Appendix 2-C. Participant four - theme four - audit trail.

| Theme 4 - Need for transparency and open communication - Melissa 48 | | |
|---|---|---|
| Initial Codes | Narrative Summary | Illustrative Quotes |
| Lack of certainty on why a counsellor was chosen instead of a Clinical Psychologist. | In this theme Melissa describes how she felt that the lack of communication and transparency from the rehabilitation clinic was counteracted by the openness by her counsellor. Melissa's counsellor was able to explain things to her that had not been explained by other professionals such as the support and help available by other centres, and the difference in rehabilitation needs for different types of amputation. It is evident that Melissa started feeling suspicious towards the rehabilitation centre since no explanations were given as to why she would access psychological support through counselling and not a therapist or a psychologist and whether she would be able to access further physical support if it was needed. | I suppose this part of me that thinks...like thinking about this out loud, why is counseling offered and not for example, CBT or clinical psychologist... like who has decided that counseling is what's required when you lose a limb? And I... Because you would... Yeah, I don't know. I suppose so that's just me thinking out loud... I don't know. |
| Counsellor raising awareness. | | I didn't realize I could go to another centre. I didn't realize they didn't do it all in groups, and that was just about numbers. So, I think she raised my awareness of what was accessible and out there. And the reality of that was just too far. If I wanted to work, that was just too far to travel to. |
| Counsellor explaining things that were not explained properly by other professionals. | When Melissa expressed her dissatisfaction to her counsellor about having to attend group sessions that were not very helpful for her as she had to compare and compete with others, she was offered an extra two individual sessions. Melissa started doubting whether she would have been able to access this had she declined the support from the counsellor and she ultimately started doubting how | So, in some ways, going forwards, I think they should just separate that rehab. Whether they can financially, I don't know. Because I don't think it was... I think it was a quite an odd thing to be part of this group where people were jumping out of their seats and moving and then there was a few of us but weren't and kind of couldn't move. So, I think that was helpful because the counsellor had the time, I think to kind of explain that actually people might have lost a leg, but you've lost it in different places. Just real obvious stuff that wasn't ever really explained because we were kind of mixed. So, I think for me, the counsellor was a real support. |
| Thoughts that further support wouldn't open up without psychological help. | | 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. thinking that and I'm only reflecting on this now... thinking about it now, if I'd have said "no, thank you, I don't want counseling into the |

| | | |
|--|--|--|
| | <p>confidential her sessions were given that the information might have been shared from her counsellor to the team without her knowing. This theme highlights the importance of transparency and open communication both in sessions and in the general rehabilitation process.</p> | <p>physio''. Would I have got those two, you know, sessions that were pretty much one to one. So, I don't know actually. When I think about it, whether I definitely think it helped me, but I would like... because it's linked to the centre. I suppose that's my point. I don't know if that is an advantage or a disadvantage.</p> |
|--|--|--|

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 - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
 - Reconstructive surgery is a technique available to this group.
 - In a relatively small sample this study shows participation and social functioning improved after surgery.

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Updated 12-11-2021

Appendix 2-E. Implications for Rehabilitation.**Implications for rehabilitation**

- Psychological support needs to be provided both before planned limb removal surgery and throughout the rehabilitation process.
- Transparency regarding the stages of therapy, models used, and decisions made as well as collaborative goal setting need to be incorporated in psychological sessions.
- Psychologists and other mental health professionals offering support to individuals with limb loss need to have specialist knowledge on limb loss and its psychological entailments.
- Treatment needs to be formulation driven.

Remote access to therapy can increase engagement in psychological interventions as it allows for people with mobility difficulties to attend sessions more easily.

Chapter 3 : Critical Appraisal

Critical reflection on the exploration of individuals' experiences of receiving psychological support following limb loss.

June 2023

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Word Count: 3941 (Excluding references, appendices, tables and figures)

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Critical Appraisal

Within this critical appraisal I present a summary of the systematic literature review and empirical paper, including the clinical implications identified. Following this, practical, methodological, ethical, and personal reflections are shared in the context of the strengths and limitations of the research process undertaken for the empirical paper and recommendations for future research are made.

Summary of findings

In the systematic literature review I presented a thematic summary of studies that have used interpretative phenomenological analysis (IPA) [1] to study limb difference and rehabilitation. I identified four thematic areas: 1) The process of learning, supporting and alternative ways to receiving help; 2) Physical and psychological adjustment to limb difference; 3) Experiences of using prosthetics; and 4) Experiences of romantic relationships and sexuality. These findings highlight the intricate psychological processes of adjustment to limb difference and the complex facets of rehabilitation. The review highlighted the importance psychologists play in the care of individuals with limb difference, as part of a multidisciplinary team [2-5]. Additionally, the findings indicate the importance of psychologists in raising awareness and supporting colleagues from other disciplines to understand the psychological implications of limb difference, particularly in regards to multidisciplinary teams working in psychologically informed ways to provide support and guidance [6].

The review had a particular concern with encouraging the adoption of IPA in researching limb difference and prosthesis use, and in providing rehabilitation professionals

working with this client group with an understanding of how to appraise and design what constitutes robust IPA research. Therefore, I examined the adherence of the identified studies to IPA guidance published by Rose et al. [7]. Each study was appraised against the following criteria: 1) Theory; 2) Informants; 3) Transparency; 4) Coherence of Analysis; 5) Focus; and 6) Trustworthiness. An overall score of ‘Good’, ‘Acceptable’ or ‘Poor’ was given to each paper. Through this, the reader becomes familiar with the particular processes that need to be followed for the production of a high-quality IPA study.

In the empirical paper, I explored the experiences of receiving psychological support following limb loss. Five participants shared their experiences through semi-structured interviews. Data was analysed using IPA [1] and four themes were identified: 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. From these findings recommendations were made about the ways in which psychological care provided following limb loss can be improved. These included: 1) the importance of psychological preparation before planned amputations and 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 on the field of limb loss; 4) formulation driven treatment; and 5) remote access to therapy.

Practical Reflections

Prior to my thesis work, my experience with research had been limited and engaging in the process brought about challenges I was not anticipating. One of the main ones was the recruitment of participants. Early familiarisation with literature presenting the psychological

difficulties following limb loss [8] and stressing the need for psychological support to become an integral part of rehabilitation [2,3], led me to the understanding that despite increased need, psychological support was not something that the majority of people with limb difference were offered. Despite this, I did not anticipate that finding participants would have been as challenging, as recruitment lasted for 7 months and the target sample of 6 to 10 participants was not met. As the study was advertised on social media groups (Facebook, Reddit and Twitter) for people with limb difference, it was easier for people who would see the advert to interact with the posts published by commenting on them [9], something that offered further insight into the problem. One person commented: “You will struggle finding anyone who has had the support... that’s half the problem with amputations... there is very little support out there. If you do any studies offering the support, we are local to [area] and my husband has had a transmetatarsal amputation and would be happy to be involved”. Extensive use of IPA [1] for the completion of the study has equipped me with the skill to interpret this comment as a ‘call for help’ from an individual who is worried about a loved one and who would be willing to participate in the study, or any other study, that could offer the needed support.

The effectiveness of recruiting participants through social media is debatable with some evidence suggesting that it can help access populations that are ‘hard-to-reach’ [10]. In the case of this study, the difficulties accessing this ‘hard-to-reach’ sample were further exacerbated when administrative members of multiple groups refused to allow publication of the study advertisement. Potential reasons behind this might include ethical considerations around increasing the benefits and mitigating potential harm that could be inflicted to members of the group [11], as some of the groups’ main focus was normalisation of limb difference and peer support and advertising a research study within the group could be perceived as non-altruist or even coercive [12]. From the groups the study was advertised at,

13 individuals expressed interest to participate in the study, of which 3 who met the inclusion criteria never responded to the invitation to interview, and 5 did not meet the inclusion criteria.

The recruitment process became even more challenging when relevant limb difference charities that I approached to advertise the study shared difficulties with disseminating the information. These barriers included shortage of staff and uncertainty on how internal advertising procedures would take place since changes brought about by Covid-19. Lack of stakeholder engagement meant limited access to limb difference populations, but also lack of access to experts by experience who would be able to review the interview schedule and provide feedback [13]. This was counteracted by support provided by both the research supervisor and field supervisor who are both experienced in research and clinical practice with individuals with limb difference respectively, who offered invaluable input to further improve the interview guide.

The realisation that the planned sample size would not be met caused anxiety and worry for the feasibility of completing the study, something that was discussed with my research supervisor frequently. This led to the decision to widen the inclusion criteria to reach a sample that had been psychologically supported by any mental health professional. Having a sample that was not supported only by clinical psychologists could arguably compromise one characteristic of sample homogeneity [1], despite this, having some diversity in the professionals that provided help in this study, albeit small, would make the clinical implications for practice more transferable as they could provide guidance to the variety of mental health professionals who can support people following limb loss.

Despite not meeting the originally planned sample size, interviewing 5 participants provided rich data to address the research question. Guidance on sample sizes for IPA studies

suggest that a sample between 4 and 10 participants is preferable as it facilitates for the idiographic focus of IPA, that would become more difficult to achieve with larger IPA samples [14].

Methodological Reflections

The choice to use IPA was guided by the suitability of its theoretical underpinnings of phenomenology, idiography and hermeneutics [1], that can best address the research question of this study, facilitating the in-depth exploration and interpretation of the meaning making of participants' experiences. Unlike thematic analysis, 'that has limited interpretative power beyond mere description' [15], p.97], IPA uses a process of 'double hermeneutics' where the researcher interprets the participants' interpretations of their experiences [16]. 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 [17]. Drawing more parallels between IPA and 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 [18], it is equally important to adopt a reflexive approach whilst using IPA [1]. 'Bracketing' the researcher's experiences and assumptions allows for a more objective interpretation of the participants' narratives.

In order to adopt a reflexive approach, both during the interviews and the analysis of the results, I used a reflective diary in which I recorded my own thoughts, expectations, and assumptions, which I shared and discussed with my research supervisor. The following excerpt from the diary is reflective of some of my thoughts after the final interview:

Everyone I spoke to shared their experiences so openly and with no hesitation. They said I can ask as many questions as needed and even thanked me for the interviews. This shows their selflessness as they are willing to revisit past trauma in order to help other people in the future to get better help than they did. I just hope I am capable enough and skilled enough to do the data justice and properly present the findings to help improve future care.

The decision to conduct interviews online instead of face-to-face was a decision made collaboratively with my research supervisor, as this would increase the geographical areas and opportunity to take part in the study. Being very familiar with using Microsoft Teams for clinical sessions since the beginning of the Covid-19 pandemic, I was aware of the advantages and disadvantages of trying to engage people through a screen, and I was able to use my experience to facilitate safe and meaningful conversations. For example, through delivering sessions online I became aware that there may be individuals who, due to socioeconomic constraints, might have limited internet access or no access to digital devices such as laptops and computers [19]. To counteract this the option to attend interviews via telephone was offered to all participants.

Whilst all participants requested for the interviews to take place on Microsoft Teams, one of them (Daisy) requested for the camera to be turned off as she felt more comfortable to speak about the physical challenges of limb loss without being seen. Even though arguments have been voiced regarding the lack of body language visual cues that can indicate participants' distress or other emotional state when interviews are held over the phone, there is no evidence to suggest that the richness of the data would be compromised [20]. I personally did not find that not being able to see the participant limited my perception of their emotional state as changes in the tone of voice or sounds that indicated the need to cry were very clear throughout the interview and the option to pause the interview was instantly

offered. Even though this might not be the case for all participants, this specific interviewee felt extremely comfortable to name what was happening and expressed their appreciation for having the opportunity to participate in the interview:

...one of the things that I would like to express, I don't know if other people feel the same way, but you giving me the opportunity to just speak about my experience is so cathartic... I maybe started crying here and there, but that was like 2 less times than I would normally cry, so I would like to personally thank you for taking the time to like just research this and just to listen to me. So, I appreciate you. (Daisy)

Regarding the richness of data through the analysis, this participant's interview provided rich content relating to the emotional difficulties that led to them requesting psychological support and the quality of the support they received. This supports existing evidence that telephone interviews can make people feel more relaxed, therefore enhancing disclosure [21].

Similarly, attending the interviews online appeared to make participants feel safer to share their experiences, as they could attend privately in their own space [22]. As an approach, conducting the interviews online opens up the way for people with mobility difficulties, such as those who have experienced limb loss, to participate in research that would have otherwise been more challenging [23]. This was reflected in one of the participant's statements (Melissa) where they shared that they had stopped attending their counselling sessions as it was difficult to travel long distances following limb loss as it was exhausting. This is something that could have been the case regarding the interview as well, as they may have not participated if interviews were to be held in person.

Ethical Reflections

Ensuring that informed consent can be given is an essential part of research [24]. In order to ensure that participants were aware of what the study would entail and highlight that participation was voluntary and interviews could be stopped at any point, a participant information sheet was developed and shared publicly alongside the poster that was used to advertise the study. Consent for data collection in online qualitative research is most commonly requested via email, where the participant might be asked to read the consent form and provide an electronic signature prior to the interview [25]. Despite this, consent forms shared with participants online are not always read and sometimes, even when they are read, there can be specific areas that might not be fully understood. This can jeopardise the ability of participants to provide consent that is informed [26].

In order to ensure informed consent could be obtained for this study, the first step during the online interviews was to screen-share the participant information sheet to guarantee that everyone had the opportunity to access and understand all the information relevant to the study. Following this, specific consent statements designed to further guarantee that the most important aspects of the study were clear and understood by all participants were asked. An example is the following: ‘I understand that my interview will be video recorded and then made into an anonymised written transcript’. The participants had the opportunity to respond with ‘yes’ or ‘no’ and time was also allocated for any questions and clarifications needed. This whole process was recorded separately to the interview.

Whilst this process was necessary, and the reasons behind this were made clear to participants, I was worried that the length of time allocated to this prior to the interview could be experienced as ‘tiring’ by participants, compromising the time that would then be available for the interviews. This did not appear to be the case as all participants were able to

engage in long conversations during the interview and none requested for a break to be taken or for the process to be paused. Despite not being affected by the length of the process, one of the participants (Gordon) shared that he found consent giving ‘triggering’ of past memories. He explained that having to make clear statements of ‘yes’ or ‘no’ to questions reminded him of the litigation process he was involved in relating to the accident that led to their limb loss. The participant expressed those feelings in between the two recordings (the one for consent and the one for the interview) and requested to express those feelings without them being recorded.

My initial reaction to the above, stemming from my clinical experience of working with people who can experience distress during sessions, was to adopt an empathetic approach [27] and to actively listen to the participant’s explanation of how he felt [28]. I asked him if he wanted for the interview to not take place and asked whether he felt he would require more support on this at that moment in time. The participant reassured me that he was feeling comfortable with continuing with the interview stage and the option to stop the interview at any time was again highlighted. Throughout the interview, I ensured that he was comfortable with the interview questions, and as I did with all the interviews, I explained at the beginning that there was no obligation to answer any questions he felt uncomfortable with. The interview was completed, and the participant stated that he was happy to be contacted for a second interview if it was needed in the future.

Personal Reflections

Completing my thesis as the final assignment of the Doctorate in Clinical Psychology, has helped me to start shaping my own identity as a scientist-practitioner. Intertwining research and clinical practice is considered imperative in the field of psychology, as research

is essential for the enrichment of the psychological evidence base [29]. Psychologists with research knowledge are better equipped in clinical practice whilst also being able to lead on the investigation of important issues that come to light through clinical practice. Personally, whilst I have been comfortable the past few years with identifying as a clinician, or a psychologist, I initially struggled to feel like a ‘researcher’. Indeed, I was conducting research, learning more about research methodologies, had interviews with participants and was attending a doctoral course within which research was considered an essential component. Despite this, identifying as a ‘researcher’ felt like something I was attempting to become and that would come with more experience later on. Similar feelings have been reported with Greek family therapy trainees who have shared that despite their training they were not yet identifying with the professional title of ‘therapist’ [30].

Whilst the roles of a researcher and a clinician appear to be perceived as complementary, my experience of completing this thesis has led me to the understanding that separating the two roles is very important, especially during interviews with participants. One of the biggest challenges I encountered was transitioning from a clinician who feels the need to support individuals emotionally during distress, to a researcher who can appear containing and empathetic but does not offer psychological support to relieve the distress experienced [31]. This was particularly evident when, as discussed above, participants would express discomfort or appear upset during the interviews. The following excerpt from my reflexive diary is reflective of the difficulty I experienced remaining in the role of the researcher when one of the participants appeared upset. This happened whilst they were reflecting on the moment that they realised that their life ‘had changed forever’ following their limb loss, something they perceived entirely as their own fault:

The participant cried when talking about their limb loss and how their life changed, saying they are the one to blame. The first thing that came to mind was

how would I be able to support them through cognitive reframing and emotion regulation exercises. Despite this, I reflected that this appeared to be a very difficult experience for them and offered the option of pausing the interview.

Managing those automatic responses in my mind was very challenging initially but, as the process continued, and through reflection, I managed to redirect those emotions to focus on the end goal, which would entail using the data shared to equip clinicians that would offer the support I could not offer at that moment in time.

My first contact with the subject of limb difference and rehabilitation was at the beginning of my doctoral studies. Despite being interested in understanding the experiences of psychological support following limb loss and feeling passionate about enriching the existing evidence base, I had no prior experiences of contact with people with limb difference. To address this, I tried to actively engage with published literature and chose to focus the topic of the Thesis Preparation assignment (an assignment that was completed at the first year of my studies) on reviewing exemplar literature on the psychological difficulties experienced following limb loss [8], 37-40]. Even though I was aware that completing an assignment 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.

Despite this, after the first interview I came to the realisation that many of the topics participants would make reference 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’ is reflective of the stage I am at in my career as a psychologist, and 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.

Completing the thesis gave me the opportunity to reflect and bracket my pre-existing assumptions to privilege the meaning making of my participants. This was done in various moments during the interviews including the time when one of the participants (Daisy) shared that they felt like a burden to the professionals she was working with. Hearing this, made me wonder why she felt this way as in my mind physical and mental health professionals have a duty of care towards the people they support and a genuine drive to help, and such an interpretation had not crossed my mind. Noticing this pre-existing assumption, I noted it in my diary and also shared it with my supervisor as I wanted to be able to interpret the participant's comment accurately and without the influence of my own personal perspective. Reflecting on this further and realising my own understanding of professionals having particular roles and obligations, I wondered how people who I offer therapeutic support to view me in therapy and whether they would feel they burden me with the emotions and feelings they share. This has made me more vigilant to express my non-judgmental understanding and acceptance to clients and clarify my willingness and responsibility as a clinician to help and support them.

Future Research and Conclusion

The challenges encountered throughout the process of recruitment, including the difficulty with advertising, including stakeholders, finding participants who meet the

inclusion criteria and accounting for participants who express interest but cannot be contacted, could have potentially made it impossible to complete the study. As done with this study, it would be recommended that for any similar research conducted on a doctoral level, enough time is allocated for the recruitment process so that the recommended sample size for IPA studies [14] can be met and completion of the research is achieved in due time.

Given that the specific sample comprised of people with acquired limb loss, the experiences of psychological support of individuals with congenital limb absence was not explored. Future IPA research could focus on this and draw comparisons with the current study to identify convergent and divergent themes. This will allow for specific recommendations for clinical practice to be made that will ensure that the particular needs and difficulties of the two populations can be addressed through psychological support.

Future studies could also focus on the experiences of managing psychological distress in clients by professionals that have not received training on mental health difficulties such as prosthetists, physiotherapists, orthotists, and occupational therapists. In particular it would be useful to explore how they understand, formulate, and manage psychological distress in their clients.

To conclude, this thesis has presented novel findings regarding the experiences of psychological support of people with limb loss. The exploration and interpretation of participants' experiences through IPA has brought to light detailed evidence of what constitutes helpful and unhelpful clinical practice, which has led to the development of recommendations regarding future psychological support. 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 clinical psychologists, other allied mental health professionals and professionals involved in the general rehabilitation process.

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Chapter 4 : Ethics

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Word Count: 4417 (Excluding Appendices)

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Research Ethics Application Form v1.3

Research Ethics Application Form v1.3

Research Ethics Application Form v1.3 RECR



Experiences of receiving formal psychological support by people with limb loss - Approved

Information Regarding this Research Project

Are you conducting a research project?

(for more information on research projects please see our [ethics pages](#))

Yes No

Does your research only involve animals?

Yes No

Are you undertaking this research as/are you filling this form out as:

- Academic/Research Staff
- Non Academic Staff
- Staff Undertaking a Programme of Study
- PhD or DClinPsy student
- Undergraduate, Masters, Master by Research, MPhil or other taught postgraduate programme

Which Faculty are you in?

Faculty of Health and Medicine

Which department are you in?

Health Research

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

Yes No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

Yes No

Have you got external ethical approval from another organisation? For example another University, the NHS, or an institution abroad (e.g. IRB in USA)

Yes No

Is this an amendment to a project previously approved by Lancaster University?

Yes No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

- Human Participants
- Data relating to humans (Secondary/Pre-existing data only)
- Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
- Human Tissue
- None of the above

Project Information

Please confirm/amend the title of this project.

Experiences of receiving formal psychological support by people with limb loss

Estimated Project Start Date

Estimated End Date

Is this a funded Project?

Yes No

Research Site(s) Information

Will you be using Research Site(s) outside of Lancaster University?

Yes No

Applicant Details

Are you the named Principal Investigator at Lancaster University?

Yes No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Rania

Surname

Malouta

Department

Health Research

Faculty

Health and Medicine

| |
|---------------------------|
| Email |
| r.malouta@lancaster.ac.uk |
| |

Principal Investigator

You have stated that you are the Principal Investigator for this project.

First Name

Rania

Surname

Malouta

Department

Health Research

Email

r.malouta@lancaster.ac.uk

Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.*

| |
|-----------------|
| First Name |
| Craig David |
| Surname |
| Murray |
| Department |
| Health Research |

| | |
|---|-------------------------------------|
| Faculty | |
| Faculty of Health and Medicine | |
| Email | |
| c.murray@lancaster.ac.uk | |
| Do you need to add a second supervisor to sign off on this project? | |
| <input type="radio"/> Yes | <input checked="" type="radio"/> No |

Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

- I am not working with any other team members.
- Staff
- Student
- External

Please list all external contacts here:

First Name

Linda

Surname

Bouquillon

Organisation

NHS

Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your [Ethics Officer](#) before proceeding.

What's the minimum number of participants needed for this project?

What's the maximum number of expected participants?

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

Yes No

Will you get written consent and give a participant information sheet with a written description of your research to all potential participants?

Yes No I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

Yes No I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

Yes No I don't know

Is your research with any adults (aged 18 or older)?

Yes No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

Yes No

Is your research with adult participants (aged 18 years, or older) in private interactions (for example, one to one interviews, online questionnaires)?

Yes No

Is your research with any young people (under 18 years old)?

Yes No I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

Yes No I don't know

Could the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life?

Yes No I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

Yes No I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

Yes No I don't know

Details about Participant relationships

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

Yes No I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

Yes No I don't know N/A

Will you be using a gatekeeper to access participants?

Yes No I don't know
if I will be
using a
gatekeeper

The gatekeeper will be in a position of authority or have influence over potential participants (e.g., a teacher or manager). However, I will take the gatekeeper's assurance that they will stay completely impartial and that I will ensure that there is no perceived pressure to participate, and I will explain to participants that their decision on whether to participate or not will have no effect on their treatment or rights (e.g., learning or assessment).

Yes No I don't know

The gatekeeper will be able to tell who has participated (e.g., participants' responses will be made directly to the gatekeeper or if the researcher will inform the gatekeeper of who has participated), but I have assurance that they will not use this knowledge to treat participants differently.

Yes No I don't know

Will participants be subjected to any undue incentives to participate?

Yes No I don't know

Will you ensure that there is no perceived pressure to participate?

Yes No I don't know

Participant data

Will you be using video recording or photography as part of your research or publication of results?

Yes No

Will you be using audio recording as part of your research?

Yes No

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

Yes No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

No
 Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
 Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

No
 Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

Yes No

Online Sources

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the '[Social Media Guidance for Researchers](#)'

Yes No It's unclear in the terms and conditions

Is there a reasonable expectation of privacy?

Yes No

As there is a reasonable expectation of privacy you must obtain consent from site users.

I confirm that I will obtain consent from relevant site users prior to undertaking this research.

General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affect the independence of the research?

Yes No I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

Yes No I don't know

Can the research results be freely disseminated?

Yes No I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

Yes No I don't know

Will you be gathering/working with any special category personal data?

Yes No I don't know

Are there any other ethical considerations which haven't been covered?

Yes No I don't know

REC Review Details

21 June 2023

Reference #: FHM-2022-0645-RECR-2

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Based on the answers you have given so far you will need to complete some additional questions to allow reviewers to assess your application. It is recommended that you do not proceed until you have completed all of the previous questions. Please confirm that you have finished answering the previous questions and are happy to proceed.

I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Evidence suggests that psychological support following limb loss can be beneficial for individuals. Suggested interventions include psychoeducation, peer groups, counselling and Cognitive Behavioural Therapy. Moreover, innovative interventions such as Cognitive-Behavioural-Physical therapy, which combines psychotherapy and physical therapy have been trialed with the aim to improve mobility and social integration following amputation. Despite this, the offer of psychological support for amputation in the UK has been inconsistent and many rehabilitation centers do not offer psychological services despite high demand. While rehabilitation guidelines encourage the involvement of psychologists in the rehabilitation of people following limb loss, and existing literature indicates the ways in which formal psychological interventions might be drawn upon, to date there is no research examining the experiences of such samples in receiving this care. Understanding how particular groups of people with particular health care needs utilise and experience psychological support is important in appropriately tailoring interventions. Given this, the proposed study will focus on the experiences of formal psychological support of people who have experienced limb loss. This will be facilitated through interviewing people with amputations and analysing the content using Interpretative Phenomenological Analysis. The study will aim to understand the experiences and meaning making of participants, focus on similarities and differences in the experiences and make suggestions on how to shape the delivery of psychological support in the future.

State the Aims and Objectives of the project in Lay persons' language.

The aim of the project is to study the experiences of formal psychological support of people who have experienced limb loss. Through this important areas to improving the delivery of psychological care can be identified.

Participant Information

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

The current study aims to recruit 6-10 participants. The number of participants is in line with previous studies published in the available research when using Interpretative Phenomenological Analysis, where the aim is to recruit small, homogenous samples. The project aims to use online interviews with people who have experienced limb loss to study their experiences of psychological support received.

The recruitment of participants will be completed in two stages in the case that during the initial recruitment not enough people with the inclusion criteria have expressed interest in participating:

Recruitment stage 1:

The process of recruiting participants will initially focus on finding individual with the following specific characteristics: Individuals, over the age of 18, who have experienced traumatic or surgical amputation of an upper or lower extremity and have received psychological support by Psychologists / Clinical Psychologists / Psychotherapists / Counsellors.

Recruitment stage 2:

If a sample cannot be recruited with the above characteristics within a reasonable time frame (e.g., 3 months) then broader participant criteria will be used: Individuals who have experienced traumatic or surgical amputation of an upper or lower extremity and have received psychological support by any healthcare professional.

You have selected that you are not getting written consent using a Participant Information Sheet with a written description of your research. Please indicate why you are not using a Participant Information Sheet, and how you are obtaining consent.

Interviews will be completed online so verbal consent will be recorded (via audio and video) prior to the interview starting. Despite this, participants will be given the Participant Information Sheet and the Consent form a few days prior to the interview (via email) in order to be informed about what the study entails and be able to give informed consent the day of the interview.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

Talking about the experience of receiving psychological support following limb loss is a sensitive topic and people are likely to share both positive and negative aspects of the experience. It is likely that this can cause some level of upset or discomfort. Individuals will be informed that sharing their experiences is optional and at any point during the interviews they are free to inform the facilitator that they are not willing to participate in the study any more. Any data collected to this point will be destroyed. Participants will also be provided with numbers of charities they can contact in case of experiencing distress during the interviews. These will be included in the information sheet that will be shared prior to conducting the interviews.

Participant Relationships

Your answers about gatekeepers has indicated that there is a power imbalance due to gatekeepers knowing the identity of participants. Please explain the situation and how you plan to mitigate and manage the effects of this.

The gatekeepers (charity managers) will not be informed about who expressed interest to participate / has participated in the study.

Participant Data

Explain what you will video or photograph as part of your project, why it is appropriate and how it will be used.

The online interviews will be conducted using Microsoft Teams. Microsoft Teams allows for video and audio recording of the interviews as well as transcription of the content. The recordings will then be used for the transcription of interviews / correction of the transcription provided by Teams. For participants within the UK who are not able to use Microsoft Teams the interviews will be contacted via telephone. In this case transcription of the content will be completed directly by the interviewer.

How will you gain consent for the use of video/photography?

Participants will be asked to give verbal consent prior to the interview starting, which will be video and audio recorded.

State your video/photography storage, retention and deletion plans and the reasons why.

Audio recordings of interviews will be stored on the university's secure encrypted server or university-approved secure cloud storage until the research has been examined; at this point, the audio files will be deleted. Data (including transcripts of interviews) will be stored in electronic format by the Doctorate in Clinical Psychology program's administration team. Data will be transferred electronically using a secure method that is supported by the university. It will then be stored on the university's secure encrypted server, or in university-approved secure cloud storage, as per usual course procedures. Audio recordings will be deleted when the thesis has been examined and transcripts and consent recordings will be kept for 10 years.

What would you do if a participant chose to make use of their GDPR right "of being forgotten" or "right to erasure"? Could you remove their data/video/picture from publication? (please see help text).

Any content recorded, transcribed or used in the analysis can be deleted upon request from the participant for up to two weeks following the interviews. After this stage and once published data cannot be deleted. As all data will be anonymised, and all real names, place names and dates will be changed, it is unlikely that individuals will be identifiable.

Will you take all reasonable steps to protect the anonymity of the participants involved in this project?

Yes No

Explain what steps you will take to protect anonymity.

No names or other personal data will be transcribed. Participants will be given a pseudonym. Exceptions could include age and gender to which participants will be asked to consent to prior to conducting the interviews. As all data will be anonymised, and all real names, place names and dates will be changed, it is unlikely that individuals will be identifiable. All steps will be taken to ensure participant identifiers are removed and the data is anonymised. Transcription will be completed through amending the Teams transcription available or directly by the interviewer (Rania Malouta) in the case that the interviews have been completed over the phone.

Information about the Research

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

Dissemination plans include a DClinPsy thesis and publication in an academic journal.

Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Consent will be given verbally and will be captured in the audio and video recording on Teams.

Data Storage

How long will you retain the research data?

Once transcription has been completed and checked, the recordings of interviews will be deleted. Audio and video recordings of verbal consent provided by participants will be retained by the Doctorate in Clinical Psychology research administration team for a period of ten years. These will be stored separately from transcriptions of interviews. Upon completion of the research, interview transcripts will be transferred to the Doctorate in Clinical Psychology research administration team using a secure university-approved procedure. The data will be retained for a period of ten years. Following this retention period, the data will be deleted by the administration team under the supervision of the research supervisor.

How long and where will you store any personal and/or sensitive data?

Please see above.

Please explain when and how you will anonymise data and delete any identifiable record?

Data will be anonymized at the stage of transcription. Pseudonyms will be given to participants.

Project Documentation*

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

[FST Ethics Webpage](#)

[FHM Ethics Webpage](#)

[FASS-LUMS Ethics Webpage](#)

[REAMS Webpage](#)

- I confirm that I have followed the guidance.

As you are in FHM please upload your Research Proposal for this project.

| Type | Document Name | Documents | | | |
|-------------------|---------------|---------------|--------------|---------|---------|
| | | File Name | Version Date | Version | Size |
| Research Proposal | Protocol | Protocol.docx | 04/03/2022 | 1 | 62.0 KB |

In addition to completing this form you must submit all supporting materials. Upload documents that you will use and that participants will see. Please indicate which of the following documents are appropriate for your project:

- Advertising materials (posters, emails)
- Letters/emails of invitation to participate
- Consent forms
- Participant information sheet(s)
- Interview question guides
- Focus group scripts
- Questionnaires, surveys, demographic sheets
- Workshop guide(s)
- Debrief sheet(s)
- Transcription (confidentiality) agreement
- Other
- None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

Please upload all consent forms to be used in this project.

| Documents | | | | | |
|--------------|--------------------------|-------------------------------|--------------|---------|---------|
| Type | Document Name | File Name | Version Date | Version | Size |
| Consent Form | Participant consent form | Participant consent form.docx | 04/03/2022 | 1 | 41.7 KB |

Please upload all Participant Information Sheets:

| Documents | | | | | |
|-------------------------------|--|---|--------------|---------|---------|
| Type | Document Name | File Name | Version Date | Version | Size |
| Participant Information Sheet | Participant information sheet - Recruitement Stage 2 | Participant information sheet - Recruitement Stage 2.docx | 20/12/2021 | 2 | 49.2 KB |
| Participant Information Sheet | Participant information sheet - Recruitment stage 1 | Participant information sheet - Recruitment stage 1.docx | 20/12/2021 | 1 | 49.2 KB |

Please upload all advertising materials (posters, emails)

| Documents | | | | | |
|-----------------------|--|---|--------------|---------|----------|
| Type | Document Name | File Name | Version Date | Version | Size |
| Advertising materials | Poster for Recruitment stage 1 | Poster for Recruitment stage 1.pub | 20/12/2021 | 1 | 338.0 KB |
| Advertising materials | Poster for Recruitment stage 2 | Poster for Recruitment stage 2.pub | 20/12/2021 | 2 | 338.0 KB |
| Advertising materials | Email of invitation to participate - Recruitment Stage 1 | Email of invitation to participate - Recruitment Stage 1.docx | 20/12/2021 | 1 | 38.2 KB |
| Advertising materials | Email of invitation to participate - Recruitment stage 2 | Email of invitation to participate - Recruitment stage 2.docx | 20/12/2021 | 2 | 38.3 KB |
| Advertising materials | Social Media Advertisment | Social Media Advertisment.docx | 20/12/2021 | 1 | 12.8 KB |

Please upload all different Interview Question Guides.

| Documents | | | | | |
|--------------------------|--------------------|-------------------------|--------------|---------|---------|
| Type | Document Name | File Name | Version Date | Version | Size |
| Interview question guide | Interview Schedule | Interview Schedule.docx | 20/12/2021 | 1 | 41.0 KB |

Please upload all Questionnaires, surveys, demographic sheets

| Documents | | | | | |
|---|------------------------|-----------------------------|--------------|---------|---------|
| Type | Document Name | File Name | Version Date | Version | Size |
| Questionnaires, surveys, demographic sheets | Expression of Interest | Expression of Interest.docx | 20/12/2021 | 1 | 38.6 KB |

Please upload a copy of your Debrief sheet.

| Documents | | | | | |
|---------------|---------------------------|--------------------------------|--------------|---------|---------|
| Type | Document Name | File Name | Version Date | Version | Size |
| Debrief sheet | Participant Debrief Sheet | Participant Debrief Sheet.docx | 20/12/2021 | 1 | 30.6 KB |

Declaration

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. ([Data Protection Guidance webpage](#))

- I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? ([Health and Safety Guidance](#))

- I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

Signed: This form was signed by Dr Craig Murray (c.murray@lancaster.ac.uk) on 04/03/2022 4:30 PM

Please read the terms and conditions below:

- You have read and will abide by [Lancaster University's Code of Practice](#) and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used
- You will complete a data management plan with the Library if appropriate. [Guidance from Library](#).
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek [guidance from ISS](#)
- That you have completed the ISS Information Security training and passed the assessment
- That you will abide by Lancaster University's lone working policy for field work if appropriate
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission
- If anything changes in your research project you will submit an amendment

To complete and submit this application please click "Sign" below:

Signed: This form was signed by Rania Malouta (r.malouta@lancaster.ac.uk) on 04/03/2022 4:31 PM

Appendix 4-A. Research Protocol.

Title

Experiences of receiving formal psychological support by people with limb loss.

Applicant's Name

Rania – Nikoletta Malouta

Research Supervisor(s)

| Name | Job role | Organisation/Address | Supervisory role e.g., indicate whether theoretical, methodological, clinical expertise |
|---------------------|-------------------------------------|---|---|
| Dr Craig Murray | Research Tutor Thesis Supervisor | Lancaster University | Methodological and Topic Expertise |
| Dr Linda Bouquillon | Field Supervision | Kent and Medway NHS & Social Care Partnership Trust | Clinical Expertise |

Research Supervisor approval

| Comments | |
|---|-------------------------|
| I have read and provided feedback on a previous iteration of this proposal. I am supportive of the proposed topic and implementation plan. We would welcome feedback from the review process. | |
| Name: Craig Murray | Date: 20/12/2021 |

Lay summary

Limb loss or amputation is a term used to describe the removal of a body part through surgery. This can happen for various reasons and many conditions, like diabetes, can lead to a body part being removed.

Amputation can cause many physical difficulties for a person. For example, someone might have difficulty with moving around if one of their legs has been removed or they might feel pain in the area that was operated upon. Because of this, they can feel isolated or unable to socialise as they did before.

Apart from the difficulties amputation can cause to the body, it can affect an individual emotionally as well. Some people describe feeling extreme sadness, or anxiety, whilst others feel that their body has changed and cannot see themselves as they did before. The relationships people have with loved ones can also change and this can cause additional stress and anxiety. Some people also describe being angry after the surgery and feel like they want to blame others for what happened. Supporting people who experience these emotions is very important and that is why psychology, a science that focuses on understanding and helping with emotional pain can help.

This study will try to understand how people with limb loss experience psychological support that has been provided to them by health professionals. To do this, people with limb loss will be asked about their experiences through a conversation taking place online. After all interviews are finished the researcher will try to find similar and different experiences that were reported and use this evidence to make changes for future psychological support.

Summary of the research

1. Brief background/rationale

Limb loss, otherwise known as amputation in medical settings, refers to the surgical removal of a body part. Multiple physical causes can lead to amputation some of which include diabetes, vascular disease, and trauma occurring through accidents or combat-related injuries. Around 1.6 million people lived with amputation in the US in 2005 and it is expected that this number will increase to 3.6 million people by 2050. The National Amputee Statistical Database (NASDAB) (2002) estimated that around 5,500 amputations occur in the UK each year, with a total current population of around 62,000.

The physical difficulties occurring following limb loss are well documented in the existing literature and range from physical restriction and pain to impairment of or complete loss of independence. People who have experienced limb loss have also been shown to experience various psychological difficulties. These include anxiety, depression, body image disturbance, affected relationships within the family and intimate relationships, phantom limb pain and stump pain, stigma and anger and resentment.

The British Society of Rehabilitation Medicine (2018) stresses that providing psychological support to an individual following limb loss is extremely important for a successful recovery outcome. They highlight that Prosthetic and Amputee Rehabilitations Centres (PARCS) in the UK would greatly benefit from multi-disciplinary teams that include clinical psychologists, who can offer support during both the pre-operative and post-operative stages of limb loss, and aid individuals with psychosocial adjustment.

There is some evidence in the current literature to suggest that psychological support can be beneficial for individuals following limb loss. Psychoeducation and regular psychotherapy both prior and following amputation to support with

emotional coping could prove beneficial. Attending peer groups, where contact with other people who have also experienced limb loss is facilitated, is shown to help decrease levels of anxiety and provide opportunities for social integration. Counselling has also been suggested for the support of work-related amputations and Cognitive Behavioural Therapy is recommended to support with re-appraisal of the situation. Moreover, innovative interventions such as cognitive-behavioural-physical therapy, which combines psychotherapy and physical therapy have been trialed with the aim to improve mobility and social integration following amputation. Despite this, the offer of psychological support for amputation in the UK has been inconsistent and many rehabilitation centers do not offer psychological services despite high demand.

While rehabilitation guidelines encourage the involvement of psychologists in the rehabilitation of people following limb loss, and existing literature indicates the ways in which formal psychological interventions might be drawn upon, to date there is no research examining the experiences of such samples in receiving this care. Understanding how particular groups of people with particular health care needs utilise and experience psychological support is important in appropriately tailoring interventions.

Given this, the proposed study will focus on the experiences of formal psychological support of people who have experienced limb loss. This will be facilitated through interviewing people with amputations and analysing the content using Interpretative Phenomenological Analysis (IPA). The study will aim to understand the experiences and meaning making of participants, focussing on similarities and differences in their experiences and making suggestions on how to shape the delivery of psychological support in the future.

2. Research question(s)

What are the experiences of formal psychological support for people who have experienced limb loss?

(What would be the optimal way of delivering support? What can we learn to shape the delivery of psychological support in the future?)

3. Study design/methodology

IPA is an analytical approach of qualitative data that aims to understand what is important to an individual and how they interpret and understand their own experiences. The theoretical underpinnings of IPA include phenomenology, which focuses on how things appear to be, and hermeneutics, which involves the interpretation of texts (in this case, interview transcripts).

Using IPA for this thesis will allow the researcher to examine and understand the experiences of psychotherapy of individuals who have experienced limb loss.

4. Participants

IPA typically uses small, homogenous samples due to an intensive focus of individual experience and sense making (idiography) as well as identifying patterns in the data for the sample as a whole. As sample size increases it becomes more difficult to avoid losing a discernible focus on each individual in the analysis, and analysis can begin to reflect an aggregation of experiences for the sample as a whole. Because small samples are used, participants are included on the basis of criteria that makes them as well-defined a sample as possible. Given these considerations, a target sample of 6-10 people with the following characteristics will be sought.

Recruitment stage 1:

The process of recruiting participants will initially focus on finding individual with the following specific characteristics: Individuals, over the age of 18, who have experienced traumatic or surgical amputation of an upper or lower extremity and have received

psychological support by Psychologists / Clinical Psychologists / Psychotherapists / Counsellors.

Recruitment stage 2:

If a sample cannot be recruited with the above characteristics within a reasonable time frame (e.g., 3 months) then broader participant criteria will be used: Individuals who have experienced traumatic or surgical amputation of an upper or lower extremity and have received psychological support by any healthcare professional.

Exclusion criteria:

People whose first language is not English.

Individuals who experience cognitive impairment affecting their understanding and ability to consent.

People who are currently receiving psychological support.

Interview Schedule:

Please see Interview Schedule guide as a separate document attached with the application.

The questions were developed based on the interview schedule of similar studies.

5. Recruitment plans

A poster summarising the research will be used to advertise the project. Recruitment will be completed through contacting charities in the UK and the US (such as The limbless Association, Blesma: Military Charity for Limbless Veterans, Help for Heroes, Wounded Warriors, Limbs for Life), who will be asked to put the poster on display in meeting rooms and communal areas. The project will also be advertised on Twitter (through creating a professional account) and online discussion groups for people with amputation (e.g., Reddit) and the poster will be used in the online posts. These methods have previously been used successfully in a number of DClinPsy trainee projects supervised by Dr Craig Murray, including theses on limb loss and peer mentoring, disgust and limb loss, parenting children with limb loss, and sports participation following limb loss. Please see study recruitment materials: ‘Email of invitation to participate’ (Stage 1 & 2), ‘Social Media Advertisement’, ‘Expression of Interest’ (this form will be moved to Qualtrics so potential participants can complete it online), ‘Poster for Recruitment (Stage 1 & 2) and

“Participant consent form” (this will be read out to participants and consent will be recorded separate to the interview) as separate documents attached with the application.. Please also see attached ‘Participant Debrief Sheet’ that will be given to participants at the end of interviews.

6. Data collection.

Data collection will be completed through semi-structured one-to-one interviews with participants facilitated via Microsoft Teams. Questions will aim to capture the experience of the individual interviewed but will be non-directive in nature. Please see the Interview Schedule guide.

7. Data analysis plan

Interviews will be recorded and transcribed by the interviewer. The Teams transcription tool will be used to initially transcribe the interview and the content will be then further amended by the interviewer. The transcriptions will be read multiple times and notes will be made that will help generate themes. Themes will be grouped together based on similarities identified and a label / title will be given to each of them. Detailed procedures for analysing data using IPA have been published by my supervisor and these will be adhered to.

8. Research governance approvals

The current project is under consideration by FHMREC only.

9. Particular research governance/ethical/practical/design issues

Interviews conducted around the experiences of psychological support received following limb loss has the potential to cause distress to participants. Sources of support with online presence will be supplied to all participants before and following participation. If participants become distressed during the interview the clinical skills I have developed during my training will be used to contain and direct participants to sources of support.

Risk issues will be assessed in the same manner they are in the course of my clinical work and any concerns will be discussed with my supervisor and other professionals as appropriate.

10. Service user/stakeholder involvement

The target sample are not directly involved in the design of the study. However, the involvement of my field supervisor, Dr Linda Bouquillon, will be extremely beneficial as support could be provided on interview schedules and other areas, as she is currently working as a clinical psychologist with the target population of this study.

11. Dissemination plans

The proposed research will be presented on the thesis presentation day at Lancaster University and I will also pursue publication of the study. All participants and organisations involved in recruitment will be provided with a summary of the research findings that could be also published on their websites.

12. Timetable for completing the study

Ethics application December 2021

Ethics approval: January – February 2022

Recruitment and interviews March – May 2022

Transcription and analysis May 2022 – July 2022

Draft thesis August 2022 – December 2022

Thesis edits and corrections January – March 2023

Thesis submission March 2023

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Appendix 4-B. Participant Information Sheet - Recruitment stage 1.

Participant Information Sheet

Study title: *Experiences of receiving psychological support by people with limb loss.*

My name is Rania Malouta and I am a trainee Clinical Psychologist. I am conducting this research as part of my studies for the Doctorate of Clinical Psychology programme at Lancaster University, United Kingdom. Thank you for taking the time to read the Participant Information Sheet. If you have any questions or require further information please contact me at r.malouta@lancaster.ac.uk

What is the study about?

The purpose of this study is to understand the experiences of psychological support that people have received from Psychologists /Clinical Psychologists /Psychotherapists/ Counsellors for limb loss related difficulties (other than pain management and relief). This study could help shape the delivery of future psychological support provided.

Why have I been approached?

You have been approached because the study requires information from people who have experienced limb loss and have received psychological support for it from psychologically trained professionals such as Psychologists /Clinical Psychologists /Psychotherapists/ Counsellors.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to attend an interview, lasting approximately one hour that will be conducted online by the lead researcher, Rania Malouta. The interview will focus on questions around your experience of receiving psychological support. If you agree to take part in the study and during the interview change your mind you are free to leave the process.

The interview time and date will be arranged with you and is likely to be completed via Skype or Microsoft Teams. The interview will be video / audio recorded and will be transcribed by the lead researcher. Please note that Skype interviews are not wholly secure. For more information around this please visit
<https://support.skype.com/en/faq/FA31/does-skype-use-encryption> and
<https://support.skype.com/en/faq/FA34649/protecting-your-online-safety-security-and-privacy>

Will my data be Identifiable?

The data collected for this study will be stored securely within the University approved secure cloud storage and only myself and my supervisor will have access to this data.

- Video / Audio recordings will be destroyed once the project has been submitted for publication/ has been examined.
- The transcription of data will exclude real names and any other identifiable data with the exception of gender and age.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in my thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits in taking part. Despite this, it is hoped that sharing your experience will help better understand which processes of psychological support are helpful to individuals with limb loss.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher at:
r.malouta@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith
 Research Director, Doctorate in Clinical Psychology
 Tel: +44 (0)1524 592282
 Email: i.smith@lancaster.ac.uk

Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YW
UNITED KINGDOM

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG
UNITED KINGDOM

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans

Phone: 116123
Email: jo@samaritans.org (Response time: 24h)
Website: <https://www.samaritans.org/how-we-can-help/contact-samaritan/>

Limbless Association UK

Phone: 0800 644 0185
Email: through their website
Website: <https://limbless-association.org/contact/>

Amputee Coalition of America

Phone: 888-267-5669 / 888-267-5669
Website: <https://www.amputee-coalition.org/limb-loss-resource-center/ask-an-information-specialist-2/>

**To express your interest in taking part in the study please
use the following link:**

(Qualtrics link to be inserted here)

Thank you for taking the time to read this information sheet

Appendix 4-C. Participant Information Sheet - Recruitment stage 2.

Participant Information Sheet

Study title: *Experiences of receiving psychological support by people with limb loss.*

My name is Rania Malouta and I am a trainee Clinical Psychologist. I am conducting this research as part of my studies for the Doctorate of Clinical Psychology programme at Lancaster University, United Kingdom. Thank you for taking the time to read the Participant Information Sheet. If you have any questions or require further information please contact me at r.malouta@lancaster.ac.uk

What is the study about?

The purpose of this study is to understand the experiences of psychological support that people have received from healthcare professionals for limb loss related difficulties (other than pain management and relief). This study could help shape the delivery of future psychological support provided.

Why have I been approached?

You have been approached because the study requires information from people who have experienced limb loss and have received psychological support for it from any healthcare professional.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to attend an interview, lasting approximately one hour that will be conducted online by the lead researcher, Rania Malouta. The interview will focus on questions around your experience of receiving psychological support. If you agree to take part in the study and during the interview change your mind you are free to leave the process.

The interview time and date will be arranged with you and is likely to be completed via Skype or Microsoft Teams. The interview will be video / audio recorded and will be transcribed by the lead researcher. Please note that Skype interviews are not wholly secure. For more information around this please visit

<https://support.skype.com/en/faq/FA31/does-skype-use-encryption>

and <https://support.skype.com/en/faq/FA34649/protecting-your-online-safety-security-and-privacy>

Will my data be Identifiable?

The data collected for this study will be stored securely within the University approved secure cloud storage and only myself and my supervisor will have access to this data.

- Video / Audio recordings will be destroyed once the project has been submitted for publication/ has been examined.
- The transcription of data will exclude real names and any other identifiable data with the exception of gender and age.
- Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in my thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits in taking part. Despite this, it is hoped that sharing your experience will help better understand which processes of psychological support are helpful to individuals with limb loss.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher at:

r.malouta@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith

Research Director, Doctorate in Clinical Psychology

Tel: +44 (0)1524 592282

Email: i.smith@lancaster.ac.uk

Faculty of Health and Medicine
Lancaster University

Lancaster
LA1 4YW
UNITED KINGDOM

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG
UNITED KINGDOM

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans

Phone: 116123
Email: jo@samaritans.org (Response time: 24h)
Website: <https://www.samaritans.org/how-we-can-help/contact-samaritan/>

Limbless Association UK

Phone: 0800 644 0185
Email: through their website
Website: <https://limbless-association.org/contact/>

Amputee Coalition of America

Phone: 888-267-5669 / 888-267-5669
Website: <https://www.amputee-coalition.org/limb-loss-resource-center/ask-an-information-specialist-2/>

**To express your interest in taking part in the study please
use the following link:**

(Qualtrics link to be inserted here)

Thank you for taking the time to read this information sheet.

Appendix 4-D. Poster for recruitment stage 1.

Doctorate in
Clinical Psychology

Lancaster
University



Experiences of receiving psychological support by people with limb loss.

This study looks at the experiences of receiving psychological support for limb loss related difficulties (other than pain management and relief). It is for any adult who has received psychological support from Psychologists / Clinical Psychologists / Psychotherapists / Counsellors following limb loss but is not in the process of attending sessions anymore.

We are looking for adults of any age who have are happy to attend a 45 minute - 1 hour online interview to share their experiences with the lead researcher, Rania Malouta. Participation is voluntary.

It is hoped that completing this research will significantly contribute to the improvement of future psychological support provided for limb loss related difficulties.

To express your interest in taking part please follow the link:

https://qfreeaccountssjc1.az1.qualtrics.com/jfe/form/SV_5nabZw6mBw42zFY

For any questions please contact the lead researcher, Rania Malouta at:

r.malouta@lancaster.ac.uk

Appendix 4-E. Poster for recruitment stage 2.Doctorate in
Clinical PsychologyLancaster
University

Experiences of receiving psychological support by people with limb loss.

This study looks at the experiences of receiving psychological support for limb loss related difficulties (other than pain management and relief). It is for any adult who has received psychological support from healthcare professionals following limb loss but is not in the process of receiving support anymore.

We are looking for adults of any age who have are happy to attend a 45 minute - 1 hour online interview to share their experiences with the lead researcher, Rania Malouta. Participation is voluntary.

It is hoped that completing this research will significantly contribute to the improvement of future psychological support provided for limb loss related difficulties.

To express your interest in taking part please follow the link:
(Qualtrics link for Expression of interest to be inserted here)

For any questions please contact the lead researcher, Rania Malouta at:
r.malouta@lancaster.ac.uk

Appendix 4-F. Email for recruitment through charities stage 1.**Email of invitation to participate**

Dear [charity name]

I hope you are keeping well despite the current difficult times.

My name is Rania Malouta and I am currently completing my Doctorate in Clinical Psychology at Lancaster University. As part of our studies and in order to complete the programme, we conduct research into a topic area of our choice. In collaboration with Dr Craig Murray (Research Supervisor), we are hoping to look at a valuable and under-researched topic area:

Experiences of receiving psychological support by people with limb loss.

As part of the research, we are looking for people to attend online interviews, where they will have the opportunity to talk about their experiences of psychological support they have received for limb loss related difficulties by Psychologists / Clinical Psychologists / Psychotherapists / Counsellors. It is hoped that this research will help improve the support offered in the future.

The interviews will be video / audio recorded and will be facilitated by myself, Rania Malouta, the lead researcher. No identifying information will be used for the study and any information used will be anonymised to maintain participants' confidentiality. I am hoping to interview approximately 6-10 people and in doing so I hope to make this research a valuable contribution to an under-researched area.

I would be grateful if you could please share the attached poster and information sheet with your members, via your website, social media accounts or via email.

For any questions or clarifications, or if it is not possible to advertise this project within your charity, please do not hesitate to contact me. I am available Monday to Friday, 9am – 5pm via email at r.malouta@lancaster.ac.uk

Thank you in advance for your help and I look forward to your reply.

Best wishes

Rania Malouta
Trainee Clinical Psychologist
Lancaster University

Appendix 4-G. Email for recruitment through charities stage 2.

Email of invitation to participate

Dear [charity name]

I hope you are keeping well despite the current difficult times.

My name is Rania Malouta and I am currently completing my Doctorate in Clinical Psychology at Lancaster University. As part of our studies and in order to complete the programme, we conduct research into a topic area of our choice. In collaboration with Dr Craig Murray (Research Supervisor), we are hoping to look at a valuable and under-researched topic area:

Experiences of receiving psychological support by people with limb loss.

As part of the research, we are looking for people to attend online interviews, where they will have the opportunity to talk about their experiences of psychological support they have received for limb loss related difficulties by healthcare professionals. It is hoped that this research will help improve the support offered in the future.

The interviews will be video / audio recorded and will be facilitated by myself, Rania Malouta, the lead researcher. No identifying information will be used for the study and any information used will be anonymised to maintain participants' confidentiality. I am hoping to interview approximately 6-10 people and in doing so I hope to make this research a valuable contribution to an under-researched area.

I would be grateful if you could please share the attached poster and information sheet with your members, viva your website, social media accounts or via email.

For any questions or clarifications, or if it is not possible to advertise this project within your charity, please do not hesitate to contact me. I am available Monday to Friday, 9am – 5pm via email at r.malouta@lancaster.ac.uk

Thank you in advance for your help and I look forward to your reply.

Best wishes

Rania Malouta
Trainee Clinical Psychologist
Lancaster University

Appendix 4-H. Social media advertisement.

Social Media Advertisement

Option A

Have you received psychological support for limb loss related difficulties by Psychologist / Psychotherapists / Counsellors? Research opportunity

(electronic link to Participant Information Sheet)

Option A1

Have you received psychological support for limb loss related difficulties by healthcare professionals? Research opportunity

(electronic link to Participant Information Sheet)

Option B

Have you experienced limb loss and then received psychological support by Psychologist / Psychotherapists / Counsellors? Share your experience

(electronic link to Participant Information Sheet)

Option B1

Have you experienced limb loss and then received psychological support by healthcare professionals? Share your experience

(electronic link to Participant Information Sheet)

Option C

Did you share your difficulties with limb loss with a Psychologist / Psychotherapist / Counsellor? How was the support you received? Share your experience

Option C1

Did you share your difficulties with limb loss with a healthcare professional? How was the support you received? Share your experience

Appendix 4-I. Interview Guide.**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?

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?

Appendix 4-J. Expression of Interest form.**Expression of Interest Form**
(Text will be moved to Qualtrics)**Research Study: Experiences of receiving formal psychological support by people with limb loss.****Name:****Gender:****Age:****Ethnicity:****Country of Residence:****Is English your first language? YES NO** **Please specify the nature of your limb loss (e.g., above elbow or below knee):**

_____**Have you received psychological support for your limb loss? YES NO** **If you answered YES please complete:****How long ago did you receive psychological support? _____****Job title of health-care professional that supported you? _____****I am interested in taking part in this study. YES NO** **Please contact me on (please choose preferred method of contact):****Telephone:****Email:****I would prefer to be interviewed via:****Skype Microsoft Teams Telephone**

Appendix 4-K. Participant debrief sheet.

Participant Debrief Sheet

Thank you very much for participating in this study. This study was looking to better understand the experiences of psychological support that people with limb loss have received.

If you have any questions or concerns relating to the study please contact the lead researcher, Rania Malouta at r.malouta@lancaster.ac.uk. For any complaints regarding the study please contact Dr Ian Smith, Research Director, Doctorate in Clinical Psychology, at i.smith@lancaster.ac.uk

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans

Phone: 116123

Email: jo@samaritans.org (Response time: 24h)

Website: <https://www.samaritans.org/how-we-can-help/contact-samaritan/>

Limbless Association UK

Phone: 0800 644 0185

Email: through their website

Website: <https://limbless-association.org/contact/#phone>

Amputee Coalition of America

Phone: 888-267-5669 / 888-267-5669

Website: <https://www.amputee-coalition.org/limb-loss-resource-center/ask-an-information-specialist-2/>

Finally, I would like to thank you again for participating in the study and wish you all the best for the future.

Best wishes

Rania Malouta

Trainee Clinical Psychologist

Lancaster University

Appendix 4-L. Participant Consent Form.**Study Title:****Experiences of receiving psychological support by people with limb loss.**

We are asking if you would like to take part in a research project looking at the experiences people with limb loss have had when receiving formal psychological support. Before you consent to participating in the study, we ask that you read the Participant Information Sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please contact the principal investigator, Rania Malouta, via email at: r.malouta@lancaster.ac.uk

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be video recorded and then made into an anonymised written transcript.
4. I understand that video recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to two weeks following my interview, without my medical care or legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that the researcher will discuss data with their supervisor as needed.
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will/may need to share this information with their research supervisor.
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

By proceeding to the interview, you confirm that:

- You consent to taking part in the interview.
- You have read the participant information sheet and understand what is expected of you within this study.
- You understand that any responses/information you give will remain anonymous.
- Your participation is voluntary.
- You consent for the information you provide to be discussed with my supervisor at Lancaster University.
- You consent that the data will be pooled and published and that if quotes are provided, they could be published.
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

Appendix 4-M. Approval email.

[External] FHM-2022-0645-RECR-2 Ethics Approval from FREC

Flag for follow up.

donotreply@infonetica.net
To: Malouta, Rania (Postgraduate Researcher)
Cc: Murray, Craig

Letter.pdf
110 KB

...
Tue 17/05/2022 06:25

This email originated outside the University. Check before clicking links or attachments.

Name: Rania Malouta

Supervisor: Craig David Murray

Department: Health Research

FHM REC Reference: FHM-2022-0645-RECR-2

Title: Experiences of receiving formal psychological support by people with limb loss

Dear Rania Malouta,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).
- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk