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Doctoral Thesis

Body Image and Self-Disgust as Self-Appraisals Influencing Adjustment to Limb

Amputation

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Section	Text	Appendices (including abstract & references)	Total
Literature Review	7829	6495	14,324
Empirical Paper	8000	10287	18,287
Critical Appraisal	3793	673	4466
Ethics Section	2198	8149	10,347
Totals	21,820	25604	47424

Word Count

Thesis Abstract

This thesis explored the roles of body image and self-disgust, as self-appraisals, in their relationship to psychosocial adjustment and related factors in people with limb amputations. The thesis includes a systematic literature review of body image relating to psychosocial adjustment and a research paper examining the relationship of self-disgust to psychosocial adjustment following limb amputation. A critical appraisal of the research process and an ethics section are also included.

Section one presents a quantitative systematic literature review of sixteen studies examining body image perception as a correlate or predictor of demographic, clinical and psychosocial factors related to adjustment following limb amputation. Body image concerns were found to be associated with poorer outcomes on several psychosocial factors, such as depression, anxiety, activity restriction and self-esteem, as well as prosthesis satisfaction. Findings are discussed in regard to theories of body image. Body image is proposed as an important consideration for clinical and prosthetic services, in working with people with limb amputations.

In section two, an empirical study of quantitative, cross sectional methodology is presented, in which correlational and hierarchical regression analysis are used to examine the relationship of self-disgust to psychosocial adjustment and related factors; prosthesis use, prosthesis satisfaction, and body image. Self-disgust was found to correlate with each of the outcome measures and to significantly contribute to variance in psychosocial adjustment, prosthesis use, aesthetic prosthesis satisfaction and body image. Self-disgust emerged as an important consideration in understanding poor adjustment to amputation. Section three includes a critical appraisal of the research process, in which reflections are presented on the design of the study, the importance of researching difficult topics, such as self-disgust, and potential areas for future research.

Declaration

This thesis reports research undertaken for Lancaster University Doctorate in Clinical Psychology between June 2015 - June 2016. The work presented within the thesis is my own except for those instances where due reference has been made to other authors. This thesis has not been submitted for any other academic award.

Signed
Name
Date

Acknowledgement

To my supervisors, you have been a well of knowledge, inspiration and support. Craig, thank you for your invaluable knowledge about amputation. Phil, I would have been absolutely lost without our statistics conversations. Jane, thank you for generally keeping a fire lit under me and for making sure I got there.

To my family and friends, who supported me on this long and sometimes arduous journey, I could not have done this without you and I am eternally grateful for having you all in my life.

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Contents Page

Section One: Literature Review

Abstract	
Introduction	
Methodology	
Results	1-11
Discussion	
Conclusion	1-30
References	1-31
Figures & Tables	1-38
Appendix 1-A: Highlights	1-51
Appendix 1-B: Guidance for using the STROBE quality appraisal tool.	
Section Two: Empirical Paper	
Section Two: Empirical Paper Abstract	2-2
Abstract	2-3
Abstract	2-3
Abstract Introduction Method	2-3 2-9 2-16
Abstract Introduction Method Results	2-3 2-9 2-16 2-24
Abstract Introduction Method Results Discussion	
Abstract Introduction Method Results Discussion Conclusion	

Appendix 2-B: Body Image Guidance for Authors	2-52
Section Three: Critical Appraisal	
Abstract	
Self-Disgust as a Topic of Interest	
Designing the Study	
Personal Reflections on Investigating Self-Disgust	
Future Research	
Conclusion	
References	
Section Four: Ethics	
Ethics Application Form	
PFACT project information and ethics questionnaire	4-9
Self-Assessment Form	
Approval Letter	
Appendix 4-A: Research Protocol	4-16
Appendix 4-B: Participant Information Sheet	
Appendix 4-C: Consent Form	4-38
Appendix 4-D: Participant Survey Pack	4-39

Running head: BODY IMAGE & AMPUTATION: A SYSTEMATIC REVIEW

Section One: Literature Review

Does body image predict clinical and psychosocial outcomes in people with limb amputations? A systematic literature review

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Prepared for submission to Body Image¹

¹ See Appendix 1-A for Highlights and Appendix 2-B for Body Image Guide for Authors

Abstract

Body image concerns have been associated with psychosocial difficulties in people with limb amputations. This review aimed to increase understanding of the relationship between body image and predictors of clinical and psychosocial outcomes associated with adjustment (i.e., prosthesis use, experience of depression). A quantitative systematic review of studies using correlation or regression analysis to examine body image in relation to demographic, clinical and psychosocial factors, was conducted. Sixteen papers were identified and reviewed. Some evidence was found to indicate that the relationship of body image to predictors of adjustment differs by gender. For both men and women, body image anxiety was associated with poorer self-rated adjustment and related factors (e.g., anxiety, depression, health related quality of life). The relationship of body image with prosthesis use remains unclear but body image anxiety was found to correlate with poorer prosthesis satisfaction. Body image is an important consideration for clinical and prosthetic services.

Keywords: amputation, prosthesis, body image, review

Does body image predict clinical and psychosocial outcomes in people with limb amputations? A systematic literature review

The reason for a limb amputation can range from health complications (e.g., vascular disease) to trauma but, regardless of cause, amputation is likely to result in a period of adjustment and a profound impact on an individual's personal, social, and professional life (Atherton & Robertson, 2006). Indeed, in addition to the individual's physical adjustment, such as functional ability or stump pain (Gallagher & Maclachlan, 2001), psychosocial adjustment has been associated with psychological distress, including anxiety, depression and hopelessness (Desmond & MacLachlan, 2002). The experience of amputation has been described as similar to that of losing a loved one (Gallagher & Maclachlan, 2001), as the individual grieves the loss of their limb (Parkes, 1975).

Body Image and Limb Amputation

Approaches to rehabilitation from limb loss place great emphasis on the use of prosthesis, in regard to both ambulation and cosmesis, i.e. the appearance of the prosthetic limb (Cutson & Bongiorni, 1996). Of note, qualitative exploration of individuals' expectations when entering rehabilitation has found that, while some people are interested in the appearance of the prosthesis, others intend to cover the residual limb using clothing (Ostler, Ellis-Hill, & Donovan-Hall, 2014). In either case, appearance related concerns become apparent, emphasizing the importance in considering image related worries during rehabilitation. However, assessments of rehabilitation have traditionally focused on functional aspects, without taking account of important psychological aspects of adjustment, such as body image (Goldberg, 1984).

Throughout medical, psychological and neuropsychological research, "body image" has been used interchangeably with other terms, such as "body concept", and in particular "body schema", to describe different conceptualizations of the mind and body relationship. However, this paper will henceforth use the term "body image" to refer to a more concrete operationalization offered by Cash (2002a) for use in the field of psychology, in which the individual's "body image" is the perception of, or attitude toward, their own body appearance.

Alteration to body image may lead to emotional, perceptual and psychological reactions (Kolb, 1959) and limb amputation, by its very nature, involves a considerable change to the individual's body image. Indeed, it has been suggested that the individual, following limb loss, must assimilate several body images, including the image of the intact body, the body with limb loss and the body with prosthesis (Shontz, 1974). Quantitative research methods have allowed for a better understanding of the relationship between body image and psychological well-being after amputation. For example, higher body image anxiety has been associated with worse quality of life (Breakey, 1997; Holzer et al., 2014), anxiety and depression (Atherton & Robertson, 2006; Breakey, 1997; Coffey, Gallagher, Horgan, Desmond, & MacLachlan, 2009).

Body Image Related Distress

Atherton and Robertson (2006) found that individuals who were more "appearance schematic" (i.e., invested in appearance as a measure of self-worth) and high in selfconsciousness experienced more difficulty with psychosocial adjustment and distress as a result of limb amputation. The authors offered these findings in support of Wells and Matthews (1996) Self-Regulatory Executive Function (S-REF) model in which individuals who are more concerned by appearance will experience more distress as a result of deviation from societal ideals.

Other studies of limb amputation (e.g., Breakey, 1997) have referred to the works of Cash, who proposed a cognitive-behavioral model of body image (Cash, 2002a), suggesting that body image perception is shaped through historical influences (e.g., cultural socialization, interpersonal experiences, and physical characteristics) and proximal events (e.g., appearance-schematic processing, internal dialogues, and body image emotions). Though it is of note that Szymanski and Cash (1995), in turn, drew on Higgins (1987) Self-Discrepancy Theory, which suggests that dejection-related emotions, such as depression, arise as a result of a discrepancy between the actual-self (self-perception of possessed attributes) and the ideal (desired attributes) or the ought-self (attributes the person feels they are expected to possess). Relating Self-Discrepancy Theory to body image, Vartanian (2012) noted how cultural norms promote certain standards of attractiveness and suggested that, for many, the idealized body image promoted by society is unobtainable, likely to result in discrepancies between one's perceived and ideal body image.

A common theme throughout the aforementioned models is that greater focus on societally endorsed models of appearance will lead to increased deviation from the ideal body image, resulting in higher levels of distress. The discrepancy between idealized and actual body image may be particularly true for those individuals who have experienced limb amputation, as societal norms, particularly in media, predominantly promote the image of the intact body. Media attention has, in recent years, included more body diversity (e.g., the Invictus Games and Paralympic Games). However, it is possible that individuals with an amputation experience significant discrepancy between the actual and idealized-image, leading to the association of poor body image perception with worse psychosocial outcomes following limb loss (Atherton & Robertson, 2006; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995).

Body Image and the Prosthesis

It is of note that several studies have found a relationship between body image and the use of and attitudes towards a prosthesis. For example, body image anxiety has been found to negatively correlate with prosthesis satisfaction (Coffey et al., 2009). Greater satisfaction with a prosthesis may alleviate body image concerns. Indeed, it might be considered that discrepancy related distress serves the function of promoting action to reduce body image conflicts. While the lost limb cannot be regained, for some, the prosthesis (if considered to be satisfactory) may be a semblance of normality within society, reducing the disparity between actual and ideal body image in addition to restored functional capability. Indeed, Desteli, Imren, Erdogan, Sarisoy, and Cosgun (2014) found that upper limb amputation was associated with greater levels of body image related distress than lower limb amputation and suggested that this may be due to the greater level of cosmetic, or "normal", appearance that can be achieved with a lower limb prosthesis.

In qualitative research, individuals with limb loss have reiterated the importance of appearing normal (Gallagher & MacLachlan, 2001), with some prizing realistic cosmesis over increased limb functionality (Murray, 2009). Moreover, some individuals wear their prosthesis in order to make other people more comfortable (Murray, 2005). In this way, the prosthesis might be thought of as a camouflage, allowing the person to "pass" as able bodied. Indeed, this would align with Cash's (2002a) finding, that body image discontentment was strongly associated with the coping strategies of avoidance (e.g., avoiding threatening thoughts/feelings) and appearance fixing (e.g., camouflaging). The prosthesis may act as a tool of achieving the ought self, where the individual feels that they must adhere to others' expectations of normal

body image. In addition to functional gains, a prosthesis may minimize deviation from societal models of appearance and reduce the discrepancy between the actual and the ideal body image.

Yet, despite evidence that some people strive for a "normal" appearance, others have been found not to camouflage their amputated limb. For example, Cater's (2012) qualitative exploration of amputation among army women reported how the loss of a limb can "almost become a badge of honor" (p. 1450), noting some veterans could be offended by someone hiding their stump. Additionally, Murray (2009) described the experience of people who chose to wear prostheses which were highly visible along with shorts, so that the amputated limb was not hidden. Indeed, Murray's (2004) qualitative exploration of the experience of prosthesis use found that some individuals do not desire a realistic prosthesis, but rather a functional tool, as the prosthesis was not a part of their body image. This may indicate a positive assimilation of the amputated anatomy into the individual's body image, reducing the discrepancy between an actual and ideal body image.

Aims of the Current Paper

Although several quantitative systematic reviews have explored psychosocial aspects of the amputee experience (Bragaru et al., 2013; Geertzen, Van Es, & Dijkstra, 2009; Mckechnie & John, 2014), body image has received little to no attention as a focus for a review. Bragaru et al. (2013) reviewed two studies which found physical activity to be associated with a more positive body image. An earlier (non-systematic) review by Horgan and MacLachlan (2004) found body image anxiety to be associated with poorer adjustment, as defined by measures of depression, anxiety, and activity restriction. However, despite a growing body of research incorporating measures of body image, the relationship of body image to other demographic, clinical and

psychosocial factors (e.g., age, prosthesis use, and depression) post-amputation has not yet been systematically explored.

Systematic exploration of the relationship of body image with demographic, clinical, and psychosocial factors following limb amputation would allow for a better understanding of the potential predictors of psychosocial outcomes of amputation. Additionally, exploration of the relationships of body image, as a correlate or predictor of psychosocial factors following amputation, may allow for better application of theory (e.g., Self-Discrepancy Theory). This may aid in the provision of rehabilitation services and the delivery of psychosocial interventions, which have been associated with a significant reductions in body image related distress (Srivastava & Chaudhury, 2014).

In summary, this review aims to appraise and review systematically available quantitative research exploring body image as a correlate and predictor of clinical and psychosocial variables in adults who have had a limb amputation.

Methodology

Defining the Focus of the Review

As the research question pertains to the association of body image with other factors (e.g., demographic, clinical, and psychosocial factors) after amputation, a systematic search strategy was employed to identify studies examining body image in a correlational or predictive (regression) relationship with additional variables in adults who have experienced loss of a limb.

Search Strategy

Studies were identified for review through a systematic search of four electronic research databases; Pubmed, CINAHL, PsycINFO, and Web of Science, in March 2016. These databases were chosen due to their medical, psychological, or general academic focus.

Search terms were generated through use of a "mind map", a diagram used to denote words linked to a key word or phrase (Booth, Sutton, & Papaioannou, 2016), by consulting previous reviews in the fields of amputation (Murray & Forshaw, 2013) and body image (Alleva, Sheeran, Webb, Martijn, & Miles, 2015), and utilizing the thesaurus functions in Pubmed, CINAHL and PsycINFO. Certain terms, such as "body schema", were included in the review despite recent associations with the sensory-motor relationship between mind and body, due to historic use of the terms interchangeably with "body image". The search terms, used with Boolean operators, can be found in Figure 1.

INSERT FIGURE 1 ABOUT HERE

Searching the databases returned a total of 1,388 results. This was reduced to 1250 results when restricting to English language papers only, and to 870 papers after duplicates were removed. The titles and abstracts of the remaining papers were then read to determine suitability for review. Papers were removed if they failed to meet the following inclusion criteria: the study used quantitative methodology, participants had experienced limb loss, the study examined body image (perception of body appearance) associated with limb loss, and participants were of an adult population (i.e., aged 16 years or above). Furthermore, papers were excluded if: the study was of desired or elective amputation (including diagnosis of Body Integrity Identity Disorder), there was a focus on sensory-motor (or somatosensory) body schema, the study focused on phantom limb pain.

Seventy-four papers remained that met the above criteria or for which suitability could not be determined from the title and abstract. An additional 16 papers were excluded as neither the abstract or paper could be located online and there was not sufficient information available to establish a need for further investigation. The method and results sections of the remaining 58 papers were read in full to determine suitability for review, based on additional inclusion criteria that: the study included a measure specifically designed to assess body image, the analysis included correlation or regression between body image and another variable, and the paper was written for publication in a peer-reviewed journal.

A process known as "berry picking" (Booth, 2008), the reading of reference sections to identify additional studies of interest, was employed with 26 papers which included a body image measure. This process identified 30 additional papers. However, none of the additional papers met the inclusion criteria. It is of note that, while one of these papers presented a three-item Social Discomfort Scale (SDS; Rybarczyk et al., 1992) which the authors proposed to measure body image disturbance, the paper was excluded as items in the SDS (e.g., Do you avoid being out in public because of your amputation and/or prosthesis?) were not felt to be specific to issues concerning body image. Furthermore, one paper (Wetterhahn, Hanson, & Levy, 2002) was excluded as correlations were reported between two different body image measures, but not with any other variable.²

In total, 16 papers were identified that fully satisfied the inclusion and exclusion criteria for review. An overview of the search strategy is presented in Figure 1.

Data Synthesis

Data relating to study characteristics and findings relating to body image were extracted from each of the 16 papers into a study-specific table. Data were then synthesized by comparing and contrasting the similarities and differences in findings, with regard to the study characteristics. This allowed for consideration of how findings from the studies related to the wider evidence base and to application of body image related theory.

 $^{^{2}}$ The authors of Wetterhahn, Hanson and Levy (2002) were contacted by email to confirm that no further correlational analysis were conducted.

Quality Assessment

Quality appraisal was conducted to better understand the strength of reporting for each study. However, it was recognized that strength of reporting may be subject to journal limitations and that reporting may not reflect the quality of the study methodology or the data presented. Therefore, decisions about inclusion in the review were not based on the quality appraisal. Each of the studies included for review were critically appraised according to the criteria presented in Strengthening the Reporting of Observational Studies in Epidemiology (STROBE, 2007). STROBE identifies quality criteria for 22 items, such as; background, design, and statistical methods. Some of the items contain several criteria. It became apparent while conducting the assessment that item criteria could be partially met. To account for this, a score of "0" was assigned if the paper did not meet the criteria, "1" if the paper partially met criteria and "2" if criteria were fully met. This allowed for a minimum score of zero and a maximum score of 44. A summary of the quality assessment is presented in Table 1. The relative strength of "0" the apper was held in mind when comparing findings. Where reporting of findings was found to be poor, this has been identified in the review.

INSERT TABLE 1 ABOUT HERE

Results

Study Characteristics

A summary of the main characteristics for each of the 16 studies included in the review is presented in Table 2.

INSERT TABLE 2 ABOUT HERE

Participant Characteristics

A total of 1041 individuals with a limb amputation participated across the 16 studies in

this review. Additionally, three studies (Akyol et al., 2013; Holzer et al., 2014; McDonald, Sharpe, & Blaszczynski, 2014) included a total of 419 control participants (no amputation), and a further study by Robert, Ottaviani, Huh, Palla and Jaffe (2010) included a comparison group of 33 participants who had received limb salvage surgery (reconstruction of a functional limb). There appeared to be similarities between the participants in two studies (Akarsu, Tekin, Safaz, Goktepe, & Yazicioglu, 2013; Akyol et al., 2013). However, the authors did not indicate resampling of the same participants and differences exist within the data (i.e., different body image scores). Subsequently, the samples have been considered separately within this review.

Sample sizes for the studies ranged from eight (Swanson, Stube, & Edman, 2005) to 298 (149 amputation) participants (Holzer et al., 2014). Of the participants with experience of amputation and where gender was reported, 762 identified as male and 246 identified as female. Participants ranged in age from 16 (Robert et al., 2010) to 97 years (Atherton & Robertson, 2006), with a mean age of 52.6 across 14 studies (996 participants) where age was reported.

Participants were recruited from a range of armed forces, amputation and regional rehabilitation services, prosthesis services, amputation organizations, health related organizations (diabetes and osteosarcoma), clubs for individuals with disabilities, and an online amputee discussion group. Several studies did not make clear reference to the country from which participants were recruited. However, 10 studies indicated recruitment from Australia (one study; total n = 50), Canada (one study: total n = 19), Ireland (two studies; total n = 183), Turkey (three studies; total n = 97), UK (one study; total n = 67) or USA (two studies; total n = 120).

The cause for limb amputation varied across studies, with descriptions of etiology including: trauma/accident (12 studies), cancer (9), vascular disease (8), diabetes (7), other (7), infection (3), congenital limb difference (3), clotting (1), and burns/frostbite (1). As a very small

number of participants (n = 14) with experience of congenital limb difference were found across three studies (maximum 8% of the study sample size), inclusion of these studies for review was considered appropriate. One study (Zidarov, Swaine, & Gauthier-Gagnon, 2009), employing a longitudinal design, recruited participants at point of admission to rehabilitation service. For the others studies, recruitment appears to range from 3 months (Safaz, Yilmaz, Goktepe, & Yazicioglu, 2010) to 75 years following amputation (Swanson et al., 2005). Several studies (Akarsu et al., 2013; McDonald et al., 2014; Murray & Fox, 2002; Tatar, 2010) did not provide information on participants' time since amputation. However, Tatar (2010) reported a minimum of 3 years prosthesis use and Murray and Fox (2002) reported that participants had been using a prosthesis on average for 8.1 years, with a range of 0.1 to 40 years.

Studies used a range of terms to describe the level of participants' amputations. The majority of participants had experienced unilateral lower limb amputation (LLA), of which 181 were described as "Major" or were not further clarified, 455 were transtibial (below-knee), 228 were transfemural (above-knee), 21 knee disarticulation (through-knee), 18 knee or transfemoral, and 13 hip disarticulation or hemipelvectomy. A further 28 individuals had experienced unilateral "Minor" amputations (also described as below-ankle, partial foot or Syme's amputation), and one participant had received rotationplasty surgery.

Of the 65 participants who had experienced bilateral LLA, 50 were of unspecified level, 6 were transfemural, 4 transtibial, and 5 were transtibial and transfemural. Only one study (Robert et al., 2010) recruited a participant with an upper limb amputation (shoulder disarticulation). Akyol et al. (2013) reported levels of amputation for 39 amputations. However, the study recruited only 30 participants and it was not made clear whether this included bilateral amputations. Therefore, these participants have not been included in the above summary of

amputation types.

Methodological Characteristics

The majority of studies in this review were of cross-sectional design. Only one study (Zidarov et al., 2009) was of longitudinal design, across three time points (admission to rehabilitation, discharge and 3-month follow-up) and used repeated measures analysis of variance (ANOVA) in their analysis. Eight of the studies employed between-groups analysis, four of which compared amputation against a no-amputation (control, diabetes or limb salvage) group. All of the studies utilized correlational analysis and four studies also used regression analysis (two pertaining to body image as an outcome measure, one as a predictor) for the amputee group. While it was not always made explicit, examination of the papers indicated that body image was considered a predictor variable (e.g., of health related quality of life) in five studies, outcome variable (e.g., of amputation level) in six studies and as both predictor and outcome in five studies.

Body image measures. A range of self-report measures were used throughout the 16 studies in this review to assess participants' perception of body image. The Amputee Body Image Scale (ABIS; Breakey, 1997) was the most commonly featured measure of body image perception, used by nine studies in this review. Two of these studies also calculated scores for the revised version of the ABIS, the ABIS-R (Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan, 2007), while an additional study used the ABIS-R only. The remaining 6 studies each used a different measure of body image perception, including the Appearance Schemas Inventory (ASI: Cash & Labarge, 1996), the Amputation Related Body Image Scale (ARBIS; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995), the Body Image Questionnaire (BIQ; Fisher & Hanspal, 1998), the Body Image Disturbance Questionnaire (BIDQ; Cash, Phillips,

Santos, & Hrabosky, 2004), the Multidimensional Body Self-Relations Questionnaire (MBSRQ; Cash, 2000), and the Situational Inventory of Body Image Dysphoria (SIBID; Cash, 2002b).

It is of note that only the ABIS, ABIS-R, and ARBIS were designed specifically for use with individuals who have experienced amputation. Furthermore, on all but one scale, increased scores indicate more body image related distress. However, greater scores on the MBSRQ indicate a more positive body image.

While the measures focus on different aspects of body image perception (e.g., body image anxiety, frequency of negative body image emotions and contribution of body image to self-worth), each measure draws on a cognitive understanding of body image, aligning with cognitive theories informing body image distress (e.g., Self-Discrepancy Theory) and allowing for "lumping" of the measures for review to facilitate a better evaluation of the generalizability and consistency of findings (Weir, Grimshaw, Mayhew & Fergusson, 2012).

Key Findings Relating to Body Image

Studies were examined for correlational or predictive relationships between body image and demographic, clinical, and psychosocial factors. A summary of the correlation and regression findings related to body image can be found in Table 3.

INSERT TABLE 3 ABOUT HERE

Demographic factors. Only one study (Rybarczyk et al., 1995) explored the correlation between gender and body image but did not find a significant relationship. No further correlational or regression analysis of the relationship between gender and body image has been reported. However, several studies examined between-group differences in body image by gender. Of the three studies (Holzer et al., 2014; Tatar, 2010; Zidarov et al., 2009) comparing men and women on a measure of body image, two found women to have significantly worse body image concerns (Holzer et al., 2014; Zidarov et al., 2009).

The relationship between age and body image has received more attention, with several studies demonstrating mixed findings. Three studies reported a non-significant relationship between age and body image (Breakey, 1997; Fisher & Hanspal, 1998; Safaz et al., 2010). While two studies (Rybarczyk et al., 1995; Tatar, 2010) found significant correlations between age and body image, as these were in opposite directions, no specific linear relationship between age and body image can be concluded.

Only one study (Tatar, 2010) explored the additional factor of sport and exercise, finding that, for individuals who engaged in exercise, there was a moderate correlation between age and body image, whereas for those participants who did not engage in sport, the correlation remained low.

Both Rybarczyk et al. (1995) and Tatar (2010) further explored correlations between body image and age at amputation but did not find a significant correlation. Additionally, Tatar, (2010) did not find a relationship between body image and education level or employment situation.

Clinical factors. Across the papers in this review, examination of the relationship between body image and clinical factors pertained to two broad areas: amputation characteristics, and relationship to the prosthesis.

Amputation characteristics. Robert et al. (2010) examined the difference in body image, along with quality of life, self-esteem, and social support, in individuals with experience of amputation versus limb salvage surgery. They found body image to be the only variable differing significantly between the groups, when controlling for other factors (e.g., hip

involvement, age at diagnosis, gender) in a regression model, with the amputation group exhibiting worse body image perception. However, this difference was not maintained when omitting seven participants who had experienced "late amputation".

Only one study, by McDonald et al. (2014), explored the impact of amputation on body image additional to existing health factors. They found that for individuals with a diagnosis of diabetes, when controlling for medical and demographic factors (using hierarchical regression), limb amputation remained a significant predictor of body image disturbance, accounting for 2.4% of the variance in BIDQ score.

Two further studies (Rybarczyk et al., 1995; Tatar, 2010) explored the relationship between cause of amputation and body image, but neither found a significant correlation. Additionally, a significant correlation was not found between body image and site (Rybarczyk et al., 1995) or level of amputation (Safaz et al., 2010).

Two studies (Murray & Fox, 2002; Safaz et al., 2010) assessed a potential correlation between limb pain and body image. Although the studies reported conflicting results, when the results for just men were examined, results indicated a medium to large effect size, with increased pain associated with worse body image anxiety.

Three studies (Breakey, 1997; Fisher & Hanspal, 1998; Rybarczyk et al., 1995) examined the relationship between body image and length of time since amputation, each finding the correlation to be small and non-significant.

Examining more general characteristics, two studies (Rybarczyk et al., 1995; Tatar, 2010) found correlations between body image and participant health to be non-significant and Fisher and Hanspal (1998) found that, for participants with a more positive body image, body image distress was negatively correlated with mobility.

Relationship with the prosthesis. Only Murray and Fox (2002) examined the relationship between body image and length of time with a prosthesis, but found the correlation to be non-significant. While they did find a medium, negative correlation between body image anxiety and daily duration of prosthesis use, significance was maintained for males only when examining by gender. Additionally, the effect size of the correlation increased and became significant for males but reduced to small for females. Furthermore, two additional studies (Akarsu et al., 2013; Tatar, 2010) did not find a significant relationship between body image and prosthesis use. However, both studies had a small sample size (n<40) and did not provide effect sizes for the correlations³.

Fisher and Hanspal (1998) reported a non-significant correlation between body image distress and attitude toward the prosthesis. However, the correlation coefficient was approaching medium effect (r_{τ} =-.29) indicating that body image concerns are associated with a less positive attitude. Four further studies (Coffey et al., 2009; Gallagher et al., 2007; Murray & Fox, 2002; Zidarov et al., 2009) examined the relationship between body image anxiety and prosthesis satisfaction, each finding significant negative correlations of small to large effect, suggesting that body image anxiety is associated with less satisfaction with the prosthesis.

Gallagher et al. (2007) and Murray and Fox (2002) reported small to moderate, significant correlations of body image with aesthetic, functional, and weight satisfaction. Additionally, while Murray and Fox (2002) found significance to vary for weight and function, depending on gender, effects sizes remained in the moderate range for each correlation. However, the correlation with aesthetic satisfaction, while large for women, was small and nonsignificant for men. Furthermore, Coffey et al. (2009) reported significant correlations of

³ The authors had not responded to a request for information at the time of submitting the review.

medium effect for weight and functional satisfaction only, for a sample which was predominantly (77 %) male. This indicates a different relationship between body image and satisfaction dependent on gender.

Only one study (Fisher and Hanspal, 1998) examined the relationship between body image and the rehabilitation physician's rating of prosthesis satisfaction, but found this to be non-significant.

Psychosocial factors. Body image has been explored in relation to a range of psychosocial factors within five areas: quality of life, adjustment to amputation, social restriction, emotional distress, and relationship to the self or others.

Quality of life. Five studies (Breakey, 1997; Holzer et al., 2014; Rybarczyk et al., 1995; Safaz et al., 2010; Zidarov et al., 2009) examined the relationship between body image concerns and quality of life, finding correlations of medium to large effect, indicating that body image anxiety is associated with poorer quality of life. Akyol et al. (2013) also indicated a significant correlation between increased body image anxiety and poorer quality of life. However, while they reported that correlations were positive with all subscales of the Nottingham Health Profile (McEwen, 1993), this was contradicted by the correlations provided in table format which, while predominantly in the large range, where a mixture of positive (e.g., physical disability: r=.78) and negative (e.g., pain: r=-.68) in direction.

Safaz et al. (2010) further described body image anxiety to have a negative correlation, of medium to large effect, with the mental health and physical health components of the SF-36, as well as for all subscales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health, indicating that body image anxiety is associated with poorer outcomes regarding a range of areas associated with quality of life.

The negative relationship between body image distress and functioning was supported by the finding of a significant correlation by Robert et al. (2010) and a medium, though non-significant correlation by Swanson et al. (2005). However, Robert et al. (2010) do not appear to have differentiated between amputation and limb salvage in analysis of correlations and Swanson et al. (2005) had a small sample (N=8) of individuals, each using technologically advanced prosthesis, with contradicting effect sizes reported throughout the paper⁴.

Robert et al. (2010) was the only study to report a correlation of body image with social support and spiritual well-being, each of which were found to be non-significant.

Only one study (Rybarczyk et al., 1995) conducted a regression analysis of the relationship between body image and quality of life, finding body image to be a significant predictor, accounting for 5% of the variance in quality of life, when controlling for demographic and health factors. Furthermore, using stepwise regression, body image concern, along with perceived social support, self-rated health, and time since amputation, accounted for 53% of the variance in quality of life.

Activity restriction. Only two studies explored activity restriction in relation to body image, but both found significant negative correlations. While Coffey et al. (2009) found a moderate correlation between body image anxiety and social restriction, Gallagher et al. (2007) found moderate correlations for body image anxiety with functional and social activity restriction. However, the relationship with athletic activity restriction was found to be small and non-significant. It would appear that body image concerns are better associated with social aspects of activity restriction.

⁴ The authors of Akyol et al. (2013), Swanson et al. (2005) and Robert et al. (2010) had not responded to a request for information at time of review submission.

Adjustment. Of the studies that analyzed the relationship between body image concern and self-rated adjustment to amputation, all three found significant negative correlations. While Atherton and Robertson (2006) only reported moderate correlations for the body image subscale of the ASI with two subscales of the TAPES; general adjustment and social adjustment, Coffey et al. (2009) and Gallagher et al. (2007) both found significant negative correlations in the moderate range for all 3 of the subscales (including adjustment to limitation), indicating that body image concerns are associated with poorer adjustment to limb amputation overall.

Rybarczyk et al. (1995) also found a moderate, negative and significant relationship between body image distress and prosthetists' rating of adjustment. Furthermore, they found that body image was a significant predictor, accounting for 8% of the variance in rating, after controlling for demographic and psychosocial variables in a hierarchical regression. Body image concerns, together with self-rated health, significantly predicted for 16% of variance in prosthetists' rating of adjustment in a stepwise regression.

Emotional distress. Of the studies which explored the relationship between body image and depression (Akyol et al., 2013; Atherton & Robertson, 2006; Breakey, 1997; Coffey et al., 2009; Fisher & Hanspal, 1998; Rybarczyk et al., 1995), all six found significant, moderate to large, positive correlations, indicating that greater body image anxiety is related to increased feelings of depression.

Rybarczyk et al. (1995) found body image anxiety to be a significant predictor of depression, accounting for 8% of the variance after controlling for perceived social stigma, clinical and demographic factors. In addition to perceived social stigma and perceived social support, the body image distress contributed to 40% of variance in a significant stepwise regression model.

Five studies (Akyol et al., 2013; Atherton & Robertson, 2006; Breakey, 1997; Coffey et al., 2009; Fisher & Hanspal, 1998) also found a positive and significant correlation between poorer body image perception and increased anxiety. Furthermore, four of the five studies identified correlations of large effect, indicating that body image concerns are strongly associated with experience of anxiety.

Relationship with self and others. Only one study (Atherton and Robertson, 2006) explored the relationship of body image with self-consciousness and found body image vulnerability to be significantly correlated with both social anxiety and public selfconsciousness, though both correlations were of small effect. Additionally, correlations with self-investment and private self-consciousness were not significant (Atherton & Robertson, 2006).

Three studies (Breakey, 1997; Holzer et al., 2014; Robert et al., 2010) examined the relationship between body image and self-esteem, each finding significant correlations, indicating poorer body image to be associated with self-esteem difficulties.

Finally, Rybarczyk et al. (1995) found body image concern to demonstrate significant positive correlations of medium effect with perceived social stigma and of small effect with perceived social support.

Discussion

Through a systematic review of quantitative research, a number of correlational and predictive relationships have been identified between body image and demographic, clinical, and psychosocial factors following limb amputation.

The relationship of body image to demographic factors (e.g., age and gender) remains unclear. With three studies finding no significant relationship (Breakey, 1997; Fisher & Hanspal, 1998; Safaz et al., 2010) and two studies reporting correlations in opposite directions (Rybarczyk et al., 1995; Tatar, 2010), it might be assumed that body image and age do not hold a predictable relationship following amputation. However, the studies did not appear to test for non-linear relationships and it is possible that the relationship with age varies for different age groups. Furthermore, Tatar (2010) found a moderate correlation between body image concern and age only when examining the participants who took part in regular exercise, indicating that age and exercise (or indeed other factors) may interact in their relationship with body image. Additionally, age at the time of amputation was not found to have a relationship with body image (Rybarczyk et al., 1995; Tatar, 2010). While a non-linear relationship cannot be dismissed, it may be that social comparisons in the present moment are a more salient determinant of body image concerns than historical comparisons (from time of amputation). If so, then the distress a person experiences in relation to their body image might best be understood in the context of the person's current environment and social influences.

The relationship between body image anxiety and gender also remains unclear. However, men and women were found to have different patterns of correlations between body image and other factors (Murray & Fox, 2002). This indicates that body image anxieties may manifest differently depending on gender. This is interesting, as it indicates that both men and women may experience distress relating to body image concerns after amputation but that the discrepancies arising between the person's perceived and ideal body image could, generally, be influenced by different (gender bound) societal expectations.

Few characteristics of the amputation itself have received examination regarding their relationship with body image. In particular, it is surprising that only one study has applied regression analysis to understanding the additional variance that amputation might have on body image. Furthermore, while amputation does indeed appear to contribute to body image anxiety above existing health difficulties, the variance was relatively low at 2.4% (McDonald et al., 2014). This is perhaps lower than might be expected, but might be considered in several ways. Firstly, the study used the Body Image Disturbance Questionnaire (Cash et al., 2004). While the measure does include items specific to body image, it also has several items that refer to the impact of disease on the individual's life. As such, this scale may not have been sensitive to the full impact on amputation related body changes. Secondly, it is possible that, between the deteriorating impact of diabetes on the limb prior to amputation, along with the planned nature of the amputation, the individual may have moved toward assimilating a new body image prior to limb loss, resulting in less body image discrepancy. However, if this was the case, a different relationship with body image distress might be expected for different amputation etiologies. Yet, neither Rybarczyk et al. (1995) nor Tatar (2010) found a significant correlation between body image and cause of amputation, suggesting that the impact of amputation on body image may be similar across several etiologies (e.g., cancer, vascular disease, trauma).

Body Image, Adjustment and Psychosocial Well-being

The moderate correlations found between body image anxiety and poorer adjustment (Atherton & Robertson, 2006; Coffey et al., 2009; Gallagher et al., 2007) supports the assertion that body image holds an important relationship with self-rated adjustment. Reduced quality of life, poorer adjustment to amputation, activity restriction, emotional distress (anxiety and depression), and lower self-esteem were all found to be significantly correlated with body image.

It is important to note the considerable utility that body image then has when considering the psychosocial impact of amputation and how this may relate to theories of body image. Indeed, application of theory, such as Higgins' (1987) Self-Discrepancy Theory, provides a sound understanding of how the individual's body image concerns arise and contribute to a range of emotional difficulties (e.g., depression and anxiety) that contribute to poor adjustment and reduced quality of life after amputation.

Certainly, the relationship between body image concerns and quality of life gains further credence through the findings in this review. While a number of papers exploring quality of life or functioning after amputation were found to include errors or poor reporting (Akyol et al., 2013; Robert et al., 2010; Swanson et al., 2005), several robust studies supported the relationship between body image anxiety and worsened quality of life. Furthermore, Rybarczyk et al. (1995) found body image to be a significant predictor of quality of life (5% of variance). The emerging association of body image with a range of psychosocial outcomes and overall adjustment confirms that body image is an important consideration after limb amputation.

Moreover, the emerging associations of body image concerns with increased activity restriction (Coffey et al., 2009; Gallagher et al., 2007), self-consciousness (Atherton & Robertson, 2006) and perceived social stigma (Rybarczyk et al., 1995) further suggests a link between body image concerns and social processes, in which a bidirectional relationship may occur. Indeed, in line with the body image theories presented in this review, body image discrepancy can be considered the product of societally informed ideas about the "normal" body image, a departure from which would contribute to feelings of self-consciousness and perceived stigma from others while also encouraging social avoidance. However, social avoidance, or restricted social access due to non-prosthesis use, may in turn increase anxious cognitions regarding social situations which may increase self-consciousness, perceived stigma and, ultimately, a poorer body image.

Body Image and the Prosthesis

While findings varied between studies examining the association of prosthesis use with body image for lower limb amputation, with only Murray and Fox (2002) reporting a significant correlation, it is of note that each of the studies examining this relationship had a small sample size, reducing the power of their analyses (Akarsu et al., 2013; Murray & Fox, 2002; Tatar, 2010). Only Murray and Fox (2002) reported effect sizes, finding the correlation to be negative and of medium effect. However, this indicates that the use of a prosthesis is associated with reduced rather than greater body image anxiety, which is contrary to the relationship that might be predicted if the prosthesis is used to camouflage body image concerns. Several possibilities must be considered. Firstly, considering causality, if the wearing of a prosthesis alleviates body image concerns, then restricted use due to other factors (e.g., pain) would explain the associated increase in body image anxiety. This would support the importance of the individual assimilating a prosthesis into their body image after amputation. Secondly, if body image concerns promote avoidance (Cash, 2002a) then the individual may avoid social situations, subsequently reducing the need for prosthesis use. Indeed, it is possible that the individual with body image concerns avoids contact with the amputated limb, and subsequently the prosthesis. Yet, a body image based on appearance focused schema (Atherton & Robertson, 2006) would not readily indicate limb avoidance. It is possible that other schema, contributing to body image perception, would better explain avoidant behavior.

However, overall, several studies found significant negative correlations between body image anxiety and prosthesis satisfaction or attitude toward the prosthesis (Coffey et al., 2009; Fisher & Hanspal, 1998; Gallagher et al., 2007; Murray & Fox, 2002; Zidarov et al., 2009), indicating that body image might be best understood to associate with the qualities of the prosthesis, rather than the amount of prosthesis use. Furthermore, the relationship between prosthesis satisfaction and body image may contribute to the use of a prosthesis. Again, there may be a bidirectional relationship in which increased satisfaction with the prosthesis relieves body image concerns while increased body image concerns increase the perceived need for an aesthetically pleasing prosthesis. For the person with high levels of body image concern, if the prosthesis does not appear to be satisfactory, then the discrepancy between actual and ideal body image might not be adequately resolved, leading to a rejection of the prosthesis in favor of other coverings for the amputated limb. While the relationship with the prosthesis is potentially complex, understanding the individual's needs in regard to their body image anxieties may better facilitate both prosthesis satisfaction and use.

Review Limitations and Recommendations for Future Research

While the studies in this review included a range of cohorts and sampling methods, it is of note that some studies accessed specialist services, such as military rehabilitation (Akarsu et al., 2013; Akyol et al., 2013) and prosthesis services (Fisher & Hanspal, 1998; Gallagher et al., 2007), which may have impacted on the prosthesis use and psychosocial factors under review, and their relationship with body image. In particular, it is of note that only one individual with an upper limb amputation was included in the study cohorts (Robert et al., 2010). Further research exploring body image in persons with upper limb amputations is needed, particularly in using correlational or regression analysis to understand the predictive relationship of body image to other factors. This would facilitate a greater understanding of the difference in body image related distress for upper versus lower limb amputation, and further clarify the application of theoretical understandings of body image.

The boundaries for inclusion in this review, while considered necessary due to limits in resources or focus of the review, may have additionally limited the scope or generalizability of the findings. For instance, 138 papers were excluded as they were not in English language. This may have excluded papers relevant to the review topic that would have better informed cultural differences in the relationship of body image with other variables.

The review is also limited by the designs and analysis employed by the 16 studies reviewed. Only one study used a longitudinal design, and even then did not use correlational or regression analysis across time points. Therefore, an understanding of how body image changes over time has not been achieved. Additionally, as only three studies used regression analysis, information on the ability of body image to predict variance in other factors, or how body image variance might be predicted by other factors, is very limited.

A greater understanding of the role of body image after amputation, and the application of body image theories, would benefit from continued examination of the relationship of body image with demographic and clinical factors. More specifically, further quantitative or qualitative exploration of how a person's identity and the reasons for amputation interact with societal expectations would provide a better understanding of body image variance following amputation. Furthermore, as there has been limited examination of how limb loss, as an additional factor to chronic health concerns, impacts body image perception, longitudinal studies and hierarchical analysis could further inform our understanding of the body image across, not just after, the amputation experience.

In general, psychosocial understanding of body image following amputation would benefit from greater use of predictive modelling. In particular, exploration of body image as an outcome variable in regression analysis would aid understanding of the factors that contribute to body image variance.

Recommendations for Future Practice

This review found that body image has a relationship with psychosocial factors associated with adjustment to limb amputation, and with clinical factors, namely prosthesis use and satisfaction, that form an important part of the rehabilitation process. An understanding of the role of body image after amputation, and application of psychological theory, may help in the delivery of services designed to promote rehabilitation and psychosocial well-being.

The use of brief body image measures (e.g., ABIS-R) in amputation and prosthesis services could help in the identification of body image concerns. This may have particular utility if the individual appears to be adjusting poorly after amputation, and may compliment an understanding of emotional distress (e.g., anxiety or depression) and behavioral reactions to amputation, such as avoidance (Cash, 2002a).

Ostler et al. (2014) described individuals' concerns regarding appearance when entering the rehabilitation process, either in regard to prosthesis use or clothing. Understanding the individual's body image concerns may better facilitate the rehabilitation process, through consideration of needs regarding cosmesis. This may further aid in the design and provision of prosthetic rehabilitation. Furthermore, prosthetic services should be aware of the relationship between reduced use of prosthesis and increased body image concerns. Non-use of prosthesis (e.g., due to pain) may give rise to body image concerns and associated emotional distress, which may benefit from psychosocial interventions.

Indeed, body image distress has been found to be amenable to psychosocial interventions (Srivastava & Chaudhury, 2014). Application of psychological theory, such as Higgins's (1987)

Self-Discrepancy Theory, might further aid in the formulation of psychosocial difficulties regarding body image concerns, incorporating the person's social and cultural environment, and allowing for the identification of avenues for clinical or psychosocial intervention.

Conclusion

This review set out to examine the correlations and regressions of body image with demographic, clinical, and psychosocial factors after limb amputation, to better understand the role of body image in adjustment. Body image anxiety was found to be associated with poorer psychosocial adjustment and a range of related factors, including increased anxiety, depression, and activity restriction. This indicates the importance of body image as a consideration in rehabilitation after amputation, as suggested by (Goldberg, 1984). Of particular consideration is the role of prosthesis use in rehabilitation (Cutson & Bongiorni, 1996). While the relationship of body image with prosthesis use remains unclear, there is some indication that it is associated with reduced prosthesis use (Murray & Fox, 2002) and an association between body image concerns may aid in the delivery of prosthetic services, leading to better adjustment to limb loss.

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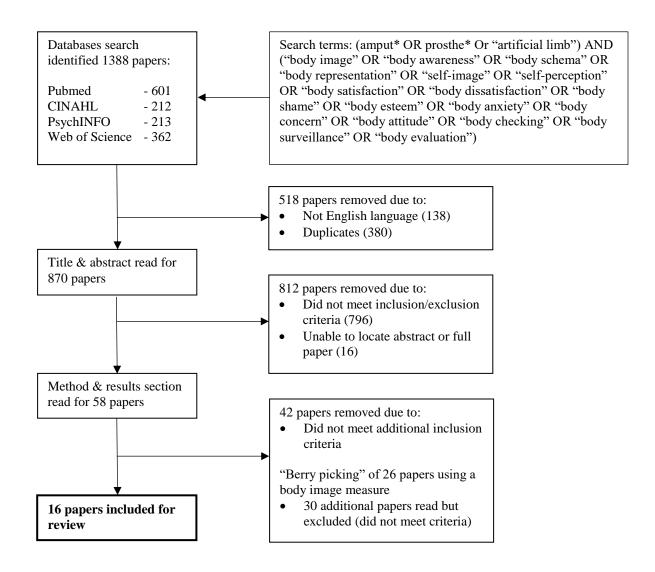


Figure 1. Search strategy to identify papers for review

	Akarsu et al. (2013)	Akyol et al. (2013)	Atherton & Robertson (2006)	Breakey (1997)	Coffey et al. (2009)	Holzer et al. (2014)	Fisher & Hanspal (1998)	Gallagher et al. (2007)
1 Title and abstract	2	1	2	0	1	2	1	1
Introduction								
2 Background/rationale	0	2	2	2	2	2	2	2
3 Objectives	1	1	2	2	1	1	2	2
Methods								
4 Study design	0	0	0	0	0	2	0	0
5 Setting	2	2	2	2	2	2	1	2
6 Participants	2	2	0	2	2	2	0	1
7 Variables	2	2	2	2	2	2	2	2
8 Data sources/measurement	2	2	2	2	2	2	2	2
9 Bias	0	0	0	0	0	0	0	0
10 Study size	0	2	0	0	0	0	0	0
11 Quantitative variables	0	0	0	0	0	0	0	0
12 Statistical methods	1	2	2	2	2	2	1	2
Results								
13 Participants	0	0	2	0	0	0	1	2
14 Descriptive data	2	2	2	2	2	2	2	2
15 Outcome data	2	2	2	2	2	2	2	1
16 Main results	1	2	2	2	2	2	2	2
17 Other analyses	0	0	0	2	0	1	0	2
Discussion								
18 Key results	2	0	1	1	1	0	2	2
19 Limitations	0	2	2	0	2	0	0	0
20 Interpretation	1	2	2	1	2	0	1	2
21 Generalizability	0	2	2	0	2	2	0	1
Other information								
22 Funding	2	0	1	0	1	0	0	0
Total score	22	28	32	24	28	30	21	28

Table 1. Quality assessment of papers included for review

	McDonald	Murray &	Robert et al.	Rybarczyk	Safaz et al.	Swanson et	Tatar (2010)	Zidarov et
	et al. (2014)	Fox (2002)	(2010)	et al. (1995)	(2010)	al. (2005)		al. (2009)
1 Title and abstract	1	2	2	0	0	0	1	2
Introduction								
2 Background/rationale	2	2	2	2	2	0	2	2
3 Objectives	2	2	2	2	2	2	1	2
Methods								
4 Study design	0	2	2	2	2	2	0	2
5 Setting	2	2	2	2	2	2	2	2
6 Participants	1	0	2	2	2	2	2	2
7 Variables	2	2	2	2	2	0	1	2
8 Data sources/measurement	2	2	2	2	2	1	1	2
9 Bias	2	0	0	0	2	0	0	0
10 Study size	0	2	2	2	2	0	1	2
11 Quantitative variables	0	2	2	2	2	0	0	0
12 Statistical methods	2	1	1	1	2	0	0	2
Results								
13 Participants	0	2	2	2	1	2	2	2
14 Descriptive data	2	2	2	2	1	0	2	2
15 Outcome data	2	2	2	2	2	0	2	0
16 Main results	2	2	2	2	1	0	1	2
17 Other analyses	0	2	2	2	1	0	0	2
Discussion								
18 Key results	2	2	2	2	2	2	1	2
19 Limitations	2	2	2	2	0	2	2	2
20 Interpretation	2	2	2	2	2	2	2	2
21 Generalizability	2	0	2	0	0	2	2	2
Other information								
22 Funding	2	0	2	0	0	0	0	2
Total score	32	35	41	35	32	19	25	38

Note: Assessment scoring has been conducted in accordance with the STROBE quality appraisal tool. Guidance for scoring can be found in appendix 1-B

Study (year)	Participant c	haracteristics	Amputation character	eristics		Method characteristics		
	Amputation (men/ women)	n Mean Age [SD; range]	Type of amputation (unilateral, lower limb, unless otherwise stated)	Reasons for amputation	Mean time (years) since amputation [<i>SD</i> ; <i>range</i>]	Setting and sampling	Design and main analysis relating to body image	Body image measure
Akarsu, Tekin, Safaz, Goktepe, & Yazicioglu (2013)	30 (ns)	Overall sample: ns [ns; 21-43] Unilateral: 27.3 [6.6; ns] Bilateral: 31.9 [8.4; ns]	13 below knee2 above kneeBilateral:4 below knee6 above knee5 above & below knee	Trauma	ns	Consecutive war veterans attending clinic at a Turkish armed forces rehabilitation and care center within a 6-month period of 2010	CS, Correlation (Spearman's rho)	Amputee Body Image Scale (ABIS)
Akyol et al. (2013)	30 (30/0) control <i>n</i> =30	31.30 [6.02; 21-44]	2 foot-ankle 18 transtibial 6 knee disarticulation 12 transfemoral 1 hip disarticulation	Trauma	6.58 [0.46; ns]	Amputee clinic at a military rehabilitation center in Turkey, between January and March 2010	CS, Correlation (Pearson's r)	ABIS
Atherton & Robertson (2006)	67 (51/16)	64.21 [14.36; 32-97]	43 below knee 16 above knee 8 bilateral	Vascular Diabetes Trauma Cancer Other	2.76 [1.32; 0.5–5.0]	Daily prosthesis users recruited from 2 artificial limb and appliance centers, Midlands UK, over 9- month period	CS, Correlation (Kendall's tau-b & Pearson's r)	Appearance Schemas Inventory (ASI)
Breakey (1997)	90 (90/0)	45 [12.7; 22–74]	60 transtibial 30 transfemoral	Trauma	17 [13.51; 1.0–70]	Participants identified from prosthetic practice files at the author's place of work	Correlation	ABIS
Coffey, Gallagher, Horgan,	38 (29/9)	66.4 [11.0, 43–85]	23 below knee 6 above knee 9 bilateral	Diabetes	3.36 [2.40; 0.5–15.0]	Identified from patient records of two limb fitting centers in Ireland.	CS, Correlation	Amputee Body Image Scale –

Table 2. Participant, amputation and methodological characteristics of the studies included in the review.

Desmond, & MacLachlan (2009)		(<i>Mdn</i> =68)					(Spearman's rho)	Revised (ABIS-R)
Holzer et al. (2014)	149 (114/35) control <i>n</i> =149	66.05 [11.3; ns]	113 below knee36 above kneeOf which:134 unilateral15 bilateral	Vascular Diabetes Cancer Trauma Other	ns (>.5)	Consecutively recruited at two specialized orthopedic rehabilitation centers.	CS, Regression analyses	Multi- dimensional Body-Self Relations Questionnaire (MBSRQ)
Fisher & Hanspal (1998)	107 (67/40)	55.5 [ns; 40–88]	transtibial transfemoral knee disarticulation hip disarticulation partial foot	Vascular Diabetes Trauma Infection Congenital Neoplasm Other	13.9 [ns; 1-54]	Attendees at routine prosthetic clinics	CS, Correlation (Kendall's tau-b)	Body Image Questionnaire (BIQ)
Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan (2007)	145 (99/46)	60.5 [17.4; ns]	73 below knee 3 through knee 52 above knee 17 bilateral	Vascular Diabetes Trauma Infection Cancer Clot Other	6.78 [11.95; ns]	Participants identified from 2 limb fitting services in Ireland. Participants were contacted and data collected by mail.	CS, Correlation (Spearman's rho)	ABIS ABIS-R
McDonald, Sharpe, & Blaszczynski (2014)	50 (39/11) non-amputed <i>n</i> =240	63.04 [11.26; 36–91]	47 "major" (above ankle) 3 "minor" (below ankle)	Diabetes	ns	Recruited through diabetes or amputation specific organizations or clinics in the metropolitan Sydney, AU	CS, Correlation (Cohen's r & Spearman's rho)	Body Image Disturbance Questionnaire (BIDIQ)
Murray & Fox (2002)	x 44 (24/17)	41.6 [12.9; 18–75]	22 below knee 14 through knee	Trauma Cancer	ns	Recruited from internet amputee discussion groups	Hierarchical regression analysis CS,	ABIS

	undisclosed gender <i>n</i> =3		6 above knee 1 bilateral 1 partial foot	Vascular Diabetes Other Congenital	prosthesis use: 8.1 [ns; 0.1–40]		Correrlation (Spearman's rho)	
Robert, Ottaviani, Huh, Palla, & Jaffe (2010)	24 (8/16) limb salvage <i>n</i> =33	37.2 [ns; 16.1–52.0]	13 transfemoral4 below knee4 hip disarticulation1 hemipelvectomy1 rotationplastyUpper limb:1 shoulderdisarticulation	Osteosarcoma	ns	Participants treated for osteosarcoma at a single institution were recruited by post between March 2007 and February 2008	CS, Correlation (Spearman's rho) Linear regression models	ABIS
Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaise (1995)	112 (73/39) er	51.5 [ns; 21–83]	62 below knee 41 above knee 5 Symes (foot) 4 hip disarticulation	Vascular Trauma Cancer Congenital Other	17 [ns; 0.75–49]	Recruited from 5 prosthetic clinics in the Chicago metropolitan area over a 10-month period	CS, Correlation (ns) Hierarchical regression Stepwise regression	Amputation- Related Body Image Scale (ARBIS)
Safaz, Yilmaz Goktepe, & Yazicioglu (2010)	re-test (1 month) <i>n</i> =37 (37/0)	27.70 [5.57; 19-51] (not provided for re-test)	56 transtibial 18 knee/ transfemoral 17 ankle/foot (not provided for re-test)	Trauma	4.75 (5.13; 0.25 – 30.0) (not provided for re-test)	Recruited from an amputee rehabilitation unit between 2003 and 2008		ABIS (scores for ABIS-R additionally calculated)
Swanson, Stube, & Edman (2005)	8 (8/0)	ns	8 transfemural	ns	ns prosthesis use: 19.95 [ns; 0.67–75.0]	Recruited from a regional rehabilitation hospital in Minneapolis, MN, USA	CS, Correlation (Spearman's rho)	Situational Inventory of Body Image Dysphoria (SIBID)

Tatar (2010)	37 (25/12) sport & exercise <i>n</i> =17 (13/4)	ns	18 transtibial 19 transfemoral	Vascular Diabetes Trauma Burns/ Frost bite Tumor Other	ns prosthesis use > 3.0	Recruited from the Centre of Rehabilitation and Orthotics-Prosthetics, Marmara University, and clubs for people with disabilities in Istanbul	CS, Correlation (Pearson's r & Spearman's rho)	ABIS
	no sport & exercise <i>n</i> =20 (12/8)							
Zidarov, Swaine, & Gauthier- Gagnon (2009)	19 (14/5)	53.4 [14.6; 26 – 78]	16 transtibial 3 transfemural	Vascular Trauma Tumor Infection	0.20 [0.25; 0.02 – 1.05]	Recruited from consecutive admissions to a rehabilitation institute in Quebec, Canada, September 2005 to December 2006	Longitudinal Correlation (Pearson's r)	

Note: ns = not stated/reported in paper, cs = cross-sectional

Study (year)	Main aim of the study	Body image measure with sample mean	Correlations or regressions with body image.
*Akarsu, Tekin, Safaz, Goktepe, & Yazicioglu (2013)	Compare QOL and functionality of persons with unilateral versus bilateral LLA	ABIS score: Unilateral ($M = 10$, range = 7-21) Bilateral ($M = 12$, range = 7-18) No significant difference between groups ($p = .345$)	Prosthesis use not found to be correlated with ABIS scores.
*Akyol et al. (2013)	Compare QOL and emotional state in lower limb amputation versus "healthy controls"	ABIS score: (<i>M</i> = 12.13, <i>SD</i> = 6.82)	ABIS scores reported to significantly correlate with all QOL sub-scales on Nottingham Health Profile and with Beck Depression Inventory and Beck Anxiety Inventory (p <.01).
	Evaluate relationship of QOL and emotional status with post- amputation pain, functional status and body image.		
Atherton & Robertson (2006)	Determine prevalence of psychological distress among lower limb amputees and identify associated variables.	ASI subscale, body image vulnerability: (M = 15.37, SD = 4.67, range = 6-24)	Body image subscale of the ASI reported to have significant negative correlations with general adjustment ($r_{\tau} =326$, $p<.001$) and social adjustment ($r_{\tau} =356$, $p<.001$) subscales of the TAPES. Body image vulnerability significantly, positively correlated with anxiety ($r_{\tau} = .315$, $p<.001$) and depression scores ($r_{\tau} = .376$, $p<.001$). The Social anxiety subscale of the SCS significantly correlated with body image vulnerability ($r_{\tau} = .263$, $p = .001$). Body image vulnerability reported to have significant correlation with the public self-consciousness subscale of the SCS ($r = .205$, $p = .048$). No significant correlations with the self-investment or private self-consciousness subscale of the SCS.
Breakey (1997)	Development of a measure of body image anxiety in lower limb amputation.	ABIS score: (Mdn = 33.5, IQR = 22, range = 4-76) Transtibial: (Mdn = 31, IQR = 17) Transfemural: (Mdn = 35.5, IQR = 32)	No significant correlation found between body image anxiety and age ($r_s =10$) or time since amp ($r_s =17$). Significant positive correlations found between body image anxiety and the Index of Self-Esteem ($r_s = .56$, $p < .001$), Generalized Contentment Scale (depression; $r_s = .64$; $p < .001$) and Clinical Anxiety Scale ($r_s = .57$; $p < .001$). A significant negative correlation reported between body image and Satisfaction with Life Scale ($r_s = .58$, $p < .001$).

Table 3. Cohort averages, correlation and regression data relating to body image, for the studies included for review.

		No significant difference between groups.	
Coffey, Gallagher, Horgan, Desmond, & MacLachlan (2009)	Explore psychosocial adjustment in diabetes related lower-limb amputation	ABIS-R score (n = 34): (<i>M</i> = 12.8, <i>SD</i> = 5.97, range = 2–27) (<i>Mdn</i> = 12.5, <i>IQR</i> = 8.5)	Body image anxiety found to be significantly, positively correlated with the HADS for anxiety ($r_s = .77$, p<.01) and depression ($r_s = .77$, p<.01). Body image also found to have a significant negative correlation with TAPES psychosocial subscales; general adjustment ($r_s =48$, p<.01), social adjustment ($r_s =51$, p<.01) and adjustment to limitations ($r_s =45$, p<.05). Body image anxiety significantly, positively correlated with social restriction ($r_s = .44$, p<.05) and negatively correlated with weight ($r_s =36$, p<.05) and functional ($r_s =46$, p<.01) satisfaction with prosthesis.
Holzer et al. (2014)	Analyze the impact of lower-limb amputation on two major components of aesthetic perception, body image and self-esteem.	MBSRQ scores: Unilateral & Bilateral combined (M = 3.09, SD = .55) Scores found to be sig lower (p<.001) than scores for control group $(M = 3.41, SD = .34)$	MBSRQ reported to correlate with Rosenberg Self-Esteem Scale ($r = .27$) and SF-36, quality of life scale ($r = .43$).
Fisher & Hanspal (1998)	To see whether patients' attitude to prosthesis and body image influence mobility.	BIQ score: (<i>Mdn</i> = 29, range = 17 – 62)	Overall BIQ scores found to correlate with anxiety ($r_{\tau} = .56$, $p < .01$) and depression ($r_{\tau} = .39$, $p < .05$). However, BIQ score was not found to have a sig correlation to mobility ($r_{\tau} = .02$), nor to time since amputation ($r_{\tau} = .12$), age ($r_{\tau} = .17$), Attitude toward Artificial Limb Questionnaire (AALQ) ($r_{\tau} = .29$) or physician's satisfaction ($r_{\tau} = .24$)
			Using median BIQ score to differentiate group with more positive body image, BIQ significantly correlated with mobility (effect size not stated, p <.01).
			(<i>Note</i> : The study abstract stated that in younger amputees (more traumatic than vascular amputation) body image was found to be significantly correlated with mobility. However, this was not reported in the results section.)
Gallagher, Horgan, Franchignoni, Giordano, &	Validate basic measurement properties of the ABIS using RASCH analysis	ABIS/ABIS-R scores: Mean/median values not reported	The ABIS was found to be significantly correlated with TAPES psychosocial adjustment subscale: general adjustment ($r =57$, $p < .0001$), social adjustment ($r =44$, $p < .0001$), and adjustment to limitation ($r =30$, $p < .001$), satisfaction with prosthesis subscales: aesthetic satisfaction ($r =30$)

1-47	
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MacLachlan (2007)			.27, $p <.005$), functional satisfaction ($r =41$, $p <.0001$), and weight satisfaction ($r =23$, $p <.01$), and activity restriction subscales: functional activity restriction ($r = .30$, $p <.001$), and social activity restriction ($r = .40$, p <.0001). However, the ABIS was not found to significantly correlate with athletic activity restriction ($r = .17$, $p = .07$) ABIS-R significantly correlated with all of the TAPES subscales: general adjustment ($r =54$, $p <.0001$), social adjustment ($r =40$, $p <.0001$), adjustment to limitation ($r =26$, $p <.005$), aesthetic satisfaction ($r =22$, p <.05), functional satisfaction ($r =37$, $p <.0001$), weight satisfaction ($r =23$, p <.05), functional satisfaction ($r = .19$, $p <.05$), functional activity restriction ($r = .31$, $p <.001$), and social activity restriction ($r = .43$, $p <.0001$).
McDonald, Sharpe, & Blaszczynski (2014)	To examine psychosocial impact of diabetes-related amputation while controlling for group differences on medical or demographic variables.	BIDQ scores: With amputation M = 1.93, range $= 1 - 4.71$) Without amputation (M = 1.42, range $= 1 - 4.43$) Groups found to be significantly different (<i>p</i> <.001)	After controlling for demographic and medical factors, group differences in body image disturbance remained significant, with amputation accounting for an additional 2.4% of variance ($\beta = .194$, $p = .005$)
Murray & Fox (2002)	To investigate the relationship between prosthesis satisfaction and body image in LLA, and to explore any gender differences in these relationships.	ABIS score: (<i>M</i> = 57.0, <i>SD</i> = 2.9, range = 23–100) (<i>Mdn</i> = 57.5, <i>IQR</i> = 25)	ABIS scores found to be significantly negatively correlated with total prosthesis satisfaction on the TAPES ($r_s =52$, p<.001) as well as subscales; functional satisfaction ($r_s =43$, p<.01), aesthetic satisfaction ($r_s =40$, $p<.01$) and weight satisfaction ($r_s =34$, p<.05). Body image anxiety correlated with daily hours of prosthesis use ($r_s =39$, $p<.001$). Body image anxiety was not found to have a significant correlation with level of pain on the McGill Pain Questionnaire ($r_s = .21$, $p>.05$), or time length of time with the prosthesis ($r_s = .10$, $p>.05$).
			Gender differences were identified across variables. Body image anxiety was found to be significantly, negatively correlated with total prosthesis satisfaction for both men ($r_s =51$, p<.01) and women ($r_s =60$, p<.01), the correlation with functional satisfaction was significant for men ($r_s =47$, p <.05) but not women ($r_s =40$, p>.05), correlation with aesthetic satisfaction was significant for women ($r_s =57$, p<.05) but not men ($r_s =18$, p>.05) and weight satisfaction was found to be significantly correlated with body image anxiety for women ($r_s =55$, p<.05) but note men ($r_s =30$, p>.05). For men, only daily hours of prosthesis use was found to be

			significantly correlated with body image ($r_s =46$, $p < .05$), with no significant correlation found with pain ($r_s = .27$, $p > .05$) or length of time with prosthesis ($r_s = .01$, $p > .05$). For women, no significant correlations were found between body image anxiety and pain ($r_s =09$, $p > .05$), length of time with prosthesis ($r_s = .09$, $p > .05$) or daily prosthesis use ($r_s =29$, $p > .05$).
* Robert, Ottaviani, Huh, Palla, & Jaffe (2010)	To compare functional and psychosocial outcomes in amputation versus limb salvage after treatment for osteosarcoma.	ABIS: Overall amputation $(n = 24)$ (M = 53.9, SD = 18.1) Primary Amputation $(n = 17)$: (M = 48.8, SD = 4.1) Late amputation $(n = 7)$: (M = 66.3, SD = 6.0) Limb Salvage $(n = 31)$: (M = 42.9, SD = 2.6)	Body image reported to demonstrate significant correlations (p <.001) with self-rating of physical function scores on the Toronto Extremity Salvage Score, physical, psychological, social and total quality of life scores on the Quality of Life – Cancer specific scale (QOL-CSS) and Index of Self-esteem. The QOL-CSS spirituality subscale and Sarason's Social Support Questionnaire scores not found to correlate with Body Image. Self-assessment of body image was associated with emotional well-being but not spiritual well-being or social support.
			(<i>Note</i> : It was not clear whether correlations are completed with full group, amputation and limb salvage together, or a subgroup for amputation).
Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser (1995)	To test the hypothesis that body image and perceived social stigma are important predictors pf psychosocial adjustment after lower limb amputation	ARBIS: Mean/median not reported	Body image reported to have significant correlation (p <.001) with; Age (r =29), Center for Epidemiologic Studies – Depression scale (CES-D; r = .52), Quality-of-Life Scale (r = .39), Prosthetist Adjustment Rating (r = -32), Perceived Social Stigma Scale (PSSS; r = .43), and Perceived Social support (r = .27). Body image not found to have a significant correlation with; gender (r = .15), cause of amputation (r = .15), time since amputation (r = .17), age at amputation (r =10), site of amputation (r =02) or self-rated health (r =02).
			The ARBIS was significantly contributed to variance in CES-D ($\Delta R^2 = .08$; $p < .001$) after control variables and PSSS. Stepwise analysis identified PSSS, perceived social support and ARBIS scores (in order) to be predictors retained in the model ($R^2 = .40$, p<.001). ARBIS contributed significantly to variance in quality of life ($\Delta R^2 = .05$, $p < .01$) after 5 control variables. Stepwise regression found ARBIS, perceived social support, self-rated health and time since amputation to be best predictors of Quality of Life ($R^2 = .53$, $p < .001$). ARBIS significantly contributed to the variance in prosthetist's rating of adjustment ($\Delta R^2 = .08$, $p < .01$). In stepwise regression, ARBIS score and self-rated health were predictors of Prosthetist Adjustment Rating ($R^2 = .16 = .06 = .01$)

.16, *p*<.001)

Safaz, Yilmaz, Goktepe, & Yazicioglu (2010)	To develop Turkish versions of the ABIS and ABIS-R and examine construct validity through correlation with health related quality of life	ABIS/ABIS-R: Mean/median values not reported	Both ABIS and ABIS-R scores found to have significant negative correlations with several subscales on the SF-36 ($n = 37$). ABIS displayed significant correlations with all subscales and summary scores; Physical Functioning ($r_s =60$, p<.01), Role-Physical ($r_s =40$, $p<.05$), Bodily Pain ($r_s =57$, p<.01), General Health ($r_s =49$, p<.01), Vitality ($r_s =56$, p<.01), Social Functioning ($r_s =44$, p<.01), Role-Emotional ($r_s =44$, p<.01), Mental Health ($r_s =33$, p<.05), Physical Component Summary ($r_s =57$, p<.01), and Mental Component Summary ($r_s =39$, p<.05)
			ABIS-R displayed significant correlations with the two component summar scores and most of the subscales; physical functioning ($r_s =59$, $p<.01$), rol physical ($r_s =33$, $p<.05$), bodily pain ($r_s =50$, $p<.01$), general health ($r_s =48$, $p<.01$), vitality ($r_s =51$, $p<.01$), social functioning ($r_s =37$, $p<.05$), role-emotional ($r_s =39$, $p<.05$), physical component summary ($r_s =53$, $p<.01$), and mental component summary ($r_s =34$, $p<.05$). ABIS-R not found to have a significant correlation with mental health subscale ($r_s =35$, p value not stated).
			Neither ABIS or ABIS-R scores found to have significant correlations with age, length of time since amputation or level of amputation (effect sizes and <i>p</i> values not provided).
* Swanson, Stube, & Edman	Explore whether use of a micro-processor- controlled prosthetic	SIBID: Mean/median values not reported	Authors reported fair but not significant correlation between body image an functional role performance ($r_s =43$, $p < .05$).
(2005)	knee joint leads to better functional independence		Note: a different correlation size was reported in the table provided (14).
	To see if increased functional abilities and independence correlates with improved body image.		
*Tatar (2010)	To investigate difference in body image in Turkish LLA's	ABIS; (<i>M</i> = 31.2, <i>SD</i> = 11.4, range ns] Sport & Exercise:	No significant correlations reported between ABIS and educational level, employment situation, reason of amputation, additional health problems, residual limb problems, and prosthesis use at home or out of home.

	who participate in sport versus those who do not	(M = 25.5, SD = 7.3; range ns) No Sport & Exercise: (M = 35.9, SD = 12.2; range ns)	Low and moderate correlations reported between reason for amputation and duration of prosthesis use at home ($r_s = .35$) and out of home ($r_s = .304$). Low correlations were reported between age and ABIS score ($r_s = .275$). Correlation between age at amputation and ABIS score not significant ($r = .12$).
			For subjects participating in sports and exercise, a moderate correlation was reported between age and ABIS ($r = .376$). No, or poor, correlations were found between the other variables and ABIS scores ($r_s < .25$).
			For individuals not participating in exercise, low correlations found between age and ABIS ($r = .25$). No, or poor correlations, were found between the other variables and the ABIS ($r_s < .25$).
Zidarov, Swaine, & Gauthier- Gagnon (2009)	Compare quality of life in individuals across 3 time points across rehabilitation; admission, discharge and 3-months post rehabilitation service discharge. Additionally, to examine the relationship between quality of life and other demographic or clinical factors (including body image).	ABIS: Time 1 (admission): scores not provided Time 2 (discharge): (M = 29, SD = 15.3; range = 1.3 – 68.8) Time 3 (3-month follow-up): (n = ,19, M = 29.1, SD = 19.3, range = 6.3 – 73.8)	Correlational analysis was not provided for time 1 or time 2. At 3-month follow up, ABIS was found to significantly, negatively, correlate with the Subjective Quality of Life Profile ($r =604$, p = .006). Prosthesis satisfaction was found to have a moderate, significant correlation with body image ($r =488$, p = .034).

Note: *denotes author contacted for additional information (no response received at time of review submission).

Data (e.g., mean, p values, correlation effect sizes) are provided where they have been reported in the original paper.

ABIS = Amputee Body Image Scale, BIQ = Body Image Questionnaire, HADS = Hospital Anxiety and Depression Scale, LLA = lower limb amputation, SCS = Self-Consciousness Scale, SF-36 = Short Form-36, SIBID = Situational Inventory of Body Image Disturbance, TAPES = Trinity Amputation and Prosthesis Experience Scales.

r = Pearson's product moment correlation coefficient, $r_s = Spearman's$ rank order correlation, $r_\tau = Kendall's$ Tau-b correlation

Appendix 1-A

Highlights

- Poor adjustment to limb amputation is associated with poor psychosocial well-being, including depression, anxiety and health related quality of life
- Rehabilitation after amputation often features prosthetic rehabilitation
- A systematic review of studies examining body image in amputation has found body image anxiety to be strongly associated with psychosocial difficulties and reduced prosthesis satisfaction
- Clinical and prosthetic services are recommended to consider body image when working with individuals with poor adjustment and non-use of prosthesis

Appendix 1-B

Guidance for using the STROBE quality appraisal tool

STROBE Statement-checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(<i>a</i>) Indicate the study's design with a commonly used term in the title or the abstract
		(b) Provide in the abstract an informative and balanced summary of what was
		done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being
-		reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of
		recruitment, exposure, follow-up, and data collection
Participants	6	(a) Cohort study—Give the eligibility criteria, and the sources and methods
		of selection of participants. Describe methods of follow-up
		Case-control study—Give the eligibility criteria, and the sources and methods
		of case ascertainment and control selection. Give the rationale for the choice
		of cases and controls
		Cross-sectional study—Give the eligibility criteria, and the sources and
		methods of selection of participants
		(b) Cohort study—For matched studies, give matching criteria and number of
		exposed and unexposed
		Case-control study—For matched studies, give matching criteria and the
		number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/	8*	For each variable of interest, give sources of data and details of methods of
measurement	0	assessment (measurement). Describe comparability of assessment methods if
measurement		there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If
	**	applicable, describe which groupings were chosen and why
Statistical methods	12	(<i>a</i>) Describe all statistical methods, including those used to control for
		confounding
		(b) Describe any methods used to examine subgroups and interactions

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		(c) Explain how missing data were addressed
		(d) Cohort study—If applicable, explain how loss to follow-up was addressed
		Case-control study—If applicable, explain how matching of cases and
		controls was addressed
		Cross-sectional study—If applicable, describe analytical methods taking
		account of sampling strategy
		(<u>e</u>) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially
Ĩ		eligible, examined for eligibility, confirmed eligible, included in the study, completing
		follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and
2 courper course		information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time
outcome dutu	15	<i>Case-control study</i> —Report numbers of outcome events of summary measures over time
		of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(<i>a</i>) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and
Main results	10	their precision (eg, 95% confidence interval). Make clear which confounders were
		adjusted for and why they were included
		(b) Report category boundaries when continuous variables were categorized
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a
0.1 1	17	meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity
		analyses
Discussion	10	
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or
		imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations,
		multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other informatio	n	
Funding	22	Give the source of funding and the role of the funders for the present study and, if
		applicable, for the original study on which the present article is based

Running head: SELF-DISGUST, PSYCHOSOCIAL ADJUSTMENT & AMPUTATION

Section Two: Empirical Paper

The Relationship of Self-Disgust to Psychosocial Adjustment after Limb Amputation

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Prepared for submission to Body Image¹

¹ Highlights for Body Image can be found in Appendix 2-A, Guide for Authors in Appendix 2-B

Abstract

This study proposed self-disgust as an emotion schema contributing to body image concerns and unhelpful factors maintaining poor adjustment in people with limb amputations. It was hypothesized that increased self-disgust would be associated with poorer outcomes regarding; adjustment, prosthesis use, aesthetic prosthesis satisfaction, and body image. A cross-sectional design was employed, sampling 83 participants (46 men, 37 women, *Mdn* age = 52.4 years) through online media. Participants were a median of 7.25 years post-amputation, with mostly lower limb amputations (n = 78), using prosthesis for a median of 14 hours/day, 31 days/month. Analysis, using bootstrapped correlation and hierarchical regression, confirmed the hypotheses and self-disgust was found to be a significant predictor of psychosocial adjustment and related factors. Identification of self-disgust in amputation services may aid delivery of psychosocial interventions and prosthetic rehabilitation. Furthermore, future research should aid in the understanding of the causal relationship between self-disgust and adjustment.

Keywords: amputation, self-disgust, body image, adjustment, prosthesis

The Relationship of Self-Disgust to Psychosocial Adjustment after Limb Amputation Psychosocial Impact of Limb Amputation

The loss of a limb will inherently lead to a period of physical, functional and psychological adjustment. However, the psychological issues associated with amputation are often overshadowed by physical rehabilitation in both healthcare (Mckechnie & John, 2014) and research (Desmond & MacLachlan, 2002). Yet, Gallagher and MacLachlan (2001), exploring experiences of adjustment, stated that the emotional and psychological consequences of limb amputation are vital considerations for the individual's adjustment.

The concept of successful adjustment - and its determinants – has been widely discussed within a number of fields relating to clinical and health psychology. Moss-Morris' (2013) working model of adjustment (explicitly to chronic illness but also relevant here) suggests that personal and social background factors influence how individuals respond to illness-specific factors, leading to critical events and illness stressors, which may result in a disruption of the person's emotional equilibrium and quality of life. While successful adjustment would involve a return to emotional equilibrium and improved quality of life, poor adjustment may occur when cognitive factors and behavioral responses are unhelpful (e.g., cognitive biases and avoidance), maintaining emotional disequilibrium.

Providing some support for Moss-Morris's (2013) model in relation to the experience of distress, Horgan and MacLachlan's (2004) quantitative review of psychosocial adjustment after amputation found that both anxiety and depression were common in the period following limb loss. Indeed, both anxiety and depression (along with quality of life and perceived health status) have been proposed by a number of researchers as operationalizations of psychosocial adjustment to amputation (Coffey, Gallagher, Horgan, Desmond, & MacLachlan, 2009).

Yet, research findings regarding long-term psychosocial adjustment to amputation have varied. While Horgan and MacLachlan (2004) reported that both anxiety and depression reduced within a two year period, a more recent systematic review of traumatic lower limb amputation found elevated levels of anxiety and depression in a number of studies with participants more than two years post-amputation (Mckechnie & John, 2014). Similarly, Desmond (2007) found anxiety and depression following traumatic upper limb amputation to be greater than that expected in the general population in a sample of participants who had a minimum time since amputation of 4.6 years.

The relationship between amputation and psychosocial difficulties remains unclear and is likely influenced by other factors. For instance, Kratz et al. (2010) found different correlation patterns for health and trauma-related amputation and suggested that different causes of amputation may affect the individual's experience of limb loss. Indeed, Bury's (1982) theory of biographical disruption suggests that the onset of a chronic illness may be a threat to a person's identity as the perception of normal life is disturbed. If we consider amputation in regard to chronic health difficulties, due to the long-term impact on physical functioning, biographical disruption may occur at different times depending on the cause of amputation, which may impact on factors associated with poor adjustment.

Successful adjustment, on the other hand, has been associated with the use of prosthesis (Murray, 2004). Indeed, prosthesis training and ambulation are considered key aspects of rehabilitation after limb loss, facilitating reintegration into the community (Esquenazi & DiGiacomo, 2001). Furthermore, prosthesis satisfaction has been related to greater quality of life and adaption to limb loss (Akarsu, Tekin, Safaz, Goktepe, & Yazicioglu, 2013), while increased

2-4

prosthesis use has also been associated with better quality of life (Zidarov, Swaine, & Gauthier-Gagnon, 2009) and lower levels of depression (Holmes & Spence, 2006; Nicholas et al., 1993).

Moreover, in a recent study, Durmus et al. (2015) found length of prosthesis use, daily hours of prosthesis use, and satisfaction with prosthesis to be negatively correlated with "general psychiatric symptomatology" (including depression and anxiety). Additionally, they found increased prosthesis use and satisfaction to be associated with greater self-esteem. Selfappraisals, and the self-schema that inform them, might therefore have an important role in adjustment to amputation, in that they may contribute to cognitions that either resolve or maintain emotional disequilibrium and reduce quality of life.

Self-appraisals and Adjustment to Amputation

An individual's identity, within the context of cognitive theory, may be considered as a set of self-schemas, generalized beliefs about the self that originate from past experiences to help the individual organize and process information related to themselves (Markus, 1977). Atherton and Robertson (2006) proposed our appearance schema to be of particular relevance following amputation, suggesting greater distress is likely to occur in individuals who are more appearance schematic (appearance held as a measure of self-worth). Additionally, Atherton and Robertson (2006) identified that increased body image vulnerability (an individual's assumption of unacceptable appearance) was associated with increased distress.

Several quantitative studies have related increased body image concerns following lower limb amputation to reduced quality of life and increased psychological distress (Akyol et al., 2013; Breakey, 1997; Coffey et al., 2009). Horgan and MacLachlan (2004) identified that body image anxiety is associated with poorer psychosocial outcomes, as well as reduced physical and social activity. Moreover, Rybarczyk, Nyenhuis, Nicholas, Cash, and Kaiser (1995), identifying a correlation between body image concerns and perceived social stigma, suggested that anxiety following amputation was related to individuals' fear of looking unattractive and a belief that they may receive negative evaluation from others.

Body image, therefore, appears to have an important relationship with adjustment to amputation. However, while body image anxiety has been associated with reduced prosthesis satisfaction (Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan, 2007; Murray & Fox, 2002), there have been mixed findings regarding the association of body image to prosthesis use (Akarsu et al., 2013; Murray & Fox, 2002; Tatar, 2010). Furthermore, while coping strategies such as "camouflaging" have been associated with (general) body image concerns (Cash, 2002), Murray and Fox (2002) found increased body image anxiety to be correlated with decreased prosthesis use, not as might be expected if the prosthesis is used to camouflage. It seems that increased prosthesis use contributes positively to body positivity. However, causality cannot be assumed and amputation may lead to additional self-appraisals that better inform our understanding of prosthesis use and adjustment. Indeed, schema pre-existing the amputation may contribute to unhelpful thoughts that maintain poor adjustment.

The Experience of Self-Disgust as an Emotion Schema

Evidence indicates that disgust evolved as a physical and emotional response to potential sources of contamination (Curtis, Aunger, & Rabie, 2004), as an emotion designed to protect violations of the body envelope (Rozin, Haidt, & McCauley, 2005). However, as with body image, disgust is socioculturally-defined and maladaptive disgust may occur as a learnt response toward stimuli which are not considered functional, including disgust toward persisting aspects of the self, or "self-disgust" (Power & Dalgleish, 2008). Consequently, self-disgust has been proposed as an emotion schema (Powell, Simpson, & Overton, 2015a) and considerable

theoretical interest has recently been directed towards self-disgust as a pan-diagnostic concept relevant to the development and maintenance of a range of psychological difficulties (e.g., Powell, Overton, & Simpson, 2015). In particular, Powell, Simpson, and Overton (2013) identified self-disgust as an antecedent to depression, suggesting a reciprocal role with dysfunctional thoughts (representations of underlying schema) in a temporal prediction of depression.

Self-directed disgust has previously been conceptualized as an aspect of emotional difficulties centered on bodily characteristics (Fox, 2009; Moncrieff-Boyd, Byrne, & Nunn, 2014; Neziroglu, Hickey, & McKay, 2010). Furthermore, Powell et al. (2013) identified physical, rather than behavioral, aspects of self-disgust to be important in predicting depression longitudinally. Disgust has also been associated with body dissatisfaction in obesity (Griffiths & Page, 2008; Park, Schaller, & Crandall, 2007) and illnesses involving body distortions (Smith, Loewenstein, Rozin, Sherriff, & Ubel, 2007).

Self-Disgust and Limb Amputation

Self-disgust, as an emotion schema related to bodily characteristics and experience of depression, may be an important consideration in relation to adjustment to amputation. Indeed, physical self-disgust may have particular salience regarding amputation, as changes in the physical self are the catalyst for changes in function and identity. As a result of limb loss, individuals may develop a physical self-disgust schema based on prior disgust-based beliefs. This might complement an existing appearance schema, the individual's self-worth and perception of others' evaluations developing from personal beliefs about the self as disgusting.

Self-disgust has been conceptualized as related but separate from other negative selfdirected constructs (Powell et al., 2013). Although often used as a synonym for shame, Ekman suggested that shame is in the sadness "family" of basic emotions, exhibiting different behavior and facial expressions from those of disgust (Ekman, 1992). Disgust, unlike shame or guilt, is associated with a visceral sense of repulsion; a physical as well as emotional reaction designed to prevent contamination (Curtis et al., 2004). It is likely that post-amputation self-disgust is important in its own right, exhibiting a qualitatively different relationship with limb loss than other constructs such as shame or self-consciousness. For example, the experience of selfdisgust may vary depending on etiology of the amputation (i.e., health or trauma) relating to different pre-amputation experiences and societal associations. As disgust can arise from both core and socio-moral elicitors (Simpson, Carter, Anthony, & Overton, 2006), internalized selfdisgust may result from both the innate nature of amputation as an invasion of the body "envelope" and through deviation from the body image that society promotes as "normal". In addition to psychosocial difficulties (e.g., adjustment and body image), self-disgust may promote the use of different coping mechanisms. Desmond (2007) found avoidance to be significantly correlated with distress and poorer adjustment. Yet, qualitative research has found that individuals experiencing self-disgust distance themselves from the aspect of self they find disgusting, engaging in behaviors that avoid the disgusting self (Powell, Overton, & Simpson, 2014). Self-disgust might give rise to avoidance of the residual limb due to the association between amputation and disease. However, avoiding care of the residual limb may cause further health problems and poorer adjustment.

Moreover, self-disgust, particularly in the early post-amputation period, may engender avoidance of the amputated limb and, by extension, reduced use of the prosthesis. Along with demographic, clinical and psychological factors, self-disgust may be a better predictor of prosthesis use than body image. However, a metasynthesis of qualitative studies by Murray and Forshaw (2013) highlighted the role of the prosthesis in social interactions by way of concealing limb loss and maintaining a "normal" appearance. Indeed, participants described wearing their prosthesis to make company feel more comfortable. Individuals with a self-disgust schema may be more aware of disgust-type reactions and/or externalize self-directed disgust onto others. It is likely that, when using a prosthesis, individuals experiencing self-disgust will feel a higher demand for the prosthesis to successfully camouflage the limb, resulting in reduced satisfaction. However, this might be expected with aesthetic, rather than functional aspects of prosthesis satisfaction.

Moss-Morris (2013) suggests that unhelpful factors maintaining disequilibrium should be identified and addressed to aid adjustment to chronic health difficulties. It is important to understand how self-disgust relates to the adjustment process, so that difficulties associated with self-disgust after amputation may be addressed. Consequently, the aim of this study was to explore the relationship of self-disgust with other demographic, clinical, and psychosocial factors following limb amputation. In particular, this study examined the role of self-disgust in predicting adjustment, prosthesis use, prosthesis satisfaction, and body image following limb loss. It was hypothesized that greater levels of self-disgust would be associated with four outcomes - poorer psychosocial adjustment, lesser prosthesis use and satisfaction, and increased body image anxiety - and that self-disgust would be more predictive than other demographic, psychological, and clinical predictors of these outcomes.

Method

A quantitative, cross-sectional design was employed, with data collected remotely using a series of self-report questionnaires. A better theoretical understanding of the relationships

between self-disgust and the limb amputation experience was facilitated through use of correlational and then regression analysis.

Ethical Considerations

Due to the potentially sensitive content of the study, Experts by Experience were contacted to review use of language. Online and hardcopy versions of the study were approved by Lancaster University Faculty of Health and Medicine Research Ethics Committee and the University Research Ethics Committee.

Participants were presented with the participant information sheet, advised to take adequate time to consider participation and asked to complete a consent procedure before taking part. Participants were reminded prior to participation that they could exit at any time if they became overly distressed and links to freely accessible international support organizations were provided in the participant information and on completion of the study. Data were not included in the study if the consent procedure was not complete or if the study was exited before the end.

Procedure and Participants

The study examined a random opportunity sample of participants recruited internationally via advertisements on social media (e.g., twitter), amputee and prosthesis related organization websites and related media (e.g., LimbLine magazine), amputee discussion forums, and an amputee ListServ group. Participants were invited to take part in the study online via Qualtrics online survey software, or to contact the researcher by email to request a hardcopy. Additionally, an amputee support group in Liverpool, UK was contacted and provided with hardcopies which could be returned via freepost. Recruitment took place over a six-month period between October 2015 and March 2016.

Inclusion/exclusion criteria. Participants were invited to take part in the study if they had experienced limb loss, had access to the use of a prosthesis, and were of 16 years or above². Participants were unable to take part if they were restricted in the use of prosthesis for any reason other than personal choice (e.g., medical recommendation) or used a prosthesis to aid with congenital limb difference (i.e., limb loss not resulting from amputation). Participation was not determined by age, ethnicity or nationality.

Measures

In addition to demographic and clinical data, the study used six measures to collect information on psychosocial adjustment; satisfaction with prosthesis, self-disgust, body image, psychological distress, and coping styles.

Predictor Variables. Predictor variables included; demographic factors, clinical variables, psychosocial variables (emotional distress and coping styles), and self-disgust.

Demographics and clinical information. Demographic data were collected regarding participant age, gender, country of residence and ethnicity³. Participants were asked to report clinical information regarding time since amputation, level and cause of amputation, residual limb pain (RLP) and phantom limb pain (PLP).

DASS-21. The DASS-21 is the short form version of Lovibond and Lovibond's (1995) Depression Anxiety and Stress Scales, a 42-item self-report measure. Each of the subscales; depression, anxiety, and stress, includes seven items scored on a four point Likert scale. Total scores for each subscale are calculated by summing item scores within that scale and then multiplying by two. This results in a potential range of 0 to 42 for each of the subscales, or 0 to

² Minimum age for consent into the study was determined in accordance with the British Psychological Society Code of Human Research Ethics (British Psychological Society, 2014)

³ Collection of ethnic data was amended in reference to; National Statistics (2003), Ethnic group statistics: A guide for the collection and classification of ethnicity data.

126 for the full measure; higher scores indicate greater distress. Henry and Crawford (2005) found good to excellent internal consistencies for the depression ($\alpha = .88$), anxiety ($\alpha = .82$), stress ($\alpha = .90$), and total scale ($\alpha = .93$).

Brief COPE. The Brief COPE (Carver, 1997) is a measure of coping reactions. It includes 28 items scored on a 4 point Likert scale. The measure is not designed to provide a total score, but consists of 14 subscales, each describing a different coping style (e.g., acceptance). Scale scores are derived from summing two corresponding items. The potential range for each subscale is 0 to 6, with higher scores indicating greater use. A recent study of coping strategies among individuals with HIV in China found Cronbach's alpha to range from .61 to .80.

SDS-R. The Self-Disgust Scale-Revised (SDS-R; Powell, Simpson, & Overton, 2015) is a measure of participants' self-disgust. It is a 22 item self-report measure using a seven point Likert scale. To score, seven items are removed and four reverse-scored before summing the remaining 15 items. Scores can range from 15 to 105, and the scale has demonstrated excellent internal consistency ($\alpha = .93$). Preliminary analysis, using principal component analysis, has indicated that the measure can be used as two separate subscales, as intended by the authors; physical self-disgust and behavioral self-disgust. For each scale, higher scores indicate higher levels of self-disgust.

Outcome Variables. Six outcome variables were collected; daily prosthesis use, monthly prosthesis use, aesthetic prosthesis satisfaction, functional prosthesis satisfaction, psychosocial adjustment, and body image.

Prosthesis Use. Participants were asked to report, on average, how many hours per day and how many days per month they wore a prosthesis.

TAPES-R Psychosocial. The TAPES-R Psychosocial, part of the Trinity Amputation and Prosthesis Experience Scales – Revised (TAPES-R; Gallagher, Franchignoni, Giordano, & MacLachlan, 2010), is a 15 item measure that assesses adjustment to amputation. The measure includes three subscales; general adjustment, social adjustment, and adjustment to limitation. Each sub-scale includes five items, using a four point Likert scale. For each item, participants may also choose "Not applicable" (unscored). Totals are calculated by averaging the items deemed applicable. Possible scores range from 1 to 4, with higher scores indicating better levels of adjustment. The three subscales are summed to obtain a total psychosocial adjustment score, with a range of 3 to12. The TAPES-R is a psychometrically revised version of the original TAPES. Rasch analysis of the TAPES (Gallagher et al., 2010) demonstrated adequate internal consistency and person separation for each subscale: general adjustment ($\alpha = .90$; *PSI* = 2.17), social adjustment ($\alpha = .89$; *PSI* = 1.92), and adjustment to limitation ($\alpha = .86$; *PSI* = 1.98).

TAPES-R Satisfaction. The TAPES-R Satisfaction includes two subscales; aesthetic satisfaction (three items) and functional satisfaction (five items). Responses are on a three point Likert scale. Totals are calculated by summing all item responses within a scale. Scores for aesthetic satisfaction range from 3 to 9, and functional satisfaction ranges from 5 to 15. Higher scores indicate greater levels of satisfaction. A total score for satisfaction is obtained by summing the two subscale scores, with a possible range of 8 to 24. Rasch analysis of the TAPES (Gallagher et al., 2010) demonstrated adequate internal consistency and person separation for the subscales: aesthetic satisfaction ($\alpha = .85$; PSI = 1.61) and functional satisfaction ($\alpha = .86$; PSI = 1.83).

ABIS-R. The Amputee Body Image Scale-Revised (ABIS-R: Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan, 2007) is a 14 item measure of body image anxiety in lower limb amputees. Items are measured on a three point Likert scale. Total scores are derived from reverse scoring two items and then summing all item scores, with a potential range of 0 to 28. The scale has demonstrated good internal consistency using person separation reliability (PSI = 0.84). One item refers to an experience specific to lower limb amputation (i.e., limping). This item was removed as it was not felt that a suitable amendment could be made to incorporate an equitable experience of upper limb amputation. An amended, 13 item version of the ABIS-R was used in this study, with scores ranging from 0 to 26.

Data Analysis Strategy

Data were analyzed using SPSS statistics package version 22. Raw scores were coded and scales scored in accordance with scale instructions. Cronbach's alpha was calculated for each of the scales/subscales.

Assumptions of normality. Normality was assessed using histograms with a normal distribution overlay, boxplots and quartile-quartile (Q-Q) plots. Additionally, Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) tests were used to provide objective assessments of distribution. Age demonstrated a non-significant variation from normal distribution on both the K-S test (p = .20) and S-W test (p = .055). Adjustment to limitation also demonstrated a non-significant variance according to the K-S (p = .184) and S-W (p = .081) tests. All other variables demonstrated a significance of p<.001 for both tests. As data were largely non-normative, descriptive data have been reported using scale medians and interquartile ranges.

Missing data analysis. Examining patterns across the missing data, one participant was observed to have a large amount of missing values and was removed from the data set. Of the 82 cases remaining, missing data analysis revealed a very small amount of missing values (0.2%) across the entire data set. Missing data were observed across six variables and across 13

participants. As more simplistic approaches (e.g., pairwise deletion) could have resulted in a large reduction in valid cases (n = 69), imputation methods of dealing with missing data were used.

No patterns emerged from a Missing Value Pattern analysis, and Little's test for missing completely at random (MCAR) was found to be non-significant ($X^2 = 1.70$, df = 958, p = 1.00), indicating that data were MCAR and that data imputation was appropriate. Due to the very low amount of missing data, an EM algorithm approach was felt to be more suitable than Multiple Imputation (Graham, 2009). All subsequent analysis was performed using an imputed "complete" data set for 82 cases.

Predictive analysis. Bootstrapping (using 1000 replications) was employed to facilitate correlation and regression analysis, as the bootstrapping technique does not rely on assumptions of normality (Efron, 1987). Subsequently, 95% bias corrected bootstrap confidence intervals were used to assess the significance of correlations using Pearson product-moment correlation coefficient (Pearson's r) and hierarchical regression analysis.

For each outcome variable, correlations were performed with demographic, clinical and psychosocial variables: age, gender, cause of amputation (trauma or health), time since amputation, whether RLP was reported (yes or no), RLP frequency and duration, whether PLP was reported, PLP frequency and duration, DASS-21 (including subscales), the 14 Brief-COPE items and the SDS-R (including subscales). The difference in effect size between physical and behavioral self-disgust, with each of the outcome variables, was assessed using Steiger's Z-test (see Uitenbroek, 1997).

Only variables with a moderate correlation ($r \ge .30$) were included in the regression models (Cohen, 1988). Variables were entered into the models in up to four blocks in order of:

demographic variables, clinical variables, psychosocial variables and self-disgust. This facilitated examination of the additional contribution of self-disgust to variance in the six outcome variables. Where suppressor effects were detected between the subscales of the DASS-21 or SDS-R, full scale totals were used.

Results

Participant Characteristics

Recruitment. The researcher aimed to recruit 105 participants, based on Cohen's (1998) estimation of the same sample size for a medium effect size ($f^2 = .15$) and ten predictor variables for regression analysis. During the recruitment window (October 2015 to March 2016), the online version of the study was accessed 150 times. A total of 110 individuals proceeded from participant information to consent procedure, of whom 95 provided full consent. However, 13 participants exited the study before the end, representing a drop-out rate of 14%. A further two hard copies of the study were returned from the Liverpool based amputee support group, of which one had completed the consent procedure. A total of 83 data sets were included for analysis. The study recruited 79% of the intended sample size.

Demographic and clinical characteristics. Of the participants included in the study, 46 identified as male and 37 as female. Mean age was 52, with participants ranging from 18 to 78. An overwhelming majority of participants identified as White/Caucasian (n = 79) and from Western countries (n = 82). A more detailed breakdown of sample demographics is provided in Table 1.

INSERT TABLE 1 ABOUT HERE

Time since amputation ranged from 0 to 48 years, with a median of 7 years. Lower limb amputation was identified by most participants (n = 78). Only three reported an upper limb

amputation and two reported "Other". Two participants used the description options provided to report bilateral amputation.

Reasons identified for amputation, in order of decreasing numbers, were: "Other" (n = 34), "Accident" (n = 28), "Diabetes" (n = 14), "Vascular Disease" (n = 10) and "Cancer" (n = 7). Ten participants identified two reasons for amputation and 34 provided an additional description (e.g., "Toxic shock"). Two individuals who identified "Other" provided descriptors indicating trauma, while two participants reporting "Accident" provided descriptions of health complications. Drawing on response categories and descriptive information together, 28 participants appear to have experienced amputation as a direct result of trauma. Sixty-eight percent (n = 56) of the study sample reported experience of RLP, while 75 percent (n = 62) reported PLP.

The majority of participants (n = 53) reported using a prosthesis 31 days per month on average. Subsequently, median prosthesis use (days/month) was 31. However, the range of use was from zero to 31 days. Participants reported a median prosthesis use of 14 hours per day, with a range of zero to 18 hours. Further information about clinical characteristics is provided in Table 2. As different patterns emerged for use of prosthesis in days/month versus hours/day, it was felt that further investigation of both as individual outcome variables was warranted. This has been seen previously in a sample of people with upper limb amputations (Raichle et al., 2008).

INSERT TABLE 2 ABOUT HERE

Descriptive and Normative Comparisons

A summary of the descriptive data for the self-report scales (minus the Brief COPE) is presented in Table 3, along with Cronbach's alpha assessment of internal consistency for this sample. All scales, aside from the Brief COPE, demonstrated good to excellent internal consistency for this study population. Two scales from the Brief COPE demonstrated poor internal consistency: self-distraction ($\alpha = .51$) and venting ($\alpha = .47$). However, all other scales in the measure demonstrated acceptable to excellent internal consistency.

INSERT TABLE 3 ABOUT HERE

Scale medians indicated generally high levels of general adjustment (Mdn = 3.8, IQR = 1.0) and social adjustment (Mdn = 3.6, IQR = 1.0) on subscales of the TAPES-R Psychosocial measure, indicating that this sample had, generally, adjusted well to amputation. However, the sample median was lower for adjustment to limitation (Mdn = 2.6, IQR = 1.2) and it is of note that participants ranged from lowest possible score to highest possible score on all subscales. Similarly, participants reported scores for the full range on all subscales of the TAPES-R Satisfaction. However, medians were in the higher range for each scale, indicating that, in general, participants were satisfied with their prosthesis in terms of aesthetic satisfaction (Mdn = 6, IQR = 4), and functional satisfaction (Mdn = 10, IQR = 5).

Normative data for the SDS-R have not yet been published. However, sample medians fell in the lower end of the subscale ranges for physical self-disgust (Mdn = 9, IQR = 9), behavioral self-disgust (Mdn = 8, IQR = 6) and self-disgust total (Mdn = 27, IQR = 20), suggesting that the participants in this sample did not experience high levels of self-disgust. Yet, a large range of scores was found across the sample (15 - 91), indicating a wide variance of the self-disgust experience across the sample.

The participants in this sample were also found to have generally low scores on the amended ABIS-R scale (Mdn = 5, IQR = 11), indicating that body image anxiety was not high

among the sample but the range of scores was large (0 - 25), suggesting that some individuals had high levels of body image anxiety.

Once more, the sample was found to have generally low scores on the DASS-21 for depression (Mdn = 4, IQR = 10), anxiety (Mdn = 2, IQR = 6), and stress (Mdn = 6, IQR = 12), indicating generally low levels of emotional distress. However, using cut-off values advised by Lovibond and Lovibond (1995), 30.1% (n = 25) of participants indicated 'mild' to 'extremely severe' levels of depression, with 21.7% (n = 18) indicating scores in the "moderate" range or higher. Scores in the range of mild anxiety or above were indicated by 18.1% (n = 15) of the sample, with 12.0% (n = 10) scoring moderate or above. Additionally, 16.9% (n = 14) of the sample indicated mild levels or higher on the stress subscale, with 12.0% (n = 10) scoring in the moderate to extremely severe range. While the scores for this sample are on the lower end for anxiety, scores for depression appear to be similar to those described by Desmond (2007) and Mckechnie and John (2014). This is of particular note, as the median time from amputation was 7.25 years.

Lastly, the active coping and planning subscales of the Brief COPE appeared to be the most endorsed coping styles, while denial, substance use, behavioral disengagement and religion appeared to represent the least endorsed coping styles. Again, it can be noted that the full range of scores was indicated for each of the Brief COPE subscales.

Correlational Analysis

As the primary predictor variable of interest, correlations between self-disgust and the outcome variables are explored in full. However, a summary of all the correlations can be found in Table 4, Table 5, and Table 6.

INSERT TABLE 4, 5, AND 6 ABOUT HERE

Prosthesis Use. Daily prosthesis use significantly and negatively correlated with both SDS-R subscales: physical self-disgust (r = -.36) and behavioral self-disgust (r = -.21), and with the self-disgust total (r = -.31), indicating that increased self-disgust is associated with less daily use. The correlation coefficients of physical and behavioral self-disgust were not found to be significantly different (z = 1.65, p = .098).

Monthly prosthesis use was also significantly correlated with physical self-disgust (r = -.32) and the self-disgust total (r = -.20), but behavioral self-disgust was not found to be significant (r = -.04). While the correlations indicate that self-disgust is significantly associated with reduced monthly use of a prosthesis, this association appears to be maintained for physical, but not behavioral self-disgust, as might be expected. Again, the correlation coefficients of physical and behavioral self-disgust were not found to be significantly different (z = 1.31, p = .190).

Prosthesis Satisfaction. Aesthetic satisfaction was found to have medium to large significant, negative correlations with physical self-disgust (r = -.54) and behavioral self-disgust (r = -.35), and with the self-disgust total (r = -.50). A significant difference was found between the correlation coefficients for physical and behavioral self-disgust (z = 2.28, p = .023), indicating that physical self-disgust is a significantly stronger correlate of aesthetic prosthesis satisfaction.

Similarly, functional prosthesis satisfaction was found to have significant correlations of medium effect with physical self-disgust (r = -.40), behavioral self-disgust (r = -.30), and the self-disgust total (r = -.42). A significant difference was not found between the correlation coefficients of physical and behavioral self-disgust (z = 1.13, p = .257). The correlations indicate

that increased self-disgust is associated with lower aesthetic and functional prosthesis satisfaction.

Psychosocial Processes. Psychosocial adjustment was found to have significant negative correlations in the moderate to large range with physical self-disgust (r = -.60), behavioral self-disgust (r = -.42), and with the self-disgust total (r = -.60), indicating that self-disgust is strongly associated with poorer psychosocial adjustment. Physical self-disgust was found to be a significantly stronger correlate of psychosocial adjustment than behavioral self-disgust (z = 2.28, p = .023).

Finally, body image was found to have significant, large and positive correlations with physical self-disgust (r = .74), behavioral self-disgust (r = .56), and the self-disgust total (r = .75). The correlations indicate that self-disgust is very strongly associated with an increase in body image anxiety. Again, physical self-disgust was a significantly stronger correlate of body image than behavioral self-disgust (z = 2.70, p = .007).

Regression Analysis

Analysis of tolerance scores revealed that all scores were above .2, indicating that multicollinearity was not an issue (Menard, 1995). However, exploration of the models revealed suppressor effects within the SDS-R and DASS-21 subscales for four models; aesthetic satisfaction, functional satisfaction, psychosocial adjustment and body image, with beta weights changing direction from those seen in the correlational relationships (Tu, Gunnell, & Gilthorpe, 2008). Subsequently, for these models, scale totals for the DASS-21 and SDS-R were used instead of subscales.

Prosthesis Use: Hours/Day. Physical self-disgust was the only variable to demonstrate a correlation with daily prosthesis use of moderate effect. Subsequently, physical self-disgust was

the only predictor to meet criteria for inclusion in a hierarchical regression model. Hierarchical regression was not performed, but a simple linear regression indicated that physical self-disgust was a significant predictor, accounting for 13.2% of variance in daily prosthesis use ($R^2 = .13$, $R^2_{adjusted} = .12$, p < .006). Physical self-disgust was a significant individual predictor of daily prosthesis use (B = -.31, B SE = .11, CI = -.53, -.13, $\beta = -.36$, p = .001).

Prosthesis Use: Days/Month. The overall model for monthly prosthesis use was found to be significant ($R^2 = .22$, $R^2_{adjusted} = .20$, p < .001) with two variables representing two blocks; psychosocial (active coping), and self-disgust (physical self-disgust). While Model 1 was significant ($R^2 = .14$, $R^2_{adjusted} = .13$, p < .001), physical self-disgust significantly contributed in Model 2, accounting for an additional 8% of the variance ($\Delta R^2 = .08$, p = .006). In the final model, both active coping (B = 1.53, B SE = .47, CI = .62, 2.45, $\beta = .34$, p = .001) and physical self-disgust (B = -.36, B SE = .15, CI = -.68, -.12, $\beta = -.15$, p = .006) were found to be significant individual predictors of monthly prosthesis use. While the standardized beta for active coping was larger than that for physical self-disgust, examination of confidence intervals for the standardized beta weights revealed more than a 50% overlap, indicating that the beta weights are not significantly different (Cumming, 2009). A summary of the regression model for prosthesis use (days/month) is presented in Table 7.

INSERT TABLE 7 ABOUT HERE

Aesthetic Satisfaction. An overall model for aesthetic satisfaction was found to be significant ($R^2 = .37$, $R^2_{adjusted} = .31$, p < .001), with two blocks of variables; psychosocial variables (DASS total, self-distraction, behavioral disengagement, venting, planning, self-blame) and self-disgust (total). Model 1 was found to be significant ($R^2 = .33$, $R^2_{adjusted} = .27$, p < .01). However, the addition of self-disgust resulted in a significant contribution to the model, accounting for a

further 4% of the variance ($\Delta R^2 = .04$, p<.05). While the unstandardized beta for self-disgust did not meet significance level (p>.05), the confidence interval was found to be wholly in the negative range and standardized beta did meet significance (B = -.04, B SE = .03, CI = -.10, -.003, $\beta = -.32$, p = .039), indicating that self-disgust was the only significant individual predictor in the final model. A summary of the regression model for aesthetic satisfaction is presented in Table 8.

INSERT TABLE 8 ABOUT HERE

Functional Satisfaction. The overall model for functional satisfaction was found to be significant ($R^2 = .27$, $R^2_{adjusted} = .24$, p<.001), with two blocks of entry; psychosocial variables (DASS total, self-distraction, self-blame) and self-disgust (total). However, the addition of self-disgust in the final model did not make a significant contribution to the model ($\Delta R^2 = .01$, p = .251). Furthermore, while self-distraction was found to be a significant individual predictor in the final model (B = ..46, B SE = ..17, CI = ..79, -.09, $\beta = -.27$, p<.05) self-disgust was not. A summary of the regression model for functional satisfaction is presented in Table 9.

INSERT TABLE 9 ABOUT HERE

Psychosocial Adjustment. The overall model for psychosocial adjustment was found to be significant ($R^2 = .42$, $R^2_{adjusted} = .37$, p > .001), using three blocks of entry; clinical variables (time since amputation), psychosocial variables (DASS total, self-distraction, behavioral disengagement, self-blame) and self-disgust (total). Furthermore, while Model 1 ($R^2 = .09$, $R^2_{adjusted} = .08$, p = .006) and Model 2 ($R^2 = .35$, $R^2_{adjusted} = .31$, p < .001) were significant, selfdisgust provided a significant contribution in Model 3, accounting for an additional 7% of variance ($\Delta R^2 = .07$, p = .004). Moreover, in the final model, self-disgust was the only significant individual predictor (B = -.05, B SE = .02, CI = -.09, -.01, $\beta = -.42$, p = .004). A summary of the regression model for psychosocial adjustment can be found in Table 10.

INSERT TABLE 10 ABOUT HERE

Body Image. The overall model for body image was significant ($R^2 = .66$, $R^2_{adjusted} = .63$, p<.001), using three blocks of entry; clinical variables (RLP frequency), psychosocial variables (DASS total, self-distraction, behavioral disengagement, self-blame), and self-disgust (total). Model 1 ($R^2 = .17$, $R^2_{adjusted} = .16$, p<.001) and Model 2 ($R^2 = .58$, $R^2_{adjusted} = .55$, p<.001) were both significant. However, self-disgust contributed significantly to the final model, accounting for an additional 8% of variance ($\Delta R^2 = .08$, p<.001). Furthermore, self-disgust was a significant individual predictor in the final model of body image (B = .18, B SE = .06, CI = .08, .29, $\beta = .47$, p<.001). Behavioral disengagement also presented as a significant individual predictor. However, the overlap of the confidence interval sizes was calculated and found to be less than 50%, indicating that they are significantly different to each other (p<.05; Cumming, 2009), with self-disgust appearing to be a greater individual predictor of body image. A summary of the regression model for body image can be found in Table 11.

INSERT TABLE 11 ABOUT HERE

Discussion

Key Findings

This study aimed to explore the relationship of self-disgust to psychosocial adjustment after amputation. The findings from this study support the hypothesis that self-disgust is a significant independent predictor of psychosocial adjustment and the related factors of prosthesis use, prosthesis satisfaction and body image. The generally high scores on the TAPES-R psychosocial adjustment and satisfaction scales, along with high levels of daily and monthly prosthesis use, and low scores on the DASS-21, amended ABIS-R and SDS-R, indicate that the participants in this sample had, overall, adjusted well to limb amputation. However, participants were found to demonstrate a wide range of scores on all measures, indicating that some participants experienced poor adjustment to amputation. Furthermore, adjustment to limitation was found to have a lower median than general or social adjustment, indicating that, in this sample, people found adjustment to the restrictions of limb amputation the most difficult.

Correlational analysis revealed that none of the outcome variables were significantly associated with gender or trauma related amputation. This indicates that the level of disruption to emotional equilibrium and quality of life (Moss-Morris, 2013) does not differ based on gender or cause of amputation. However, considering the emergent role of self-disgust in adjustment to amputation, the unhelpful factors (e.g., cognitions and behaviors) maintaining disequilibrium are likely to vary between groups.

The emotion schema of self-disgust was found to correlate significantly with all outcome measures; daily prosthesis use, monthly prosthesis use, aesthetic and functional prosthesis satisfaction, psychosocial adjustment and body image. While the correlations were small to medium for daily and monthly prosthesis use and functional satisfaction (with increased self-disgust associated with less prosthesis use and satisfaction), correlations with each of the other outcome measures were of large effect. Self-disgust is strongly associated with reduced aesthetic prosthesis satisfaction, poorer adjustment, and increased body image concerns. It might be hypothesized that self-disgust leads to decreased prosthesis use (through avoidance), dissatisfaction with prosthesis (due to increased aesthetic demand), poorer adjustment (due to

self-disgust cognitions and behaviors), and increased body image anxiety (as a contributing schema). However, causality cannot be assumed at this time, and it may be that a bidirectional relationship is a more accurate reflection of the data.

Regardless of its precise causal role, the predictive ability of self-disgust, in particular physical self-disgust, in regard to adjustment is striking. Moreover, for aesthetic prosthesis satisfaction, psychosocial adjustment and body image, physical self-disgust demonstrated significantly larger correlation coefficients than behavioral self-disgust, supporting the proposition that physical aspects of self-disgust, arising from invasion of the body envelope, have more salience with aspects of adjustment. This may indicate a greater impact of unhelpful cognitions related to self-disgust, than unhelpful behaviors, in maintaining disequilibrium of emotions and quality of life (Moss-Morris, 2013).

Additionally, the coping strategies found to be most consistently of medium to large effect were; self-distraction, behavioral disengagement and self-blame, supporting previous research findings that passive or emotion focused coping styles are associated with poorer psychosocial outcomes (Desmond & MacLachlan, 2006; Desmond, 2007). Moreover, these coping styles are avoidant or a negative assessment of self, fitting with the proposed profile of self-disgust in amputation (i.e., avoiding the amputated limb or exposure to others and activation of self-disgust schema).

Furthermore, physical self-disgust was the only predictor meeting criteria for the regression model of daily prosthesis use and, when controlling for demographic, clinical and psychosocial variables, self-disgust significantly contributed to prediction of variance in monthly prosthesis use, aesthetic prosthesis satisfaction, body image, and psychosocial adjustment. Only for functional prosthesis satisfaction was the SDS-R found not to significantly add to the model.

2-26

Self-disgust appears better aligned with aesthetic aspects of the adjustment experience. Yet, importantly, self-disgust presented as an overall useful predictor of psychological adjustment to limb amputation. Indeed, this was further supported by the self-disgust beta weights in the final models, demonstrating that self-disgust is a significant individual predictor in a range of adjustment related outcomes.

These findings demonstrate the particular relevance of self-disgust as a predictor of psychosocial adjustment and related variables. Depression has previously been used as an indicator of psychosocial adjustment after amputation (e.g., Horgan & MacLachlan, 2004). While Powell et al. (2013) identified self-disgust as an antecedent to depression, the impact of self-disgust, in this study, appears to reach beyond that of depression, correlating significantly with prosthesis use and demonstrating significant predictive weights where the DASS-21 did not. Moreover, self-disgust significantly contributed to and demonstrated the largest beta weight in the final model of body image, supporting the suggestion that, alongside an appearance schema (Atherton & Robertson, 2006), a self-disgust schema contributes to a larger body image construction. Finally, while Murray and Fox (2002) suggested that body image anxiety was associated with less prosthesis use, this was not found to be significant and was contrary to what might be expected if the prosthesis was used to hide the amputated limb. Self-disgust may promote avoidance and camouflaging using clothing rather than engaging with the residual limb, as would be needed with a prosthesis. Consideration of self-disgust as a predictor of adjustment draws on sound theoretical utility, in that increased self-disgust can be understood to maintain disequilibrium and poorer adjustment (Moss-Morris, 2013) while contributing to an individual's body image and promoting avoidant behavior (Desmond, 2007; Powell et al., 2014) resulting in reduced use of a prosthesis.

Limitations and Future Research

The study recruited 79% of the intended sample size. While the use of bootstrapping in analysis will have increased the robustness of the findings, future research would additionally benefit from replication in a larger sample size. Furthermore, the vast majority of participants taking part in the study were recruited online. While 14% of participants chose not to proceed before completion of the study, the reasons for this cannot be assumed, due to the anonymous nature of online participation. However, possible reasons may include: length of the survey, content of the questionnaires, and competing demands in the participation environment (e.g., home life). Although competing demands cannot be resolved by the researcher, and the study was reviewed and wording amended based on feedback from experts by experience, attempts to present the survey in a more engaging way or allowing participants to track progress through the survey may have reduced early exiting from the study.

Despite this, increasing ease and access to online technologies continues to expand opportunities for research practice, particularly on the international scale; however, this may come with certain restrictions. For example, individuals from poorer countries, where internet access is inhibited (Wallsten, 2005), may not be able to access such studies as readily. It is possible that access to online resources, along with presentation in English language, contributed to the majority participation from Western countries. It cannot be assumed that the emerging relationships between self-disgust and the amputation experience will be representative of nonwestern countries or cultures, particularly as self-disgust is socioculturally defined. Future research might benefit from exploring the relationship of self-disgust to amputation adjustment in non-western cultures. Similarly, it is not known whether the individuals sampled in this study are currently in access of services regarding amputation and prosthesis use. The relatively high levels of psychosocial adjustment and low levels of psychological distress indicate that the majority of participants had successfully adjusted to amputation and may not be representative of a clinical sample. While it is important to note that the findings may be representative of the wider community of individuals with limb amputation, it would be of interest to explore the relationship of self-disgust in clinical samples or with people who specifically choose not to wear prostheses.

Individuals with upper limb amputation were also underrepresented in this study. Furthermore, it is not clear how many participants experienced bilateral amputation. It cannot be assumed that the findings of this study are valid for either of these groups. Indeed, the relationship of self-disgust may be different for upper limb amputation due to increased visibility of the residual limb and in bilateral amputation the individual will have experienced two points of invasion to the body envelope. It would be of benefit to explore the role of self-disgust in upper limb and bilateral amputation.

Qualitative exploration of prosthesis use may further enhance the findings of this study in that daily and monthly prosthesis use are influenced by different factors. These patterns may indicate different reasons for prosthesis use (e.g., work, shopping, attendance at a religious service) and may then hold different associations with self-disgust and other factors related to adjustment after amputation.

Further research may contribute to the theoretical understanding of a causal relationship between self-disgust and adjustment to amputation.

Clinical Recommendations

The emergence of self-disgust as a correlate and predictor of psychosocial adjustment and related factors has great clinical potential, particularly in addressing difficulties with adjustment to limb amputation and informing delivery of prosthesis services.

It is, of course, possible that individuals will choose not to wear a prosthesis for a variety of reasons, including successful adjustment to, and satisfaction with, the amputated limb. However, understanding the potential for self-disgust to predict reduced prosthesis use, prosthesis services may benefit from identifying individuals who experience elevated levels of self-disgust as an insight into reasons for non-use of prosthesis. This may open avenues for resolving difficulties with self-disgust and promoting greater use of the prosthesis.

Furthermore, as a strong individual predictor of aesthetic satisfaction with prosthesis, it is important to consider how self-disgust appraisals may influence a person's relationship with the prosthesis. It is possible that a reduction in self-disgust will result in greater satisfaction with the prosthesis. However, considering the potential directionality and temporal dynamics of selfdisgust and adjustment, it is also possible that continued development of realistic or aesthetically pleasing prosthesis will contribute to a reduction in self-disgust after amputation. Though, in this case, it will pay to be mindful of the role of the prosthesis in avoiding disgust related cognitions or emotions. Increased aesthetic satisfaction may indicate better camouflaging of the individual's amputated limb, but self-disgust might be particularly salient on removal of the limb.

Murray and Forshaw (2013) have identified interventions, such as psychotherapy, psychosocial initiatives, training and peer group support, to affect the experience of limb loss and prosthesis use positively. Moreover, psychological therapy has been associated with significant reductions in distress for both lower and upper limb amputees (Srivastava et al., 2010; Srivastava & Chaudhury, 2014). However, individuals who have had difficulty in adjusting to amputation due to the experience of self-disgust may benefit from psychosocial interventions targeting self-disgust appraisals. A recent study by Powell, Simpson and Overton (2015) found that, when compared against a control group, self-affirming kindness led to a significant reduction in appearance directed disgust. Self-affirming may have clinical utility as an intervention to reduce distress in individuals with limb loss who demonstrate elevated self-disgust. Indeed, on a societal level, publicized events such as the Paralympic and Invictus games may already be contributing to social affirmation for some people.

Conclusion

This study aimed to examine the relationship of self-disgust to adjustment after limb amputation and related factors. Self-disgust was found to correlate with all of the outcome variables; psychosocial adjustment, prosthesis use, prosthesis satisfaction and body image. It is conceived that self-disgust may have an important role in maintaining emotional disruption after amputation and may contribute to reduced prosthesis use through avoidance of the limb. Future research exploring causality will aid a better understanding of these relationships. Self-disgust has demonstrated great potential as a significant predictor of psychosocial adaption and prosthesis use and the identification of self-disgust in individuals attending amputation and prosthesis clinics may help in delivery of psychosocial interventions for adjustment difficulties and with prosthesis rehabilitation.

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	N (%)	Mean (SD)	Range
Gender			
Male	46 (55.4)		
Female	37 (44.6)		
Age (Valid $n = 82$)		52.4 (14.1)	18 -78
Ethnicity			
Black/ African/ Caribbean	1 (1.2)		
Hispanic	2 (2.4)		
White/ Caucasian	79 (95.2)		
Other	1 (1.2)		
Country of residence			
Australia	10 (12.0)		
Canada	2 (2.4)		
South Africa	1 (1.2)		
Switzerland	1 (1.2)		
United Kingdom	12 (14.5)		
United States	57 (68.7)		

Table 1. Participant Characteristics

Note: participant N = 83

	N (%)	Mean (SD)	Median	Percentiles (25 th , 75 th)	Range
Level of Amputation					
Lower limb	78 (94.0)				
Below-knee	55 (66.3)				
Through-knee	1 (1.2)				
Above-knee	22 (26.5)				
Upper limb	3 (3.6)				
Below-elbow	1 (1.2)				
Above-elbow	2 (2.4)				
Other level of amputation	2 (2.4)				
Cause					
Vascular disease	10 (12.0)				
Cancer	7 (8.4)				
Diabetes	14 (16.9)				
Accident/Trauma	28 (33.7)				
Other	34 (41.0)				
Residual limb pain (RLP)	56 (67.5)				
Frequency in last week*		8.1 (9.0)	5	2, 10	1 - 35
Average duration (mins)		163.4 (309.4)	60	9.5, 180	0 - 24 (hrs)
Phantom limb pain (PLP)	62 (74.7)				
Frequency in last week*		7.25 (10.1)	3	2,7	0 - 35
Average duration		201.9 (407.5)	30	5, 150	0 - 24 (hrs)
Time since amputation (years)		12.7 (14.1)	7.25	2.5, 19.0	0 - 48
Prosthesis use (hours/day)*		12.6 (4.8)	14	9, 16	0 - 18
Prosthesis use (days/month)*		27.6 (8.3)	31	30, 31	0 - 31

Table 2. Clinical Characteristics

*Valid *n*: RLP Frequency = 51, PLP Frequency = 59, Prosthesis Use (Hours/Day) = 79, Prosthesis Use (Days/Month) = 81

	Valid	Mean (SD)	Median	Perce	entiles	Range	Scale	α
	Ν			25th	75th	-	Range	
TAPES-R Psychosocial								
General adjustment	83	3.4 (0.7)	3.8	3.0	4.0	1.0 - 4.0	1 - 4	.893
Social adjustment	83	3.5 (0.6)	3.6	3.0	4.0	1.0 - 4.0	1 - 4	.858
Adjustment to limitations	83	2.4 (0.8)	2.6	2.0	3.2	1.0 - 4.0	1 - 4	.830
Psychosocial total	83	9.3 (1.2)	10.0	8.2	10.8	5.2 - 12	3 - 12	.896
TAPES-R Satisfaction								
Aesthetic satisfaction	83	6.6 (2.1)	6	5	9	3-9	3 – 9	.920
Functional satisfaction	83	10.6 (3.0)	10	8	13	5 - 15	5 - 15	.888
Satisfaction total	83	17.2 (4.6)	19	13	21	8 - 24	8 - 24	.915
SDS-R		. ,						
Physical self-disgust	83	11.5 (6.1)	9	6	15	5 - 31	1 - 35	.875
Behavioral self-disgust	83	9.8 (5.1)	8	6	12	5 - 30	1 - 35	.895
Self-disgust total	83	31.5 (15.6)	27	19	39	15 - 91	15 - 105	.939
ABIS-R (13 item)								
Full scale total	82	7.4 (6.1)	5	2	13	0 - 25	0 - 26	.923
DASS-21		~ /						
Depression	81	3.7 (4.9)	4	0	10	0 - 42	0 - 42	.949
Anxiety	82	2.1 (2.9)	2	0	6	0 - 30	0 - 42	.813
Stress	82	4.3 (4.2)	6	2	14	0 - 34	0 - 42	.893
Total	81	10.1 (10.9)	14	4	28	0 - 100	0 - 126	.953

Table 3. Descriptive statistics and Cronbach's alpha (*a*) for SDS-R, TAPES-R Psychosocial Adjustment, TAPES-R Satisfaction with Prosthesis, ABIS-R and DASS-21

Note: TAPES-R = Trinity Amputation and Prosthesis Experience Scales – Revised, SDS-R = Self-Disgust Scale-Revised, ABIS-R = Amputee Body Image Scale-Revised, DASS-21 = Depression Anxiety and Stress Scales, α = Cronbach's alpha

			Prosthesis		
		Hours	/day	Days/r	nonth
		r	BCa 95% CI	r	BCa 95% C
Demographic	Age	.255*	.103, .404	.084	058, .22
Variables	Gender (male or female)	177	391, .047	147	342, .05
Clinical	Etiology (trauma vs health)	.103	130, .325	.079	163, .26
Variable	Time since amputation	.215	026, .403	.087	148, .23
	Experience of RLP (yes vs no)	249*	406,074	187*	305,04
	RLP frequency	.288*	514,045	174	506, .09
	RLP duration	187	381, .012	111	447, .11
	Experience of PLP (yes vs no)	160	305, .000	141*	246,02
Variables Clinical Variable Psychosocial Variables	PLP frequency	239*	456,042	157	459, .08
	PLP duration	183	438, .109	243	612, .10
Psychosocial	DASS depression	114	437, .071	094	346, .08
Psychosocial Variables	DASS anxiety	141	375, .034	.033	156, .15
	DASS Stress	070	291, .096	.033	102, .14
	DASS Total	115	336, .047	020	154, .08
	Self-distraction	156*	324,007	.049	110, .19
	Active coping	.197	002, .368	.378*	.220, .51
	Denial	109	280, .097	079	262, .10
	Substance use	042	240, .174	.093	051, .18
	Emotional support	.140	058, .324	.132	075, .29
	Instrumental support	042	244, .129	.060	154, .24
	Behavioral disengagement	232*	416,040	151	355, .04
	Venting	.000	220, .227	.029	196, .22
	Positive reframing	066	290, .139	.120	109, .30
	Planning	084	261, .075	.084	125, .26
	Humor	.081	146, .326	.106	156, .35
	Acceptance	.287*	.069, .486	.296*	.050, .51
	Religion	.029	189, .224	.196*	.038, .30
	Self-blame	110	298, .048	054	211, .08
Self-Disgust	Physical self-disgust	364*	569,159	323*	491,16
	Behavioral self-disgust	205*	446,024	041	234, .09
	Self-disgust total	307*	526,119	196*	359,07

Table 4. Bootstrap correlations using Pearson's R, with BCa 95% Confidence Intervals, for Prosthesis Use.

Note: Scale totals, where provided, are in bold

RLP = Residual Limb Pain, PLP = Phantom Limb Pain, DASS = Depression, Anxiety and Stress Scales, *BCa* 95% *CI* = Bias corrected 95% confidence interval

* Denotes significant correlation based on confidence intervals

			TAPES-R Sati	sfaction	
	_	Aes	thetic	Funct	ional
		r	BCa 95% CI	r	BCa 95% CI
Demographic	Age	.005	171, .190	.109	098, .302
Variables	Gender (male or female)	161	369, .050	107	299, .111
Clinical	Etiology (trauma or health)	.091	123, .290	.125	095, .347
Variable	Time since amputation	.144	056, .318	.116	098, .333
	Experience of RLP (yes vs no)	173	363, .015	200	391, .030
	RLP Frequency	282*	436,106	161	349, .041
	RLP Duration	214*	369,073	278*	451,082
	Experience of PLP (yes vs no)	143	357, .070	148	348, .056
	PLP Frequency	255*	444,046	131	304, .047
	PLP Duration	250*	382,135	234*	408,039
Psychosocial	DASS Depression	450*	626,263	401*	581,221
Variables	DASS Anxiety	301*	475,097	288*	444,144
	DASS Stress	475*	649,289	455*	616,28
	DASS Total	463*	607,302	430*	583,27
	Self-distraction	414*	569,248	393*	565,198
	Active coping	122	342, .119	.036	177, .269
	Denial	187*	318,033	040	338, .17
	Substance use	.035	181, .204	079	349, .11
	Emotional support	022	257, .212	.102	117, .32
	Instrumental support	199	417, .031	.014	206, .22
	Behavioral disengagement	339*	489,181	209	444, .01
	Venting	309*	481,143	195	437, .020
	Positive reframing	012	225, .194	.017	183, .213
	Planning	309*	479,122	098	317, .11.
	Humor	.277*	.052, .504	.250*	.025, .45.
	Acceptance	.106	115, .329	.155	067, .364
	Religion	.059	168, .267	.122	089, .32
	Self-blame	428*	592,251	383*	549,210
Self-Disgust	Physical self-disgust	541*	678,396	398*	554,241
	Behavioral self-disgust	353*	497,186	299*	487,112
	Self-disgust total	503*	622,372	417*	572,26

Table 5. Bootstrap correlations using Pearson's R, with BCa 95% Confidence Intervals, for Satisfaction with Prosthesis.

Note: Scale totals, where provided, are in bold

RLP = Residual Limb Pain, PLP = Phantom Limb Pain, DASS = Depression, Anxiety and Stress Scales, *BCa* 95% *CI* = Bias corrected 95% confidence interval

* Denotes significant correlation based on confidence intervals

		$\begin{array}{cccccccccccccccccccccccccccccccccccc$						
		Psychosocial	Adjustment	Body-	Image			
		r	BCa 95% CI	r	BCa 95% CI			
Demographic	Age	.118	071, .335	241*	450,051			
Variables	Gender (male or female)	048	265, .149	.151	058, .386			
Clinical	Etiology (trauma vs health)		129, .313	.034	177, .264			
Variables	Time since amputation	.300*	.114, .491	182	334, .003			
	Experience of RLP (yes vs no)	158	385, .057	.214	013, .431			
	RLP Frequency	276*	518,011	.409*	.221, .589			
	RLP Duration	271*	407,135	.204*	.022, .425			
	Experience of PLP (yes vs no)	080	305, .140	.144	102, .376			
	PLP Frequency	204	447, .044	.251*	.059, .426			
	PLP Duration	240	443, .000	.170	042, .406			
Psychosocial	DASS Depression	478*	632,313	.679*	.518, .809			
Variables	DASS Anxiety	396*	560,184	.509*	.313, .669			
	DASS Stress	511*	652,349	.666*	.523, .791			
	DASS Total	514*	658,361	.694*	.554, .806			
	Self-distraction	336*	541,140	.333*	.106, .567			
	Active coping	.039	173, .234	086	295, .121			
	Denial	293*	453,105	.251*	.001, .447			
	Substance use	110	289, .037	.159	052, .409			
	Emotional support	.137	093, .357	068	293, .199			
	Instrumental support	112	336, .105	.000	207, .239			
	Behavioral disengagement	374*	524,202	.405*	.244, .560			
	Venting	178*	360,008	.263*	.035, .501			
	Positive reframing	.029	218, .237	172	357, .034			
	Planning	133	337, .060	.125	100, .354			
	Humor	.230	019, .459	279*	458,099			
	Acceptance	.291*	.028, .519	285*	477,083			
	Religion	.234*	.055, .400	194*	378,008			
	Self-blame	473*	632,294	.680*	.511, .813			
Self-Disgust	Physical self-disgust	597*	741,426	.736*	.606, .842			
	Behavioral self-disgust	420*	612,197	.564*	.366, .710			
	Self-Disgust Total	596*	740,416	.745*	.625, .833			

Table 6. Bootstrap correlations using Pearson's R, with BCa 95% Confidence Intervals, for psychosocial adjustment and body image.

Note: Scale totals, where provided, are in bold

RLP = Residual Limb Pain, PLP = Phantom Limb Pain, DASS = Depression, Anxiety and Stress Scales, *BCa* 95% *CI* = Bias corrected 95% confidence interval

* Denotes significant correlation based on confidence intervals

Model	$R^{2}\left(p ight)$	$\Delta R^2(p)$	Predictors		Bootstrap				
					B (CI)	B SE	Р		
1	.143 (<.001)		Constant Active Coping	19.145 1.678	12.15725.920.6692.732	3.490 .550		.378	<.001 <.001
2	.221 (<.001)	.078 (.006)	Constant Active coping Physical Self-	23.983 1.527	(17.578, 29.768) (.616, 2.447)	2.857 .488	.001 .016	.344	<.001 .001
			disgust	355	(683,119)	.151	.039	281	.006

Table 7. Hierarchical regression, using Bootstrap and BCa 95% Confidence Intervals, for prosthesis Use (days/month)

Model	$R^{2}\left(p ight)$	$\Delta R^2(p)$	Predictors		Bootstrap	1		β	Р
					B (CI)	B SE	Р		
1	.327		(Constant)	9.773	(8.461, 11.629)	.613	.001		.000
	(<.001)		DASS Total	031	(055, .009)	.013	.017	323	.052
			Self Distraction Behavioral	258	(533, .012)	.153	.082	220	.057
			Disengagement	235	(721, .304)	.231	.252	124	.295
			Venting	124	(531, .233)	.216	.546	074	.514
			Planning	131	(396, .107)	.123	.267	116	.306
			Self-Blame	.042	(548, .373)	.271	.850	.032	.856
2	.365	.038	(Constant)	10.183	(8.749, 12.198)	.635	.001		.000
	(<.001)	(.039)	DASS Total	018	(046, .034)	.017	.238	187	.280
			Self Distraction Behavioral	199	(467, .069)	.142	.153	169	.140
			Disengagement	047	(565, .583)	.260	.853	025	.841
			Venting	149	(569, .273)	.215	.460	089	.424
			Planning	171	(407, .031)	.116	.125	151	.179
			Self-Blame Self-Disgust	.107	(511, .490)	.279	.679	.081	.640
			Total	042	(096,004)	.027	.105	319	.039

Table 8. Hierarchical regression, using Bootstrap and BCa 95% Confidence Intervals, for aesthetic satisfaction with Prosthesis

Model	$R^{2}\left(p ight)$	$\Delta R^2(p)$	Predictors	Bootstrap			β	Р	
			-		B (CI)	B SE	Р		
1	.260		(Constant)	13.715	(11.974, 15.783)	.945	.001		.000
	(<.001)		DASS Total	045	(098, .008)	.027	.087	322	.056
			Self Distraction	489	(808,119)	.165	.005	286	.007
			Self-Blame	049	(873, .625)	.401	.891	025	.880
2	.273	.013	(Constant)	14.120	(12.091, 16.480)	1.126	.001		.000
	(<.001)	(.251)	DASS Total	033	(101, .028)	.033	.312	241	.184
			Self Distraction	462	(785,087)	.169	.011	270	.012
			Self-Blame	.034	(744, .745)	.377	.929	.018	.919
			Self-Disgust Total	032	(100, .034)	.036	.362	168	.251

Table 9. Hierarchical regression, using Bootstrap and BCa 95% Confidence Intervals, for functional satisfaction with Prosthesis

Model	$R^{2}(p)$	$\Delta R^2(p)$	Predictors	Bootstrap			β	Р	
					B (CI)	B SE	Р		
1	.090		(Constant)	9.067	(8.562, 9.552)	.256	.001		.000
	(.006)		Time Since						
			Amputation	.003	(.001, .005)	.001	.005	.300	.006
2	.348	.258	(Constant)	11.105	(9.878, 12.179)	.613	.001		.000
	(<.001)	(<.001)	Time Since						
			Amputation	.002	(-3.720E-5, .004)	.001	.064	.180	.064
			DASS Total	024	(051, .006)	.013	.066	306	.059
			Self Distraction						
			Behavioral	169	(368, .051)	.101	.101	179	.074
			Disengagement	182	(475, .313)	.140	.104	119	.292
			Self-Blame	072	(456, .208)	.190	.684	068	.687
3	.417	.069	(Constant)	11.427	(10.061, 12.516)	.611	.001		.000
	(<.001)	(.004)	Time Since						
			Amputation	.002	(.000, .004)	.001	.103	.173	.062
			DASS Total	009	(039, .015)	.013	.426	119	.473
			Self Distraction	131	(317, .055)	.098	.181	138	.149
			Behavioral						
			Disengagement	.017	(323, .556)	.153	.896	.011	.924
			Self-Blame	021	(384, .267)	.165	.886	019	.905
			Self-Disgust Total	045	(085,009)	.021	.026	424	.004

Table 10. Hierarchical regression, using Bootstrap and BCa 95% Confidence Intervals, for psychosocial adjustment

Model	$R^{2}\left(p ight)$	$\Delta R^2(p)$	Predictors		Bootstrap			β	Р
					B (CI)	B SE	Р		
1	.167		(Constant)	5.747	(4.504, 7.103)	.752	.001		<.001
	(<.001)		RLP Frequency	.300	(.156, .504)	.077	.001	.409	<.001
2	.579	.412	(Constant)	360	(-2.480, .852)	1.345	.776		.820
	(<.001)	(<.001)	RLP Frequency	.174	(.036, .323)	.066	.004	.237	.004
			DASS Total	.092	(.001, .155)	.051	.069	.329	.013
			Self Distraction	.248	(317, 1.062)	.328	.475	.072	.370
			Behavioral						
			Disengagement	263	(-1.442, .682)	.599	.613	047	.610
			Self-Blame	1.421	(058, 3.678)	.799	.086	.366	.009
3	.659	.080	(Constant)	-1.600	(-3.812, .284)	1.246	.189		.276
	(<.001)	(<.001)	RLP Frequency	.121	(026, .287)	.070	.076	.165	.031
			DASS Total	.040	(034, .106)	.040	.285	.143	.260
			Self Distraction	.122	(372, .748)	.277	.663	.035	.628
			Behavioral						
			Disengagement	962	(-1.912,241)	.504	.039	173	.055
			Self-Blame	1.147	(125, 2.882)	.708	.110	.296	.020
			Self-Disgust Total	.181	(.077, .285)	.055	.003	.470	<.001

Table 11. Hierarchical regression, using Bootstrap and BCa 95% Confidence Intervals, for body image

Appendix 2-A

Highlights

- Limb amputation can lead to poor adjustment associated with psychosocial difficulties, such as depression, anxiety and non-use of prosthesis
- Self-disgust has emerged as a significant predictor of psychosocial adjustment after amputation, as well as; prosthesis use, prosthesis satisfaction and body image
- Self-disgust can aid in understanding poor adjustment to amputation and is an important consideration for clinical and prosthetic services

Appendix 2-B

Body Image Guide for Authors

GUIDE FOR AUTHORS

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Running head: APPRAISING THE STUDY OF SELF-DISGUST AFTER LIMB LOSS

Section Three: Critical Appraisal

A critical appraisal on the study of self-disgust as a predictor of adjustment following amputation

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Abstract

Following the examination of self-disgust in its relation to psychosocial adjustment and related factors in people with limb amputation, I have engaged in a critical appraisal of the research process, including methodological and personal reflections. In particular, I have considered; how I arrived at the research of self-disgust in amputation, the epistemological position from which the research was approached, aspects of the research design (e.g., sampling strategy and inclusion criteria), and a broader reflection on studying potentially "taboo" subjects, such as that of self-disgust, in relation to visible difference. Finally, I have considered potential areas for future research.

A critical appraisal on the study of self-disgust as a predictor of adjustment following amputation

A quantitative study of cross sectional design, was used to examine the relationship of body image to adjustment and related factors in people with limb amputations. The study found significant correlations between increased self-disgust and poorer psychosocial well-being, as measured by the following outcome measures; psychosocial adjustment, prosthesis use (hours/day and days/month), prosthesis satisfaction (aesthetic and functional), and body image. Furthermore, using a series of six hierarchical regression analyses, self-disgust was found to contribute significantly to the variance in psychosocial adjustment, prosthesis use (hours/day and days/month), aesthetic prosthesis satisfaction, and body image. As self-disgust has not previously been examined in relation to amputation, these findings make a unique contribution to the understanding of adjustment difficulties in people with limb amputations. In line with Moss-Morris' (2013) working model of adjustment to chronic health difficulties, it was proposed that self-disgust, as an emotion schema, contributes to unhelpful cognitions that maintain disruption in emotional equilibrium, leading to poor adjustment. Moreover, self-disgust is felt to be an important consideration for clinical and, in particular, prosthetic services in supporting individuals with limb amputations due to its relationship with poor adjustment and non-use of a prosthesis.

I will discuss how I came to research self-disgust in relation to amputation, considerations regarding the research process, including limitations and strengths of the research, reflections on my experience of examining self-disgust in this area, and potential areas for future research in the fields of self-disgust and amputation.

Self-disgust as a Topic of Interest

Disgust is an extremely powerful and visceral emotion, associated with feelings of repulsion (Curtis, Aunger, & Rabie, 2004). As a common human reaction to unpleasant or potentially hazardous stimuli, such as spoiled food (Rozin, Haidt, & McCauley, 2005), the experience of disgust can easily be imagined. However, as the concept of self-disgust is less usual, I found it to be of particular interest. It struck me that the experience of self-disgust, toward aspects of yourself that could not readily be changed, would be very distressing and I was keen to explore this further.

While consulting with colleagues working in the field of self-disgust, I considered several areas that may be related to self-disgust (e.g., eating disorders, psychosis). However, I recalled an experience related by a colleague, in which she had worked with a young girl with congenital limb difference. The young girl, of four years of age, did not appear to take any notice of her limb being different. Yet, her mother would dress the limb in scarves, seemingly to hide or camouflage the girl's limb. At the time, I wondered whether these actions, along with societal reactions to limb difference, would influence the girl's self-perception, perhaps contributing to negative self-appraisals such as shame, embarrassment or self-disgust.

As an extension of congenital limb difference, I then considered how acquired limb amputation may be further associated with self-disgust. In addition to social comparisons regarding "normal" limb appearance, the individual would have experienced a surgical or traumatic severing of the body, resulting in a considerable change to physical appearance. In this way, I thought that the experience of limb amputation would be different from that of congenital limb difference, with potentially greater association with self-disgust, which would be of interest, and clinical benefit, to examine through research.

Designing the Study

Use of Quantitative Methods to Examine Self-Disgust and Amputation

Thinking about my initial research interest: "How does self-disgust impact on the amputation experience?", I considered whether a quantitative or qualitative approach would be more appropriate. I believe that there are shared experiences, with associated physical and emotional phenomena, that can be understood through empirical research. However, while this is synonymous with a positivist stance, I also acknowledge that we cannot ever reach a true understanding of what is "real", as there may not be a singular truth; experiences are likely to be shaped by the backdrop of history, culture and society, and the nature of that which is "real" will continually evolve and evade us. In this way, I move toward a post-positivist, critical-realist stance. I believe that, while we will never reach a complete understanding of the human experience, we can use empirical research to continually advance our understanding of it. Furthermore, I do believe that an individual's experiences and personal meanings will be socially informed. Yet, approaching social meaning from a critical realist, rather than a social constructionist position, I think that social constructions and meanings can also be understood as "real" and observable (Scott, 2005).

Quantitative and qualitative methodologies are often mixed in a pragmatic approach to research, disregarding consideration of the epistemological position in favor of applied research (Tillman, Clemence, & Stevens, 2011). However, I believe that the two methodologies can be both pragmatic and complimentary in their use together without dismissing an epistemological underpinning. Indeed (Habermas, 1978) described three areas of interest, regarding knowledge; "technical" interest regarding instrumental knowledge and rationality, "practical" interest relating to the understanding of meaning, and "emancipator" interest, or release from power, through

self-reflection. In this way, quantitative and qualitative approaches investigate different aspects of the same experience.

Considering self-disgust, I believe that qualitative research can bring us closer to understanding the individual's subjective experience, the meaning and values relating to selfdisgust, within a social context (e.g., Powell, Overton, & Simpson, 2014), while quantitative methodologies can help us observe commonalities in the experience of self-disgust, which can then be understood through theory and applied a clinical context.

As no previous research had been conducted examining the relationship between selfdisgust and limb loss, I felt that an initial examination using quantitative methodologies could be helpful in establishing whether self-disgust, as a psychological construct, held relationships with well-established variables relating to adjustment in amputation. This would also have the benefit of building on a growing evidence base regarding self-disgust as a unique contributor to a range of psychological difficulties (Powell, Overton, & Simpson, 2015).

The strength of using a quantitative approach for this study is in the emerging relationship and clinical predictions that might be made between self-disgust and adjustment to amputation. Furthermore, these results can be (cautiously) generalized to the wider community of individuals with limb amputations and applied to clinical provision. However, what the study gains in regard to theoretical application and clinical utility, it perhaps loses in regard to the meaning and values attached to self-disgust for the individual with an amputation. Qualitative research would then complement the current study, in attributing meaning to the relationships observed between self-disgust and adjustment.

Determining the Inclusion Criteria

In determining the scope of the study, several inclusion and exclusion criteria for participation were employed. As the study was of an adult population, children and adolescents were excluded from the study. However, whereas many studies of an adult population exclude people who are under 18 years of age, The British Psychological Society (BPS; 2014) indicates that individuals of 16 years or above can provide informed consent to take part in a study without additional parental consent. This positions people of 16 years and above within the adult population. For this reason, I felt that an inclusion criteria of 16 years or above, based on the British Psychological Society (2014) code of research ethics, was appropriate.

The study also excluded individuals with congenital limb differences and people meeting criteria for Body Integrity Identity Disorder (BIID). I felt that the change in appearance and invasion of the body envelope associated with limb amputation would separate this experience from that of congenital limb difference, regarding self-disgust. While people with congenital limb differences experience self-disgust, this would not be influenced by pre-amputation schema or avoidance of wound anatomy as proposed for acquired amputation. People with a diagnosis of BIID, on the other hand, may have experienced acquired amputations that were in line with their desired anatomy (Bayne & Levy, 2005) and therefore likely to elicit a different set of schema. However, investigation of self-disgust in both groups of people would be of interest.

In focusing on limb amputation, the study naturally excluded the experience of other forms of amputation, such as mastectomy. It can be assumed that there are great differences between the experience of limb amputation and mastectomy, not least in the different ways that amputation impacts on the person's image and functional ability. However, it may be worth considering the similarities that occur across both experiences. For instance, the use of prosthesis is associated with both mastectomy and limb amputation. Furthermore, the experience of disgust has been identified as a potential long term psychological impact of mastectomy (Arroyo & López, 2011). This study may provide a basis from which to explore the role of self-disgust in regard to other visible differences or types of amputation.

Of note, individuals with upper limb amputations were included in this study. I hoped to examine differences that might exist between upper and lower limb amputation regarding the experience of self-disgust. The majority of existing research in the field of amputation is in regard to lower limb loss, reflecting the higher proportion of all amputations (65% in the United States) for which lower limb amputations account (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008). However, I felt that the use of an online recruitment strategy provided a potential opportunity to build on the research base for upper limb amputation. Yet, despite international recruitment, the number of participants with upper limb amputations was very low (n = 3). This meant that I was not able to perform between-group analysis for upper versus lower amputation.

A particular limitation of this was the amendment of the Amputee Body Image Scale -Revised (ABIS-R; Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan, 2007) to facilitate inclusion of people with upper limb amputations. Although the removal of an item allowed for the inclusion of an additional 3 participants, the measure cannot be directly compared to other studies examining body image using the ABIS-R.

On balance, it may have been beneficial to include the full measure within the study. However, I think that a caveat would have been necessary - that the participants need not complete items which they did not feel applied to them. A potential outcome of this would have been an overall reduction in completed items (increase in missing data) necessitating a greater amount of data imputation. Alternatively, the design of the measure could be amended, as with the TAPES-R psychosocial scale (Gallagher, Franchignoni, Giordano, & MacLachlan, 2010) in which missing or "not applicable" items are incorporated into the scoring mechanics for the scale. However, as this design has not yet been provided for the ABIS-R, using such an approach for the current study would have, again, moved away from the original measure.

Of course, a strength of the study was in considering body image as one of the primary outcome measures. As such, analysis and findings regarding body image can be considered on their own and the amendment of the body image scale does not influence the analysis of other outcome measures in the study. Furthermore, despite amendment of the scale for this study, the associations between self-disgust and body image was revealed to be very strong, suggesting that inclusion of the measure was of theoretical interest.

In future research, I would consider examining upper and lower amputation separately to avoid amendment of materials, or employ a stratified sampling strategy over a longer recruitment period, to promote greater participation of people with upper limb amputations.

Considering the Use of Language in the Study

I was aware that some people may find the term "disgust" provocative and that reference to this in a study title may have had a detrimental impact on recruitment. With this in mind, I considered whether to use the term "self-disgust" in the title or participant information for the study. It is, of course, important to provide participants with enough information about the content and procedure of a study so that they make an informed decision about whether to take part. However, having consulted with Experts by Experience regarding use of language in the study, I decided that it was appropriate to refer to "thoughts and feelings about amputation" instead of self-disgust. Furthermore, this allowed the use of disgust related words (i.e., repulsive) to be localized to the Self-Disgust Scale-Revised (SDS-R; Powell, Simpson, & Overton, 2015). Of interest, none of the participants who engaged in the study exited participation at the point of the self-disgust scale, indicating that completion of the scale was not overly distressing.

Benefits, Drawbacks and Ethical Considerations of Online Participation

Using online survey software provided benefits regarding both the study design and resources. For instance, I was able to advertise the study and recruit internationally, allowing for an increased sampling pool and, potentially, a broader range of sample characteristics (increasing generalizability of the findings). Additionally, use of online survey software facilitated collection of large amounts of information with less data administration time, which was a valuable consideration due to the limited time in which to conduct the study. Finally, a recent meta-synthesis found that people are more likely to disclose sensitive information in computerized studies than with pen-and-paper (Gnambs & Kaspar, 2015). Considering the potentially sensitive nature of visible diversity and self-disgust, online recruitment may have allowed people to feel more comfortable answering the questionnaire items.

However, it is of note that, despite an international reach and advertisement on a range of online media, I did not meet the recruitment target intended for the study. A restriction of online sampling was that I could not assess reasons for non-participation, or for exiting the study early. It is possible that media, such as twitter, was not reaching the right audience or that people were receiving the "tweets" at an inopportune time. Furthermore, the design of the study did not record where consenting participants found out about the research. Using online recruitment in the future, I would incorporate this into the design so that I could amend my recruitment strategy accordingly. In addition, I would apply for ethical approval for access to NHS services

simultaneously, so that I could access two recruitment streams at the same time. This would also have the advantage of increased participation from individuals in receipt of clinical or prosthetic services.

It is also important to consider potential ethical issues that may differ, or even be specific to, online recruitment and participation. Indeed, online participation offers new opportunities for participant anonymity but, in doing so, one cost is the absence of face-to-face contact with the participant. In this way, some of the subtler aspects of the research process are lost and restrictions arise. For instance, I was unable to gauge participants' state of engagement and wellbeing throughout the research process. An ethical consideration of this was the potential for a participant to experience distress as a result of participating in a study, without the presence of a professional to engage in the ensuing process regarding that distress (i.e., signposting of services). Indeed, where participants recruited from clinical services have a known support structure in place, this may not be the case for participants accessed online. Acknowledging these restrictions, I felt it was important to provide information for internationally available support agencies within the online recruitment process. Additionally, I provided a contact email address in case participants wanted to discuss the study further.

Appropriateness of Preset Response Variables

While data were collected and analyzed regarding cause of amputation, it is of note that several individuals used a description option to provide additional information on the cause of their amputation. This may indicate that participants found preset response categories too arbitrary or attributed particular importance to the narrative of their amputation. Further use of open ended response options within the study may have gathered additional data relevant to the relationship between self-disgust and adjustment to amputation.

Indeed, while the study presented options for a range of health difficulties and for accident/trauma, this did not access the cause behind the trauma. It could be imagined that the experience, and associated self-appraisals, connected to traffic related accidents might be different from that of war trauma. Accessing this information may have better informed analysis of between-group differences.

Similarly, while data were collected regarding prosthesis use and satisfaction, the study did not access information on which aspects of the prosthesis made it aesthetically or functionally satisfactory, nor where and when the prosthesis is used. Future research may focus further on the aesthetic needs of the prosthesis for the individuals experiencing self-disgust and the reasons for prosthetic use (e.g., work), further enlightening the role of self-disgust in these relationships.

Personal Reactions and Reflections on Investigating Self-Disgust

Having provided participants with a means of contact, I found myself concerned that people would get in touch to complain about the investigation of self-disgust in relation to amputation, or more widely in regard to visible diversity. Similarly, I experienced feelings of caution when non-psychologists enquired as to my research topic, despite my interest and passion for the study. However, while face-to-face communication allowed for discourse around the personal and professional motivations for research, a particular aspect of online methodology is that this was not immediately possible, and people accessing the research were left to make assumptions based on the participant information provided. Of note, no one contacted me to dispute aspects of the research content or process. However, reflecting on my feelings of caution, I realized that I was wary of people thinking that the research, and I by extension, insinuated that people with limb amputations are disgusting, or should feel disgust toward themselves. Even in documenting my reflections, I feel drawn toward a defensive position, eager to justify the research and deflect the possibility of negative appraisals. However, it is helpful for me to reflect on this, as fear of being judged negatively by others may be representative of a wider societal issue that poses barriers to discussions and research that could be of benefit.

The Taboo of Visible Differences

The subjects of taboo are often in regard to physical processes (e.g., defecation) or interactions (e.g., sexual intercourse). However, as society changes and we have become more aware of discrimination, so too have certain topics become taboo. For instance, Burnett (2015) suggested that, as people do not want to appear racist, the subject of race has become taboo and "anti-racism" subsequently prevents discussion around race issues. Other kinds of visible diversity may be regarded in a similar way.

Indeed, Keith (1996) describes how, without clear social "rules" regarding disability (or impairment), people fear saying something wrong, which gives rise to avoidance. This then can contribute to psycho-emotional disablism (Reeve, 2015) in the relationships that individuals, who experience impairments, have with others or themselves. If we extend this to the field of research, avoidance of difficult topics, such as self-disgust, for fear of negative appraisal, would not only deny the historic contribution, as Hughes (2012) described, of disgust (toward disability) in creating ableism (the projection of a species-typical self and body) but also the distress that people may be experiencing. Indeed, if we assume the possibility that individuals with amputation might experience self-disgust, then to not acknowledge this in research would be to invalidate the person's experience, while stagnating development of knowledge and understanding that could aid in the relief of distress.

The Role of Researcher Versus the Role of Clinician

As a clinician, I work with individuals experiencing distress, but the hope and, usually, the aim is to reduce that distress. As a researcher conducting this study, I was not in a position to engage with the experience of distress, yet I realized, on entering my data analysis phase, that I was hoping to find high levels of self-disgust within the sample.

While I did not wish for people to experience distress, I was hoping to discover "interesting" findings. Of course, if analysis of the data had found no relationship between selfdisgust and adjustment to amputation, this would in itself have been interesting theoretically. However, publishing bias is such that non-significant findings are much less likely to be published (Franco, Malhotra, & Simonovits, 2014). Subsequently, there is an investment for the researcher to find significant results within their analysis.

While the differences in roles can create a tension between that of researcher and that of clinician, I believe that several strengths arise from the dual role. For example, the ability to reflect on experiences throughout the research process has helped me understand my own relationship to exploring difficult topics. I can then draw from this experience into my clinical practice as well as my research practice. Moreover, experience within clinical services can identify areas of need for research and facilitate an understanding of how research findings will be applicable in clinical practice.

Future Research

Having appraised the study of self-disgust relating to adjustment in people with limb amputations, several areas of potential research have emerged. In particular, it would be of interest to examine the role of self-disgust, regarding amputation, in different populations such as; individuals with congenital limb differences, people with a diagnosis of BIID, a targeted population with upper limb amputations, and individuals who have received other types of amputation (e.g., mastectomy). In each of these cases, it would be expected that self-disgust would demonstrate different relationships with psychosocial well-being or adjustment processes.

Furthermore, while qualitative research has been conducted regarding the experience of self-disgust (Powell et al., 2014), it might be expected that the meanings and values related to self-disgust will be different in people with experience of amputation. Therefore, a qualitative investigation in this population would be helpful in expanding our understanding of the personal meanings of self-disgust in amputation. This may also reveal the relationship that self-disgust holds with engagement with the amputated limb (e.g., hygiene practice), patterns of prosthesis use (e.g., social uses) or the specific qualities of a prosthesis that may help or hinder with the self-disgust experience.

Of particular interest might be the investigation, both quantitatively and qualitatively, of self-disgust in a clinical sample of individuals with amputations. It might then emerge that those people in access of clinical services express different adjustment patterns and different relationships with self-disgust schema.

Lastly, it is important to acknowledge the potential barrier that might be in place regarding discussion of self-disgust in individuals with visible diversity. An exploration of these barriers within professionals may highlight whether potentially important conversations are not taking place in clinical settings.

Conclusion

In critically appraising the study of self-disgust and its relationship to psychosocial adjustment and related factors in people with amputations, areas of both strength and of limitation have become apparent. While the study is novel in examining, and demonstrating the relevance of self-disgust to the amputation experience, future research may build on these findings further. Ultimately, self-disgust emerges as an important, though potentially difficult area that warrants further exploration in both research and clinical practice.

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Running head: ETHICS

Section Four: Ethics

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Word Count (excluding references, appendices, tables & figures): 2198



Ethics Application Form

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research involving direct contact with human participants

Instructions

- 1. Apply to the committee by submitting:
 - a. The University's **Stage 1 Self-Assessment (part A only)** and the **Project Questionnaire**. These are available on the Research Support Office website: <u>LU Ethics</u>
 - b. The completed application FHMREC form
 - c. Your full research proposal (background, literature review, methodology/methods, ethical considerations)
 - d. All accompanying research materials such as, but not limited to,
 - 1) Advertising materials (posters, e-mails)
 - 2) Letters/emails of invitation to participate
 - 3) Participant information sheets
 - 4) Consent forms
 - 5) Questionnaires, surveys, demographic sheets
 - 6) Interview schedules, interview question guides, focus group scripts
 - 7) Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing handbooks or measures, which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

- Submit all the materials electronically as a <u>SINGLE</u> email attachment in PDF format by the deadline date. Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing show markup>balloons>show all revisions in line.
- 3. Submit one <u>collated</u> and <u>signed</u> paper copy of the full application materials in time for the FHMREC meeting. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
- 4. Committee meeting dates and application submission dates are listed on the <u>FHMREC website</u>. Applications must be submitted by the deadline date, to:

Dr Diane Hopkins					
B14, Furness College					
Lancaster University,					
LA1 4YG					
d.hopkins@lancaster.ac.uk					

- 5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.
- 6. Attend the committee meeting on the day that the application is considered, if required to do so.

Title of Project: Self-disgust as a predictor of prosthesis use (Working title: Exploring the relationship between prosthesis use and thoughts about amputation)
 Name of applicant/researcher: Nicolas Burden

3. Type of study

X Includes *direct* involvement by human subjects.

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: <u>LU Ethics</u>. Submit this, along with all project documentation, to Diane Hopkins.

4. If this is a student project, please indicate what type of project by marking the relevant box: (please note that UG and taught PG projects should complete FHMREC form UG-tPG , following the procedures set out on the <u>FHMREC website</u>						
PG Diploma Masters dissertation DClinPsy SRP PhD Thesis	PhD Pall. Care					
PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health	MD					
DClinPsy Thesis X						

Applicant Information

5. Appointment/position held by applicant and Division within FHM Postgraduate student, Clinical Psychology, Department of Health and Medicine						
6. Contact information for applicant: E-mail: n.burden@lancaster.ac.uk Telephone: 07898604906						
Address : Department of Clinical Psychology, Division of Health Research, Lancaster University, Lancaster, LA1 4YG						
7. Project supervisor(s), if different from applicant:	Dr Jane Simpson Dr Craig Murray					
 8. Appointment held by supervisor(s) and institution(s) where based (if applicable): Academic Supervisor: Dr Jane Simpson, Research Director, Department of Clinical Psychology, Lancaster University Field Supervisor: Dr Craig Murray, Deputy Research Director, Department of Clinical Psychology, Lancaster University 						

9. Names and appointments of all members of the research team (including degree where applicable)
 Nicolas Burden, Principal Researcher, ClinPsyD
 Dr Jane Simpson, Academic Supervisor
 Dr Craig Murray, Field Supervisor

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (indicative maximum length 150 words):

In a period of adjustment post-amputation, individuals may often experience a period of psychological distress. While prosthesis use is often considered part of recovery from amputation, duration of use has been associated with psychological and emotional well-being as well as demographic and clinical factors. Newer emerging psychological phenomena such as self-esteem could be particularly useful in understanding and predicting prosthesis use. It is hypothesised that self-disgust, in a hierarchical regression analysis, will demonstrate significant predictive value above other predictors. A quantitate approach will be used, with data collected online, through Qualtrics survey software, and using questionnaire packs provided to amputee meetings groups. Participants will be collected internationally, primarily via organisations involved with amputation and prosthesis use, and will include prosthesis users who are 16 years of age or above and of any gender, ethnicity and nationality. Data will be analysed using multiple regression analysis. Results will be written for a doctoral thesis and may inform health care practice.

11. Anticipated project dates (month and year only)

Start date: 08/2015 End date: 05/2016

12. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

The study will recruit a minimum of 105 participants. This is based on Cohen's (1998) suggestion that a minimum of 105 participants would be required to detect a significant effect (p = .05) at a power level of 0.8 when estimating a medium effect size with eight to ten predictors. The appropriateness of the power calculation will be assessed at certain points throughout the data collection period. There will be no maximum number of participants. Recruitment will end at the close of the recruitment period (10/2015). However, if the minimum number of participants has not been met by this time, the recruitment window will be extended to facilitate this. At the end of recruitment, the online survey will be closed.

Inclusion Criteria

Participants will;

• Have an acquired amputation (surgical removal of a limb due to complications associated with disease or trauma).

- Have the availability of a prosthesis.
- Be 16 years of age or above
- **Exclusion Criteria**

Participants will not;

• Use a prosthetic limb to aid with a congenital limb anomaly (an absent or poorly developed limb from birth).

• Be restricted in use of prosthesis for any reason outside of personal choice (e.g. medical recommendation).

Participation will not otherwise be determined by gender, age, ethnicity or nationality. However, these demographics will be collected as part of the study. As the study will primarily be completed online and presented in English language, it is possible that this will impact on demographics of the individuals participating in the study.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited online. Online advertisements will be posted on various platforms, including twitter and a Lancaster University hosted webpage

(<u>http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/</u>). Specialist amputation and prosthesis organisations and support groups, such as the Amputee Coalition and the Limbless Association, will be contacted by telephone or professional email and invited to advertise a link to the study on their media, including; magazines, internet domains and social media (e.g. twitter). The principal researcher will also use a professional Twitter account to connect with the Twitter accounts of organisations and to promote the study. No organisations, groups, individuals or otherwise will be contacted through facebook.

Individuals who are interested in taking part in the study will follow the link to a web address where they will be able to read information about the study and consent to participation. The participant information and consent process appear as separate web pages. The survey section of the study cannot be reached without first accessing the participant information and consenting to all aspects of the study.

As an alternative to online completion of the study, participants will be informed that they can contact the principal researcher (Nicolas Burden) via email to request a hard copy of the materials. The participant information, the consent form and the questionnaires will be posted to the address provided with the request, along with a stamped addressed envelope for return of the study materials. All hard copies of the materials will remain the same as the electronic versions. Organisations posting the link to the study will be requested to provide this information with the principal researcher's professional email alongside the link to the electronic version. Participants will also find this information in the participant information preceding the online version.

The organisers/moderators of amputee discussion or support meeting groups will be contacted by telephone, email or post requesting that they share information about the study and requesting permission to provide them with hardcopies of the Participant Information, Consent Forms and Participant Survey Packs which can be disseminated to interested parties in the group. The principal researcher will also offer to attend meeting groups in the North West area of England to speak about the study.

14. What procedure is proposed for obtaining consent?

A consent procedure has been incorporated into the online survey. Participants are first presented with the participant information for the study and are advised to take adequate time to consider this information before proceeding. Participants are then presented with a series of statements relating to

consent to participate, to which they must indicate agreement by checking the corresponding box. If the participant does not indicate agreement with all of the consent items, the participant will automatically be redirected to the end of the survey.

If a participant requests a paper copy of the study materials, this will be supplied with a paper version of the consent procedure to match the electronic version. Participants must indicate consent by checking/marking a box corresponding to each of the consent statements. On return of the study, if the participant has not marked all items on the consent sheet then the participant's responses will not be included in the study.

15. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

There are no risks anticipated with participating in this study. However, it is possible that participants may become distressed while completing the survey. Participants will be informed prior to commencing the study that they may opt out at any time during test completion and that their information will not be included in the data. However, due to the anonymity associated with online completion of the test battery, if a participant completes the test process, their data cannot be extracted after this point.

On participation in the study, individuals will be advised to seek professional medical assistance or contact a support line if they are experiencing physical or mental health difficulties. As the study will be made available for participation internationally, the details for online support agencies that can be accessed internationally have been provided.

While every effort has now been taken to ensure the acceptability of the participation process, through consultation with experts by experience, it is possible that participants will disagree with aspects of the content or use of language. Participants will be provided with contacts at Lancaster University who they may contact if they wish to lodge a complaint.

16. 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).

As the researcher will not be meeting with participants on a one-to-one basis, it is considered that risk to the researcher is minimal. When attending amputee meeting groups to present the study, the researcher will adhere to the Lancashire Care NHS Foundation Trust lone working policy (available at: http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/onlinehandbook/appendices/lcft_lone_working_policy.pdf).

If a researcher becomes distressed in response to conducting the study, they are able to access peer support from the Department of Clinical Psychology at Lancaster University. The principal researcher will have access to additional support from the academic and field supervisors and from a clinical tutor.

17. 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.

We hope that participants will find the survey interesting and that the study will lead to a better understanding of prosthesis use that will aid healthcare provision. However, there are no direct gains to taking part in the study.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants: There will be no incentives/payments made to participants.

19. Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

The study will be a quantitative, cross-sectional design to best investigate the predictive relationship between self-disgust and prosthesis use. Data will be collected using a series of self-report questionnaires hosted through Qualtrics online survey software or provided as hardcopy on participant request or via amputee meeting groups.

Having completed the consent procedure, participants may then proceed to the questionnaire section of the survey. Participants will complete a series of questionnaires relating to demographic information, information about prosthesis use and the experience of pain, and measures of psychological distress (e.g. self-disgust, body image). The data from these questionnaires will be uploaded into a database for statistical analysis using SPSS statistical software.

Participants must be of 16 years age or above to take part in the study. Other demographic data (e.g. gender, ethnicity or nationality) will not be used to determine a participant's involvement in the study. However, as the study will be completed online and presented in English language, it is possible that this will impact on the demographics of the individuals participating in the study. It is also possible that difference in demographic factors (e.g. male vs female), will be associated with differences in prosthesis use.

Data will be analysed using multiple regression analysis and possibly, depending on the pattern of associations revealed by the preliminary correlational analysis, mediator or moderator analysis. The nature of the online electronic data collection will ensure complete anonymity as no personally identifiable information will be collected. To match this, the hard copies of the study materials which may be requested by a participant will remain the same as the electronic version and will not request any personally identifiable information. Participants will be advised that all their data will be confidential and securely stored and may only be accessed by members of the research team.

The anonymity of online participation also dictates that any cause for concern (e.g. low levels of psychological well-being, experience of physical pain) will not be directly detected by a professional. On participation in the study, individuals will be advised to seek professional medical assistance or contact a support line if they are experiencing physical or mental health difficulties.

As the email addresses of the research team will be made available for further queries or request of a hard copy of the study, it is possible that a participant will disclose a concern for welfare in communication. Participants will be advised that, if this happens, the research team may forward the email on to a health or support service in their area (e.g. general practitioner). This is dependent on the level of information known about the participant through the communication.

	be the involvement of your target participant group in the <i>design and conduct</i> of						
your research . Experts by experience	in the field of amputation and prosthesis use (e.g. from the Amputee Coalition)						
will be invited to review the study design, planned procedure and materials. Feedback from experts by							
	experience will be incorporated into the study alongside any feedback from ethical review.						
	ce for the storage of data (electronic, digital, paper, etc.)? Please ensure that hte bata Protection Act 1998.						
All electronic data will	be stored securely in the principal researcher's personal file space on the						
Lancaster University se	ecure server (H drive). Returned hard copies of the study materials will be						
	onto an electronic database and the hard copy destroyed. No identifiable						
information will be col							
	at the end of the study for transfer to long-term storage. The data will be sent to rch Coordinator using an electronically secure method of data transfer and stored						
	ed file space on the university server. Data will be stored for ten years. It will be						
	e programme Research Coordinator to delete the data after this time.						
22. Will audio or video							
	ents have been made for audio/video data storage? At what point in the gital recordings/files be destroyed?						
research win tapes/ up	gital recordings/ mes be destroyed :						
-	s for dissemination of findings from the research? If you are a student, include						
here your thesis.							
-	en as a doctoral thesis and submitted to Lancaster University. ndings will be written and offered to organisations, groups or forums involved in						
recruitment of particip							
	en for publication in an academic peer reviewed journal.						
-	dy may be presented at conferences or to healthcare teams and support groups						
involved with amputat	ion and prosthesis use.						
-	hical considerations, not previously noted on this application, do you think there udy? Are there any matters about which you wish to seek guidance from the						
FHMREC?							
No further ethical cons	iderations identified.						
Signatures:	Applicant:						
	Date:						

*Project Supervisor (if applicable):

Date:

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

THE UNIVERSITY OF LANCASTER

PFACT project information and ethics questionnaire

(To be completed by the student together with their supervisor in all cases)

Name of student: Nicolas Burden

Name of supervisor: Dr Jane Simpson

Project Title: Self-disgust as a predictor of prosthesis use

1. <u>General information</u>

1.1 Have you, if relevant, discussed the project with

the Data Protection Officer?

the Freedom of Information Officer?

N/A

(Please tick as appropriate.)

1.1 Does any of the intellectual property to be used in the research belong to a third party? N

1.2 Are you involved in any other activities that may result in a conflict of interest with this research?

1.3 Will you be working with an NHS Trust?

Ν

ETHICS

2.

1.4	If yes to 1.3, what steps are you taking to obtain NHS approval?	
1.5	If yes to 1.3, who will be named as sponsor of the project?	
1.6	What consideration has been given to the health and safety requirements of	f the research?
	As the study will be advertised and completed online, there will be no di researchers and the participants. As such, there will be no environmental study and a lone working/risk policy is not necessary.	
	nation for insurance or commercial purposes we put N/A where relevant, and provide details where the answer is yes.)	
2.1	Will the research involve making a prototype?	N
2.2	Will the research involve an aircraft or the aircraft industry?	Ν
2.3	Will the research involve the nuclear industry?	Ν
2.4	Will the research involve the specialist disposal of waste material?	Ν
2.5	Do you intend to file a patent application on an invention that may relate in research in this proposal? If YES, contact Gavin Smith, Research and Ente (ext. 93298)	

3. Ethical information

(Please confirm this research grant will be managed by you, the student and supervisor, in an ethically *appropriate manner according to:*

- the subject matter involved; *(a)*
- (b) the code of practice of the relevant funding body; and
- (*c*) the code of ethics and procedures of the university.)

(Please put N/A where relevant)

- 3.1 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to the avoidance of plagiarism and fabrication of results.
- 3.2 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to the observance of the rules for the exploitation of intellectual property.
- 3.3 Please tick to confirm that you are prepared to accept responsibility on behalf of the institution for your project in relation to adherence to the university code of ethics.
- 3.4 Will you give all staff and students involved in the project guidance on the ethical standards expected in the project in accordance with the university code of ethics?
- 3.5 Will you take steps to ensure that all students and staff involved in the project will not be exposed to inappropriate situations when carrying out fieldwork?
- 3.6 Is the establishment of a research ethics committee required as part of your collaboration? (This is a requirement for some large-scale European Commission funded projects, for example.)
- 3.7 Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans, human tissue etc.?

 \mathbf{N}

 \checkmark

M

Y

Y

Y

N/A

3.7.2 Will you take the necessary steps to find out the applicable
--

- 3.7.3 Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
- 3.7.4 Will you take appropriate action to ensure that the position under 3.7.1 3.7.3 are fully understood and acted on by staff or students connected with the project in accordance with the university ethics code of practice?
- 3.13 Does your work involve animals? If yes you should specifically detail this in a submission to the Research Ethics Committee. The term animals shall be taken to include any vertebrate other than man.
 - 3.13.1 Have you carefully considered alternatives to the use of animals in this project? If yes, give details.

3.13.2 Will you use techniques that involve any of the following: any experimental or scientific procedure applied to an animal which may have the effect of causing that animal pain, suffering, distress, or lasting harm? If yes, these must be separately identified.

N/A

N/A

Signature (student):	Date:
Signature (supervisor):	Date:

N.B. Do not submit this form without completing and attaching the Stage 1 self-assessment form.

Y

Y

Y

Y

Stage 1 Self-Assessment Form (Part A) - for Research Students

(To be completed by the student together with the supervisor in all cases; send signed original to Research Support)

Student name and email: Nicolas Burden n.burden@lancaster.ac.uk

Supervisor name: Dr Jane Simpson Department: Clin. Psychology

Title of project: Self-disgust as a predictor of prosthesis use

Proposed funding source (if applicable): n/a

- Please confirm that you have read the code of practice, '<u>Research Ethics at Lancaster: a code of practice</u>' and are willing to abide by it in relation to the current proposal? Yes
 If no, please provide explanation on separate page
- 2. Does your research project involve non-human vertebrates, cephalopods or decapod crustaceans? No *If yes, have you contacted the Ethical Review Process Committee (ERP) via the University Secretary (Fiona Aiken)?* ?
- 3a. Does your research project involve human participants i.e. including all types of interviews, questionnaires, focus groups, records relating to humans etc? Yes

If yes, you must complete Part B unless your project is being reviewed by an ethics committee

- 3b. If the research involves human participants please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data **Yes**
- 3c. If the research involves human participants, are any of the following relevant:
 - **No** The involvement of vulnerable participants or groups, such as children, people with a learning disability or cognitive impairment, or persons in a dependent relationship
 - No The sensitivity of the research topic e.g. the participants' sexual, political or legal behaviour, or their experience of violence, abuse or exploitation
 - No The gender, ethnicity, language or cultural status of the participants
 - **No** Deception, trickery or other procedures that may contravene participants' full and informed consent, without timely and appropriate debriefing, or activities that cause stress, humiliation, anxiety or the infliction of more than minimal pain
 - **No** Access to records of personal or other confidential information, including genetic or other biological information, concerning identifiable individuals, without their knowledge or consent
 - **No** The use of intrusive interventions, including the administration of drugs, or other treatments, excessive physical exertion, or techniques such as hypnotherapy, without the participants' knowledge or consent
 - No Any other potential areas of ethical concern? (Please give brief description)

4. Are any of the following potential areas of ethical concern relevant to your research?

No Could the funding source be considered controversial?

No Does the research involve lone working or travel to areas where researchers may be at risk (eg countries that the FCO advises against travelling to)? If yes give details.

No Does the research involve the use of human cells or tissues other than those established in laboratory cultures?

No Does the research involve non-human vertebrates?

If yes, has the University Secretary signified her approval? ?

No Any other potential areas of ethical concern? (Please give brief description)

5.	Please select ONE appropria the fully signed original self		v action indicated below and in all cases submit
			e to all parts of Q.4 is 'NO'. No further action
			her information. If Lancaster will be named as
		wed by other external ethics com ls of the information to submit with	
			ee your School or Department and submit this
			l ontact RSO to register your intention to submit a
	Research involves human pa)-(e) above not ticked or more parts of Q.4 is 'YES' but ethical risk is <u>ART B</u> and submitting with this <u>signed original</u>
Stu	udent signature:		Date:
Su	pervisor signature:		Date:
He	ead of Department (or delegate	d representative) Name:	
Sig	gnature:	Da	ate:

Approval Letter



Applicant: Nicolas Burden Supervisor: Jane Simpson Department: Health Research FHMREC Reference: FHMREC15035

14 December 2015

Dear Nicolas

Re: Self-disgust as a predictor of prosthesis use (Working title: Exploring the relationship between prosthesis use and thoughts about amputation)

Thank you for submitting your research ethics amendment 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 University Research Ethics Committee (UREC), 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 (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 the Diane Hopkins (01542 592838 fhmresearchsupport@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

Jone Havis

Dr Diane Hopkins Research Development Officer

CC Ethics@Lancaster; Professor Roger Pickup (Chair, FHMREC)

Appendix 4-A

Research Protocol

Self-disgust as a predictor of prosthesis use

Nicolas Burden, Lancaster University Dr Craig Murray, Lancaster University Dr Jane Simpson, Lancaster University

Introduction

Adjustment to amputation is a major life event that can often lead to the experience of psychological distress. Several studies have identified an increase in the experience of depression in individuals following amputation, in comparison to community norms (Kashani, Frank, Kashani, Wonderlich & Reid, 1983; Rybarczyk et al., 1992; Carter, 2000). It has been reported that only on resolving psychological distress can amputees derive full benefit from prosthesis use (English, 1989). Yet, while demographic and clinical factors have been seen to affect prosthesis use (Raichle et al., 2008), psychological states have also been found to have a relationship with an individual's duration of prosthesis use. Durmus et al., (2015) found several psychiatric symptoms to be negatively correlated with daily prosthesis use, including; somatization, depression, anxiety and interpersonal sensitivity, among others. Body image disturbance has also been found to correlate with prosthesis satisfaction, which was further associated with an individual's pain experience and hours of prosthesis use (Murray & Fox, 2002). However, newly emerging psychological concepts, such as self-disgust, have yet to be considered in relation to prosthesis use.

ETHICS

A universal and normative emotional reaction, disgust is both biologically and socio-culturally defined (Rozin & Haidt, 2013) and can arise from a wide range from stimuli, from behaviours perceived as immoral through to unattractive body features. Rozin, Lowery, Imada and Haidt (1999) proposed that elicitors of disgust developed from a core set, based on an oral incorporation process, to include interpersonal threats, immorality and reminders of human's animal nature (e.g. violations of the body envelope). In considering the body envelope, physical bodies which do not match sociocultural and evolutionary fitness ideals may be framed as one elicitor of disgust (Powell, Simpson & Overton, 2015a). Disgust has been associated with body dissatisfaction (Griffiths & Page, 2008), judgements of unattractiveness (Park, van Leeuwen & Stephen, 2012) physical health distortions of the body (Smith, Loewenstein, Rozin, Sheriff, & Ubel, 2007).

Disgust may also be self-directed toward the individual's own psychological characteristics, behaviour or body (Powell, Overton, & Simpson, 2014) and heightened self-disgust has been associated with mental health problems involving the body, including body dysmorphic disorder (Ondem-Lim et al., 2012), eating disorders (Espeset, Gulliksen, Nordbø, Skårderud, & Holte, 2012) and depression (Castle & Phillips, 2002). Self-disgust toward the body can be theoretically distinguished from other self-directed phenomena (e.g. shame) by nature of its cognitive-affective content, including the phenomenon of repulsion (Powel, Simpson, & Overton, 2015b).

As heightened self-disgust toward the individual's own body is negatively associated with psychological well-being (Powell et al., 2015b), there presents a need to explore the impact that self-disgust may have with physical health presentations. However, the interaction of self-

ETHICS

disgust with amputation and its correlates in emotional health and recovery has not been explored to date. Amputation by its very nature could be conceived as a violation of the body envelope, a reminder of our animal nature as described by Rozin et al. (1999). Both body image disturbance and perceived social stigma, each of which may be associated with self-disgust, have been indicated as independent predictors of depression post amputation (Rybarczyk et al., 1995). Exploring self-esteem and its interaction with other psychological correlates of prosthesis use might facilitate a better understanding of recovery after amputation. The aim of this study is to explore the predictive relationship that self-disgust has with prosthesis use among adults.

It might be conceived that, in an initial period following amputation, self-disgust may be associated with avoidance of the amputated limb and avoidance of prosthesis use. However, self-disgust may later be associated with perceived stigma from others and an increase in the use of prosthesis, masking the amputation from others. This time element will be explored in the analysis.

In a hierarchical regression with block entry for the different class of variables (clinical, demographic etc), it is hypothesised that self-disgust will explain an additional and significant amount of variance when entered in a final block of the regression model with prosthesis use as the outcome variable.

Method

Participants

Using an electronic power calculator, G*Power 3.1.9.2, with an estimated medium effect size ($f^2 = 0.15$) and ten predicators indicates a minimum sample size of 89 participants. Cohen (1988) suggests a minimum of 105 participants would be required to detect a significant effect (p = .05) at a power level of 0.8 when estimating a medium effect size with eight to ten predictors. The study will recruit a minimum of 105 participants.

Participants will be recruited internationally via organisations and meetings groups involved with amputation and prosthesis use, such as the Amputee Coalition and Limbless Association, and using social media and other online forums (e.g. amputee-related discussion groups) to advertise the study.

Inclusion Criteria

Participants will;

- Have an acquired amputation (surgical removal of a limb due to complications associated with disease or trauma).
- Have the availability of a prosthesis.
- Be 16 years of age or above.

Exclusion Criteria

Participants will not;

- Use a prosthetic limb to aid with a congenital limb anomaly (an absent or poorly developed limb from birth).
- Be restricted in use of prosthesis for any reason outside of personal choice (e.g. medical recommendation).

Participation will not otherwise be determined by age, gender, ethnicity or nationality. However, these demographics will be collected as part of the study. As the study will be presented in English language, it is possible that this will impact on demographics of the individuals participating in the study.

Design

The study will be a quantitative, cross-sectional design to best investigate the predictive relationship between self-disgust and prosthesis use. Data will be collected using a series of self-report questionnaires. Questionnaires will be hosted online, through Qualtrics online survey software, or provided as hardcopy participant survey packs.

Materials

All study materials can be accessed online or completed as a hardcopy questionnaire pack. Participants entering the study will be presented with an electronic participant information sheet before declaring consent to participate in the study. Participants will then be asked for socio-demographic information, including age, gender, ethnicity, nationality. Participants will also answer a series of questions regarding their amputation (causation, type of limb loss, time since amputation) and time use of their prosthesis (hours per day and days per month). Participants will then compete a test battery of questionnaires, including;

Self-Disgust Scale Revised (SDS-R; Powell, Overton & Simpson, 2015):

The 22-item SDS-R measures trait disgust toward the self. Participants rate their agreement with each statement (e.g. "I find the way I look nauseating") on a 7-point Likert scale (from 1 = strongly agree to 7 = strongly disagree). The test-retest reliability of the original Self-Disgust Scale (SDS) is excellent (Overton et al., 2008; Powell et al., 2013) and the SDS-R was modified from the SDS (4 additional items and 5 revised items) to increase face validity. A total score for the SDS-R are obtained by reverse coding 4 items and removing 7 filler items before summing the 15 scores. Higher total scores indicate a greater level of self-disgust. The SDS and SDS-R are currently the only measures of self-disgust as a psychological phenomenon.

Depression Anxiety Stress Scale 21 (DASS-21; Lovibond & Lovibond, 1995):

The DASS-21 is 21 item short form version of Lovibond and Lovibond's (1995) 42-item measure and includes subscales measuring depression, anxiety and stress. The DASS – 21 is reported to have very good reliability estimates (Antony et al., 1998; Clara et al., 2001) and adequate construct validity (Henry & Crawford, 2005). Participants indicate the presence of a symptom item over the previous week (from 0 = 'Did not apply to me at all over the last week', to 3 = 'Applied to me very much or most of the time over the past week'). For each scale, depression, anxiety and stress, scores are summed and then multiplied by 2 (to reflect a full version DASS score). Higher scores indicate a higher levels of distress.

The Trinity amputation and Prosthesis Experience Scales – Revised (TAPES – R; Gallagher, Franchignoni, Giordana, & MacLachlan, 2010):

The TAPES-R is multidimensional self-report measure to aid understanding of adjustment to lower limb prosthesis. It consists of two parts, of which Part I contains three sections (psychosocial issues, activity restriction, satisfaction with the prosthesis) and Part II explores phantom limb pain, residual limb pain and other medical conditions. Each section can be used independently. This study will use two sections from Part 1; psychosocial issues and satisfaction with prosthesis. It will also use Item 4 and Item 5 from Part II to assess the experience of Pain.

Psychosocial Issues is a five point Likert scale consisting of 15 items. Participants are asked to rate how much they agree with each statement (e.g. "I don't care if somebody looks at my prosthesis") from 0 = strongly disagree to 4 = strongly agree or 5 = not applicable.

Satisfaction with prosthesis is a three point Likert scale consisting of eight items. Participants are asked to identify whether they are not satisfied, satisfied or very satisfied with different aspects of the prosthesis (e.g. appearance). Participants also identify how satisfied they are

with the prosthesis on an 11-point visual analogue scale (from 0 = not at all satisfied to 10 = very satisfied).

Residual limb pain (RLP) and phantom limb pain (PLP) will be assessed using Part II, items four and five respectively. In each item, participants will be asked to identify if they have experienced RLP or PLP. If they identify 'Yes', the participant will be asked how many times they have experienced pain and how long, on average, each episode of pain lasted. Using five-point visual analogue scales, participants will be asked to identify the average level of pain experienced in the last week (from 5 = 'Excruciating' to 1 = 'Mild') and the extent to which pain interfered with normal lifestyle (from 5 = 'A lot' to 1 = 'Not at all').

The Amputee Body Image Scale - Revised (ABIS-R, Gallagher et al., 2007):

The ABIS-R is three point Likert scale comprised of 14 items, assessing how individuals who have had an amputation perceive and feel about their body. As one of the items refers specifically to lower limb amputation (limping when walking), this item has been removed and will be compensated for at analysis. Participants are asked to identify the most appropriate response for them (from 0 = 'None of the time' to 3 = 'Most/all of the time') for each of the 13 statements presented (e.g. "I avoid looking into a full-length mirror in order not to see my prosthesis"). To score, 2 items are reverse scored and then responses are totalled, with a higher total score indicating high body image disturbance (BID).

ETHICS

The Brief COPE (Carver, 1997):

The Brief COPE is a brief measure of coping reactions, based on the COPE inventory (Carver et al., 1989). The measure is a four point Likert scale comprising 28 items. Participants are asked to respond to each item by indicating how often (from 0 = 'I haven't been doing this at all' to 3 = 'I've been doing this at all') they have been doing what the item says (e.g. "I've been getting emotional support from others"). The measure is not designed to give a total score. Rather, it includes individual subscales of coping (e.g. Acceptance) which are scored by combing the responses from the 2 corresponding items, giving a score of 0 to 6 for each scale.

Procedure

Participants will be recruited online and from amputee discussion and support meeting groups. Online advertisements will be posted on various platforms, including twitter and a Lancaster University hosted webpage (http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/).

Members of amputation and prosthesis organisations have now been involved as experts by experience, to review and offer feedback on the suitability and acceptability of the study content and use of language (e.g. use of a working title that does not reference 'self-disgust'). These members will be invited to advertise a link to the study on their media, including magazines, internet domains and social media (e.g. twitter). A professional Twitter account will also be used to contact organisations and share the link to the study. The research team will not use facebook to contact any organisation, group or individual.

Individuals who are interested in taking part in the study online will follow the link to a web address where they will be able to read information about the study and consent to participation. The participant information and consent process appear as separate web pages. The survey section of the study cannot be reached without first accessing the participant information and consenting to all aspects of the study. Completion of the study procedure (demographics and questionnaires) will automatically populate a database, from which data will be withdrawn and analysed using SPSS statistical software.

Should they prefer to complete a hardcopy of the study, participants accessing the study online will be informed that they can contact the principal researcher (Nicolas Burden) via email to request a hard copy of the materials. The participant information, the consent form and the questionnaires will be posted to the address provided with the request, along with a stamped addressed envelope for return of the study materials. All hard copies of the materials will remain the same as the electronic versions.

Organisations posting the link to the study will be requested to provide this information with the principal researcher's professional email alongside the link to the electronic version. Participants will also find this information in the participant information.

The organisers/moderators of amputee discussion or support meeting groups will be contacted by telephone, email or post requesting that they share information about the study and requesting permission to provide them with hardcopies of the Participant Information, Consent Forms and Participant Survey Packs which can be disseminated to interested parties in the group. The principal researcher will also offer to attend meeting groups in the North West area of England to speak about the study.

Analysis

Data will be collected through Qualtrics and via surveys returned by post, and analysed using SPSS software. Data will be analysed using multiple regression analysis and possibly, depending on the pattern of associations revealed by the preliminary correlational analysis, mediator or moderator analysis. Analysis will be conducted by the principal researcher and reviewed by a member of the research team to ensure quality of the analysis.

Practical Issues

As all aspects of the study can be completed online, this facilitates complete anonymity in participation and allows participants to take part at a time and place that is most convenient to them. To maintain this anonymity, hardcopies of the participant materials do not request any identifiable information. Hardcopies of the survey that are completed and returned to the research team will first be checked for consent. If the participant has indicated consent to all aspects of the study (on the returned consent form) then data from the questionnaires will be manually entered into an excel software spreadsheet with electronically returned data sets, before analysis using SPSS statistical software. All electronic data will be stored securely in the principal researcher's personal file space on the Lancaster University secure server (H drive). Returned hard copies of the study materials will be immediately uploaded onto an electronic database and the hard copy destroyed. No identifiable information will be collected or stored.

Data will be encrypted at the end of the study for transfer to long-term storage. The data will be sent to the programme Research Coordinator via an electronic secure file transfer system and stored in a password-protected file space on the university server. Data will be stored for ten years. It will be the responsibility of the programme Research Coordinator to delete the data after this time.

Lancaster University will fund the involvement of amputation organisations in the advertisement of the study. However, no other costs (e.g. participant involvement) will be reimbursed.

Ethical Concerns

There are no risks anticipated with participating in this study. However, it is possible that participants may become distressed while completing the test battery. Participants will be informed prior to commencing the study that they may opt out at any time during test completion and that their information will not be included in the data. However, due to the anonymity associated with online completion of the test battery, if a participant completes the test process, their data cannot be extracted after this point. Similarly, once a participant returns a questionnaire pack via post, their data cannot be extracted.

Participants, having read the participant information, must complete a consent procedure to demonstrate informed consent before gaining access to the test battery. If a participant does not provide consent to all aspects of the study, they will be unable to take part/any data provided will not be included in analysis.

The anonymity of participation also dictates that any cause for concern (e.g. low levels of psychological well-being, experience of physical pain) will not be directly detected by a professional. On participation in the study, individuals will be advised to seek professional medical assistance or contact a support line if they are experiencing physical or mental health difficulties.

As the email addresses of the research team will be made available for further queries or request of a hard copy of the study, it is possible that a participant will disclose a concern for welfare in communication. Participants will be advised that, if this happens, the research team may forward the email on to a health or support service in their area (e.g. general practitioner). This is dependent on the level of information known about the participant through the communication.

While every effort has now been taken to ensure the acceptability of the participation process, through consultation with experts by experience, it is possible that participants will disagree with aspects of the content or use of language. Participants will be provided with contacts at Lancaster University who they may contact if they wish to lodge a complaint. As the researcher will not be meeting with participants on a one-to-one basis, it is considered that risk to the researcher is minimal. When attending amputee meeting groups to present the study, the researcher will adhere to the Lancashire Care NHS Foundation Trust lone working policy, available at:

http://www.lancaster.ac.uk/shm/study/doctoral_study/dclinpsy/onlinehandbook/appendices/l cft_lone_working_policy.pdf).

Timescale

The principal researcher will apply for ethical approval from the Lancaster University Research Ethics Committee in July/August 2015, with a view to the study commencing in August/September 2015. Liaison with amputation and prosthesis organisations will occur alongside online participant recruitment and data collection, which will take place between August and October 2015. Data will be analysed by 1st January 2016. The study will be written and submitted as part of a doctoral thesis to Lancaster University by May 2016. The study will be appropriately amended and submitted for publication by September 2016, and the Ethics Committee henceforth notified of study completion.

Appendices

See attached documents for;

Participant information

Consent procedure

Test materials (demographic information and questionnaires)

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Appendix 4-B

Participant Information Sheet

Exploring the relationship between prosthesis use and thoughts about amputation

My name is Nicolas Burden and I am conducting this study as part of my doctoral programme in Clinical Psychology at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the relationship between thoughts or feelings about amputation and the extent to which adults who have an amputated limb use a prosthesis or artificial limb.

Why would you like me to take part?

We are interesting in gathering information from individuals who have an amputated limb and who have access to a prosthetic limb. If you fit the following criteria for inclusion in the study, then we would be very grateful if you could complete our survey.

Inclusion criteria

- If you have an acquired amputation (limb removed due to complications with disease or an accident)
- If you have the availability of a prosthetic limb
- If you are 16 years of age or above

In some circumstances, other factors might change the nature of your prosthesis use. You should not take part in the survey if;

- Your use of a prosthetic limb is restricted for any reason outside of your own choice (e.g., medical recommendation)
- You use a prosthetic limb to aid with a congenital limb anomaly (the limb was absent or differently developed from birth)

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you do chose to take part, you can still change your mind at any point up until completion of the survey. However, once you send the survey back to us, it will not be possible for us to take out your data.

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

If you decide you would like to take part, you will be asked to fill in a series of questionnaires including demographic information and questions about your thoughts, feelings or actions that we think might be related to prosthesis use. The survey can be sent back to us using the stamped and addressed envelope provided with the survey. The length of time to complete the survey will vary from person to person, but it should take no longer than 20 (twenty) minutes.

Note: If you would prefer to complete an online version of the study, you can access this at http://tinyurl.com/ProsthesisStudy

Will my data be confidential?

The information you provide is completely confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to the information. The information you provide will be stored on a secure network at Lancaster University and only the members of the research team will be able to access the information. Electronic information will be stored for ten years and at the end of this period deleted.

[There are some limits to confidentiality: due to the nature of the survey, it is unlikely that the research team will be able to intervene if information gathered raises concern for the welfare of yourself or other people. However, if information shared via email (e.g., when requesting additional information) raises concern for the welfare of yourself or other people (i.e. if you indicate that harm may be caused to yourself or others) this information may be forwarded to a health or support agency (e.g. a general practitioner). If you feel that you could benefit from help for your emotional or physical wellbeing, it is advised that you contact your local health or support services].

What will happen to my data?

Your data will be pooled with data from other participants. The data will then be analysed and reported to Lancaster University as a doctoral thesis. The results may also be written up for publication in an academic or professional journal, and for written or verbal presentation to organisations involved with amputation or prosthesis, conferences and health or research teams. A summary of the results from this study will be made available to participants on request, after the study has completed. It is expected that summaries will be available from July

2016. If you would like a summary of the results, please contact the principal researcher, Nicolas Burden, by email; n.burden@lancaster.ac.uk

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you may wish to exit the survey and/or contact support from a health agency or helpline available in your area.

Sources of support

If you feel you need support with 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 below websites, with international coverage, where you will find details for how you can find support.

Befrienders 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".

Are there any benefits to taking part?

We hope that you will find the survey interesting and that the study will lead to a better understanding of prosthesis use that will aid healthcare provision. However, there are no direct gains to taking part in the study.

Who has reviewed the project?

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

ETHICS

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

If you have any questions about the study, please contact the principal researcher: Nicolas Burden, by email;

n.burden@lancaster.ac.uk

Alternatively you can contact Dr Jane Simpson, Research Director for Clinical Psychology at Lancaster University;

j.simpson2@lancaster.ac.uk

Complaints

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

Professor Bruce Hollingsworth Tel: (01524) 594154

Professor, Head of Department; Email: b.hollingsworth@lancaster.ac.uk

Division of Health Research

Lancaster University

Lancaster

LA1 4YG

Thank you for taking the time to read this information. Please ensure that you take adequate time to consider your participation before completing the survey.

An online version of this information and the survey can be found at:

https://tinyurl.com/ProsthesisStudy

Appendix 4-C

Consent Form

Lancaster University

Consent form: Hardcopy Version 1, Nov 2015

Study Title: Exploring the relationship between prosthesis use and thoughts about amputation

Doctorate in

We are asking if you would like to take part in a research study exploring the relationship between thoughts or feelings about amputation, and the use of prosthesis.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below if you agree with the corresponding statement. If you have any questions or queries before completing the consent form please contact the principal investigator, Nicolas Burden.

Please mark the box after each statement to indicate if you agree.

1.	I have read the information (presented in the Participant Information Sheet) and fully understand what is expected of me taking part in this survey	
2.	I have had the opportunity to contact the research team, to ask any questions I have about the study and to have them answered	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time during completion of the survey	
4.	I understand that once I have completed the survey it will not be possible for my responses to be withdrawn	
5.	I understand that any information I give will remain strictly confidential unless it is thought that there is a risk of harm to myself or others, in which case the principal researcher may need to share this with health or support services	
6.	I understand that the information from my responses will be stored electronically and I consent to Lancaster University keeping my responses for 10 years after the study has finished.	
7.	I give my consent for my responses to be pooled with the responses of other participants for analysis and for the results of this analysis will be written as part of a doctoral thesis	
8.	I understand that the principal researcher will share and discuss data with supervisors of the study	
9.	I consent to the analysis of my responses being written for publication and used in reports, conferences and training evening	
10	. I consent to take part in this study.	

Appendix 4-D

	Participant Survey Pack
What gender do y	you identify as?
Male	Female
Other gender, ple	ase specify:
How old are you?	·
What ethnicity ar	re you?
Asian	Black/ African/ Caribbean
Hispanic C	Native American
Pacific Islander	White/ Caucasion
Other ethnicity, p	lease specify;
In which country	do you reside?
How long ago did	you have your amputation?
Length of time:	YearsMonths
How much do you	u currently wear your prosthesis?
I wear my prosthe	esis, on average: days per month hours per day
What type of am	putation do you have?
Below-knee	Below-elbow
Through-knee	Through-elbow
Above-knee	Above-elbow
Other [
What was your a	mputation a result of? (Please tick any that apply)
Peripheral Vascula	ar Disorder 🔲 Diabetes 🔲
Cancer	Accident
Other:	

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

]
]
_
]
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]
]
]
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]
]
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]
]
]

ETHICS

Please <u>tick the box</u> that represents the extent to which you are satisfied or dissatisfied with <u>each</u> of the different aspects of your prosthesis mentioned below:

	Not Satisfied	Satisfied	Very Satisfied
16. Colour	[1]	[2]	[3]
17. Shape	[1]	[2]	[3]
18. Appearance	[1]	[2]	[3]
19. Weight	[1]	[2]	[3]
20. Usefulness	[1]	[2]	[3]
21. Reliability	[1]	[2]	[3]
22. Fit	[1]	[2]	[3]
23. Comfort	[1]	[2]	[3]

Please circle the number (0-10) that best describes how satisfied you are with your prosthesis?

0	1	2	3	4	5	6	7	8	9	10	
Not at all										Very Sa	tisfied
Satisfied											

(For the following questions, please tick the appropriate boxes) **1(a).** Do you experience **residual limb (stump) pain** (pain in the remaining part of your amputated limb)? No [_0] ... (If no, go to question 2)

Yes [1] ... (If yes, answer part (b), (c), (d) and (e))

(b) During the last week, how many times have you experienced stump pain?

(c) How long, on average, did each episode off pain last?

(d) Please indicate the average level of stump pain experienced <u>during the last</u> week on the scale below by ticking the appropriate box:

Excruciating Horrible Distressing Discomforting Mild

(e) How much did stump pain interfere with your normal lifestyle (e.g. work, social and family activities) <u>during the last week</u>?

A lot	Quite a Bit	Moderately	A Little Bit	Not at All
[5]	[4]	[3]	[2]	[1]

2(a). Do you experience phantom limb pain (pain in the part of the limb which was amputated)?

No [0] ... (If no, go to next page)

Yes [1] ... (If yes, answer part (b), (c), (d) and (e))

(b) <u>During the last week</u>, how many times have you experienced phantom limb pain? _____

(c) How long, on average, did each episode off pain last?

(d) Please indicate the average level of phantom limb pain experienced <u>during</u> <u>the last week</u> on the scale below by ticking the appropriate box:

ExcruciatingHorribleDistressingDiscomfortingMild[5][4][3][2][1]

(e) How much did phantom limb pain interfere with your normal lifestyle (e.g. work, social and family activities) <u>during the last week</u>?

A lot	Quite a Bit	Moderately	A Little Bit	Not at All
[5]	[4]	[3]	[2]	[1]

ETHICS

This questionnaire is concerned with how you feel about yourself. When responding to the statements below, please circle the appropriate number according to the following definitions: 1 = Strongly disagree; 2 = Very much disagree; 3 = Slightly disagree; 4 = Neither agree nor disagree; 5 = Slightly agree; 6 = Very much agree; 7 = Strongly agree.

Strongly disagree					Strongly agree		
1. I find myself repulsive	1	2	3	4	5	6	7
2. I am proud of who I am	1	2	3	4	5	6	7
3. I am sickened by the way I behave	1	2	3	4	5	6	7
4. Sometimes I feel tired	1	2	3	4	5	6	7
5. I can't stand being me	1	2	3	4	5	6	7
6. I enjoy the company of others	1	2	3	4	5	6	7
7. I am revolting for many reasons	1	2	3	4	5	6	7
8. I consider myself attractive	1	2	3	4	5	6	7
9. People avoid me	1	2	3	4	5	6	7
10. I enjoy being outdoors	1	2	3	4	5	6	7
11. I feel good about the way I behave	1	2	3	4	5	6	7
12. I do not want to be seen	1	2	3	4	5	6	7
13. I am a sociable person	1	2	3	4	5	6	7
14. I often do things I find revolting	1	2	3	4	5	6	7
15. I avoid looking at my reflection	1	2	3	4	5	6	7
16. Sometimes I feel happy	1	2	3	4	5	6	7
17. I am an optimistic person	1	2	3	4	5	6	7
18. I behave as well as everyone else	1	2	3	4	5	6	7
19. It bothers me to look at myself	1	2	3	4	5	6	7
20. Sometimes I feel sad	1	2	3	4	5	6	7
21. I find the way I look nauseating	1	2	3	4	5	6	7
22. My behaviour repels people	1	2	3	4	5	6	7

This questionnaire is designed to measure how you see and feel about your body image. It is not a test so there are no right or wrong answers. Please answer each item as carefully and as accurately as you can by placing the appropriate number beside each question as follows.

1 = None of the time 2 = Sometimes 3 = Most/all of the time

- 1. ____ Because I am an amputee, I feel more anxious about my physical appearance in social situations than when I am alone
- 2. ____ I like my overall physical appearance when wearing my prosthesis
- It concerns me that the loss of my limb impairs my body's functional capabilities in various activities of daily living
- 4. ____ I avoid looking into a full-length mirror in order *not* to see my prosthesis
- 5. ____ Because I am an amputee, I feel anxious about my physical appearance on a daily basis
- 6. ____ Since losing my limb, it bothers me that I no longer conform to society's idea of normal appearance
- 7. ____ It concerns me that the loss of my limb impairs me ability to protect myself from harm
- 8. ____ When I am *not* wearing my prosthesis, I avoid situations where my physical appearance can be evaluated by others (e.g., I avoid social situations, swimming pool or beach activites, etc.)
- 9. ____ I like my physical appearance when *not* wearing my prosthesis
- 10. ____ When I am wearing my prosthesis, I avoid situations where my physical appearance can be evaluated by others (e.g., I avoid any social situations, and/or I avoid swimming pool or beach activities etc.)
- 11. ____ People treat me as disabled
- 12. ____ I feel I must have four normal limbs to be physically attractive
- 13. ____ I avoid looking into a full-length mirror in order *not* to see my stump anatomy

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement. The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

These items deal with ways you've been coping with the stress in your life since you had a limb amputation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 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. ____l'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._____l've been getting help and advice from other people.
- 11._____l'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.____l'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.
- 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.____l've been expressing my negative feelings.
- 22._____l've been trying to find comfort in my religion or spiritual beliefs.
- 23._____l've been trying to get advice or help from other people about what to do.
- 24.____l've been learning to live with it.
- 25._____I've been thinking hard about what steps to take.
- 26.____l've been blaming myself for things that happened.
- 27.____I've been praying or meditating.
- 28.____l've been making fun of the situation.

Thank you for taking the time to complete this survey.

Your responses are most appreciated

Please note: if you feel you need support with any of the issues covered in the study, please contact your doctor who will be able to help further and refer you to the appropriate service if necessary. Alternatively, please visit the below websites, with international coverage, where you will find details for how you can find support.

Befrienders 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.amputeecoalition.org]

- [We aim] "to reach out to and empower people".

If you would like to be informed about future opportunities to take part in research related to amputation or prosthesis use, please contact;

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