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**Doctoral Thesis**

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**Experiences of Intimacy, Romantic Relationships, and Dating Following Limb Loss**

Keanu Court

Trainee Clinical Psychologist

k.court1@lancaster.ac.uk

Doctorate in Clinical Psychology

School of Health and Medicine

Division of Health Research

Lancaster University

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**Table of Word Counts**

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<b>Section</b>	<b>Text</b>	<b>References and Appendices</b>	<b>Total</b>
Thesis Abstract	265	N/A	265
Systematic Literature Review	7982	9918	17896
Empirical Paper	7869	7289	15158
Critical Appraisal	3755	617	4372
Ethics	2046	2976	5022
Total	21917	20800	42717

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## **Abstract**

Chapter one presents a systematic literature review and thematic synthesis of qualitative studies on the experiences of intimacy, romantic relationships, and dating following limb loss. Thematic synthesis led to the identification of four themes: 1) the self as undesirable, 2) the management of undesirability, 3) support: a double-edged sword, and 4) diverse experiences of intimacy. It was concluded that limb loss appeared to present a number of challenges in relation to intimacy, romantic relationships, and dating. Recommendations for clinical practice were provided, including offering psychological therapies to those who are struggling to cope, referring or signposting individuals with limb loss to peer-support groups, and involving spouses or main carers in the rehabilitation process.

Chapter two details an empirical study on the experiences of intimacy, romantic relationships, and dating following limb loss. Data were gathered from online sources (Reddit and The Amputee Discussion and Support Forum) and reflexively thematically analysed, leading to the development of two themes: 1) feelings of undesirability and 2) defying expectations. Taken together, these themes highlighted the variable impact of limb loss on intimacy, romantic relationships, and dating. Whilst some posters experienced challenges, others felt that limb loss was unimportant or positive in relation to their romantic and sexual lives. Recommendations for clinical practice were provided, such as avoiding assumptions that limb loss is an inherently negative experience.

Chapter three documents a critical appraisal of the systematic literature review and empirical paper. Both papers are summarised and clinical implications arising from their similarities and differences are presented. A reflective account concerning the process of completing the thesis is detailed, particularly in relation to the use of pre-existing data.

Finally, chapter four provides the ethics application and approval email for the empirical study. The associated research proposal is appended.

## **Declaration**

The present thesis is a report of the research I have undertaken between October 2021 and September 2024 as a requirement of the Doctorate in Clinical Psychology at Lancaster University. The thesis presented here is my own work, except where references are made, and has not been submitted for any other academic award.

Signed: Keanu Court

Date: 09/09/2024

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## **Chapter One**

### **Systematic Literature Review**

Experiences of Intimacy, Romantic Relationships, and Dating Following Limb Loss: A  
Systematic Review and Thematic Synthesis of Qualitative Papers

Keanu Court

Trainee Clinical Psychologist

k.court1@lancaster.ac.uk

Doctorate in Clinical Psychology

School of Health and Medicine

Division of Health Research

Lancaster University

Prepared for Submission to the Journal of Disability and Rehabilitation

## **Abstract**

### **Background**

Individuals with limb loss may face challenges in relation to intimacy, romantic relationships, and dating. As core components of wellbeing and quality of life, challenges in these areas may engender a number of adverse consequences, such as reduced self-worth. Existing research has tended to focus on the physical aspects of sexual functioning and, by doing so, has neglected the multi-dimensional nature of human sexuality. This limits the focus and success of rehabilitation and prevents understanding of how limb loss might affect sexuality in its broad sense.

### **Objective**

To inform recommendations for clinical practice by systematically reviewing and thematically synthesising qualitative literature on the experiences of intimacy, romantic relationships, and dating following limb loss.

### **Methods**

Five databases were systematically searched in April 2023: Academic Search Ultimate, CINAHL, Medline Complete, PsycINFO, and Web of Science. The search yielded 4022 papers, which were subsequently screened in accordance with the inclusion and exclusion criteria. A total of 19 papers (each presenting a unique study) were identified to be included within the present review. These papers were thematically synthesised using the method outlined by Thomas and Harden (1).

### **Results**

Thematic synthesis led to the development of four themes: 1) the self as undesirable, 2) the management of undesirability, 3) support: a double-edged sword, and 4) diverse experiences of intimacy.

### **Conclusion**

Limb loss appears to present a number of challenges in relation to intimacy, romantic relationships, and dating. Recommendations include offering psychological therapies to those who are struggling to cope and involving spouses or main carers in the rehabilitation process.

**Keywords:** Limb Loss, Sexuality, Intimacy, Romantic Relationships, Dating

## Introduction

### Amputation Definition, Classification, and Prevalence

Amputation refers to the complete or partial surgical removal of a limb or limb part (2). The removal of a limb part, such as a digit, is typically classified as a minor amputation, whereas the removal of a limb itself, either mostly or entirely, is classified as a major amputation. Beyond this classification, amputations may be further delineated by their location (e.g., above-knee or below-knee). The location of an amputation is an important consideration for surgeons as different 'levels' of amputation are associated with variable outcomes. Above-knee amputations, for example, may affect walking more greatly than below-knee amputations, in that the presence of a knee joint is known to support ambulation (3,4).

The worldwide prevalence of amputation is difficult to estimate, largely due to an incompleteness of data from epidemiological research and varying definitions of what constitutes a clinically significant amputation (5). Research in this area has mostly been carried out in the United Kingdom (UK) and United States (US; (6). In the UK, it is estimated that around 5000 major amputations are performed annually (7). Accounting for the difference in population, a slightly higher incidence is reported in the US, with estimates ranging from 30,000 to 40,000 major amputations being carried out per year (8).

Amputations may be performed for a number of reasons, including peripheral vascular disease, diabetes mellitus, and trauma (9). The predominant reasons for undergoing an amputation (henceforth referred to as limb loss) differ according to geographical location. Within industrialised countries, such as the UK and US, limb loss is most typically the result of medical complications associated with age (e.g., peripheral vascular disease, either primary or secondary to diabetes; (5). Trauma is the most common reason for limb loss in

non-industrialised countries, with higher rates of war and conflict, less developed medical systems, and a relatively larger occurrence of farming occupations accounting for this (10). Considering these geographical differences, individuals experiencing limb loss within non-industrialised countries tend to be younger than their industrialised counterparts.

The worldwide prevalence of limb loss is on the rise. This has been attributed to a proliferation of motorised transportation and increased war and conflict, leading to higher incidences of trauma (11). It is expected that levels of worldwide conflict will remain high and, in line with this, the global incidence of limb loss, particularly for younger individuals, is predicted to continue rising (5).

### **Impact**

Limb loss can be a profoundly difficult experience, physically, psychologically, and socially (12). Following limb loss, individuals will likely be presented with the immediate challenges of reduced dexterity or mobility, and the demands of physical rehabilitation (13). Depending on the underlying cause, individuals may also be required to contend with physical comorbidities or concurrent injuries (5).

Considering the physical impact alone, it is unsurprising that psychological difficulties are relatively common following limb loss (14). In a systematic review of psychosocial adjustment, Horgan and MacLachlan (15) reported an increased incidence of depression and anxiety amongst those with limb loss, as compared to the general population. Numerous other psychological sequelae may follow limb loss and, whilst it is not within the scope of the present review to detail these, an altered body image and post-traumatic stress disorder are commonly reported within the literature (16,17).

The physical and psychological consequences of limb loss can limit the ability of individuals to engage in activities and participate socially (5). In this sense, returning to work,

taking part in leisure activities, and forming/maintaining social relationships may represent areas of difficulty (18–20). Due to the range of potential challenges, and their associated costs to healthcare systems (see (21), limb loss has been identified as a global health concern (9).

## **Sexuality**

In addition to the aforementioned challenges, individuals with limb loss may face difficulties in relation to their sexuality (22). Although this term has come to be conflated with a person's sexual orientation, here it is used to refer to an individual's sexual knowledge, beliefs, attitudes, values, and behaviours (23). Concepts such as romantic relationships, intimacy, and dating are included within this definition and, together, broadly represent what may be termed a person's 'romantic life'. The notion that limb loss affects sexuality is supported by Geertzen et al. (24) who, in their systematic review of limb loss and sexuality, found that all of their included papers reported difficulties with, or concerns about, sexual functioning following limb loss.

As with Geertzen et al. (24), research on limb loss and sexuality has tended to focus on the physical aspects of sexual functioning (25). Such a focus negates the multi-dimensional nature of sexuality and, consequently, limits the scope and success of rehabilitation (26). Similarly, focussing on sexual functioning impedes understanding of how limb loss might affect sexuality in its broad sense. This is unfortunate when it is considered that the limited research in this area (e.g., (6,27) does appear to highlight that limb loss can negatively affect individuals across the spectrum of their sexuality. Certainly, in Western societies, narrow ideas of physical beauty may contribute to a view of those with limb loss as unattractive (28) and unsuitable for dating or romantic relationships (29). For those with limb loss, the internalisation of these views may lead to feelings of shame (30) and the adoption of a celibate lifestyle (29)

The potential impact of limb loss on sexuality is particularly concerning when it is recognised that this concept, in its broad sense, is considered to be a core component of wellbeing and quality of life (31,32). Although not an exhaustive list, an individual's sexuality is known to influence their identity, self-image, and self-worth (33). In line with this, Kelly (34) argues that a person's sense of self is strongly linked to their capacity to engage in sexual relationships. It stands to reason, then, that difficulties with sexuality may represent a further challenge for individuals already contending with the aforementioned physical, psychological, and social sequelae of limb loss.

### **Support**

To address the various challenges associated with limb loss, multi-disciplinary support is often provided. Although the involvement of specific team members varies according to need, most individuals will access a combination of physical therapy, psychological support, and social work (35). Physical therapists will typically address issues with dexterity and mobility, whilst psychological therapists and social workers will usually focus on the psychological and social sequelae of limb loss, respectively. Medical staff may also be involved in the management of comorbid health conditions or concurrent injuries (35).

Despite the importance of sexuality amongst a population who may face challenges in this area, this aspect of care is often overlooked by rehabilitative services (6,24). Whilst this might be expected for the wider components of sexuality, such as dating and romantic relationships, it would appear that issues relating to sexual functioning are also rarely addressed (36). Research outside of limb loss (e.g., (37,38)) offers an explanation for this: clinicians often feel uncomfortable and ill-equipped to discuss issues relating to sexuality. By



doing so, clinicians may inadvertently contribute to the persistence of ableist societal views and their concomitant effects on wellbeing and quality of life (29).

### **The Current Review**

Previous systematic reviews (24,39) have addressed the concept of sexual functioning following limb loss. Although this has not led to widespread changes in clinical practice, it could be argued that this would be expected to happen over time, with the implementation of research often being a long and onerous process (40). The same cannot be said for the wider components of sexuality, for which there are no existing systematic reviews. This is surprising given the deleterious impact of limb loss across the spectrum of sexuality, and the concomitant effects this can have on wellbeing and quality of life (31,32). Most of the existing research in this area is qualitative, largely due to the appropriateness of this methodology to explore broad concepts, such as sexuality (41). Such research is, nonetheless, disparate, making it difficult to understand how sexuality is experienced following limb loss. The present review, therefore, aims to synthesise the findings from qualitative papers exploring limb loss and sexuality. In particular, the present review will focus on the concepts of intimacy, romantic relationships, and dating. It is hoped that this will provide a fuller picture of how sexuality is experienced following limb loss and, consequently, enable the development of recommendations for clinical practice.

## **Methods**

### **Reporting Guidelines**

Due to its widespread use in the reporting of qualitative syntheses (42), the present review followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines. The ENTREQ consists of 21 items, grouped into five domains: introduction, methodology, literature search and selection, appraisal, and synthesis of findings (43).

### **Search Strategy**

To identify eligible, qualitative papers exploring limb loss and sexuality, the following five databases were systematically searched: Academic Search Ultimate, CINAHL, Medline Complete, PsycINFO, and Web of Science. These databases were selected to provide coverage of the literature from a variety of disciplines, including psychology, medicine, and nursing.

Searches were conducted in April 2023 using pre-defined terms relating to the phenomena of interest (limb loss and sexuality) and methodological approach (qualitative). Table A1 provides an overview of the search terms used. To support the identification of potentially relevant papers, no date restrictions were applied. The choice of databases and search terms were reviewed by a specialist Librarian at Lancaster University, with it being agreed that the search was sufficiently broad to capture the available literature.

In May 2023, following the initial database searches, all the identified papers were exported into a reference management programme (Endnote Version 21). Duplicates were removed, with a title and abstract screen of the remaining papers being undertaken as per the inclusion and exclusion criteria (see below). The full texts of the remaining papers were reviewed, again in accordance with the inclusion and exclusion criteria, to identify eligible

papers for the present review. An additional search was conducted in June 2023 by reviewing the reference lists of eligible papers.

### **Inclusion and Exclusion Criteria**

To be included within the present review, papers were required to have: 1) sampled adult participants (aged 18 or over) who had experienced major limb loss, regardless of the type, underlying cause, or time since amputation; 2) utilised a qualitative methodology or mixed-methods approach; 3) documented the source of quotes if individuals without major amputations were included within the sample; 4) included findings relevant to the concept of sexuality; 5) been published in a peer-reviewed journal; and 6) been written in English.

Grey literature was excluded from the present review. As with the choice to exclude papers written in languages other than English, this decision was made because of the limited time and resources available for the present review.

### **Search Results**

The initial search returned 4022 papers, with 1525 duplicates being identified and removed. The titles and abstracts of the remaining 2497 papers were screened by the lead researcher, leading to the exclusion of 2444 papers. A full-text review of the remaining 53 papers was, then, undertaken. To reduce the possibility of bias, a second researcher (WL, Trainee Clinical Psychologist, Lancaster University) was involved in screening the full-texts of the identified papers. No disagreements in the screening process occurred, with both researchers identifying the same 17 papers for inclusion. Two additional papers were identified by reviewing the reference lists of the included papers. The reference lists of these papers were also searched, though no further papers were identified. In total, 19 papers (each presenting a unique study) were selected to be included in the present review. A flow diagram of the search process is presented in Figure A1.

## **Synthesis**

Although a number of methods for the synthesis of qualitative papers exist, thematic synthesis was selected due to its appropriateness in analysing research that focuses on experiences and perspectives (1). Furthermore, as several of the included papers did not focus on the phenomena of interest, they contained relatively ‘thin’ descriptions of the experiences of intimacy, romantic relationships, and dating. Thematic synthesis has been suggested as a suitable method for synthesising research that contains such descriptions (44) and, therefore, appeared to be the most appropriate method.

Thematic synthesis was undertaken in line with the method outlined by Thomas and Harden (1). Initially, the included papers were read, with participant quotes and author interpretations relevant to the concepts of intimacy, romantic relationships, and dating being extracted and imported into Microsoft Word. Both quotes and interpretations were taken from the ‘results’ or ‘findings’ sections of the included papers, and an additional search of the ‘discussion’ sections was conducted to identify additional author interpretations. Following this, the dataset was re-read to promote familiarisation, with inductive codes being applied throughout. This was an iterative process, involving the generation of new codes, and their translation into existing codes, where necessary. Codes were subsequently reviewed (to ensure their consistency) and organised into related areas, allowing for the development of descriptive themes (e.g., financial support from spouse, spousal support as valued, and the importance of communication). Reviewing and interpreting the descriptive themes led to the development of analytical themes, which are reported in the ‘results’ section. For an example of the theme-generation process, please see Table A2.

## **Description of the Included Papers**

The included papers were published between 2001 (45) and 2022 (27,46). Sample sizes ranged from four (6,27) to 42 (47), with the mean number of participants being 14. With the exceptions of Amoah et al. (48), Bernhoff et al. (49), and Horne and Paul (50), all of the included papers reported age ranges for their participants. Across the dataset, the youngest participant was 18 (6) and the oldest was 86 (51). On the basis of papers providing ages for their participants or the average age ( $n = 12$ ), the mean age was calculated to be 51.4 years. The ethnicity of participants was not routinely reported. Papers reporting this ( $n = 7$ ) included the following ethnicities: Caucasian ( $n = 48$ ), Saudi Arabian ( $n = 13$ ), White-British ( $n = 7$ ), African American ( $n = 5$ ), Chinese ( $n = 4$ ), Malay ( $n = 3$ ), Indian ( $n = 2$ ), and Native American ( $n = 1$ ). Two papers (48,52) did not report the genders of their participants. Of those that did ( $n = 17$ ), the majority ( $n = 12$ ) included mixed-gender samples. Four papers (6,22,53,54) included all female samples, whilst two (27,55) included all male samples. In total, 140 men and 101 women were reported to have participated in the included papers.

The most common method of data collection was semi-structured interviews ( $n = 15$ ). This was followed by focus groups ( $n = 2$ ), in-depth interviews ( $n = 1$ ), unstructured interviews ( $n = 1$ ), workshop presentations ( $n = 1$ ), and free-response questions ( $n = 1$ ). It is noteworthy that two papers (25,56) used mixed methods of data collection, combining semi-structured interviews with a focus group (56) or workshop presentation (25). Interpretative phenomenological analysis was the most common method of data analysis ( $n = 7$ ). Thematic analysis was the second most commonly utilised method ( $n = 6$ ). Additional methods included content analysis ( $n = 2$ ), descriptive phenomenological ( $n = 1$ ), qualitative empirical phenomenology ( $n = 1$ ), and categorical analysis ( $n = 1$ ). Two of the included papers (51,53) reported that their analyses were not underpinned by any specific method, whilst one (47) utilised mixed methods of data analysis (thematic and categorical analysis). Further details on the included papers, such as the reported aims and themes, can be found in Table A3.

## Quality Appraisal

The Critical Appraisal Skills Programme (CASP) for qualitative research (<https://casp-uk.net/casp-tools-checklists/>) was used to assess the methodological quality of the included papers. Although other checklists exist, the CASP was selected as the most common tool for the critical appraisal of qualitative papers, in addition to its endorsement from the Cochrane Qualitative and Implementation Methods Group (57). The CASP consists of 10 questions to support in the evaluation of qualitative research. Whilst the first two questions can be used to screen the applicability of papers, the remaining eight are intended to support in the assessment of quality across various methodological domains, such as design, recruitment, and data selection.

In line with Duggleby et al. (58), a three-point rating system was applied to each of the eight methodological domains. A low score (1 point) was given to papers that offered little to no explanation or justification for a particular methodological domain. Moderate scores (2 points) were assigned to papers that addressed the relevant methodological domains, though only partially. Finally, high scores (3 points) were given to papers that fully explained and justified their methodological choices. Using this system, it was possible to score each paper out of 24, with higher scores indicating a greater methodological quality. To reduce the likelihood of bias, a second researcher (WL) was involved in using the CASP to assess the included papers. Disagreements were discussed and resolved verbally. As a final note, considering that there is no broad consensus on what constitutes methodological quality in qualitative research (59), the CASP was not used to exclude any papers from the present review. Instead, the results of the CASP review are presented in Table A4 as a means by which the reader can better consider the methodological quality of the included papers.

## Results

Analysis of the dataset led to the development of four themes: 1) the self as undesirable, 2) the management of undesirability, 3) support: a double-edged sword, and 4) diverse experiences of intimacy. Each theme was composed of two to three sub-themes, which have been detailed below. For an overview of the papers contributing to each theme and sub-theme, please see Table A5.

### **The Self as Undesirable**

Twelve of the included papers contributed to this theme, which describes changes to how individuals viewed themselves and others following limb loss. Two sub-themes are presented: 1) the loss of desirability and 2) negative beliefs about the views of others.

#### *The Loss of Desirability*

Ten of the included papers reported that participants had described themselves negatively following limb loss, such as by stating they were ‘disgusting’ or ‘ugly’. Taken as a whole, these descriptions appeared to suggest that participants had lost a sense of romantic or sexual desirability.

‘I’ve got this, this leg missing now as you know. Sometimes, sometimes I’d get this scary, um, scary thought . . . what if nobody will be interested in me now. I mean, why would they be? I have a leg missing, right? I remember thinking to myself, shortly after [the amputation] what if, it might put girls off. I might see a woman that I really like or something and she just might be disgusted by it. That worried me a lot actually. Sometimes it still does. Like, how can anybody fancy me?’ (25: p.694)

‘When you don’t have a piece of something to bring that strength, you are not so desirable.’ (46: p. 8)

Four papers (6,22,25,27) described the loss of desirability as emanating from ableist societal views about those with disabilities. Indeed, disabled individuals are often portrayed as asexual within the media, and participants seemed to have an awareness of this.

‘We (female friends) discuss sex and stuff but when you think and read about it so far I haven’t read one romance novel where the lady stops and takes off her leg or arm lol (laugh out loud).’ (6: p.398)

Feelings of undesirability appeared to be particularly pronounced when participants were confronted with their limb loss (e.g., when seeing themselves without their prostheses).

‘I still, even up to yesterday, don’t know what happened yesterday (starts crying), I was coming out of the shower and I just...the mirror is straight ahead, my towel wrapped around me and I normally leave the towel on while I dry my hair cause I let the body oils soak in and I looked and I just got the head towel and I wrapped it around my legs so I couldn't see.’ (22: p.254)

Here, it might be argued that confronting one’s body highlights a discrepancy between the ‘real’ self and internalised ideas about beauty, leading to a sense of the self as undesirable.

### ***Negative Beliefs About the Views of Others***

Participants in seven of the included papers reported believing that others would appraise them negatively because of their limb loss. As examples of this, participants felt that others would be ‘put off’ by seeing their residual limb, or that their spouses or potential partners would react badly to being touched by it.

‘You're very conscious of the fact that ... I mean, me and my wife don't find it [the residual limb] off-putting but I think other people would.’ (55: p.874)



‘The thought of my stump touching her body, her legs terrified me... I thought she would react badly.’ (25: p.696)

Negative beliefs about the views of others may be interpreted as projections of an altered self-image following limb loss. In support of this, individuals who reported positive views of themselves appeared more likely to assume that others would view them positively.

‘Once I was comfortable with it [limb loss], everyone around seemed to be...’ (6: p.399)

For participants in romantic relationships, negative beliefs about the views of others often translated to worries that their spouses would leave them or cease to find them attractive.

‘You kind of think am I attractive or is she here just because, you know, because we’ve been together so long and got kids and stuff.’ (27: p.213)

For those without partners, and for one married participant, said beliefs appeared to lead to concerns that others would not want to date them.

‘One of my biggest worries, one of the things I worried about most after the operations was whether I would be able to find a girlfriend... Women might look but not for the right reasons . . . they probably wouldn’t be attracted to me in a sexual sort of way.’ (25: p.694)

‘If my wife would die, I assume there will be no other woman waiting for me. Because my body is not complete anymore.’ (26: p.190)

Participants in five of the included papers (6,27,46,60) did report that their beliefs about others had been confirmed, such as when their spouses had left them or potential partners had rejected them. However, the opposite was found to be true in an equal number of papers (6,46,53,55), with participants reporting that, despite their expectations, current or potential partners had been accepting of their limb loss.

‘I met a guy and we were talking about running so I told him right away that I wear a running prosthesis and I realized he was cool with it and wanted to know more, his positive reaction helped me learn that guys can be that way.’ (6: p.399)

As beliefs about the views of others were both confirmed and disconfirmed, it might be argued that, whilst these beliefs are founded, they do not consistently reflect the realities of forming and maintaining romantic relationships after limb loss. Interestingly, Ward-Khan et al. (22) noted that, when their participants were presented with evidence of their desirability, they tended not to believe this. This observation, that beliefs about the views of others could be, somewhat, incorrigible, appear to highlight the power of societal views and one’s self-image in mentalising the perceptions of others.

### **The Management of Undesirability**

To manage their feelings of romantic and sexual undesirability, participants in 11 of the included papers employed various coping strategies. The following three sub-themes represent these strategies: 1) compensation, 2) exclusion, and 3) safeguarding.

#### ***Compensation***

One method by which participants sought to address their feelings of undesirability related to gendered displays of masculinity or femininity. Gendered displays accorded to the sex of participants, with men and women seeking to masculinise and feminise themselves, respectively.

For women, gendered displays of femininity tended to involve efforts to please their partner, such as by engaging in sexual activities, in addition to ensuring their physical appearance met perceived societal expectations.

‘...I don’t feel sexual you know, I don’t feel attractive you know, so all of this is going churning around in my head, at the same time I’m doing it [sex] to please him...’ (22: p.255)

‘I was more self conscious than before, I thought everything else had to be perfect (hair, skin, nails, weight, clothes) because I had a ‘defect’.’ (6: p.397)

For men, gendered displays of masculinity typically involved providing financially for their families; participating in sports, despite not doing this prior to limb loss; and revealing their prosthesis to potential partners, viewing the mechanics of it to be demonstrative of power and strength.

‘I felt like I had to put more effort into proving that I can do things, get off my arse and being involved in activities. Get out in the garden, doing jobs around the house, get out and get a good job so I can bring the money in, make sure the kids were alright, provide for them, make it safe for them. It was a lot to deal with.’ (25: p.698)

‘I’m still using the tractor... They called my brother-in-law to operate the milling cutter. I was annoyed and said ‘Leave me, do not try to convince me!’.’ (52: p.5)

Interestingly, Keeling and Sharratt (27) noted that displays of masculinity did not appear to be conducive to romantic relationships. The reason cited for this related to the masculine value of strength encouraging a lack of communication between participants and their partners.

### ***Exclusion***

Participants in four of the included papers reported concerns that, should their residual limb be seen or touched during intimacy, their partners would be disgusted. To mitigate these concerns, participants reported excluding their residual limb from sexual activities. This

tended to involve placing the limb outside of sexual spaces, such as the bed, or ensuring that it could not be seen (e.g., by dimming the lights).

‘I would be there . . . sort of just lay there with my stump hanging out the side of the bed. It was like it wasn’t my leg . . . it wasn’t mine, and it didn’t belong to me. I didn’t want it to either...’ (25: p.696)

Excluding one’s residual limb from sexual activities may be interpreted as a rejection or denial of their disabled identity and the concomitant feelings of undesirability associated with this. In line with this, participants reported that sexual activities were particularly illuminative of their disability.

‘I usually don’t consider myself as a disabled person, except during sex... In bed my amputation feels as a real disability.’ (26: p.190)

The use of exclusion as a strategy to reject one’s disabled identity was not limited to excluding the residual limb from sexual spaces. This was due to seven of the included papers (6,22,25,46,52,53) reporting that their participants had excluded potential partners who viewed them as disabled.

‘It gave me more to add to the list of what to look for in a guy, one who isn’t afraid of women with one leg, and doesn’t think I’m a fragile thing.’ (6: p.398)

In essence, participants appeared to seek out partners with whom they could reject their disabled identities and, therefore, feel desirable. The use of exclusion, whether it be in relation to one’s residual limb or potential partner, therefore, seemed to serve the purpose of maintaining a sense of desirability, and it is for this reason that both these aspects of exclusion have been captured within the present sub-theme.

### ***Safeguarding***

As has been noted, feelings of undesirability appeared to lead participants to expect that others would reject them. To safeguard themselves against this possibility, participants in five of the included papers reported several strategies: the avoidance of romantic relationships, exercising caution when dating, waiting to be approached by potential partners, and the early disclosure of limb loss.

‘Yeah I don’t usually approach them (guys), I’m confident but you won’t find me in the middle of the dance floor.’ (6: p.398)

‘...because I found, you know, if you wait until the second or third date it’s even worse because you can really get on and make a connection with someone and then drop it in and they’re ‘oh, why didn’t you tell me sooner?’ ... if you start getting a connection you’ve just got to throw it in otherwise you waste your time, you waste their time and [pause] it hurts, so...’ (27: p.214)

Unlike compensation and exclusion, which may be seen as methods to challenge one’s disabled identity and increase feelings of desirability, the aforementioned strategies appeared to represent ways in which individuals coped with the view of themselves as undesirable.

‘I’m just cautious because I don’t want to get hurt. I think at times it can make me a bit vulnerable.’ (6: p.398)

Considering this, strategies to manage feelings of undesirability may not be limited to increasing feelings of desirability, but rather include safeguards to manage the view of oneself as undesirable.

### **Support: A Double-Edged Sword**

Sixteen of the included papers reported experiences relating to the provision of spousal support, or the desire to be supported by potential partners, following limb loss. A range of experiences were noted, leading to the formation of the following sub-themes: 1) spousal support as beneficial and 2) support facilitates dependence.

### ***Spousal Support as Beneficial***

Ten of the included papers stated that spouses would provide emotional, physical, or financial support following limb loss.

‘My family and children were very supportive financially and they are still taking care of me...’ (48: p.3)

Support was typically valued by participants, with them viewing it as helpful for their wellbeing and necessary whilst they adapted to the physical challenges of limb loss. It is, perhaps, for this reason that participants who were not in romantic relationships sought out supportive partners.

‘I need someone who won’t be weird about my scars, who will carry my purse if I’m on crutches, who doesn’t mind when I ask him to get me stuff because I already took my leg off and I don’t feel like hopping and who will be supportive.’ (6: p.398)

Participants in romantic relationships often attributed their ability to cope to the support provided by their spouses.

‘One of the effective factors in coping with amputation is my spouse.’ (60: p.233)

Emotional support appeared to be particularly valued, with several participants highlighting this as central to their coping. Specifically, participants stated that being able to talk about their difficulties, whilst being met with understanding and acceptance, supported them in managing the challenges of limb loss. In line with this, some participants noted that,

where their spouses had struggled to understand, accept, or cope with their limb loss, they had found it difficult to cope themselves.

‘My husband’s difficulty in coping has made it more difficult for me to cope.’ (54: p.747)

In addition to aiding the ability to cope, two papers (27,51) described the provision of support as strengthening romantic relationships. A number of factors were reported to facilitate this, such as spending more time in each other’s company, improved communication, working towards common goals, and helping each other through various challenges.

‘I think we’re better now than what we have been...we’ve um [pause] made some changes and stuff, well mainly me, to be fair. Um [pause] so I think we communicate a lot better now. I used to kind of bottle things up and [pause] um, not really communicate well and just kind of do my own thing, where now, you know, I express myself a lot more, um [pause] again, that stops, stops the arguments and stops us from going [pause] you know, in a bad place again.’ (27: p.213)

### ***Support Facilitates Dependence***

Despite its reported helpfulness, seven of the included papers described support as fostering a sense of dependence amongst those with limb loss on their spouses.

‘I became more isolated from my colleagues and friends, and more dependent on my family...’ (47: p.184)

Feelings of dependence seemed to be more pronounced for those whose roles had changed from providing support to being supported. The following quote, from an individual who was described as previously providing for his family, highlights this sub-theme:

‘My whole family was next to me... my wife and father-in-law took turns staying with me at the hospital. I was embarrassed. Instead of me helping them, they were helping me.’

(52: p.6)

Due to the support provided by their spouses, participants reported feelings of burdensomeness. These feelings seemed to be compounded when their spouses had experienced difficulties in managing their own emotions.

‘Sometimes I almost think that they took the hard part... it was almost as if it was worse for them – my partner and her kids – because they're close by. My partner also went to see a psychologist for a time, in conjunction with the accident or maybe half a year after.’ (49: p.693)

Participants responded to their feelings of burdensomeness via a number of strategies to assert their independence. These included maintaining previous occupational roles, despite advice from their spouse not to do this; not talking about their difficulties; being reluctant to accept help; and isolating themselves. One participant, who described his partner as a ‘tremendous help’, followed on to say that he would not:

‘...sit there and go into a discussion about it [phantom pain] because people don't want to hear what is going on with you.’ (50: p.272)

Although the aforementioned strategies may have engendered a sense of independence, they appeared to have reduced the time spent with spouses, prevented the provision of support, and impeded communication. Considering the aforementioned finding that the strengthening of relationships depended on spending time together, supporting one another through challenges, and communicating effectively, the assertion of independence, as is described above, may be seen as harmful to romantic relationships. In line with this, Keeling and Sharratt (27) reported that being concerned with one’s own needs, rather than



those of the couple, appeared to present challenges to relationships, at times resulting in their cessation.

### **Diverse Experiences of Intimacy**

Participants in four of the included studies reported diverse views in relation to intimacy. For some participants, intimacy was viewed as problematic, whilst others felt that it was unimportant. These views have been captured within the following two sub-themes: 1) physical and psychological issues with intimacy and 2) intimacy as unimportant.

#### ***Physical and Psychological Issues With Intimacy***

Physical and psychological issues with intimacy, such as erectile dysfunction, problems with positioning during intercourse, and ruminative thoughts, were noted by three of the included papers.

‘I have said it before: I have one amputated leg, they can have the other one immediately if I can get my erection back.’ (26: p.189)

‘In the beginning you try leaning on the stump and yes, that is very hard to do. You slip away and you’re not used to it. [...] I also experience more cramps because of the different position I have to adhere to while having sex.’ (26: p.190)

‘I was thinking [sic] him looking at me and I’ve no foot and he’s thinking of that but he’s kind of alright but I’m thinking, I’m thinking what he should be thinking and I’m thinking it as well.’ (22: p.255)

For some participants, issues with intimacy appeared to be a direct consequence of limb loss, having not been previously noted. Others reported previous difficulties with intimacy, arising from pre-existing health conditions. Regardless of their underlying cause,

issues with intimacy appeared to generate a vicious cycle of anxiety about one's sexual performance, leading to it being worsened.

'My partner finds it difficult to look at my stump... I'm actively thinking about that while having sex. [...] Mentally, it's playing in your head, you can't focus 100% on what you would like to do, on what you're doing at that moment [...]. I always look through her eyes to see how she sees me.' (26: p.190)

Issues with intimacy were also noted to cause tension between participants and their spouses, at times leading to arguments.

'...a lot of our disagreements and arguments sort of stem from that [sex]. You know, she wants it [sex] and I'm physically unable to. That's [pause] that's a pretty big blow and that can be a catch-22 cycle of, you know [pause] of wanting to, not being able to, bit sad, which then adds to not being able to and things like that. It's quite a hard cycle to break.' (27: p.214)

As can be seen in the above quote, and particularly for male participants, issues with intimacy were viewed as problematic, though difficult to resolve, leading to a feeling of being 'let down' by their bodies.

### ***Intimacy as Unimportant***

As has been stated, issues with intimacy were predominantly noted by male participants. This may be due to the view expressed by female participants in three of the included papers that physical intimacy was unimportant to them.

'I: Was sex ever important to you? H: Never was, never was no, I don't think. Funny it's...I'd say its more importance in my head now than it ever had been, and that's because the option is not there (laughing) I think. You know that you're thinking about it more,

not, it's not, nah it's companionship I'm thinking about really I think. You know and that would be part of it too (obstacle to pursuing a relationship), that I'd be fucking going look that's all I want really I don't want sex.' (22)

Several reasons were cited for this, including a preference for romance and connection over sexual intercourse, and the desire to focus on the 'more pressing' aspects of the physical rehabilitation process.

'...Maybe they could have addressed [sexuality]. But you're so busy with other things. Getting better, learning to stand up. [...] I just wanted to get better and go home.' (26: p.191)

In keeping with these views, it was uncommon for intimacy to be discussed as part of the rehabilitation process. The reasons for this were not given, perhaps as they relate to the views and attitudes of health professionals not included within the present review.

Despite viewing intimacy as unimportant, female participants did report that they would have liked this to be addressed as part of the rehabilitation process: a view espoused by several male participants across the included papers.

'Whether it is someone who is trained for this or a wanderer, so to speak, that doesn't matter, as long as you can talk to someone...' (26: p.191)

The timing of this seemed to be important, with participants stating that they would prefer to discuss sexual issues once 'more pressing' physical limitations had been addressed. Discussing issues relating to intimacy later in the rehabilitation process was also reported to allow for the development of trust, with this being viewed as helpful to facilitate conversations about an area that would otherwise be difficult to address.

## Discussion

The present paper aimed to systematically review and thematically synthesise qualitative literature on the experiences of intimacy, romantic relationships, and dating following limb loss. The significance of findings are discussed below in relation to theory and previous research, and implications for clinical practice and future research are presented.

### **The Self as Undesirable**

Feelings of undesirability were commonly noted by participants within the included papers. Similar findings were reported in a systematic review of limb loss and sexual health (25), which noted an association between limb loss and a negative body image, in addition to views of the self as asexual. As has been suggested by Batty et al. (25), the loss of a limb may represent the loss of an able body, leading individuals to internalise societal ideas about disability, including ideas about the self as sexually and romantically undesirable.

To mitigate their feelings of undesirability, participants reported several coping strategies: compensation, exclusion, and safeguarding. Although these strategies have been noted elsewhere in the literature, their collective conceptualisation as means by which to manage feelings of undesirability appears to be novel. Consequently, having an awareness of these strategies may enable health professionals to identify and support individuals experiencing feelings of undesirability, such as by using the methods described below.

Social identity theory (61) proposes that identifying with stigmatised groups, such as people with disabilities, may lead individuals to employ 'normalisation' strategies. These strategies include efforts to downplay one's disability or emphasise aspects of the self that afford membership to higher-status groups, such as those without disabilities (62,63). The strategies of compensation and exclusion noted in the present review might be viewed as

forms of 'normalisation', in that they aim to support individuals in attaining membership to non-disabled groups.

Social identity theory elaborates that, if individuals perceive themselves as being able to attain higher-status group membership, they will be more likely to employ 'normalisation' strategies (64). This concept is referred to as group permeability, with Dirth and Brandscombe (65) stating that individuals with less impactful/more easily concealable disabilities are more likely to perceive higher group permeability. It is possible, then, that individuals employing compensatory or exclusionary strategies may view themselves as able to attain membership to non-disabled groups. The same cannot be said for individuals employing safeguarding strategies, which appeared to represent efforts to protect oneself from the impact of stigma associated with belonging to a lower-status group. For these individuals, the use of safeguarding strategies may have emanated from the perception of low group permeability, leading to efforts to cope with, rather than remedy, stigma.

Whilst 'normalisation' strategies may support individuals to attain the benefits of membership to higher-status groups, they may also have a number of negative consequences, such as overexertion and the rejection of support for one's disability (64,66). Similarly, whilst safeguarding strategies may protect individuals from experiencing stigma, it is asserted here that they may also prevent them from attaining the benefits of membership to higher-status groups. Much research (e.g.,(67,68) has been conducted on the advantages and disadvantages of various strategies used to manage stigma, and it is not within the scope of the present review to discuss these in detail. Rather, it is recommended that clinical psychologists have an awareness of the various strategies individuals may use to manage stigma following limb loss. It is hoped that this will facilitate conversations about the potential advantages and disadvantages of these strategies, enabling individuals to make informed decisions about how they cope with or manage limb loss.

Participants within the present review did note a number of unintended consequences arising from their use of the aforementioned strategies. For example, compensatory strategies involving masculine displays, such as not talking about one's needs or emotions, had the potential to reduce communication in relationships and, thus, weaken them. Similarly, the use of exclusionary or safeguarding strategies seemed to impede opportunities for the disconfirmation of beliefs about the self as undesirable. This is a vivid illustration of the cognitive-behavioural model of anxiety (see 69) which posits that avoidance behaviours serve to maintain unhelpful beliefs (about the self, others, and the world) by preventing the acquisition of evidence to the contrary. Indeed, several of the included papers reported that, when participants had engaged in sexual activities or sought out romantic partners, their beliefs about undesirability had, at times, been disconfirmed. Although disconfirmatory evidence did not consistently lead to changes in beliefs, this might be expected when it is considered that the modification of beliefs can be a long and difficult process, often depending on the initial strength of the beliefs to be modified (70).

As beliefs about the self as undesirable appear to emanate from societal views, it might be assumed that, for many individuals, they have been repeatedly reinforced and are, therefore, strongly held. Perhaps this is why previous research (e.g., 45,71,72) has found that disturbances to one's body image following limb loss can be persistent, though do improve over time; it may take numerous instances of disconfirmation to modify internalised societal ideas (72). Regardless of the time taken to modify beliefs, exposing oneself to opportunities for disconfirmation may support those with limb loss to challenge their views of the self as undesirable. Psychological therapies may be useful here, particularly for those with entrenched views, in that they can help individuals to identify and challenge unhelpful beliefs (73). Compassion-focussed therapy (70) may also be useful here, in that there is a focus on

the recognition and management of unintended consequences arising from the use of unhelpful coping strategies (70)

### **Support: A Double-Edged Sword**

In line with previous research (e.g., 74) the present review found that spouses typically assumed the role of a supporter following their partner's limb loss. It was common for participants to attribute their ability to cope to the support received from their spouse, with the provision of understanding and acceptance being highlighted as key reasons for this. Research from the field of counselling (e.g., 75,76) has found that the provision of understanding and acceptance may support individuals to understand and accept themselves, thus giving a possible explanation as to how spousal support enabled individuals to cope with limb loss. Considering this, encouraging the development of understanding and acceptance amongst spouses, such as by involving them in the rehabilitation process, may offer a helpful means by which to support individuals with limb loss.

For those without a spouse, the provision of support is often assumed by family members or friends (74). Due to its focus on romantic relationships, however, the present review did not include papers exploring these forms of support. It is, therefore, unclear as to whether individuals without a spouse receive the same level of understanding and acceptance as those with a spouse. Because of their proximity and knowledge of the person, it might be argued that spouses are particularly well positioned to acquire understanding and demonstrate acceptance. Individuals without a spouse might, therefore, face specific challenges in relation to coping with limb loss. Although this is uncertain, involving a person's main supporter in the rehabilitation process may, nonetheless, provide a helpful means by which to encourage coping.

Previous research (e.g., 77) has reported that individuals with spouses, as compared to those without, typically receive more social support. The reasons for this relate to the provision of spousal support, in addition to the presence of larger social networks amongst those in romantic relationships. The benefits of being in a romantic relationship might, therefore, not be limited to the provision of understanding and acceptance, but also to the possibility of increased opportunities for support from a variety of sources. This is not to say that individuals in romantic relationships will be well supported, but rather that individuals without such relationships may be at an increased risk of receiving comparatively less support following limb loss. Healthcare professionals will likely benefit from being mindful of this, so as to support in the identification of individuals who may receive relatively little social support following limb loss. For such individuals, peer support groups may offer a potential solution, in that they can provide opportunities for support from a range of understanding and accepting others (78).

In addition to the aforementioned benefits, spousal support had the potential to improve romantic relationships. Improved communication, working towards common goals, and spending more time together were cited as reasons for this, with literature on the development of healthy relationships (e.g., 79–81) supporting these findings. Interestingly, in papers that reported relationship difficulties, it appeared that some or all of these factors had been compromised. The desire to assert one's independence following limb loss seemed to be particularly counterproductive to relationships, in that it prevented the acceptance of support, impeded communication, and reduced the time that couples spent together. Consequently, the assertion of independence may reduce opportunities for the provision of understanding and acceptance, making it more difficult for individuals to cope with limb loss. This highlights the case for the provision of psychological support following limb loss; it may help couples



to communicate their needs and renegotiate the assertion of independence in ways that are not harmful to their relationship.

### **Diverse Experiences of Intimacy**

Although physical and psychological barriers to engaging in intimacy were noted within the present review, they were relatively uncommon, having only been captured by four of the included papers. Previous research (e.g., 82) has reported contrasting findings, stating that issues with sexual functioning are prevalent amongst those with limb loss. It is, therefore, possible that participants in the included studies did not wish to disclose issues relating to intimacy. In support of this idea, participants did note that issues with intimacy reminded them of their disability, leading to the presumption that they may have avoided discussing these issues as a means by which to reject or deny their disabled identities. Difficulties talking about issues with intimacy have been noted elsewhere in the literature (see 83) and, considering this, the present review may have been subject to an underreporting bias.

Despite the above possibility, it is conceivable that participants experienced few difficulties in relation to intimacy. Verschuren et al. (36) has stated that, where sexual issues are present, they may relate more strongly to pre-existing health conditions or age than limb loss. As such, participants who did experience issues with intimacy may not have reported these as they did not relate to their limb loss, but rather to other factors. Similarly, as many of the included studies did not focus on the wider concept of sexuality, they may not have captured information relating to the presence or absence of issues with intimacy. Ultimately then, the impact of limb loss on intimacy remains unclear.

Whilst issues with intimacy were relatively uncommon in the present review, their presence does highlight the importance of discussing sex as part of the rehabilitation process. Unfortunately, despite participants reporting a desire for support with their sex lives, many

found that this was not discussed by healthcare professionals. There are several possible explanations for this, including a reluctance from those with limb loss to discuss aspects of themselves that might highlight their difficulties, a potential lack of such difficulties, or the initial desire to focus on other aspects of the rehabilitation process. Maurice and Yule (84) offer a further explanation, stating that healthcare professionals may not believe it is necessary to discuss sexual issues unless they are directly asked by their patients. Considering these explanations, healthcare professionals may benefit from initiating conversations about issues with intimacy, potentially later in the rehabilitation process to allow time for other issues to be addressed. Similarly, if these issues are discussed later in rehabilitation process, this may allow for the development of trust, thereby making it easier for individuals to disclose any difficulties they may be experiencing (36).

It is noteworthy that participants who did report issues with intimacy were predominantly male: a finding highlighted previously in the literature (85,86). This contrasts with previous epidemiological research (87) that has reported either comparable or higher rates of sexual issues amongst women in the general population. As has been suggested by Verschuren et al. (36), the greater prevalence of sexual issues amongst men with limb loss may be explained by the cultural stereotype of men as more active during sex, meaning they are more likely to experience and notice physical difficulties with their sexual functioning. Furthermore, as cultural ideas about masculinity equate this concept with sexual performance, men with limb loss may feel pressured to 'perform' and, consequently, experience difficulties engaging in sexual activities. For several male participants, 'performing' masculinity enabled them to cope with the perceived loss of desirability, suggesting that pressures to perform sexually may only be amplified amongst men with limb loss. To address these issues, healthcare professionals may benefit from offering advice on suitable sexual positions or alternatives to penetration. Although men appeared more likely to

experience sexual issues, it is recommended that advice should be given to anyone with limb loss, regardless of gender, where appropriate.

### **Limitations and Future Research**

The present review aimed to understand how intimacy, romantic relationships, and dating are experienced following limb loss. As these concepts are reasonably broad, it was challenging to ensure that the terms utilised for database searching captured all of the relevant literature. Indeed, as a doctoral thesis, the constraint of time meant that only titles and abstracts were searched for relevant terms. Similarly, medical subject headings (which can be used within databases such as Medline to index records on a particular subject, regardless of the terminology used by authors; 88) were not used, and grey literature and non-English papers were excluded. Consequently, some relevant papers may have been missed. Future reviews may wish to broaden the scope of the present review by including additional terms relating to the concepts of interest, performing full-text searches for such terms, or including grey literature and non-English papers.

A further limitation of the present review relates to the variable reporting of demographic information within the included papers. As examples, whilst ages, ethnicities, and types of limb loss were reported by many of the included papers, it was not typical for such information to be linked to participant quotes. As such, it was difficult to understand whether the findings of the present review reflected the experiences of particular groups. In line with this, as gender was often reported alongside quotes, it was possible to conclude that men appeared more likely to experience issues with intimacy following limb loss. Unfortunately, as this was not the case for other demographic variables, their impact on the experience of intimacy, romantic relationships, and dating remains unclear. Future research

may support subsequent reviews in addressing this limitation by linking participant quotes to any demographic information that has been collected.

There is a relative dearth of research on intimacy, romantic relationships, and dating amongst individuals with limb loss. As such, few papers were included within the present review. This limits the generalisability of the reported findings, particularly in relation to groups that were not well represented within the included papers. For example, only five of the included papers (48,56,60,89,90) reported conducting their studies within non-Westernised countries and, amongst the papers that reported the ethnicities of their participants, the majority ( $n = 55$ ) were stated to be Caucasian or White-British. Similarly, no papers reported including individuals from sexual minorities. It is, therefore, unclear as to how well the present review reflects the experiences of these individuals. Furthermore, individuals who participated in the included papers may have done so on the basis of experiencing difficulties in relation to the concepts of interest. Considering this, the present review may have been skewed towards negative experiences. To better understand the impact of limb loss on intimacy, romantic relationships, and dating then, future research may wish to sample individuals from non-Western countries, sexual minorities, or those reporting positive experiences of sexuality.

## **Conclusion**

The present review found that individuals faced a number of challenges in relation to intimacy, romantic relationships, and dating following limb loss. Challenges included concerns about undesirability, the unintended consequences of coping strategies, spousal dependency, and issues with intimacy. To support in addressing these issues, health professionals are advised to offer psychological therapies to individuals who are struggling to cope or experiencing relationship difficulties; have an awareness of the strategies used to

manage stigma following limb loss; refer or signpost individuals to peer-support groups; involve spouses or main carers in the rehabilitation process, particularly when other forms of social support are not available; and discuss sexuality as part of the rehabilitation process, namely after time has been allowed for the development of a trusting relationship.

**Declaration of Interest**

The author reports that there are no competing interests to declare.

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## Appendix A

**Table A1.** *Overview of the Search Terms Applied to Each Database*

Database	Search Terms
<p><b>Academic Search Ultimate, CINAHL, Medline, and Psych Info</b></p>	<p>Qualitative</p> <p>TI (Qualitative OR “interpretative phenomenological analysis” OR ethnograph* OR “thematic analysis” OR narrative OR “grounded theory” OR “case study” OR “case studies” OR “focus group*” OR interview* OR “semi-structured interview*” OR “semi structured interview*” OR “content analysis” OR “discourse analysis” OR “descriptive study” OR exploratory OR hermeneutic OR naturalistic OR “participant observation*” OR phenomenolog* OR “constant comparison”)</p> <p>OR</p> <p>AB (Qualitative OR “interpretative phenomenological analysis” OR ethnograph* OR “thematic analysis” OR narrative OR “grounded theory” OR “case study” OR “case studies” OR “focus group*” OR interview* OR “semi-structured interview*” OR “semi structured interview*” OR “content analysis” OR “discourse analysis” OR “descriptive study” OR exploratory OR hermeneutic OR naturalistic OR</p>

“participant observation\*” OR phenomenolog\* OR “constant comparison”)

AND

Limb Loss

TI ((amput\* OR “limb absence” OR “limb loss” OR (limb\* OR hand\* OR feet OR foot OR “below knee” OR “above knee”)  
N3 (loss OR removal) OR limbless OR “limb amput\*” OR prosth\* OR disarticulation OR “artificial limb\*”))

OR

AB ((amput\* OR “limb absence” OR “limb loss” OR (limb\* OR hand\* OR feet OR foot OR “below knee” OR “above knee”)  
N3 (loss OR removal) OR limbless OR “limb amput\*” OR prosth\* OR disarticulation OR “artificial limb\*”))

AND

Sexuality

TI (sex\* OR intercourse OR “physical contact\*” OR affection\* OR relation\* OR roman\* OR love OR dating OR psychosexual

OR partner\* OR intima\* OR “significant other” OR “close relationship\*” OR couple\* OR spouse\* husband OR wife OR boyfriend\* OR girlfriend\* OR marriage\* OR married OR courtship)

OR

AB (sex\* OR intercourse OR “physical contact\*” OR affection\* OR relation\* OR roman\* OR love OR dating OR psychosexual OR partner\* OR intima\* OR “significant other” OR “close relationship\*” OR couple\* OR spouse\* husband OR wife OR boyfriend\* OR girlfriend\* OR marriage\* OR married OR courtship)

## Web of Science

## Qualitative

TI=(Qualitative OR “interpretative phenomenological analysis” OR ethnograph\* OR “thematic analysis” OR narrative OR “grounded theory” OR “case study” OR “case studies” OR “focus group\*” OR interview\* OR “semi-structured interview\*” OR “semi structured interview\*” OR “content analysis” OR “discourse analysis” OR “descriptive study” OR exploratory OR hermeneutic OR naturalistic OR “participant observation\*” OR phenomenolog\* OR “constant comparison”)

OR

AB=(Qualitative OR “interpretative phenomenological analysis” OR ethnograph\* OR “thematic analysis” OR narrative OR “grounded theory” OR “case study” OR “case studies” OR “focus group\*” OR interview\* OR “semi-structured interview\*” OR “semi structured interview\*” OR “content analysis” OR “discourse analysis” OR “descriptive study” OR exploratory OR hermeneutic OR naturalistic OR “participant observation\*” OR phenomenolog\* OR “constant comparison”)

AND

Limb Loss

TI=(((amput\* OR “limb absence” OR “limb loss” OR ((limb\* OR hand\* OR feet OR foot OR “below knee” OR “above knee”) N3 (loss OR removal)) OR limbless OR “limb amput\*” OR prosth\* OR disarticulation OR “artificial limb\*”)))

OR

AB=((amput\* OR "limb absence" OR "limb loss" OR ((limb\* OR hand\* OR feet OR foot OR "below knee" OR "above knee") N3 (loss OR removal)) OR limbless OR "limb amput\*" OR prosthe\* OR disarticulation OR "artificial limb\*"))))

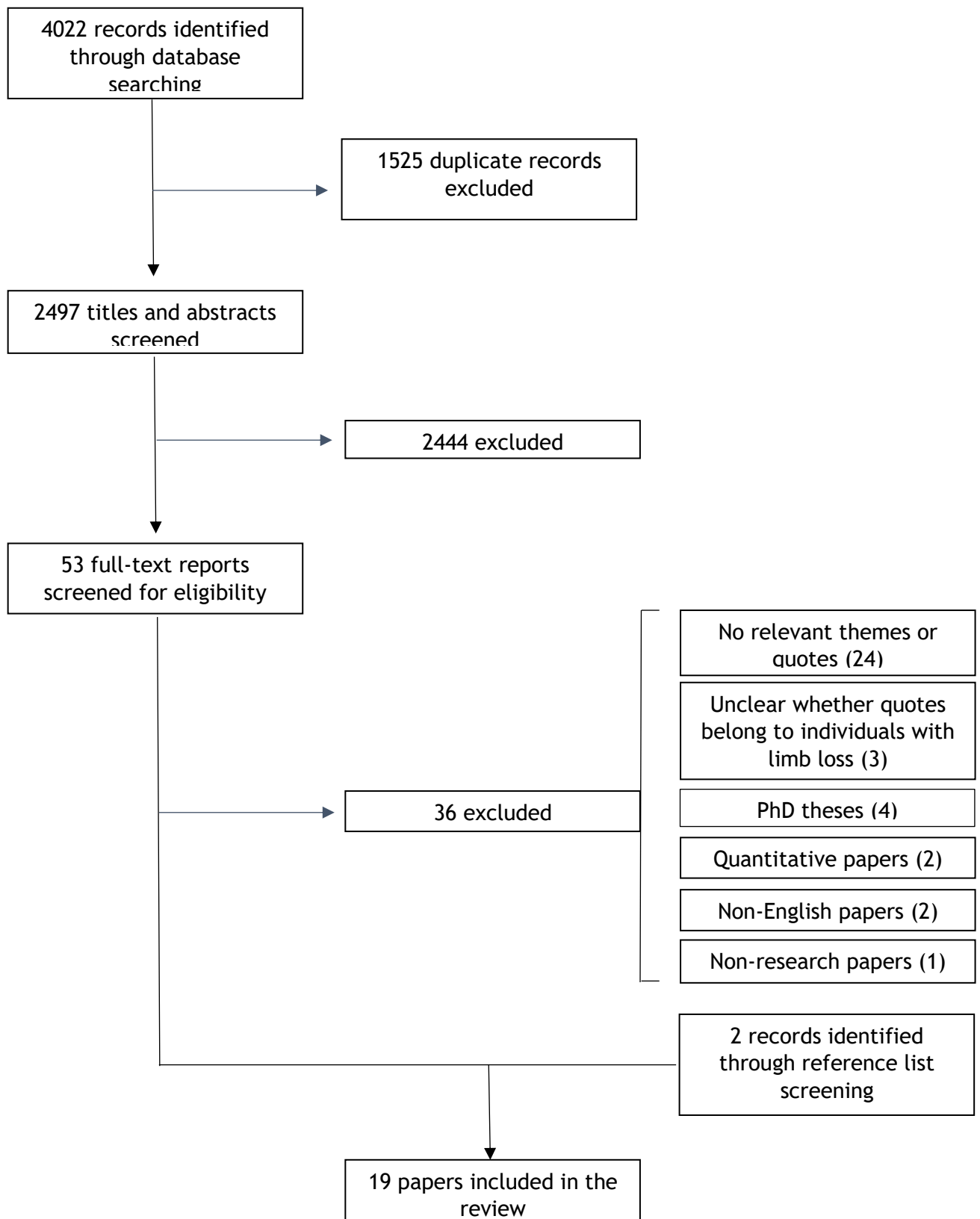
AND

Sexuality

TI=(sex\* OR intercourse OR "physical contact\*" OR affection\* OR relation\* OR roman\* OR love OR dating OR psychosexual OR partner\* OR intima\* OR "significant other" OR "close relationship\*" OR couple\* OR spouse\* husband OR wife OR boyfriend\* OR girlfriend\* OR marriage\* OR married OR courtship)

OR

AB=(sex\* OR intercourse OR "physical contact\*" OR affection\* OR relation\* OR roman\* OR love OR dating OR psychosexual OR partner\* OR intima\* OR "significant other" OR "close relationship\*" OR couple\* OR spouse\* husband OR wife OR boyfriend\* OR girlfriend\* OR marriage\* OR married OR courtship)

**Figure A1.** *Flow Diagram of the Search Process*

**Table A2.** *Example of the Theme Generation Process (Support: A Double Edged Sword)*

Theme	Sub-Themes	Codes	Author Interpretations	Author Themes	Author Sub-Themes	Illustrative Quotes
Support: A Double Edged Sword	Spousal Support as Beneficial	Financial support from spouse	<i>'The immediate family members, spouse and children provided support in the form of advice, financial assistance....' (48: p.3)</i>	Coping Strategies	Dependence on Immediate Family Members	<i>'My family and children were very supportive financially and they are still taking care of me... ' (48: p.3)</i>
	Spousal support as valued		<i>'...participants expressed that friends and family</i>	Non-Empathetic Support Systems	Lack of Understanding	<i>'[my spouse is a] tremendous help, don't know where</i>



were very  
supportive.’ (50:  
p.272)

I'd be if it wasn't  
for her’ (50:  
p.272)

<p>Romantic relationship improved following limb loss/importance of communication and not ‘bottling up’ emotions</p>	<p>‘Cognitively, new forms of masculinity were established by reassessing values that no longer served them and had previously negatively impacted their romantic relationships such</p>	<p>Loss of the Super Soldier</p>	<p>Establishing New Masculinity</p>	<p>‘I think we’re (relationship with partner) better now than what we have been...we’ve um [pause] made some changes and stuff, well mainly me, to be fair. Um [pause] so I think we communicate a lot better now. I</p>
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*as internalising  
masculine body  
ideals, bottling up  
emotion, and  
valuing ableism.  
Reassessing and  
decentralising  
these masculine  
values benefitted  
their relationships  
and their self-  
worth. ' (27: p.213)*

*used to kind of  
bottle things up  
and [pause] um,  
not really  
communicate well  
and just kind of  
do my own thing,  
where now, you  
know, I express  
myself a lot more,  
um [pause] again,  
that stops, stops  
the arguments  
and stops us from  
going [pause] you  
know, in a bad*

*place again.’ (27:  
p.213)*

---

Lack of spousal support can worsen the ability to cope	<p><i>‘...another common person who contributed to the lack of social support was the individual’s spouse/partner.’</i></p> <p><i>(54: p.747)</i></p>	Social Support	None reported	<p><i>‘My husband’s difficulty in coping has made it more difficult for me to cope.’</i></p> <p><i>(54: p.747)</i></p>
<hr/>				
Practical support from spouse	<p><i>‘Another participant stated that his wife has hidden financial</i></p>	Social Support	None reported	<p><i>‘Thank God I have a great wife. She never told her family my</i></p>

*problems from her family. In addition, she has retained her and her family's self-esteem and independence.'*  
 (60: p.233)

*problems. Once a week, she would go to his father's home without jacket in the winter blizzard. She would say it does not matter to me...'* (60: p.233-234)

Emotional support from spouse

*'They all emphasized the importance of their partner's reaction towards*

Role of the Partner

None reported

*'I have mostly talked about [sexuality] with [my partner]. He helped me the*

*the amputation  
and how this  
reaction was  
helpful in learning  
to accept and deal  
with the  
amputation. Also,  
most participants  
indicated that they  
were able to talk  
about sexuality  
with their  
partner.’ (26:  
p.191)*

*most. He gave me  
the feeling that it  
was all ok. I think  
that is the best  
way to handle it.’  
(26: p.191)*



*presents*  
*additional*  
*physical*  
*challenges at the*  
*start of a*  
*relationship and*  
*can also give them*  
*more to consider*  
*in terms of any*  
*specific qualities*  
*they are looking*  
*for in their ideal*  
*partner...*  
*Elizabeth*  
*described how the*  
*qualities did not*

*might be*  
*physically*  
*dependent earlier*  
*in life, childbirth,*  
*raising a child,*  
*things like*  
*that.'* (6: p.398)

*only relate to the  
short-term...’ (6:  
p.398)*

---

Loss of helper role/independence	<i>‘There is a difference in coping for participants assisted by family members and those who are alone. In the case of the former, we found the same feeling of embarrassment</i>	Role Constraints and Limitations	Social and Family Ties	<i>‘My whole family was next to me... my wife and father-in-law took turns staying with me at the hospital. I was embarrassed. Instead of me helping them, they were helping me.’ (52: p.6)</i>
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*and frustration.*

*Feeling helpless*

*and unable to fulfil*

*the role of*

*provider, one*

*participant had*

*difficulties in*

*accepting the*

*support his family*

*offered.'* (52: p.5-

6)

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Dependence leading to depression	<i>'Patients'</i> <i>verbalizations</i> <i>about the</i> <i>diagnosis and</i>	Reactions and Feelings About Becoming an Amputee	The Emotional Impact of Amputation	<i>'...I became more</i> <i>isolated from my</i> <i>colleagues and</i> <i>friends, and more</i>
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*becoming an  
amputee reported  
different kinds of  
meanings. Most (n  
= 20) verbalized  
reactions and  
feelings such as  
sadness, shock,  
insurgence,  
surprise, non-  
acceptation of the  
situation, anger  
and suicidal  
thoughts. ' (47:  
p.184)*

*dependent on my  
family ...I was  
feeling very sad  
depressed... ' (47:  
p.184)*

---

Loss of provider role	<p><i>‘Losing part of one’s leg or foot also resulted in a sense of incompleteness, confusion, and bewilderment which further intensified the experience incapacity. A sense of incompleteness, incapacity, and disability deriving from the absence</i></p>	<p>Physical Loss Disrupted Normality</p>	<p>Disabled and Incomplete</p>	<p><i>‘I’m searching— middle of the night I’m searching for my leg? Where’s the rest of my foot? I am incomplete. How am I going to survive? How am I going to work? Because – I can’t walk anymore, I’ve to sit on a wheelchair. Not being able to play</i></p>
-----------------------	--	--	------------------------------------	--

*of the lower  
extremity hindered  
participants' daily  
life and activities  
and made them  
feel a loss of  
identity and the  
loss of ability to  
perform familial  
and social roles,  
thus disrupted  
their normality.'*  
(89: p.3)

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*my role, as a  
father, as a  
husband... As a...  
breadwinner.'*  
(89: p.3)

**Table A3.** *Overview of the Included Papers*

<b>Author (Year)</b>	<b>Aim</b>	<b>Sample</b>	<b>Age (Years)</b>	<b>Race/Ethni city</b>	<b>Sex</b>	<b>Type of Limb Loss</b>	<b>Time Since Limb Loss</b>	<b>Methods (Data Collection and Analysis)</b>	<b>Author's Themes</b>
Abouam moh et al. (56)	To explore the experiences and needs of lower limb amputees for social and psychological adjustment in Saudi Arabia, according to	$n = 13$	26 – 71 (mean = 47)	Saudi Arabian	3 men and 5 women	9 above- knee, 3 below-knee, and 1 at ankle level	4 – 15 years	A focus group and semi- structured interviews; thematic analysis	Experiences and needs before amputation, experiences in social and psychological adjustment after amputation, and physical and

their own  
perspective

psychological  
support

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Amoah et al. (48)	To explore the experiences of patients with diabetes-related lower limb amputation at the Komfo Anokye Teaching Hospital	<i>n</i> = 10	No age range is reported, though participants were eligible for inclusion if they were aged 25 - 70	Not reported	Not reported, although it is noted that more men than women participated	Not reported, though it is stated that participants were selected if they had been amputated at the foot, ankle, below the knee, at the knee, above the	Not reported	Semi-structured interviews; thematic content analysis, as described by Miles and Huberman	Physical experiences and coping strategies
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knee, or at  
the hip

Batty et al. (25)	To explore participants' experiences in order to examine how participants attempted to construct the self in the context of embodied disability	<i>n</i> = 7	23 – 57 (no mean reported )	White-British	5 men and 2 women	4 participants were missing one lower extremity and 2 were missing both their right and left legs, with 1 also missing an arm	Not reported	A workshop presentation and semi-structured interviews; thematic analysis	Loss of 'wholeness': In body, sexuality and relationships; exclusion as a strategy for managing sexuality; displaying gender: strategies of compensation
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and  
empowerment

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Bernhoff et al. (49)	To give in depth descriptions of how patients experience life years after severe lower extremity trauma with vascular injury	<i>n</i> = 8	Not reported, though participa nts are stated to be over 18	Not reported	5 men and 3 women	Little information is given, though one participant is stated to have undergone an above-knee amputation	4 – 15 years	Semi- structured interviews; descriptive phenomenolog ical modified by A. Giorgi	An everlasting reminder of physical and cosmetic impairments in daily life with a changed perception of self; experience of decisive encounters, relations, and need for
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interpersonal support; the way to “normal life” – and still never the same

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Bosmans et al. (51)	To explore the impact of an amputation and of phantom pain on the subjective well-being of amputees	<i>n</i> = 16	39 – 86 (mean = 66.6)	Not reported	11 men and 5 women	13 below-knee, 11 unilateral, 5 bilateral, and 3 above-knee	1 – 6 months	Semi-structured interviews; no specific analysis method was reported	The influence of an amputation and of phantom pain on long-term behaviour and the influence of an amputation and of phantom
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pain on  
 subjective well-  
 being

Cater (53)	To increase our understanding of the psychosocial adjustment issues American servicewomen experience after a	<i>n</i> = 6	20 – 36  (mean = 24)	Caucasian	6 women	2 below- knee, 2 above-knee, 1 bilateral below-knee, 1 bilateral above-elbow, and 1 right arm disarticulatio n	3 – 6 years	In-depth interviews; no specific analytical method was used, though a phenomenolog ical approach was taken	Physical disability adjustment issues, psychosocial adjustment and coping skills, and protective factors
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traumatic  
 amputation  
 using  
 phenomenolo  
 gical research  
 methodology

Gallagher and MacLachl an (45)	To identify factors considered to be important in the adjustment to amputation and the wearing of a	<i>n</i> = 14	20 – 50 (no mean reported )	Not reported	8 men and 6 women	7 below- knee, 5 above-knee, and 2 bilateral	Not reported	Focus groups; thematic analysis	Initial reaction to amputation and the artificial limb, self- image, social interaction, effect on family and friends, acceptance,
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prosthetic  
limb from the  
perspective of  
the person  
who has had a  
lower limb  
amputation

support,  
problems with  
prosthesis,  
practical  
consideration,  
and long-term  
effects

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Horne and Paul (50)	To understand the lived experience of chronic pain support among those who have undergone a	<i>n</i> = 11	No age range reported (mean = 60.82)	African American ( <i>n</i> = 5), Caucasian ( <i>n</i> = 5), and Native American ( <i>n</i> = 1)	56% male	All participants were stated to have had a lower extremity amputation	No range reported, though it is stated that limb loss occurred more than 6 months	Semi- structured interviews; qualitative empirical phenomenolog y	Phantom pain is non-treatable pain, support systems were non-empathetic, and participants experienced
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diabetes-  
related lower  
limb  
amputation

prior to the  
study

identification of  
a new normal

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Keeling and Sharratt (27)	To understand how physically injured male UK combat veterans whose appearance changed due to their injury, experienced and made	<i>n</i> = 4	33 – 42 (no mean reported )	Not reported	4 men	1 above-knee and 1 below- knee	Not reported	Semi- structured interviews; interpretative phenomenolog ical analysis	(Loss of) the super soldier, new states of vulnerability, and injury tests the foundation of relationships
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sense of their  
 changed  
 appearance in  
 relation to  
 their romantic  
 relationship

Mathias and Harcourt (6)	To gain an in- depth understanding of the experiences and emotional responses of women with below-knee	<i>n</i> = 4	18 – 29 (mean = 24.5)	Not reported	4 women	3 below-knee and 1 right ankle (unclear whether above or below)	4 – 13 years	Semi- structured interviews; interpretative phenomenolog ical analysis	Revealing and exposing: disclosing the amputation and prosthesis, judging and judged: internal fears and self- doubt, trusting
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amputations  
to dating and  
intimate  
relationships

and accepting:  
good guy/bad  
guy elimination,  
taking it further:  
the need for  
depth; and  
realisation:  
accepting and  
feeling accepted

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Morgado	To explore the	<i>n</i> = 17	22 – 68	Not	10 men	13 above-	4 – 40 years	Semi-	Living and
Ramirez	lived		(mean =	reported	and 7	elbow, 3		structured	adapting to life,
et al. (88)	experiences of		37)		women	below-elbow,		interviews;	productivity
	people with					1 at elbow,		thematic	and
	upper limb					and 1		analysis	participation,

absence of shoulder and living  
 (PWULA) disarticulation within the wider  
 living in environment  
 Uganda

Rosca et al. (52)	To identify the psychological changes that result from the amputation of a limb and the ways in which patients coordinate	<i>n</i> = 7	41 – 75 (no mean reported)	Not reported	Not reported	6 ‘inferior’ limbs and 1 upper limb	Approximately 4 months (for all participants)	Semi-structured interviews; interpretative phenomenological analysis	Emotional impact, negative affects, tendency towards isolation, role constraints and limitations, phantom limb, and emotional balancing
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their daily  
lives

Saradijan et al. (55)	To gain a rich understanding of the experience of living with an upper limb amputation and of using a prosthetic arm and hand	<i>n</i> = 11	31 – 64 (mean = 51.6)	Not reported	11 men	5 below- elbow, 4 above-elbow, 1 shoulder disarticulatio n, and 1 wrist disarticulatio n	7 – 48 years	Semi- structured interviews; interpretative phenomenolog ical analysis	Impact of amputation: awareness of physical difference and disability, role of prosthesis and terms of use, psychosocial adjustment, physical/functio nal adaptation,
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coping style  
 facilitating  
 adjustment, and  
 self-worth

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Senra et al. (47)	To explore adults’ experiences of lower limb amputation, focusing on the changes in self-identity related to the impairment	<i>n</i> = 42	22 – 82 (mean = 61)	Not reported	35 men and 7 women	26 below- knee and 16 above-knee	0.3 – 17 years	Semi- structured interviews; thematic and categorical analysis	Reactions and feelings about becoming amputee, changes in own life, problems in well-being, relation with the prosthesis, self- perceptions,
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aims related to the rehabilitation and future plans, relation with the rehabilitation, and perceived social support

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Stutts et al. (54)	To examine the experience of a limb amputation from the	<i>n</i> = 30	23 – 81 (mean = 50)	White Caucasian ( <i>n</i> = 28) and African	30 women	14 below-knee, 11 above-knee, 2 upper limb, 2 bilateral	< 1 year – 41 years	Free response questions; interpretative phenomenological analysis	Coping, social support, discrimination, support group for individuals
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female American (*n* = 2) arm, and 1 with  
 perspective = 2) bilateral above-knee amputations,  
 acceptance,  
 other concerns  
 related to  
 gender identity

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Valizadeh et al. (60)	To explain understanding the trauma of patients and the experience of support sources during the	<i>n</i> = 20	25 – 57 (mean = 41.7)	Not reported	19 men and 1 woman	Not stated, though participants were reported to have lower-limb amputations	2 – 31 years	Unstructured interviews; qualitative content analysis	Supportive family, gaining friends support, gaining morale from peers, and assurance and satisfaction
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process of  
adaptation to  
a lower limb  
amputation

with the  
workplace

Verschuren et al. (26)	To describe how people with a lower limb amputation experience (changes in) their sexual functioning and sexual well-being	<i>n</i> = 26	22 – 71 (no mean reported; median = 47)	Not reported	17 men and 9 women	15 below-knee, 6 above-knee, 2 bilateral, 2 hip disarticulations, and 1 knee disarticulation	Not reported	Semi-structured interviews; thematic analysis	Importance and definition of sexuality, changes in sexual functioning, changes in sexual well-being, practical problems concerning
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sexuality, self-  
 image, feelings  
 of shame, role  
 of the partner,  
 and  
 communication  
 about sexuality  
 with  
 professionals

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Ward- Khan et al. (22)	To gain an in- depth understanding of women's experience of	<i>n</i> = 9	35 – 62  (mean = 51)	Caucasian	9 women	6 below- knee, 2 above-knee, and 1 high- level pelvic	1.5 – 31 years	Semi- structured interviews; interpretative	I don't like the way I am, broken/not wanted,
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sexuality and  
 body image  
 following  
 amputation of  
 a lower limb  
 to inform  
 rehabilitation  
 and clinical  
 practice

phenomenolog  
 ical analysis and same but  
 different

Zhu et al. (89)	To explore the experiences of patients living with diabetic lower extremity	<i>n</i> = 9	37 – 72 (mean = 59)	4 Chinese, 3 Malay, and 2 Indian	6 men and 3 women	1 below-knee and 1 ‘multiple’ amputations (other participants	1.5 months – 11 months	Semi- structured interviews; interpretative phenomenolog ical analysis	Physical loss disrupted normality, emotional impact aggravated the
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amputation  
(DLEA) and  
its post-  
amputation  
wound in  
primary care

had minor  
limb loss and  
were,  
therefore, not  
included)

disrupted  
normality,  
social  
challenges  
further  
provoked the  
disrupted  
normality, and  
attempt to  
regain  
normality

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**Table A4.** CASP Ratings for the Included Papers

<b>Paper</b>	<b>Was there a clear statement of the aims of the research?</b>	<b>Is a qualitative methodology appropriate?</b>	<b>Was the research design appropriate to address the aims of the research?</b>	<b>Was the recruitment strategy appropriate to the aims of the research?</b>	<b>Was the data collected in a way that addressed the research issue?</b>	<b>Has the relationship between researcher and participants been adequately considered?</b>	<b>Have ethical issues been taken into consideration?</b>	<b>Was the data analysis sufficiently rigorous?</b>	<b>Is there a clear statement of findings?</b>	<b>How valuable is the research?</b>	<b>Score</b>
Abouammoh et al.	Yes	Yes	2	1	1	2	2	2	3	2	15

oh et al.

(56)

Amoah et al. (48)	Yes	Yes	2	1	2	1	2	1	3	2	14
Batty et al. (25)	Yes	Yes	3	2	3	1	2	2	3	3	19
Bernhoff et al. (49)	Yes	Yes	2	2	3	1	2	1	3	2	16
Bosmans et al. (51)	Yes	Yes	3	2	3	1	1	2	3	2	17
Cater (53)	Yes	Yes	3	2	3	1	2	2	3	2	18
Gallagher and MacLachlan (45)	Yes	Yes	2	2	3	1	2	2	3	2	17
Horne and Paul (50)	Yes	Yes	2	2	2	1	1	2	3	2	15

Keeling and Sharratt (27)	Yes	Yes	3	2	2	3	1	2	3	3	19
Mathias and Harcourt (6)	Yes	Yes	3	2	3	2	2	2	3	3	20
Morgado Ramirez et al. (88)	Yes	Yes	1	2	3	1	1	2	3	2	15
Rosca et al. (52)	Yes	Yes	2	2	2	1	2	2	3	2	16
Saradijan et al. (55)	Yes	Yes	3	2	2	2	2	2	3	3	19

Senra et al.	Yes	Yes	1	2	2	1	2	2	3	2	15
(47)											
Stutts et al.	Yes	Yes	3	2	2	1	1	3	3	2	17
(54)											
Valizadeh et al. (60)	Yes	Yes	2	3	2	1	2	2	3	2	17
Verschuren et al. (26)	Yes	Yes	2	1	2	1	2	2	3	2	15
Ward- Khan et al.	Yes	Yes	2	2	2	3	2	2	3	2	18
(22)											
Zhu et al.	Yes	Yes	2	2	2	1	2	2	3	2	16
(89)											

**Table A5.** *Supporting Papers for Each Theme and Sub-Theme*

<b>Themes</b>	<b>Sub-Themes</b>	<b>Supporting Papers</b>
The Self as Undesirable	The Loss of Desirability	Abouammoh et al. (56) Amoah et al. (48) Batty et al. (25) Keeling and Sharratt (27) Mathias and Harcourt (6) Morgado Ramirez et al. (88) Rosca et al. (52) Saradijan et al. (55) Verschuren et al. (26) Ward-Khan et al. (22)
The Self as Undesirable	Negative Beliefs About the	Abouammoh et al. (56)
The Management of Undesirability	Views of Others	Batty et al. (25) Cater (53) Keeling and Sharratt (27) Mathias and Harcourt (6) Morgado Ramirez et al. (88) Saradijan et al. (55) Valizadeh et al. (60) Verschuren et al. (26) Ward-Khan et al. (22)
	Compensation	Amoah et al. (48) Batty et al. (25)

		Cater (53)
		Mathias and Harcourt (6)
		Rosca et al. (52)
		Ward-Khan et al. (22)
<hr/>		
The Management of	Exclusion	Batty et al. (25)
Undesirability		Cater (53)
Support: A Double-Edged		Mathias and Harcourt (6)
		Morgado Ramirez et al. (88)
		Rosca et al. (52)
		Verschuren et al. (26)
		Zhu et al. (89)
<hr/>		
	Safeguarding	Keeling and Sharratt (27)
		Mathias and Harcourt (6)
		Morgado Ramirez et al. (88)
		Senra et al. (47)
		Ward-Khan et al. (22)
<hr/>		
	Spousal Support as	Abouammoh et al. (56)
	Beneficial	Amoah et al. (48)
		Bosmans et al. (51)
		Cater (53)
		Horne and Paul (50)
		Keeling and Sharratt (27)
		Stutts et al. (54)
		Valizadeh et al. (60)
		Verschuren et al. (26)

		Zhu et al. (89)
Support: A Double-Edged	Support Facilitates	Amoah et al. (48)
Diverse Experiences of	Dependence	Bosmans et al. (51)
Intimacy		Mathias and Harcourt (6)
		Rosca et al. (52)
		Senra et al. (47)
		Valizadeh et al. (60)
		Zhu et al. (89)
	Physical and Psychological	Keeling and Sharratt (27)
	Issues with Intimacy	Mathias and Harcourt (6)
		Verschuren et al. (26)
		Ward-Khan et al. (22)
Diverse Experiences of	Intimacy as Unimportant	Mathias and Harcourt (6)
Intimacy		Verschuren et al. (26)
		Ward-Khan et al. (22)

## **Appendix A1**

### ***Notes for Contributors (Journal of Disability and Rehabilitation)***

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- 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.
6. **Acknowledgement.** Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants:* This work was supported by the under Grant . *For multiple agency grants:* This work was supported by the under Grant ; under Grant ; and under Grant .
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*Updated 12-11-2021*

**Chapter Two**

**Empirical Paper**

**Experiences of Intimacy, Romantic Relationships, and Dating Following Limb Loss: A  
Reflexive Thematic Analysis of Online Posts**

Keanu Court

Trainee Clinical Psychologist

k.court1@lancaster.ac.uk

Doctorate in Clinical Psychology

School of Health and Medicine

Division of Health Research

Lancaster University

Prepared for Submission to the Journal of Disability and Rehabilitation

## **Abstract**

### **Background**

Sexuality is a broad concept, encompassing an individual's sexual knowledge, beliefs, attitudes, values, and behaviours. As a core component of wellbeing and quality of life, sexuality has received considerable attention by researchers in recent years. Disability has been a common focus within the literature on sexuality, though there remains a number of poorly understood populations who may experience difficulties in this area, such as individuals with limb loss. Of the few studies that have explored sexuality and limb loss, all have involved direct contact between researchers and participants. This can influence the data collected, making it less ecologically valid and more likely to be influenced by researcher or social desirability biases. Social media research offers one possible solution, though no existing studies in this area have utilised this method of data collection.

### **Objective**

To provide recommendations for clinical practice by analysing social media posts regarding experiences of intimacy, romantic relationships, and dating following limb loss.

### **Methods**

Posts relevant to the concepts of limb loss, intimacy, romantic relationships, and dating were searched for within Reddit and The Amputee Discussion and Support Forum. Searching led to the identification of 56 posts and 245 comments to be included within the present study. Included posts and comments were analysed using the method of reflexive thematic analysis (RTA) detailed by Braun and Clarke (1,50).

### **Results**



RTA led to the development of two themes: 1) feelings of undesirability and 2) defying expectations.

### **Conclusion**

Limb loss appeared to have a variable effect on the experience of intimacy, romantic relationships, and dating. Whilst some posters experienced challenges, others felt that limb loss was unimportant or positive in relation to their romantic and sexual lives.

Recommendations for clinical psychologists and wider health professionals, such as avoiding assumptions that limb loss is an inherently negative experience, are provided.

**Keywords:** Limb Loss, Sexuality, Intimacy, Romantic Relationships, Dating

## **Introduction**

### **Sexuality**

Sexuality is a broad and variably defined term. Although it is often conflated with the concept of sexual orientation, sexuality may be understood as encompassing an individual's sexual beliefs, attractions, behaviours, and identities (2). Sexuality can be expressed in a number of ways, often in what is termed a person's intimate, romantic, or dating life (3,4). Research on sexuality has consistently identified this concept as a core component of wellbeing and quality of life (5,6). There are a number of reasons for this, with the various expressions of sexuality each playing a role. Although not an exhaustive list, intimacy and romantic relationships may provide individuals with a sense of closeness and connection to others, whilst dating may help to promote self-acceptance and sexual self-esteem (7,8).

Considering the importance of sexuality, it follows that difficulties in this area may lead to a number of adverse effects, such as reduced connections to others (9) and decreased sexual self-esteem (10). It is for this reason that, over recent years, sexuality has received considerable attention by researchers and clinicians seeking to improve the wellbeing and quality of life of individuals experiencing difficulties in this area (5,11). Disability has been a common focus within the literature on sexuality, largely due to the ongoing exclusion of disabled individuals from intimacy, romantic relationships, and dating (12). Indeed, societal discourses often infantilise disabled individuals, positioning them as asexual and incapable of romantic relationships (13,14). The internalisation of these views may lead those with disabilities to adopt asexual lifestyles, despite desires to engage in intimacy, romantic relationships, and dating (15).

### **Limb Loss**

Whilst there has been a recent proliferation of research on sexuality, there remain a number of poorly understood populations who may experience difficulties in this area. Individuals with major limb loss (henceforth referred to as limb loss) represent one such population (11,16) and, whilst some parallels may be drawn from the broader research on sexuality and disability, the unique challenges of limb loss call for specific research in this area. In particular, limb loss typically occurs later in life, meaning individuals are often required to navigate the challenges of their newfound disabled identities (17). The use of prosthetic limbs may also mean that individuals are able to conceal their limb loss, creating challenges relating to the disclosure of their disabilities (18).

Although research exploring limb loss and sexuality does exist, studies (e.g., 19,20) have typically focussed on the physical aspects of sexual functioning (21). Of the few studies that have explored sexuality in its broader sense, a number of adverse consequences have been identified following limb loss. These include a negative body image, the cessation of romantic relationships, and the avoidance of intimacy and dating (22-24). In addition to their impact on wellbeing and quality of life, these consequences may serve to disrupt the process of physically and psychologically adjusting to limb loss. The cessation of romantic relationships, for example, may reduce opportunities for practical and social support, making it harder for individuals to cope with, and adapt to, limb loss (25).

Professional support is usually provided following limb loss, with individuals typically accessing a combination of physical therapy, psychological support, and social interventions (26). This can help to address the aforementioned challenges, and clinical psychologists may be particularly well suited to exploring and addressing issues relating to sexuality. This is due to the focus of clinical psychologists on issues relevant to wellbeing and quality of life, in addition to their ability to discuss sensitive issues, such as those relating to sexuality (27,28). Despite this, the limited research on limb loss and sexuality has meant

that this aspect of care is often overlooked (29). Considering the importance of sexuality to wellbeing and quality of life, and the adverse consequences that difficulties in this area can engender, it follows that failing to address sexuality may negatively impact the process of rehabilitation for those with limb loss (30).

### **Previous Research**

The few studies that have explored limb loss and the wider concept of sexuality do appear to be limited by homogeneity in their recruitment and data collection methods. Recruitment, for example, has typically taken place in hospital settings or via amputee support groups, leading samples to be commonly composed of older adults, often with co-morbid health conditions (see 31-33). Furthermore, as individuals have elected to participate, it might be argued that research in this area reflects the experiences of those drawn to taking part, potentially on the basis of experiencing sexual difficulties (34,35). Additional methodological issues arise when it is considered that all the research exploring limb loss and sexuality has involved direct contact between researchers and participants. Rohlfing and Sonnenberg (36) argue that this can influence the data collected, making it less ecologically valid and more likely to be influenced by researcher or social desirability biases.

### **Social Media**

In recent years, social media has become a rich source of data for qualitative researchers seeking to gain naturalistic accounts of various experiences (37). Social media sites, such as Reddit (<https://www.reddit.com>), offer a large degree of anonymity, with it being uncommon for identifying information to be present within individual profiles. Single-use accounts are not rare, and it is these functionalities that can enable users to speak freely, particularly in relation to sensitive topics, such as sexuality (38). Sites such as Reddit typically attract a younger base (39) and, as the collection of data from these sources does not

necessarily involve the direct participation of individuals, it might be argued that subsequent findings are less likely to reflect the experiences of older individuals desiring to participate in research. It does remain possible that those who post on social media do so on the basis of experiencing difficulties in relation to a particular phenomenon. However, as sites such as Reddit allow for the posting of comments, a range of experiences are often reported, enabling researchers to gather a breadth of data in relation to their topics of interest (40).

### **The Present Study**

Within the literature on limb loss and sexuality, there exist no studies that have utilised social media as a means of data collection. Considering the benefits of social media research, the importance of better understanding the experience of sexuality following limb loss, and the suitability of qualitative approaches to experiential research (41), the present study aimed to qualitatively explore experiences of intimacy, romantic relationships, and dating following limb loss, using data gathered from social media sites. It was hoped that doing so would shed light on the experiences of individuals not typically included within limb loss research, thus enabling the development of recommendations for clinical practice. Whilst recommendations for wider health professionals involved in the care of those with limb loss will be provided, clinical psychologists will be given particular consideration due to the suitability of their role to explore and address issues relating to sexuality.

## Methods

### Data Collection

The present study utilised publically available data from Reddit: a global social media site, with 1.22 billion users as of January 2024 (42). Reddit is organised into a collection of forums, termed ‘subreddits’, where users can post about, or comment on, various topics. Whilst anyone can view posts or comments, individuals must be registered with the site if they wish to make them (40). Previous research (e.g., 43,44) has utilised Reddit for the purpose of data collection, particularly in cases where specific populations have been sought (45). Indeed, the organisation of this site into various subreddits enables easy access to a variety of populations, such as those with limb loss.

To extract the relevant data from Reddit, the four most popular subreddits relating to the phenomena of interest were searched: r/amputee (8900 members), r/relationships (3.5 million members), r/sex (2.6 million members), and r/dating (3.7 million members). Although other relevant subreddits exist (e.g., r/datingoverthirty), it was felt that those selected would provide sufficient coverage of the areas of interest, particularly as cross-posting (posting the same content in multiple subreddits) is known to occur within Reddit (46). Furthermore, as a preliminary search of the aforementioned subreddits returned few relevant results outside of r/amputee, the decision to limit the search to the most popular subreddits appeared appropriate.

Following their identification, each subreddit was checked to ensure that there were no restrictions on the use of data for research purposes. As no restrictions were found, each subreddit was individually searched in February 2024 using a variety of terms relating to limb loss, romantic relationships, intimacy, or dating. To support in the identification of suitable posts and comments, no date restrictions were applied. It is noteworthy that the search terms

used differed in accordance with the topic of each subreddit; the search in r/amputee, for example, did not contain any terms relating to limb loss, in that this was unnecessary considering the subreddit's focus. Furthermore, as Reddit's search function only returns results that contain all the terms used, only one term was searched at a time. For an overview of the search terms used in each subreddit, please see Table B1.

The subreddit searches returned 1859 potentially suitable posts. All posts, and their associated comments, were manually screened to determine their suitability for the present study. Posts and comments were considered suitable if they were made by individuals reporting to have experienced (major) limb loss and contained data relevant to the concepts of intimacy, romantic relationships, and dating. Posts and comments were excluded if they were made by individuals reporting to be under the age of 18. It was common for posters and commenters (henceforth collectively referred to as posters) to have reported experiencing limb loss, though where this was not the case, poster profiles were searched for this information.

Whilst it was necessary for posters to have reported limb loss, ages were not explicitly searched for, but rather used to exclude posts or comments where users had reported being under 18. This decision was made due to it being relatively uncommon for posters to report their age; in effect, excluding those who had not reported this would have drastically reduced the number of included posts and comments. In total, the subreddit searches led to the identification of 49 posts and 218 comments. Following their identification, posts and comments were exported into Microsoft Word and formatted uniformly (size 12 Trebuchet MS, with 1.5 line spacing) for subsequent analysis.

To identify additional sites for data collection, the following terms were entered into Google ([www.google.co.uk](http://www.google.co.uk)): 'limb loss', 'amputation', 'amputee', 'discussion', and 'forum'.

This returned 1.29 million results. As a doctoral thesis, the constraints of resource and time meant that it was not possible to search each of these results. Consequently, the first 10 pages of results were reviewed to identify sites containing posts or comments relevant to the phenomena of interest that had been made by individuals reporting to have experienced limb loss. The decision to search the first 10 pages was made due to Google presenting the most accessed and relevant sites first (47). Although this choice was, somewhat, arbitrary, it was felt that, as Google users do not tend to view results past the first three pages (48), reviewing 10 pages would be sufficient to identify additional sites for data collection.

The Google search yielded one relevant site: The Amputee Discussion and Support Forum (<https://amputees.proboards.com>). This site provides a space for individuals to post about, or comment on, a variety of topics relating to limb loss. All posts and comments are organised into categories (e.g., health and wellness) and sub-categories (e.g., sexuality and relationships). As with Reddit, although individuals must be registered with the site to make posts or comments, anyone can view these. At the time of searching (February 2024), The Amputee Discussion and Support Forum had 1117 posts, containing a total of 4527 comments. No restrictions on the use of data for research purposes were reported in the site's terms and conditions.

For the purposes of the present study, the 'sexuality and relationships' sub-category was searched to identify relevant posts and comments. Whilst the inclusion and exclusion criteria applied during the Reddit search remained the same, search terms were not required on The Amputee Discussion and Support Forum. This was because all relevant posts and comments were listed under the 'sexuality and relationships' sub-category. This sub-category contained eight posts and 77 comments. Screening these posts and comments in accordance with the inclusion and exclusion criteria yielded seven posts and 27 comments to be included within the present study. As with the Reddit search, included posts and comments were



exported into Microsoft Word and formatted uniformly (size 12 Trebuchet MS, with 1.5 line spacing) for subsequent analysis.

## **Sample**

In total, the dataset was comprised of 56 posts and 245 comments, made up by 162 unique accounts. An additional 14 accounts were included in the dataset, though as they had been deleted, without any identifying information being provided, it was not possible to determine how many unique posters they represented. The total number of unique accounts would, therefore, appear to be between 163 and 176.

Particularly on Reddit, it was common for posters to report the type of limb loss they had experienced, with 110 unique accounts providing this information. Below-knee was the most common type of limb loss ( $n = 53$ ), followed by above-knee ( $n = 36$ ) and bilateral above-knee (6). Age and gender were less commonly reported, though were provided by 23 and 19 posters, respectively. The average age of posters providing this information was 35.7 years. However, as the data did not appear to be evenly distributed, the median (31 years) may provide a more representative age (49). Gender was essentially evenly split, with 10 women and 9 men providing this information.

## **Analysis**

The present study utilised Braun and Clarke's (1,50) method of reflexive thematic analysis (RTA). RTA is a theoretically flexible approach to qualitative data analysis that facilitates the identification and analysis of patterns within a dataset (51). As a theoretically flexible approach, RTA can be applied to a variety of research questions, sample sizes, data collection methods, and approaches to meaning generation (52). The present study used a relatively large, heterogeneous (in terms of ages, types of limb loss, and genders) sample, and it is for this reason that RTA appeared to represent a suitable analytic method.

A key principle within RTA relates to the view that meaning is generated as a result of interactions between the researcher and data; interpretations are, therefore, subjective (53). Prior to beginning this research, I had completed a literature review on limb loss and sexuality. Having not experienced limb loss personally, my knowledge of this area largely stemmed from this review, and it felt pertinent that I considered my assumptions throughout the analytic process. In addition to the aforementioned reasons, RTA was, therefore, selected as my chosen method of analysis.

Conducting the RTA involved reading and re-reading the dataset to promote familiarity. During this process, I began to generate ideas about the dataset, such as that posters appeared to feel sexually or romantically undesirable following limb loss. Some of the ideas I had generated, such as those relating to the prior example, had been noted in my literature review. In this sense, my knowledge about limb loss and sexuality seemed to guide what I noticed, and I felt that it would be important to both explore my initial ideas and remain open-minded to other possibilities.

Within RTA, the process of coding is predominantly inductive, meaning codes are generated in accordance with the content of the dataset, rather than being based on pre-existing theories or conceptual frameworks (51). Braun and Clarke (53) do, however, argue that it is not possible to conduct an exclusively inductive analysis, in that researchers require some form of knowledge or criteria to identify whether data may be conducive to answering their research questions (51). Inductive and deductive analyses may, therefore, be seen as a continuum, rather than a dichotomy. In line with this, the use of inductive and deductive approaches to coding is not problematic, though it is critical researchers endeavour to be reflexive and transparent about the process of meaning generation, should they wish to avoid theoretical and conceptual confusion (53). Considering this, and that I had generated ideas about the dataset during the familiarisation process, I opted to inductively code each line of

the dataset, in addition to the ideas I had previously generated. Whilst coding aspects of the dataset I had noted during the familiarisation process, I also tried to remain mindful of exceptions and how my prior knowledge may influence my interpretations. As an example of this, because I was aware that romantic relationships might end as a result of limb loss, it felt important to search for lasting relationships and recognise when their cessation, though reported, may have not have been a direct consequence of limb loss.

The coding process was iterative and, as it progressed, I formed new ideas and interpretations about the dataset. After forming these ideas, I looked back through the dataset for examples of (and exceptions to) them, whilst also considering whether my existing codes/ideas might be interpreted differently. Once the coding process had been completed, I formally began to organise my codes into related categories. These categories were reviewed to ensure that they were internally homogenous and externally heterogeneous. This enabled the development of themes and sub-themes, which were then cross-referenced across the dataset to ensure that they were well represented. For examples of the data coding and theme generation processes, please see Appendix B1 and Table B2, respectively.

### **Philosophical Stance**

It is recommended that qualitative studies make clear their underlying philosophy for the generation of findings, with this being considered an indication of methodological rigour (54). Inquiries into the lived experiences of individuals, as is the case with this study, lend themselves well to social constructivist paradigms (55). In line with my choice of analytical approach, social constructivism posits that meaning is generated through interactions between the researcher and data (56). In this sense, I recognise that the present analysis reflects my prior knowledge, beliefs, and attitudes, and it is for this reason that I have not made efforts to reduce bias (such as via the use of a second coder) within the present study.

**Ethics**

The present study was approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. Although the dataset was publically available, and sites were checked to ensure that they did not prohibit the use of data for research purposes, the usernames of all posters have been removed from the written report to uphold their anonymity. To support readers in understanding the source of quotes, all posters with existing usernames were assigned a unique numerical value.

## Results

Analysis of the dataset led to the development of two overarching themes: 1) feelings of undesirability and 2) defying expectations. Theme one was composed of three sub-themes: 1) expectations of rejection, 2) when to reveal: early or late, and 3) coping mechanisms. Theme two was composed of two sub-themes: 1) limb loss as unimportant and 2) limb loss as positive.

For an overview of the posters contributing to each theme and sub-theme, please see Table B3. Please note that, where available, demographic information (age, gender, and type of limb loss) has been provided alongside poster quotes.

### **Feelings of Undesirability**

One hundred posters (including 10 deleted accounts) contributed to the development of this theme, which describes the impact of limb loss on views of the self. Behaviours and coping mechanisms associated with these views are also captured within this theme.

#### ***Expectations of Rejection***

Following limb loss, 48 posters (including five deleted accounts) reported feelings of sexual or romantic undesirability. It was common for posters to describe themselves negatively, such as by stating that they were ‘unattractive’ or ‘worthless’.

‘Not only am I missing a limb... I’m also covered in ugly ass scars... I can’t help seeing myself as absolute and worthless trash...’ (50)

Feelings of sexual or romantic undesirability were often accompanied by expectations of rejection. For posters without romantic partners, these expectations were typically expressed as concerns that others would be unwilling to date them. Several explanations were

offered for this, such as that others would not want a disabled partner or would find them unattractive due to their limb loss.

‘Being young, it feels like most girls my generation are extremely superficial and would much rather chose someone able bodied than someone with [sic] a limb.’ (126, M21, AKA)

‘I’ve been a through [sic] knee amputee since I was 9, so went through my teenage years thinking that because I had a prosthetic leg it would affect others being attracted to me.’  
(Deleted)

For those in romantic relationships, expectations of rejection often manifested as worries that their partners would leave them.

‘I honestly think he [partner] will leave me. He will want a better life than caring for me.’  
(160)

At times, expectations of rejection were confirmed in reality, with 13 posters reporting that their partners had left them because of their limb loss.

‘She dumped me essentially because she couldn’t handle having a sedentary boyfriend in and out of the hospital and was no longer attracted to me.’ (126, M21, AKA)

Other posters reported that, after disclosing their limb loss, potential romantic partners had lost interest in them.

‘i [sic] keep matching with people but the last 2 i [sic] connected with, i [sic] felt obligated to tell then i’m [sic] a BTK. both [sic] blocked me after.’ (149, BKA)

Although experiences of rejection were noted throughout the dataset, this was not the case for several posters, despite their expectations.

‘I didn’t expect any actual responses [on dating applications], but guys were really casual about it [limb loss]... To us it feels like our entire being was suddenly deformed, but no one else sees it that way.’ (134, 24F, BKA)

Similarly, whilst some posters expected to be rejected, despite having no previous experiences of this, other posters reported struggling to believe that others had shown romantic interest towards them.

‘Any time a guy shows something that seems like interest I just assume he feels bad for me.’ (128, 22F)

### ***When to Reveal: Early or Late***

Questions about when limb loss should be revealed to potential partners were common within the dataset, with 35 posters (including six deleted accounts) contributing to this sub-theme.

‘I’m a RBKA and am kinda nervous now about dating in the future, like how do I tell someone i [sic] wear a prosthetic?’ (74, BKA)

Although posters did not directly link their questions about revealing to feelings of undesirability, by querying when to disclose, it might be suggested that they viewed limb loss as an important topic to broach. In effect, posts about revealing may be interpreted as highlighting a recognition that potential romantic or sexual partners may be unaccepting of limb loss. It is for this reason that the present sub-theme has been included within the overarching theme of feelings of undesirability.

A strong majority of posters (29) advocated for the early disclosure of limb loss. A variety of methods by which to do this were suggested, such as including a picture of one’s

prosthesis on dating profiles, bringing up the topic when meeting potential partners, or wearing revealing clothing (e.g., shorts) to dates.

‘I haven’t outright told her but I do have 1 or 2 pictures showing my leg...’ (153, AKA)

‘I told him right away [on the date]...’ (1, bilateral BKA)

‘I quit wearing clothing that covers my prosthetics just to eliminate that conversation...’

(84)

The predominant reasons cited for the early disclosure of limb loss related to the ideas that doing so helps to avoid surprise, disappointment, and investing time in unaccepting others.

‘...if we're going to be hanging out for a while and it might come up, I try to mention it casually at some point so we can get the surprise part out of the way...’ (129)

‘I don’t even say hello to any of them i [sic] just go immediately to im [sic] a bilateral bka... Thats [sic] it dont [sic] give myself any time to make a connection with before telling them that only leads to disappointment.’ (Deleted, bilateral BKA)

Despite the majority opinion, six posters reported a preference for disclosing their limb loss comparatively late. Although specific timeframes were not provided, these posters felt that revealing their limb loss before time had been given for potential partners to get to know them meant that they were more likely to be viewed as disabled, infantilised, or rejected.

‘I think I’d wait just long enough to feel comfortable with each other so that it won’t become an issue. What I mean is that if people find out first thing – they are always asking, Are [sic] you okay? Do you need [sic] with that? If he sees you as normal, and then learns the reality – you’ll continue to be normal...’ (138, BKA)



As is shown above, the preference for comparatively late disclosure appeared to reflect the desire to not be defined as disabled. This is not to say that posters preferring early disclosure wished to be viewed in this way, but rather that those preferring relatively late disclosure may have had specific concerns that potential partners would place greater importance on their limb loss in the absence of other information.

### *Coping Mechanisms*

This sub-theme, which was supported by 13 posters, describes the various ways in which feelings of undesirability were coped with following limb loss.

The avoidance of intimacy, romantic relationships, and dating appeared to represent a common strategy by which posters managed their feelings of undesirability.

‘I seldom look in the mirror anymore. I haven’t been intimate with anyone since. Sometimes I long for some type of companionship but who wants to deal with the extra hassle.’ (19, BKA)

The avoidance of romantic or sexual relationships may be interpreted as emanating from the expectation of rejection and the desire to protect oneself from the negative feelings associated with this. The following quote, from a poster reporting to have not engaged in dating or intimacy, highlights this idea:

‘I think I was just scared of the rejection part of it all...’ (2, BKA)

Interestingly, it appeared that avoidance served to amplify concerns about rejection. In line with this, several posters who reported concerns about being rejected also reported that they had not dated or been intimate with others following limb loss. Conversely, posters who had dated or engaged in intimacy appeared less likely to report these concerns.

A further method employed by posters to manage their feelings of undesirability involved dating individuals who did not view them as disabled. Oftentimes, posters achieved this by concealing their limb loss during the initial stages of forming a relationship, so as to prevent potential partners from defining them in this way.

‘It may be that I’ve struggled with defining myself as an amputee since my amputation over 10 years ago. In my experience, when people learn about my leg first, it becomes a novelty and I’m “the guy with one leg”. If they get to know me for 30 minutes, or an hour, and find out the things I believe, actually define me first, the relationship (platonic or romantic) seems to have a little more substance.’ (142, BKA)

Not being viewed as disabled appeared to facilitate feelings of desirability, with posters reporting that this had helped them to cope with limb loss. Despite this, some posters did not cope with their feelings of undesirability by seeking out partners who would overlook their disability. Instead, these posters reported a preference for engaging in romantic or sexual relationships with individuals who desired them because of their limb loss. Within the limb loss community, these individuals are referred to as ‘devotees’ (a term describing able-bodied people who have sexual or romantic preferences for individuals with limb loss; 57). By engaging in relationships with devotees, posters reported experiencing feelings of desirability.

‘Personally, i [sic] really appreciate them [devotees]. It’s comforting (when I’m feeling insecure) to know that there’s an entire group of people who are specifically attracted to that which makes me feel insecure.’ (61)

For most posters commenting on this topic, devotees were to be avoided. They were often described in unfavourable terms, and it was felt that their interests did not focus on the person, but rather their limb loss.

‘...to [sic] me, a devotee is more interested in me being an amputee and the stump than me as a person.’ (150, BKA)

Engaging in romantic or sexual relationships with devotees may, therefore, be seen as a double-edged sword; doing so may promote feelings of desirability, though also lead to experiences of being fetishised.

Taken as whole, posters in the present study appeared to respond to their feelings of undesirability in one of two ways. On the one hand, some posters sought out partners who did not view them as disabled, enabling them to experience feelings of desirability. On the other hand, some posters appeared to accept the view of themselves as disabled and undesirable, leading them to avoid sexual or romantic relationships, reveal their limb loss to potential partners early to prevent later rejection, or engage in relationships only with others who desired them because of their limb loss.

### **Defying Expectations**

Although feelings of undesirability were prevalent within the dataset, limb loss was not exclusively viewed as having a negative impact on intimacy, romantic relationships, and dating. For 85 posters (including six deleted accounts), limb loss was viewed as unimportant or positive in relation to their romantic and sexual lives, and it is these views that have been captured within the present theme.

#### ***Limb Loss as Unimportant***

This sub-theme reflects the views of 46 posters (including five deleted accounts) who described limb loss as having little to no impact on their romantic or sexual experiences.

‘...the women I met/dated never cared about my amputee [sic] one way or another... it was never mentioned.’ (48, BKA)

Posters often stated that their romantic or sexual partners had few, if any, issues with their limb loss. A common reflection related to the idea that, whilst those who have experienced limb loss may view it as important, this is not necessarily the case for others.

‘I tell you honestly from experience - potential partners don't care about your missing leg. It's your hangup, not theirs, and if you're comfortable with it, they will be too.’ (129)

Posters supporting this sub-theme did report concerns that revealing their limb loss to potential romantic or sexual partners was, at times, difficult. Nonetheless, it was felt that doing so led to no discernible differences in their relationships, other than potential reactions of curiosity or surprise.

‘Honestly, most people don't care that much, in my experience. They might show some surprise or curiosity [sic], but they quickly get over it and it becomes part of life, just as your hair color or sense of fashion might be.’ (29, BKA)

As is captured in the above quote, posters often likened their limb loss to various physical traits that may be conceptualised as areas of difference, rather than disability. Thus, it might be suggested that, by conceptualising their limb loss as a difference and, in turn, viewing it as unimportant, posters were able to reject their disabled identities. In keeping with this, some posters described their experiences of dating as no different from those who are able-bodied.

‘Dating as an amputee is really no different than dating as able bodied in my experience.’ (38, BKA)

As has been previously noted, feelings of undesirability appeared to be more prevalent amongst posters with little to no experience of sexual or romantic relationships following limb loss. A similar finding was noted within the present sub-theme: posters who viewed their limb loss as unimportant often reported experiences of engaging in intimacy, romantic relationships, or dating. As was suggested by several posters, engaging in romantic or sexual relationships

may, therefore, provide opportunities for individuals with limb loss to meet others who do not view their disability as important, enabling them to internalise these views.

‘Yeah look most people don’t seem to mind when you’re dating... I think once you just put yourself out there and you start seeing responses and how good people are about the whole situation your self-confidence will boost, over thinking it and worrying about how theyll [sic] act or react will just put you in a negative headspace and kill your confidence...’

(Deleted)

### ***Limb Loss as Positive***

Despite the potential for limb loss to engender feelings of undesirability, 22 posters (including one deleted account) reported positive experiences of intimacy, romantic relationships, and dating. As an example of this, it was common for posters to state that their romantic or sexual partners had viewed their limb loss as interesting and indicative of positive qualities, such as strength.

‘There are also those that see how strong we are in the face of our challenges, and find it sexy as hell.’ (110)

Others highlighted the practical benefits of limb loss, such as that it had allowed them to spend more time with their partners or dates and, resultantly, improved their communication.

‘...the women I know have been showing more interest in me. Part of the reason I know is that I now have more time to talk and I have learned to open up a little more...’ (129)

One well cited benefit of limb loss related to its use as screening tool for romantic or sexual partners. In effect, those who reject others on the basis of limb loss were viewed as

judgemental and superficial, and it was felt that rejection on these grounds helped to filter out unsuitable partners.

‘Don’t let it [rejection] get to you. Anyone that is that superficial, doesn’t deserve us.’

(110)

‘It’s [limb loss] also a good litmus test for telling if someone is worth talking or not.’ (64, AEA)

It was for this reason that one poster described limb loss as a blessing in disguise:

‘What I will say to your point about girls being superficial is that this is actually a blessing in disguise. You get to skip out on those women pretty quickly, and tend to connect with more genuine women.’ (108, 42M, AKA)

Posters attributed their positive experiences of intimacy, romantic relationships, and dating to being confident and feeling comfortable in themselves.

‘Dating’s no different really with or without specific limbs, it almost always comes down to confidence and comfort in being yourself.’ (38, BKA)

Similarly, humour was reported to be an important quality when forming romantic relationships, in that the ability to joke about limb loss was seen as a helpful way to encourage others to respond on dating applications.

‘But I figured hey fuck it, and actually started messaging guys on bumble with some dark pickup lines (“hey, I only have one leg so I can’t run away” or “you’ve got me running in circles and it’s not just because i [sic] have one leg”) and you know what? THEY WORKED.’ (134, 24F, BKA)

## Discussion

The following section will discuss the findings of the present study in relation to theory and previous research. Each theme will be discussed separately, and particular consideration will be given to how the findings inform clinical practice and future research.

### Feelings of Undesirability

Feelings of sexual or romantic undesirability were common following limb loss: a finding noted previously in the literature (see 58,59). The present study, therefore, lends support to the assertion that limb loss engenders negative views of the self. Interestingly, feelings of undesirability were reported by posters noting a diverse range of limb loss types, suggesting that these feelings represent a general consequence of limb loss. Consequently, health professionals, and particularly clinical psychologists, are encouraged to screen for feelings of undesirability, irrespective of the type of limb loss an individual has experienced. It is hoped that this will facilitate the identification of individuals who may benefit from interventions (which are described below) aimed at addressing these feelings.

Social identity theory (60) proposes that identifying with stigmatised groups can engender negative views of the self (61). Multiple authors (e.g., 15,62) have argued that society conceptualises those with disabilities as sexually or romantically undesirable, and it is possible that posters who viewed themselves in this way may have acquired a disabled identity following limb loss. Dirth and Brandscombe (61) suggest that fostering positive views of disability, such as by involving individuals in disability pride and disabled communities, can help to buffer the negative effects of identifying with stigmatised groups. It is, therefore, recommended that clinical psychologists and wider health professionals support individuals to develop positive views of limb loss, such as by encouraging their involvement in the aforementioned communities.

Posters reporting feelings of undesirability often questioned when to reveal their limb loss to potential partners. Expectations of rejection were common amongst these posters, particularly when they had engaged in few (if any) sexual or romantic relationships following limb loss. Here, it is suggested that a lack of sexual or romantic relationship experience might encourage a reliance on ableist, societal views when mentalising the perceptions of others. Engaging in sexual or romantic relationships may, therefore, offer an experiential means by which to buffer the impact of societal views, and it did appear that this was the case for some posters included within the present study. Consequently, health professionals and clinical psychologists are encouraged to support individuals to engage in romantic and sexual relationships, particularly amongst those with few experiences of this following limb loss.

Expectations of rejection appeared to lead the majority of posters to advocate for the early disclosure of limb loss, with it being stated that this helps to avoid disappointment and investing time in unaccepting others. Mathias and Harcourt (63) have previously documented the concept of early disclosure, though attributed this to increased feelings of confidence. Whilst this is not disputed, the findings of this study highlight that clinical psychologists and wider health professionals should not assume the underlying reasons for early disclosure; this may be a decision based on a number of potential factors. Open conversations regarding the motives of early disclosure might, instead, offer a useful means by which to support the decision-making of those with limb loss.

Despite the majority of posters advocating for the early disclosure of limb loss, others chose to conceal this during the initial stages of forming a romantic or sexual relationship. Batty et al. (21) and Murray (64) have reported similar findings, stating that participants chose to conceal their limb loss during intimate or romantic situations. Within the present study, the choice to conceal was attributed to the desire to not be defined by limb loss. In this sense, posters may have sought to distance themselves from their disabled identities. Social



identity theory refers to this process as individual mobility, whereby individuals may seek to escape, avoid, or deny their belonging to a devalued group (65). Whilst posters reported that concealing their limb loss had helped potential partners to see them for who they are, Dirth and Brandscombe (61) suggest that denying aspects of the self may prevent acceptance and wellbeing. The present study does not wish to comment on the acceptability of this strategy, but rather highlight that there are pros and cons to the concealing of limb loss. As with early disclosure, it is recommended that health professionals, and particularly clinical psychologists, facilitate open conversations about concealment as a means by which to support the decision-making of those with limb loss.

For some posters, feelings of undesirability led to the avoidance of intimacy, romantic relationships, and dating. As this finding has been noted previously in the literature (see 66), the present study lends support to the assertion that the avoidance of romantic or sexual relationships may represent a common coping strategy following limb loss. Unfortunately, the pre-existing nature of the dataset meant that it was not possible to fully understand the impact of avoidant coping. However, there exists a significant body of research (67,68) to suggest that avoidance may maintain unhelpful beliefs and prevent the development of alternate coping mechanisms. Extrapolating this to limb loss, it might be suggested that avoidant coping supports the preservation of beliefs about the self as undesirable, whilst also preventing individuals from developing arguably more helpful strategies. Clinical psychologists and wider health professionals are, therefore, encouraged to be mindful of avoidant coping strategies, in that they may represent a possible area for intervention.

Engaging in sexual or romantic relationships with devotees represented a further method by which posters coped with their feelings of undesirability. This appeared to be a double-edged sword; doing so had the potential to engender feelings of desirability, though possibly at the cost of being fetishised. As has been discussed by Solvang (69), there exists a

debate within the limb loss community as to the acceptability of devotees, and this debate did arise within the present study. For some posters, devotees offered a means by which their bodies could be valued and desired. For others, however, devotees were viewed as predatory and to be avoided. Solvang (69) puts forward the idea that negative views about devotees may reflect ableist ideas about beauty. In effect, those who wish to avoid devotees may view their disabled bodies as undesirable, and partners may be selected on the basis of their ability to overlook limb loss. In contrast, those preferring devotees may not wish to reject or deny their limb loss, but rather have it be celebrated. As with the concealing of limb loss, there are merits to both approaches, and it is suggested here that initiating conversations about intimacy, romantic relationships, and dating may enable clinical psychologists and wider health professionals to support those with limb loss in exploring their views.

### **Defying Expectations**

Despite the aforementioned findings, which conceptualise limb loss as negatively affecting sexuality, many posters reported positive experiences of intimacy, romantic relationships, and dating. Specifically, limb loss was described as allowing more time to be spent with one's partner, whilst also being viewed by others as indicative of positive qualities, such as strength. For some posters, although limb loss had led to experiences of rejection, this was viewed as a blessing in disguise, in that rejecting others were viewed as unsuitable partners. Batty et al. (21) and Mathias and Harcourt (63) have previously noted the use of limb loss as a screening tool, and the present study supports the view that limb loss may, at least in part, be beneficial in relation to the formation of romantic or sexual relationships.

Posters noted that confidence, comfortability, and humour were important qualities in promoting positive sexual and romantic experiences. These qualities might, therefore,

mediate the relationship between limb loss and a person's romantic or sexual life, at least to some degree. This has a number of important implications, such as that interventions to improve romantic and sexual confidence may engender positive experiences of intimacy, romantic relationships, and dating. Clinical psychologists and wider health professionals may, consequently, benefit from initiating conversations about the aforementioned qualities, so as to facilitate the identification of individuals requiring support in this area.

Although positive views of limb loss have been noted elsewhere in the literature (e.g., 21), there do appear to be some important differences captured within the present study. Most notably, Batty et al. (21) reported that individuals with limb loss may conceptualise their prosthesis as indicative of strength. The present study reported a similar finding that potential partners may conceptualise those with limb loss as having positive qualities, such as strength. Despite the similarities in these findings, Batty et al. (21) concluded that the conceptualisation of limb loss as indicative of strength represents a strategy to compensate for the loss of an able body. Social identity theory refers to the emphasis of positive qualities, or the re-evaluation of stigmatised qualities, as 'social creativity' strategies. Particularly for individuals who might struggle to attain membership to higher-status social groups, perhaps because of severe or impactful disabilities, these strategies can support in the development of psychological well-being (61). The present study does not dispute the findings of Batty et al. (21), but rather asserts that, as beliefs about strength were reported to be present in others, they may represent a positive impact of limb loss, rather than a coping strategy. Certainly, it is possible that views of oneself as strong may support individuals to cope with limb loss. However, it is also possible that these views may represent the internalisation of positive qualities identified by others. Considering this, clinical psychologists and wider health professionals are advised to not assume that limb loss is an inherently negative experience in

relation to intimacy, romantic relationships, and dating. Instead, open conversations about the impact of limb loss are encouraged.

Whilst the potential for limb loss to have a positive impact on sexual and romantic relationships has been previously noted, the view of limb loss as unimportant appears to be a novel finding within the present study. Indeed, many posters reported that limb loss had no discernible impact on their experiences of intimacy, romantic relationships, and dating. One possible explanation for this relates to the average age of posters included within the present study, which was found to be 35.7 years. This contrasts with the average age of participants included within the wider research on limb loss and sexuality (51.4 years). Verschuren et al. (30) has reported that sexual difficulties may be more strongly related to age (and physical health comorbidities) than limb loss, suggesting that the age of posters within the present study might account for their views of limb loss as unimportant, at least in relation to intimacy. The potential for limb loss to have no impact on sexuality in its broader sense may also be attributable to age, in that the internalisation of ageist, societal views, which position older adults as asexual, may lead individuals to avoid dating and romantic relationships (70). Considering this, because of their age, posters included within the present study might have been less likely to internalise the aforementioned views and, therefore, experience limb loss as unimportant in relation to their intimate and romantic lives. Interventions aimed at addressing sexual difficulties or challenging ageist, societal views may, therefore, support older individuals to engage in sexual and romantic relationships following limb loss. Narrative or cognitive-behavioural therapies (see 71,72) may be particularly useful here due to their focus on 'reauthoring' social discourses and challenging beliefs, respectively, and clinical psychologists are advised to be mindful of these approaches when working with older individuals following limb loss.

Interestingly, posters reporting positive experiences of intimacy, romantic relationships, and dating had a diverse range of limb loss types; all those listed in the above methodology section were included within the sub-theme of 'limb loss as positive'. This would suggest that positive sexual and romantic experiences were not an artefact of the type of limb loss posters had experienced. Indeed, it could be assumed that positive experiences would be more prevalent amongst those with relatively less impactful or more easily concealable limb loss types, as would be predicted by social identity theory (see 61). However, as this was not found to be the case, positive views may exist independently from the type of limb loss a person has experienced. Considering this, clinical psychologists and wider health professionals are advised to not assume a relationship between limb loss type and experiences of intimacy, romantic relationships, and dating. Rather, open conversations about the sexual and romantic impact of limb loss are encouraged.

### **Limitations and Future Research**

Whilst the benefits of online research have been discussed, the methods of data collection used in the present study did introduce a number of limitations. For example, Reddit is known to be predominantly used by younger males (18 – 29) located in the United States (73). However, the use of online data meant that it was not possible to verify the demographics of users. Consequently, whilst the present research may be skewed towards the experiences of the aforementioned individuals, interpretations made on the basis of this information (such as that the younger age of the sample may have led to views of limb loss as unimportant) are, therefore, tentative. Interestingly, several posters did warn others about devotees posing as those with limb loss, and it is possible that some of these individuals may have been included within the present study. As future, online research may not be able to verify the demographics of posters, studies utilising typical methods of data collection may

wish to explore the impact of demographic variables, such as age, on the experience of limb loss and sexuality.

In relation to demographics, the present sample ostensibly included a number of limb loss types, ages, and genders. However, when the concept of sexuality is considered, little variance was reported amongst the sample. Most all posters reported engaging in heterosexual relationships, or did not disclose this information, meaning it was not possible to understand the experiences of intimacy, romantic relationships, and dating amongst individuals from sexual minorities. Two posters did identify as homosexual males, and their experiences seemed to highlight difficulties in navigating their community as disabled people. Future research may, therefore, seek to explore the experiences of intimacy, romantic relationships, and dating amongst sexual minorities with limb loss.

Finally, as a result of using online posts, no contact was made between the researcher and posters included within the present study. As such, it was not possible to explore areas of interest arising within the dataset or verify the interpretations made. Indeed, as the data was shallow at times, a number of questions were left unanswered. For example, although several posters reported avoiding sexual or romantic relationships, the consequences of this coping strategy remain unclear. Similarly, as it was not possible to discuss novel findings, namely that some posters felt their limb loss was unimportant in the context of sexual or romantic relationships, it remains unclear as to why some individuals may be more or less impacted by limb loss. Future research may wish to address these limitations by utilising methods (e.g., interviews) that allow for the in-depth exploration of concepts. This may enable areas of interest arising within the present dataset to be explored in detail, so as to inform clinical practice.

## **Conclusion**

The present study found that individuals with limb loss may experience a number of challenges in relation to intimacy, romantic relationships, and dating. These include feelings of undesirability, expectations of rejection, and concerns about when to reveal limb loss to potential partners. Despite the potential for limb loss to negatively impact sexuality, many posters described positive or inconsequential experiences of intimacy, romantic relationships, and dating. Considering this, health professionals, and particularly clinical psychologists, are advised to: support those with limb loss to engage in sexual or romantic relationships; be mindful of avoidant coping strategies; encourage individuals to develop positive views of limb loss, such as via involvement in disability pride; facilitate open conversations about dating devotees, ageism, ableism, and the process of disclosure; and not assume the underlying reasons for the early disclosure of limb loss or that individuals will experience difficulties in relation to their sexuality.

**Declaration of Interest**

The author reports that there are no competing interests to declare.



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## Appendix B

**Table B1.** *Overview of the Search Terms Used in Each Subreddit*

<b>Subreddit</b>	<b>Search Terms</b>
<b>r/amputee</b>	'boyfriend', 'date', 'dating', 'girlfriend', 'husband', 'intimacy', 'partner', 'relationship', 'romance', 'romantic', 'sex', 'wife'
<b>r/sex</b>	'amputation', 'amputee', 'limb loss'
<b>r/relationships</b>	'amputation', 'amputee', 'limb loss'
<b>r/dating</b>	'amputation', 'amputee', 'limb loss'

## Appendix B1. Example of the Data Coding Process

Poster 2 (M, BKA)

Dating

Hey I'm single male and a recent below the knee amputee. I've only dated people I was with before my surgery [lack of dating following limb loss/only dating known others]. How is it dating someone new that doesn't know about your condition? [possible concerns about dating] and how do you tell them ? [possible concerns about disclosure] especially when it comes to intercourse. Also the people who maybe interested and have heard or know about it but maybe discouraged by others . Any advice or experiences would help greatly thanks !

Poster 129

I lost my lower leg just before college, so I was in the midst of a heavy dating period of my life. I can honestly say, it didn't make any difference [limb loss as making no difference; dating is the same before and after limb loss] - no one was weirded out [limb loss as lacking impact] and and I don't think it changed my prospects at all [limb loss as lacking impact]. I didn't hide it [lack of hiding], but also didn't make a big deal of it - I'd just try to mention it at some point early in the evening so that it wasn't a surprise to them if things went well later [early disclosure to avoid surprise]. (Honestly it's the same approach I take when meeting anyone new - if we're going to be hanging out for a while and it might come up, I try to mention it casually at some point so we can get the surprise part out of the way.) [early disclosure to avoid surprise]

Poster 2 (BKA)

Thanks for that ! I think I was just scared of the rejection part of it all [expectations of rejection] being kinda new to this lifestyle [expectations of rejection due to a lack of experience] and trying hard to stay in good spirits [difficult to remain positive] will definitely use this concept going forward god bless ! [preference for early disclosure]

Poster 129

What they say is true - if someone rejects you because of your leg, that's not someone you want to be spending time with anyway [limb loss as a screening tool]. But realistically, that's like 0.1% of people [others do not care about limb loss; others as accepting]. Almost everyone you meet will find it interesting [limb loss as interesting] and think you're a strong person for having gone through what you have [limb loss as indicative of strength].

Poster 13 (BKA)

Exactly. Been on 20 dates or so. Only one girl ghosted me over [lack of impact on dating] it and I couldn't care less at this point [rejection is not bothersome]

Poster 105 (Bilateral BKA)

Truly, if someone can't be with you because you're missing a limb, chances are, they're not for you [limb loss as a screening tool]. They are solely focused on the lack of one body part and not on getting to know you as a person [rejecting others as shallow].

## Poster 49 (BKA)

I've been on a couple of dates since my BKA. I make sure to mention in it my dating profile so there's no surprises [preference for early disclosure; early disclosure to avoid surprise]. If they didn't read what I wrote then they find out when they see me walking up on my iWalk.

## Poster 2 (BKA)

How did the dates go ? Was it still a good vibe or awkward ? I have a prosthetic and people who don't know me personally can't tell unless I wear shorts [ability to conceal limb loss] so I get hit on a lot just don't want to be let down if they are not into me after the fact that'll kill my confidence a little [expectations of rejection; concerns about limb loss letting others down].

## Poster 105 (Bilateral BKA)

It wasn't awkward at all [lack of impact on dating], they obviously read my profile. I don't have my prosthetic yet so the iWalk is very obvious and I have to take it off when I sit [unable to conceal limb loss].

## Poster 2 (BKA)

Thanks for the advice it seems just being straightforward is the best route ! [preference for early disclosure]

## Poster 105 (Bilateral BKA)

Yeah I think straightforward is the way to go [preference for early disclosure]. They're going to find out eventually if things get intimate [intimacy as highlighting limb loss].

## Poster 55 (Bilateral BKA)

Naw bro if they trip about your prosthetic they aren't for you [limb loss as a screening tool].  
Man...do you know how many people out there aren't for you?! Nothing personal about them not being for you, ya know [rejection is not personal].

**Table B2.** *Example of the Theme Generation Process (Defying Expectations)*

Theme	Subthemes	Codes	Illustrative Quotes
Defying Expectations	Limb Loss as	Limb loss as lacking	'I just adapted and continued my life as before...' (54)
	Unimportant	impact	
		Limb loss as making	'It doesn't make any no difference difference.' (104)
		no difference	
		Dating is the same	'Dating as an before and after limb amputee is really no loss different than dating as able bodied in my experience.' (38)
	loss		
	Dating is easy	'I was kinda nervous getting back into dating again, but so far it's been a breeze.' (15)	
	Lack of impact on dating	'It was never an issue dating apart from saying no if they wanted to do something I couldn't do like ice skating.' (63)	

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Lack of 'bad' reactions	'I've never had a bad reaction from a guy...' (132)
Others do not care about limb loss	'Honestly, most people don't care that much...' (29)
Others view limb loss differently	'Most people may be interested but definitely are not thinking it is as big a deal as you probably think they are, we're often guilty of being overly critical of ourselves, all limbs or not.' (41)
Others as accepting	'As for dating It [sic] won't be a big deal. People in general are becoming more accepting and accommodating of people with disabilities.' (42)

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Others as curious	‘I’ve had one date who saw my bare nub and she was mostly curious as she never saw one up close in person before.’ (49)	
Limb loss does not impact attractiveness	‘Never had an issue with guy [sic] or gals being less attracted to me.’ (107)	
Lack of impact is surprising	‘It’s actually been really surprising how my prosthetic leg isn’t an issue.’ (30)	
Limb loss does not impact sex	‘I’m a RBK, and there’s never been any issues with my amputation in the bedroom (nearing 20 years).’ (24)	
Limb Loss as Positive	Limb loss as a talking point	‘...if anything its [sic] something



interesting to talk  
about.’ (12)

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Limb loss as a screening tool	‘What they say is true - if someone rejects you because of your leg, that's not someone you want to be spending time with anyway.’ (129)
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Limb loss as an ‘icebreaker’	‘Pluss [sic] the leg is aaaalways [sic] the best icebreaker...’  (15)
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Limb loss as ‘cool’	‘A vast majority of people won’t give a shit, or might think it’s cool.’ (8)
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Limb loss as intriguing	‘Actually get told regularly that it makes me more intriguing lol.’ (30)
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Limb loss as interesting	‘Almost everyone you meet will find it interesting...’ (129)
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Limb loss as admirable	‘...it’s admirable and cool to look at in a good way.’ (54)
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Limb loss as indicative of strength	‘Almost everyone you meet will find it interesting and think you're a strong person for having gone through what you have.’ (129)
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Limb loss increases romantic interest	‘And I feel like I got more likes than I had gotten when I had my leg.’ (113)
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Limb loss as improving openness	‘...the women I know have been showing more interest in me. Part of the reason I know is that I now have more time to talk and I have learned to open up a little more over the last year.’
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(3)

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Limb loss as improving communication	‘My partner and I (together 5 yrs) are closer emotionally and mentally than ever because we have had to communicate to each other so openly and supportively.’ (70)
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Positive gaze	‘I’m married so never act on anything, but definitely clock positive look and comments.’ (107)
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Importance of confidence	‘Regardless [sic] how many limbs we’re left with, most of dating and meeting people comes down to how secure and confident you are in yourself. It’ll only be an issue
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for you if you let it  
be.’ (38)

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Importance of comfortability with oneself	‘It’s your hangup, not theirs, and if you’re comfortable with it, they will be too.’ (129)
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Use of humour	‘For my dating profile I had a couple of photos of me and my amputation in outdoor/hobby settings as well as highlighting it in the body of the profile with humour.’ (41)
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Limb loss as attractive	‘...in my experience a lot of women are sort of into it.’ (38)
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Relationships as better following limb loss	‘In fact I am in a new relationship that would have put my 20’s to shame.’ (32)
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**Table B3.** *Overview of the Posters Supporting Each Theme and Subtheme*

Themes	Subthemes	Supporting Posters (With Available Demographics)
Feelings of Undesirability	Expectations of Rejection	2 (M, BKA), 3, 10, 14 (26M, bilateral AKA), 18 (57, BKA), 19 (43F, BKA), 22, 23 (BKA), 26 (AKA), 41 (BKA), 44 (bilateral AKA), 50, 63 (BKA), 70, 72 (BKA), 74 (BKA), 75 (BKA), 79 (63F, BKA and BEA), 82, 84, 86, 90, 91 (BKA), 96, 101 (31M, AKA), 102 (19F, bilateral AKA), 106 (AKA), 113 (AKA), 114 (26M, AKA), 115 (23F, AKA), 119, 122 (60, AKA), 124, 125 (23, AKA), 126 (21M, AKA), 127 (AKA), 128 (22F), 130, 134 (24F, BKA), 149 (BKA), 153 (AKA), 159, 160, 161 (AKA), Deleted Poster, Deleted Poster,

		Deleted Poster, Deleted Poster
When to Reveal: Early or Late		1 (bilateral BKA), 2 (M, BKA), 6, 7 (BKA), 11 (BKA), 22, 29 (BKA), 31, 35, 41 (BKA), 49 (BKA), 55 (bilateral BKA), 62, 64 (AEA), 65, 82, 84, 97, 108 (42M, AKA), 109, 113 (AKA), 129, 131, 137, 138 (BKA), 140 (BKA), 142 (BKA), 144 (bilateral BKA), 153 (AKA), Deleted Poster (bilateral BKA), Deleted Poster, Deleted Poster, Deleted Poster, Deleted Poster, Deleted Poster
	Coping Mechanisms	11 (BKA), 19 (43F BKA), 20 (BKA), 22, 35, 61, 99, 122 (60, AKA), 127 (AKA), 136, 138 (BKA), 142 (BKA), 153 (AKA)
Defying Expectations	Limb Loss as Unimportant	4 (AEA), 6, 7 (BKA), 8 (BKA), 9 (BKA), 13 (BKA), 15 (AKA), 23 (BKA), 24

(BKA), 29 (BKA), 30 (41F,  
 BKA), 32 (49F), 35, 38  
 (BKA), 41 (BKA), 42 (39F,  
 AKA), 48 (57, BKA), 54, 56  
 (AEA), 63 (BKA), 64  
 (AEA), 65, 78, 79 (63F,  
 BKA and BEA), 81 (BKA),  
 92, 103 (43F, BKA), 104  
 (AKA), 105 (bilateral  
 BKA), 107 (BKA), 108  
 (42M, AKA), 125 (23,  
 AKA), 129, 131, 132, 134  
 (24F, BKA), 140 (BKA),  
 144 (bilateral BKA), 146  
 (BKA), 148, 152 (bilateral  
 BKA), Deleted Poster,  
 Deleted Poster, Deleted  
 Poster, Deleted Poster,  
 Deleted Poster

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Limb Loss as Positive

3, 8 (BKA), 11 (BKA), 15  
 (AKA), 30 (41F, BKA), 31,  
 33 (AKA), 35, 38 (BKA), 43  
 (BKA), 55 (bilateral BKA),  
 85 (bilateral AEA and  
 bilateral AKA),

93 (AKA), 107 (BKA), 110

113 (AKA), 120 (BKA),

129, 154 (BKA), 156

(BKA), Deleted Poster

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**Appendix B2. Notes for Contributors (*Journal of Disability and Rehabilitation*)****About the journal**

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*Updated 12-11-2021*

**Chapter Three**  
**Critical Appraisal**

Keanu Court

Trainee Clinical Psychologist

k.court1@lancaster.ac.uk

Doctorate in Clinical Psychology

School of Health and Medicine

Division of Health Research

Lancaster University



The following critical appraisal begins by presenting an overview of the key findings and clinical implications arising from the systematic literature review (SLR) and empirical paper. Shared findings, strengths, and limitations will be discussed, and consideration will be given to how the interactions between these papers informs clinical practice and future research. Finally, a reflective account concerning the process of completing the thesis will be presented.

## **Summary of the SLR**

### ***Key Findings and Clinical Implications***

The SLR presented a thematic synthesis of qualitative studies on the experience of intimacy, romantic relationships, and dating following limb loss. Analysis of the dataset led to the development of four themes: 1) the self as undesirable, 2) the management of undesirability, 3) support: a double-edged sword, and 4) diverse experiences of intimacy.

Data supporting the first theme identified that feelings of undesirability were common following limb loss: a finding highlighted by previous research (e.g., 1,2). It was suggested that these feelings emanated from the internalisation of societal ideas about beauty, leading participants to cope via the use of compensatory, exclusionary, or protective (safeguarding) strategies. The collective conceptualisation of these strategies as methods to manage feelings of undesirability appeared to be novel, and it was stated within the second theme that their use engendered a number of unintended consequences. Health professionals were, therefore, advised to be mindful of the aforementioned strategies, so as to identify individuals requiring support (e.g., via the provision of psychological therapies).

The third theme documented the value of spousal support following limb loss. The provision of understanding and acceptance appeared to be particularly important, and it was suggested that involving spouses (or main carers) in the rehabilitation process may offer a

helpful means by which to indirectly support those with limb loss. Despite its helpfulness, spousal support did have the potential to foster feelings of dependence, leading some participants to employ strategies aimed at asserting their independence. These strategies, such as the rejection of support, appeared to damage romantic relationships, and it was stated that the provision of psychological therapy might enable couples to renegotiate the assertion of independence in ways that are not harmful to their relationship.

Findings from the fourth theme, that issues with intimacy were reasonably infrequent, contrasted with those of previous research (e.g., 3). A number of possible explanations were offered, such as that the SLR may have been subject to an underreporting bias. Irrespective of this, issues with intimacy did appear to be more prevalent amongst male participants. The cultural stereotype of men as more active during sexual activities (see 4) was cited as a possible reason for this, and it was recommended that health professionals provide advice on suitable sexual positions and alternatives to penetration.

## **Summary of the Empirical Paper**

### ***Key Findings and Clinical Implications***

The empirical paper detailed a study on the experiences of intimacy, romantic relationships, and dating following limb loss. Data were gathered using online sources (Reddit and The Amputee Discussion and Support Forum) and analysed in accordance with the method of reflexive thematic analysis (RTA) described by Braun and Clarke (5,6). RTA of the dataset led to the development of two themes: 1) feelings of undesirability and 2) defying expectations.

The first theme noted that feelings of sexual or romantic undesirability were common following limb loss: a finding noted within the SLR and wider literature (e.g., 7,8). Feelings of undesirability appeared to be relatively prevalent amongst posters with little experience of

engaging in sexual or romantic relationships after limb loss. This finding was used to suggest that supporting individuals to engage in such relationships might offer a potential means by which to challenge their feelings of undesirability. Cognitive-restructuring techniques (see 9) and narrative therapies (see 10) were also suggested as potential methods to address feelings of undesirability.

To manage the aforementioned feelings, posters within the empirical paper reported the use of several strategies, including the early disclosure of limb loss, the avoidance of sexual and romantic relationships, and the dating of devotees (a term describing able-bodied people who have sexual or romantic preferences for individuals with limb loss; 11). Whilst avoidant coping appeared to maintain beliefs about the self as undesirable, it was felt that there were merits to the other reported strategies. This led to the recommendation that clinical psychologists and wider health professionals might support the decision-making of those with limb loss by initiating open conversations about early disclosure and the dating of devotees.

Despite the potential to engender feelings of undesirability, many posters described limb loss as having a positive or neutral impact on their sexual and romantic lives. For example, whilst some posters felt that limb loss helped to screen out unsuitable partners, others described how their experiences of intimacy, romantic relationships, and dating had not changed. Consequently, clinical psychologists and wider health professionals were advised to not assume that limb loss is an inherently negative experience.

## **Synthesis of the SLR and Empirical Paper**

### ***Key Findings and Clinical Implications***

As has been described above, both the SLR and empirical paper found that feelings of undesirability were a common consequence of limb loss. The average age of participants and posters within these papers was 51.4 and 35.7 years, respectively. When this difference is

combined with the finding that feelings of undesirability were reported by individuals with a variety of limb loss types, it might be inferred that these feelings represent a general consequence of limb loss, rather than being related to the demographic variables of age and limb loss type. Similarly, as feelings of undesirability were noted amongst posters who had not elected to participate in research, they would also not appear to be an artefact of participation bias. Considering this, clinical psychologists and wider health professionals are advised to initiate conversations about the impact of limb loss on views of the self. Such conversations should take place with individuals at the beginning of the rehabilitation process, ideally during routine assessments, so as to identify those in need of additional support (e.g., via the provision of psychological therapies).

Similar coping mechanisms to manage feelings of undesirability were noted within the SLR and empirical paper. These included the avoidance of romantic and sexual relationships or the selection of partners on the basis of their ability to overlook limb loss. Within both papers, it was found that, for some participants and posters, avoidance served to exacerbate feelings of undesirability. Although recommendations were provided for each coping mechanism, the shared findings relating to avoidance (and its deleterious impact) suggest that this strategy may represent a common area for intervention. Clinical psychologists are, therefore, advised to be particularly mindful of avoidant coping when working with individuals who have experienced limb loss. Screening for the presence of this coping mechanism during initial assessments may support in the provision of suitable, subsequent interventions, such as encouraging individuals with limb loss to engage in romantic or sexual relationships.

Whilst several shared coping mechanisms have been identified, it is noteworthy that the dating of devotees arose only within the empirical paper. There are a number of possible explanations for this, such as demographic differences (namely age) between the papers or

the paucity of in-depth data within the SLR. Although it is not possible to determine why this difference exists, a likely explanation relates to difficulties talking about intimate issues, particularly in the context of researcher/participant relationships. Indeed, as the development of trust is known to support disclosure (12), it is possible that participants within the SLR did not feel comfortable to discuss the dating of devotees. Consequently, health professionals, and particularly clinical psychologists, may benefit from allowing time for the development of trust, so as to enable the subsequent disclosure of sensitive issues.

A further shared finding between the SLR and empirical paper related to the use of limb loss as a screening tool to filter out unsuitable partners. The empirical paper expanded on this, identifying several potential benefits of limb loss, such as being viewed by others as interesting and strong. It is possible that, because of participation bias, the SLR may have been skewed towards negative experiences, meaning it failed to fully identify the potential benefits of limb loss. Regardless of the underlying reason(s) for this, clinical psychologists and wider health professionals are encouraged to recognise the heterogeneity of experiences following limb loss; it may not, for example, be an inherently negative experience. Furthermore, initiating conversations about positive experiences may support individuals to identify the potential benefits of limb loss and, in turn, support their coping (see 13).

Although both the SLR and empirical paper highlighted the potential benefits of limb loss, only the latter identified views of limb loss as unimportant in relation to romantic and sexual relationships. The relatively younger age of posters included within the empirical paper offers a possible explanation for this: youth is associated with increased dating opportunities (14) and fewer issues with sexual functioning (15). Similarly, as the SLR may have been skewed towards negative experiences, it may have failed to identify the aforementioned views. Ultimately, it remains unclear as to why posters in the empirical study felt that limb loss was unimportant in relation to their romantic and sexual lives. This finding

does, nonetheless, highlight the importance of the previous recommendation: individuals with limb loss represent a heterogeneous population and professionals should not be assume that their experiences will be negative.

As a final note, views regarding spousal support and the unimportance of intimacy were observed only within the SLR. The 2021 census data from England and Wales (16) reports that individuals in the 30 – 35 year age bracket (the average age of posters in the empirical paper) had the greatest reductions in the proportion of married individuals. Similarly, older adults, and particularly older women, are more likely to have reduced desires for intimacy (17,18). Perhaps, then, the absence of these findings reflects the younger age of posters included within the empirical paper. Although this is tentative, clinical psychologists and wider health professionals are advised to be particularly mindful of the recommendations regarding spousal support and the unimportance of intimacy when working with older adults. This is not to say the aforementioned recommendations will not apply to younger individuals, but rather that they may be more relevant to those of comparatively older age.

### ***Strengths, Limitations, and Future Research***

Whilst the SLR included a range of papers relevant to the topics of interest, there was considerable homogeneity in the reported methods of data collection. Interviews were ubiquitous and, in cases where they were not used, contact between researchers and participants did still occur. Intimacy, romantic relationships, and dating can be sensitive topics, and it is possible that the aforementioned methods of data collection may have influenced the findings of the SLR (19). As an example of this, it was felt that the dating of devotees may not have arisen due to the sensitivity of discussing this topic in the context of a researcher/participant relationship.

The empirical paper sought to overcome the above limitation by utilising pre-existing data, gathered from online sources. At present, the empirical paper represents the only study to have utilised pre-existing data in context of limb loss and, therefore, provides novel insights into the experiences of intimacy, romantic relationships, and dating. As the empirical paper did not involve contact between the researcher and posters, it might be inferred that the overlapping findings from the SLR are not an artefact of the interactions between researchers and participants. Consequently, the empirical paper supports the notions that limb loss can engender feelings of undesirability, lead to the use of potentially unhelpful coping mechanisms, and provide a means by which to select suitable partners. Nonetheless, as the empirical paper was the first of its kind, future research may wish to build on its findings by collecting data from unexplored sources, such as additional social media sites (e.g., Facebook) or the multitude of unsearched subreddits (e.g., r/datingoverthirty).

Although the methods of data collection used within the empirical paper might be considered a strength, the choice to utilise pre-existing data did present a number of challenges. Most notably, it was not possible to gather in-depth data for every aspect of each theme and, as there was no direct contact between the researcher and posters, interpretations could not be discussed or verified. The SLR was subject to similar limitations; several papers did not focus on the concepts of interest, meaning the data were shallow at times, and interpretations could not be discussed with participants. Whilst the presented themes, sub-themes, and interpretations were evidenced, this left number of questions unanswered, such as why some individuals reported positive experiences of limb loss, whilst others appeared to be more greatly affected. Considering this, future research may wish to expand on the findings of the SLR and empirical paper by exploring the factors that promote positive experiences of intimacy, romantic relationships, and dating following limb loss. Similarly,

discussing interpretations with participants or involving additional researchers may offer a means by which to strengthen the reliability of subsequent findings.

As a final point, the SLR and empirical paper appeared to represent the experiences of heterosexual individuals. The SLR did not include any participants from sexual minorities, and the empirical paper included only two posters identifying as homosexual males. As such, the findings from these papers may not reflect the views of individuals from sexual minorities. The two posters identifying as homosexual males did highlight difficulties in navigating their community as disabled people, suggesting a need for research in this area to be conducted. Future researchers are, thus, encouraged to explore the experiences of intimacy, romantic relationships, and dating amongst individuals with limb loss from sexual minorities.

### **Reflective Account**

Having discussed the interactions between the SLR and empirical paper, I will now provide a reflective account concerning my journey of completing the thesis, illustrated with quotes from a diary I kept throughout the process. Finlay (20) suggests that reflexivity improves the transparency and trustworthiness of qualitative research, and I do hope that the following section provides some insight into the context within which the thesis was completed.

My initial interest in limb loss stemmed from a close friend being affected by congenital limb difference. Whilst the impact of this had largely remained dormant throughout her life, it did seem to become more prominent when she began to date. We would often talk about how she would conceal her limb difference when meeting potential partners, and it did seem that she held a certain level of shame about this. We had known each other for many years and, perhaps because I viewed her difference as insignificant, I



was surprised at the impact it had on her when dating. This is where the initial idea for the thesis was born and, although I knew little about limb difference, I did feel as though I brought a small degree of vicarious experience.

I was fortunate to be allocated a supervisor with an interest in limb difference. However, as his research largely focussed on individuals with limb loss, we decided that this would be a more suitable population for my thesis to sample. Furthermore, as the body of research on congenital limb difference was, in comparison, rather scant, the choice to focus on limb loss appeared to better lend itself to conducting a literature review. It was here that I recall thinking how little I knew about limb loss and how this might influence the process of completing the thesis. Nonetheless, as I consider myself to have a 'can do' attitude, I decided to read the relevant literature, particularly in relation to how limb loss might affect sexuality in its broad sense.

Having read about limb loss, I was struck by the lack of research in relation to intimacy, romantic relationships, and dating. Many papers (e.g., 21,22) seemed to focus on the concept of sexual functioning only, and there appeared to be a distinct lack of research amongst sexual minorities. As part of my doctorate in clinical psychology, I completed a thematic review around this time, focussing on the experiences of sexuality and intimate relationships amongst individuals with limb loss or congenital limb differences. Conducting this review led me to note similar findings to the reading I had completed: studies tended to focus on sexual functioning amongst heterosexual participants. It was here that I decided to explore the experiences of intimacy, romantic relationships, and dating amongst sexual minority individuals with limb loss. In particular, as my supervisor and I had elected to use interpretative phenomenological analysis (a method requiring homogenous samples; 23), I chose to focus my empirical research on homosexual males with acquired, major limb loss.

Perhaps the first major challenge I experienced related to difficulties recruiting participants for my study. I was looking to explore the views of a niche population and had anticipated that recruitment might take some time. However, I was surprised that, after almost a year of recruitment efforts, I was no further than I had been at the start of the thesis. My supervisor and I felt that changing the project to a broader population might be helpful, and I consequently aimed to explore the male experience of intimacy, romantic relationships, and dating following limb loss. Unfortunately, I experienced similar difficulties; I was able to recruit participants, though prior to conducting the interviews, I received emails requesting financial compensation. In a diary entry from the 29<sup>th</sup> of September 2023, I wrote:

Participants have asked for money... This seems fair and it is frustrating I am not able to offer this. Will this continue to be an issue?

Despite my views that offering compensation would be fair, it does raise a number of ethical issues; individuals from lower socio-economic backgrounds may feel compelled to participate, for example (24). Following discussions with my supervisor, I elected to change the topic of my thesis again, this time landing on the idea to utilise pre-existing data to explore experiences of intimacy, romantic relationships, and dating following limb loss.

Changing the thesis to utilise pre-existing data resolved my issues with recruiting participants, though did introduce a number of challenges. The most personally salient of these related to having no contact with the posters included within my study. In a diary entry from the 23<sup>rd</sup> of February 2024, I noted:

Parts of the dataset are comparatively thin; it is not entirely clear, for example, why some posters report positive experiences. Confidence? Time since limb loss? Exposure to romantic and sexual relationships?

As can be seen, it was difficult to make sense of the data at times, and a number of questions were left unanswered. Whilst I have previously discussed this limitation, here I would like to highlight the personal feelings that my choice of data collection methods engendered. In particular, as I did not have direct contact with any posters, I was left feeling as though I was writing about a population I had come to know only from an academic perspective. Dwyer and Buckle (25) refer to this phenomenon as being an ‘outsider’ in qualitative research: a term I identified with. I did make efforts to evidence my analysis and be transparent in the reporting of its findings, and do not wish to undermine my empirical paper here. Rather, I am left wondering how the analysis might be different should I have opted to utilise more direct methods of data collection. At times, then, there were feelings of unease and uncertainty whilst completing my thesis. Although I have not fully resolved these feelings, there is a degree of catharsis in writing about them, and perhaps this is as much as I can do.

As was mentioned in the introduction to my empirical paper, there exists a debate regarding the ethical implications of using pre-existing data from social media sites. In short, the use of such data raises a number of concerns relating to ownership, anonymity, informed consent, and the potential risk of harm (26). I do not intend to summarise these issues, though instead wish to highlight that I experienced a sense of unease in using data that I had not personally gathered. Perhaps I was primed to experience this sense of unease considering my concerns about being an ‘outsider’ within the research. However, I do feel that my concerns are legitimate, and there does not appear to be a straightforward answer.

Hennell et al. (26) suggests that reflexivity in the research process and an awareness of the issues regarding the use of pre-existing data may support researchers to navigate the ethical issues arising from studies of this kind. I do think that my awareness of this debate supported me in designing the empirical study with ethical implications in mind. As

examples, I ensured that data were only taken from the public domain, that no restrictions on the use of data existed, and that usernames were anonymised. Nonetheless, my concerns do not feel fully remedied, particularly as I was not able to discuss my research with the people it concerned. Perhaps then, I am left in a similar position to the point regarding my interpretations of the data: there is a catharsis in making my thoughts known, and this might be as much as I can do.

## **Conclusion**

Both the SLR and empirical paper found that limb loss had the potential to engender feelings of undesirability. To manage these feelings, individuals employed a range of coping mechanisms, such as the avoidance of romantic relationships and the selection of partners on their ability to overlook limb loss. Both papers noted that limb loss can be beneficial in the formation of romantic relationships, in that it can be used as a screening tool to filter out unsuitable partners. The empirical paper extended these findings by highlighting that, at times, limb loss may not impact experiences of intimacy, romantic relationships, or dating. A number of shared clinical implications and areas for future research were provided, such as that professionals should not assume individuals with limb loss are a homogenous population and that researchers may wish to explore the views of sexual minorities, respectively. A reflexive account concerning the process of completing the thesis was presented, and particular attention was given to the use of pre-existing data. Although I am left with a sense of unease, reflecting on the process has been a cathartic experience, and I do hope that the present critical appraisal has provided some insight into the context within which the research was completed.

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## **Chapter Four**

### **Ethics**

Keanu Court

Trainee Clinical Psychologist

k.court1@lancaster.ac.uk

Doctorate in Clinical Psychology

School of Health and Medicine

Division of Health Research

Lancaster University



## Ethics Application Form (Substantial Amendment Version Two)

Substantial Amendment Form v1.8

Substantial Amendment Form v1.9.2 SA



### The Experience of Intimacy, Romantic Relationships, and Dating Following Limb Loss - Approved

#### Amendment Information

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Please note:

This form is for making substantial amendments to applications previously approved in REAMS. All "Substantial Amendments" will go through the review process again. Please check the "Amendment Guidance" to see if you can use the "Minor Amendment" form.

#### Amendment Summary

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Please summarise your changes and the reasons why you are making them. Ensure that you indicate which parts of the form have been altered.

My previous research aimed to explore the experience of intimacy, romantic relationships, and dating amongst men with limb loss. Unfortunately, I struggled to recruit participants and have, therefore, changed my data collection procedure to utilise publicly available, pre-existing data, gathered from online sources. As demographic details can be difficult to gather when using pre-existing data, I will no longer be focussing exclusively on the male experience of intimacy, romantic relationships, and dating following limb loss. The title of the project has been changed to reflect this and is now 'The Experience of Intimacy, Romantic Relationships, and Dating Following Limb Loss'. In addition to the change of title, I have made the following changes to my research design and ethics application:

- The start and end dates of the research have been updated to reflect the later start of the current research.
- The expected number of participants has been increased. I previously planned to conduct semi-structured interviews with a minimum of four participants. However, as my data will now be collected from online sources, it is expected that the amount of data per participant will be significantly less. Reviewing previous research using online posts highlighted the number of participants/posts to be between 83 and 217. I anticipate that the number of participants/posts I use will fall within this range.
- The method of data analysis will now be thematic analysis (TA), rather than interpretive phenomenological analysis (IPA) as previously planned. I have made this change due to updates in the expected number of participants. As IPA is typically used to gather an in-depth understanding of experiences from few participants, it would no longer appear suitable as a method of analysis. Instead, TA now appears more suitable, in that it can be used to analyse experiences from many individuals.
- Recruitment will no longer take place as data will be gathered using online sources. Consequently, the present research will not use any study advertisements.
- Participants will not have any contact with the researcher. This is because data will be gathered from pre-existing, online sources. As such, no participant information sheets or consent forms will be used. Data sources will be checked to ensure that there are no restrictions about the use of data for research purposes. Similarly, as no contact between the research and participants will occur, there is no risk of disclosure from participants. Participants will also not be required to talk about distressing topics.
- Gatekeepers will not be used to access data. This is because I will be using publicly available data from online sources. Sources will be checked to ensure they permit/do not prohibit the use of data for research purposes.
- Interviews will no longer be taking place. Consequently, interviews will not be recorded using any devices.
- No age limits will be placed on participants. The previous project aimed to utilise an exclusively adult sample, namely due to the content of the interview schedule focussing on issues regarding sexuality. However, as no such interview will take place, participants will not be required to be over 18. It is, nonetheless, expected that participants will be adults due to the general demographics of those who have lost limbs and report issues in relation to intimacy, romantic relationships, and dating.

Please note that I have uploaded a research proposal under the sections for attaching participant information sheets and consent forms. I have done this as, whilst participant information sheets and consent forms will not be used, the form would not submit without having these attached.

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 already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

- No, I do not need ethical approval from an external institution.
- Yes, I have already received ethical approval from an external institution.
- Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

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

- Yes  No

*To note: please do not change your answer to this question, as you are completing the Substantial Amendment form therefore it is apparent that this is an amendment to a previously approved Lancaster University project .*

Which Faculty are you in?

Faculty of Health and Medicine

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

Will your research involve any of the following? (Multiple selections are possible, please see 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.

The Experience of Intimacy, Romantic Relationships, and Dating Following Limb Loss

Estimated Project Start Date

08/01/2024

Estimated End Date

21/06/2024

Is this a funded Project?

 Yes No

### Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? (E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)

 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

Keanu

Surname

Court

Department

Doctorate in Clinical Psychology

[Redacted]

Faculty

Health and Medicine

[Redacted]

Email

k.court1@lancaster.ac.uk

[Redacted]

Please enter a phone number that can be used in order to reach you, should an emergency arise.

07477849622

### Supervisor Details

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

[Redacted]

First Name

Craig

[Redacted]

Surname

Murray

[Redacted]

Department

Health Research

[Redacted]

Faculty

Faculty of Health and Medicine

[Redacted]

Email

c.murray@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

- Yes  No

### Additional Team Members

Other than 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

### 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?

58

What's the maximum number of expected participants?

2000

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 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

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 the relationships with participants

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

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

### Details about 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 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

## Data Origin

Is the data you will be using in the public domain or from data repositories?

- Yes  No

Has consent for the use/reuse of the data for research purposes been obtained?

- Yes  No  I don't know

Will you protect confidentiality and anonymity in your (re)analysis of the data?

- Yes  No  I don't know

### Data Analysis

Do you intend to conduct a secondary analysis of existing research data?

- Yes  No

### Details about the online sources

You stated that you will be engaging in data collection from online sources such as social media platforms, discussion forums, online chat-rooms. Please confirm that the data you intend to collect and the mode of analysis and communication is either:

- Clearly in compliance with the online source(s) published terms and conditions  
 Not clearly within the online source(s) published terms and conditions, therefore you have obtained written approval from the platform to conduct your project  
 Neither of the above

### Data Source

Is the online data you will be using in the public domain?

- Yes  No

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

- Yes  No  I don't know

Do you need consent for the use of the data for research purposes?

- Yes  No  I don't know

Will you protect anonymity in your use and analysis of the data?

- Yes  No  I don't know

### General Queries

19 June 2024

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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

Based on the answers you have given so far you will need to answer 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).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ 'problem' the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

Losing a limb can be life-changing and may lead to problems with intimacy, romantic relationships, and dating. Understanding experiences of intimacy, romantic relationships, and dating following the loss of a limb can help professionals to support individuals with limb loss. Although previous research has explored this topic, data has been collected directly by researchers, such as via interviews and focus groups. This may influence the data collected, making it less naturalistic. I, therefore, plan to collect data on intimacy, romantic relationships, and dating from individuals with limb loss using online sources. Such data will be pre-existing and not be influenced by the researcher. Data will be collected from online sources in the public domain, such as limb loss forums and social media platforms.

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

The project aims to better understand the experience of intimacy, romantic relationships, and dating amongst individuals with limb loss. It is hoped that this will highlight areas for further research and provide a better understanding for professionals who may work with individuals with limb loss.

## 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).

There exists no particular guidance on the number of participants/posts for qualitative research utilising pre-existing, online samples. Similarly, the method of thematic analysis is flexible in the number of participants used to generate insights into the data (Clarke & Braun, 2017). As such, to support my understanding of how many participants might be considered sufficient, I reviewed a variety of papers outside the area of limb loss which utilised pre-existing, online samples. Of the papers I reviewed, there was a significant range in the number of participants/posts used. For example, whilst one paper (Sit et al., 2024) included 98 participants/posts, others included in excess of 1000 (Gauthier et al., 2022). It appeared that the number of participants/posts analysed reflected the amount of available data. Consequently, I conducted a brief review of Reddit alone to better understand the availability of relevant posts. I was able to find 58 relevant posts, with over 1000 comments. This was not an exhaustive search and, therefore, I anticipate that my sample will likely be in excess of this. Regardless, it would appear that there exists sufficient data to perform a TA that is able to generate meaningful insights into the available data.

### References

Clarke, V., & Braun, V. (2017). Thematic analysis. *The journal of positive psychology*, 12(3), 297-298.

Gauthier, R. P., Costello, M. J., & Wallace, J. R. (2022). "I Will Not Drink With You Today": A Topic-Guided Thematic Analysis of Addiction Recovery on Reddit. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems* (pp. 1-17).

Sit, M., Elliott, S. A., Wright, K. S., Scott, S. D., & Hartling, L. (2024). Youth mental health help-seeking information needs and experiences: a thematic analysis of Reddit posts. *Youth & Society*, 56(1), 24-41.

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.

Data will be collected from online sources, such as Reddit and The Amputee Discussion and Support Forum. The data will be pre-existing and in the public domain. Data sources will be checked for any restrictions on the use of data for research purposes, and only sources which either do not prohibit this or explicitly allow the use of data will be used. Considering the data source, a participant information sheet will not be possible to use and the researcher will have no contact with participants. Furthermore, as the data is available in the public domain, and will only be used where this is not prohibited or explicitly allowed, explicit consent would not appear to be required.

You have indicated that participants will be asked to take part in the study without their knowledge or consent, or that deceit is involved. Please explain why this is the case, and what debrief will be given to the participants.

Data will be collected from online sources, such as Reddit and The Amputee Discussion and Support Form. The data will be pre-existing and in the public domain. Data sources will be checked for any restrictions on the use of data for research purposes, and only sources which do not prohibit/allow the use of data will be used. Considering the data source, that the data is available in the public domain, and that data will only be used where this is not prohibited or explicitly allowed, explicit consent is not required. No deceit will be involved in the study. No debrief will be given to participants as deceit will not be used and the researcher will have no contact with participants.

It is possible that posters or commentators on publically available forums may not have lost a limb and, therefore, do not meet the inclusion criteria. To account for this, only posts which explicitly state that the poster/commentator has lost a limb or limbs will be included. On forums such as Reddit, it is also possible to publically view the post history of posters/commentators. Should there be any doubt as to whether an individual making a potentially suitable post/comment meets the inclusion criteria, their post history will be checked to clarify this. This will involve reviewing the individual's post history to identify if they have explicitly reported losing a limb.

Please indicate how this group is to be recruited.

The data will be collected from pre-existing, publically available, online sources. As such, participants will not be recruited.

As you have indicated that you don't know if you are working with young people (under 18 years old), please describe the intended participants, and why they are needed for this research.

Participants will be required to have a lost a limb. As data will be collected from online sources, it will not be possible to obtain data on participant's ages. In some cases, ages may be reported. It is expected that participants will be adults due to the topics of interest (limb loss and intimacy/romantic relationships/dating) generally affecting adults. Nonetheless, the age of participants is not relevant to the study; rather, it is the loss of a limb and the reporting of information about intimacy, romantic relationships, and dating which is of interest.

You stated that the study could 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. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

N/A

My research will use pre-existing data from online sources, so there is not risk that the research will 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.

### Additional Information

Will you be sharing your data with any other organisation?

Yes  No

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

I plan to publish my research in an academic journal.

### Data Sources

You have stated that you do not need consent for the use of the data. Please explain why you do not need consent.

Data will be taken from publically available, online sources. As the data is in the public domain, consent will not be required. Nonetheless, data sources will be checked for any rules or guidelines on the use of data for research purposes. If this is explicitly prohibited, data will not be used. However, in cases where this is not explicitly prohibited, or actively allowed, data will be used, where relevant.

### Data Origin

You have stated that you have not obtained permission to reuse the data for this project. please explain your rationale for using data without informed consent.

It will not be possible to obtain explicit informed consent from participants as there will be no contact with the reseacher. However, as participants will have provided data in the public domain, on websites which do not explicitly prohibit this or actively allow this, informed consent is not required.

### Online Sources

Briefly describe your data collection methods from the online source(s), state which online sources you intend to use, and why the data is relevant to your research.

Google will be used to search for online forums relating to the phenomena of interest (limb loss, intimacy, romantic relationships, and dating). Once potential forums have been identified, each will be checked for guidelines on the use of data for research purposes. In the event of any uncertainty, the lead researcher will contact moderators to obtain permission for the use of data. Although this search has not yet been performed, a preliminary search would suggest that Reddit and The Amputation Support and Discussion Forum appear suitable as sources of data.

Following the identification of suitable forums, searches will be performed relating to the phenomena of interest. The searches made will depend on the nature of the forum. For example, forums for individuals with limb loss will be searched with the terms 'intimacy', 'romantic relationships', and 'dating'. Synonyms for these terms will also be searched. For forums that focus on intimacy, romantic relationships, or dating, search terms will relate to limb loss and its synonyms. Identified posts will be screened to ensure they meet the inclusion criteria (see the attached Research Proposal). Any posts that meet the inclusion criteria will be included within the analysis. No identifiable information (e.g., usernames) will be included within the analysis.

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.

I will not obtain explicit consent for the use of data. However, I will ensure that data sources allow the use of data for research purposes or do not explicitly prohibit this. To ensure anonymity, any identifiable information, such as online usernames, will not be included in the written report or transcripts.

### Additional Information for REC Review

How long will you retain the research data?

Data will be kept indefinitely for potential secondary analyses and/or confirmation of the results.

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

Data will be kept indefinitely for potential secondary analyses and/or confirmation of the results. Data will be stored securely using OneDrive via the Lancaster University Virtual Private Network.

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

No identifiable data, e.g., names and addresses, will be collected or stored. Online usernames will be anonymised and stored alongside the data. Anonymisation will use a numerical system, e.g., 'poster 1', 'poster 2' etc... Records will not be deleted, but rather stored for potential future secondary analyses.

## Document Upload

### **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 Protocol:

Type	Document Name	Documents			
		File Name	Version Date	Version	Size
Research Proposal	Research Proposal 2	Research Proposal 2.docx	11/01/2024	2	82.7 KB

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- Research Proposal (DClinPsy)
- 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 a copy of all of the consent forms that you will be using:

Type	Document Name	Documents		Version	Size
		File Name	Version Date		
Consent Form	Research Proposal 2	Research Proposal 2.docx	11/01/2024	2	82.7 KB

Please upload a copy of all of the Participant Information Sheets that you will be using in this study.

Type	Document Name	Documents		Version	Size
		File Name	Version Date		
Participant Information Sheet	Research Proposal 2	Research Proposal 2.docx	11/01/2024	2	82.7 KB

## Declarations and Sign off

### \*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 31/01/2024 13:28

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 ISB](#)
- That you have completed the ISB 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 Mr Keanu Court ([k.court1@lancaster.ac.uk](mailto:k.court1@lancaster.ac.uk)) on 31/01/2024 12:58

## Appendix C

### Appendix C1. *Research Proposal Version Three*

N.B. Please note that sections highlighted in yellow represent changes from the previous research proposal relating to the first substantial amendment form.

#### Introduction

Amputation refers to the complete or partial surgical removal of a limb or limb part (Ali & Haider, 2017). In the US, it is estimated that 30,000 to 40,000 amputations are performed annually, amounting to 1.6 million people living with limb loss (Ziegler-Graham et al., 2008). In the UK, approximately 5000 amputations are carried out each year (Ahmad et al., 2014), typically as a result of diabetes mellitus, peripheral vascular disease, trauma, or malignancy (Ephraim et al., 2003). Regardless of the underlying cause, limb loss can have profound physical, psychological, and interpersonal consequences (Dillingham et al., 2002). In addition to the challenges of reduced mobility and physical rehabilitation, individuals may have to navigate an altered body image (Freysteinson et al., 2017) and depressive symptomatology (Horgan & MacLachlan, 2004). Considering the range of potential difficulties, and their associated costs to healthcare systems (see Kerr et al., 2019), it is perhaps unsurprising that limb loss has been recognised as a global health concern (Ephraim et al., 2003).

One particularly pertinent challenge of limb loss relates to its potential impact on intimacy, romantic relationships, and dating (Mathias & Harcourt, 2014). Particularly in Western societies, in which there are narrow ideas of physical beauty (Mathias & Harcourt, 2014; Rybarczyk & Behel, 2008), people with limb loss may be viewed as asexual, unattractive, and unsuitable for relationships (Milligan & Neufeldt, 2001; Taleporos & McCabe, 2001). The internalisation of societal views may lead to feelings of shame

(Rybarczyk et al., 1997; Rybarczyk & Behel, 2008) and the adoption of an asexual lifestyle amongst those with limb loss (Milligan & Neufeldt, 2001). This is despite those with limb loss reporting desires for intimacy and partnership (Mathias & Harcourt, 2014).

Following the loss of a limb, multi-disciplinary support is often provided, and professionals frequently refer people with limb loss to specialist psychological services for many of their difficulties (Andrews et al., 2009; Keszler et al., 2020). Nonetheless, despite the potential challenges to intimacy, romantic relationships, and dating, this aspect of care is often overlooked (Geertzen et al., 2009; Mathias & Harcourt, 2014). In line with this, research and policy literature (e.g., the British Society of Rehabilitation Medicine, 2003) has largely focussed on the physical aspects of limb loss (Hanley et al., 2004; Miller et al., 2002). The impediment of intimacy, relationships, and dating is particularly concerning when it is considered that these areas are well acknowledged as core components of wellbeing and quality of life (Althof & Parish, 2013; Anderson, 2013; Berkman et al., 2014). Intimacy, relationships, and dating are known to influence, amongst other things, identity, self-image, self-concept, and self-worth (Heath, 2011). Comfort and support, which can be provided by intimate relationships, may help to buffer the impact of change, loss, and difference (Heath, 2002). Similarly, partners of those with limb loss often provide emotional and practical support, which has been shown to aid in recovery (Williams et al., 2004). It follows, then, that difficulties with intimacy, relationships, and dating may serve to compound the aforementioned challenges associated with limb loss. A lack of comfort and support, for example, may hinder adjustment to, and coping with, the loss of a limb (Rybarczyk et al., 2000).

Considering the impact that limb loss can have on intimacy, relationships, and dating, it would appear important to better understand how these areas of wellbeing and quality of life are experienced by those with limb loss. This may help to inform health professionals

how they might best support those with limb loss. Although previous research (e.g., Mathias & Harcourt, 2014; Ward-Khan et al., 2021) has explored these topics, they have utilised methods of data collection (e.g., interviews and focus groups) which rely on interactions between the researcher and participants. Jowett (2015) argues that this might influence the data collected, in that it is less naturalistic and potentially biased by the presence of the researcher. As such, I plan to explore the experiences of intimacy, romantic relationships, and dating following limb loss using pre-existing data collected from online sources, e.g., Reddit and The Amputee Discussion and Support Form. It is hoped that this will provide a naturalistic account of how intimacy, romantic relationships, and dating are experienced by those with limb loss, consequently highlighting areas for clinical consideration and providing an overview of specific issues for subsequent research to address.

## Methods

### Design

The present study is interested in understanding the experiences of intimacy, romantic relationships, and dating following limb loss. Thematic Analysis (TA; Braun & Clarke, 2006) would appear to be a suitable approach due to its accessibility and flexibility in examining data from a variety of sources (Braun & Clarke, 2006). The flexibility of TA would appear particularly important considering my choice to utilise pre-existing, online data, in that this method is suited to various sample sizes, data collection methods, and approaches to meaning generation (Clarke & Braun, 2017).

Whilst a variety of data collection methods may be used in TA (Clarke & Braun, 2017), the present study will utilise online discussion groups. It is hoped that this will provide a naturalistic account of the phenomena of interest which, in turn, may generate novel insights into the experiences of intimacy, romantic relationships, and dating following limb loss.

### Sample

There exists no particular guidance on the number of participants for qualitative research utilising pre-existing, online samples. Similarly, the method of TA is flexible in the number of participants used to generate insights into the data (Clarke & Braun, 2017). As such, to support my understanding of how many participants might be considered sufficient, I reviewed a variety of papers outside the area of limb loss that utilised pre-existing, online samples. Of the papers I reviewed, there was a significant range in the number of participants/posts used. For example, whilst one paper (Sit et al., 2024) included 98 participants/posts, others included in excess of 1000 (Gauthier et al., 2022). It appeared that the number of participants/posts analysed reflected the amount of available data.

Consequently, I conducted a brief review of Reddit alone to better understand the availability of relevant posts. I was able to find 58 relevant posts, with over 1000 comments. This was not an exhaustive search and, therefore, I anticipate that my sample will likely be in excess of this.

## **Recruitment**

Data will be collected from pre-existing, online sources, such as Reddit and The Amputation Discussion and Support Forum. As such, recruitment will not take place. Rather, forums will be checked to ensure that they either allow the use of data collection for research purposes or do not explicitly prohibit this. In the event of any uncertainty, the lead researcher will contact moderators to clarify whether posts can be used for research purposes.

## **Inclusion Criteria**

Participants will:

- Have undergone an amputation, regardless of the underlying cause.
- Made a post to a publically available forum relating to the areas of intimacy, romantic relationships, and/or dating.
- Posted in English.

## **Exclusion Criteria**

Participants will not:

- Have been born with a missing limb or limbs.

N.B. Due to the nature of the data source, it is unlikely that demographic information will be available for participants. As such, it will not be possible to exclude participants based

on age. It is, however, expected that participants will be over 18 due to the demographics of those with limb loss and issues relating to intimacy, romantic relationships, and dating.

## **Materials**

The present research will analyse pre-existing, online posts, and not involve any interaction between the researcher and participants. As such, no recruitment flyer, participant information sheet, consent form, or debrief form will be used.

## **Procedure**

Google will be used to search for online forums relating to the phenomena of interest (limb loss, intimacy, romantic relationships, and dating). Once potential forums have been identified, each will be checked for guidelines on the use of data for research purposes. In the event of any uncertainty, the lead researcher will contact moderators to obtain permission for the use of data.

Following the identification of suitable forums, searches will be performed relating to the phenomena of interest. The searches made will depend on the nature of the forum. For example, forums for individuals with limb loss will be searched with the terms 'intimacy', 'romantic relationships', and 'dating'. Synonyms for these terms will also be searched. For forums that focus on intimacy, romantic relationships, or dating, search terms will relate to limb loss and its synonyms. Identified posts will be screened to ensure they meet the inclusion criteria. Any posts that meet the inclusion criteria will be included within the analysis. No identifiable information (e.g., usernames) will be included within the analysis.

## **Analysis**

The step-by-step method to conducting TA set out by Braun and Clarke (2006) will be used to analyse the data. This guide will help to ensure that the method is adhered to. A clear



audit trail, explicitly highlighting the coding process, will be generated so that it is clear where the themes emerged from. The research supervisor will also be involved in the analysis as a means of quality assurance, rigour, and validity.

### **Ethical Concerns**

The use of online forums for qualitative research raises the question of whether pre-existing data can be considered public or private. Whilst some take the view that messages posted to public forums are in the public domain and, therefore, do not require consent, others disagree, claiming that the use of such data is a violation of privacy (Jowett, 2015). Although guidance in this area is sparse, the British Psychological Society (2013) do not preclude the use of online data, stating that where there is not an expectation of privacy, the use of such data may be justifiable. When considering forums such as Reddit, it would appear that posts are not made with the expectation of privacy, but rather the opposite; many users make posts indicating an expectation that they will be read by others whom they do not know (Jowett, 2015).

Although there is no particular resolution to the disagreements regarding privacy, the anonymisation of online usernames may help to ensure a degree of privacy. Although some authors (e.g., Herring, 1996) advocate for transparency in the reporting of identifiable information, the present research plans to anonymise the usernames of those included in the analysis, so as to support in ensuring privacy is upheld as best possible. The present research will also only use data from sources where there does not appear to be a reasonable expectation of privacy, e.g., publically available forums.

It is noteworthy that, as there will be no interaction between the researcher and participants, there is no risk of distress or disclosure in the present research. Similarly, participants will not be required to talk about sensitive topics.

## Timescale

The lead researcher will submit an application to the Faculty of Health and Medicine Research Ethics Committee for ethical review in **January 2024**. It is anticipated that data collection will begin in **February 2024**, with this being completed by **March 2024**. Data analysis will begin in **March 2024** and be completed by **April 2024**. The research will be written up between **April 2024** and **July 2024**, and submitted for publication in September 2024. Following completion of the write-up, the Ethics Committee will be notified of the study completion.

Submission of the thesis to the Lancaster University DClinPsy programme will occur by **July 2024**. A viva is expected to take place between **July 2024** and **August 2024**, with post-viva amendments being made in August 2024.

## References

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**Appendix C2. *Email Confirming Ethical Approval***

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

FHM-2024-0952-SA-3 The Experience of Intimacy, Romantic Relationships, and Dating  
Following Limb Loss

Dear Keanu Court,

**Please note that this is an automated e-mail (Please do not reply to this e-mail).**

Thank you for submitting your ethics amendment application in REAMS. The amendment has been approved by the FHM.

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 further 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,

Research Ethics Officer on behalf of FHM