Submitted in partial fulfilment of the

Lancaster University Doctorate in Clinical Psychology

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Doctoral Thesis

Coping and adjustment in adults with limb loss.

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Word Count

Section	Text	Appendices(including abstract tables & references)	Total
Literature Review	8095	7538	15,633
Empirical Paper	8856	3891	12,747
Critical Appraisal	2479	422	2,901
Ethics Section	5878	5776	11654
Totals	25,308	17,627	42,935

Abstract

This thesis is comprised of a literature review, a research paper and a critical appraisal of the research process.

A meta-synthesis methodology was used for the literature review in order to identify and synthesise 29 studies exploring the experiences of individuals living with limb loss. Four themes emerged which offered an understanding of how individuals with limb loss experience and cope with appearance related stigma. These were: 'The need for social connection versus independence', 'Identity formation: renegotiating self', 'Concealing and/or avoiding', and 'Internal resilience: new ways of thinking and relating'. The themes capture the way individuals navigate stigma experiences, make sense of difference and establish control. The review offers implications for future research and offers recommendations for the provision of psychological input on a systemic, individual and institutional level.

The research paper investigated prosthetist communication style in predicting psychosocial adjustment across three outcome measures. A cross sectional design was utilised in order investigate service user satisfaction with their prosthetists' communication style, in order to establish whether this demonstrated significant predictive value in prosthesis related adjustment outcomes above that consistently demonstrated by other predictors. Results were interpreted using hierarchical regression analysis. One significant finding revealed that service user satisfaction with prosthetist communication style in consultations demonstrated significant predictive value above other predictors in explaining prosthesis satisfaction, particularly functional and aesthetic components to the prosthesis. Furthermore, service user satisfaction with consultation emerged as a significant independent predictor. The findings have implications for theory, clinical practice and future research in this field. Specifically, theoretical considerations of adjustment, introduction of staff training in

communication and suggestions relating to more specific policy guidance in relation to prosthetic consultation are offered.

The critical review reflects on the findings of the literature review and research paper, with consideration given to epistemological stance, critically appraising the research process overall and its clinical relevance.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster University's Division of Health Research between June 2017 and June 2018. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Shaneela Malik
Signature: S. Malik
Date: 18th June 2018

Acknowledgements

I am sincerely grateful to my supervisors for all their continued support and encouragement, I cannot imagine getting to this stage without them. And special thanks to my mum and dad, whose unconditional love and belief in me gave me the courage to endure even the most difficult stages of this process. I do not have the words to express how much you mean to me. Thanks being my strength on the days I felt I was running on empty. This is for you.

Section One: Literature Review

Section Two: Research Paper

Section Three: Critical Review

Section Four: Ethics

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Doctoral Thesis

How do people with limb loss experience and cope with appearance-related stigma?: A qualitative metasynthesis

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8095 words

(Excluding tables and figures, reference lists and appendices)

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[1] Please note this manuscript was prepared in line with author guidelines for *the British Journal of Health Psychology* (See Appendix 1B). The word count is in line with University guidelines rather than journal guidelines

Abstract

Purpose: To identify and synthesise qualitative studies on the stigma-related experiences and coping strategies of individuals with limb loss following the guidelines of Noblit and Hare's (1988) meta-ethnographic approach.

Method: A systematic search strategy was undertaken whereby four databases were accessed to collate original research papers relevant to the review question. The Critical Appraisal Skills Programme (CASP) quality guidelines were used to evaluate the included studies. Data were extracted and themes synthesised through meta-ethnography, an accepted procedure for qualitative metasyntheses.

Results: Twenty-nine papers were included in the analysis, producing four themes: The need for social connection versus independence', 'Identity: renegotiating self', 'Concealing and/or avoiding', and 'Internal resilience: new ways of thinking and relating'.

Conclusion: The findings are discussed in relation to theory and research with implications for clinical practice, namely, developing pathways within rehabilitation services for service users and family members to gain better access to psychological support.

Statement of contribution

What is already known on this subject?

- Psychological distress (such as anxiety and/or depression) may be a common experience following limb loss, and a factor relating to this may involve coping with the stigma that is associated with losing a limb.

- Further understanding of how individuals psychosocially adjust to limb loss is important, and a key goal for rehabilitation services is to move beyond the medical and physical components of amputation, in order to provide a more holistic approach to rehabilitation interventions.

What does this study add?

- At present, there is a growing body of qualitative research concerning the stigma-related socio-contextual experiences for individuals following limb loss, however to the author's knowledge, this has not been subject to a review.

- This metasynthesis integrates existing findings concerned with how people with limb loss experience and cope with appearance-related stigma.

- The findings have implications for improving clinical practice.

Limb loss and limb deficiency are potentially life-limiting conditions, which impact on the health and wellbeing of individuals affected. There are multiple pathways to losing a limb, involving acquired conditions such as peripheral vascular disease, diabetes mellitus, trauma, and malignancy. Congenital limb deficiency on the other hand, may be a result of genetic abnormalities, a gene-environment interaction, or exposure to an environmental teratogen (Ephraim, Dillingham, Sector, Pezzin & MacKenzie, 2003).

Thus, both acquired limb loss and limb deficiency are potentially disabling conditions (Richie, Wiggins & Sanford, 2011) influenced by a range of health related factors such as reduced mobility and physical limitations, and sociocontextual factors such as adjustment to a new body image and changes in social engagement. Public perception may be altered and, as such, individuals with limb loss are more likely to be viewed and treated as ‘disabled’ (for a review, see Horgan & MacLachlan, 2004). Thus, the way society understands and conceptualises disability can have implications for the adjustment process following amputation. Although ‘adjustment’ is a term with no clear definition in the literature, it is commonly understood as the absence or presence of psychological distress (Moss-Morris, 2013) which can be mediated by the individuals’ environment.

In relation to adjustment, it is well established that psychological wellbeing is affected amongst some people with amputations. A systematic review concluded prevalence rates of 20.6–63% for depression and 25.45–57% for anxiety (Mckechnie & John, 2014), although there was heterogeneity between the studies included due to use of differing scoring systems, populations and follow up times. Prosthesis use has been known to reduce feelings of psychological distress in some individuals as it offers feelings of ‘normality’ (Jefferies, Gallagher & Philbin, 2018).This reinstates the importance for prosthetic rehabilitation (involving the supply of an artificial limb) in not only mastering the medical and physical components of amputation (van Velzen, 2006), but also how individuals psychosocially adjust to limb loss.

A relating factor for many individuals with limb loss is coping with the stigma that is associated with losing a limb (Stancu, Rednic, Grad, Mironiuc, & Gherman, 2016). Stigma can be understood as a method of conveying social disapproval and discreditation (Goffman, 1963) towards difference relating to a distinguished characteristic or identity. This often results in a devaluation of that individual through a complex interplay of discrimination and feelings of discomfort (for a review see, Schmitt et al., 2014). Experiencing appearance related stigma typically takes two forms; one that is enacted, where the stigmatised person experiences actual discrimination, and one that is felt or perceived, where the individual has an awareness of having a stigmatised identity (i.e. believing that one is defective, inferior and socially undesirable) (Goffman, 1963; Scambler & Hopkins 1986).

People with limb loss may experience their body as unfamiliar, strange and mutilated (Sjödahl, Gard, & Jarnlo, 2004), and perceive themselves as incomplete as individuals (Batty, McGrath & Reavey, 2014). For instance, individuals are known to compare their body to how it was pre-amputation, and find difficulty in adapting to life both with and without a prosthetic device (Sousa, Corredeira & Pereira, 2009). In addition, individuals who are visibly different often encounter difficulties in social interaction. This process can affect an individual emotionally (i.e. anxiety), cognitively (negative thought patterns around social evaluation) and behaviourally (avoidance of social situations; for a review, see Norman & Moss, 2015).

Although adjustment to limb loss is a subjective experience, contextual factors may impact on felt stigma and social integration, which is considered beneficial for quality of life, that is, an individual’s self-assessment of their overall wellbeing and satisfaction across a variety of health and wellbeing measures (Bishop, 2005). This is evident in a study by

Rybarczyk, Nyenhuis, Nicholas, Cash and Kaiser (1995) who found body image concerns following amputation correlated with perceptions of social stigma, with higher levels of reported body image concerns resulting in a higher perception of social stigma. Such perceptions increased anxiety, due to fears regarding unattractiveness and anticipation of negative evaluation from others.

The influence of the social environment is evident in a recent scoping review addressing negative observer responses towards individuals with visible differences. Across the 16 studies included, a general finding was that the less contact observers had with individuals with a visible difference, the more likely they were to have negative threat based responses towards them such as disgust and avoidance, in a similar manner to how individuals may innately respond to disease and/or contamination (for a review, see Jewett, et al., 2018). While there are no current systematic reviews specifically addressing public attitudes and responses to individuals with limb loss, discrete quantitative studies in the field of amputation have investigated measured constructs relating to stigma experiences, with findings demonstrating the impact of perceived stigma experiences on wellbeing and daily living (Rybarczyk et al., 1995; Nicolas et al., 1993).

For instance, Rybarczyk et al. (1995), using the Perceived Social Stigma Scale (PSSS), found that depression scores were more severe when individuals with an amputation experienced higher rates of stigmatisation from others. In a study examining perceived vulnerability in adjustment to lower extremity amputation, Behel, Rybarczyk, Elliott, Nicholas, Nyenhius and Caplan (2002) found increased vulnerability resulted in adjustment difficulties, specifically lower quality of life and increased low mood. The authors concluded that individuals experiencing vulnerability had high levels of social discomfort, and had a perception that others saw them as unattractive and ‘disabled’.

Perceived or actual stigma experiences also impact an individual's daily activity levels and social engagement. A metasynthesis exploring the experience of amputation and prosthesis use in adults reported that individuals wear a prosthetic device to appear 'normal' and improve social interactions (Murray & Forshaw, 2013). Despite this, quantitative studies suggest that this may not always be effective. For example, Nicolas et al. (1993) investigated individuals' perceptions of feelings and problems regarding their prosthesis. The findings of the questionnaire highlighted that 72% of individuals had harassment concerns and perceived they would not be able to defend themselves when out in public; 20% avoided public places and only 6% chose to use public transport. This suggests that some individuals developed socially excluding behaviours due to a perception of altered appearance in the eyes of others and, as a result, daily living activities were affected. Similarly, in a longitudinal study examining social support following amputation, Williams, Czerniecki, Hoffman, and Robinson (2004) found individuals with higher perceived social support had greater participation in vocational, social and leisurely activities. However, the authors suggested that overall social integration rates were lower when compared with samples without amputation. Such findings are concerning as generally, being active in one's community and being socially integrated is beneficial for health and wellbeing (for a review, see Tough, Siegrist & Fekete, 2017). Consequently, social integration is important for psychological adjustment, and an impeding factor appears to include how the individual evaluates their changed bodies, and both the actual and presumed evaluations of others towards them (Rybarczyk, Nyenhuis, Nicholas, Schulz, Alioto & Blair, 1992).

Adaptive coping strategies can mediate the adjustment process and act as a buffer for individuals who are devalued and seen as socially unacceptable (Nario-Redmond , Jeffrey & Fern, 2013). Coping is a complex phenomenon and individuals may respond to adverse experiences in various ways, such as problem focused coping (problem solving to actively manage the stressor) or emotion focused coping (responding to the emotions associated with the stressor such as avoidance or denial; for a review see, Zeidner & Endler, 1996). There is no current agreement on the most effective style of coping for maintaining psychological wellbeing and authors have many perspectives on how coping should be conceptualised and measured (for a review, see Skinner, Edge, Altman, Sherwood and Cooper, 2003).

Despite this, a number of studies have used quantitative designs to assess the relationships between measured constructs of coping and well-being. A systematic review on psychosocial adjustment to amputation concluded that the coping strategies employed by those with amputation are not distinct from those utilised by people without amputations. In this review, problem focused coping amongst individuals (such as finding positive meaning, acceptance and positively reframing their perspective of the situation) resulted in better health outcomes and physical capabilities (Horgan & MacLachlan, 2004).

The findings of the above studies are informative, providing detailed statistical relationships regarding the psychosocial challenges associated with adjustment following amputation. However, such findings use limited-choice options using predetermined categories in questionnaires (Lavrakas, 2008) which do not provide a nuanced view of the subjective experience of the individual (Murray & Forshaw, 2013). This is an important consideration in relation to stigma as a construct, as according to Miller and Kaiser (2003), “understanding on how stigmatized people cope with stigma requires that we take their perspective and study their responses to stress” (p 89). Thus, qualitative approaches may extend the findings from quantitative studies, by offering a deeper an understanding of stigma which can be more broadly understood within the context of a multi-dimensional social process (Yang, Kleinman & Link, 2007).

At present, there is a growing body of qualitative research concerning the stigma-related socio-contextual experiences for individuals following limb loss, however the studies that comprise this corpus need to be “put together meaningfully” (Noblit & Hare 1988), “in order to provide an encompassing, integrated and cumulative examination of qualitative evidence on a given topic” (Murray & Forshaw, 2013, p.1134). A systematic and rigorous way of achieving this is through the literature review method of a metasynthesis. Metasynthesis has been defined as “the theories, grand narratives, generalization, or interpretive translations produced from the integration or comparison of findings from qualitative studies” (Sandelowski, Docherty & Emden 1997, p. 366).

Thus a metasynthesis is more likely to offer a comprehensive account of the matter in question that is both in-depth and original, as it considers similarities and differences across the data and provides an integrated sum which exceeds the findings of the original studies (Finfgeld, 2003). A metasynthesis can assist in informing clinical practice through increasing health provider insight into individuals’ experiences, providing a guiding framework, refining assessments and being able to better support individuals and their families (Finfgeld-Connett, 2014; Kearney, 2001). Although a previous metasynthesis has explored psychosocial aspects of the amputation experience (Murray & Forshaw, 2013), qualitative research on stigma and stigma-related coping following amputation has not been subject to a review. Therefore, the broader aim of this review is to expand on and encourage further research in this context which may inform policy and service provision. Specifically, the review question aimed to integrate existing findings concerned with how people with limb loss experience and cope with appearance-related stigma.

Method

The meta-synthesis was conducted following the guidelines of Noblit and Hare’s (1988) meta-ethnographic approach, which offers guidelines on conducting interpretative analysis of qualitative studies. This method for metasynthesis was selected above others due to it being the most commonly cited in the literature, and possibly the leading approach to synthesising health related qualitative research (Coughlan & Croning, 2016). The use of this approach enables the data to be synthesised in an integrative thematic structure which goes above a descriptive summary of each study, based on second order constructs (the authors' interpretations contained in the reviewed studies) of first order constructs (the participants' narrative of their experiences) (Atkins et al., 2008). Similarities and differences are compared across the studies which form the production of 'third-order constructs', such as themes and concepts. Findings can be "reciprocal" (directly comparable), "refutational" (opposing each other) or in a line of argument (an overall general interpretation based on the concept/themes from each study which produces an overall story) (Polit & Beck, 2010, p.529).

Search and Selection Strategy

The screening and appraisal process was conducted independently by the author. In order to be included within the review, papers had to meet the following inclusion criteria: (1) the study was written in English; (2) the study sample was comprised of adults who had limb loss at any point in their lives or where other samples were used, the paper reported findings that were clearly discernible as applying to this sample; (3) focus group or individual interviews were conducted in the study utilising an inductive qualitative method for data analysis; (4) the study explored the personal accounts of individuals with limb loss with the original data excerpts provided;(5) the authors of the study provided an interpretative account of participant experiences through the data provided; (6) the study need not have a central focus explicitly on appearance related stigma, but needed to have some findings related to this (7) to ensure a basic level of quality, the study ought to be published in a peer-reviewed journal. Papers that did not address stigma and reported coping strategies in relation to limb loss experiences were excluded.

A systematic search was then conducted in order to identify the relevant papers to be included in the review. The research question was separated into three components (“amputation”, “coping” and “qualitative”). In order to generate key search terms and better construct an effective and comprehensive search strategy, an academic university librarian was consulted for feedback. Sole use of the search team ‘qualitative’ could omit the vast number of different research methods that represent this term (Evans, 2002), thus the search strategy involved using the relevant database subject headings and combining these with a variety of free text search terms under ‘title’ and ‘abstract’. Terms were searched using Boolean operators such as ‘OR’ and ‘AND’ to combine or exclude the key words in the search. An illustration of the strategy utilised and included search terms for each bibliographic database can be found in appendix 1-A, table 1.

[Insert Table 1]

The search was conducted in November 2017 and four bibliographic databases were searched which included MEDLINE (1150 papers) for health and biomedical related literature, PsycINFO (270) for any social and behavioural literature, AMED (89) for literature related to allied health practise and CINAHL (329) for any studies concerning the allied health professional and nursing sector. A total of 1485 search results were retained after extracting 353 duplicates. A referencing software programme was use to collate the results prior to the screening process, which involved reading the title and abstract in order to determine relevance for inclusion. The full text of a paper was examined if relevance could not be deemed from title or abstract alone. Following this strategy, the reference lists of all the papers deemed suitable were examined to elicit any further suitable papers. This strategy returned 2 additional papers. In total, 29 papers were identified. The systematic search process is summarised in appendix 1-A, figure 1.

[Insert Figure 1]

Selected studies. A methodological summary of the final studies is presented in appendix 1-A, Table 2. Studies were conducted in England (8), Sweden (4), USA (3), Ireland (3), Denmark (3), Portugal (1), Wales (1), Taiwan (1), The Netherlands (1), Nepal (1), South Africa (1) , Malta (1),and Australia (1), with sample sizes ranging from 4 to 68 participants. All the studies included adult samples, with three studies investigating single sex samples (male or female) and the remaining studies including a mixed gender (male and female) sample. All the studies used interviews for data collection, and some also included a visual group workshop (Batty et al., 2014); participant observation (Christensen, Langberg, Doherty, & Egeord, 2017) and a focus group (Gallagher & Maclachlan, 2001). Data analysis in all studies was presented in the form of thematic analysis, drawing upon different methods: phenomenological approach/analysis (Cater, 2012; Grech & Debono, 2014; Hamill, Carson & Dorahy, 2009; Ligthelm & Wright, 2014; Liu, Williams, Liu & Chien,2010; Sjödahl et al., 2004; Sjödahl, Gard & Jarnlo,2008); grounded theory (Ferguson, Richie & Gomez, 2004; Jefferies, Gallagher & Philbin,2017); Krantz, Bolin & Persson, 2008); Livingstone, van de Mortel & Taylor, 2011; Madsen, Hommel, Baath & Berthelsen, 2016; Oaksford Frude & Cuddihy,2005); thematic analysis (Batty, et al., 2014; Bragaru, Wilgen, Geertzen, Ruijs, Dijkstra & Dekke , 2013; Christensen et l., 2017; Gallagher & Maclachlan, 2001; Heavey, 2013; Ostler, Ellis-Hill & Donovan-Hall, 2014,Sousa et al., 2009); interpretative phenomenological analysis (Mathias & Harcourt, 2014; Murray, 2005; Murray, 2009; Norlyk, Martinsen & Kjaer-Petersen, 2013; Saradjian, Thompson & Datta, 2008; Stutts, Bills, Erwin & Good ,2015;Washington & Williams, 2016); and content analysis (Järnhammer, Andersson, Wagle & Magnusson, 2017; Torbjörnsson, Ottosson, Blomgren, Boström & Fagerdahl, 2017). From the author’s perspective, the studies seem to be broadly characterised as critical-realist in epistemological position, that objectivity exists, but retrieving or agreeing on this may vary as the phenomenon of interest is observed through the subjective lens of the individual (Edgley, Stickley, Timmons & Meal, 2016).

[Insert Table 2]

Quality. The Critical Appraisal Skills Programme (2013) qualitative checklist was used in order to evaluate the studies for their quality. The first two items of the checklist are screening questions related to how suitable qualitative methodology was for the research aims. The remaining eight questions relate to the design of the research, method for data collection and analysis, the ethics, reflexivity, and the wider implications of the research.

A summary of the table of scores for each study, as applied to the eight quality appraisal questions, can be found in appendix 1-A, Table 3. The scores were assigned using Duggleby et al.'s (2010) scoring system. A high score (3) was given to the studies that explained and justified their choices of method for analysis, and provided clear identification of the steps taken. A medium score (2) was offered when studies explained the steps taken, but lacked detail. For instance, Grech and Debono (2014) discussed having ethical approval but with no further mention of ethical considerations. Finally, a weak score (1) was provided when studies offered minimal explanation or justification, such as using interviews for data collection but not providing a rationale.

The studies scored between 10 to 24 indicating a significant variation in quality. The scores were not used to determine inclusion or exclusion criteria for this review, as exclusion on the basis of 'quality' may largely be due to subjective assessment variations (Rubin & Babbie, 2010). Despite the variation in reporting quality, none of the themes presented in the results are reliant on weaker scoring papers.

[Insert Table 3]

Synthesising the data. The first step of the synthesis involved reading the studies repeatedly in order to become familiar with the data and take note of any significant features (Noblit & Hare 1988). Following this, ensuring that interpretations were grounded within the data, the second order constructs present in each paper which had relevance to the research question were identified and extracted (the key themes, concepts and ideas generated by the authors) into a table together with the related participant quotes from the studies (first order constructs). The iterative nature of this process allowed for similarities and differences between the studies to be noted. Each interpretation was then compared and contrasted across the studies and were grouped according to concepts in order to produce third order interpretations. For instance, the theme 'The need for social connection versus independence' emerged from participants frequently reporting a desire to feel 'normal and 'worthy'. For some people this involved heavy reliance on their close friends and family, for others this meant becoming independent and self-sufficient.

The following themes were generated to offer a narrative to reflect the ways in which individuals with a limb loss cope with appearance related stigma experiences. Concepts relating to themes can be seen in appendix 1-A Figure 2, and the contribution each paper made to each theme is presented in Table 4

[Insert Figure 2]

[Insert Table 4]

Results

Theme One: The need for social connection versus independence

This theme is concerned with reintegration into society and how individuals coped and responded to support from others (Batty et al., 2014; Bragaru et al, 2013; Cater, 2012; Ferguson et al., 2004; Grech & Debono, 2014; Hamil et al., 2010; Järnhammer et al., 2017; Krantz et al., 2008; Murray, 2005, 2009; Saradijian et al., 2008; Sousa et al, 2009; Stutts et al., 2015; Washington & Williams, 2016). Negotiating this reintegration was often positively achieved through the support of immediate family and close friends, "I have a very supportive husband, two grown daughters who are very helpful and kind, an extended family who does what they can to make me feel 'normal" (Stutts et al., 2015, p. 746). Gaining acceptance from others seemed a key priority, with some individuals relying on their friends to soothe them from their own emotional discomfort, "… people stare at you … That's because I have lost my leg. I don't feel like a proper person … Maybe it will be different when friends do start coming round but at the moment I feel such a burden" (Washington & Williams, 2016, p. 48).

Thus, the ways in which participants felt others perceived them was clearly important, emphasising that a social support system was a positive coping strategy for some who were experiencing self-stigma. A lack of social support increased feelings of disconnectedness as individuals accustomed themselves to a new identity; "The isolation of not knowing…any youngish females that are in my position. It was very lonely and a shock to my identity" (Stutts et al., 2015, p. 746). Interestingly, this feeling of separateness was still present for some despite their experiences being in a social group as described by one individual; "it can be hard to constantly be half inside, half outside the group, to get looks and comments and possible negative attitudes and prejudices aimed at you'' (Krantz et al., 2008, p.221). Thus the responses of others functioned as a 'mirror' for individuals, reflecting and reinforcing how they were being perceived in their environment (Sousa et al., 2009, p. 246; Järnhammer et al., 2017, p.5).

The lack of social engagement and validation increased a tendency for self-defeating, negative thought processes which were a common hindrance to some individuals as they reflected:

I was just thinking about what I was experiencing…how my family wouldn't even look at me any more even if, let's say, I survived, because as far as anyone else was concerned, I would have become a loathsome person without a leg (Ferguson et al., 2004, p. 935).

Other participants spoke of their relationships failing because of others' inability to cope:

I just recently finally came to the realization that some people have much more difficulty dealing with this than I do. I have a dear friend who has withdrawn from me. Too busy to talk with me, will not return my calls, etc. I hope that someday she will come back to me. But she finally told me this week that she just cannot handle this… (Murray, 2005, p. 432).

This change in experience and/or perception of desirability also affected individuals' romantic relationships (Murray, 2009; Batty et al., p.694) which one participant stating; "Some mothers didn't want their daughters to date me. One of them even paid for her daughter to move to Australia" (Grech & Debono, 2014, p.56). This perpetuated feelings of defectiveness and hopelessness; "…Last, for now, my boyfriend dumped me like a broken Barbie Doll, what are my chances of finding a guy that will accept my new body?" (Murray, 2005, p.437), and some individuals predicted they were less desirable to others (Cater, 2012, p. 1450)

Not all people relied so heavily on social support in order to feel accepted or integrated (Bragaru,et al., 2013; Hamil et al., 2010; Saradjian, et al., 2008; Sousa et al., 2009). Some individuals reflected that those around them would overcompensate by doing everything for them as though they were incapable. Thus, in response to other people's attempts to rescue, remedy or fix, one individual felt less of a person and consequently low in self-worth, describing; "I don't like classing myself, putting the label on me as 'disabled', but people fussing around me, trying to do things for me, trying to encourage me to do things made me feel more as if I was disabled" (Hamil et al., 2010, p 734).

Some individuals even rebelled against this by reasserting their independence as much as possible:

Sometimes it's a bit annoying cause they're always wanting to do things for me…Like buttering bread or toast in the mornings. You know, I can do it now myself… I wanted to do it but they wouldn't let me...At one stage, when they were finished I went up and I made my own so that sort of killed that then. So I do everything now myself" (Hamil et al., 2010, p. 735). Thus social support can unintentionally reinforce stigma experiences and some coped better demonstrating their self-worth through their independence (Saradjian et al., 2008, p. 877).

Theme two Identity formation: renegotiating self

This theme pertains to body image alteration following amputation which had implications for individuals' social experiences, and identity. Identity conceptualisation following amputation had a stigmatizing effect (Bragaru et al., 2013; Ferguson et al., 2004; Ligthelm & Wright, 2014; Livingstone et al., 2014; Liu et al., 2010; Mathias & Harcourt, 2014; Norlyk, et al., 2013; Saradjian, et al., 2008; Sousa et al., 2009), "Well now I am handicapped. Now I am done" (Madsen et al., 2016, p.5) or an empowering effect (Batty et al., 2014; Cater, 2012; Christensen et al., 2017; Ferguson et al., 2014; Gallagher & Maclachlan, 2001; Murray, 2005; Murray, 2009; Sjodahl et al., 2004; Sjodahl et al., 2008) as discussed by one individual, "…I probably do it on purpose, but I want people to see how I am.I don't have problems in showing my body. When I go to the gym I don't wear pants but shorts and everybody can see my leg is artificial. I feel good in shorts" (Sousa et al., 2009, p.247).

In terms of how identity was constructed, some individuals gave themselves their new identity and felt very in control of this, with one participant describing a time she claimed the right to use the disabled toilet, thus implying her ownership of the disability status:

She made some catty comment about, ‘Some of us have to use the disabled loo.’ So I said ‘Yes, we do, don’t we?’ (laughs) […] I think because you’re not coming out in a wheelchair, or coming out on two sticks, they wonder why you’ve gone into the disabled loo! (Heavey, 2013, p. 136).

Others spoke of having their identity label (i.e. as a person with a disability and a cognitive deficit) given to them with one individual describing having very little control over this, “Well, it is this phenomenon, when you sit in a wheelchair, everyone who talks to you talk loudly and articulate, to get me to understand. But it is not my head I have amputated” (Torbjörnsson et al., 2017 p. 60). Such narratives infer there was incongruence at times between the individuals’ self-concept and the identity that others perceived them to have (Stutts et al., 2015).

One individual did not assign themselves to any particular identity stating; “I suppose that I live this sort of twilight existence, you know. I was disabled to able-bodied people but to disabled people, I wasn’t because I wasn’t in a wheelchair” (Saradjian et al., 2008, p.874). Here, the individual had awareness that they were different to the seemingly informed socially defined categories regarding what is or is not a disability.

Resistance to or accepting the disabled identity. In the process of individuals making sense of their identity, social processes seemed to have a role in shaping the individuals’ identity construction which consequently influenced resistance or acceptance towards a disabled identity. Such individuals wanted a clear distinction between who they were as individuals and the disability they were perceived as having (Krantz et al., 2008, p.

219; Sousa, 2009, p.250), with some individuals stating; “We’re just a group of people who happen to have lost our legs, not ‘a group of disabled’” (Heavey, 2013, p. 132).

Some individuals, however, embraced a prosthetic identity (Sousa et al., 2009 p 249) and spoke of the gains disability had afforded them with reference to acceptance from others “. . . they [females] felt more comfortable approaching me themselves, because they felt sorry for me…they would come to me . . . I would then choose the best one!” (Grech & Debono, 2014, p. 56). Thus, exposure of a missing limb sometimes seemed beneficial in enhancing relationships and drawing positive attention from members of the opposite sex (Batty et al., 2014). Similarly, individuals from a military background saw their disability as a mark of pride and honour (Cater, 2012, p. 1450), as it offered some societal recognition for heroic sacrifice; “Being a wounded veteran gives some advantages due to the public appeal” (Christensen et al., 2017, p, 4).

However, not all individuals who accepted their disability experienced societal acceptance (Ferguson et al., 2004, p. 934). ‘Prosthetic limb display’ was a tactic embedded with personal significance and meaning to self and social identity for one individual describing, “[the prosthesis is] a tool which I USE, not wear… As my small effort to forward the cause of disability awareness I am always dressed in shorts, everywhere” (Murray, 2009, p. 578). This was a strategy for self-empowerment as one person reflected: “if we can demonstrate that we are capable of negotiating our way around in public and have the right to do so, there seems to be more acceptance of any disability” (Murray, 2005, p. 432).

For some, peer support from others with a disabled identity was comforting as it fostered integration, support and understanding (Gallagher & Maclachlan, 2011; Järnhammer et al., (2017). However, there were also some ‘within disability’ differences. For instance individuals from a military background described segregating themselves from those who did not have a military background:

I found it difficult to relate to …[non-veteran amputees] … It felt like we were from two different worlds with different ambitions for rehabilitation and for our subsequent lives (Christensen et al., 2017, p. 4). On a similar note, one participant stated she was "not nearly as disabled as some people' and not 'particularly [disabled]'" (Heavey, 2013, p. 123), implying that there was a hierarchical spectrum of disabilities, reflecting the complex and multifaceted nature of identity**.**

Theme three: Concealing or avoiding

In this theme, identity formation and reconstruction following limb loss was mediated by coping through concealing or avoiding. A number of different concealment strategies were employed which included, managing appearance through selective choice of clothing (Murray, 2009), being strategic about personal disclosures regarding limb loss (Saradjian et al., 2008), using a prosthesis (Jefferies et al., 2017; Mathias & Harcourt, 2014; Sousa et al., 2009) and psychological concealment such as suppressing inner emotional distress from others (Sjodahl et al., 2004).

Regardless of concealment type, the aim was to avoid discrimination or judgement and appear "normal" in the eyes of others: "Of course people look at us in a different way… people look at us with pity, as disabled, because there is a big prejudice regarding disability… I'd wear a raincoat and gloves so no one would notice my problem." (Sousa et al., 2009, p.251). Also in response to managing uncomfortable social situations, some individuals adopted a systematic approach to concealment where disclosure was restricted only to safe and predictable environments:

The pub where I go to, the local pub, they're all friends, they all know me. We can laugh and joke about it. It's great...But the friend who I was with . . . expected me then to go from that pub into our local club with no leg on. I wouldn't go. I wouldn't let anyone in the club see me with no leg on. It's a different type of people… (Murray, 2005, p. 433).

Using a prosthesis to moderate reactions. This strategic decision making enabled individuals to reduce uncomfortable public encounters and any negative attributions associated with this. Participants spoke of either experiencing (Cater, 2012; Ferguson et al., 2004; Hamil et al., 2010; Sjodahl et al., 2008; Sousa et al., 2009) or perceiving (Batty et al., 2014; Gallagher & Maclachlan, 2001;Grech & Debono, 2014; Hamil et al., 2010; Jeffries et al., 2017; Liu et al., 2010; Mathias & Harcourt, 2014; Murray, 2005; Murray, 2009; Ostler, Ellis-Hill & Maggie Donovan-Hall, 2014; Saradjian et al., 2008; Sjodahl et al., 2004) negative evaluations from others. Prosthesis use was a concealment strategy employed by individuals to manage social interactions and reduce the distress others felt towards a visible difference:

My brother, my brother cannot stand to see me without a limb on...I know deep down it's because he can't accept it...it's his problem…when I know my brother's coming round, I tend to make sure I've got my limb on. So really, I'm catering for others rather than myself (Murray 2005, p 433).

Similarly, individuals referred to prosthesis use as helping them to appear 'normal' or complete (Jeffries et al., 2017) and foster relationships (Mathias & Harcourt., 2014; Murray, 2005). Some individuals reflected on this pragmatically, and did this for the purpose of conforming to social norms (Murray, 2009). However, for others, concealment often came at the expense of a heightened sensitivity to the response of others (Saradjian, et al., 2008), being 'careful' (Murray, 2009), vigilance and awkwardness (Jefferies et al., 2017), and feelings of self-deception (Sjodahl et al., 2004).

Another way of managing sensitivity around appearance was through enhancement and compensatory strategies. Here, the motive was not to deter attention but to gain a sense of personal control over the public reactions they evoked:

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'. Even when I tried to look pretty . . . people would be drawn to asking me about it or they'd stare (Mathias & Harcourt, 2014, p. 398).

Enhancing other features was often an attempt at upholding a socially acceptable self-image (Sousa et al., 2009 p, 249), although others protested against this by accentuating the prosthesis, "I have made myself a very inexpensive water peg [. . .] it is canary yellow and fluorescent orange. Why? ... People are going to look and stare anyway so I figured they ought to have something interesting to stare at!" (Murray, 2009, p. 578). For some individuals concealing was purposeful in regulating their own inner feelings of shame and body image disgust, "…When it (artificial leg) was attached, I felt like a complete person; when it was removed, I felt monstrous and deformed" (Jefferies et al., 2017, p. 6).

Avoidance of public reactions. Rather than concealing, for some individuals the impact of people staring (Ligthelm et al., 2014), patronising and displaying shock (Gallagher & Maclachlan., 2001) and voicing negative comments (Cater et al., 2012) resulted in them being fearful of judgement and avoiding going out in public:

I got a comment made to me …that, 'I was a real spastic bastard now'... I let that get to me, and at one stage I completely thought about not coming back…[to the rehabilitation centre] …'What's the use… if people are going to treat you like that?" (Hamil et al., 2010, p 737).

Individuals avoided social encounters due to internal feelings of shame and consciousness and this also impacted social activities, "My friend has got a hot tub and she says oh you'll have to come in the hot tub and I'm not going to be able to do anything really like that" (Ostler et al., 2014, p. 1173). Even without negative comments by others, the perception of what others may think when limb loss was exposed influenced avoidance behaviour, suggesting individuals make choices in order to manage other people's responses towards them.

Avoidant coping for some individuals was not just restricted to social encounters, but was also a very private affair:

My biggest problem was …look in the mirror and see myself; to see a different person. I used to think how ugly I was…no one would look at me as an attractive person. I felt disturbed… very sad, as something was stolen from me" (Sousa et al., 2009, p244).

This also highlights that emotional avoidance is also significant whereby individuals struggled to accept their new reality. Avoidant coping interfered with activities of daily living (Cater, 2012), friendships (Liu et al., 2010), romantic relationships (Grech & Debono, 2014) and involved feelings of anxiety, anger, frustration, depression and helplessness (Ferguson et al., 2004,Sjodahl et al., 2004).When this was unbearable, the individuals chose to isolate themselves rather than face the consequences of social rejection. Therefore home was described by one person as a place of safety; "...well, I just wanted to be at home . . . inside my four walls. . . where I felt safe, you know. . ." (Sjodahl et al., 2008, p. 1201) although some struggled to find safety and relax without the prosthesis on in case unexpected guests visited (Gallagher & Maclachlan, 2001).

Theme Four: Internal resilience and new ways of thinking and relating

For individuals not engaging in avoidant coping, this theme related to the additional cognitive investments required to manage when out in public. One individual described; "I always have to go into situations where I don't know people. . . . I have one arm and being mentally prepared for that is an ongoing challenge" (Cater, 2012, p. 1450). Having an active coping style encouraged internal resilience and individuals did this through humour (Batty et al., 2014; Cater, 2012; Murray, 2005; Oaskford, 2005;Saradjian et al., 2008;), having a positive attitude (Cater, 2012; Gallagher & Maclachlan, 2001; Sjodahl et al., 2004) and acceptance of their situation (Jeffries et al., 2017; Ligthelm et al., 2014; Murray, 2009; Norlyk et al., 2013; Saradjian, et al.,, 2008; Sousa et al., 2009).

Some individuals spoke of humour as being useful in maintaining connections and it was used as a social bonding exercise amongst individuals and their friends (Oaksford et al., 2005). For example,

Now they're [friends] careful when they turn round and say, 'oh Terry, just give us a hand', because now I just unclip my hand and give it them. It's like, oh yeah, funny bugger, just because you can do it (Saradjian et al., 2008, p. 876).

In such instances, acknowledging and integrating 'difference' into daily life through humour seemed to be a proactive way of reframing potential stigma related experiences, in attempt to be socially inclusive rather than exclusive. Similarly, humour offered some individuals' a strategy to better navigate uncertain situations. For example, individuals used it help strangers relax within their presence (Cater, 2012), and was a way of inviting non-threatening responses, "I do like the attention it gets me . . . being a bit of a clown with it [stump]. I find that the fellas enjoy it and so in a way [they] are enjoying me (Batty et al., 2014, p. 700).

Thus humour could be a form of acceptance, and acceptance seemed an influencing factor in how individuals mediated their social experiences. Some individuals not using humour, adapted to public curiosity and questions without taking it personally, accepting that; "it's human nature . . . they wouldn't be normal if they didn't ask" (Saradijan et al., p. 876). For others, this introspection evoked feelings of discomfort, serving as a continuous reminder of difference as reflected in the following narrative; "The most difficult thing to accept is the way people look at me and the kind of approach they make. . .The worst is to face the other's questions and the other's stares" (Sousa et al., 2009, p. 246). One individual considered impartial outlook, suggesting; ''… most people do not care at all, and if they care, it does not have to be in a negative way" (Krantz, Bolin & Persson, 2008, p. 219). Thus inferring that they were receptive to more than one perspective. Perspective seemed important, as one individual reflected, "staying optimistic and having a good attitude are the most important things. . ." (Cater, 2012, p. 1451), enabling some to "adapt to everyday life, going out in public and dealing with the reactions of people on the street" (Cater, 2012, p. 1451).

Some individuals spoke of a psychological benefit, such as increased confidence and self-esteem, stating; "… I think it has given me a confidence I think I wouldn't have had… I feel that I can certainly go out and hold my head up to the world and I don't feel . . . inadequate in any way" (Gallagher & Maclachlan, 2001, p. 91). Others spoke of feeling empowered which transcended into a sense of righteousness and equality stating; "…I'm entitled to everything that anybody else is entitled to. It's not acceptable that you don't have a ramp for this restaurant. You will put in a ramp for me because I am entitled to it" (Cater, 2012, p. 1449). This positive sense of self enabled some individuals to reject or deflect the demeaning attitudes others had towards them suggesting; "If people want to have a dig, I'm not bothered . . .I think that they're narrow-minded" (Saradjian et al., 2008, p. 876), thus attributing any negative attitudes as a fault located within others.

Discussion

The present review synthesised qualitative findings on how individuals cope with appearance related stigma following limb loss. The review identified themes which encompass four broad approaches to coping with stigma; 'The need for social connection versus independence', 'Identity formation: renegotiating self, 'Concealing or avoiding', and 'Internal resilience and new ways of thinking and relating'.

Seeking out social connection versus being independent from family and close friends (theme one) was useful for individuals who wished to continue to feel normal and worthy following amputation. At present, research on limb amputation and social connection regarding appearance related stigma coping has been underreported. However, other research on stigmatised identities shows if close friends and family are accepting and supportive of the individual, this fosters and facilitates self-identity acceptance (Weinstein, Ryan, Legate, Sedikides, 2017) and social interactions (Chaudoir, Earnshaw & Andel, 2013). Social connection, in the form of support from close friends and family offered individuals access to psychological resources (such as emotional soothing and containment) as demonstrated in other research (Cohen & Wills, 1985; Hatzenbuehler, 2009). However, some individuals found this threatening to their self-concept and identity, reinforcing the idea that they were disabled or incapable. Thus, self-concept (an individual's internal understanding of who they perceive themselves to be), and identity (the 'self' that can be shared with, and defined by others, Baumeister, 1999) were both recognised as important in the process of developing a sense of self. Overall, despite wanting social support or independence, all individuals were trying to control social connection in order to manage internal cognitive and/or emotional responses.

Another way individuals coped with stigma experiences was to affiliate themselves with individuals who shared similar experiences. Part of identity formation (theme two) involved individuals preferring to integrate with those they perceived had a similar identity. This is congruent with social identity theory, suggesting that individuals perceive there are two groups in their social world, one in which they belong to and one in which they don't. When individuals feel they belong in a group, this promotes a positive self-concept and self-esteem (Tajfel & Turner, 1979). In accordance with self-categorization theory (Turner, Oakes, Haslam, & McGarty, 1994), sharing a social identity offers unity and enables stigma resistance (Hejnders & Van Der Meij, 2006).

Not all individuals resisted stigma overtly or accepted having a stigmatised identity, as such, strategies such as concealment or avoidance (theme three) were employed by such individuals to manage stigma experiences. For many, this form of coping was initially helpful but often resulted in negative psychological consequences. Such consequences in previous studies relate to individuals feeling guilt and shame (Pachankis, 2007). However, in this review, participants also spoke of the benefits to concealment, as it enabled individuals to limit discrimination and maintain relationships. Studies show that being strategic in when, how and whether to disclose can offer an individual a psychological degree of personal control (Kelly & McKillop, 1996). A valuable finding in this review is that some concealed pragmatically as a practical strategy for social bonding, contradicting the commonly held view that avoidance/withdrawal and concealment behaviours are always linked to shame (Romero-Trillo, 2014).

Additionally, previous research has focused on negative consequences accompanying stigma (Crocker & Quinn 2000) reflecting those with visible difference as subject to devaluation, rejection and despair, with little acknowledgement of individuals living proactively, despite being perceived to have a devalued social identity (Shih, 2004). Cognitive strategies such as developing internal resilience and new ways of thinking and relating (theme four) were employed by individuals to manage social situations and wellbeing. Using humour as a strategy to cope with stigma was utilised by some individuals to maintain a positive sense of self. Other studies have similarly acknowledged humour as a proactive strategy to avoid unwanted remarks and detract the interaction away from the visible difference (Egan, Harcourt & Rumsey, 2011). Finding positive meaning following limb loss has been shown in previous research to help individuals enable optimism and control (Dunn 1996). One study found being visibly different encouraged self-acceptance and appreciation of their other characteristics that they could contribute in a relationship

(Griffiths, Williamson & Rumsey, 2012). Thus, in line with the empowerment model, individuals who are stigmatized are active in their social world, and can foster positive outcomes (Oyserman & Swim 2001).

Clinical implications and service provision

Within the review studies, two individuals reflected on the general absence of psychological input (Sjodahl et al., 2008, p. 1197; Stutts et al., p.747), only one person received support from a psychologist (Sousa et al., p.245), and another concealed internal distress to mask feelings of insecurity associated with limb loss (Sjodahl, 2004, p. 857). In light of the above, there is a need for further psychological support, and although there is a recognised role for clinical psychologists within amputation rehabilitation services (e.g., to offer input to those with an identified psychological need; British Society of Rehabilitation Medicine, 2003), the guidelines are vague and psychological difficulties need more adequate recognition and management in rehabilitation contexts (NICE, 2009). A key role for clinical psychologists involves leadership and being involved in service provision (BPS, 2011), which may involve developing pathways within rehabilitation services. This could enable individuals and family members to gain better access psychological support during the pre and postoperative stage, and further attention could be given to psychological factors within multi-disciplinary discussions. Given the reliance on social connection, family and friends may unintentionally endorse or undermine individuals' identity processes, thus systemic support could be offered for them to facilitate autonomy support in the individual, as through the social learning experience, this encourages authenticity and identity acceptance (Weinstein, et al., 2017). The cognitive behavioural theory (CBT) model of body-esteem and disfigurement (Cash & Grant, 1996), is used in reducing self- stigma and the psychological distress associated with visible difference (for a review, see Norman & Moss, 2015). Acceptance based approaches may be considered when it is not appropriate to challenge unhelpful thoughts (Roemer & Orsillo, 2010), or a compassion focussed approach to manage self-criticism and shame (Gilbert, 2010). Further research is needed to evaluate the effectiveness of such approaches for visible difference (Harcourt et al., 2018) however, as some participants spoke of support seeking as reinforcing stigmatised notions of dependency, this could manifest as a psychological barrier to seeking and accessing psychological support.

Limitations of review. Despite the broad range of studies included in the review, there was a variation in quality. Although it is not a requirement for studies to be excluded based on quality (Walsh & Downe, 2005), the implications should be acknowledged, alongside the screening and quality appraisal process being completed solely by the author. To limit subjectivity, it is recommended for more than one author to be involved in this process. In spite of this, the review included studies involving general adjustment to limb amputation, which enabled a thorough exploration of coping strategies that original authors may not have identified as stigma related.

Conclusion

The review suggests there is a link between stigma related experiences and feeling unworthy, which is a consequence of having a devalued social identity. This process involved reflectively appraising ‘difference’ and using self-expression in order to establish control following stigma experiences. Further research could explore how the self-appraisal process informs stigma related coping following limb loss.

The present review is the first to synthesise qualitative findings regarding how individuals cope with appearance related stigma following limb amputation through a process of meta-ethnography (Noblitt & Hare, 1988). Four themes capture the way individuals navigate the stigma experience, make sense of difference and establish control. The review offers recommendations for the provision of psychological input on a, systemic, individual and service level.

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Appendix 1-A

Contents

Table 1

Search terms applied to each database (combined using Boolean operator "OR" within terms and "AND" across terms)

	Free Text Search Terms	PsycINFO Thesaurus	CINAHL headings	Medline MeSH	Amed Indexes (subjects)
Amputation	Amputation or amputee* or limb loss or prosthetic* or prosthesis or prostheses or limb difference* or limb absence or congenital limb absence or limb difference	(DE "Amputation")	(MH "Amputation") OR (MH "Amputation Stumps") OR (MH "Below-Knee Amputation") OR (MH "Above-Knee Amputation") OR (MH "Amputation, Traumatic")	(MH "Phantom Limb") OR (MH "Artificial Limbs") OR (MH "Limb Deformities, Congenital") OR (MH "Amputation") OR (MH "Amputation Stumps") OR (MH "Amputation, Traumatic")	(ZU "amputation") or (ZU "amputation stumps") or (ZU "amputation traumatic") or (ZU "amputees") or (ZU "limb deformities congenital")
Coping	Coping or cope or adjust* or adapt* or deal or coping styles or coping strat* or coping behaviour*or coping skill* or coping mechanism*	(PsychINFO) DE "Coping Behavior" OR DE "Adjustment" OR DE "Adaptation" AND DE "Stigma"	(MH "Stigma") OR (MH "Adaptation, Psychological") OR (MH "Social Adjustment")	(MH "Social Stigma") OR (MH "Adaptation, Psychological")	(ZU "stigma") or (ZU "adaptation physiological")
Qualitative	interview* or grounded theory or qualitative or phenomenolog* or narrative or thematic analysis or semi-structured or focus group* or life experience* or life change* or experience* or perception* or IPA or phenomenol* or content analysis" or ethnog*	DE "Qualitative Research"	(MH "Qualitative Studies") OR (MH "Phenomenology")	(MH "Qualitative Research")	(ZU "qualitative research")

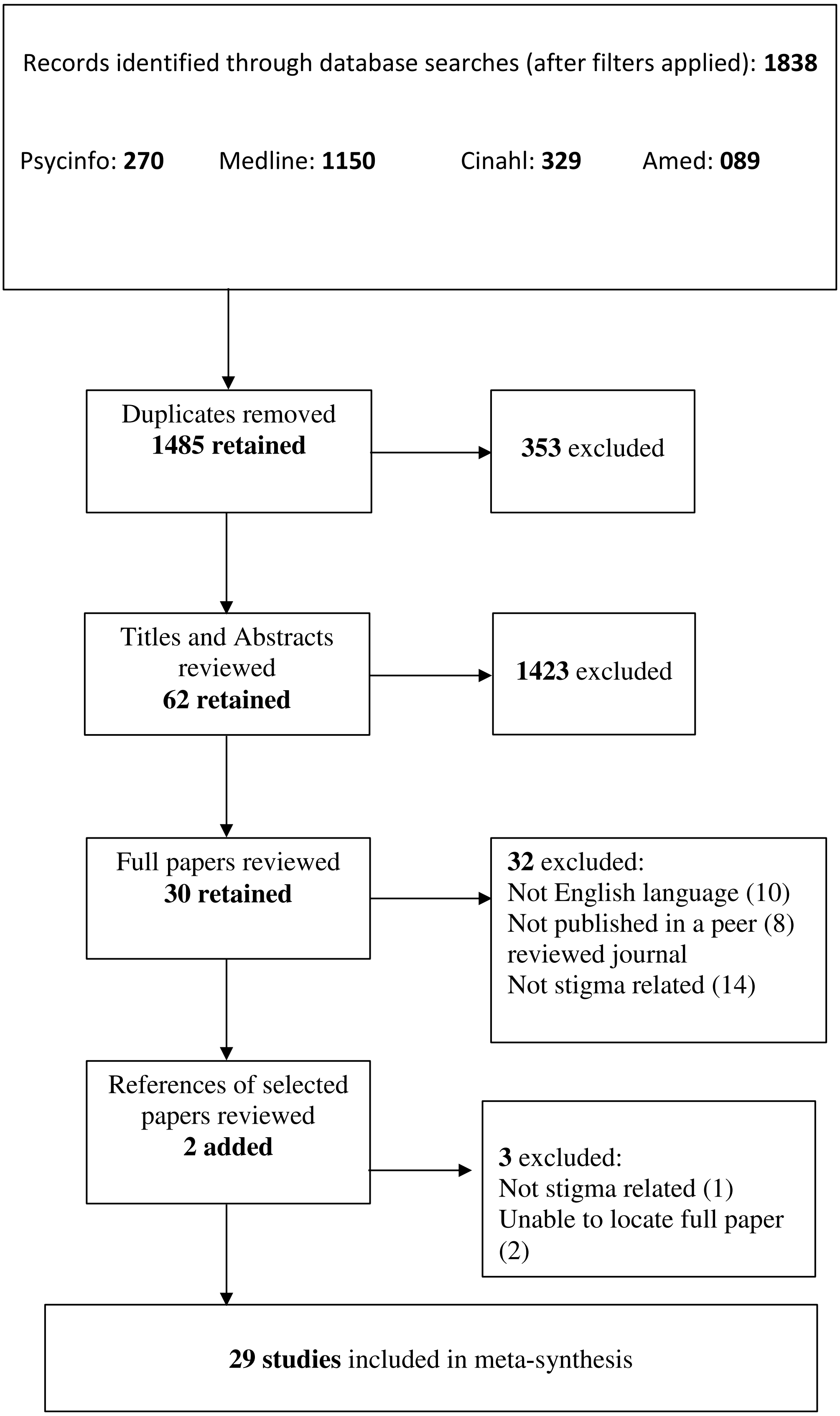

Figure 1. Diagrammatic representation of search procedure

Table 2

Methodological summary of included papers

Author(s)	Year	Country	Aims/Research Question	Participants	Data Collection	Methodology
Batty, MacGrath & Reavey	2014	England	To explore participants' experiences in order to examine how participants attempted to construct the self in the context of embodied disability (both congenital and acquired limb absence)	7 participants (5 males, 2 females) aged 23-51	Visual group workshop, followed up with individual interviews	Thematic analysis
Bragaru, Wilgen, Geertzen, Ruijs, Dijkstra & Dekke	2013	The Netherlands	To identify the barriers and facilitators that influence participation in sports for individuals with lower limb amputation	26 participants (gender or age not specified)	Semi structured interviews	Thematic analysis
Cater	2012	United States	To increase understanding of the psychosocial adjustment issues American servicewomen experience after a traumatic amputation. To learn how military women adapted to traumatic limb loss	6 females (aged 20-36)	In-depth interviews	Phenomenology

Christensen, Langberg, Doherty & Egerod	2017	Denmark	To increase understanding of the military identity influence on the organization of rehabilitation and investigate factors of importance for successful rehabilitation services	6 males (aged 25–46)	Semi-structured one-on-one interviews and participant observations	Thematic analysis
Ferguson, Richie & Gomez	2004	United States	This study examines the psychosocial factors, coping strategies, and resilience characteristics of survivors of limb loss across differing cultural, societal and economic backgrounds. One of the primary guiding questions throughout the study centered on: What psychological and psychosocial factors were utilized by survivors to facilitate recovery from a landmine injury that lead to psychological health	68 participants (49 male, 19 female) age range not specified.	Unstructured interviews	Grounded Theory
Gallagher & Maclachlan	2001	Ireland	To describe adjustment to a lower limb prosthesis from the perspective of the prosthesis-wearer	14 participants (6 males and 8 females) aged 20-50.	Focus Groups	Thematic analysis
Grech & Debono	2014	Malta	This study aims to contribute to this literature by exploring the lived experience of Maltese	4 participants (2 male and 2 female), aged 30-80 years.	Semi-structured Interviews	Interpretative phenomenological analysis

			individuals with a lower or upper limb amputation			
Hamill, Carson & Dorahy	2009	Belfast	To explore participants' experiences of psychosocial adjustment within 18-months following amputation in a manner that can inform further research and clinical practice	8 participants (3 females and 5 males), age rage not specified.	Semi structured interviews	Interpretative phenomenological analysis
Heavey	2013	England	To explore how individuals with and amputation engage with the notion of disability in relation to their own lives and bodies. Do they consider themselves disabled, and if so, what is it that 'makes' them disabled? How do these individuals define disability?	9 participants (4 male and 5 were female (approx. age 40-70 years)	Ethnographic interviews	Thematic narrative analysis
Järnhammer, Andersson, Raj Wagle & Magnusson	2017	Nepal	To explore experiences of persons in Nepal using lower-limb prostheses, in relation to specific articles in the Convention on the Rights of Persons with Disabilities that consider mobility, education, health, rehabilitation, and work and employment	16 participants (6 female and10 male) aged 21- 67 years.	Semi structured interviews	Content analysis

Jefferies, Gallagher & Philbin	2017	Ireland	To develop an integrative understanding of prosthesis use in order to inform both practice and further scholarly enquiry.	19 male and 5 female, aged 18–62 years	Unstructured interviews	Grounded theory
Krantz, Bolin & Persson	2008	Sweden	To develop a grounded theory regarding stigma-handling strategies used in everyday life by women with transversal upper limb reduction deficiency	4 participants (aged 20-30)	Interview (type not specified)	Grounded Theory
Ligthelm & Wright	2014	South Africa	To provide an evidence base for supportive interventions through exploring the lived experience of persons in Tshwane with an upper limb amputation from a physical and psychosocial perspective.	8 participants (gender and age not specified)	Interviews (type not specified)	A Phenomenological approach
Liu, Williams, Liu & Chien	2010	Taiwan	To describe and understand the lived experience of Taiwanese people with lower extremety amputations from the pre-amputation phase to six months after surgery	22 participants ("mostly male") aged 56-84 years	Semi- structured interviews	Phenomenological analysis
Livingstone, van de Mortel & Taylor	2011	Australia	The research aimed to invite individuals who had undergone a diabetes-related amputation to	5 participants (1 female, 4 male) aged 41-77 years	Interviews (type not specified)	Grounded theory

			describe their experiences of amputation, with a specific research question What is the person with diabetes experiencing in day-to-day life, post-amputation?’			
Madsen, Hommel, Baath &Berthelsen	2016	Denmark	To construct a grounded theory (GT) explaining patients’ behaviour shortly after having a leg amputated because of vascular disease	.11 particiants (8 males, 3 females) aged 45-84	In depth interviews	Grounded theory
Mathias & Harcourt	2014	England	To gain an in-depth understanding of the experiences and emotional responses of women with below-knee amputations to dating and intimate relationship	4 females (aged 18-29)	Semi-structured Interviews	Interpretive phenomenological analysis
Murray	2005	England	To explore the meaning of artificial limbs for amputees and people with congenital limb absence who choose to use prosthetics	35 participants (16 males, 19 females) aged 16-75	Semi structured interviews (face to face & online)	Interpretative Phenomenological Analysis

Murray	2009	England	The present research seeks the personal meanings of prosthesis use, employing prosthesis users themselves as experts upon their own experiences.	35 participants (16 males, 19 females) aged 16-75	Semi structured interviews (face to face & online)	Interpretative Phenomenological Analysis
Norlyk, Martinsen & Kjaer-Petersen	2013	Denmark	To explore the lived experience of losing a leg as described by the patients themselves after discharge.	12 participants (8 males, 4 females) aged 33-87	In depth interviews	Interpretive Phenomenological analysis
Oaksford Frude & Cuddihy	2005	Wales	To explore how individuals cope with a lower limb amputation and to examine the influence of positive coping and stress-related psychological growth on adjustment	12 participants (2 females, 10 males (aged 51-83)	Semi- structured interview	Grounded theory
Ostler, Ellis-Hill & Donovan-Hall	2014	England	To explore the expectations of patients about to undergo prosthetic rehabilitation following a lower limb amputation	8 participants (6 males, 2 females) aged 22-77 years	Interviews (type not specified)	Thematic analysis
Saradjian, Thompson & Datta	2008	England	To understand the experience of living with an upper limb amputation and of using a prosthetic arm and hand	11 participants (all males) aged 31-64 years	Semi-structured interviews	Interpretative Phenomenological Analysis

Sjödahl, Gard & Jarnlo	2004	Sweden	The aim of this study was to describe and get a better understanding of how relatively young trans-femoral amputees, experienced their amputation and their coping strategies in the acute phase and over time.	11 participants (gender not specified) aged 16-60 years	Semi-structured interview	A phenomenological approach
Sjödahl, Gard & Jarnlo	2008	Sweden	To describe how transfemoral amputees experience their first meeting and subsequent interaction with hospital staff in the acute phase, in the long term and suggestions for future care-giving.	11 participants (gender not specified) aged 16-51 years	Semi-structured interview	A phenomenological approach
Sousa, Corredeira & Pereira	2009	Portugal	The study intended to comprehend how people with amputation(s) view their bodies and perceive how others view them	14 participants (10 males and 4 females) age ranged from 17 to 42 years old)	Semi-structured Interviews	Thematic analysis
Stutts, Bills, Erwin & Good	2015	USA	To examine coping strategies, perceptions of social support, experiences with discrimination, attendance in support groups, reported level of acceptance of limb loss, and perceived post traumatic growth in	30 participants (all female) aged 23-81 years	Semi-structured interviews	Interpretative phenomenological analysis

			women with amputations			
Torbjörnsson, Ottosson, Blomgren, Boström & Fagerdah	2017	Sweden	The aim of this study was to describe the patient's experience of an amputation due to peripheral arterial disease	13 participants (9 males and 4 females) average age 75 years.	Semi-structured interviews	Content analysis
Washington & Williams	2016	England	To explore the experiences of people with diabetes and/or peripheral vascular disease following an amputation and the impact on their psychological wellbeing	6 participants (4 males and 2 females) age not specified.	Semi-structured interviews	Interpretive phenomenological analysis

Table 3

Quality appraisal of included review papers

Paper	Research Design	Recruitment Strategy	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value	Total
Batty, MacGrath & Reavey (2014)	3	2	3	1	2	3	1	1	16
Bragaru, Wilgen, Geertzen, Ruijs, Dijkstra & Dekke (2013)	3	3	3	3	3	2	2	2	21
Cater (2012)	3	2	3	3	3	3	3	3	23
Christensen, Langberg, Doherty & Egerod (2017)	3	2	2	2	3	1	3	2	18
Ferguson, Richie & Gomez (2004)	3	1	1	1	1	1	1	1	10
Gallagher & Maclachlan. (2001)	3	2	3	2	1	2	2	2	16
Grech & Debono (2014)	2	2	2	1	2	2	2	2	15
Hamill, Carson & Dorahy (2010)	3	3	3	3	3	3	3	3	24

Heavey (2013)	3	2	2	1	1	2	1	1	13
Järnhammer, Andersson, Raj Wagle & Magnusson (2017)	2	2	2	1	3	3	3	3	18
Jefferies, Gallagher & Philbin (2017)	2	3	3	1	3	3	3	3	21
Krantz, Bolin & Persson (2008)	3	2	2	2	2	2	2	2	17
Ligthelm & Wright (2014)	2	2	2	2	1	1	3	3	16
Liu, Williams, Liu & Hui Chien (2010)	3	3	3	1	3	3	3	3	22
Livingstone, van de Mortel & Taylor (2011)	3	2	2	1	3	3	3	2	19
Madsen, Hommel, Baath &Berthelsen (2016)	3	3	3	2	2	3	3	2	21
Mathias & Harcourt (2014)	3	3	3	1	1	2	3	3	19

Murray (2005)	3	2	3	2	3	2	3	2	20
Murray (2009)	3	3	3	2	3	3	3	3	23
Norlyk, Martinsen & Kjaer-Petersen (2013)	3	2	2	1	3	2	2	3	18
Oaksford Frude & Cuddihy (2005)	2	2	2	1	2	3	3	3	18
Ostler, Ellis-Hill & Donovan-Hal (2014)	3	1	2	3	2	3	3	2	19
Saradjian, Thompson & Datta (2008)	3	2	2	3	2	3	3	3	21
Sjödahl, Gard & Jarnlo (2004)	2	2	2	1	1	2	3	3	16
Sjödahl, Gard & Jarnlo (2008)	2	2	3	1	2	3	3	3	19
Sousa, Corredeira & Pereira (2009)	3	2	3	1	2	3	3	1	18

Stutts, Bills, Erwin & Good (2015)	2	2	2	1	3	2	3	3	19
Torbjörnsson, Ottosson, Blomgren, Boström & Fagerdah (2017)	1	3	1	3	3	3	3	2	19
Washington & Williams (2016)	3	2	2	2	1	2	3	2	17

Theme one: The need for social connection versus independence [1]

- To be treated as normal and worthy [2]
- Managing support
- Demonstrating capability
- Wanting autonomy
- Relating to others (connecting or disconnecting)

Theme two: Identity formation: renegotiating self [1]

- Relationship with the disability status [2]
- Self-versus public perception
- Different patterns of interaction with others
- Having a shared identity
- Stigma resistance

Theme three: concealing and/or avoiding [1]

- Attitude(s) to appearance change [2]
- Being (in)visible (sharing or hidden self)
- Safety behaviors/avoidance
- Managing emotional consequences

Theme four: Internal resilience: new ways of thinking and relating [1]

- Acceptance [2]
- A positive attitude
- A new found confidence
- A sense of entitlement
- Humour

Figure 2: *Representation of concepts corresponding to metasynthesis themes*

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[1] Refers to the third order interpretations (generated by the researcher)
[2] Refers to the initial concepts, themes and ideas (informed by authors)

Table 4

Studies corresponding to themes

Contribution of each study to the meta-synthesis themes

Study

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29
Theme 1	X	X	X		X		X	X		X		X						X	X				X			X	X		X
Theme 2	X	X	X	X	X	X	X	X	X	X		X	X	X		X	X	X	X	X			X	X	X	X	X	X	
Theme 3	X		X		X	X	X	X			X		X	X			X	X	X			X	X	X	X	X			
Theme 4	X		X			X					X	X	X		X		X	X		X	X		X	X		X			

Note. The numbers represent the corresponding studies: 1) Batty, MacGrath & Reavey (2014); 2) Bragaru, Wilgen, Geertzen, Ruijs, Dijkstra & Dekke (2013); 3) Cater (2012); 4) Christensen, Langberg, Doherty & Egerod (2017); 5) Ferguson, Richie & Gomez (2004); 6) Gallagher & Maclachlan (2001); 7) Grech & Debono (2014); 8) Hamil, Carson & Dorahy (2010); 9) Heavey (2013); 10) Järnhammer, Andersson, Raj Wagle & Magnusson (2017); 11) Jefferies, Gallagher & Philbin (2017); 12) Krantz, Bolin & Persson (2008); 13) Ligthelm & Wright (2014); 14) Liu, Williams, Liu & Chien (2010); 15) Livingstone, van de Mortel & Taylor (2011); 16) Madsen, Hommel, Baath &Berthelsen (2016); 17) Mathias &Harcourt (2014); 18) Murray (2005); 19) Murray (2009); 20) Norlyk, Martinsen & Kjaer-Petersen (2013); 21) Oaksford Frude & Cuddihy (2005); 22) Ostler, Ellis-Hill & Donovan-Hall (2014); 23) Saradjian, Thompson & Datta (2008); 24) Sjödahl, Gard & Jarnlo (2004); 25) Sjödahl, Gard & Jarnlo (2008); 26) Sousa, Corredeira & Pereira (2009); 27) Stutts, Bills, Erwin & Good (2015); 28) Torbj€ornsson, Ottosson, Blomgren, Bostr€om, & Fagerdah (2017);29) Washington &Williams (2016)

Appendix 1-B

As required for the thesis, the author guidelines from the target journal have been adhered to. Where these guidelines are brief or non-specific, the APA 6th edition formatting style has been used. The target journal is the same for both the literature review and the empirical paper, so the guidelines are only bound here.

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the JournalOverview.

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal

- the methods and/or sample size are appropriate for the questions being addressed

- research with student populations is appropriately justified

- the word count is within the stated limit for the Journal (i.e. 5000 words, or 6,000 words for qualitative papers)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help your prepare your paper.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use this template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

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13. Early View

SECTION TWO

EMPIRICAL PAPER

Does service user satisfaction with prosthetist communication style predict prosthesis related adjustment following a limb amputation?

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Please refer to Appendix 1-A for manuscript preparation guidelines.

Statement of contribution

What is already known on this subject?

- The loss of a limb can result in difficulties with physical, functional and psychological adjustment.
- Prosthesis use has an important role in the adjustment process, and a key concern for both service users and professionals within rehabilitation is ‘prosthesis rejection’. Investigating factors influencing prosthesis use are of importance in order to optimise the adjustment process.
- To date, limited studies in this field have investigated professional factors such as health provider communication, which may influence rate of prosthesis use and consequently affect adjustment outcomes.

What does this study add?

- This study investigates how prosthetist communication impacts on prosthesis related adjustment.
- The findings show prosthetist communication style was statistically significant in predicting service user functional and aesthetic satisfaction towards their prosthesis above other controlled predictors.
- This emphasises the importance of health provider communication on adjustment.
- Theoretical and clinical implications are discussed, with recommendations for future research in this field.

DOES SERVICE USER SATISFACTION WITH PROSTHETIST COMMUNICATION STYLE PREDICT PROSTHESIS RELATED ADJUSTMENT FOLLOWING LIMB AMPUTATION?

Abstract

Purpose : To investigate whether service user satisfaction with prosthetist communication style demonstrated significant predictive value in prosthesis related adjustment above that consistently demonstrated by other predictors.

Methods : 54 participants completed the cross sectional online survey. Alongside demographic and clinical information, measures were incorporated to collect data on coping style, shared decision making, consultation satisfaction and social support. The outcome measures involved three prosthesis related adjustment scales on psychosocial adjustment (general adjustment, social adjustment and adjustment to limitation), activity restriction (whether having a prosthesis limits daily activities and to what extent) and satisfaction (how satisfied individuals are with the functional, practical and aesthetic characteristics of their prosthesis).

Results : Results were interpreted using hierarchical regression analysis. Communication variables did not meet the criteria for inclusion into the regression models for the psychosocial adjustment and activity restriction outcome measures. However, satisfaction with prosthetist communication style in consultations demonstrated significant predictive value above other predictors on the satisfaction outcome measure. Furthermore, service user satisfaction with consultation emerged as significant independent predictors.

Conclusion: The findings have implications for theory, clinical practice and future research in this field. Specifically, theoretical considerations of adjustment, introduction of staff training in communication and suggestions relating to more specific policy guidance in relation to prosthetic consultation are offered.

Although the incidence of amputation worldwide is highly variable (Moxy et al., 2016), around 6000 lower limb amputations are performed annually in the United Kingdom (Davie-Smith, Coulter, Kennon, Wyke Pau, 2017), and an estimated 158,000 amputations take place annually in the United States (Raichle et al., 2008). For the vast majority of individuals, limb amputation is a life altering procedure. Individuals may respond to limb amputation in ways that are both complex and varied but generally adjustment is mediated by range of personal, contextual, physical, social (for a review see, Dadkhah , Valizadeh , Mohammadi & Hassankhan, 2013) and healthcare related factors (for a review see, Kelley, Kraft-Todd,, Schapira, Kossowsky, & Riess, 2014). ‘Adjustment’ is a widely used term in health psychology, yet it is difficult to define and measure due to differences among theoretical and professional disciplines on both its definition and its value as a term (Moss-Morris, 2013). For the purpose of this study, adjustment is acknowledged as referring to a broader level of acceptance and integration of impairment (following amputation) into an individual’s life.

Understanding factors that influence adjustment are important following amputation. A study by Unwin, Kacperek and Clarke (2009) investigated demographic (age, gender), clinical (phantom pain , level of amputation) and psychosocial variables in influencing psychosocial adjustment, and found that social support and coping through ‘hope’ significantly predicted positive psychosocial adjustment following amputation. Although this study was insightful at clarifying established variables in explaining adjustment, a standard multiple regression analysis was used which determined the total variance explained by all the predictor variables. As there was no fixed order entry of variables, such variables were not tested against other known predictors of outcome from control variables. In such circumstances, results should be interpreted tentatively in instances where there may be no control for other factors as this could well artificially inflate the importance of variables measured (Allison, 1999).

Other, influencing factors that inform the degree of adjustment in this context can be related to levels of activity (for a review, see Horgan & MacLachlan, 2004). For instance, physically, the individual may have to adjust to changes in functionality, performing activities of daily living and pain, with findings from a systematic review reporting at least 44% of individuals experience phantom limb pain that has persisted more than once over 3 decades (Bamford, 2006; Othman, Mani, Krishnamurthy & Jayakaran, 2017). Socially, individuals may experience changes in relationships and maintaining connections (Sinha, van den Heuvel & Arokiasamy, 2014), and psychologically, the individual may experience loss of body wholeness (feeling incomplete) (Batty, McGrath, Reavey, 2013), changes in body image and perception (Holzer et al., 2014) and adjusting to an artificial limb (Spiess et al., 2014). Although some individuals report a less challenging adjustment process than others (Desmond & MacLachlan, 2006; Pezzin et al., 2000), it is generally agreed that psychosocial adjustment, (although conceptually subjective), is considered to be multifaceted, multidimensional, and one that evolves continuously over time.

In light of the above, understanding factors that influence health outcomes following limb amputation is an important element within rehabilitation services, and is typically measured by quality of life (QoL), that is, the subjective life quality an individual ascribes in relation to their values, standards, goals and concerns (WHO, 1997). However, while QoL is an important consideration in this population and most studies have looked at it in detail, they are typically informed by use of generic QoL measures for health disabling conditions. While there is no universally accepted measure, amputation specific QoL assessments have demonstrated good psychometric properties (Condie, Scott, Treweek, 2006; Davidson, 1997). However, such measures may miss out on obtaining prosthesis related adjustment information relevant to the specific population. In addition, prosthesis use and characteristics are important for psychosocial adjustment, and the factors affecting its use could either help or hinder outcomes (Quartey, Asamoah, Armah, Baidoo, Essuman, 2015).

In light of this, there is more to be known regarding the factors influencing prosthesis-related adjustment. Adjustment may be socially and contextually informed, and increasing attention in other heath disciplines now pays attention to health provider influences on adjustment outcomes. For instance, a systematic review investigating physician–patient outcomes in any medical speciality (Stewart, 1995) confirmed that individuals had improved (physical and psychological) health outcomes when their physician employed good communication, involved them in discussions regarding their healthcare and formulated a management plan. To the author’s knowledge, no prior study has addressed this association in the field of limb amputation. This may be necessary in order to consider whether this influences prosthesis use and non-use. For instance, a large number of people do not use a prosthesis following amputation (Raichle et al., 2008). Schaffalitzky et al. (2011) provided a summary of the reported rates of prosthesis use across a set of studies, highlighting that prosthesis use ranged between 49% to 95% in those with a lower limb amputation. Prosthesis use for those with upper limb amputations is comparatively less, ranging between 27-56% (Kumar, Charan, Kanagaraj, 2017). Thus, although its definition is subjective, prosthesis rejection is a key issue affecting adjustment in individuals with amputated limbs (Murray, 2004) and is a re-occurring problem for service providers within prosthetic rehabilitation.

This suggests further understanding is warranted, and current underlying reasons for prosthesis non-use suggest prosthetic factors are often involved, with many individuals reporting prosthesis use to be problematic due to discomfort (Biddiss & Chau, 2007) and are dissatisfied with how the prosthetic limb is fitted (Resnik & Borgia, 2011). Poor prosthetic fit and alignment is concerning, as it can also affect levels of satisfaction, and result in other health conditions in the long term such as osteoporosis, osteoarthritis, back pain, and other musculoskeletal problems (for a review, see Gailey, Allen, Castles, Kucharik, & Mariah, 2008). Thus the prosthesis prescription process can make improvements to an individual's quality of life (Resnik & Borgia, 2011), although some individuals have chosen not to re-visit their local prosthetist for repairs or adjustment (Gauthier-Gagnon et al. 1998). Schaffalitzky, Gallagher, MacLachlan and Wegener (2012) conducted an electronic Delphi study consulting both service providers and service users in order to investigate prosthetic prescription with reference to outcomes, predictors and facilitators of lower limb prosthesis use. Service related factors were found to be of considerable importance, suggesting that a service user's engagement experience of the prosthesis fitting process had the potential to impact the individual's relationship with the prosthesis in the long term. This is important, considering that, on an annual basis, individuals have been known to visit a prosthetist around 9 times, and almost one fifth of individuals report a new prosthesis being fitted for them (excluding adjustments) at least once a year (Pezzin et al., 2004). Thus, the study outcomes are important both for considering professional practice, involving service users in communication regarding health-related decisions, and an overall need for improved service provider-user interaction.

One of the most important issues in relation to this, as concluded by Ostler et al. (2014), is that, within prosthetic rehabilitation, "more time should be dedicated to talking, rather than just walking" (p. 1174). The value of this has been further evidenced in a qualitative study highlighting the importance of professionals displaying good communication skills during the prosthetic process (Murray, 2013). This study used on-line discussion groups for people with lower-limb amputations and analysed those discussions which related to their off-line interactions with their prosthetists. Relational and communication difficulties with prosthetists was found to be an important issue for the service users, with the overall implications of the study suggesting a strong need for improved communication, use of accessible language and service user choice based decisions being employed by prosthetists.

However, an inhibitory factor in relation to optimising this is that the majority of studies in the amputation literature have investigated adjustment outcomes based on service user characteristics in order to explain factors influencing adjustment to amputation and prosthesis use (Sinha, van den Heuvel & Arokiasamy, 2014), rather than focusing on professional or service related factors. Professional factors are important, as The American Board for Certification in Orthotics Prosthetics & Pedorthics (ABC) Scope of Practise document suggests skills in communication are necessary for professional certification (Parr, Allen, Barringer, et al. 2012), and guidelines are available in the UK (HCPC standards of proficiency for Prosthetist and Orthotics, 2013; The British Association of Prosthetists and Orthotists standards for best practice, 2013) and internationally (International Society of Prosthetics & Orthotics; Krug, 2008) that advise on using professional interpersonal skills to promote service user participation in consultations. However, limited focus has been given to specifying what good patient-practitioner communication looks like within the field of prosthetics (Sherwood, Brinkman, Fatone, 2017), and there is a general lack of research evidence to inform ‘good’ decision making within prosthetic prescription. Findings from a retrospective cohort study surveying 935 service users reinforced this, revealing that around 26% of individuals had negative feedback on the interpersonal skills of their prosthetists, with reports that their prosthetist ‘did not explain’, ‘did not discuss’ and ‘was in a hurry’ (Pezzin et al., 2004).

In consideration of the raised issues, an important subject that needs exploration is how service user satisfaction with provider communication style relates to their wellbeing and overall adjustment. A recent systematic review investigating goal setting using shared decision making across a range of physical health conditions in rehabilitation settings found that when shared decision making (SDM) was employed as a communication style, service users were more satisfied with their clinician, they had improved motivation, were more engaged in their rehabilitation, and they liked ‘tailor made goals that were specific to their needs’ (Rose, William & Soundy, 2016, p. 71). Despite this, of the studies included, service user involvement varied, and only a few teams advocated an entirely patient centred approach. Indeed, research into linking elements of health provider communication to rehabilitation outcomes is limited, as Jesus and Silva (2016), in a review article on adapting existing models of communication to rehabilitation settings acknowledged that, “the field lacks a conceptual understanding on how rehabilitation outcomes can be improved by communication” (p 315).

“No decision about me without me’’ (Coutler & Collins, 2011; Department of Health, 2010) is a government document proposing change to NHS consultations and encourages the adoption of a more person centred approach in the UK. This advocates the uptake of SDM across all healthcare services. This communication stance could involve seeking to understand and elicit the service user’s perspective with reference to their unique psychosocial context, sharing a congruent understanding of the clinical issue and how it is to be treated (Epstein et al. 2005). Furthermore, a person centred approach to decision making is a useful strategy according to the amputation literature, which shows that service users are eight times more likely to accept their prosthesis if they have been involved in the consultation process (Biddiss & Chau, 2008). Such findings reinforce professional communication as being an influencing factor on service user satisfaction, and a recent review on the communication styles employed by orthotists and prosthetists acknowledged that, as there was not enough research in this field, their review was informed by research on doctors' communication in order to transfer recommendations to the context of orthotic and prosthetic encounters (Sherwood, Brinkman & Fatone, 2017).

Consequently, the aim of this study is to bring attention to the current gap in the evidence base concerning communication styles in the field of prosthetics specifically with regards to its impact on health outcomes, and encourage further research in this area. More specifically, the main aim of study was to investigate service user views on their experience of prosthetic consultation (how decision-making was made, the content and characteristics of prosthetist communication), service user satisfaction with this, and if this impacted on several prosthesis-related adjustment outcomes. For the purpose of this research, satisfaction with prosthetist's communication style is operationalized as a service user's positive or negative evaluation of their interaction with their prosthetist following consultation(s). Such findings could be of importance as they could have implications for rates of prosthesis use. It was predicted that satisfaction with prosthetist communication style in consultations, in a hierarchical regression analysis, would demonstrate significant predictive value in prosthesis related quality of life outcomes above that consistently demonstrated by other predictors. Specifically, this study will use 3 TAPES- R (revised) outcome measures. It is hypothesised that greater satisfaction with prosthetist communication style would be associated with better outcomes (higher scores) on TAPES-R Psychosocial and TAPES-R Satisfaction, and lower satisfaction with communication style would be associated with greater scores (more activity restriction) on TAPES-R activity restriction.

Method

Participants

For the purpose of this study, it was necessary for participants to 1) have an acquired limb amputation (surgical removal of a limb upper and/or lower) either due to trauma or disease, or congenital limb absence /deficiency 2) have experienced a prosthesis prescription consultation process, 3) have a prosthesis, 4) have access to the internet and the ability to read and understand English, 5) be over 18 years of age, 6) be willing to take part in the research. In order to determine the sample size for participants, an electronic power calculator, G*Power 3.1.9.2, was used to estimate sample size based on a medium effect size ($F^2 = 0.15$), a maximum of 23 possible predictors (gender, age, time since amputation, amputation aetiology (trauma or disease), phantom pain, stump pain, communication and satisfaction with communication, coping (14 sub scales), social support) and at conventional power probability (b = 0 .80). The results of the G Power analysis indicated that in order for a significant effect (p = <.05) to be detected, a minimum of 166 participants would need to be recruited to the study.

Procedure. In order to investigate the predictive relationship between how satisfied service users were with their prosthetist's communication style and adjustment outcomes, a quantitative approach in the form of a cross sectional design was used. This research was approved by the University Research Ethics Committee at Lancaster University in July 2017 with amendments approved in August 2017. The applications submitted to the ethics committee alongside the approval document can be found in section 4, ethics. An online platform was used to recruit participants, and the principal researcher liaised closely with relevant online organisations in order to access the target population. Organisations included Limbs4life, Limbless Association, Amputee Coalition and Blesma. These organisations advertised the study on their websites and social media platforms. A Twitter account was also used to contact organisations and advertise the research which included a weblink to access the survey. A Lancaster university hosted webpage (http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/) was also used as platform to advertise the study. Data collection took place through an online platform using Qualtrics online survey software (https://tinyurl.com/ybk5ovl). This online survey was designed to access participants both nationally and internationally, and involved utilising a variety of self-report measures as well as the relevant research related materials for participants to complete.

At the start of the online survey, participants were presented with a participant information sheet, which required them to read and accept, prior to moving onto consent to participate. The consent process involved a series of statements relating to the research and participants were asked to agree to each one. It was only after each statement was agreed to that participants could proceed to the next step which involved participants providing their demographic/clinical information. Participants were asked at the start of the survey to consider answering each questionnaire specifically in relation to their prosthesis adjustment.

Measures. Demographic and clinical information was collected, and phantom limb pain and stump pain (binary variables) were dichotomised as present or absent. Measures were incorporated to collect data on prosthesis related adjustment (as measured by the three subscales of the TAPES-R), coping, SDM, consultation satisfaction and social support (copies of the questionnaire are in section 4, appendix B).

Predictor variables included demographic factors (gender and age), clinical variables (time since amputation, amputation aetiology- trauma or disease, phantom pain, stump pain), psychosocial variables including coping and social support, and the additional variables of interest (SDM and consultation satisfaction).

The Brief Cope (Carver, 1997). Based on the original Cope Inventory (Carver et al., 1989), this brief 28 item measure comprises 14 sub scales concerned with varying coping strategies that may or may not be effective depending on the situation. Each of the 14 scales comprised 2 items and these are rated on a 4 point Likert scale, for instance, a score of 4 'I have been doing this a lot' or 1, 'I haven't been doing this at all'. Scale scores are derived from summing two corresponding items. The potential range for each subscale is 2-8. The greater the score, the greater the use of that particular coping strategy. Cronbach's alpha values for the scales all meet or exceed the minimally accepted value ($\alpha = .50$; Carver, 1997) and the measure has good construct validity (Feuerstein, 2007). It has also been used in previous research on individuals with an amputation (Peroni, Cornaggia, Cesare & Celilia, 2017), and has been recommended for use in adult samples (Windle, Bennert & Noyes, 2011).

The 9-item Shared Decision Making Questionnaire (SDM-Q-9; Kriston, Scholl, Lars, lzel, Simon, Andreas, Harter, 2010). This measure comprises 9 statements centred on experiencing of shared decision making in healthcare consultations, and participants rated each statement according to a 6 point Likert scale. For example, participants can score between 5 for 'completely agree' to 0 for 'completely disagree'. The total sum of scores ranges between 0-45, with the greater the score, the greater the extent of shared decision making. This measure was adapted to capture more precise data on participants' perspectives of shared decision making with their prosthetists. Adaptations were minimal and simply involved replacement of the word ‘doctor’ with ‘prosthetist’ due to the study being explicitly concerned with participant preferences and opinions on the communication style employed by the prosthetist. No further adaptations were made to the questions. Although the author recognises that significant changes to a scale will result in its validity being compromised, validity may not be affected if alterations are kept to a minimum, and the questions remain ‘simple and obvious’ (Hackshaw, 2015 p.158). This questionnaire has previously been adapted for use with other professional disciplines (for a review see, Doherr, Christalle, Kriston, Harter, Scholl, 2017. The SDM Q-9 is the most common assessment for measuring shared decision making in clinical practice, and has excellent internal consistency ($\alpha = > 0.9$; Kriston et al., 2010)

The Interview Satisfaction Questionnaire (ISQ; Grayson-Sneed et al., 2016). The ISQ is comprised of 12 items which are made up of four different types of satisfaction (open-endedness, empathy, confidence and general). This questionnaire was originally a 25 item scale which was reduced to 12 items which still demonstrated high reliability and construct validity (Grayson-Sneed et al., 2016). Participants could score between 1-5, where 5 indicated ‘strongly agree’ and 1 which indicated ‘strongly disagree’ to statements regarding the empathy of the physician, and how confident and generally satisfied the participant is in their physician and the interaction between the physician and the participant. The total score which can be obtained is 60, thus the higher the score, the greater the participants’ satisfaction. For the purpose of this study, this questionnaire was adapted to specifically focus on the relationship between the participant and their prosthetist and also measure satisfaction across an on-going clinical encounter. The only adaptation involved replacement of the word ‘physician’ with ‘prosthetist’. This measure has excellent internal consistency ($\alpha = .90$).

Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley 1988) is a 12 item scale comprised of three perceived sources of social support: family, friends and a significant other. Participants were asked to read each statement and provide a rating on the extent to which they agreed or disagreed with each statement based on a Likert scale of 1-7. For example, a rating of 7 corresponds to if participants 'very strongly agreed' and 1 corresponds to if participants 'very strongly disagreed'. The higher the score, the greater the perceived social support. The MSPSS can be scored per subscale (family, friends, and significant other) (Sajatovic & Ramirez, 2012), or the overall sum of the 12 items can be used to obtain a global MSPSS scale score of which the maximum total is 84 (Osman, Lamis, Freedenthal, Gutierrez, & McNaughton-Cassill, 2014) and mean totals can be obtained by dividing the score total by the number of scale items. For this study, subscales were totalled to provide a global MSPSS score. Cronbach's alpha of the subscales and total scales are excellent ($\alpha = 0.85 – 0.91$; Zimet, Dahlem, Zimet, & Farley, 1988) and has been previously in research on social support following limb amputation (Williams et al., 2004).

Outcome variables. The Trinity Amputation and Prosthesis Experience Scales-Revised (TAPES-R; Gallagher, Franchigoni, Giordana, & MacLachlan, 2010) is a multidimensional measure, specifically for use with individuals with a lower limb amputation and includes scales addressing psychosocial adjustment, activity restriction and satisfaction. Psychosocial adjustment refers to psychosocial adaptation to prosthesis use. It comprises 15 items on a 4 point Likert scale including 3 subscales: general adjustment, social adjustment and adjustment to limitation. Each subscale comprises 5 items on a 4 point Likert scale. For items 1-10, a score of 4 is selected if the participant 'strongly agrees' or a score of 1 is selected if the participant strongly disagrees. For items 11 to 15, a score of 1 is selected if the participant 'strongly agrees' or a score of 4 is selected if the participant 'strongly disagrees'. Higher scores indicated better adjustment, and participants could also select ‘not applicable’, which would not be scored. The total of the three subscales can be summed to provide the overall psychosocial adjustment score, with a range of 3 to 12. TAPES-R activity restriction refers to limitation in activities that involve physical effort, functional effort and social engagements. It is a 10 item measure on a 3 point Likert scale comprising functional, athletic and social restriction. Participants may select from 0 (not limited at all) to 2 (yes limited a lot). A high score indicates greater limitation in activity restriction. TAPES-R Satisfaction with prosthesis includes 2 subscales aesthetic satisfaction (3 items) and functional satisfaction (5 items). Responses are scored according to a 3 point Likert scale. All item responses within the scale are summed to provide a total. Scores for aesthetic satisfaction range from 3 to 9 and functional satisfaction range from 5 to 15. Higher scores reflect greater levels of satisfaction. The two subscales can be summed together with a possible range of 8 to 24. Overall, The TAPES-R is a psychometrically revised update from the original TAPES, which has demonstrated high Cronbach’s alpha values psychosocial adjustment ($\alpha = .89$), activity restriction ($\alpha = .87$ and satisfaction ($\alpha = .85$) (Gallagher, & MacLachlan, 2000).

The TAPES-R was preferred in this study due to it being tailored to the population of interest (Gallagher & MacLachlan, 2000; Condie, Scott, Treweek, 2006) and its practical applicability for use in online research. Given that use of generic QoL measures may fully not capture specific prosthesis related outcomes following amputation, the development of the TAPES was designed to further enhance investigation of the specific psychosocial processes involved in adjusting to, and wearing a prosthesis following limb amputation (Gallagher & MacLachlan, 2000). For example, using the TAPES, Gallagher and MacLachlan (2004) investigated the different elements of prosthetic experience in order to assess which had the strongest association with QoL using The World Health Organization

Quality of Life Questionnaire (WHOQOL-BREF, WHOQOL group, 1998). Aesthetic satisfaction with prosthesis, physical ability and level of amputation as measured using TAPES predicted 72% of variance, indicating that higher scores on these subscales were associated with more positive scores on the psychological domain of the WHOQOL-BREF. Length of time with the prosthesis and degree of prosthesis use predicted 63% of the variance, thus indicating that greater scores on these variables were associated with more positive scores on the social relationships domain of the WHOQOL-BREF. This suggests that TAPES can be used to evaluate QoL in this population.

Data Preparation & Analysis. Data were analysed using IBM SPSS Statistics version 23. All questionnaires were scored according to scale instructions and reverse coded as required. This refers to items 11-15 on the TAPES psychosocial adjustment scale, “a prosthesis interferes with the ability to do my work”, “having a prosthesis makes me more dependent on others than I would like to be”, “having a prosthesis limits the kind of work that I can do”, “being an amputee means that I can’t do what I want to do” and “having a prosthesis limits the amount of work that I can do”. Statistical significance was determined by using a *p* value of .05 which is a common threshold for statistical significance (Field, 2013). The recruitment window took place from December 2017-March 2018, during which time the survey was accessed 147 times. All participants proceeded from reading the information to providing consent; however, 93 participants (63%) were excluded on the basis of them exiting immediately following consent, and not proceeding to complete any outcome measures. Bennett (2000) recommends excluding cases where considerable data are missing. Therefore the study recruited 32.5% of the intended sample, which was a total of 54 participants. A detailed breakdown of sample characteristics is provided in table one, appendix 2-A.

Rational for statistical approach. The decision to pursue the current statistical approach despite having a limited sample size is based on Tabachnick and Fidell's (1989) suggested minimum of 5:1 sample to variable ratio as justification for the stability of the regression model using a sample size of 54 with a maximum of 10 predictors. The authors suggest "a bare minimum requirement is to have at least 5 times more cases than IVs (independent variables)" (Tabachnick & Fidell 1989, p.128). Sample size considerations in regression analysis are generally subject to controversy, and there are varying rules of thumb provided by authors as guidelines for regression prediction equations. For instance, in a review of the literature, seven primary rules of thumb were identified to justify minimum sample sizes for regression. These ranged from the highest being 119:1 (Maxwell, 2000) to the lowest being 5:1 (Tabachick & Fidell, 1989) and the most common being 10:1 (Harrel, 2001). Given the variation in subject to variable ratios, researchers argue that "there is no consensus among researchers on what sample size is required to conduct a multiple regression analysis" (Abu-Bader, 2011, p. p.323), and "although many rules of thumb exist, no one can really be substantiated" (Lomax, 1998; p. 60). It is generally agreed that "the selection of adequate and appropriate sample sizes is not always an easy matter in regression" (Brooks & Barcikowski, 2012 p.1). In light of the subjectivity regarding case to variable ratios, some authors suggest that they are "almost always misleading….[whereby] in some instances, fewer than ten participants per variable are needed…[and] the general rule that the more participants for an experiment the better, is also misleading" (Heppner, Kivlighan & Wampold, 1992, p. 356). A more recent study used Monte Carlo simulations to investigate the impact the number of participants per variable had in offering an accurate estimation of regression coefficients, confidence intervals, standard errors and the overall accuracy of the R^2 fit. The authors concluded that linear regression models require much fewer participants per variable in comparison to logistic and cox models, with only two participants per variable being able to permit accurate estimate of the linear regression results (Austin & Steyerberg, 2015).

Considering the subjectivity, some authors consider the application of such rules to be "perpetuating a statistical urban myth: [that] there is a single 'correct' estimate of sample size that may be obtained using one of the many formulae's offered" (Lance & Vanderberg, 2014; pp.166). They continue to suggest that this is problematic due to there being no consistent agreement on sample size, and one must consider the context and purpose that the original authors used to guide the development of each heuristics (Lance & Vanderberg, 2014; pp.167).

The variation in agreed sample sizes for regression analysis is also reflected in published research. A literature review in developmental research by Ekins and Schneider (2006) used the smallest recommendation of 5 subjects per variable as their minimum criteria for inclusion when evaluating studies. They found a proportion of published research adhering to this rule of thumb. For instance, for every predictor variable, Muter and Snowling (1998) used less than 10 participants (in a sample of 34 participants). Menyuk et al. (1991) adhered to 5 participants for every predictor variable, and McCormick et al. (1994) used less than this minimum recommendation. The same is also true within published health research, with one study investigating an implicit test in the prediction of anxiety which used a sample size as small as 33 to conduct a hierarchical regression analysis using 7 predictor variables (Egloff & Schmukle, 2002)

[INSERT TABLE 1]

Data were assessed for missing values, and an analysis on the patterns of missing values was conducted. It appeared that 33 cases (61.1% of the sample) had incomplete data across 109 (97.32%) of the data points. Little's (1988) Missing Completely At Random (MCAR) test was non-significant ($X^2 = 644.503$, $df = 1145$, $p = 1.000$), indicating that the null hypothesis of data being missing at random could be assumed. Listwise or pairwise deletion methods were not considered an option due to an already high number of missing cases, and the potential for this to reduce further the power and sample size. Multiple imputation was conducted to generate replacement values for missing data. The imputation involves multiple repetitions, so more than one data set is analyzed and a pooled (combined) result is offered (Li, Stuart, & Allison, 2015). Five iterations of imputation were conducted, as this is considered to be sufficient (Schafer, 1999).

Cronbach alpha was used to estimate the internal consistency of the items on each scale used in the analysis. Although the interpretation of Cronbach's alpha is debatable (Cortina, 1993), the general consensus is that an alpha level between .65 and .80 is considered adequate (Vaske, Beaman & Sponarski, 2017), and the scales in this study were all within or exceeding this range, thus demonstrating an acceptable level of reliability (alpha values are provided in table two, appendix 2-A).

[INSERT TABLE 2]

The Kolmogorov-Smirnov test and Shapiro-Wilk test were conducted on all continuous measures to assess for normality. Large numbers of measures were significant, $p < .05$, indicating non-normal distributions. Logarithmic transformations were performed on the data set in an attempt to achieve a normal distribution (Weinberg & Abramowitz, 2016).

However, this resulted in only a slight reduction of skew, therefore non-parametric testing using Spearman's rank order correlation was conducted on non-transformed data to investigate the correlational relationships between each potential determinant and each of the three TAPES- R scales. The decision to continue with regression analysis despite non-normal data was based on the understanding that linear regression models are often robust to assumption violations, and data that deviates from a normal distribution can still yield valid findings (Schmidt & Finan, 2018).

The variables selected for the regression analysis were based on examination of effect size as opposed to *p* values. This decision was based on the fact that *p* values do not always indicate clinical significance, and effect sizes are not directly affected by sample size (Lantz, 2013). This is important, considering the sample in this study was lower than anticipated (N = 54). Spearmans r_s was used to estimate correlations (see table 3, appendix 2-A), and the coefficients were examined to indicate effect size (Durlak, 2009). Cohen's (1988, 1992) recommendations were applied, small (0.1), medium, (.03) and large (0.5) criteria effect size for correlation. Use of effect sizes to justify variables for inclusion into regression models has been used in previous health research (Keeling, Bamborough & Simpson, 2013; Chisari & Chilcot, 2017), and hierarchical regression analysis was chosen in order to investigate the contribution of new predictors (communication) above other established predictors through statistical control (Lewis, 2007). Thus, variables were entered into the model in blocks, starting with the theoretically known variables, clinical, psychosocial, and lastly communication, in order to assess the change in variance contributed by each variable

The Durbin-Watson (d) test was examined for autocorrelation across the three TAPES-R measures (TAPES-R psychosocial, d = 2.023; TAPES-R activity restriction, d= 2.116; TAPES-R satisfaction, d = 1.655). All were considered within the acceptable range of 1.5 to

2.5 (Huck, 2008), thus indicating there was no pattern to any errors in the regression model and no autocorrelation was present. SPSS does not provide collinearity statistics for pooled data.

[INSERT TABLE 3]

Results

The mean values of the predictor and outcome variables are shown in table four (appendix 2-A). Of the Brief Cope scale variables, participants scored highest on acceptance (*M* = 6.8 ; *SD* = 1.4) and humour (*M* = 5.0 ; *SD* = 1.9), indicating greater use of these coping style among participants. Participants scored lowest on behavioural disengagement, indicating less use of this coping style (*M* = 2.6 ; *SD* = 1.2). The SDM-Q-9 score showed that the mean of the sample scored around the midpoint of the scale (*M* = 23.7 ; *SD* = 10.8), indicating that they perceived shared decision-making was present in their consultations with their prosthetists. The ISQ showed that the mean of sample scored above the midpoint of the scale (*M* = 46.4 ; *SD* = 11.2), suggesting participants were relatively satisfied with the nature of consultation. The TAPES-R scores revealed that the sample overall were relatively well adjusted on scores of psychosocial adjustment (*M* = 9.1 ; *SD* = 1.5), and reasonably satisfied with functional and aesthetic components of their prosthesis (*M* = 16.0 ; *SD* = 4.1). Activity restriction scores were in the middle range (*M* = 1.0 ; *SD* = 0.4), indicating that this sample were ‘limited a little’ in their daily activities. The social support scores of this sample indicated moderate levels of support (*M* = 4.6 ; *SD* = 1.1).

The correlations are presented in table three (appendix 2-A). Correlations with the largest effect sizes were Brief cope instrumental support (-.470, TAPES-R psychosocial), Interview satisfaction (-.457, TAPES-R satisfaction), Brief cope behavioural disengagement (-.447, TAPES-R psychosocial), Brief cope emotional support (-.429, TAPES-R psychosocial) and Brief cope venting (-.403, TAPES-R psychosocial). Correlations with medium effect sizes included stump pain (-.301, TAPES-R psychosocial). Although a small to medium effect size was present for social support (.227, TAPES-R psychosocial; .164, TAPES-R satisfaction; -.161, TAPES-R activity restriction) this was less than the .3 entry criteria and was therefore not included in the regression analysis. The smallest effect sizes for clinical and demographic information were age (.026, TAPES-R psychosocial) and phantom pain (-.077, TAPES-R satisfaction; .065, TAPES-R activity restriction).

Brief cope behavioural Disengagement had large negative correlations across all three adjustment measures psychosocial adjustment (-.447), activity restriction (-.358) and satisfaction (with prosthesis) (-.344). Behavioural disengagement can refer to the tendency for individuals to reduce efforts when dealing with stressful situations. In the Brief cope, behavioural disengagement is comprised of the statements “I've been giving up trying to deal with it”, and “I've been giving up the attempt to cope”. A negative correlation between behavioural disengagement and activity restriction suggests that lower scores on behavioural disengagement (i.e. less avoidant coping) was associated with higher scores on activity limitation (i.e. greater restricted activity).

[INSERT TABLE 4]

Hierarchical Regression Analysis. Variables entered into the regression model were selected according to the relationships between each potential determinant and each of the three TAPES- R scales. These can be found in table three, appendix A. Variables at or exceeding 0.3 were considered for inclusion into the regression models, which is indicative of a medium effect size at the least, or moderately strong relationship between each predictor and each outcome. Three separate regression analyses were performed for each of the dependent variables (TAPES-R psychosocial, TAPES-R Activity Restriction, TAPES-R Satisfaction).

For TAPES-R psychosocial, 10 predictor variables were entered into the hierarchical regression model in two blocks (a) clinical variable (stump pain), and (b) psychosocial (i.e. coping; self-blame, instrumental support, denial, acceptance, humour, venting, emotional support, substance use, behavioural disengagement,) variables. The hierarchical regression analysis revealed that at block one, stump pain contributed significantly to the regression model F (1,52) = 5.505, $p < .05$), and accounted for 9.6% of the variation in TAPES-R psychosocial adjustment ($R^2 = 0.96$, $R^2_{\text{adj}} = 0.78$). After introducing the psychosocial (coping) variables (block 2) the variance of the total model increased to 47.8%, ($R^2 = 0.478$, $R^2_{\text{adj}} = .356$, $p = .003$). Thus, there was a 38.2% ($\Delta R^2 = .382$) increase in predictive capacity explained by adding the psychosocial variables in block 2. The total model was significant, F (9, 43) = 3.493 $p < .05$. As SPSS does not provide standardised Beta (β) coefficients for pooled data, the unstandardized β values were examined to indicate each variable's individual contribution to the model. A significant independent predictor of TAPES-R psychosocial adjustment within the model was stump pain ($\beta = -4.912$, $p = <0.05$). This suggests that when controlling for other variables in the model, when there is an increase in stump pain by the value of 1, there is an expected decrease of 4.9 in TAPES-R psychosocial adjustment.

For TAPES-R activity restriction, six psychosocial (coping) predictor variables (emotional support. instrumental support, behavioural disengagement, self-blame, substance use, and venting) were entered into the regression model in one block. The total model was significant, F (6, 47) = 3.583, $p \leq .05$ with 31.4% ($R^2 = .314$, $R^2_{\text{adj}} = .226$) of the variance in TAPES-R activity restriction being explained by the coping variables entered into the model. There were no significant independent predictors of TAPES-R activity restriction.

For TAPES-R Satisfaction, five predictor variables were entered into the regression model in two blocks (a) psychosocial (coping) variables (substance use, behavioural disengagement, self-blame), (b) prosthetist communication style (shared decision making, interview satisfaction). The results of the analysis showed that in block one, the psychosocial variables accounted for 11.7% ($R^2 = .117$, $R^2_{\text{adj}} = .064$) of the variation in TAPES-R satisfaction, however the model was non-significant, $F(3, 50) = 2.206$, $p > 0.05$.The addition of communication variables (shared decision making and interview satisfaction) increased the predictive capacity to 29.0%. ($R^2 =.290$, $R^2_{\text{adj}} = .216$). Thus the change from 11.7% to 29.0% could be explained by an increase of 17.3% ($\Delta R^2 = .173$, $p = .005$). The overall total model was significant F(5, 48) = 3.917, $p \leq 0.05$. Interview Satisfaction (satisfaction with prosthetist communication style) was an independent predictor of TAPES-R satisfaction (β = .175, p = <0.05), indicating that increased satisfaction with prosthetist communication style resulted in greater satisfaction with functional and aesthetic components of the prosthesis on TAPES-R satisfaction.

Discussion

In sum, the hypothesis that greater satisfaction with prosthetist communication style would demonstrate significant predictive ability above other established predictors in explaining positive psychosocial adjustment was only supported by one regression which used TAPES-R satisfaction as the dependent variable. Communication variables did not correlate to a medium effect size with TAPES-R psychosocial or TAPES-R activity restriction, and were therefore not entered into the regression analysis.

In investigating psychosocial adjustment (TAPES-R Psychosocial), a two block hierarchical regression was conducted between clinical variables and established psychosocial determinants. The addition of psychosocial (coping) determinants increased the variance significantly in explaining psychosocial adjustment outcomes by 38.2%, highlighting that coping variables were an important element of adjustment in this study. Findings from previous research have also shown associations between certain coping styles in predicting psychological adjustment to limb amputation (Desmond & Maclachlan, 2006).

The hypothesis that lower satisfaction with communication style would be associated with greater scores in activity restriction was not supported. Again, prosthetist communication variables were not correlated at a medium effect size with TAPES-R activity restriction, and thus not entered into the regression. A one block regression was conducted with accepted determinants and the overall model was significant, lending further support in showing certain coping styles (emotional support, instrumental support, behavioural disengagement, self-blame, substance use and venting) predicting outcomes in adjustment (activity restriction). Low scores on behavioural disengagement in particular, was associated with greater activity limitation. This is in contrast to findings from other health research, in particular pain management, where greater use of avoidant coping styles have generally been positively correlated with higher levels of activity limitation (Ferrari, 2006).

Overall, the hypothesis was only supported by TAPES-R Satisfaction. Specifically, greater satisfaction with prosthetist communication style was associated with higher scores on the aesthetic and functional characteristics of the prosthesis. Furthermore, service user satisfaction with consultation showed to be a significant independent predictor in this model when their determinant power was assessed against that of the other established determinants. This confirms previous research findings also suggesting that service user satisfaction with the cosmetic and functional components is important in obtaining good prosthesis related adjustment, psychological wellbeing and restoration (Cairns, Murray, Corney, & McFadyen, 2013; Webster et al., 2012). The current study goes beyond this understanding by showing that prosthetist communication style is a statistically significant contributor in achieving prosthesis related cosmetic and functional satisfaction.

An interesting and surprising observation was that satisfaction with communication variables were not predictive of TAPES-R psychosocial adjustment, and TAPES-R activity restriction. Reasons for this lack of association need further exploration. The risk of conceptual confounding was limited, as the items on the communication variables differed to items on the outcome measures. Indeed, some findings from previous health research have confirmed mixed findings for the benefit of health provider communication on adjustment outcomes (for a review see, Shay, Aubree, Lafata, & Elston, 2015), Although no previous studies have investigated communication variables using TAPES outcomes, other adjustment related studies using TAPES have reported mixed findings. For instance, one study investigated whether TAPES psychosocial, activity restriction and satisfaction (alongside other variables) predicted negative emotions in a sample of individuals with lower limb amputations (Zanfir et al., 2017). The study found psychosocial adjustment was a significant contributor to the regression model, whereas activity restriction and satisfaction did not significantly contribute to the variance of negative emotions.

Consideration should be given to statistical concerns relative to the small sample size used in this study. This sample size is reflective of the difficulties in recruiting for this study. A possible reason for this was that a similar research project was being conducted with this clinical population at the same time and through the same online organisations, so it could be that participants only wanted to take part in one project, rather than two simultaneously or had a preference. A factor which could have remedied this would be to have gained further ethical approval to recruit through NHS services and offered a paper copy version of the survey as this could have enabled further access to participants not only from an online sample but also currently receiving prosthetic consultation. Generalisability of study findings is limited as the majority of the sample had traumatic amputations. Consideration should be also given to contextual and personal factors surrounding traumatic amputations which may have an impact on the findings, and future research may wish to explore other contributory life events as part of the analysis.

Other than statistical considerations, the pattern of results found in this study may reinforce current theoretical understanding of adjustment being a complex and multifaceted construct to investigate, with measurement of adjustment being difficult when there is no unified theory and no agreed way of conceptualising it (Moss-Morris, 2013). Adjustment itself may be reciprocal, and dynamic, and influenced by multiple factors (context, individual factors, lifestyle, physiology and psychological state). In consideration of this, the hypothesis suggesting that communication influences adjustment outcomes may be vague and simplistic as it may overlook the complexity of adjustment. Adler’s theory of social interest explains that adjustment is a social process (Crandall & Hogan, 1980), influenced by the interactions between the individual and their social context, which has meanings for both parties (Oliver, Zarb, Sliver, Moore & Salisbury, 1988), thus should not be measured solely based on the viewpoint of the individual. Thus, given the inter-connected and inter-related nature of adjustment, discrete unidimensional variables on outcome measures may not provide a full explanation. Considering this, it is easy to see how some items on the TAPES-R psychosocial, ‘I feel that I have dealt successfully with this trauma in my life’, ‘Although I have a prosthesis, my life is full’, ‘I find it easy to talk about my limb loss in conversation’ can be socio-contextual in nature, and thus could be influenced by factors outside of the prosthetic consultation, hence the non-significant findings in this study. Despite this, defining adjustment using outcome measures are still considered operationally helpful and beneficial in providing a simple measurement strategy to explain phenomena. It may be concluded that adjustment is comprised of multiple components and influenced by many factors. In this study, prosthetist communication significantly contributed to one type of adjustment. Moving closer to a unified theory of adjustment may enable services to implement a guiding framework for how assessment of adjustment is translated into clinical practice. Further training of staff in the theoretical underpinnings of adjustment may enhance a broader and more thorough assessment of adjustment difficulties in health care contexts, to improve the adjustment process in individuals and their families.

Clinical Implications

This study has some important implications. For instance, the statistically significant finding of prosthetist communication style in predicting prosthesis functional and aesthetic satisfaction above other predictors emphasises the importance of health provider communication on adjustment, and suggests communication variables are to be acknowledged as playing some role in shaping service users' healthcare experiences and outcomes. A move towards health providers advocating SDM in consultation has already been established in many health contexts, although the evidence suggests that service users are seldom involved in shared discussions about their goals in rehabilitation services (for a review see, Rose, Rosewilliam & Soundy, 2017). This could be due to a lack of specific guidance regarding communication and how this translates in clinical practice. Furthermore, there is generally a lack of research regarding the role of the prosthetist and service users do not have clear expectations of what to expect during this encounter. This could influence passive behaviour from service users, a break-down in communication, and reduced service engagement (Ostler, 2014). Managing service users' expectations regarding receiving a prosthesis is considered a least favourable aspect of the prosthetist's role (Sansam, O'Connor, Neuman, & Bhakta, 2014), and service users report a negative first experience of getting their prosthesis, and feel disappointed when expectations are not met (Sjodahl, Gard & Jarnlo, 2008). It would be of further interest to explore how prosthetists manage service user expectations within their consultation process, if they believe they manage expectations effectively, and whether or not they believe further training for this is required.

SDM is advocated on ethical grounds, and NICE guidelines state that service providers should have systems in place to offer staff training in professional communication, and all health professionals should be competent in this (NICE, 2012). Clearer service guidelines and the implementation of staff training to better manage communication dynamics in consultation could improve consistency and continuity of good practice. Findings from a systematic review investigating training in optimising health professionals' psychological skills (including communicative and interpersonal elements) suggests that this type of training can be beneficial on service user outcomes (Mann, Wyrzykowska, & Kanellakis, 2015). Similarly, further provision dedicated to the interpersonal and psycho-emotional elements of the prosthetic consultation process could similarly be of use. However, the impact of this training would need to be empirically investigated.

Strengths and limitations. This study has been an important first step in investigating the role of prosthetist communication in influencing quality of life outcomes in the context of limb amputation. However, there are also limitations that need to be considered. For instance using online samples and recruiting from specific organisations restricted participant inclusion to those who were computer literate and had access to technology, which is therefore not entirely representative of the general population. There could have been more specificity regarding the instructions for completing the Brief Cope. For instance, a reminder at the start of the questionnaire for participants to consider the statements in relation to their prosthesis adjustment, as well as this being specified at the start of the survey. In addition, information on broader sample characteristics such as nationality should have been collected alongside demographic information in order to check for a diverse sample range. There may be differences in the service models both across and within countries and services which could offer some contextual background in terms of service satisfaction. For example, the influence of public versus private services and different service reimbursement models may also be influential. Another limitation is that the study did not meet the target sample size required by the power analysis. A larger sample size could have influenced the pattern of results and variables included for regression analysis, particularly with regards to social support and interview satisfaction, which could have yielded stronger effect sizes on adjustment measures as a result.

Although the sample size was less than anticipated according to the power calculation, power analysis should only be taken as an approximation (Leong, James & Austin, 2006), and despite a lower sample size, statistically significant results were still obtained, thus suggesting adequate power. Furthermore, effect size rather than *p* values were used as criteria for entry into the regression models. As the variables demonstrated medium to large effect sizes, a smaller sample size was able to detect this.

As this study used some correlational investigation, no definitive explanations can be attributed to the causal relationships occurring between the variables investigated. Thus, any significant or non-significant findings could be explained by other unrelated factors (such as personality, attitudes, or expectations). Furthermore, with this study being cross-sectional, it offers findings at one point in time, and any future attempts in investigating this may consider research over a period of time, given that adjustment is a process as well as an outcome, thus outcomes could change at any point. However, as an investigative piece of research examining hypothesised associations between variables, the current study offers a good foundation for further research to further expand upon in exploring provider communication and service user quality of life outcomes in the context of limb amputation.

Future research. As a continuation, future research may wish to consider prosthetist perspectives on communication style, as it is important to consider that service user perspectives alone are unlikely to offer a complete perspective. Potential bi-directional influences and the reciprocal nature of communication in consultation should be considered, which is not always possible to capture through self report measures. Capturing clinical interactions which includes the mutual influence of prosthetists, service users and the context in which the interaction took place may better enable an understanding of the impact of the interrelation between verbal and nonverbal communication. Furthermore, a qualitative element to research would be of interest, which could offer further insight into how the communicative style (and which elements in particular) personally informed adjustment.

Broadly, there is still so much more to learn about the role of professional SDM and the impact this has on service user health reported outcomes. For instance, shared decision making has attracted much interest in healthcare and policy guidelines, however findings show it is not always implemented across health disciplines (for a review see, Légaré, Ratte´ Gravel, Graham, 2008), and some findings have found mixed results for a statistically significant relationship between SDM and service user outcome (for a review see, Shay, Aubree, Lafata, & Elston, 2015). It could be that more needs to be understood regarding the underlying mechanisms of SDM, and research needs to investigate multiple interactions in consultation over a long period of time. Previous research may have missed the complexity of

SDM, as it has merely focused on the observable aspects of the decision making process (Matthias, Salyers & Frankel., 2013). Other factors could be inclusive of the content of the session and structure (Strohschein, Bergman, Carnevale,, & Loiselle, 2011). Further research could look beyond the verbal element, considering the influence of professional behaviour (attitude, motivation, body language) and emotion to provide a more comprehensive overview of how such factors may influence psychosocial adjustment (for a review, see Hajjaj, Salek, Basra, & Finlay, 2010). For instance, a systematic review investigating non-verbal communication in clinics across a range of health settings found that that factors other than verbal communication (such as warmth and listening skills) were significantly associated with service user satisfaction.(Henry, Fuhrel-Forbis, Rogers, & Eggly, 2012).

Conclusion. Overall, this study raises some important findings in relation to service user satisfaction with prosthetist communication, and the statistically significant finding this showed in predicting better outcomes over other coping styles in explaining functional and aesthetic satisfaction towards prosthesis. Clearly, more research needs to be established in this field, which may further refine theoretical understandings and support the need to invest in health service policy and planning in this context. Ultimately it may be of use for more comprehensive policy regarding communication to be introduced to guide the prescription consultation in implementing such findings in clinical practice.

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Appendix 2-A

Contents

Table 1

Demographic and clinical characteristics (N = 54)

		n	%	Mean (SD)	Range
Gender					
	Male	28	51.9		
	Female	26	48.1		
Age				43.68 (11.89)	22-67
Reason for amputation					
Disease:	Peripheral Vascular Disorder	2	3.7%		
	Diabetes	4	7.4%		
	Cancer	6	11.1%		
Trauma:	Accident	29	53.7%		
Other:		13	24.1%		
Type of amputation					
	Below-Knee	32	59.3%		
	Above-Knee	17	31.5%		
	Below-Elbow	3	5.6%		

	Through-Elbow	1	1.9%		
	Above- Elbow	1	1.9%		
Time since amputation (years)				8.60 (11.26)	0-49
How long have you had a prosthesis? (years)				8.26 (11.19)	0-49
How long have you had your current prosthesis? (years)				1.92 (3.30)	0-21
Stump pain	Yes	36	67%		
	No	18	33%		
Phantom pain	Yes	19	35%		
	No	35	65%		
Daily prosthesis use (hours)	0-3	5	9%		
	4-7	6	11%		
	8-11	15	28%		
	12-15	20	37%		
	16-19	8	15%		

Table 2

Cronbach's alpha values

Measure	α
TAPES-R psychosocial	.844
TAPES-R activity restriction	.753
TAPES-R satisfaction	.896
BC self distraction	.703
BC active coping	.691
BC denial	.739
BC substance use	.737
BC emotional support	.679
BC instrumental support	.675
BC behavioural disengagement	.732
BC venting	.705
BC positive reframing	.724
BC planning	.675
BC humour	.771
BC acceptance	.748
BC religion	.727
BC self blame	.735
MSPSS	.966
Shared decision making	.957
Interview satisfaction	.957

Note: BC = Brief Cope

Table 3

Spearman's correlation for predictor and outcome variables (Rho followed by p)

		TAPES -R Psychosocial	TAPES-R Activity Restriction	TAPES-R Satisfaction (Functional & Aesthetic)
Clinical variables	Stump pain[a]	-.301 .033*	.200 .147	-.197 .170
	Time since Amputation	.242 .078	-.230 .014*	.215 .120
	Phantom Pain[a]	-.116 .412	.065 .643	-.077 .592
Demographic variables	Age[a]	-.026 .851	.215 .121	.154 .271
	Gender[a]	-.199 .396	-.225 .105	-.158 .256
Psychosocial variables	BC denial	-.312 .022*	0.80 .566	-.181 .205
	BC substance use	-.397 .022*	.332 .014**	-.313 .023*
	BC Emotional support	-.429 .001**	.362 .008**	-.147 .316
	BC instrumental support	-.470 .001**	.342 .012*	-.184 .191
	BC behavioural disengagement	-.447 .001**	-.358 .008**	-.344 .024*

	BC venting	-.403 .001**	.335 .014*	-.239 .097
	BC humour	.318 .003*	.276 .049*	.276 .049*
	BC acceptance	.330 .020*	-.150 .286	.245 .077
	BC self blame	-.305 .029*	.399 .003*	-.333 .024*
	BC positive reframing	.103 .484	.112 .425	.156 .299
	BC planning	-.189 .178	.247 .076	-.156 .277
	BC self distraction	-.205 .144	.226 .105	-.034 .817
	BC active coping	-.245 .077	.271 .052	-.128 .382
	BC religion	-.202 .144	.150 .282	.025 .860
	MSPSS	.227 .106	-.161 .259	.164 .263
Communication Variables	Shared decision making	.248 .077	-.095 .506	-.356 .012*

Interview satisfaction	.291 .039*	-.067 .693	-.457 .001**

*p <.05.; **<0.01. A two tailed p value was used to determine significance.

a:These were entered as binary variables; (do you experience) stump pain: 0 = no, 1= yes; (do you experience) phantom pan: 0 = no, 1= yes; gender: 1= male, 2= female)

Table 4

Descriptive statistics for predictor and outcome variables.

Variable	Possible range	Range	minimum	maximum	M	SD	Median
Stump pain	0-1	1	0	1			
BC denial [a]	2-8	5.0	2.0	7.0	2.7	1.17	2.0
BC Substance use	2-8	6.0	2.0	8.0	2.8	1.4	2.0
BC emotional support	2-8	6.0	2.0	8.0	4.4	1.6	4.4
BC instrumental support	2-8	6.0	2.0	8.0	3.9	1.6	4.0
BC behavioural disengagement	2-8	6.0	2.0	8.0	2.6	1.3	2.0
BC venting	2-8	5.0	2.0	7.0	3.2	1.1	3.0
BC humour	2-8	6.0	2.0	8.0	5.0	1.9	5.0
BC acceptance	2-8	6.0	2.0	8.0	6.8	1.4	7.0
BC self blame	2-8	6.0	2.0	8.0	3.18	1.5	3.0
Shared decision making [b]	0-45	40.0	0	40.0	23.7	10.8	23.7
Interview satisfaction [c]	1-60	48.0	12.0	60.0	46.4	11.2	46.2
TAPES- R Psychosocial [d]	3-12	6.4	5.4	11.8	9.1	1.5	9.3
TAPES-R Activity restriction [e]	0-2	1.5	0.30	1.80	1.0	0.4	1.0
TAPES-R Satisfaction [d]	8-24	15.0	8	23	16.0	4.1	16
Phantom pain	0-1	1	0	1	-	-	-
Age	22-67	45	22	67	43.6	11.8	43.3

Gender	1-2	1	1	2	-	-	-
BC planning	2-8	6.00	2.00	8.00	5.1	1.8	5.0
BC self distraction	2-8	6.00	2.00	8.00	4.9	1.5	5.0
BC active coping	2-8	6.00	2.00	8.00	5.5	1.8	5.5
BC religion	2-8	6.00	2.00	8.00	3.3	1.6	3.0
MSPSS[f]	1-7	5.00	1.00	6.00	4.6	1.1	4.6

Note: For all BC subscales higher scores indicate greater use of that strategy.

b = the greater the score, the more shared decision making was present in consultation

c = the greater the score, the more satisfied participants were with their consultation

d = the greater the score, the better the adjustment

e = the greater the score, the greater the limitation in activity

f = mean scores from 1 to 2.9 could be considered low support; a score of 3 to 5 could be considered moderate support; a score from 5.1 to 7 could be considered high support.

Section Three: Critical Appraisal

Submitted in partial fulfilment of the
Lancaster University Doctorate in Clinical Psychology

May 2018

Doctoral Thesis

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2479 words

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In this critical review, I will discuss the process of conducting the research with regards to my epistemological stance, and offer an overview of the research process with an initial presenting summary of the main findings of the literature review and research paper. I will discuss the strengths and limitations of the research process, particularly within the requirements of a Doctorate in Clinical Psychology thesis. Finally, I will offer my personal reflections on conducting the research, with regards to how it may inform my clinical practice.

My epistemological position

Overall, my reason for undertaking research in this field is related to my broad interest in psychosocial adjustment following limb loss. This process has enabled me to further consider my epistemological position and whether a qualitative or quantitative methodology was more suitable. Epistemological positions may be viewed as being on a continuum, with positivism and social constructionism being the furthest apart from each other. In between these two stances lies critical realism (Mills & Birks, 2014) which is the position I have come to adopt. In line with positivism, I acknowledge that psychosocial occurrences can be measured through experimental means, but objectivity may not be value free, as reality is shaped according to the subjective interpretations of individuals. Therefore reality can be observed and interpreted through the use of empirical research, but this does not inherently mean it is the ‘truth’ (Cruickshank, 2003). Thus in line with this perspective, both qualitative and quantitative approaches were incorporated into my research as, regardless of epistemological position, both can complement each other to further explore a phenomenon of interest (Borland Jr, 2002).

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Summary of research. The literature review was conducted to explore how individuals with limb loss experience and cope with appearance related stigma. The findings highlight that stigma related experiences have the potential to alter people's life experiences, specifically relationships, social engagement, identity and how then go on to relate to themselves and their environmental context. Four themes were identified through this meta-synthesis of 29 studies, 'the need for social connection versus independence', 'identity formation: renegotiating self', 'concealing or avoiding', 'internal resilience and new ways of thinking and relating'. The findings of the review suggest that stigma related experiences are apparent in the lives of some individuals with limb loss. Clinical psychologists are in a privileged position to challenge discrimination and promote opportunities for social inclusion. Some even suggests that psychologists should take on advocacy (Cohen & Lee, 2012), as this facilitates the implementation of research findings at local and national levels. Influencing policy is considered an important initiative within the profession of psychology (Matthews & Anton, 2007). On an individual level, this meta-synthesis has highlighted the implications of experiencing stigma which had negative consequences for identity and self-worth. This offers a direction for practitioners considering psychological input on an individual, systemic and organisational level.

The aim of this study was to investigate service user satisfaction with their prosthetists' communication style in consultation in order to identify whether this predicted several prosthesis related adjustment outcomes above other predictors. A total of 54 participants completed online self report questionnaires concerned with shared decision making, satisfaction with consultation and psychosocial adjustment. Demographic and clinical variables were also collected. An initial interesting observation was that there was a relatively equal balance between male and female participants taking part, which contradicts that of previous research which has been largely dominated by male respondents (Sarvestani &

TaheriAzam, 2013). Through hierarchical regression analysis, the findings of the study highlighted that the addition of communication predictors made a significant contribution to the overall model in TAPES-R satisfaction in functional, aesthetic and weight of their prosthesis, with an additional predictive value of 29.0% over other known determinants. The finding have implications for rehabilitation services, particularly in communication skills training being made available to prosthetists and more comprehensive policy guidelines on the role of communication in the prosthetic consultation process. A surprising finding was that communication variables were not predictive of TAPES-R psychosocial adjustment, and TAPES-R activity restriction, and this may reflect statistical issues and/or the complexity of understanding, conceptualising and measuring adjustment. This current study could have been further enhanced through the use of a qualitative element, which would lend further insight into service user views and personal stories regarding professional communication style and satisfaction before during and after the prosthetic consultation, and how this personally informed adjustment.

Benefits, draw backs and ethical considerations regarding the research. The choice of using an online survey for data collection was appealing due to its administrative ease (given the limited time frame to conduct the study) and its applicability in being able to target large and diverse international samples (Gosling & Mason, 2015). Despite this, there are concerns that online samples may often lack diversity and thus findings may not be entirely representative of the general population. For instance, research suggest that in the west, individuals from ethnic minority backgrounds and those classed as having a lower socioeconomic status are underrepresented in online research samples (Van Dijk & Hacker, 2013). It may have been useful to offer a viable alternative to participants who wanted to take part in the research but did not have access to a computer or the internet. In such instances, a paper copy of survey could have been made available and posted out with a free return envelope. Furthermore, alongside other demographic information, the survey could have collected information on broader sample characteristics such as nationality in order to check for a diverse sample range. Incomplete data was another issues related to this research, and although multiple imputation techniques were used to alleviate the impact of this, possible preventive measures could have been put in place to lessen this risk. For example, the application of validation rules, which requires participants to answer all the questions on each page of the survey in order for them to proceed to the next section. However it was decided against this as it could be coercive, and burden participants into answering questions they may have otherwise chose not to. Due time limitations a pilot study was not conducted, however this may have shed light on some of these issues prior to the research taking place. Drop-out rates are generally more common in online research due to the ease in closing down the web-browser and having no conformity pressure to the researcher as with in person assessment (Coulson, 2015). A possible way of reducing attrition in the future would be to use shorter outcome measures, thus reducing the duration of the survey and attrition related factors such as concentration, fatigue and motivational factors. There are also ethical concerns, that psychological research online naturally goes against the way behaviour and phenomena is typically observed and assessed by psychologists, which could lead to important elements being missed, and limiting the generalizability to daily life. An attrition reducing factor in research other than that conducted online is that the researcher could have more control over monitoring and engagement factors, especially in instances where participants are unsure or confused by questions on measures or have any psychological responses. It should be acknowledged that the outcome measures used in this study were psychologically sensitive and thus could have evoked an avoidant response in participants, which could explain the missing data on some outcomes measures across the data. Although this was carefully managed through providing researcher contact details and signposting options for relevant support services, in the future, I may provide contact details on every page of the questionnaire to encourage participants to get in contact if they have any queries' as this may reduce the risk of discontinuation. Reasons for non- participation or premature discontinuation would be of interest to help inform and improve the design and nature of future research, as this was a limitation in the current research.

The sample size for this study was significantly lower than what was required. The final sample size was 54, which was less than a priori power calculation, which recommended a sample size of 166. This sample size is reflective of the difficulties in recruiting for this study. A possible reason for this was that a similar research project was being conducted with this clinical population at the same time and through the same online organisations, so it could be that participants only wanted to take part in one project, rather than two simultaneously or had a preference. A factor which could have remedied this would be to have gained further ethical approval to recruit through NHS services and offered a paper copy version of the survey as, this could have enabled further access to participants not only from an online sample but also currently receiving prosthetic consultation. Thomas, Turpin & Meyer (2002) state that, due to NHS financial cuts and an increase in clinical responsibilities, the role research plays in clinical psychology is under threat, and the value of research and its associated credentials could be lost. Research opportunities should be made available to every service user accessing the NHS (NHS Confederation, 2008). Clinical psychologists have contradictory attitudes towards evidence based practise and differ according to the value they place on research guiding clinical activities (Trull & Prinstein, 2012). Despite this, it is generally agreed that for psychology to continue being recognised as a leading behavioural science, evidence base practise is imperative (Bohall & Bautista, 2017), and clinical psychologists actively involving themselves in NHS research could further advocate both the need and value for this.

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It is assumed that some individuals who took part in the research may have been providing retrospective accounts of their experiences when scoring the outcome measures. It is important to consider the potential biases with retrospective data such as difficulty with memory recall or psychological state. A further consideration is that cognitive impairment is more prevalent in the amputation population in comparison to the general population (for a review see, Coffey, O'Keeffe, Gallagher, Desmond & Lombard, 2012), and the longest completion time one individual took was 75954 seconds (approx. 21 hours), although participants were able to take breaks and return to the questionnaire. Factors such as memory and psychological state could have been assessed in this research, however measures were selected sensitively, as use of lengthy outcomes measures should not override the burden this may place on participants. To improve my research skills in the future, I would consider additional factors such as this, and rather than overwhelm participants with measures, facilitate research adaptations so the design is more appropriate in meeting the needs of a diverse population. This could involve a shorter survey and multisensory formatting, such as audio recorded questions to ease the load on cognitive function.

Reflections on conducting the research. Overall, I believe conducting this research has been both rewarding and challenging. I have gained a further appreciation for the value of the scientist practitioner paradigm within clinical psychology, and I believe both the combination of research and clinical practice is necessary to improve the delivery of healthcare. I believe my research experience will benefit my clinical practise as the two disciplines can involve the same core skills. For example, assessing, formulating and critically evaluating interventions can be drawn upon both in clinical practice and in research.

Through conducting this research, I have learned the value of bringing a psychological perspective to health and rehabilitative care, and generally integrating a psychological perspective across disciplines. The thesis journey has enabled me to reflect on the complex interlink between theory, research and clinical practise, and how research can be an important facilitator in merging the connection between the two (Kenney, 2002). Theoretical importance varies according to professional discipline, and some may argue that theory has limited relevance to clinical practise, as theoretical concepts are often tested in controlled conditions which can make it difficult to practically apply findings in dynamic real-life environments (Ajani & Moez, 2011). For others, theory and practise cannot be isolated, for practise requires knowledge and both are vital in order for any discipline to progress forward in line with the ever changing context (Goodson, 2010). I believe an important question following this research is how theory can be merged closer to clinical practise in order to re-affirm its value. Some suggest there will always be a dynamic tension in attempting to achieve this, which may well serve to be the continuing driving force for change (Rafferty, Allcock, & Lathlean, 1996).

In sum, by seeking to investigate the health provider factors that may influence prosthesis related adjustment rather than the traditional approaches focusing on service user factors, I hope to have offered a contribution in guiding clinical practise by highlighting aspects that current services could see as amenable to change. This research reaffirms the importance of the contextual/environmental impact on acquired disability, and how healthcare services can improve service design and delivery in order to optimise service user wellbeing.

Thinking about disability more broadly, there has been a movement towards recognition and influence of psychosocial factors. For example, although not a theoretical model, The World Health Organization's International Classification of Functioning Disability and Health (ICF; WHO, 2001) has theoretical elements and is regularly referred to by rehabilitation practitioners. It has biopsychosocial components to classify and explain human functioning and disability through attending to the integrative link between body, the individual, and wider contextual factors (Benyamini, Johnston & Karademas, 2015). However, while this offers professionals a shared language and understandable method of classifying function (McPherson, Gibson, & Leplege, 2015), use of such measures in disability contexts should be further reflected upon in services. Whilst outcome/classification measures are a useful way for professionals to describe human functioning in order to understand how impairment may impact on life quality (Hengeveld & Banks, 2013), any tools that classify or categorise may reinforce that disability is a problem to be overcome, and that to be different is to deviate, which may inadvertently perpetuate stigma and exclusion experiences (Hammell, 2004). One limitation of using health classification outcome measures is that it may ‘foster a view of disabled people as catalogues of deficits and deprivations, rather than as people with various abilities and resources’ (Hammell, 2006, p. 18). This is of considerable importance, given the metasynthesis findings highlighting stigma as apparent in the lives of individuals with limb loss. Such findings are a reminder of ways services may continue to attend to the lives and individual journeys of indivduals’ with a disability, and not just focus on functional limitations per se. The individuals own appraisal of adjustment should be considered and services may seek to explore issues relating to identity following amputation, being aware of stigma and where possible, seek to reduce its impact. It is suggested that “the perspectives of disabled people are rarely permitted to infiltrate or influence professional theories” (Hammond, 2004, p.410), thus more attention to the individual beyond the use of adjustment tools may move one step closer to this.

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CRITIAL APPRAISAL

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Doctoral Thesis

Section Four: Ethics Section

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Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research[guidance1]

for additional advice on completing this form, hover cursor over guidance .

Guidance on completing this form is also available as a word document

Title of Project[guidance 2]: Does prosthetist communication style predict psychosocial adustment and satisfaction with a prosthesis?

Name of applicant/researcher: shaneela malik

ACP ID number (if applicable)*: **Funding source (if applicable)**

End date:

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:

E-mail: s.malik1@lancaster.ac.uk **Telephone**: 07487646933 (please give a number on which you can be contacted at short notice)

Address: 4 Westfield Road, Nelson, Lancashire, BB9 7YN

3. **Names and appointments of all members of the research team (including degree where applicable)**

Shaneela Malik Principal Researcher, DClinPsy
Dr Craig Murray Academic Supervisor
Dr Jane Simpson Field Supervisor

ETHICS SECTION

3. **If this is a student project, please indicate what type of project** by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

N/A

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words[guidance 9]):

Limb amputation can be a life altering experience and quality of life can be reduced. Successful adaptation requires both physical and psychosocial support and this can be enhanced by health services involved in offering treatment and care.

Communication styles within healthcare consultations can impact service users, and treatment outcomes are likely to be more successful if health providers employ shared decision making. Using a quantitative approach, this study will investigate if service user satisfaction with communication during the prosthetic prescription process is related to adjustment outcomes. Data will be collected internationally online using Qualtrics survey software. Recruitment will be via groups and organisations involved in amputation and prosthesis use, and will included prosthesis users aged 18 and above, of any gender, nationality and ethnicity. Data will be analysed using a hierarchical regression analysis. Findings may have implications for future healthcare practise, and will be written for a doctoral thesis.

2. **Anticipated project dates (month and year only**[guidance 10])

Start date: 08/2017 End date: 05/2018

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender[guidance 11]):

The minimum and maximum number of participants included in the study was inferred using an electronic power calculator, G*Power 3.1.9.2, with an estimated medium effect size (F^2=0.15) and 10 predictors (Gender, age, time since amputation, amputation aetiology (trauma or disease), phantom paIn, stump pain, communication and satisfaction with communication, coping, social support). G Power indicates that in order to detect a significant effect, (P= .05), at a power level of 0.8, the study would need to have a minimum sample size of 114 participants. Therefore, a minimum of 114 participants will be recruited. There will be no maximum number. All participants who complete the survey during the data collection period will be included
One sample will be sought:

A sample comprised of people who have lost a lower limb through amputation, or who have congenital limb absence /deficiency, and who have gone through a prescription consultation process with a prosthetist for the purpose of receiving an artificial limb.

ETHICS SECTION

Inclusion criteria:

Participants will be people who are:

(1) Adults of any gender, ethnicity and nationality, aged 18 or over, who have lost a lower limb through amputation, or who have congenital lower limb absence /deficiency

(2) Have gone through a prescription consultation process

(3) Are able to read and understand English and are willing to take part in the research.

Exclusion criteria: No additional exclusion criteria will apply

4. How will participants be recruited and from where? Be as specific as possible[guidance 12]. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be contacted through online charities, organisations and forums and if they are willing to take part in the research, they will be asked to complete a survey online.

Participants will be sought via advocacy organisations for people with limb loss/difference, using on -line websites, forums and appropriate social media (such as Twitter) as well as advertising in the on-line and print editions of these organisations publications. Examples of such organisations include the Limbless Association in the UK, and the Amputee Coalition (in the USA).
Consent to advertise will be sought from the website forum moderator prior to any advertising taking place.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Self-report questionnaires will be administered and the following will be used:

Shared Decision Making Questionnaire (SDM-Q-9) (Kriston et al., 2010)
Interview Satisfaction Questionnaire ISQ; Grayson-Sneed et al., 2016).
Multidimensional Scale of Perceived Social Support ; MSPSS) (Zimet, Dahlem, Zimet & Farley, 1988)
Brief Cope (Carver 1997).
The Trinity Amputation and Prosthesis Experience Scales- Revised ,TAPES-R(Gallagher & MacLachlan, 2000)

The rational for use of these measures can be found in the research protocol attached.

Analysis

A survey created using Qualtrics software will be used to collect data, and SPSS software will be used to analyse the data, using hierarchical regression analysis. Mediator or moderator analysis may also be used depending on the patterns of associations highlighted by the preliminary correlational analysis. Data will be analysed using SPSS statistics package version 23.

Hierarchical regression analysis will be used to identify psychological adjustment outcomes ('wellbeing') as a product of the communicational style of prosthetists and patients' satisfaction with this. It is hypothesised that, satisfaction with prosthetist communication style in consultations, in a hierarchical regression analysis, will demonstrate significant predictive value in adjustment outcomes above other predictors.

Raw scores will be coded and scales will be scored in line with scale instructions. Cronbach's alpha s will be calculated for each of the scales to measure scale internal consistency.

Descriptive statistics for all data and formal measures used in the study will be provided which will give more detail on the clinical characteristics of the sample.

Normality will be assessed using histograms, box plots and quartile-quartile plots. In order to assess for objective assessments of distribution, Kolmogrov -Smirnov (K-S) and Shapiro -Wilk (S-W) tests will be conducted on all continuous data. Any skewed variables will be corrected using the appropriate transformations. Missing data will be analysed and appropriately handled.

Data will be examined to assess whether the data is missing at random or not at random, and the appropriate insertions will be made.

Predictive analysis

Correlational analysis (using Pearsons r: two-tailed) will be conducted in assessing for the strength of any relationship between predictor variables and the outcome variables (psychosocial adjustment, activity restriction, satisfaction with the prosthesis). Variables which are strongly correlated will be suitable or insertion into the regression analysis.

Hierarchical regression analysis will be used to explore the study hypothesis. Predictor variables (currently estimated at 10) will be entered into the regression model in three blocks:

1) Demographic variables (Gender, age)/Clinical variables (time since amputation, amputation aetiology-trauma or disease, phantom and/or residual limb pain)
2) Psychological variables (social support, coping)

3) communication and satisfaction with communication

The dependent variables are:

TAPES- R: Psychosocial adjustment (General Adjustment, Social Adjustment, and Adjustment to Limitation), Activity Restriction, Satisfaction with the Prosthesis.

Tolerance and inflation statistics will be computed due to the possibility of high multicollinearity levels in regression models that have a large and similar number of determinants. Tolerance levels should exceed 0.2 and the variance inflation factor (VIF) should be fewer than ten (Field, 2010). To assess for levels of autocorrelation, Durbin–Watson statistics will be calculated (Edgar & Skinner, 2003).

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998[guidance 13].

The participants identity and personal information will be protected. Every participant will be given an anonymised number which makes the data identifiable only to the researchers. Any related documents with personal or identifiable information (such as consent forms) will be transferred onto a password protected file space on the university server. These will be kept until the project is marked and will be destroyed after this. Consent forms will be kept on the secure university server for 10 years or 10 years from publication if published.

7. Will audio or video recording take place? no audio video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.[guidance14]

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed[guidance 15]?

no video or audio recordings will take place

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. [guidance16]PURE?

The principle researcher will be allocated a personal file space on the lancaster university secure server (H) drive, where all electronic data can be stored securely . No identifiable information will be stored or collected. At the end of the study, all data will be encrypted for transfer to long term storage. The data will be sent to the programme research coordinator using an electronically secure method of data transfer and stored in a password protected file space on the university server. Data will be stored for 10 years. After this time, the programme research coordinator will be responsible for deleting the data 8b. Are there any restrictions on sharing your data [guidance17]?

Data will only be accessible to members of the research team.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent[guidance 18]?

A procedure for obtaining consent will be incorporated into the online survey. Initially, the participant information sheet for the study will be provided, and participant will be advised to take sufficient time to understand this and consider whether they would still like to proceed with the survey. Next, participants will be presented with a number of statements relating the research, of which they would need to consent to, by checking the corresponding box . If all of the consent boxes are not checked, any missing information will be highlighted before the person can proceed to the questionnaire. Any data that has been inputted will be included in the final analysis.

10. What discomfort (including psychological e.g. distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks[guidance 19]. State the timescales within which participants may withdraw from the study, noting your reasons.[guidance 20]

There are no anticipated risks associated with this research. However consideration must be given to the possibility of participants becoming distressed when completing this survey. Sources of support will be provided at the start and the end of the questionnaire. Prior to starting the survey, participants will be informed that they are able to opt out at any moment during the survey/ All completed data will be used from the survey, even if the whole questionnaire is completed. However, as the online completion of the survey is anonymous, if a participant completes the whole survey, it will not be possible to extract their data at this stage.After participating in the research, if participant experiences mental or physical health difficulties they will be advised to contact a support line or seek professional medical support. As this study is open to people internationally, signposting options will be made available which includes online international support agencies. Every effort will be taken to ensure study acceptability of the participation process. However if a participant disagree's with aspects of the research in terms of its content or language use, they will be provided

ETHICS SECTION

with contact details at Lancaster university should they wish to make a formal complaint.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take[guidance 21]).

As the researcher will not be meeting participants in person, it is considered that there will be minimal risks to the researcher.If the researcher decides to present the research to amputee meeting groups, the Lancashire Care NHS Foundation Trust Lone Worker Policy Guidelines will be adhered to. This is available at: http://www.lancaster.ac.uk/shm/doctoral_study/dclinpsy/onlinehandbook/appendices/lcft_lone_working_policy.pdf
After conducting the study, if the researcher becomes distressed, they will be able to seek peer support from the department of clinical psychology at Lancaster University. Additional support will also be made available from the field and academic supervisor, and the clinical tutor.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study[guidance 22].

There are no direct gains to taking part in the study. It is hoped that the survey will be of interest to participants, and that the study will benefit healthcare provision by leading to a better understanding of prosthesis use.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants[guidance 23]:
There will be no incentives or payments made to participants.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality[guidance 24].

This study will take a quantitative, cross sectional design. Using Qualtrix online survery software, data will be collected via a series of self report. No personally identifiable information will be collected. The nature of collecting data online ensures complete anonymity, as no personally identifiable information is required. Participants will also be made aware that their data will be confidential, and stored securely, and may only be accessed by members of the research team.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research[guidance 25]. N/A
N/A

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis[guidance 26].

The research will be submitted to Lancaster university as a doctoral thesis. The findings will be made available in short report, and disseminated to organisations, groups or forums involved in recruiting participants.

The research will be written for publication in an academic peer reviewed journal. The research findings may be presented at conferences, support groups or to health care teams in the field of amputation and prosthesis use

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study[guidance 27]? Are there any matters about which you wish to seek guidance from the FHMREC?
There are no further ethical consideration identified.

SECTION FOUR: signature
Applicant electronic signature[guidance 28]: S.Malik Date 27/06/17

ETHICS SECTION

Student applicants: please tick to confirm that you have discussed this application with your supervisor, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Craig Murray Date application discussed 27/06/2017

Research Protocol

Limb amputation is known to result in numerous physical and psychosocial challenges (Horgan & MacLachlan, 2004), and successful adaptation requires both physical and psychosocial support (Murray, 2009). This can be enhanced through not only the individual, but their family and the health services involved in offering their treatment and care (Unwin & Kacperek, 2009). Quality of life, although subjective, is generically defined as the perception someone places on their life, relative to their standards, values and interests, life satisfaction and wellbeing in relation to their context (Larsen & Lubkin 2009).

A key issue for the multi-disciplinary team involved in post-amputation care is prosthesis rejection (Murray, 2009), whereby many people with limb loss do not become 'successful' prosthesis (artificial limb) users. Research would indicate that the communicational styles of prosthetist (professionals who provide artificial limb replacements for individuals experiencing limb loss) can impact on whether the person will learn and continue to use a prosthesis (Pezzin et al., 2004). More understanding of the communication styles between prosthetists and service users could be beneficial in improving the quality of health care in this context, enhancing the care experience of people who have had an amputation, and informing and guiding future practice (Murray, 2013).

Thus, the impact of prosthetist communication style on service user health outcomes needs further consideration. One study looking at service user satisfaction with prosthetic services found that prosthetist communication was an important element. Here service users generally rated their prosthetist acceptable in terms of their technical expertise, but they were less satisfied with their interpersonal skills and felt that consultations lacked any discussion around wellbeing (Pezzin et al, 2004). Considering this, it can be suggested that not only is the treatment itself vital, but equally vital is the development of the care provided throughout this process, and the manner that this is delivered by health providers (Del piccolo & Goss, 2012; WHO, 2007).

The majority of previous research addressing the impact of communication styles in the health care context involves the doctor-service user relationship. The literature suggests that shared decision making (SDM) is the preferred model of health provider- health receiver communication, and has been advocated (Whitney, McGuire & McCullough, 2004) due to its repeated association with positive service user outcomes (Guadagnoli, 1998, Joosten et al., 2008, Légaré et al., 2012; Ong et al., 1995). However, it has since been argued that the focus should not be limited to just physicians or the medical encounter (Kraszewski & McEwan, 2010). Furthermore, there is currently little emphasis on the impact of communication styles within consultations between prosthetists and people with limb loss/absence, and by improved communication within the prescription process, service users could be further supported in making informed decisions regarding their treatment and care (Murray, 2013), T

This study will investigate the service users experiences of prosthetic consultation, their satisfaction with this, and investigate the impact this has on a number of adjustment outcome. It terms of a formal hypothesis, it is predicted that satisfaction with prosthetist communication style in consultations, in a hierarchical regression analysis, will demonstrate significant predictive value in quality of life outcomes above that consistently demonstrated by other predictors.

Method

Design

The research will be quantitative and a cross sectional design will be used to best investigate the predictive relationship between service user satisfaction with their prosthetist's communication style, and quality of life outcomes. Data will be collected using a number of self-report questionnaires and these will be made available to access online, through Qualtrics online survey software. The survey can be accessed here:

https://lancasteruni.eu.qualtrics.com/SE/?SID=SV_bgvmPKahig9NflX&Q_CHL=preview&Q_JFE=0&Preview=Survey

All study materials will be available online. Upon entering the study, participants will be presented with an electronic information sheet, before initiating their consent to participation. Once consent has been given, participants will be asked to provide socio-demographic information, including, gender and age. A number of questions will follow, asking participants to provide further details on their amputation (type of limb loss, cause of amputation, time since amputation) and time using their prosthesis (hours per day and days per month). Following this, a test battery of questionnaires will be presented (Please see copies of the questionnaires attached in the appendix).

Participants

Participants will be recruited internationally, through groups and organisations that are involved in prosthesis use and amputation. For instance, organisations such as the Limbless Association and the Amputee Coalition will be approached to advertise the study and online forums will be approached. Participant sample size was inferred using an electronic power calculator, G*Power 3.1.9.2, with an estimated medium effect size (F^2=0.15) and 10 predictors (Gender, age, time since amputation, amputation aetiology (trauma or disease), phantom pain, stump pain, communication and satisfaction with communication, coping, social support). G Power indicates that in order to detect a significant effect, (P= .05), at a powerlevel of 0.8, the study would need to have a minimum sample size of 114 participants. Therefore, a minimum of 114 participants will be recruited. It is important to note that this is a power analysis which has been estimated based on the whole of the regression model (with all variables included, not just the additional block contribution) as this requires more participants than an individual block analysis. It is not a power calculation for the additional variance that is going to be explained by the variables of interest in this study).

Inclusion Criteria

Participants will;

- Have an acquired lower limb amputation (surgical removal of a limb due to trauma or disease), or who have congenital limb absence /deficiency
- Have gone through a prescription consultation process
- Be able to read and understand English and are willing to take part in the research.
- Be aged 18 or over
- Have a prosthesis.

Exclusion Criteria

- No additional exclusion criteria will apply.

Due to the study being presented in the English language, it may be a possibility that this will impact on the demographics of the individuals who choose to take part.

Materials

The Trinity amputation and Prosthesis Experience Scales (TAPES-R; Gallagher, Franchigoni, Giordana, & MacLachlan, 2010). The TAPES-R is a multidimensional measure, which enables understanding of an individual's adjustment to a lower limb prosthesis. It comprises of three sections which can be used independently. Section one is made up of three sub sections, psychosocial adjustment, activity restriction and satisfaction with the prosthesis (both aesthetic and functional), and section two also comprises three sub sections (phantom limb pain, residual limb pain and other medical conditions). The TAPES- R Psychosocial is one aspect of the Trinity Amputation and Prosthesis Experience Scales Revised (TAPES-R: Gallagher, Franchignoni, Giordano, & MacLachlin, 2010), which is a scale comprising of 15 items assessing psychosocial factors relating to the amputation process. This measure in made up of three subscales five items each, general adjustment, social adjustment and adjustment to limitation. Participants select choices from a four point likert scale, scores on item 1-10 range from 1

(strongly disagree) to 4 (strongly agree), and 11 to 15 range from 4 'strongly disagree' to 1 'strongly agree'. Participants can also select 'not applicable' which will not be scored. The sum is calculated by the average of the applicable items and the greater the score, the more this indicates enhanced adjustment. The total psychosocial adjustment score is computed by the total of the three subscales, which ranges between three to twelve.

The section 'activity restriction' is comprised of 10 items and is a three point likert scale which asks participants to rate how limited they are in doing certain activities in day. Participants are asked to select from 0= no, not limited at all, 1= limited alittle and 2= yes, limited a lot.

A further aspect of The TAPES-R is satisfaction which is made up of two subscales, aesthetic satisfaction (comprised of three items) and functional satisfaction (five items). Participants can select from a three point likert scale, 1 'not satsified', to 3 'very satisfied' . To obtain a total, responses are summed for each subcale. For aesthetic satisfaction, scores range from three to nine, and total scores functional satisfaction range between five to fifteen. The greater the score, the more this is indicative of satisfaction. To obtain the total satisfaction score, the total from both subscales can be combined, and the range for this is between eight and twenty four.

The TAPES-R is a psychometrically revised update from the original TAPES. The measure has adequate psychometric properties, demonstrating good validity and reliability and is deemed suitable when implemented in the adult population, both for research and clinical purposes (Gallagher & MacLachlan, 2000; Gallagher et al., 2010). It has adequate internal consistency, general adjustment (α =.90), social adjustment (α = .89), and adjustment to limitation (α = .86); aesthetic satisfaction (α = .85) and functional satisfaction (α =86; Gallagher et al., 2010).

The Brief Cope (Carver, 1997). Based on the Cope inventory, this is a brief measure of coping responses (Carver et al., 1989). This measure is made up of 28 items and is a four point likert scale. Participants are instructed to read each item and then rate how often they are doing that particular statement. Rather than this measure giving a total score, but is comprised of 14 subscales of coping (e.g.'acceptance') which are scored by combining the results from the 2 corresponding items, resulting in a range of 2-8 for each scale. The increase in the score indicates an increase in frequency. Research provides evidence that the Brief COPE has good psychometric properties (Teresa et al., 2017). The Brief COPE is considered to have good reliability and validity when assessing for coping strategies (Norlander, Von Schedvin, & Archer, 2005) and health studies report it demonstrating a good internal consistency (cronbach's alpha = 0.50 – 0.90) and construct validity (Carver, 1997; Michael, 2007). Is considered suitable for use with the general adult population (Windle, Bennert & Noyes, 2011) as well as for both clinical and research purposes (Carver, 1997).

The 9-item Shared Decision Making Questionnaire. (SDM-Q-9; Kriston, Scholl, Lars, lzel, Simon, Andreas, Harter, 2010). This questionnaire is made up of nine statements and there is a 5 point scale that the participant can use to rate their answer. This ranges from 0= 'completely disagree' to 5= 'completely agree'. A raw total score between 0 to 45 can be found by adding up all the items. The content of each statement in centred on understanding the level of shared decision making for the participant in their consultations and how much they agree or disagree with each statement. The information collected will aim to capture what participants say about their prosthetists as well as their own perspectives. Therefore questions will be modified for the audience and context in mind. Thus, statements in the questionnaire will be adapted by replacing the word ‘doctor’ with ‘prosthetist’ and ask more directly about participant preferences.

The Interview Satisfaction Questionnaire (ISQ; Grayson-Sneed et al., 2016).

The brief ISQ is comprised of 12 items which cover four elements of satisfaction: opportunity to disclose concerns, the empathy of the physician, and how confident and generally satisfied the participant is in their physician and the interaction. Items are measured on a 5 point Likert scale, which range between 1= ‘strongly disagree’ to 5= strongly agree. For the purpose of this study, the wording in the questionnaire will be adapted to assess more the relationship between the prosthetist and the service user. Therefore statements in the questionnaire will be adapted by replacing the word ‘physician’ with ‘prosthetist’. Research has shown that the ISQ, when reduced to 12 items, retains a high level of reliability and concurrent and construct validity (Grayson-Sneed et al., 2016).

Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley., 1988). The MSPSS is made up of 12 items which cover three main areas, family, friends and a significant other. Participants are asked to go through each statement and rate how much they agree or disagree with each one. The range goes from 0= strongly disagree to 7= strongly agree. Therefore the higher the rating, the greater the perceived level of social support. Good internal reliability has been shown for each of the three subscales (Libertus & Hauf, 2017). In a study examining a health related debilitating condition in an adult population, the cronbach alpha's reliability of the MSPSS ranged from 0.85- 0.98 and for the subscales, test-retest reliability ranged between 0.72-0.85 (Gunbey & Karabulut, 2014).It is considered useful for use in international research for its well established psychometric properties in international populations (Hodapp, 2010).

Procedure

The principal researcher will liaise with amputee support and discussion groups and use an online platform in order to recruit participants. A professional Twitter account will be used to contact organisations and a Lancaster university hosted webpage (http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/) will be used to advertise and share a link to the research study. For individuals who want to take part in the study, they will click on the research link which will then open up a webpage, where they will be provided information about the research and electronically sign a consent form if they still wish to participate. Participants will first be presented with pages for the participant information sheet and the consent form, and without the participant accessing these two first, the survey section cannot be reached. The survey will collect demographic information and questionnaire information. Completion of this section will automatically populate a database. This data will be extracted and analysed using SPSS statistical software (Version 23).

Analysis

Qualtrics will be used to collect data. Hierarchical regression analysis will be used to identify psychological outcomes (‘adjustment’) as a product of the communicational style of prosthetists and patients' satisfaction with this. It is hypothesised that, satisfaction with prosthetist communication style in consultations, in a hierarchical regression analysis, will demonstrate significant predictive value in quality of life outcomes above other predictors. Raw scores will be coded and scales will be scored in line with scale instructions. Cronbach alpha’s will be calculated for each of the scales to measure scale internal consistency.

Descriptive statistics. Descriptive statistics for all data and formal measures used in the study will be provided which will give more detail on the clinical characteristics of the sample.

Normality will be assessed using histograms, box plots and quartile-quartile plots. In order to assess for objective assessments of distribution, Kolmogrov-Smirnov (K-S) and Shapiro-Wilk (S-W) tests will be conducted on all continuous data. Any skewed variables will be corrected using the appropriate transformations.

Missing data analysis. Data will be examined to assess whether the data is missing at random or not at random, and the appropriate insertions will be made.

Predictive analysis. Correlational analysis (using Pearsons r: two-tailed) will be conducted in assessing for the strength of any relationship between predictor variables and the outcome variables (psychosocial adjustment, activity restriction, satisfaction with the prosthesis).

Variables which are strongly correlated will be suitable or insertion into the regression analysis.

Hierarchical regression analysis will be used to explore the study hypothesis. Predictor variables (currently estimated at 10) will be entered into the regression model in three blocks:

1) Demographic variables (Gender, age)/ Clinical variables (time since amputation, amputation aetiology- trauma or disease, phantom and/or residual limb pain);
2) Psychological variables (social support, coping)
3) communication and satisfaction with communication

Dependent variables (3): TAPES- R: Psychosocial adjustment (General Adjustment, Social Adjustment, and Adjustment to Limitation), Activity Restriction, Satisfaction with the Prosthesis.

Tolerance and inflation statistics will be computed due to the possibility of high multicollinearity levels in regression models that have a large and similar number of determinants. Tolerance levels should exceed 0.2 and the variance inflation factor (VIF) should be fewer than ten (Field, 2010). To assess for levels of autocorrelation, Durbin–Watson statistics will be calculated (Edgar & Skinner, 2003).

Practical Issues

In order to limit practical difficulties, all elements of the research will be completed online. This ensures participant anonymity and enables participants to complete the study where and when it is convenient to individuals. A personal file space will be made available to the principle researcher on a hardrive (Lancaster university secure server), in order to secure store electronic data.

On completion of the study, data will be encrypted so it is transferrable for long term storage. An electronic file transfer secure system will be used to transfer this data to the programme

Research Coordinator and this will be stored on the university server, in a personal protected file space.

Funding may be provided by the DclinPsy programme at the discretion of the Programme Director in order to involve amputation organisations in the research advertisement process. There will be no other reimbursements (for participation) or expenditures.

Ethical concerns

There are no anticipated risks for participation in this study. However, there is a chance, while completing the questionnaires, for participants to become distressed. Before starting the study, participants will be made aware that they can opt out, without giving reason, at any point during the test process and their data will not be included in the research. Data however, cannot be extracted if the test battery has been completed, due to all the online information being anonymous.

One the participant has read and understood the participant information sheet, they will need to provide consent before accessing the questionnaires. Participants will only be able to take part and provide their data if they consent to all aspects of the research process.

Due to the anonymity involved, it may be difficult for the principle researcher to identify any cause for concern. The participant information sheet will also include information advising the participant to seek medical and/or professional support if they are experiencing and mental or physical health difficulties. The email contact details of the researchers will be provided for participants to use if they have any other questions.

Despite having the involvement and feedback from the experts by experience, it is still a possibility for participants to disapprove of the study content and/or its language use. If this was to occur and the participant wanted to make a complaint, they will be provided with the relevant details for staff at Lancaster University who they can contact.

It is considered that the risk to the researcher is minimal, as no face to face contact will be made with participants. The researcher will follow the Lancashire Care NHS Foundation Trust lone working policy guidelines provided by Lancaster University when visiting Amputee support groups. This policy is available at:

http://www.lancaster.ac.uk/smh/study/doctoral_study/dclinpsy/onlinehandbook/appendices/lcft_lone_working_policy.pdf.

Appendix 3-C

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Participant Information Sheet

Title of Research:

Does prosthetist communication style predict psychosocial adjustment and satisfaction with a prosthesis?

Hi my name is Shaneela Malik and I am conducting this research study as part of my doctoral programme in Clinical Psychology at Lancaster University, Lancaster, United Kingdom.

What is the study about?

This research is investigating the communication styles in consultations between people who have an amputated limb and their prosthetist. It will also investigate how satisfied the person is with the communication style employed by their prosthetist, and whether this then impacts on quality of life.

Why would you like me to be involved?

We are interested in collecting information from individuals who have an amputated limb, and who have accessed or still are accessing, consultations with a prosthetist. Below is a list of inclusion criteria for this study. If you meet all of the criteria, we would be very grateful if you could take the time out to complete this survey.

Inclusion criteria:

(1) Adults of any gender, ethnicity and nationality, aged 18 or over, who have lost a limb through amputation, or who have congenital limb absence /deficiency

(2) Have gone through a prescription consultation process

(3) Are able to read and understand English and are willing to take part in the research

Is it compulsory for me to take part?

No. It is entirely your choice whether you decide to partake in this research.

If you decide to participate, it is still possible to change your mind at any point prior to completing the survey. Any data that has been entered in the survey will be included in the final analysis and once the survey is complete, it will not be possible to take out the data. Your care and relationship with your healthcare providers will not be adversely affected if you decide not to participate in the study.

What will be required of me if I take part?

By taking part in this research, you will be asked for your demographic information, and to complete a number of questionnaires relating to the communication style between you and your prosthetist, your satisfaction with this, and your general wellbeing and quality of life. The duration of the survey should take no longer than 20 minutes, although the exact time taken will vary from person to person.

Will my information be confidential?

All the information provided by you will be kept confidential. All data collection will be stored on a secure network at Lancaster University, and the only people who will have access to this information is the researchers themselves. The data will be kept for 10 years after which, deleted. Limits to confidentiality: As the survey will be completed online, it will be unlikely that researchers will be able to monitor the wellbeing of yourself or others. However, if there is any email communication which would concern the researchers about your welfare and that of those around you (e.g a deterioration in mental state and/or an increase in harm to self and/or others), the researchers would need to communicate such concerns with a support or health agency (general practitioner). If you are having any difficulties managing your physical and/or emotional health, we encourage you to contact your local health provider.

What will you do with my data?

Your data will be merged together with that of other participants. The data will then be analysed and written up as part of a doctoral thesis, and then examined by Lancaster University. The results may also be published in a professional or academic journal, and verbally presented to organisations, research and/or health teams who work in the field of amputation and prosthesis. If participants request, a brief summary of the findings will be made available to them. Please get in touch with the principal researcher if you would like this, by emailing:

s.malik1@lancaster.ac.uk

What are the risks to taking part in this research?

There are no anticipated risks to being involved in this study. However, following participation, if you notice an increase in distress, it is advisable that you terminate the study and contact your general practitioner or health provider in your area.

Sources of support

Here are some organisations that will be able to offer you support for emotional wellbeing, if at any point, you feel you need it. These services provide support are internationally located, please see their website for further details.

Befriender's Worldwide (http://www.befrienders.org)

'providing emotional support to prevent suicide worldwide- we listen to, and help people without judging them'

The Amputee Coalition (http://www.amputee-coalition.org)

'(We aim) to reach out to, and empower people' **Who can I contact if I wish to gain further information about the study?**

For further information, please contact the principal researcher Shaneela Malik on the following email:
s.malik3@lancaster.ac.uk

Complaints

If you have any concerns or if you wish to make a complaint about any aspect of this study and would prefer to speak to someone not directly involved in the research, please contact:

Programme Director: Bill Sellwood
b.sellwood@lancaster.ac.uk
Tel: +44 1524 593998
Clinical Psychology
Division of Health Research
Lancaster University
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If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email:
r.pickup@lancaster.ac.uk Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster

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Consent Form

Study Title: Does prosthetist communication style predict psychosocial adjustment and satisfaction with a prosthesis?

This research is investigating the communication styles in consultations between people who have an amputated limb and their prosthetist. It will also investigate how satisfied the person is with the communication style employed by their prosthetist, and whether this then impacts on quality of life.

Before signing the consent form, please take some time to read the participant information sheet

If you agree with each statement below, please mark each box.

1. I have read and understood the participant information sheet and I know what is expected of me in taking part in this research ☐

2. I have been given the opportunity to be in contact with, and ask the research team any questions I have relating to the study, and my questions have been answered sufficiently. ☐

3. I understand that I am voluntarily participating, and that I can withdraw at any stage prior to completion of the survey. ☐

4. I understand that once the survey has been completed, it will not be possible for me to withdraw my data. ☐

5. I understand that the information I provide will be strictly confidential, unless there are concerns that I may be at risk of harm to myself or others, in which case the principle researcher may share this information with support or health services. ☐

6. I understand that the information I provide will be electronically stored on a secure data base, and I consent to Lancaster university keeping my information for 10 years after the study has completed. ☐

7. I consent to my information being pooled with the responses from other participants for analysis, and for the results of this to be written up as part of a doctoral thesis. ☐

8. I understand that the principal researcher will discuss and share data with the supervisors of this study. ☐

9. I consent to the analysis of my responses being included in reports and publications, training events and conferences. ☐

10. I consent to take part in this study. ☐

☐

TAPES-R

What is this survey about?

This questionnaire looks at different aspects of having a prosthesis. The information gathered will be used to improve our understanding of aspects of prosthesis use and to assist in the development of better services for prosthesis users.

Demographic information (such as age and gender) is being collected as it may be useful for the researchers to see if differences in these are associated with preferences for prosthetist communication style, satisfaction with this, and psychological adjustment

1. Age: ________________________

2. Male: ☐

Female: ☐

Other: __________

3. How long ago did you have your amputation?

_______________ years _______________ months (If you have had more than one amputation surgery please refer to your first amputation surgery).

4. How long have you had a prosthesis?

_______________ years _______________ months

5. How long have you had the prosthesis that you wear at the moment?

_______________ years _______________ months

6. What type of prosthesis do you have? *(Please tick the appropriate box)*

Below-Knee [ ] Below-elbow [ ]

Through-Knee [ ] Through-elbow [ ]

Above-Knee [ ] Above-elbow [ ]

Other (please specify) _______________________________

8. What was your amputation a result of? *(Please tick the appropriate box)* Peripheral Vascular Disorder [ ]

Diabetes [ ]

Cancer [ ]

Accident [ ]

Other (please specify) ______________________________

Part I

Below are written a series of statements concerning the wearing of a prosthesis. Please read through each statement carefully. Then *tick the box* beside each statement, which shows how strongly you agree or disagree with it.

		Strongly disagree	Disagree	Agree	Strongly agree	Not applicable
1.	I have adjusted to having a prosthesis....................	[1]	[2]	[3]	[4]	[ ]
2.	As time goes by, I accept my prosthesis more.........	[1]	[2]	[3]	[4]	[ ]
3	I feel that I have dealt successfully with this trauma in my life	[1]	[2]	[3]	[4]	[ ]
4.	Although I have a prosthesis, my life is full	[1]	[2]	[3]	[4]	[ ]
5.	I have gotten used to wearing a prosthesis............	[1]	[2]	[3]	[4]	[ ]
6.	I don't care if somebody looks at my prosthesis	[1]	[2]	[3]	[4]	[ ]
7.	I find it easy to talk about my prosthesis	[1]	[2]	[3]	[4]	[ ]
8.	I don't mind people asking about my prosthesis......	[1]	[2]	[3]	[4]	[ ]
9.	I find it easy to talk about my limbloss in conversation	[1]	[2]	[3]	[4]	[ ]
10.	I don't care if somebody notices that I am limping	[1]	[2]	[3]	[4]	[ ]
11.	A prosthesis interferes with the ability to do my work	[4]	[3]	[2]	[1]	[ ]
12	Having a prosthesis makes me more dependenton others than I would like to be	[4]	[3]	[2]	[1]	[ ]
13 .	Having a prosthesis limits the kind of work that I can do	[4]	[3]	[2]	[1]	[ ]
14	Being an amputee means that I can't do what I want to do	[4]	[3]	[2]	[1]	[ ]
15.	Having a prosthesis limits the amount of workthat I can do	[4]	[3]	[2]	[1]	[ ]

2. The following questions are about activities you might do during a typical day. Does having a prosthesis limit you in these activities? If so, how much? *Please tick the appropriate box.*

	Yes, limited a lot	Limited a little	No, not limited at all	
(a) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports..................................	[2]	[1]	[0]	
(b) climbing several flights of stairs.................	[2]	[1]	[0]	
(c) running for a bus	[2]	[1]	[0]	
(d) sport and recreation	[2]	[1]	[0]	
(e) climbing one flight of stairs	[2]	[1]	[0]	
(f) walking more than a mile..........................	[2]	[1]	[0]	
(g) walking half a mile..................................	[2]	[1]	[0]	
(h) walking 100 metres	[2]	[1]	[0]	
(i) working on hobbies	[2]	[1]	[0]	
(j) going to work..	[2]	[1]	[0]	[ ] Not applicable

3. Please *tick the box* that represents the extent to which you are satisfied or dissatisfied with *each* of the different aspects of your prosthesis mentioned below:

	Not satisfied	Satisfied	Very Satisfied
(i) Colour.	[1]	[2]	[3]
	[1]	[2]	[3]
(ii) Shape	[1]	[2]	[3]
(iii) Appearance	[1]	[2]	[3]
(iv) Weight . . .	[1]	[2]	[3]
(v) Usefulness .	[1]	[2]	[3]
(vi) Reliability . .	[1]	[2]	[3]
(vii) Fit	[1]	[2]	[3]
(viii) Comfort . . .	[1]	[2]	[3]

Part II

On average, how many hours a day do you wear your prosthesis? ____________ hours

(a) Do you experience residual limb (stump) pain (pain in the remaining part of your amputated limb)? No [ ] Yes [ ]

(b) Do you experience phantom limb pain (pain in the part of the limb which was amputated)? No [ ] Yes [ ]

Brief COPE (Carver, 1997)

The next questions deal with ways you've been coping. Please read each statement carefully. Please indicate how you feel about each statement by selecting the appropriate response

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.	
2. I've been concentrating my efforts on doing something about the situation I'm in.	
3. I've been saying to myself "this isn't real."	
4. I've been using alcohol or other drugs to make myself feel better.	
5. I've been getting emotional support from others.	
6. I've been giving up trying to deal with it.	
7. I've been taking action to try to make the situation better.	
8. I've been refusing to believe that it has happened.	
9. I've been saying things to let my unpleasant feelings escape	
10. I ve been getting help and advice from other people.	

11. I've been using alcohol or other drugs to help me get through it.	
12. I've been trying to see it in a different light, to make it seem more positive.	
13. I ve been criticizing myself.	
14. I've been trying to come up with a strategy about what to do.	
15. I've been getting comfort and understanding from someone.	
16. I've been giving up the attempt to cope.	
17. I've been looking for something good in what is happening.	
18. I've been making jokes about it.	
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	
20. I've been accepting the reality of the fact that it has happened.	
21. I've been expressing my negative feelings.	
22. I've been trying to find comfort in my religion or spiritual beliefs.	
23. I ve been trying to get advice or help from other people about what to do.	

24. I've been learning to live with it.	
25. I've been thinking hard about what steps to take.	
26. I ve been blaming myself for things that happened.	
27. I've been praying or meditating.	
28. I've been making fun of the situation.	

The 9-item Shared Decision Making Questionnaire (SDM-Q-9)

[Example] **Please indicate which health complaint/problem/illness the consultations were about:**

[Example] **Please indicate which decision was made:**

Nine statements related to the decision-making in the above mentioned consultations are listed below.
For each statement please indicate how much you agree or disagree.

1. The prosthetist made it clear to me that a decision needs to be made.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

2. The prosthetist wanted to know how I wanted to be involved in making the decision.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

3. The prosthetist informed me that there are different options for treating my condition.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

4. The prosthetist precisely explained to me the advantages and disadvantages of the treatment options.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

The prosthetist helped me understand all of the
5.information

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

6. The prosthetist asked me which treatment option I prefer.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

7. The prosthetist and I thoroughly weighed up the different treatment options.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

8. The prosthetist and I selected a treatment option together.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

9. The prosthetist and I reached an agreement on how to proceed.

completely disagree | strongly disagree | somewhat disagree | somewhat agree | strongly agree | completely agree

completely disagree = 0
strongly disagree = 1
somewhat disagree = 2
somewhat agree = 3
strongly agree = 4
completely agree= 5

. Interview satisfaction questionnaire (ISQ;)—short, 12-item version

Please indicate how much you agree or disagree with each statement regarding your visits with your prosthetist	Strongly Disagree	Somewhat Disagree	Undecided	Somewhat Agree	Strongly Agree
I was able to tell the prosthetist what was bothering me	1	2	3	4	5
I had confidence in the prosthetist's abilities	1	2	3	4	5
The prosthetist made it easy to understand what, if anything, was wrong with me	1	2	3	4	5
The prosthetist gave me undivided attention	1	2	3	4	5
The prosthetist spent the right amount of time with me	1	2	3	4	5
I was pleased with my visit(s) with the prosthetist	1	2	3	4	5
The prosthetist always seemed to know what he/she was doing	1	2	3	4	5
I have a good deal of confidence in the prosthetist	1	2	3	4	5

The prosthetist treated me with a great deal of respect	1	2	3	4	5
The prosthetist tried to make me feel relaxed	1	2	3	4	5
The prosthetist made it easy for me to ask questions	1	2	3	4	5
Overall, I am satisfied with the prosthetist	1	2	3	4	5

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988) Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you **Very Strongly Disagree**
Circle the “2” if you **Strongly Disagree**
Circle the “3” if you **Mildly Disagree**
Circle the “4” if you are **Neutral**
Circle the “5” if you **Mildly Agree**
Circle the “6” if you **Strongly Agree**
Circle the “7” if you **Very Strongly Agree**

There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
My family really tries to help me.	1	2	3	4	5	6	7	Fam
I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
My friends really try to help me.	1	2	3	4	5	6	7	Fri
I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

Debrief

Thank you for taking the time to complete this survey. Your responses are most appreciated.
If you feel you need support following any of the issues covered, please contact your doctor who will be able to help further and refer you to the appropriate service if necessary. Alternatively, please visit the following websites (with international coverage), where you will find information on how you may be further supported.

Befriender's Worldwide (http://www.befrienders.org)
'providing emotional support to prevent suicide worldwide- we listen to, and help people without judging them'

The Amputee Coalition (http://www.amputee-coalition.org)
'We aim) to reach out to, and empower people'.

Who can I contact if I wish to gain further information about the study?
For further information, please contact the principal researcher Shaneela Malik on the following email:
s.malik1@lancaster.ac.uk

Complaints
If you have any concerns or if you wish to make a complaint about any aspect of this study and would prefer to speak to someone not directly involved in the research, please contact:

Programme Director: Bill Sellwood
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If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

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Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
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Lancaster University
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Doctorate in Clinical Psychology | Lancaster University

Have you had a limb amputation?

….If so, we would like to know more!

We are conducting a research study investigating the communication styles between people who have an amputated limb and their prosthetist.

If you meet all of the criteria below, we would be very grateful if you could take the time out to complete our survey.

Inclusion criteria:

- Adults of any gender, ethnicity and nationality, aged 18 or over, who have lost a limb through amputation, or who have congenital limb absence /deficiency
- Have gone through a prescription consultation process with a prosthetist.
- Are able to read and understand English and are willing to take part in the research.

The survey should take around 20 minutes to complete
You can find out more information about the study by following the link below.

To access the survey, please follow this link:

https://tinyurl.com/ybk5vovl

Lancaster
University

Applicant: Shaneela Malik
Supervisors: Craig Murray and Jane Simpson
Department: Health Research
FHMREC Reference: FHMREC16131

29 August 2017

Dear Shaneela

Re: Does prosthetist communication style predict psychosocial adjustment and satisfaction with a prosthesis?

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal 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 licenses 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 details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC