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**Doctoral Thesis:** 

'I am simply an athlete': A psychological exploration of athletic identity in physical

# impairment and amputation

Kimberley Keegan

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Division of Health Research

Faculty of Health and Medicine

Lancaster University

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# **Table of Word Count**

Thesis Section	Main Text	Abstract (as per journal guidelines)	Appendices (including tables, figures and references)	Total
Thesis Abstract	289	8010011103)		289
Literature Review	8,493	133	4,969	13,595
<b>Empirical Paper</b>	7,355	186	4,677	12,218
Critical Appraisal	3,988		871	4,859
Ethics	5,950		3,859	9,809
Total	26,075	319	14,376	40,770

## **Thesis Abstract**

Individuals with limb loss or other physical impairments are subject to devalued 'disability' identities. There is an increasing amount of research to show that negative experiences of 'disability' can be attributed to stigmatising societal attitudes. The first aim of the thesis was to complete a meta-synthesis exploring the identity-related experiences of elite athletes with physical impairments. This review demonstrated that sport facilitated valued identities, whereby individuals could adopt 'athlete' as a dominant identity, move from 'incompetence' to 'competence', and use sport as a path to agency. However, the findings also captured the challenges to valued identities, which included the experience of social stigma, challenging the social meanings of 'disability', and the simultaneous marginalisation of gender. The review concluded that the development of valued identities within sport may help to challenge the common social views attached to a 'disability' identity.

The second aim of the thesis was to examine whether perceived social stigma mediated the relationship between physical activity and athletic identity for individuals with amputations. There is an established direct relationship between increased physical activity and stronger athletic identity within the general population, however it is indicated that this relationship is somewhat disrupted for people with limb loss. The findings confirmed that the relationship between increased physical activity and stronger athletic identity operated through a reduction in perceived social stigma for the sample. The findings demonstrate the positive psychological effects associated with physical activity for individuals with amputation. Theoretical, clinical and research implications are discussed regarding the implementation of physical activity as an effective element of physical rehabilitation following limb loss. Finally, the critical appraisal aimed to capture the author's reflections on the subject topic within clinical psychology, strengths and limitations of the project and recommendations for future research.

# Declaration

This thesis presents research submitted in May 2018 as a requirement of the Doctorate in Clinical Psychology at Lancaster University. The research reported is the authors own and has not been submitted for any other academic award.

Name: Kimberley Keegan

Signed:

Date:

## Acknowledgments

Firstly, I would like to thank all the participants who completed the survey which contributed towards this research. From our brief interactions on social media you have inspired me as a group who know no bounds. I would also like to thank the many individuals, friends, and organisations who kindly helped to disseminate the study advertisement.

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To my cohort, it has been a pleasure to share the despair, desperation, humiliation and elation every step of the way with you, let it long continue; and to my family and friends for creating a home in which I can think and grow.

Finally, to James. Thank you for joining me on a journey into madness; let's find our way out together. You are my greatest test.

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## Thesis Section One: Systematic Literature Review

## The identity-related experiences of elite athletes with physical impairments: A meta-

synthesis

Kimberley Keegan

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Division of Health Research

Faculty of Health and Medicine

Lancaster University

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Correspondence should be addressed to: Kimberley Keegan, Doctorate in Clinical Psychology, C14, Furness College Lancaster University, Lancaster, L1 4YG Email: k.keegan@lancaster.ac.uk

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#### Abstract

People with physical impairments are at risk of having devalued identities; what is unknown, is how elite athletes with physical impairments negotiate these challenges to identity. Subsequently, the aim of this review was to synthesise the identity-related experiences of elite-athletes with physical impairments. A systematic search of five databases (PsycINFO, MEDLINE Complete, CINAHL, SocINDEX, and Scopus) was completed. Themes were extracted and synthesised via established procedures for conducting meta-syntheses. Sixteen papers were identified which met the inclusion criteria. Two themes were identified: 'Sport facilitated valued identities' and 'The challenges to valued identities' associated with a social 'disability' identity. The review concluded that athletes used their role as elite athletes to tackle social stigma related to physical impairment; however, their actions also had the potential to inadvertently further stigmatise in-active individuals with physical impairments.

Keywords: physical impairment, disability, identity, elite-athlete, physical activity, sport

# The identity-related experiences of elite athletes with physical impairments: A metasynthesis

Physical impairments defined as "problems in body function or structure such as a significant deviation or loss" (The World Health Organisation; WHO, 2002, p. 10), can lead to changes in physical function, including reduced strength (Raya, Gailey, Fiebert, & Roach, 2010), decreased range of motion (Gaunaurd, Gailey, Hafner, Gomez-Marin, & Kirk-Sanchez, 2011), diminished sensation (Neumann, Wong, & Drollinger, 2005) and pain (Behr et al., 2009). Such factors have the potential to impede an individual's mobility and range of movement, however it is these factors combined with external social barriers and restrictions which limit access to employment, education, and the environments and activities they enjoy (Gallagher, O'Donovan, Doyle, & Desmond, 2011; Papworth Trust, 2016). These secondary activity limitations and participation restrictions associated with physical impairment are generally referred to as 'disability' (WHO, 2002). This differentiation will be maintained throughout this review, with a focus on how each may impact upon identity.

Identity has been conceptualised by several theoretical models. Cognitive accounts propose that identity captures a distinct set of meanings and values about the self, formed by past experiences (Markus, 1977), which help individuals organise and process new information related to the self (Luyckx et al., 2007). Whereas, narrative and biographical definitions refer to identity as an individual's internalised life story formed through an interaction between personal experience and dominant social discourses (Singer, 2004). Identity can also be considered as a definition placed on an individual or group (Baumeister, 2011). Together these theoretical positions demonstrate that understandings of the self are inextricably linked to past social experiences and in such a way identity encapsulates both the personal and the social (Carless & Douglas, 2013).

While physical impairment and 'disability' can be theoretically connected (e.g. Reeve, 2012), it is not the case that all individuals with physical impairments will selfidentity as 'disabled'; indeed, certain functional and cognitive changes may be viewed as part of the natural ageing process and may therefore not pose a threat to individual identity. However, it is the case that some individuals report the personal experience of living with physical impairment and 'disability' as a challenge to identity in both acquired and congenital differences (Pack, Kelly, & Arvinen-Barrow, 2016). With regards to physical impairments acquired later in life, participant accounts of adjustment describe the loss of previously held activities, traits and values considered central to their identity, leading them to feel as though they have become a different person (Sousa, Corredeira, & Pereira, 2009) and finding themselves asking the question: 'who, am I?' (Levins, Redenbach, & Dyck, 2004; Peers, 2012). People with congenital impairments, a term used to capture impairments present at birth (Correa-Villaseñor et al., 2003), have generally reported fewer, or less acute, challenges to identity in comparison to those with acquired impairments (Bogart, Tickle-Degnen, & Ambady, 2012). However, participants with congenital and acquired differences alike, describe difficulties associated with the way a'disabled' status is generally considered by others as abnormal (Valeras, 2010) or incompetent (Taub, & Greer, 2000).

These accounts highlight how acquired and congenital physical impairments are often perceived by society as a personal tragedy to be overcome by returning, as much as possible, to the physicality and identity of the non-impaired norm. Research indicates that people with physical impairments frequently experience negative and excluding reactions from others, which can lead to isolation, social discomfort, and the concealment of physical impairment (Murray, 2005, Sousa et al., 2009; van Amsterdam, Knoppers, & Jongmans, 2015). Reeve (2012) termed this effect *psychoemotional disablism*, whereby society may actively limit individuals with impairments through excluding direct (e.g. discriminatory comments) and indirect (e.g. inaccessible environments) social-relational interactions. In this way, 'disability' can be viewed as a dynamic interaction between the individual and the environment.

While social and relational barriers have emerged as the primary challenges to the maintenance of a positive identity in the context of physical impairment, psychological research has continued a limited focus on individualistic approaches to these issues (Simpson & Thomas, 2015). For example, models of adjustment to physical impairment (DeLoach & Greer, 1981; Gibson, 2006; Kerr, 1977; Liveneh, 1986; Vash, 1981) have focused on the protective value of accepting impairment-related information and incorporating this into identity. Acceptance within these models can be considered to refer to the individual's acknowledgement of their physical difference. The empirical evidence-base has further developed this theoretical standpoint by defining and researching the concept of a 'disabled' identity. Disability identity, measured as an individual's incorporation of impairment into their sense of identity and feeling of belonging to the disability community (Hahn & Belt, 2004), is believed to help individuals adapt to the challenges of impairment and disability (Bogart, 2014; Bogart, 2015; Dunn & Burcaw, 2013). By focussing on how individuals assign personal meaning to their impairment, these theoretical standpoints neglect to consider the wider social responses to a 'disabled' identity and how these may negatively impact upon the incorporation of impairment into identity.

Indeed, the above described process of empowered acceptance may prove difficult to achieve within a society that devalues individuals with physical impairments (Thomas, 2000). Approaches which conceptualise the 'acceptance' of impairment and 'disability' into identity have, certainly by advocates of the social model of disability (Reeve, 2012), been critically compared to medical understandings of impairment which conceptually assume that physical impairment and the psychological effects of disability are intrinsically linked (Supple, 2005).

#### IMPACT OF SPORT ON IDENTITY

Such approaches, in concordance with the medical approach, imply that it is the individual's responsibility to adapt to the psychological 'obstacle' of physical difference. This perspective can also be considered to guide the process of rehabilitation and psychological adjustment to physical impairment within health care services.

Psychosocial adjustment to physical impairment is currently guided by a process of multi-disciplinary rehabilitation, which aims to support individuals to be independently mobile, engage in the activities they enjoy, and integrate the personal meaning of their impairment into identity. Aspects such as physical activity, mobility and ambulation form an essential focus within the rehabilitation process, due to their contribution in assisting individuals to engage in social and physical activities. Engagement in physical activity can allow individuals with physical impairments to connect with others in a similar situation (Jeffress & Brown, 2017), develop supportive friendships (Martin, 2006), and reduce levels of anxiety and depression (Gioia et al., 2006). Improved health, fitness and strength may also support the use of prosthetic limbs and manually-powered wheelchairs (Bragaru, Dekker, Geertzen, & Dijkstra, 2011) and reduce the comorbid health-related risk factors related to certain physical impairments (Ryan et al., 2014). Such outcomes may all contribute towards enabling individuals to take part in valued social roles and activities, thereby enabling individuals to receive feedback on the aspects of their identities they value.

In addition to the way increased fitness and mobility may indirectly influence identity, evidence suggests that physical activity, and particularly participation in sport, may play a further role within the process of rehabilitation by alleviating the social and relational difficulties associated with a 'disabled' identity. Ashton-Shaeffer, Gibson, Autry, and Hanson (2001a) revealed that men and women with physical impairments used their experience at a sports camp to resist the expectations and stereotypes imposed on them by society. Similarly, participants described adaptive sports as a way to experience freedom

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from the socially imposed negative aspects of a disability identity, enabling the realisation that they could be defined by aspects other than their impairment (Lundberg, Taniguchi, McCormick, & Tibbs, 2011). Kissow (2015) described this as *disability management*, a process by which individuals challenged the negative stereotypical views of impairment at a personal level. Kissow (2015) found that sport played an integral role in this process by allowing individuals to demonstrate physical competence, enhanced bodily appearance, and an active lifestyle which enhanced a sense of control over their identity. Furthermore, sport allowed participants to develop an athletic identity which could offset the challenges of a disability identity by allowing individuals to be part of a valued community in which they felt empowered (Kissow, 2015). These findings suggest that participation in sport may facilitate individuals to actively challenge social stereotypes and reinforce positive aspects of a disability identity; thereby shifting the therapeutic focus from the revision of the actions and beliefs of the individual to change in the wider society.

Empirical data show that the positive effects of sport on identity increase with level of sport participation (Brewer, Van Raalte, & Linder, 1993; Perrier, Sweet, Strachan, & Latimer-Cheung, 2012) to the point where sport can become central to identity. *Athletic identity* has been defined as the extent to which an individual identifies with the role of an athlete (Brewer et al., 1993), and can be considered to include self-evaluative beliefs such as perceptions of whether other people view them as an athlete, the degree of reliance on their athlete role, and views about the self as an athlete, for example, in terms of competence and appearance (Anderson, 2004; Martin, Eklund, & Mushett, 1997). Athletic identity has been found to have multiple beneficial effects on the psychological wellbeing of individuals with physical impairments, including increased quality of life (Groff, Lundberg, & Zabriskie, 2009), reduced social physique anxiety (Martin, 1999), greater life satisfaction, and significantly lower depression (Tasiemski & Brewer, 2011). These findings suggest that

identifying as an athlete can support psychological wellbeing in the context of physical impairment.

This proposition may be supported by the growth in representation of the Paralympic and Invictus Games in the national media (BBC Media Centre, 2014; Paralympic Media Centre, 2017). The Paralympic movement has served to increase awareness around the potential for sport to transform the lives of those who take part (Blauwet & Willick, 2012), demonstrating the effects of sport beyond the known physical and health-related benefits. Athletes' personal narratives provide an affirmative view of what it means to be physically impaired; for example, one professional sitting volleyball athlete described their experience of the transformative nature of sport with the comment: "I am reborn" (Charalampos, Silva, & Kudlacek, 2015, pp. 38). Indeed, the reflections of Paralympic athletes (e.g. Peers, 2012) support the proposition that increased sport involvement allows for the development of more empowered and robust identities. Such accounts suggest that there are certain aspects unique to the practice of sport which may help individuals understand and shape their identities.

Subsequently, if holding an athletic identity is known to play an advantageous role in adapting to the challenges of physical impairment, and athletic identity increases with increased sport involvement, how might sport shape the identities of individuals classed as elite-level athletes? It could be argued that individuals competing at the Paralympian level have succeeded the purpose of rehabilitation by regaining, maintaining, and improving functional mobility, increasing their engagement in social activities and interests, and publicly acknowledging their identity as an individual with a physical impairment. With psychosocial approaches offering limited intervention for the impact of disability on individuals (De Silva et al., 2009), it may prove worthwhile to look to this group of experts by experience to understand the unique ways in which they manage the identity-related challenges associated with physical impairment.

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The exploration of personal experience and meaning attached to identity within a sporting social context lends itself to an inductive approach, whereby data is collected to generate new theory. Indeed, there has been an increasing number of inductive studies of athletic identity in elite athletes with physical impairments in the qualitative literature. However, these findings would benefit from being combined to allow for a deepened understanding of this phenomenon. The process of meta-synthesis allows for the integration of individual accounts across multiple samples and contexts, to deepen an understanding of a specific phenomenon (Walsh & Downe, 2005). Such methodologies are becoming increasingly used in health care research as a valid approach to inform policy and practice guidance (Toye et al., 2014). It is therefore hoped that by synthesising the qualitative experiences of individuals with strong athletic identities, more may be understood about the ways in which sport can ameliorate any negative effects associated with a disability identity. Further exploration of identity in this way may also facilitate a deeper critique of how psychological theory may be used to understand and provide interventions for identity-related difficulties experienced by people with physical impairments. Consequently, the research question was: what are the identity-related experiences of elite athletes with physical impairments?

#### Method

## **Systematic Search**

The following databases were systematically searched to identify eligible articles: PsycINFO, MEDLINE Complete, CINAHL, SocINDEX, and Scopus (see Appendix A and B for database search details and example of full electronic search strategy). Searches were completed according to pre-defined search terms (see Figure 1) which were reviewed by a specialist university librarian. Additional searches were conducted on Google Scholar and the reference lists of selected studies. Searches were completed on 16<sup>th</sup> October 2017. Following the search process (see Figure 2) 16 studies were identified as suitable for inclusion in this review.

# [INSERT FIGURE 1]

## [INSERT FIGURE 2]

## **Eligibility Criteria**

To explore the research question, essential study inclusion criteria were defined as: (1) written in English language; (2) published in a peer-reviewed journal to ensure a minimum level of quality; (3) utilised qualitative approaches to collect data and inductive methods of analysis; (4) the sample consisted of adults (18 years and over) with physical impairment; (5) the sample consisted of elite athletes, defined as competition at Paralympic or national/international level, or participation at competitive level sport for minimum duration of two years; (6) first person accounts of athlete experience were provided; (7) study results included key thematic areas within which the experiences of identity or self-concept were explored in further depth by the authors. Charalampos et al. (2015) is an example of a study that was excluded on criteria number seven; while this study explored athletes' experiences of 'disability', the results were not conceptually explored with relation to identity. Studies were excluded if: (1) data included coach/family accounts, or experiences of people without physical impairments; (2) the sample included a majority of non-elite athletes. **Critical Appraisal** 

The Critical Appraisal Skills Programme qualitative checklist (CASP; 2017) was utilised as a framework for assessing the quality of the included papers. To apply the framework, a three-point scoring system was used as described in Duggleby et al. (2010). The system allocates a score to indicate whether studies: (1) lack evidence relating to the relevant quality criteria; (2) show partial evidence; or (3) meet the full criteria. Studies were screened independently by the lead author; where the relevance of a study was in doubt, a second reviewer was consulted. Study scores ranged from 11 - 23 out of a possible 24 points. The included studies demonstrated generally higher scores for criteria including research design and data collection however achieved lower points for reflexivity and ethical issues. Table 1 demonstrates the included study CASP scores.

## [INSERT TABLE 1]

There is mixed consensus regarding the quality assessment of qualitative studies (Campbell et al., 2011; Toye et al., 2014), which is in part, based on the variety and subjectivity of available appraisal tools and included criteria. To use appraisal scores to exclude studies would potentially bias certain methodologies and on this basis, studies were not excluded from inclusion based on their quality score. Instead, a process of sensitivity analysis was adopted, in which care was taken to ensure meta-synthesis themes were represented by studies which covered the full range of CASP scores (for a review of this method see Carroll & Booth, 2015).

Following the critical appraisal process, two studies (Le Clair, 2011; Wickman, 2007) were identified as evidencing poorer quality, however it is important to note that this related to the reporting quality of the study as opposed to the quality of the research being conducted. For example, there were differences between studies in whether they reported participant demographics as some authors withheld detail to protect participant anonymity. One article (Wickman, 2007) did not contribute to the production of theme data as much as the others however this was due to the study method (discourse analysis) meaning not all data was appropriate for the review epistemological position. All 16 studies contributed towards the third-order constructs, with no study contributing disproportionately.

## **Data Analysis**

The meta-synthesis was conducted adopting Noblit and Hare's (1988) metaethnographic approach, which has been adapted for health research (Britten et al., 2002). Through a process of translating studies into one another, meta-ethnography aims to develop new interpretations and insights from independent studies of comparable topic and method (Shaw, 2012). To complete the translation, studies are treated as primary data with participant accounts providing first-order constructs<sup>1</sup> and study author interpretations forming second-order constructs. Within this review, sentences, phrases and quotes deemed relevant to the meta-synthesis research question were extracted from each study's results and conclusions section and entered in to a conceptual grid (see Table 2 for an excerpt of this grid) which adopted the same format as the grid utilised by Britten et al. (2002, p. 212). Once the study data were deconstructed in this way, data were coded line by line and then manually rearranged and grouped according to common and recurring content. These groupings formed key concepts (a combination of conceptually grouped first and second order constructs) deemed to be relevant to the research question. Subsequent studies were coded into pre-existing concepts and new concepts were created when deemed necessary. Data were used more than once if they were considered to relate to more than one key concept.

#### [INSERT TABLE 2]

At this stage, a process of reciprocal translation (Noblit & Hare, 1988) was performed, whereby the key concepts were used as a framework to return to the original selected studies to review whether any data had been missed or could contribute further to an understanding of a key concept. The key concepts were then considered, in line with the meta-synthesis research question and study second-order interpretations, to develop the synthesis interpretations (third-order constructs), thereby producing an "interpretation of an interpretation of an interpretation" (Noblit & Hare, 1988, p. 35). Noblit and Hare's (1988) three forms of synthesis include: reciprocal, where concepts easily encompass one another; refutational, where concepts are contested across papers; and line of argument, where

<sup>&</sup>lt;sup>1</sup> See Malpass et al. (2009) for further definition of these constructs

concepts relate to different aspects of a wider phenomenon, and a more comprehensive understanding may be created by arranging study themes to construct an overall argument (Shaw, 2012). The line of argument analysis was completed by reorganising key concepts in a third-order construct grid (see Table 3 for an excerpt of this grid) with use of a *conceptual map* (Figure 3), such as the one included in Malpass et al. (2009), to visualise how third-order constructs were related.

#### [INSERT TABLE 3]

## **Characteristics of the Selected Studies**

Information about the included studies can be found in Table 4. Study publication years ranged from 2001 - 2017. Samples were comprised of British, Canadian, American, Taiwanese, South African, Swedish, Moroccan, Turkish, Romanian, Iranian, and Yemeni participants. Participants took part in a range of individual and team sports. Where reported, male participants formed the slight majority (female, n = 75; male, n = 84). The included samples were predominantly comprised of elite athletes currently or previously competing at Paralympic, international and national levels. One study (Hardin, 2007) included one participant who was described as non-elite, however was recruited from a workshop for aspiring national-level athletes, and one study included five development-level athletes who were classified as having "less than 2 years playing experience and/or had competed in few national tournaments" (Richardson, Papathomas, Smith, & Goosey-Tolfrey, 2017, p. 194). As these participants did not form the majority within their respective studies, the articles were included in the review. Where reported, people who had acquired physical impairments later in life comprised the majority of the combined sample (n = 105); participants within the included studies who experienced difference from birth or in the early stages of life (n = 58)were defined as having congenital differences (e.g. cerebral palsy; Hardin, 2007).

## [INSERT TABLE 4]

The majority of the included studies (n = 15) collected data via semi-structured interviews; within this, two studies reported utilising a life-story approach (Day, 2013; Smith, Bundon, & Best, 2016) and four adopted a narrative approach (Day & Wadey, 2016; Huang & Britten, 2006; Kavanagh, 2012; Swartz et al., 2016). Goodwin et al. (2009) collected data via focus groups. Four studies (Ashton-Shaeffer, Gibson, Holt, & Willming, 2001b; Day, 2013; Le Clair, 2011; Smith et al., 2016) supported the interview data with researcher observation notes. All the included studies adopted a form of inductive thematic analysis, including grounded theory, narrative thematic analysis, content analysis, and phenomenological analysis. Study methodologies were inferred to originate from a critical realist epistemology. This framework acknowledges that the language used by participants represents their 'truth' (Maxwell, 2012), and may therefore be used to understand their inner attitudes, beliefs, and experiences relating to the objective reality of living with a physical impairment. One of the included studies (Wickman, 2007) cited a method of discourse analysis. While this approach would be considered to adopt a constructivist stance, the study described "an attempt to fully investigate the experiences and representations of the wheelchair racers and their multiple identities" (Wickman, 2007, p. 155). On this basis, the study was included however only data relating to experiences, meanings, and beliefs were included, while data pertaining to constructions or positions within discourse were not included in the data synthesis.

#### Results

The synthesis produced 20 key concepts which were arranged into two overarching third-order themes, comprised of three subthemes each. For a visual representation of how synthesis themes were represented across studies see Table 5.

#### [INSERT TABLE 5]

#### **Theme 1: Sport Facilitated Valued Self-Identities**

In all of the included papers, participants discussed the ways in which sport facilitated valued self-identities. Sport allowed participants to pin their dominant identity to that of 'athlete' which held positive personal and social meaning. Athletes then incorporated physical impairment and 'disability' into their athlete identities in personally meaningful ways. This provided a sense of control over how participants saw themselves, and sought to project themselves to others. Three subthemes captured how participants incorporated physical impairment and 'disability' into their identities in personally meaningful ways.

## Subtheme 1.1: Athlete as a dominant identity.

Being an elite athlete was an empowered identity and was influential in many participants' sense of self. Participants primarily saw themselves as athletes, which was often regarded as their dominant identity; for example, Li-li explained how her identity as an athlete was positioned above other self-identities: "being an elite powerlifter is my major identity, definitely" (Huang & Brittain, 2006, p. 365), while Max asserted his preference to adopt a single identity as an athlete: "I'm not a disabled sportsman... I am simply a sportsman" (Wickman, 2007, p. 162). This contrasted with other accounts which referred to multiple coexisting identities; as Juen-juen described: "I think I am not just a disabled person. Sometimes I am an athlete. I am also a wife, a mother. I have different identities, which depend on what situations I am in" (Huang & Brittain, 2006, p. 364). It seemed that for Juenjuen sport facilitated the perspective that identity could shift in different situations which may have enabled the fulfilment of other important societal roles.

## Subtheme 1.2: Evolving identity: Moving from incompetence to competence.

Pinning their dominant identity to that of athlete allowed the focus of participants' identities to shift from incompetence to competence. As Tony described, through participation in swimming he could be defined by his functional ability as opposed to his

physical difference: "so I was known as the swimmer and not that kid with the disability" (Pack et al., 2016, p. 2065). This allowed participants to aspire to and compete with a nonimpaired standard: "my victory was that I could compete in able-bodied competitions" (Day & Wadey, 2016, p. 134); adopt the same norms as able-bodied athletes, such as holding performance goals and considering sport as critical to daily life (Spencer-Cavaliere & Peers, 2011); and, in some cases, outperform able-bodied rivals: "I could play tennis better than they could" (Richardson et al., 2017, p. 197). Through the demonstration of ability and competence, impairment became "far less obvious and, according to some participants, invisible and irrelevant" (Spencer-Cavaliere & Peers, 2011, p. 304) to their sense of self; as one participant described the moment in sport where: "you just get so caught up in everything that you forget you're disabled" (Day, 2013, p. 2069). This occurred to the point where participants did not consider their impairment as central to their sense of self and as such their identities became "disembodied" (Pack et al., 2016, p. 2065).

## Subtheme 1.3: Sport as a path to agency.

In all cases, it seemed participation in sport facilitated a sense of agency whereby participants could "reclaim their body from the rights of public scrutiny" (Pack et al., 2016, p. 2067) to rebuild or strengthen a valued sense of self. The personal control, responsibility, and risk-taking involved in sport allowed individuals to assert control over the way they saw themselves, and sought to portray themselves. Participants felt that it was their commitment to sport which defined them as athletes: as Heather said: "hopefully people will recognise us as elite athletes, that we do put the training in" (Ashton-Shaeffer et al., 2001b, p. 16). This was echoed by other participants who felt that it was not their level of sporting ability which defined them as athletes but their commitment to training, physical discipline, team membership, and passion for sport. In this way an athletic identity was accessible to all individuals who were perceived to want it, as evident in Michaela's description of the desired

attitude of swim team members: "...we have had a few people along the way, they were like I've got a disability, you owe me something, and it was like no, kind of go away, you're here to work, you're here as a swimmer" (Pack et al., 2016, p. 2066).

However, there were also aspects related to the competitive sport environment which required participants to relinquish control. To enter the realm of 'disability' sport, individuals must be classified and categorised as 'disabled' and, in that sense, are required to formally and publicly accept herself or himself as disabled (Wickman, 2007). While this presented a challenge to individuals who do not wish to self-identify as disabled, this requirement enabled the acceptance of physical impairment while maintaining a valued identity as an athlete, as one female swimmer described: "...it was an element that I struggled with because in order to participate in Paralympic sport you have to first say I have a disability... I'm an athlete first and I happen to have a disability" (Le Clair, 2011, p. 1124). Furthermore, athletes' impairments were often required, by the nature of the sport, to be visible in the competitive sporting environment, particularly in sports such as swimming (Pack et al., 2016). However, authors considered that the visibility of impairment in sport facilitated an acceptance of difference and of being seen by others (Swartz et al., 2016). Participation in sport also served to highlight individuals' physical limitations, leading them to be more aware of what they could not do. While these initial hurdles were often experienced as uncomfortable or challenging for participants, they also served as important turning points (Day, 2013), as through accepting limitations participants could focus on their physical abilities. One individual described how sport helped them to overcome the personal loss attached to an acquired impairment: "you have to learn to get over that and still learn how to do things without that" (Hull Garci & Mandich, 2005, p. 172). Overall, the presence of these environmental challenges in competitive sport, meant that participants had "very

little chance... to avoid incorporating their impairment into sport identity" (Huang & Brittain, 2006, p. 367).

#### **Theme 2: The Challenges to Valued Identities**

Within participant accounts across all the papers, the valued aspects of identity which sport served to strengthen were challenged by societal conceptions of impairment. This theme included the conflict experienced between athletes' self and social identities and the resulting challenges directed at societally held stereotypes.

## Subtheme 2.1: The experience of social stigma.

Participants described negative meanings attached to a disabled identity, as one participant explained: "I don't see myself as disabled... I don't like that word. It's a very disgusting word... I believe that word puts people down, makes their self-esteem low" (Le Clair, 2011, p. 1120). Participants felt that sport provided a way out of the "disability ghetto" (Hardin, 2007, p. 46) where individuals with impairments were perceived as socially isolated and flawed. By identifying as an athlete, participants could be viewed as more 'able'; in this sense, participants felt that sport created "hierarchies of disability" (Wickman, 2007, p. 163). For example, in performing, what author's termed "downward comparisons" (Day & Wadey, 2016, p. 134) between themselves and others with similar impairments, participants sought favourable perspectives on their level of ability. This was evidenced in the way participants described themselves as "able-disabled" and in the "upper echelon" of disability (Hardin, 2007, p. 46). This could evolve to the point where participants differentiated themselves from other individuals with impairments, for example, David, who sought to distance himself from other people with impairments said: "they were really disabled and I was not" (Day & Wadey, 2016, p. 135).

This manifested in participants contrasting their experiences of agency with perceptions of people with impairments who were "sloppy or overweight" (Hardin, 2007, p.

46) and out to get "disability grants" (Swartz et al., 2016, p. 39). Within this social process, authors perceived there was the potential for the actions of athletes to indirectly reinforce the social view of impairment they sought to challenge. Subsequently, in their pursuit of the non-impaired athletic standard, athletes with impairments were sometimes viewed by non-active individuals with impairments as ascribing to the 'able-bodied' ideal, e.g. "Oh, they're trying to be more able-bodied" (Hardin, 2007, p. 47). This occurred alongside a strong affinity and shared identity felt between athletes, which authors described as providing a sense of belonging and connection to other individuals with impairments, emotional security, and a safe haven from society's 'pity'.

Participants directly acknowledged the difference between self-identities, how they saw themselves and sought to project themselves, and social identities, how they believed others saw them; as Susan a 24-year old Paralympian explained: "I like to think of myself as an athlete first. I know that people don't see it that way, but me, personally, I think of myself as athlete first" (Hardin, 2007, p. 44). There was variation in the degree to which participants felt social identities impacted on their own self-identity. Some participants felt their self-identity was only partially influenced by external perceptions, particularly if their impairment could be concealed; as Edna reported: "I really don't know where my identity lies... Even though I'm disabled, I put on a pair of jeans and walk around and people have no clue" (Hardin, 2007, p. 45).

On the other hand, many participants felt that negative stereotypes of disability, such as weakness, inferiority and lack of ability, were more influential than their own selfperceptions. In some cases, participants alluded to the fact that having an impairment meant having an identity of being less than human; as one Taiwanese participant said: "I was nobody... as a disabled person" (Huang & Brittain, 2006, p. 365), with another participant expressing the difficulty he felt in being visible in society: "they don't understand that we also exist" (Swartz et al., 2016, p. 39). Sport provided a threshold for these participants to enter personhood by allowing them to be seen and acknowledged as people. While this was often framed as a positive experience, Robert's response indicates how stereotypical views of impairment may be internalised by individuals with impairments: "through sport I have realised that disabled people are people" (Swartz et al., 2016, p. 39).

## Subtheme 2.2: Challenging the social meanings of disability.

It was through athletic participation and identification that participants could begin to resist and challenge the social barriers, oppression and stigma associated with having a physical impairment. On a group level, resistance occurred when participants challenged societal stereotypes of impairment, as passive, sedentary, and fragile. This was achieved by expressing alternative characteristics, as powerful, strong, and competitive, as captured by one wheelchair rugby athlete: "When you think of a wheelchair 'oh so fragile' and we beat the living snot out of each other" (Goodwin et al., 2009, p. 112). However, resistance also occurred on an individual level, whereby participants used sport to resist external notions of disability from defining their self-identities. Sipho described how his identity as a physically competent athlete enabled him to reappraise his difference and challenge disablist attitudes: "You know, sometimes I can tell myself that if these people tell me about my self-image (that I am disabled), I can actually tell them back, 'No! What, what, what?' Now I just say, 'That it's my (ability)'" (Swartz et al., 2016, p. 37).

Some participants used their identities as athletes to reject the social meanings attached to disability. Participants favoured their athlete identity to the point where some authors felt it "over-powers a disability identity" (Richardson et al., 2017, p. 198) and played a role in off-setting the stigma associated with having a physical impairment. As one female athlete explained, her commitment to sport meant she wanted to be seen as an athlete not as "disabled": "I think of myself as an athlete, not as a woman, certainly not as disabled" (Smith et al., 2016, p. 142). By rejecting the meaning attached to a disability identity, participants could accept their physical impairment as part of their sense of self without subscribing to the idea that their impairment was detrimental their physical competence. Subsequently participants "did not deny their impairment but their identities were not completely determined by it" (Huang & Brittain, 2006, p. 360). Impairment was then incorporated into athletic identity in a way that participants found empowering, one swimmer stated: "I don't perceive myself as disabled... I just happen to have one leg" (Le Clair, 2011, p. 1125).

This contrasted with participants who spoke of a disabled identity in an empowered way. Some participants found their status, as an individual with an impairment, validated through sport and therefore personally meaningful. One participant, Mark, described an affirmative identification to 'disability': "I'm disabled, and that defines me. I'd describe myself as a disabled athlete, in that order. I'm an athlete, for sure. But I'm more than an athlete. I'm first and foremost a disabled person" (Smith et al., 2016, p. 142). In this way Mark believed disability was political and therefore in choosing to identify as someone who is 'disabled' he could project an affirmed connection with other individuals with impairments and counter negative perceptions of disability. Identifying primarily as someone with a disability, allowed for the development of another empowered identify, that of a political activist. The individuals interviewed by Smith et al. (2016) who identified as disabled athletes also identified as political activists. These individuals used their status as elite athletes to bring disability rights to public attention; as Mark went on to say: "If I can use my identity as an athlete to help change things, I will and do. I'm proud of being an athlete, and have a very strong identity as a political disabled athlete too" (Smith et al., 2016, p. 142).

## Subtheme 2.3: Gender: Simultaneous marginalisation.

Interestingly, every study with a majority or all female sample included data relating to the challenge of maintaining valued identities. Women reflected that despite holding empowered identities as athletes, they experienced simultaneous oppression from the stigma associated with their impaired status and deflated social status of gender within the sporting environment. As one female basketball player said: "Because you're a girl, you have to prove yourself before they'll [men] play with you" (Hardin, 2007, p. 49). On occasion, it appeared the lower social ranking of women within adapted sport led them to adopt male identities, as a female athlete described: "I think I became rather laddish in some way" (Wickman, 2007, p. 160). In some cases, this seemed to be a conscious approach employed in an effort to be seen as equal to men: "Yeah, I am going to be a lifter in a competition. I am going to be equal to men.' And then I can dress up tonight and look feminine" (Huang & Brittain, 2006, p. 363). However, in other cases it seemed the adoption of masculine identity was an unwanted consequence of the male dominated environment; as Anna reflected: "It might have to do with being together with only guys, they are much harder and tougher, so I became like them in some way" (Wickman, 2007, p. 160).

Both female and male participants described using sport to achieve fit and toned bodies. For example, males felt that sport supported their desire to maintain a masculine image: "I think doing powerlifting... it proves my masculinity" (Huang & Brittain, 2006, p. 362). However, for females there was a line between looking fit and looking masculine, as one female wheelchair basketball player explained: "I just want to be fit, and I definitely wouldn't want to be mannish" (Hardin, 2007, p. 48). Females were aware their participation in sport could make them look masculine, for example by increasing muscle tone in their arms and neck. They therefore made efforts to achieve the feminine ideal outside of the sporting environment; as one female stated: "Off the court, I want to be perceived as feminine" (Hardin, 2007, p. 49). It therefore seemed that women struggled to maintain valued identities within the context of their status as an individual with an impairment, their deflated status as a female within the sporting environment, and the imposition of the feminine ideal.

#### **Third-order Analysis**

To complete the analysis the above themes were conceptualised in a third-order conceptual diagram (Figure 3) which demonstrates a line of argument synthesis for a model of identity. The diagram demonstrates how individual understandings of identity, formed within the context of elite sport, interacted with social views of disability identity to facilitate activism.

## [INSERT FIGURE 3]

## Individual understandings of identity.

Participation in sport facilitated the expression of valued identities for individuals with physical impairments. While there were differences in how self-identities were defined, all participants described positive associations with the role of athlete, which enabled the verification of ability-related self-concepts. The confidence to assert agency over selfdefinition appeared to develop alongside participants' confidence in regaining control over their bodies.

## Social views of disability.

Despite this apparent freedom to reaffirm and strengthen valued parts of themselves, elite athletes were not immune to the influence of societal notions of an impaired or disabled identity. The stigma attached to a disability identity was evident in the way participants experienced this identity as limiting and restrictive, but also in the way they compared themselves to other people with impairments who were not active. Athletes often engaged in a process of 'othering' (Tajfel & Turner, 1979) whereby they made downward social comparisons between themselves and in-active individuals or athletes with more severe impairments. In doing so, athletes served to create distance between themselves and other individuals with impairments, inadvertently reinforcing a disablist attitude and potentially marginalising individuals with impairments who are not active. Subsequently, through stigma elite athletes were oppressed by, and contributed towards, discriminatory ideas of disability.

#### Activism.

However, it was also evident that sport facilitated athletes to actively challenge societal understandings of what it means to be physically impaired. Participants found many opportunities within the sporting environment to demonstrate alternative attributes including physical robustness, competitiveness, strength, and competence. Through this, participants questioned the need to self-identify as 'disabled' or be solely defined by their impairment. This led athletes to use their identity as an elite athlete to empower others and politically address disability human rights issues. Despite the finding that many athletes did not selfidentify as activists, a common interpretation between study authors was that all athletes were engaged in indirect activism through their pursuit of an alternative affirmative identity.

#### Discussion

The findings demonstrate the positive transformation sport provided for individuals who have been subject to a social 'disability' identity, facilitating a context where alternative identities from that of 'disabled' could be explored and enhanced. However, this process occurred in relation to simultaneous societal oppression and stigma as captured by the third order model. This discovery echoes the idea postulated by Foucault (1979): "where there is power, there is resistance" (p. 95), which will be used to form the framework of this discussion. This reference describes how acts of power, in this case the social view of impairment, lead to resistance among the disempowered, which in the context of this review occurred alongside the expression of valued identities.

#### **Social Views of Impairment**

Traditionally, the medical model has conceptualised society's view of physical impairment as a deviation from the norm, thereby contributing towards the understanding of physical impairment as a loss or personal tragedy (Hargreaves, 2000). In the case of these elite athletes, their access to valued interests and meaningful identities was not limited by their physical difference; however, it remained the case that their identities were limited by societal responses to their impairment. This can be considered in line with previous findings which have highlighted how people with impairments feel they have, or are treated as though they have, lesser, spoiled or sub-human identities (Campbell, 2008; Peers, 2012; Sousa et al., 2009). In contrast to the medical view of disability, these findings support a social model of disability (Oliver, 1983) which proposes that it is the societal understanding of disability, rather than the physical difference itself, which leads to discrimination and shame felt on behalf of the individual. This certainly captures the sentiments of these athletes, who despite holding multiple ability-related self-concepts, still felt that society viewed them as disabled.

Due to the limits of societal labels and ascriptions, individuals with impairments often have a limited range of identities from which to choose (Riddell, Baron, & Wilson, 2001). However, sport facilitated a sense of agency over identity enabling participants to resist dominant social norms. Agency has been an important concept to emerge from research exploring narrative identity: an individual's internalised life story (Singer, 2004). Within such research, agency is conceptualised as the degree to which individuals are able to affect their own lives and the environments around them (McAdams & McLean, 2013). Furthermore it is this abilty to influence which helps maintain a coherent self across time (Adler, 2012).

Despite this, participants remained limited by the range of identities they felt they could own. It seemed this was not only influenced by social understandings of 'disability'

but also related to gender norms. Within this review, males felt a pressure to pursue masculine body norms, while females expressed a resistance to adopting a masculine image. Research with individuals taking part in non-elite physical activity also found that males believed sport enabled them to fulfil important masculine roles such as driving a car, raising children and providing income (Rattray, 2013), and women predominantly used exercise to pursue the image of the feminine body ideal (Guthrie & Castelnuovo, 2001). These findings, considered alongside the findings from this review, indicate that participation in sport may be influenced by both disability and gender social identities.

Furthermore, cross-cultural differences may have also influenced the social responses to physical impairment described by athletes in the included studies and may therefore have shaped the value of participation in sport. For example, Richardson et al. (2017) found that athletes from developing countries (e.g. Yemen and Romania) particularly valued the social aspect of wheelchair tennis because it provided the opportunity to gather information about medical treatment options. Whereas participants from a Canadian team (Goodwin et al., 2009) emphasised the importance of strength in numbers. The majority of the included studies recruited participants from countries including Britain, America and Canada, and therefore the findings may be particularly influenced by a Western approach to physical impairment and sporting identity. However, it is interesting to note that the themes developed within this review were shared by studies who recruited participants from Eastern (e.g. Huang & Brittain, 2006) and Southern (e.g. Swartz et al., 2016) countries.

## Resistance

It was in the presence of discriminatory attitudes, experienced through stigma, that athletes began to resist and challenge commonly held views about impairment and disability to take back control of their self-identities. The concept of resistance has been supported by research into the experiences of individuals taking part in non-elite sport. Ashton-Shaeffer et

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al. (2001a) interviewed adults with physical impairments who had attended a summer sports camp. After participation in the activities at the camp, participants expressed an increased feeling of entitlement to taking part in physical activity which they felt countered the pervasive attitude among a non-impaired society that they should remain sedentary and dependent. In such a way participants felt able to challenge disempowering comments made by individuals without impairments, which included one of the coaches at the camp. Similarly, participants taking part in non-elite physical activity saw their involvment as a way to break social stereotypes (Jeffress & Brown, 2017) and prove their physical competence to non-impaired peers (Anderson, 2009). The consistency between the accounts of elite and non-elite athetes suggests that physical activity at varying levels can provide the opportunity for individuals to challenge conceptions of impairment and resist these attitudes defining identity at a personal level.

Interestingly, through resistance participants also engaged in social practices which inadvertently served to reinforce stigma. With regards to chronic illness and physical difference, sociological models (e.g., Parsons, 1951) propose that illness disrupts the functioning of society and therefore while those who are 'sick' may be exempt from their usual social roles and responsibilities, they should attempt to 'recover' by seeking support. Subsequently, people who are perceived to adopt the 'sick' role, may be discriminated against by 'functioning' members of society. The findings from this review demonstrated how athletic activity provided a way for athletes to portray themselves as 'deserving' and making concerted efforts to 'function' in society. However, within this social process there was the potential for the actions of athletes to indirectly reinforce the social view of impairment they sought to challenge, leading to marginalisation of non-active individuals.

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## **Valued Identities**

While most of the participants in the included samples rejected the term 'disabled', and othered people whom they viewed as being 'disabled', this did not prevent them from integrating impairment into their self-identities. Athletes incorporated impairment into their identity in such a way that they were not solely defined by it, a finding echoed in research looking at the effects of sport for those participating at a non-elite level (Lundberg et el., 2011). It was this process which appeared to harness the potential of athletes with physical impairments to positively challenge and change societal notions of 'disabilty'. With the personal agency sport provided, athletes could choose how they identified with their impairment. For some, this included identifying as an athlete 'with one leg', for others they chose to adopt a disabled athlete identity in order to bring disabilty rights to public attention. Subsequently, the potential for individuals to positively impact societal views of disabilty through indirect or direct activism did not appear to be limited to the language used to define their identity.

## **Clinical Implications**

Based on the findings of this review several clinical implications were identified which will be relevant to professionals working with individuals with physical difference in health care settings. Firstly, the findings evidence the importance of identifying and validating negative discriminatory responses to individuals with physical impairments and the ways in which they affect identity. Support should be provided to enable individuals to separate societal understandings of 'disability' from identity to allow for an exploration of how they personally would like to incorporate impairment into their own identity. This may be achieved by enabling a sense of personal agency; healthcare providers can be guided by the individual's understanding what constitutes a valued identity for them as opposed to focussing on how the limits of physical difference and societal responses may define them.
Individuals may also benefit from being supported to engage in indirect and direct activist activities, such as sport, which seek to challenge dominant ideas about impairment.

It is hoped this review will increase knowledge around the positive psychological effects of engagement in physical activity and sport for people with physical impairments. While this review has identified several challenges, which may be encountered in participation in sport, it can be concluded that overcoming these challenges can lead to the development of a valued identity which incorporates affirmative personal meaning attached to physical impairment. In such a way it is important for healthcare providers to acknowledge both the personal challenges that may arise alongside physical impairment, such as pain and functional limitations, as well as the personal opportunities which may accompany physical impairment, such as developing an affirmative disabled identity and being a role model to others.

# **Strengths and Limitations**

This review identified several key identity-related opportunities and challenges individuals with physical impairments experience through participation in elite-level sport. Furthermore, the findings revealed the similarities and discrepancies in how these elite athletes negotiated challenges to identity to produce a model of identity. The application of a meta-synthesis approach allowed for the synthesis and contrast of these experiences across different demographic samples, sporting environments, and study methodologies, providing support for the validity of the developed key concepts. Claims of generalisability cannot be proposed for the general population of individuals living with physical impairments, yet the findings may be used to further understand the impact of societal notions of 'disability' upon valued identities.

By focussing on elite athletes, this review runs the risk of contributing towards the view that elite-level participation is necessary to develop affirmative identities. This

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understanding may implicitly exclude individuals who do not take part in sport. Similarly, a focus on Paralympic-level participation within the media may contribute towards individuals with impairments being held to an unrealistically high athletic standard, which may further impact on their inclusion within recreational sport. The findings demonstrate the value of sport in the expression of meaningful identities. It is important that this knowledge is made available to all individuals who experience physical difference regardless of how active or in-active they present.

# **Future Research**

Currently, the focus within clinical health care practice is on individual adjustment to societal restrictions and attitudes to physical impairment. Future research may benefit from further exploration of how social responses to physical impairment, disability, and gender may be challenged by those who feel disempowered by such labels. Research into the relationship between individual and societal experience of these identities may illuminate where efforts may be best focused in the pursuit of supporting individuals with physical impairments to hold valued identities. It may also be insightful to compare the experiences of females with physical impairments participating at elite-level, and those exercising for health reasons, to understand how females interact with gender-specific psychological barriers to developing athletic identities.

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Physical	amput* OR physical disability OR physical impairment OR prosthe* OR
impairment	wheelchair*
search strand	
	AND
Qualitative	identit* OR self* OR experience* OR attitude* OR view* OR interview*
search strand	OR perception*
~ 1	AND
Sport search	sport* OR disabled athlete OR athlete* OR paralympi* OR elite athlete*
strand	

**Tables and Figures** 

Figure 1. Search strategy adopted for meta-ethnography.



Figure 2. PRISMA diagram of search process.

Study	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value	Total
Ashton-Shaeffer et al. (2001b)	3	2	3	1	1	3	2	2	17
Braye (2016)	3	1	2	1	1	2	3	2	15
Day (2013)	3	2	3	3	3	3	3	3	23
Day & Wadey (2016)	3	3	3	2	3	3	3	3	23
Goodwin et al. (2009)	2	2	3	1	2	3	3	2	18
Hardin (2007)	1	2	3	3	3	2	3	3	20
Huang & Brittain (2006)	2	3	3	1	1	3	3	2	18
Hull Garci & Mandich (2005)	2	2	3	1	3	2	2	2	17
Kavanagh (2012)	3	2	3	1	2	2	2	2	17
Le Clair (2011)	2	2	1	1	1	1	2	1	11
Pack et al. (2016)	2	2	3	3	2	3	3	2	20
Richardson et al. (2017)	3	3	3	2	2	2	3	3	21
Smith et al. (2016)	2	3	3	2	2	3	3	3	21
Spencer-Cavaliere & Peers (2011)	2	2	3	3	2	3	3	3	21
Swartz et al. (2016)	2	2	2	1	3	2	3	3	18
Wickman (2007)	2	1	2	1	1	2	2	2	13

Table 1: CASP critical appraisal of study quality

Note. Weak/lacking evidence = 1; Moderate/partial evidence = 2; Strong/meeting full criteria = 3

Table 2:	Excerpt	of Kev	Conce	pts Grid

1	<u> </u>	Ashton-Shaeffer et al.,			
Key concept	Key concept summary	(2001b)	Braye (2016)	Day (2013)	Day and Wadey (2016)
Athlete identity	Sport appeared to encourage the development of an identity based on the role of athlete which was often regarded as having master identity status; self-identities were most often perceived as athlete; differences in where athlete was placed in identity hierarchy; all participants described a positive association with the athlete identity; social barriers could make acquiring an athletic identity difficult; athlete was an empowered identity	The women felt empowered in their lives as elite sport affected their identity, Cassie explained how being an athlete was a major part of her identity: "It means a lot. It has to do with my identity. I'm an athlete"	Brian preferred the term 'athletes with disabilities', because it highlighted, for him, that Paralympians should be seen as athletes first and disabled second.	All participants identified themselves to be successful athletes.	This sporting ability contradicted his early beliefs after the trauma and made him consider what might be possible. Thus, his story of positive accommodation focuses on an emerging belief in his potential as a disabled athlete. Perrier et al. (2014) proposed that a strong attachment to past definitions of sport can lead to a plot that limits the (re)development of the future self as an athlete.
Explanation/theory (second-order interpretation)		Involvement in sport enabled the women to regain control over their bodies and establish an identity based on athlete not disabled, in this way they were able to resist the stereotyped expectations associated with their disability and feel empowered	Ente athletes who do not identify as activists may contribute to equality for people with disabilities by indirectly challenging socially constructed barriers	Participation in sport can facilitate positive accommodation and the emergence of a disabled athlete identity; or enable individuals to recapture previous athletic identity using previous definitions of sport, physical activity and identity (recovery)	w neelchair rugby provides a psychological sense of community; identification with "we" makes the community more than the sum of its parts and creates the possibility of growth, transformation, exploration of alternative identities and expresses the power of bidirectional influence between the individual and the group

Note. Key concept = combination of conceptually grouped participant quotes and study author interpretations; second-order interpretation = study author interpretation

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# Table 3. Excerpt of Development of Third-order Construct Grid

Key concept	Key concept summary	Second-order constructs	Third-order constructs
Athlete identity	Sport appeared to encourage the development of an identity based on the role of athlete which was often regarded as having master identity status; self-identities were most often perceived as athlete:	Athletes acknowledged that 'disabled' identities result from social prejudice and discrimination and therefore	Athletic participation allowed for the expression of valued identities.
	differences in where athlete was placed in individual identity	questioned the need to self-identify as	
	athlete identity; social barriers could make acquiring an athletic identity difficult; athlete was an empowered identity.	disabled. Sport provided a way out of identifying as 'disabled' by allowing individuals to pin their dominant identity on that of athlete.	
Redefinition	Sport allowed for redefinition of identity and reframing of impairment; participants described new life meanings associated with their disability; sport presented the opportunity to define their identity beyond their impairment; through sport participants could reclaim their body from the rights of public scrutiny to develop a holistic self-concept which transcended negative stereotypical beliefs.	Participation in sport facilitated personal meaning making and assisted individuals to accept their physical impairment and limitations and realise future possibilities by providing an environment where risks and responsibilities could be taken.	
Embracing ability	Sport allows the focus of participants' identities to shift from incompetence to competence; allowed them to be validated by an able-bodied society and escape the "disability ghetto"; sport allowed comparison to able-bodied peers; sport seen as a 'fix' to being physically flawed; athletic identity is disembodied; reframing of impairment outside of 'disability'.	Participation in sport allowed individuals to verify self-concepts related to ability.	

Note. Key concept = combination of conceptually grouped participant quotes and study author interpretations; second-order construct = study author interpretation; thirdorder construct = present review author interpretation

Table 4. Study characteristics

Study	Methodology	Research question/aim	Participants	Impairment	Sport (level; type)
Ashton- Shaeffer et al. (2001b)	Grounded theory	To investigate the meaning of elite wheelchair basketball for women with physical disabilities	Sample size: n = 10; Age: 18-32; Sex: 10 females; USA; Race: Caucasian n = 9, Hispanic n = 1	Congenital difference: $n = 2$ (spina bifida, polio); Acquired difference: $n = 8$ (SCI ( $n = 4$ ), post-traumatic degenerative arthritis, degenerative neuromuscular disease, AKA, knee degeneration)	Paralympic; wheelchair basketball
Braye (2016)	Narrative thematic analysis	To examine the reflections of retired British Paralympic athletes on the relationship between the Paralympic Games and disability equality in the UK	Sample size: n = 6; Age: 39-50; Sex: 1 females, 5 males; Nationality: British	Congenital difference: $n = 4$ ; Acquired difference: $n = 2$	Paralympic (retired); NS
Day (2013)	Holistic content analysis and fieldwork	To explore athletes' experiences of becoming physically active after disability and the role this may have played in their psychological growth	Sample size: n = 7; Age: >18; Sex: 3 females, 4 males; Nationality: British	Acquired difference: n = 7 (SCI, SLA)	Paralympic (n = 2), remainder taking part in Paralympic trials, no competitive sport prior to disability; NS
Day & Wadey (2016)	Narrative analysis	To explore how participation in sport may assist an individual in working through experiences of physical trauma	Sample size: n = 2; Age: late 30's - mid 40's; 2 males; UK	Acquired difference: n = 2 (SCI, amputation)	National (n = 1) and international; NS
Goodwin et al. (2009)	Phenomenolo gical thematic analysis	To explore the social experience of wheelchair rugby from the perspective of the players	Sample size: n = 11; Age: 22-48; Sex: 1 female, 10 males; Nationality: Canadian	Acquired difference: n = 11 (SCI)	Competing at National championships, 3-20 years' participation; wheelchair rugby
Hardin (2007)	Iterative analysis	How do gender and disability intersect in the lives of competitive female athletes with a disability?	Sample size: n = 10; Age: 18-31; Sex: 10 females; USA; Race: Caucasian n = 9, Latina n = 1	Congenital difference: $n = 6$ (from birth/early life; including cerebral palsy); Acquired difference: $n = 4$ (accident during/post puberty)	Paralympic (n > 5), all hoping to compete at National level, all but one were elite-level; wheelchair basketball
Huang & Brittain (2006)	Life story approach, thematic analysis	To explore the identity construction of elite disabled athletes	Sample size: n = 21; Age: 23-61; Sex: 9 females, 12 males; Nationality: British, Taiwanese	Congenital: Polio ( $n = 10$ ); spina bifida ( $n = 4$ ); SCI ( $n = 1$ ); cerebral palsy ( $n = 1$ ). Acquired: visual impairment ( $n = 4$ ), SCI ( $n = 1$ )	Paralympic (n = 9), World championships (n = 5), Far East and South Pacific Games (n = 3), 4-23 years' participation; powerlifting, track and field
Hull Garci & Mandich (2005)	Grounded theory and observations	To explore the meaning of participation in elite-level wheelchair basketball	Sample size: n = 16; Age: >18; Sex: 6 females, 10 males; USA	Congenital difference: $n = 2$ ; Acquired difference: $n = 14$ (SCI)	Paralympic and International, 5-21 years' participation; wheelchair basketball
Kavanagh (2012)	Narrative thematic analysis	To explore the personal narrative of a British Paralympic wheelchair tennis player	Sample size: n = 1; Age: 30; Sex: 1 female; Nationality: British	Acquired difference: n = 1 (SCI)	Paralympic, 8 years' participation; wheelchair tennis

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(continued)

Study	Methodology	Research question/aim	Participants	Impairment	Sport (level; type)
Le Clair (2011)	Reflexive analysis and fieldwork	To explore the narratives of swimmers with disabilities during a period of change from disability-based to sport-based Paralympic Games	Sample size: NS; Age: NS; Nationality: Canadian	NS	Paralympic; swimming
Pack et al. (2016)	Interpretive phenomenolo gical analysis	To explore the role of swimming on Paralympic athletes' perceptions of self and identity development	Sample size: n = 5; Age: 20-24; Sex: 3 females, 2 males; Nationality: British	Congenital difference: $n = 5$ (amputation, cerebral palsy, multiple sclerosis, SCI)	Paralympic; swimming
Richardson et al. (2017)	Thematic analysis	To investigate how and why sport participation impacts psychosocial wellbeing and cultural perceptions of disability	Sample size: $n = 16$ ; Age: 18-40; Sex: 2 females, 14 males; Nationality: Turkish ( $n = 6$ ), Romanian ( $n = 3$ ), Iranian ( $n = 2$ ), Yemeni ( $n = 2$ ), South African ( $n = 2$ ), Moroccan ( $n = 1$ )	Congenital difference: $n = 2$ (disorder of spine and limbs); Acquired difference: $n = 14$ (SCI, double and triple amputation, polio, spinal virus, chronic hip injury)	Paralympic/Grand Slam (n = 4), National (n = 7), Development (n = 5); wheelchair tennis
Smith et al. (2016)	Narrative thematic analysis	To examine the narratives of activism amongst elite athletes with impairment and their adoption/rejection of activist identities	Sample size: n = 36; Age: 23-40; Sex: 16 females, 20 males; Nationality: British	Congenital difference: $n = 9$ ; Acquired difference: $n = 27$ . Including amputation, cerebral palsy, SCI, visual impairment	Elite-level inclusion criteria, average of 8 years' participation; athletics, canoe, cycling, swimming, triathlon, wheelchair basketball
Spencer- Cavaliere & Peers (2011)	Content analysis	To explore how female athletes experience reverse integration in wheelchair basketball	Sample size: n = 9; Age: 22-55; Sex: 9 females; Nationality: Canadian	Including paraplegia, quadriplegia, spina bifida, polio, degenerative osteoarthritis, ligament laxity. Age acquired not reported	National level, 3-25 years' participation; wheelchair basketball
Swartz et al. (2016)	Thematic content analysis	To investigate how athletes with disabilities talk about their experiences of taking part in competitive disability sport	Sample size: n = 22; Age: >18; Sex: 6 females, 16 males; Nationality: South African	Congenital difference: $n = 12$ (visual impairment, hemiplegia, multiple sclerosis, cerebral palsy); Acquired difference: $n = 10$ (paraplegia, amputation, hemiplegia, visual impairment)	National championships; goalball, powerlifting, athletics, soccer, swimming
Wickman (2007)	Discourse analysis	To explore the meaning-making process whereby athletes construct and manage practice their identities	Sample size: n = 9; Age: NS; Sex: 4 females, 5 males; Nationality: Swedish	NS	International level; wheelchair racing

 Table 4. Study characteristics (continued)

Note. Reverse integration = athletes without impairments taking part in disability sports; NS = not stated; SCI = spinal cord injury; AKA = above knee amputation; SLA = single leg amputation

Table 5. Third-order Concepts across Studies

Third-order themes	-				3t			•	_			5 0		N		
encompassing second-order	.et		)13		in e		Š	arci lich	igh,	Ľ.	al.,	lsoi 17)	3) it	ë 7 Se	et	an,
themes	on- ffer	, e,	, 20	ey, &	мр 000	ы с	ng ain,	) and	ana	) (	et : 5)	ard, 20	th e 016	ncel lier 3,	rtz 016	→ km
	shto	3ray )16	Jay	Jay /add 016	; 2	ard 00	Hua ritta 006	Hull M D	Kav 012	ле ( 011	ack 010	Rich al.	., 2	pei ava eers	wa ., 2	Vic 007
	ASI	ВЯ	Ð	5 ¥ €	al (C	Н	5 B (F	びるむ	5 (F	5( (I	$\frac{1}{2}$	et (F	al (S	S D C S	al (S	22
Valued identities																
Athlete identity																
Athlete identity	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$
Redefinition of identity	$\checkmark$		$\checkmark$	$\checkmark$			$\checkmark$		$\checkmark$		$\checkmark$				$\checkmark$	
Repair of identity	$\checkmark$		$\checkmark$		$\checkmark$		$\checkmark$		$\checkmark$				$\checkmark$			
Evolving identity																
Embracing ability				$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	
Visibility/invisibility	$\checkmark$		$\checkmark$		$\checkmark$	√ -				$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	
Beyond impaired-			$\checkmark$				$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$		
non-impaired																
Path to agency																
Commitment to sport		$\checkmark$		$\checkmark$			1	,		$\checkmark$	$\checkmark$			$\checkmark$		
Choice over self-			1	$\checkmark$	./	•	•	<b>√</b>		$\checkmark$						
identification			•		v			$\checkmark$								
Challenges to identities																
Stigma																
Societal limitations		$\checkmark$				$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	
Personhood	$\checkmark$					$\checkmark$	$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	
Social comparison		$\checkmark$		$\checkmark$					$\checkmark$		$\checkmark$					$\checkmark$
Reinforcing disablism						$\checkmark$	$\checkmark$								$\checkmark$	
Shared identity	$\checkmark$			$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	
Resistance																
Resistance	$\checkmark$		1						/							
Challenging stereotypes			•				$\checkmark$		v		$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	
Rejecting 'disability'					$\checkmark$	$\checkmark$		$\checkmark$		$\checkmark$		$\checkmark$		$\checkmark$	$\checkmark$	
Political identity	$\checkmark$			$\checkmark$			$\checkmark$	·		$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Activist identities	$\checkmark$	$\checkmark$					$\checkmark$	/			$\checkmark$		$\checkmark$	$\checkmark$		
Acceptance of impairment			$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	v		$\checkmark$	$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$
Gender																
Gender	$\checkmark$					$\checkmark$	$\checkmark$									$\checkmark$



Figure 3. Third-order line of argument model.

Database	Search Details
PsycINFO	searchable years 1949-2018, limited to
	"English", "peer reviewed", and "adulthood:
	18 years and over"
MEDLINE Complete	searchable years 1978-2017, limited to
	"English", "all adult: 19+ years"
CINAHL	searchable years 1988-2017, limited to
	"English", "all adult"
SocINDEX	searchable years 1904-2018, limited to
	"English", "peer reviewed"
Scopus	searchable years 1982-2018, limited to
	Psychology, Nursing, Social Sciences, and
	Health Professions subject areas, "English",
	and journal articles

Appendix 1-A: Database Search Details

# Appendix 1-B: PsycINFO Search Strategy

- 1. Amput\*
- 2. "Physical disability"
- 3. "Physical impairment"
- 4. Prosthe\*
- 5. Wheelchair\*
- 6. 1 OR 2 OR 3 OR 4 OR 5
- 7. Identit\*
- 8. Self\*
- 9. Experiences OR perceptions OR attitudes OR views
- 10. Interview\*
- 11. 7 OR 8 OR 9 OR 10
- 12. Sport\*
- 13. "Disabled athletes"
- 14. Athlete\*
- 15. Paralympi\*
- 16. Elite athlete\*
- 17. 15 OR 16 OR 17 OR 18 OR 19
- 18. 6 AND 14 AND 20
- 19. Narrow by language: English
- 20. Narrow by subject age: adulthood (18 yrs & older)
- 21. Limiters: full text

# **Appendix 1-C: Body Image Guide for Authors**

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# **Thesis Section Two: Empirical Paper**

# Does Perceived Social Stigma Mediate the Relationship between Physical Activity and

# Athletic Identity for Individuals with Amputations?

Kimberley Keegan

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Division of Health Research

Faculty of Health and Medicine

Lancaster University

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Correspondence should be addressed to: Kimberley Keegan, Doctorate in Clinical Psychology, C14, Furness College Lancaster University, Lancaster, L1 4YG Email: k.keegan@lancaster.ac.uk

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#### Abstract

Objectives: This study aimed to investigate whether perceived social stigma mediated the relationship between increased physical activity and greater athletic identity in people with limb loss. Participants (males: n = 150; females: n = 186) took part in various levels of physical activity. Design: A quantitative, cross-sectional design collected participant responses via an internationally available online survey. Measures included the Perceived Social Stigma Scale and the Athletic Identity Measurement Scale. Methods: Mediation analyses were used to examine the relationship from physical activity, via perceived social stigma, on athletic social identity (model one) and athletic self-identity (model two). Results: Perceived social stigma mediated the relationship between physical activity and athletic social and self-identity. Conclusions: Physical activity may form an effective intervention in the reduction of internalised stigma, and the associated effects on identity, in the early stages of rehabilitation to amputation. Therapeutic approaches which focus on an individual's present and future circumstances may be more effective in building valued identities for people with amputations. Professionals and service users may collaboratively challenge social stigma on a systemic level to positively influence the lives of individuals with limb loss.

Keywords: amputation, limb loss, physical activity, stigma, athletic identity

# **Statement of Contribution**

What is already known on this subject?

- There is a relationship between increased physical activity and greater athletic identity for the general population.
- Athletic identity is associated with positive psychosocial outcomes for people with physical impairments.

What does this study add?

- This relationship is mediated through a reduction in perceived social stigma for people with amputations.
- Physical activity reduces the effects of internalised stigma on identity for individuals adjusting to limb loss.

# Does Perceived Social Stigma Mediate the Relationship between Physical Activity and Athletic Identity for Individuals with Amputations?

Athletic identity (AI) has been defined as the extent to which an individual identifies with the role of an athlete (Brewer, Van Raalte, & Linder, 1993). Empirically, AI has been conceptualised in different ways. For example, factor analyses of the Athletic Identity Measurement Scale (AIMS; Brewer, Van Raalte, & Linder, 1990) demonstrated that AI loads on four aspects; self-identity, which captures the individual's thoughts about themselves as an athlete; social identity, which reflects athletes' perceptions of whether other people view them as an athlete; exclusivity, which captures the degree to which an individual relies on their role as an athlete over other roles; and negative affectivity, which measures the emotional response that would accompany not being able to participate in sport (Martin, Eklund, & Mushett, 1997). However, other studies have found that individuals may also conceptualise AI in terms of beliefs about their athletic appearance, and physical competence (Anderson, 2004). Considered together, it may be concluded that AI represents a range of beliefs related to one's view of the self as an athlete.

The relationship between increased physical activity (PA) and the development of AI has been well established in research with able-bodied samples taking part in different types and levels of PA and sport. Studies have demonstrated that, generally, stronger AI is associated with increased PA participation (Anderson, 2004; Brewer et al., 1993; Horton & Mack, 2000). The considerable effect of sport participation on AI has been observed in males ( $n^2 = .36$ ) and females ( $n^2 = .60$ ) participating in a range of individual and team sports (Lamont-Mills & Christensen, 2006). Furthermore, the difference in activity involvement between participants with high AI (M = 51.09, SD = 5.28, n = 79) compared to those with low AI (M = 30.97, SD = 4.77, n = 79), has been demonstrated as highly statistically significant (p < .001; Horton & Mack, 2000). From this it can be understood that, for the

general population, the more an individual takes part in sport the more they will think of themselves as an athlete, and importantly, the more they will believe other people perceive them as an athlete.

Holding a view of oneself and being viewed by others as athletic has been associated with several positive outcomes which have important implications for different areas of psychological wellbeing. In a study exploring AI in able-bodied marathon runners (Horton & Mack, 2000), composite scores on a combined measure of body image, self-confidence, overall self-image, energy level, and anxiety level, were significantly associated with increased AI (r = .31, p < .001). Furthermore, marathon runners with 'high' AI (M = 51.09, SD = 5.28, n = 79) reported a significantly expanded social network as a result of running and an increased number of good friends (both at p < .001 level) compared to marathon runners with 'low' AI (M = 30.97, SD = 4.77, n = 79). Ryska (2002) also found that AI, as measured by the social identity subscale of the AIMS, predicted greater perceived vocational competence ( $\beta = -.24$ , p < .01) in a sample of male able-bodied high school students, demonstrating that identification as an athlete can increase confidence in other areas of life. These findings show that with increased PA, the associated development of AI may contribute towards further psychological benefits relating to different aspects of identity.

The investigation of AI and the psychological benefits of sport participation for individuals with physical impairments was stimulated by an objective to understand how identifying as an athlete may mitigate the undesirable associations attached to a 'disabled' identity. Social-relational understandings of 'disability' (e.g. Reeve, 2012) have argued that social responses to physical impairments (physical differences in anatomical function or structure<sup>1</sup>) can further restrict and exclude people with physical difference within their social

<sup>&</sup>lt;sup>1</sup> The World Health Organization International Classification of Functioning, Disabilty and Health Framework (WHO ICF; WHO, 2002).

environment. Indeed, research has shown that the negative connotations ascribed to a 'disability' social label, such as passive, sedentary, and fragile (Goodwin et al., 2009), can lead individuals with physical differences to often feel as though they have, or are treated as though they have, lesser, spoilt or sub-human identities (Campbell, 2008; Peers, 2012; Sousa, Corredeira, & Pereira, 2009). This process of societal marginalisation has been referred to as stigma, whereby society judges and discredits an individual based on the presence of a stigmatised attribute (Goffman, 1963). Socially stigmatising attitudes have the potential to negatively impact an individual's perception of self if oppressive attitudes are internalised (e.g. Rohleder & Gibson, 2006). In this instance, individuals will adopt stigmatising judgments of what it means to have an impairment in the process of self-evaluation, which will in turn impact an individual's perception of who they feel they can be. Thus, how people believe they are viewed by others (social identity) can affect how they view themselves (selfidentity).

In contrast to the experience of a 'disabled' identity, qualitative accounts of individuals with physical impairments participating in sport have described positive identity-related experiences attributed to PA. In a review of the qualitative literature, Kissow (2015) found that participants with physical impairments who took part in various levels of PA (from recreational to elite) used sport to manage the effects of 'disability' stigma at a personal level. Participants felt this was achieved through the opportunity sport provided to display physical competence, enhance bodily appearance, negate perceptions of incompetence, challenge stereotypical views, and stimulate positive attitudes towards the body (Kissow, 2015). In this way, AI has been experienced as freedom from a 'disabled' identity, facilitating the realisation that identity can be defined by aspects other than impairment (Lundberg, Taniguchi, McCormick, & Tibbs, 2011). While societal change is necessary to reverse the negative associations attached to a 'disability' identity, these findings demonstrate how some

individuals have made efforts to mitigate the oppressive effects of a disabled identity with the use of sport and the development of AI.

However, despite the established benefits of AI for people with physical impairments (e.g. Hawkins, Coffee, & Soundy, 2014; Scarpa, 2011; Shapiro & Martin, 2010), this group repeatedly report lower AI than the non-impaired population. In a study of 678 people with spinal cord injury (SCI), Tasiemski, Kennedy, Gardner, and Blaikley (2004) discovered that average AI scores reported by people with SCI were consistently lower than normative values reported for AI among people without impairments; furthermore, the authors reported that this difference was observed in comparisons between physically impaired and non-impaired individuals taking part in low level PA and those taking part in elite-level sport. One explanation for this difference is that perceived social understandings of a 'disabled' social identity influence the strength of AI for this population. This is supported by qualitative studies exploring the experiences of elite athletes with physical impairments (Hardin, 2007; Huang & Brittain, 2006; Spencer-Cavaliere & Peers, 2011) which showed that while this population believed their identity to be centred on the role of athlete, they were aware that other people predominantly perceived them as 'disabled'. Thus highlighting an important difference between social and self-identity for people with physical impairments taking part in sport.

It therefore appears that for individuals who have experienced physical impairment, the linear relationship between PA and AI appears somewhat disrupted. This may not be surprising given the range of environmental, social and psychological barriers associated with involvement in sport and the development of AI for this population. Difficulties in access, limited knowledge of available facilities, and lack of funding, alongside the anticipated perceived negative feelings and attitudes of others (e.g. pity), were reported to increase selfconsciousness and reduce confidence in a sample of individuals with SCI, which lead participants to stop attending the sporting environments in which these instances occurred (Levins, Redenbach, & Dyck, 2004). It can therefore be understood that for people with physical impairments participation in PA may require the navigation of multiple physical, cognitive, emotional, and social barriers.

While a considerable amount of research has focussed on access to PA and resultant development of AI in clinical populations such as SCI (e.g. Scarpa, 2011; Tasiemski & Brewer, 2011; Tasiemski et al., 2004), a variety of groups with physical impairments have not received the equivalent amount of research attention. One group of clinical concern, and the focus of the present research, is people with acquired limb loss. There are a range of benefits of increased PA for people who have experienced an amputation; these include physical outcomes (improved cardiopulmonary function, muscle force, and body mass) related to reduced rehabilitation time (Bragaru, Dekker, Geertzen, & Dijkstra, 2011), and psychological outcomes including: reduced body image anxiety (Wetterhahn, Hanson, & Levy, 2002) and greater psychosocial adjustment (Güçhan Topcu, Bayramlar, Ergun, & Ercan, 2017). Consequently, PA forms an essential focus within the multi-professional rehabilitation process for amputation (Esquenazi & DiGiacomo, 2001) due to its role in helping people to maintain mobility and increase their access to valued activities and interests.

Despite the focus on PA within rehabilitation, it remains the case that the majority of individuals with amputations are at risk of low levels of PA (Langford, Dillon, Granger, & Barr, 2018) and are less likely to be active than their non-impaired peers (Halsne, Waddingham, & Hafner, 2013), meaning they are less likely to develop an AI. What remains unclear, and critical to addressing the public health concern regarding low activity in this population, are the specific factors that mediate the relationship between PA and AI for people with limb loss. It has been established that individuals with amputation experience similar barriers to participation in PA as those previously outlined for people with SCI (e.g. Bragaru et al., 2011). However, in addition to these challenges, individuals with limb loss also have to overcome the barriers imposed by a prosthetic limb. Individuals with lower limb amputations reported that using a prosthesis during PA often resulted in discomfort, corns or blisters, which meant they had to stop PA or avoid certain PA environments (e.g. swimming; Bragaru et al., 2011). Many of the participants in this study negotiated the hinderance of their prosthesis by choosing to take part in a sport which did not require a prosthetic limb, such as wheelchair basketball; however, this option may not be available to all people with limb loss. This raises a new set of challenges for individuals with limb loss with regard to participation in PA and the development of AI.

Further to the increased number of barriers to PA and AI for this population, it is also known that people with amputations are exposed to the deleterious effects of social stigma (Andregård & Magnusson, 2017), and are therefore at risk of feeling as though they have a devalued identity. With the increasing presence of individuals with amputations sharing stories of achievement and affirmation through sport in the media (e.g. Bhardwaj, 2018; Wallace, 2016; Wright, 2016), awareness among the general population has increased around the potential for sport to transform the lives of those who take part (Blauwet & Willick, 2012). It is therefore not surprising that, in a recent survey by one of the United Kingdom's leading amputation charities, 83% of 249 people with limb amputation or impairment expressed a desire to take part in more PA and sport in the future (LimbPower, 2016). It therefore appears timely that the exploration of AI among people with amputations should occur within the empirical evidence-base.

To summarise, the research has demonstrated a strong link between increased PA and AI for the general population, however this has not yet been established for individuals with limb loss. Amputation is associated with reduced activity levels and increased health risks,

consequently there are multiple benefits to individuals with amputations taking part in PA. Alongside the physical benefits of PA, individuals with amputations may also benefit from developing an AI. However, it is known that AI is reportedly lower in this population despite, in some cases, high levels of PA. The finding that AI loads on both the perception of the self as an athlete (self-identity), and the beliefs that others view the self as an athlete (social identity), suggests that perceptions of how one is viewed by society may have a role to play in the relationship between PA and AI.

In this study this proposition is theoretically positioned within a mediation analysis. Mediation is a statistical procedure which allows for a deepened exploration of how a predictor variable produces an effect on an outcome variable (Preacher & Hayes, 2004). The analysis is used to identify the mechanisms which explain how a proposed causal agent has an effect on an outcome (Hayes, 2018). To this extent, mediators can be considered variables which account for the relationship between a predictor and an outcome (Baron & Kenny, 1986). What is missing from the existing studies is an examination of how PA is related to AI in individuals with amputations, and whether the internalised perception of societal stigma mediates this relationship. Consequently, this study aimed to investigate whether perceived social stigma mediated the relationship between PA and AI, measured in terms of athletic self-identity and athletic social identity. This was tested in two mediation models: model one examined whether perceived social stigma mediated the relationship between PA and social AI, and model two explored the same indirect relationship on the outcome of self-AI.

# Method

#### Design

The study employed a quantitative, cross-sectional design to explore whether perceived social stigma mediated the relationship between PA and AI for a sample of individuals with amputations. Mediation analyses were performed on two hypothesised models, model one tested whether perceived social stigma mediated the relationship between PA and athletic social identity, and model two explored the same indirect effect on athletic self-identity. Participants were required to a) have had an amputation (upper or lower surgical limb removal due to disease or trauma); b) be aged 16 years or over; c) read English language. Participants were unable to take part if they a) had a limb absence from birth; b) used a prosthesis to aid a congenital limb difference (e.g. to help support a poorly developed limb); c) had a physical impairment other than amputation. In order to determine the sample size, a multiple linear regression power analysis was conducted using G\*Power (Faul, Erfelder, Bucnhner, & Lang, 2014). With a medium effect size ( $f^2$ ) of .15, an alpha of .05, a standard power level of .80, and a total of 2 predictors, the results of the power analysis showed that a minimum of 68 participants would be required to achieve an appropriate power level for this study.

# Procedure

Participants were recruited online and invited to complete the study measures via Qualtrics online survey software (Qualtrics, 2018), or to contact the researcher by email to request a hardcopy (this option was not utilised by any of the participants). Although to the author's knowledge, the study measures have not previously been administered through an online platform, the content and format of both measures was deemed suitable for this purpose. Similar self-report measures have previously been utilised successfully online (e.g. Curvis, Simpson, & Hampson, 2018), and participants were provided with the lead author's email address should they have encountered any difficulties (none were identified). The study advertisement was posted on various online platforms, including Twitter and Facebook. Specialist amputation, prosthesis and sport organisations were contacted to advertise the study on their online social media domains. Recruitment took place over a six-month period between August 2017 and January 2018; it was decided to leave the survey open for as long as possible to increase participant numbers not for the power calculation but specifically to increase the stability of the mediation model.

#### **Ethical Considerations**

The study was approved by the lead author's faculty Research Ethics Committee (FHMREC). A sample (n = 4) of individuals with amputations volunteered to review the study advert, participant information and consent form and deemed the use of language to be satisfactory. Participants were reminded to take adequate time to read through the study information before progressing to the consent form. Due to the potentially sensitive nature of the topic, general advice and contact numbers of freely accessible international support organisations were provided in the information sheet prior to completion of the survey. Participants were provided with the opportunity to withdraw from the study at any time. To allow for data withdrawal requests, participants were required to provide a unique four-digit code to allow the researcher to identify their responses should they wish to withdraw their data. The option to withdraw data was not requested by any of the participants.

# Measures

In addition to demographic and clinical data, the study used two measures to collect information on the mediator and outcome variables.

# Stigma.

The 22-item Perceived Social Stigma Scale (PSSS; Rybarczyk et al., 1995) requires respondents to rate how they believe others see them according to a list of 14 negative attributes (e.g. clumsy) and eight antonyms (e.g. intelligent). The PSSS was designed as a general measure for use with different physical impairments, however the validation study (Rybarczyk et al., 1995) also included a sample of individuals with lower amputations accessing prosthetic centres. Respondents answer on a four-point scale of not at all true (1) to very much true (4). A total score (ranging from 22 - 88) is obtained by reversing the

scores on the antonyms and summing the 22 scores, with high scores indicating high perceived social stigma. Cronbach's alpha for a sample of people with lower amputations (*a* = .91) indicated high internal consistency (Rybarczyk et al., 1995). Information on test-retest reliability was not available.

#### Athletic identity.

AI was measured with the Athletic Identity Measurement Scale (AIMS; Brewer et al., 1990). This 10-item scale was developed to assess AI across four subscales; self-identity, social identity, exclusivity, and negative affectivity (Martin, Mushett, & Eklund, 1994). Participants are asked to rate their agreement with a list of athlete-related statements using a Likert-scale ranging from strongly agree (7) to strongly disagree (1). Responses are grouped to produce total scores for the four subscales; subscale scores range from 2 - 14 for self-identity, social identity, and negative affectivity, and 3 - 21 for exclusivity. Subscale totals are summed to produce a measure total score ranging from 10 - 70 with a higher score indicating greater AI. Alpha coefficients ranging from .64 to .72 have demonstrated low but adequate internal consistency across the four subscales (Martin et al., 1994). The measure authors (Martin et al., 1997) cited a test-retest coefficient of .89 (r = .89), which they concluded provided adequate construct and discriminant validity for the measure. Although this measure is not amputation specific, it has been validated in a sample of people with cerebral palsy (Martin et al., 1997), and a sample including people with amputations (Van de Vliet, Van Biesen, & Vanlandewijck, 2008).

# Physical activity.

Participants were asked to self-report how many hours and/or minutes they took part in physical activity (PA) per week and how long they had taken part in this level of PA in years and/or months. PA was defined as an activity or sport which exerts some degree of physical exertion on the body. Median scores indicated that participants generally completed PA or sport for five hours a week (Mdn = 5, IQR = 8); it can therefore be interpreted that the majority of the sample believed they were exerting their bodies, on average, approximately 43 minutes per day, and had been involved in this level of activity for an average of eight years (Mdn = 8, IQR = 28.25). In comparison to a recent study of PA among individuals with lower limb amputations (Langford et al., 2018), the average level of activity reported by the sample in the current study was comparable to activity-levels classified as 'moderate' by the authors. Similarly, in a study by Wetterhahn et al. (2002), 'active' individuals were classified as those who participated in at least two hours of aerobic activity per week, a definition which accounted for the additional energy cost associated with prosthetic use (Farber & Jacobson, 1995). According to these standards, it can therefore be understood that the sample, on average, were comparable to 'active' individuals with amputations taking part in 'moderate' PA.

# **Data Analysis Strategy**

Data analysis was completed with the Statistical Package for the Social Sciences (SPSS) Version 22. Responses were scored in accordance with measure instructions. Cronbach's alpha was calculated for each of the measures. Internal consistency was interpreted as  $\alpha =: > .9$  excellent; > .8 good; > .7 acceptable; > .6 questionable; > .5 poor; < .5 unacceptable (George & Mallery, 2003).

Initially, a total of 416 participants entered the Qualtrics online survey, however 80 participants exited the survey before completion. As per the study consent form (Ethics section: Appendix 4-B and 4-C), participants were advised that they could withdraw from the study at any time during the completion of the survey, thereby indicating their decision to opt out. It was determined that the incomplete responses indicated participants who had decided to opt out and therefore this data was not used in the analysis leaving 336 fully completed

survey responses (Appendix B demonstrates the flow of participants through the study survey). The study measures were counterbalanced to control for order effects.

Data were tested (Shapiro-Wilk) for assumptions of normality; all three variables were non-normal at the p < .05 level. Given that that the dataset violated assumptions of normality, non-parametric analyses were performed. Screening and assumption diagnostics were completed for the detection of univariate and multivariate outliers and for the assumptions of linearity, homoscedasticity, and multicollinearity. Tests statistics confirmed that all model assumptions were achieved.

Descriptive statistics were carried out through medians and interquartile ranges (owing to the non-normal distribution of the data) for continuous variables, and frequencies and percentages for discrete variables. Within the dataset, there were 20 demographic and clinical data points outside the possible ranges for the corresponding variables; these were substituted for the corresponding variable means.

Correlational analysis (Spearman's  $r_s$ : two-tailed) was used to examine the relationship between PA, AI and perceived social stigma. For the purposes of interpretation, Spearman's  $r_s$  correlation coefficients were estimated to represent a small association at  $r_s = .10$ , a medium association at  $r_s = .30$ , and a large association at coefficients of  $r_s = .50$  and above (Watson, 2016).

Finally, mediation analyses as outlined by Hayes (2018) were undertaken to examine whether perceived social stigma mediated the relationship between PA and AI. This was tested in two models; model one assessed whether perceived social stigma mediated the relationship between PA and athlete social identity, and model two examined whether perceived social stigma mediated the relationship between PA and athlete self-identity. Preliminary analyses were completed to establish whether the variables met mediation assumptions to assess whether mediation analysis for the two models was justified. Traditional accounts of mediation (Baron & Kenny, 1986) have proposed certain criteria that need to be achieved before mediation can be considered: 1) the predictor variable (*X*) must significantly predict the outcome variable (*Y*), labelled the *c* path; 2) the predictor variable (*X*) must significantly predict the mediator (*M*), the *a* path; 3) the mediator (*M*) must significantly predict the outcome variable (*Y*), known as the *b* path; and lastly, 4) the predictor variable (*X*) must predict the outcome variable (*Y*) less strongly with the addition of the mediator in the model (*M*), the *c'* path. Within this approach, mediation is suggested if the relationship between *X* and *Y* is significantly reduced with the addition of *M* in the model (*c* - *c'* path). Although, more recent debates have argued whether all these conditions need to be met for mediation to occur, instead placing a greater emphasis on whether *M* can causally be located between *X* and *Y* (Hayes, 2018). For the purpose of this analysis, the steps outlined by Baron and Kenny (1986) were followed along with updated mediation procedures described by Hayes (2018).

The mediation tool used to perform the analysis (PROCESS macro for SPSS version 3; Hayes, 2018) provided regression coefficients between each of the variables of interest to assess whether the mediation conditions had been achieved. Bias-corrected confidence intervals (95%), with 5000 bootstrap replications, were used to determine whether the indirect effect was significant at the p < .05 level. The completely standardised indirect effect was used as a measure of effect size as currently recommended by Hayes (2018). The more traditionally utilised Sobel test (Sobel, 1982) was administered as an indication of significance.

#### **Participants**

# **Demographic characteristics.**

The sample consisted of 336 participants, 186 females and 150 males, aged 17 - 80 years (M = 46.11, SD = 13.45). The majority of the sample identified as White British<sup>2</sup> (86.3%), predominantly living in the USA (58.9%) and UK (21.4%). A more detailed summary of demographic information is presented in Table 1.

## [INSERT TABLE 1]

# **Clinical characteristics.**

Time since amputation ranged from two months to 57 years, however a median of 4.42 years indicated that this sample predominantly (53.9%) consisted of individuals who had had their amputation five years or less. Lower limb amputation was reported by most participants (87.8%), with below-knee amputation forming this majority (62.2%). The majority of amputations were as a result of accidents (48.2%). Descriptive information pertaining to the type and cause of amputations reported as 'other' can be found in Appendix A. Median scores indicated that this sample tended to use a prosthesis every day (*Mdn* = 30 days per month, *IQR* = 5.62), for most of the waking day (*Mdn* = 12 hours per day, *IQR* = 8). Further information relating to the clinical characteristics of the sample can be found in Table 2.

# [INSERT TABLE 2]

## Results

# Measures

Descriptive data for the self-report measures is presented in Table 3, along with Cronbach's alpha assessment of internal consistency. Both scales included in the mediation

 $<sup>^2</sup>$  Survey dropdown responses included 'White American' however this option was not selected by any of the participants

analysis demonstrated excellent (PSSS,  $\alpha = .918$ ; AIMS,  $\alpha = .928$ ) internal consistency for this sample. Subscales of the AIMS indicated acceptable to good internal consistency.

#### [INSERT TABLE 3]

# Perceived social stigma.

Sample scores on the PSSS indicted a mid-range average (Mdn = 42, IQR = 66) given that possible scores on the measure range from 22 - 88 with higher scores indicating greater perceived stigma. The relatively large interquartile range suggested stigma was experienced by participants to varying degree.

# Athletic identity.

The distribution of total AIMS scores for the sample indicated that participant scores were negatively skewed generally indicating low AI, however there was considerable variation within individual scores which raised sample averages (M = 30.25, SD = 13.93; Mdn = 27, IQR = 58). AIMS social identity subscale scores were negatively skewed indicating lower levels of reported social AI (Mdn = 5, IQR = 5). There was a more even spread of higher levels of self AI (Mdn = 7, IQR = 6). Scores on the 10-item version of the AIMS from similar studies are represented in Table 4. These figures show that average total AI scores for this sample were comparable to the scores of recreational-level non-impaired female athletes (Brewer et al., 1993), demonstrating that these participants with amputation saw themselves as athletes as much as non-impaired individuals.

#### [INSERT TABLE 4]

# **Correlational Analyses**

Correlational analyses (Spearman's  $r_s$ ) confirmed that the predictor, mediator and outcome variables were associated with one another in the hypothesised direction. Increased PA correlated with reduced perceived social stigma ( $r_s = -.23$ , p < .01), greater athletic social identity ( $r_s = .35$ , p < .01), and greater athletic self-identity ( $r_s = .40$ , p < .01). Higher levels of perceived social stigma also correlated with reduced athletic social identity ( $r_s = -.17$ , p < .01), and reduced athletic self-identity ( $r_s = -.16$ , p < .01). Correlational analyses are displayed in Table 5.

# [INSERT TABLE 5]

# **Mediation Analyses**

In the first model, regression pathways showed that increased PA was a significant predictor of greater athletic social identity (the *c* pathway: b = .043, p = .001). Increased PA also predicted reduced perceived social stigma (the *a* pathway: b = -.153, p = .006). Next, lower levels of perceived social stigma predicted increased athletic social identity (the *b* pathway: b = -.039, p = .004). Finally, the relationship between PA and social AI was decreased with perceived social stigma as an adjustor (the *c'* pathway: b = .037, p = .006). The indirect effect indicated that mediation had occurred from PA to athletic social identity through perceived social stigma, ab = 0.0059, 95% BCa CI [0.0012, 0.0130]. The completely standardised effect size,  $ab_{cs} = 0.0237$ , BCa CI [0.0046, 0.0479], and the Sobel test, Z = 2.12, p = .03, also reflected this result.

In the second model, preliminary analyses indicated that higher levels of PA significantly predicted greater athletic self-identity (the *c* pathway: b = .059, p = .001). Higher PA predicted lower perceived social stigma (the *a* pathway: b = -.153, p = .006). Next, reduced perceived social stigma predicted greater athletic self-identity (the *b* pathway: b = -.043, p = .01). Finally, the relationship between PA and self AI was decreased with perceived social stigma as an adjustor (the *c'* pathway: b = .052, p = .002). The indirect effect identified that perceived social stigma also mediated the relationship between PA and athletic self-identity, ab = 0.0066, 95% BCa CI [0.0012, 0.0163]. This result was also captured by the completely standardised effect size,  $ab_{cs} = 0.0210$ , BCa CI [0.0031, 0.0464], however the

Sobel test indicated that the indirect effect did not reach the p < .05 level of significance, Z = 1.56, p = .11. Figures 1 and 2 display path diagrams of these findings.

#### [INSERT FIGURES 1 and 2]

#### Discussion

The aim of this study was to test the inter-relationships between physical activity (PA), perceived social stigma and athletic identity (AI) for people with amputations. The mediation analysis confirmed that increased PA contributed towards a reduction in perceived social stigma which indirectly increased AI. The results are in line with previous research which has established a link between increased PA and greater AI (Brewer et al., 1993; Van de Vilet et al., 2008). Moreover, the results demonstrated that the effect of increased PA on beliefs about the self as an athlete operated through the reduction of internal perceptions of stigma for this population. This finding furthers the understanding of the direct relationship between PA and AI by demonstrating that for people with amputations this relationship operates through a reduction in perceived social stigma.

The results of this study support the hypothesis that for individuals with amputations, their beliefs about how they are viewed by society play a role in the relationship between their level of participation in PA and their beliefs about the self as an athlete. The theory of psycho-emotional disablism proposed by Reeve (2012) argued that the social oppression of people with physical impairments can occur on a public level, both in terms of structural barriers and stigmatising responses from others, and at a personal level, whereby stigmatising attitudes become internalised resulting in oppressive internal self-judgements. This process relates to the existing phenomenon of internalised oppression (Goffman, 1963), which has previously been applied within disability studies; for example, Thomas (2007) highlighted the potential for internalised disability oppression to impact directly on who a person feels they can be. In relation to the present research, this theory may be used to understand why a

reduction in perceived social stigma (e.g. people view me as dependent, handicapped, shameful) can allow for an increase in alternative self-related beliefs (e.g. other people see me as an athlete).

It has been theorised that people with recently acquired impairments are more susceptible to the impact of internalised stigma due to the influence of pre-impairment attitudes (Deal, 2003; Smart, 2008). It is likely that many individuals, before acquiring an impairment, have already internalised negative societal attitudes regarding 'disability' as an undesirable social group. Subsequently, when they find themselves within this social group, negative pre-existing beliefs about impairment will be used in the process of self-evaluation (Morris, 1989). In support of this proposal, research has found that people who have lived with their physical impairment from birth report stronger affirmative identity regarding their impairment, greater affiliation with the 'disability' community, and more satisfaction with life then those with acquired impairments (Bogart, 2014). This suggests that people who undergo amputation are at potentially high risk of internalised disabilty-related stigma.

The impact of negative social 'disability' stereotypes on AI has been supported by qualitative research into the identity-related experiences of elite-level athletes with physical impairments (e.g. Hardin, 2007; Huang & Brittain, 2006; Spencer-Cavaliere & Peers, 2011). It was a common finding within these studies that participants felt their social identity continued to be seen as 'disabled' as a result of discriminatory attitudes, despite their preference to see themselves as athletes. These findings demonstrate that even with high levels of sport involvement, athletes with physical impairments experience the detrimental effects of perceived social stigma on identity. It therefore follows that people with physical impairments have reduced access to the theorised and evidenced psychological benefits of AI.

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The beneficial effects of AI for people with physical impairments have been proposed to occur because of the relationship between PA participation and the management of 'disability' stigma at a personal level. Evidence suggests that engagement in PA can enable individuals with physical impairments to internally challenge the influence of socially-held stigmatising attitudes upon their understanding of identity (Kissow, 2015; Lundberg et al., 2011). The findings from the present study contribute towards this theory by providing empirical evidence to show that PA can directly influence AI when thoughts about the self as stigmatised are reduced. A possible explanation for this effect may be that the physical and social effects of participation in PA reduce the salience of internalised stigma-related perceptions of the self. Furthermore, PA may provide a unique opportunity for individuals to develop and express characteristics and behaviours which directly challenge the negative stereotypes associated with limb loss; enabling individuals to receive positive feedback on valued aspects of their identity. In each instance, the findings evidence the importance of PA as a useful tool within the physical health care rehabilitation approach provided for people with amputations.

PA forms an essential part of the rehabilitation process used to facilitate physical and psychological adjustment to amputation. However, these findings further develop the crucial role of increased PA for this cohort by demonstrating the positive effects on internally held views of identity. In addition to a focus on increasing functional mobility, rehabilitation is predominantly concerned with the social inclusion and wellbeing of people who experience physical impairment (Stevens, Parsons, Read, & Nixon, 2017). It has been previously identified that individuals with recently acquired physical impairments are at greater risk of high internal disability-related stigma (Smart, 2008). This factor has the potential to impact on feelings of exclusion from both non-impaired and 'disability' social groups which can further reduce psychological wellbeing (Bogart, 2014; 2015). This therefore demonstrates

the crucial role PA may provide in the rehabilitation process, with specific regard to internalised stigma, for people with recently acquired limb loss.

Internalised self-stigma is known to have a deleterious impact on the process of rehabilitation to physical impairment. In their conceptualisation article, Stevens et al. (2017) explored the relationship between stigma and rehabiliation according to the WHO ICF (WHO, 2002), a central rehabilitation theory used to understand the association between social participation and health. Stevens et al. (2017) outlined that self-stigma, the internalisation of negative attitudes, contributed towards the three WHO ICF constructs thought to cause 'disabilty': 1) environmental contextual factors; 2) personal contextual factors; and 3) participation restrictions. For example, individuals may be exposed to varying amounts of negative social reactions in their social context (environmental factor), which will become internalised to a degree influenced by existing views of the self (personal factor), which can lead to the modification of behaviour such as reduced participation in leisure activities (participation restriction). Considered within this framework, the findings show that PA may be a particularly effective intervention for individual's who are exposed to increased environmental stigma, greater likelihood of internalising negative attitudes, and higher risk of reduced activity.

It is a public health concern that people with limb loss are generally at risk of reduced levels of activity and increased physical health risks, which can further compound the negative experience of 'disability'. It is therefore of public interest to increase access to PA, inspire motivation to participate in PA, and validate positive identity-related responses to PA within this population. Although, AI may not be a desired outcome by all individuals with amputation taking part in PA, rehabilitation professionals may be guided by this understanding of the psychological benefits of PA participation for this cohort to better

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support individuals who may experience reduced activity participation, increased internalised stigma and negative identity-related experiences.

#### **Clinical Implications**

The findings highlight the positive role of PA on reducing internalised stigma and increasing the opportunity to build AI for people with amputations. Considered within the context of the negative experiences often associated with a 'disability' identity, the results demonstrate that PA can be an effective intervention to challenge internalised stigma and facilitate the development of a valued identity for people with amputations. PA may therefore be considered a valuable alternative to other psychosocial approaches which have been found to offer limited intervention for the impact of disability on individuals (De Silva et al., 2009). The findings also demonstrate how PA can be helpful in challenging stigma on a wider scale; in supporting individuals with limb loss to engage in activities which defy the common stereotypes attached to amputation, the societal ideal of what it means to be 'able' may be challenged and revised.

The current sample included individuals relatively new to living with an amputation (Mdn = 4.42 years), therefore the findings demonstrate the benefits of introducing PA, or supporting individuals to return to PA, in the early stages of rehabilitation. Previous research suggests that recent exposure to an amputation may be associated with higher levels of internalised stigma as a result of pre-existing stigmatising beliefs. From the results, it can be hypothesised that PA maybe a particularly effective intervention for people who are exposed to higher levels of social stigma, or those who have an increased vulnerability to developing internalised stigma. This understanding may be used to guide rehabilitation professionals to explore the identity-related benefits of PA with stigmatised groups including: females and ethnic minority groups; individuals experiencing high levels of shame; or those identified as holding discriminatory views regarding physical impairment. However, it should be kept in

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mind that while this was an internationally recruited sample, the majority of participants identified as White British residing in America and the UK. Western cultural ideals may have therefore played a role in respondent's answers. Within the USA and UK, stigma around amputation is likely to include concerns around an individual's level of dependence on others, a need generally viewed as undesirable within Western societies. However, PA may effectively challenge this stigma by demonstrating to others an individual's level of independence, thereby reducing internalised stigma regarding this preconception. Alternatively, this specific example may not be applicable in collectivist communities where it is more expected that all individuals are interdependent.

While PA may provide an effective option for individuals to resist the impact of social stigma on a personal level, it remains the case that society as a whole can largely devalue individuals with amputations. With regards to therapeutic approaches, this may pose a limitation when using cognitive and behavioural techniques to challenge 'negative' thoughts supported by an individual's valid experience. It may therefore be more helpful to utilise methods which allow individuals to focus on positive change, growth and personal values; approaches such as Solution-Focussed Brief Therapy and Acceptance and Commitment Therapy may be more suitable in supporting people during and following the process of amputation to focus on their personal meaning in life.

The results have important implications for the health care approach to amputation by highlighting the importance of PA as an effective element of rehabilitation. Support should be provided to individuals who are undergoing amputation, or have recently had an amputation, around exploring attitudes and barriers towards PA with an emphasis on the positive psychological outcomes regarding internalised stigma and identity. Ultimately, to increase PA within this population individuals would benefit from valuing sport as a part of

their identity; for this to occur participants need to be supported to access PA and to integrate positive ability-related experiences of PA into internalised beliefs about the self.

#### **Strengths and Limitations**

The application of AI within a clinical health care perspective has allowed for a deeper understanding of the social influences on identity within the context of physical impairment and disability. AI frequently features within sport psychology research, however it has not been commonly applied within the health care evidence base. This is the first study to explore AI amongst a non-clinical sample of people with amputations therefore providing validation data for the AIMS with this population. The included sample differs demographically from the general population of people with limb loss, which most commonly includes males with amputation as a result of vascular disease. While this study provides a useful insight into a majority female group with amputation as a result of accident, the findings should be applied with caution to other groups of individuals with limb loss. A generous sample size of 336 participants indicates that power was not a pertinent issue in this study.

A potential limitation of the study is the exclusive reliance on self-report measures. While this did increase access to a larger international sample and reduce the risk of socially desirable responses, there was no opportunity for clarification on behalf of the researcher and therefore it is unclear whether responses are wholly reliable. For example, it is unclear whether the majority of participants were 'White British' or whether this reflects a miscommunication between the survey dropdown response options and participant entries (owing to the finding that most participants who completed the survey reported they were currently residing in America). Furthermore, this study did not collect descriptive data on the type of PA or sport participants were involved in, additionally a self-report measure of PA was used which may have resulted in under- or over-estimations of participation in PA. The PSSS was designed as a general measure, which means that some of the items may not be considered to directly apply to the experience of amputation. While the development of the PSSS was theoretically driven, empirical justification for the content of the measure is not yet available. There was also no supporting guidance on the online administration suitability of the PSSS and AIMS. The cross-sectional study design imposes limitations in establishing cause and effect between the variables.

# **Future Research**

Further research would benefit from a qualitative exploration of participation in PA and the experience of internalised stigma and identity in individuals who have recently undergone amputation. In addition, groups of individuals who may be exposed to greater levels of social stigma, or who may be at increased risk of internalising negative views about the self, would benefit from further focus within this area of research. It could also be beneficial to explore the effects of group-based PA on social stereotypes within a group of individuals with and without amputations. This approach may allow for a deeper understanding of how PA may positively challenge social understandings of physical impairment and whether it is this change that influences a reduction in perceived social stigma.

## Conclusion

The current study provided empirical evidence to show that the reduction in perceived social stigma mediated the relationship between increased PA and greater AI for this sample of individuals with acquired limb loss. The findings have important implications for the inclusion of PA within the physical rehabilitation approach used to support individuals with limb loss. This advancement in knowledge may also allow for the psychological formulation of when and for whom PA may be a specialised intervention, with particular suitability for individuals identified as experiencing high levels of external and internal stigma.

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# ATHLETIC IDENTITY IN AMPUTATION

	N (%)	Mean (SD)	Range
Gender			
Male	150 (44.6)		
Female	186 (55.4)		
Age (Valid $n = 335$ )		46.11 (13.45)	17 - 80
Ethnicity			
White/English/Welsh/Scottish/British	290 (86.3)		
Mixed White Black Caribbean	5 (1.5)		
Mixed White Black African	1 (.3)		
Mixed White Asian	3 (.9)		
Mixed Other	7 (2.1)		
Asian Indian	4 (1.2)		
Asian Pakistani	1 (.3)		
Asian Other	1 (.3)		
Black African	3 (.9)		
Black Caribbean	1 (.3)		
Black African Caribbean	1 (.3)		
Other	19 (5.7)		
Continent and country of residence			
Africa	9 (2.7)		
South Africa	7		
Zimbabwe	1		
Nigeria	1		
Asia	3 (.9)		
India	2		
Singapore	1		
Australasia and Oceana	38 (11.3)		
Australia	38		
Europe	81 (24.1)		
United Kingdom	72		
Germany	4		
Hungary	1		
Switzerland	2		
Belgium	1		
Greece	1		
North America	205 (61)		
United States	198		
Canada	6		
Jamaica	1		

# **Tables and Figures**
Table 2. Chilical Characteristics
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	N (%)	Mean (SD)	Median	Percentiles (25 <sup>th</sup> , 75 <sup>th</sup> )	Range
Type of Amputation					
Lower limb	295				
	(87.8)				
Below-knee	209				
	(62.2)				
Through-knee	6 (1.8)				
Above-knee	80 (23.8)				
Upper limb	19 (5.7)				
Below-elbow	12 (3.6)				
Above-elbow	7 (2.1)				
Other	14 (4.2)				
Multiple	8 (2.4)				
Cause of Amputation					
Accident	162				
	(48.2)				
Cancer	35 (10.4)				
Diabetes	30 (8.9)				
Military trauma	4 (1.2)				
Multiple	5 (1.5)				
Other	85 (25.3)				
Peripheral vascular disorder	15 (4.5)				
Time since amputation (years; $n = 333$ )		8.49 (10.59)	4	2, 11	0 - 57
Time since amputation (months; $n = 336$ )		4.73 (3.65)	4.50	1.25 - 7	0 – 19
Time since amputation (total years)		8.88 (10.55)	4.42	2.08, 11.86	0.17 - 57
Prosthesis use (days/month; $n = 328$ )		25.38 (9.91)	30	25.38, 31	0-31
Prosthesis use (hours/day; $n = 319$ )		11.39 (5.34)	12	8, 16	0 - 24
Sport participation weekly (hours; $n = 326$ )		8.40 (11.78)	5	2, 10	0 - 103
Sport participation weekly (minutes; $n = 326$ )		3.18 (9.16)	0	0, 0	0-45
Sport participation weekly (total hours)		8.46 (11.76)	5	2, 10	0 - 103
Sport duration (years; $n = 333$ )		15.16 (16.85)	8	1, 29.25	0-75
Sport duration (months; $n = 333$ )		1.32 (2.94)	0	0, 0	0 - 21
Sport duration (total years)		15.27 (16.80)	8	1, 29.25	0 - 75.92

Note. n = valid n

		Mean (SD)	Mode	Median	Perc	entiles	Range	Scale	α
					25th	75th	-	Range	
AIMS									
	Social Identity	5.66 (2.93)	4	5	3	8	2 - 14	2 - 14	.717
	Self-Identity	7.24 (3.67)	4	7	4	10	2 - 14	2 - 14	.878
	Exclusivity	7.24 (4.06)	3	6	4	10	3 - 21	3 - 21	.858
	Negative Affectivity	6.83 (3.58)	3	7	4	10	2 - 14	2 - 14	.767
	Total	30.25 (13.93)	10	27	19	40	10 - 68	10 - 70	.928
PSSS									
	Total	43.33 (11.96)	34/39	42	34	50	22 - 88	22 - 88	.918
17		14	1 000	- D	. 10	· 1 a.:	0 1	0 1	1.

Table 3. Descriptive Statistics and Cronbach's Alpha ( $\alpha$ ) for AIMS and PSSS

*Note*: AIMS = Athletic Identity Measurement Scale, PSSS = Perceived Social Stigma Scale,  $\alpha$  = Cronbach's alpha

Study	Ν	Level	AI total M	AI social	AI self
			(SD)		
Present study	336	'Moderate' activity	30.25 (13.93)	5.66 (2.93)	7.24 (3.67)
Brewer et al. (1993)	90	Male university football team (non-impaired)	51.08 (9.48)		
(1770)	77	Female recreational athletes (non-impaired)	30.39 (11.02)		
	67	Male recreational athletes (non-impaired)	34.76 (9.92)		
	23	Female nonathletes	15.74 (5.27)		
	6	Male nonathletes	19.67 (7.55)		
Martin et al. (1995)	27	Female swimmers with PI	45.7 (12.2)		
	30	Male swimmers with PI	44.3 (11.5)		
	57	Total sample		8.5 (3.9)	11.9 (2.4)
Van de Vilet et al. (2008)	18	Paralympic athletes	46.1 (7.9)	8.7 (2.8)	12.4 (1.8)
	9	Non-Paralympic elite athletes	43.3 (10.4)	7.7 (3.1)	10.7 (2.8)
Gapin & Petruzzello (2011)	179	Non-obligatory runners (non-impaired)	34.72 (7.71)	7.38 (2.74)	11.62 (2.41)

Table 4. AIMS Scores in Comparison to other Samples

*Note*. PI = physical impairment

#### ATHLETIC IDENTITY IN AMPUTATION

		Age	Gender	Time since amputation	Prosthesis use (days/ month)	Prosthesis use (hours/ day)	PA weekly (hours)	Social stigma	AI: Social	AI: Self
Demographic	Age	1								
Variables	Gender	16**	1							
Clinical Variables	Time since amputation	.12*	03	1						
	Prosthesis use (days/month)	.09	03	.05	1					
	Prosthesis use (hours/day)	.03	21**	.10	.56**	1				
Predictor variable	PA (hours/week)	06	17**	.01	.29**	.38**	1			
Mediator variable	Social stigma	10	.06	12*	25**	26**	23**	1		
Outcome variables	AI: Social	13*	19**	04	.04	.17**	.35**	17**	1	
	AI: Self	15**	16**	02	.09	.20**	.40**	16**	.80**	1

#### Table 5. Spearman's $r_s$ Correlations

*Note.* Type of amputation valid n = 314; PA = physical activity; AI = athletic identity; \*\* correlation significant at p < .01 level; \* correlation significant at p < .05 level



*Figure 1*. Model 1: Mediated relationship between physical activity and athletic social identity with perceived social stigma as the mediator.



*Figure 2*. Model 2: Mediated relationship between physical activity and athletic self-identity with perceived social stigma as the mediator.

Type of Amoutation		Engguenau
Type of Amputation		Frequency
Other $n = 14$	~	
	Partial hand	3
	Partial foot	2
	Hip disarticulation	8
	Shoulder	1
Multiple $n = 8$		
1	Upper and lower limb amputation	2
	Bilateral lower	6
Cause of Amputation Other $n = 85$		
	Infection	30
	Congenital condition	15
	Failed medical procedure	4
	Nerve disorder	9
	Autoimmune disease	2
	Blood condition	6
	Bone conditions	8
	Necrotizing fasciitis	4
	Extreme sport	3
	Crime	1
	Undiagnosed	1
	Voluntary	2
	Voluntary	2

# Appendix A: Descriptive Clinical Information





## Appendix C: British Journal of Health Psychology Author Guidelines



## **Author Guidelines**

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

The types of paper invited are:

• papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;

• theoretical papers which report analyses on established theories in health psychology;

• we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and

• methodological papers dealing with methodological issues of particular relevance to health psychology.

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

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

## 1. Circulation

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

## 2. Length

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

## 3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined

by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified

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

## 4. Submission and reviewing

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

## 5. Manuscript requirements

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

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

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found <u>here</u>.

• Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

• Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.

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• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

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Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher. Author, A. (2013). Title of journal article. *Name of journal*, *1*, 1-16. doi: 10.1111/bjep.12031

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

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• Authors are requested to avoid the use of sexist language.

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## **Thesis Section Three: Critical Appraisal**

### A Critical Appraisal of the Study of Athletic Identity Following Amputation

Kimberley Keegan

Trainee Clinical Psychologist

Doctorate in Clinical Psychology Division of Health Research Faculty of Health and Medicine Lancaster University

Word count: 3,988 words excluding title page, abstract and references

Correspondence should be addressed to: Kimberley Keegan, Doctorate in Clinical Psychology, C14, Furness College Lancaster University, Lancaster, L1 4YG Email: k.keegan@lancaster.ac.uk

#### A Critical Appraisal of the Study of Athletic Identity Following Amputation

Following the completion of the literature review and empirical study, I will now present a critical appraisal of the thesis process. While conducting these two elements of the thesis I was alerted to several issues which spanned both papers; these issues appeared to highlight larger debates which I felt warranted further exploration in this critical appraisal. The first issue pertains to the conceptualisation and utilisation of athletic identity within clinical and health psychology. The second relates to the way psychological and rehabilitative approaches engage with the detrimental influence of social stigma on the experience of identity for people with physical impairments. As this thesis forms part of a Clinical Psychology Doctorate, I thought it pertinent to discuss the application of these concepts within the field of clinical psychology. Subsequently, these topics will be discussed alongside a personal reflection of my relationship to these issues, a consideration of the strengths and limitations of this thesis, and recommendations for future research and clinical practice.

#### **Research Findings**

The findings from the literature review demonstrated that elite-level sport facilitated the expression of valued identities for individuals with congenital and acquired physical impairments. However, these personally meaningful identities, which predominantly centred on the role of athlete, were challenged by the restrictions imposed by societal perceptions of a 'disability' identity. The findings from the empirical paper contributed to this understanding by providing evidence that perceived social stigma mediated the linear relationship between increased physical activity and stronger athletic identity (AI) for people with amputations. This effect was marginally stronger for social AI (whether participants felt other people saw them as an athlete), than for self-AI (whether participants viewed their own identity as an athlete), which bears resemblance to the qualitative accounts presented in the literature review. Together, the findings highlight the effects of social stigma on the strength and expression of AI for individuals who are subject to a 'disabled' social identity.

#### **Deciding on the Research Topic**

Amputation was an area of interest to me due to my wish to work clinically with military veterans. As a result of recent overseas operations, partial and complete amputation is a realistic health risk to individuals who are deployed (Ministry of Defence, 2017). An understanding of the impact of trauma, injury and amputation is therefore helpful for clinicians working with the veteran population. There were also several personal factors which led to my interest in exploring AI. As part of the clinical psychology training programme we are assigned clinical tutors who assist with our development both personally and professionally. Conversations with my tutor raised my awareness of how I hold many different and changing identities, several of which included sport, e.g. 'climber', 'swimmer' 'dancer'; furthermore, I was alerted to the idea that other people's perceptions of me may not always match with how I identify internally, e.g. on the training course I was predominantly seen as a 'psychologist'. I was therefore particularly interested in the concept of AI and the theory of self-complexity (Linville, 1985; Linville, 1987), which posits that multiple distinct identities are valuable for resiliency and psychological adjustment to difficult life events. This allowed me to consider the advantages of forming multiple and varied self-identities. Consequently, I was keen to explore the potential beneficial effects of AI for people with amputation.

Following a brief review of the evidence-base there also appeared to be theoretical justification to adopting identity as an outcome measure in the study of adjustment to limb loss. Within the research into amputation there is considerable debate regarding the use of different physical, social and psychological variables as valid measures of adjustment (Gallagher & Desmond, 2007; Horgan & MacLachlan, 2004). Indeed, the concept of

'adjustment' within the context of chronic physical health conditions can be considered to relate to multiple factors (Moss-Morris, 2013). Within amputation research, successful adjustment has been associated with a number of clinical outcomes, including increased prosthesis use (Murray, 2004), absence of anxiety and depression (Horgan & MacLachlan, 2004), and engagement in social activities (Nimhurchadha, Gallagher, Maclachlan, & Wegener, 2013). This variation may have contributed towards fragmentation within the evidence-base regarding the development of an integrated understanding of adjustment to amputation. It may have also resulted in the neglect of broader and conceptually complex aspects of adjustment, including changes to internal constructs such as identity, body image and self-schema (Horgan & MacLachlan, 2004). Subsequently, the focus on identity within this thesis can be considered a strength, owing to the understanding that identity will apply to all individuals with amputations regardless of their stage of adjustment.

However, identity as a concept holds many definitions and theoretical conceptualisations. For example, cognitive models describe identity as a set of meanings and values about the self, formed by past experiences (Markus, 1977), whereas narrative and biographical accounts position identity as a coherent internalised story formed within the context of dominant social stories (Singer, 2004). Together, these accounts demonstrate an interaction between external events and internally adopted views about the self. Within the context of physical impairment, other constructs such as body image have also been explored with regards to identity. *Body image* is used to capture self-perceptions, beliefs, and attitudes about one's appearance (Cash, 2002). Although the two may be considered to share conceptual properties, e.g. both pertain to thoughts about the self, research has shown that body image is related to identity as a distinct predictor variable (Kamps & Berman, 2011). This suggests that thoughts and feelings about bodily appearance can be considered as distinct from internal views about the self. For the purposes of the literature review, which

aimed to capture the identity-related experiences of elite athletes, identity was defined as any experience, attitude or perception about the self or the self as viewed by others within the context of sport. Subsequently, articles relating to attitudes about the body were excluded if they did not also include reference to or exploration of how these attitudes impacted on internalised views of the self.

#### **Epistemological Position**

It was during the early stages of my background reading that I began to think about how I have come to understand the experiences of individuals living with physical difference. Initially, I started from a position of believing there to be no one 'external truth', and therefore I understood the difficulties associated with physical difference to be a product of socially constructed ideas. That is, the experience of living with a physical impairment is shaped through human interaction and language and in such a way 'disability' is created. However, through my reading I came to realise that these attitudes and beliefs had the ability to create excluding social structures and systems within society which could also affect the way individuals identified internally. In this way, socially constructed ideas about physical impairment contributed towards a 'real' and lasting experience for this population. I was also exposed to the idea that a purely postmodernist view can neglect the role of the anatomical body in the experience of living with a chronic illness or physical impairment (Williams, 1999). Therefore, by acknowledging the combined influence of social and 'embodied' experiences I began to view the effects of physical impairment on identity from a critical realist perspective. This framework would propose that the existence of an objective 'reality' (in this case the physical impairment) is shaped by the influence of personal and societal perspectives.

3-5

#### **Clinical psychology and Athletic Identity**

While conducting preliminary research, I approached different clinical psychologists working within the field of amputation and health psychology, to understand how AI may present clinically within health psychology. I was surprised to hear that AI could be viewed and described as an unhelpful clinical characteristic in the population of people psychologists saw within the National Health Service (NHS). It seemed psychologists more often encountered strong AI in individuals who used to be athletic, for example before an accident, who then found themselves unable to be as physically active following this event. In these cases, it seemed the psychologists I talked to understood that AI contributed negatively to psychological wellbeing as it represented a previously held identity which was no longer available.

However, findings on the Athletic Identity Measurement Scale (AIMS) in the empirical study show that individuals with amputations report AI to the same extent as a sample of non-impaired individuals taking part in similar levels of physical activity (Brewer, Van Raalte, & Linder, 1993). This therefore indicates that AI remains available to individuals following life-altering events such as traumatic accidents. This proposition may also be supported by findings from the literature review, which identified that many athletes who were active before acquiring an impairment used sport to recapture valued pre-trauma aspects of identity. This does not mean to say AI will be available in the same form as before an accident; a person may have to engage in sport in a different way, for example, using assistive technology such as a wheelchair. However, it is here where the skills of clinical psychologists may be applied. By supporting individuals to positively accommodate (Joseph, 2011) new information about the body into AI, individual assumptions of what it means to be physically active may be revised to account for physical impairments.

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The hesitancy shown by clinical psychology, as a profession, to emphasise and develop the adaptive aspects of AI may be explained by the outcomes associated with an exclusive AI. Research has warned of the risks associated with an exclusive AI (Carless & Douglas, 2009; Douglas & Carless, 2009); over-identification with the athlete role has been associated with disengagement from other important aspects of life such as education (Adler & Adler, 1985), and family life (Carless & Douglas, 2013), and an increase in harmful preoccupations such as 'disordered' eating (Gapin & Petruzzello, 2011). It seems these effects have primarily been observed in individuals participating in a higher-level of sport and therefore this theoretical argument may have been based on this sub-section of the population. These findings, considered alongside the evidence for the psychosocial benefits of AI, suggest that AI is most advantageous when it is held as one self-concept alongside other equally valued definitions of the self which together form a multifaceted identity (in support of this theoretical position see Linville, 1985;1987).

In their exploration of the narrative development of AI, Carless and Douglas (2013) demonstrated how individuals may come to over-identify with the role of athlete. Their study followed the journey of two non-impaired young athletes through their increased participation in competitive sport. The analysis revealed that AI developed through a constant interaction between dominant social ideas about elite sport involvement (e.g. training should be prioritised) and the participant's individual alternative stories (e.g. my relationships are important to me). To conceptualise this process, the authors applied narrative identity theory (McAdams & McLean, 2013), which posits that identity is shaped through the integration of life experiences into an internal evolving story. Carless and Douglas (2013) found that AI was forged when dominant and alternative stories collided; in these occasions individuals are presented with a dilemma: to modify individual behaviour to adhere to the dominant narrative, or to challenge the dominant narrative by drawing on

alternative individual narratives. The study concluded that over-identification with the athlete role may occur when an individual repeatedly dismisses alternative stories in favour of the dominant social view, for example an individual may neglect important relationships in order to adhere to the dominant social narrative of the importance of attending every training session. Such sacrifices may detract from an individual's identity outside of sport, potentially leaving them vulnerable when they reduce their involvement in sport, either due to injury or retirement.

Overall, the positive outcomes associated with physical activity and subsequent AI for individuals with physical impairment within the available evidence-base is convincing, indicating that this population's access to sport should not be curbed by restrictive societal perceptions of 'disability' as associated with physical weakness or incapability. However, it may be the role of clinical psychologists to support individuals to understand the advantages and disadvantages of relying on one aspect of identity over others within the context of any psychological distress.

#### The Role of Stigma

The findings of the empirical study demonstrated the role of perceived social stigma in the development of AI for this sample of people with amputations. My personal experiences have informed me that people with amputations can be just as, if not more, 'athletic' than people without amputations. However, I am aware this is not a common perception; within my gym, there is only one person with an amputation among an approximal total of 350 members. This individual's presence is not much remarked upon, however I am aware that he invokes thoughts and feelings of admiration, respect, and intrigue in me which is much the same as when my attention is drawn to other people in the gym, for example mothers juggling their baby in between classes or pensioners weaving in and out of the crowd setting off on their mile run. I often wonder whether people who do not have these insights into the wonderful world of sport would share my opinion that anyone can be active, regardless of their appearance, weight, strength, or health. This led me to think that it was the community aspect of my gym which really sought to challenge the status quo and make everyone feel welcomed and involved in its shared identity. Reflecting on my work within clinical psychology, it seems that many people who experience social stigma may not have exposure to supportive community environments where 'face-value' judgments are not made.

Throughout the reading and supervision required for the completion of this thesis, I became more closely acquainted with social models of disability and began to think how these related to clinical psychology. The social model of disability proposes that it is social processes, not physical differences, which cause 'disability' (Shakespeare, 1993). The findings from both the literature review and empirical paper offer support for this theoretical stance, evidencing the impact of social attitudes on the expression of valued identities. However, when I came to think about the application of these findings to clinical practice, I began to notice areas of difference between the way the issue of stigma is approached by clinical psychology research and the area of disability studies. During my reading I was exposed to the distinction between the terminology: 'physical impairment' and 'disability'. Documents such as the 'Reducing bias in language' guidelines (American Psychological Association, 2010), have emphasised the role of language in separating impairments from identity. For example, by using the phrase 'she/he has an impairment' rather than 'she/he is impaired', in this way individuals may be viewed as having a difference as opposed to being defined by it. I was therefore surprised to discover the frequency with which the word 'disability' is used to represent 'physical impairment' in the psychological evidence-base (e.g. Bogart, 2014; Dunn & Burcaw, 2013). Such use has the potential to perpetuate the medical view that 'disability' is an individualised physical problem (Supple, 2005).

This led me to think about how physical impairment was conceptualised and responded to within clinical psychology. From a critical realist perspective, anatomical differences and social experiences create psychological difficulties which become the focus of 'treatment' within clinical psychology. Clinical psychologists are required to draw on and integrate a wide range of interpersonal, biological, social and cultural factors when making sense of an individual's difficulties (Division of Clinical Psychology, 2011). However, when it comes to psychological intervention, therapeutic approaches remain largely focussed on an individualistic strategy to change. For example, cognitive-behavioural therapy (CBT), the therapy adopted by the NHS to increase the general public's access to psychological therapies (Clark, 2011), predominantly pursues psychological change by challenging an individual's thoughts and behaviours (Beck, 1976). It can therefore be argued that this approach fundamentally places full responsibility for distress and change within the individual. Within the context of critical realism, this form of psychological intervention neglects to acknowledge the valid contribution of constructed attitudes and meanings to the problem. For those people with physical impairments, CBT may not directly acknowledge the objective truth that 'disability' is not considered a 'desirable' identity within our society (Deal, 2003).

There are however, approaches which I would consider to helpfully integrate the influence of social and personal factors. For example, systemic conceptualisations of psychological distress (such as the model outlined by Prest and Robinson, 2006) and narrative theory (White & Epston, 1990) place emphasise on understanding the objective views of others and how these are experienced by the individual. Subsequently, I feel these approaches do not place 'blame' within the individual for the problem however do place 'responsibility' within the individual to work towards change (a principle discussed by Merrett, 2015). Through this reflection I have considered how, firstly, an individualistic

focus within clinical psychology may further contribute towards a 'medical' understanding that the individual is at fault, and secondly, how systemic approaches such as community psychology may redirect this focus to changing public perceptions and assumptions of a 'problem'.

I will now move on to discuss how these reflections influenced the research design, with reference to the strengths and limitations of the project, before concluding with areas of future research and practice which may contribute towards a social approach to physical impairment within clinical psychology.

#### **Designing the Study**

#### A Change in Direction

The empirical study began with the research question: does AI mediate the relationship between increased physical activity and appearance-related concerns for people with amputations. During the initial analysis it became apparent that this effect was not observed within the sample. This caused me to consider whether there was another interaction between the variables which might have impacted on the role of AI for this sample. I therefore decided to theoretically reconsider how the variables may be related. From the findings of the literature review I knew that the valued experience of holding an AI was influenced by negative societal views of 'disability'. I therefore wondered whether this interaction also occurred within the numerical dataset. Due to my increased understanding of a social model of disability, I thought it important to explore the effects of social stigma on the internal experience of identity for people with amputations. I therefore wanted to understand whether internalised stigma influenced the development of AI for the sample. Mediation analyses confirmed that this was the case, indicating that the relationship between increased physical activity and greater AI was mediated by perceived social stigma.

In his most recent account of mediation, Hayes (2018) places emphasis on the researcher's responsibility to interpret and place meaning on mathematical procedures as opposed to relying on these procedures to provide meaning. I decided that the analysis of perceived social stigma as a mediator would be a more effective story to share within the empirical evidence-base. Primarily, it provides quantitative support for the findings of the literature review, and secondly, it highlights an important area of psychological change (internalised stigma) as a result of physical activity which may benefit the lives of individuals adjusting to limb loss. In order to avoid a bias in responses, the study advertisement and information sheet did not contain specific information pertaining to the original hypothesised data analysis procedure. Therefore, I did not deem it unethical to change the focus of the analysis post data collection. The above amendments were submitted and subsequently approved by the Research Ethics Committee Board.

#### **Sample Characteristics**

There was a purposeful difference between the samples included in the literature review and the sample recruited for the empirical study. In the literature review, a focus was applied on elite athletes with both congenital and acquired physical impairments. This was partly due to the majority of suitable studies not differentiating between the two populations, however it was also completed due to an interest in whether the synthesis of identity-related experiences revealed differences between the two groups. Theoretically, there are differences between how individuals with congenital and acquired differences incorporate impairment into identity (Smart, 2008). For example, Bogart (2014) discovered that individuals with congenital differences reported a stronger 'disability' self-concept than participants with acquired impairments. Disability self-concept was measured as the incorporation of impairment into identity, holding an affirmative identity as someone with a physical impairment, and a sense of connection to others with physical impairments. Crucially,

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stronger disability self-concept was associated with greater satisfaction with life (Bogart, 2014), suggesting that the processes more commonly observed in people with congenital differences may promote psychological wellbeing.

Overall, the differences between the experiences of athletes with congenital and acquired differences in the literature review were not strong enough to form a third-order construct, however one paper (Hardin, 2007) explored these differences in an all-female sample in more detail. This study found that 'disability' as part of self-concept was more visible to women who had acquired their impairment in their adolescent years compared to women who had lived their whole lives with their impairment. For example, Elizabeth, aged 22, who was born with a tumour on her spine, stated: "I've never known anything else. I was born disabled, so to me... It's really not an issue" (Hardin, 2007, p. 44). Whereas Amanda, also aged 22, who acquired a back injury in high school said: "...my life was so different before my disability and so very different after... I would definitely say disability is my number one [identity]" (Hardin, 2007, p. 44). This therefore shows that the stage in life at which people become aware of their physical difference can play a role in the way that information is incorporated into identity. It may be considered a limitation of this thesis that further understandings of the differences in AI between people with acquired and congenital differences cannot be provided. However, the finding that none of the included articles referred to differences in the way individuals with congenital and acquired impairments used sport to express valued identities seems to suggest that sport is a context in which this sample characteristic is not as evident.

With regards to the focus on individuals with acquired amputations in the empirical paper, it may be considered that the study sample, who had on average lived with their amputation for a period of four years, may have been experiencing greater difficulties with the incorporation of impairment into identity. Although identity-related distress was not

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explored within the scope of this study, it can be concluded from previous research that acquired impairments may result in a period of increased vulnerability to the negative effects of a 'disability' identity. The findings from this study show that for individuals who have recently undergone amputation, physical activity can play a beneficial role in the reduction of perceived social stigma and the development of a valued identity.

#### Conclusion

To conclude, this thesis has developed the evidence-base with regard to the relationship between physical activity, social stigma, and AI for individuals with physical impairments. Overall, the findings suggest there are aspects unique to the practice of physical activity which challenge the dominant social stereotypes of 'disability'. Developments in future research and practice may look towards tailoring physical rehabilitation activities to allow for the reconceptualisation of an individual's abilities.

Personally, the completion of this thesis has increased my knowledge and confidence in several clinical areas including identity, AI, stigma and physical impairment. However, I think the most pertinent learning I plan to take forward into clinical practice is a greater integration of the issues deemed important in both clinical psychology and disability studies (an issue explored in depth in Simpson & Thomas, 2015). This shift includes a greater recognition of the dominant social forces which impact on an individual's distress, a concept held pertinent within disability studies, while still recognising the need to encourage individual responsibility to change, held central within clinical psychology practice. Hopefully, an integration of these two theoretical standpoints within my clinical work will validate people's experiences within an unjust world, while increasing their confidence to create meaningful change.

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Running head: ETHICS

**Thesis Section Four: Ethics** 

Kimberley Keegan

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Division of Health Research

Lancaster University

Word Count: 5,950

(excluding printed words on FMREC ethics application form,

references, appendices, tables & figures)



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

## Application for Ethical Approval for Research

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

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

**Title of Project**: Does Perceived Social Stigma Mediate the Relationship between Physical Activity and Athletic Identity for Individuals with Amputations?

ACPID number (if applicable)\*:

Funding source (if applicable)

Grant code (if applicable):

 $\label{eq:starses} * If your project has \textit{not} been costed on ACP, you will also need to complete the Governance Checklist [link].$ 

### Type of study

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

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

### SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist								
2. Contact information for applicant:								
Address: C14 Furness College Lancaster University Lancaster, UK LA1 4YG								
3. Names and appointments of all members of the research team (including degree where applicable)								
Kimberley Keegan (Principal Researcher) Dr Craig Murray (Research Supervisor) Dr Jane Simpson (Field Supervisor)								
<b>3. If this is a student project, please indicate what type of project</b> by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete <b>FHMREC form UG-tPG</b> , following the procedures set out on the <u>FHMREC website</u>								
PG Diploma	Masters by research PhD	) Thesis	PhD Pall. Care					
PhDPub.Health	PhD Org. Health & Well Being	PhD M	ental Health	MD				

DClinPsy SRP

DClinPsy Thesis X

**4. Project supervisor(s), if different from applicant**: Dr Craig Murray (Research Supervisor) Dr Jane Simpson (Field Supervisor)

**5.** Appointment held by supervisor(s) and institution(s) where based (if applicable): Dr Craig Murray (Senior Lecturer, Lancaster University); Dr Jane Simpson (Research Director and Senior Lecturer, Lancaster University)

### SECTION TWO

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

1. Anticipated project dates (month and year) Start date: Enddate:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

#### Data Management

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

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no

### ETHICS

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no 4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons N/A

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

6a. Is the secondary data you will be using in the public domain? no6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

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

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

### 8. Confidentiality and Anonymity

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

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

### SECTION THREE

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

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

Research has previously established a strong relationship between increased physical activity and stronger athletic identity for the general population however this relationship is thought to be somewhat disrupted for people with physical impairments owning to multiple social-relational barriers associated with a 'disabled' identity. From the research, it is understood that participation in sport can have beneficial outcomes for people who have had an amputation; assisting physical aspects of rehabilitation but also the adaptation to a new identity and the social responses that accompany it. This study therefore aims to explore whether perceived social stigma mediates the relationship between increased physical activity and stronger athletic identity for people with amputations. A quantitative approach will be used; participants will be asked to complete questionnaires via online survey software or return hardcopy survey packs. Participants will be recruited internationally via social media and amputation and prosthetics organisations.

2. Anticipated project dates (month and year only)

Start date: 01/08/2017 End date: 31/08/2018
# Data Collection and Management

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

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

In order to determine the sample size, a multiple linear regression power analysis was conducted using G\*Power (Faul, Erfelder, Bucnhner, & Lang, 2014). With a medium effect size ( $f^2$ ) of .15, an alpha of .05, a standard power level of .80, and a total of 2 predictors, the results of the power analysis showed that a minimum of 68 participants would be required to achieve an appropriate power level for this study. The appropriateness of the power calculation will be assessed at certain points throughout the data collection period. If power falls below the required level at any point the effect size will be recalculated based on the data received as opposed to the data estimated and the recruitment time period may be extended. There will be no maximum number of participants. Recruitment will end at the close of the recruitment period (12/2017). 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.

Participants will;

• Have had an acquired amputation (upper or lower surgical limb removal due to disease of trauma). Exclusion Criteria

Participants will not;

• Have limb absence from birth.

• Use a prosthesis to aid a congenital limb difference (e.g. to help support a poorly developed limb).

• Have a physical disability other than amputation.

Participants must be of 16 years of age or above to take part in the study. Personal data (e.g. gender, 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. Personal data including age and gender will be entered into the analysis. Nationality and ethnicity will not be entered into the analysis due to the categorial nature of these variables; this information will be collected to inform the descriptive statistics of the sample only.

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

Participants will be recruited online. The study advertisement will be posted on various platforms, including Twitter, Facebook and a Lancaster University hosted webpage

(http://www.lancaster.ac.uk/shm/study/doctoral\_study/dclinpsy/). Specialist amputation and prosthesis organisations and support groups, such as the Amputee Coalition and the Limbless Association, will be contacted by Twitter, 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, Facebook). The principal researcher will also use a professional Twitter account to connect with the Twitter accounts of organisations and individuals to promote the study. The study advertisement will also be shared via online support networks (e.g. Facebook).

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.

The online advertisement will read as follows:

 I am conducting a study on how physical activity might affect a person's feelings about appearance following an amputation.

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• I am interested in gathering information from individuals who have had, in the past, an amputation. You do not need to take part in exercise or sport to contribute to this study. If you fit the following criteria, then I would be very pleased for you to complete the survey.

Inclusion criteria:

Participants will have had in the past an acquired amputation (upper or lower surgical limb removal due to disease or trauma).

Aged 16 years and over.

Exclusion Criteria:

Participants will not have limb absence from birth

Use a prosthesis to aid a congenital limb difference (e.g. to help support a poorly developed limb). Have a physical disability other than amputation.

The survey should take around 15 minutes to complete.

If you would like to take part, you can find more detailed information about the study via this link (link provided). Please take adequate time to consider this information before proceeding to the survey link provided below.

To access the survey please follow this link (link provided). Alternatively, if you would like to receive a paper copy of the survey, or would like to ask any questions, please contact the lead researcher on k.keegan@lancaster.ac.uk.

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

The study will adopt a quantitative approach to investigate whether perceived social stigma mediates the relationship between physical activity and athletic identity.

Data will be collected via a series of quantitative self-report questionnaires. Direct quotes and comments will not be collected. Questionnaires will be hosted by the Lancaster University supported online survey software (Qualtrics) or provided as hardcopy participant survey packs.

Data collected by Qualtrics and surveys returned by post will be entered into the Statistical Package for the Social Sciences (SPSS) Version 22 for analysis. Kolmogorov-Smirnoff tests will be conducted on all continuous variables to assess for normality of the distribution. Non-normal variables will affect how the results are interpreted and will be corrected using the most effective transformation for that data set (e.g. logarithmic transformation). Missing data will be addressed with the appropriate procedure and software on SPSS depending on the nature of the missing data (random or not random). Descriptive statistics will be reported and analysed for all variables. Correlations (Pearson r: two-tailed) will be used for descriptive purposes to identify significant patterns between the predictor variable, mediator and outcome.

Model parameters will be assessed by a series of statistics. VIF, tolerance and eigenvalues will be calculated to assess collinearity within the dataset. The Durban-Watson test will be applied to check for autocorrelation of residuals. Casewise diagnostics will be examined to check for bias within the residuals. Standardised residuals will be plotted against standardised predicted values to check for heteroscedasticity and non-linearity. If the dataset meets these assumptions and the conditions to indicate mediation, mediations analysis will be completed as outlined by Hayes (2018). Analysis will be completed by the principal researcher and reviewed by a member of the research team.

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

All electronic data will be stored securely on the principal researcher's Lancaster University box storage facility, a secure electronic file storage and transfer system. Hardcopy surveys will be destroyed immediately after the data had been uploaded onto the excel spreadsheet. Data will be encrypted following completion of the research study for transfer to long-term storage. The data will be sent to the university Doctorate in Clinical Psychology Research Coordinator via box, and stored under password protection on the university server. Data will be stored

for 10 years, when it will be the responsibility of the Research Coordinator to delete the data.

7. Will audio or video recording take place? In o audio video a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. No identifiable information will be collected.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files bedestroyed

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

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE? Supporting electronic data will be stored in Lancaster University's institutional data depository (PURE) and made freely available with an appropriate data license.

8b. Are there any restrictions on sharing your data ?  $\ensuremath{\mathsf{N/A}}$ 

9. Consent

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

b. Detail the procedure you will use for obtaining consent?

A consent procedure will be incorporated into the online survey. Participants will have access to the participant information sheet for the study via a link in the online study advertisement. Participants will be advised to take adequate time to consider this information before proceeding to the study via the online survey link, also presented in the advertisement. When accessing the online survey link, participants will then be presented with a series of statements relating to their agreement to consent to participate. Participants will be advised that by continuing on to the next page of the survey they will be indicating that they have read the participant information sheet and consent to participate. If the participant does not wish to consent to the study they will be advised to exit the online survey at this point, before completion of the questionnaires.

If a participant requests a paper copy of the study materials (by contacting the lead researcher via the contact details provided in the advertisement), the participant information sheet, 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. Participants will be advised to read the participant information sheet and consent form. Participants will be advised that by completing and returning the questionnaires they are thereby indicating their consent to participate. There will be an electronic consent form and a hard copy consent form, they will outline the respective procedures listed above.

10. 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. State the timescales within which participants may withdraw from the study, noting your reasons.

It is not anticipated that any risk will occur during completion of this study. However, it is possible that participants may become distressed whilst filling out the questionnaires. To minimise potential distress, participants will be provided with general advice (i.e. contact general practitioner) and suitable support group contact details prior to beginning the questionnaires. If participants contact the principal researcher via email to disclose a concern for their welfare, they will be advised to contact their general practitioner. If the research team is concerned for the safety of a participant, they will be informed that their personal email may be forwarded onto a health professional or support service in their area.

Participants will be informed prior to starting the questionnaires that they are able to opt out at any time during the completion of the questionnaires. However, participants will be informed that data entered up until the point

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they stop completing the questionnaires will be used in the analysis. Participants will be able to contact the lead researcher to request removal of all their data. This process will require participants to enter a four-digit code as part of the completion of the online survey/return of the hardcopy survey. Participants will be informed that this code should be unique to them and not likely to be entered by someone else, and that this code will be used by the lead researcher to identify their responses should they wish to withdraw their data at a later date This option will be available to participants up until the study analysis period expected to begin on 1<sup>st</sup> January 2017.

Participants will be provided with the contact details of an independent member of the Lancaster University staff team to be able to lodge a complaint should they wish.

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

As members of the research team will not be meeting one-to-one with participants, it is not anticipated that they will come to any harm during the completion of this study. 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 ).

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

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

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants: Lancaster University will be approached to fund the costs of involving amputation organisations in the involvement of this study (e.g. for advertising the study), however individual participants will not be reimbursed for taking part.

14. Confidentiality and Anonymity

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

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

Participants will not be asked for their name or contact details. Although age, gender, nationality and ethnicity information will be collected there will be no way to identify participant answers. Due to this, it is unlikely that the research team will be able to intervene if information gathered raises concern for the welfare of participants. However, if information shared via email (e.g. when requesting additional information) raises concern for the participant's or another's welfare this information may be forwarded to a health or support agency (e.g. a general practitioner).

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The principal researcher had conversations with people with amputations via a professional Twitter account. Conversations centred on the topic of physical activity following amputation and its perceived benefits and discussions have been used to guide the development of the protocol. Organisations involved in the rehabilitation of people with amputations (e.g. LimbPower, Liverpool Prosthetics and Wheelchair service) have also been approached to discuss the feasibility of the study and relevance to clinical practice.

People with amputations and professionals involved in amputations and prosthetics (e.g. from LimbPower) have reviewed the study design, planned procedure and materials.

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

The study will be written as a doctoral thesis and submitted to Lancaster University.

A short report of the findings will be written and offered to organisations involved in recruitment of participants on request.

The study will be submitted for publication in an academic peer reviewed journal.

The findings of the study may be presented at conferences or to healthcare teams and support groups involved with amputation, sport and prosthesis use.

All disseminated information will be presented in an anonymous format.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC? No further ethical considerations have been identified. References:

Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2008). *G\*Power Version 3.1.2* [computer software]. Uiversität Kiel, Germany. Retrieved from http://www.psycho.uniduesseldorf.de/abteilungen/aap/gpower3/download-and-register

Hayes, A. F. (2018). Introduction to mediation, moderation, and conditional process analysis: A regression-based approach (Second edition). New York: The Guilford Press.

# SECTION FOUR: signature

Applicant electronic signature: K.Keegan

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

Project Supervisor name (if applicable): Craig Murray

Date application discussed 20/03/2018

Date 10/05/2018

### Submission Guidance

1. Submit your FHMREC application <u>by email</u> to Diane Hopkins (<u>d.hopkins@lancaster.ac.uk</u>) as two separate documents:

### i. FHMREC application form.

Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.

### ii. Supporting materials.

Collate the following materials for your study, if relevant, into a single word document:

- a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
- b. Advertising materials (posters, e-mails)
- c. Letters/emails of invitation to participate
- d. Participant information sheets
- e. Consent forms
- f. Questionnaires, surveys, demographic sheets
- g. Interview schedules, interview question guides, focus group scripts
- h. Debriefing sheets, resourcelists

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

- 2. Submission deadlines:
  - i. Projects including direct involvement of human subjects [section 3 of the form was completed]. The *electronic* version of your application should be submitted to Diane Hopkins by the

**committee deadline date.** Committee meeting dates and application submission dates are listed on the <u>FHMREC website</u>. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

- ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. [Section 3 of the form has *not* been completed, and is not required]. Those involving:
  - a. existing documents/data only;
  - b. the evaluation of an existing project with no direct contact with human participants;
  - c. service evaluations.
- 3. You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

# Doctorate in Clinical Psychology



### **Research Protocol**

# Does Perceived Social Stigma Mediate the Relationship between Physical Activity and Athletic Identity for Individuals with Amputations?

Kimberley Keegan, Lancaster University Dr Craig Murray, Lancaster University Dr Jane Simpson, Lancaster University

Individuals are faced with many challenges following an amputation, including the adjustment to the emotional, social and physical effects of losing a limb. Previous research suggests that psychosocial adjustment following amputation is influenced by multiple biopsychosocial factors including; social support, satisfaction with prosthesis, level of amputation, time since amputation, pain, personality traits and coping styles (Desmond & Maclachlan, 2006; Hanley et al., 2004; Horgan & MacLachlan, 2004). This provides a wide range of theoretical and practical points to consider when choosing a focus within empirical research and when aiming to support an individual in their path to recovery. Research studies have tended to focus on the absence of depression as a main indicator of successful adjustment to amputation, thereby neglecting important aspects of rehabilitation such as changes in adjustment and identity (Horgan & MacLachlan, 2004).

Following an amputation, individuals are required to adjust to a new image of their body and the reaction this creates from society. Not only do individuals with amputations experience a change in the way they view themselves, they can also experience a change in the way they think others see them. This has been defined as perceived social stigma and refers to an individual's belief that others hold negative attitudes towards them based on their disability. Perceived social stigma has been related to a number of negative outcomes for people with amputations (Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995) and is thought to impact on who a person feels they can be.

In contrast to the negative associations attached to a 'disabled' identity, qualitative findings suggest that participation in sport can reduce perceived stigmatisation and facilitate identity negotiation in people taking part in a community-based setting (Lundberg, Taniguchi, McCormick, & Tibbs, 2011). Furthermore, taking part in a competitively high level of sport was found to enhance personal and social identities of people with disabilities (Pack, Kelly, & Arvinen- Barrow, 2016). These findings suggest that participation in sport can have effects on the construct of identity. Moreover, having an athletic identity was found to significantly predict quality of life in individuals with cerebral palsy over and above the severity of their disability (Groff, Lundberg, & Zabriskie, 2009).

Despite this, it remains the case that the majority of individuals with amputations are at risk of low levels of physical activity (Langford, Dillon, Granger, & Barr, 2018) and are therefore less likely to access the beneficial outcomes of an athletic identity. There are a range of benefits of increased physical activity for people who have experienced an amputation and therefore it forms an essential focus within the multi-professional rehabilitation process for amputation (Esquenazi & DiGiacomo, 2001). While there is a direct relationship between increased physical activity and athletic identity for the general population (Anderson, 2004), this relationship appears somewhat disrupted for people with amputations owing to the lower reported physical activity and athletic identity for this group (Tasiemski, Kennedy, Gardner, & Blaikley, 2004).

Although there is research into the positive effects of sport on post traumatic growth in people with amputation (Day, 2013), research has not yet considered the specific role of athletic identity in adjustment and rehabilitation. From the research outlined above, it can be hypothesised that participation in sport can have beneficial outcomes particularly around the adaptation to a new identity and the social responses that accompany it. To date, research has not explored what mediates the relationship between increased physical activity and athletic identity for this population. This study therefore aimed to test whether perceived social stigma mediated the relationship between increased physical activity and greater athletic identity for people with amputations.

### Method

### Procedure

To test the above hypothesis, people who have had an amputation will be recruited to fill in a series of online questionnaires. This set of questionnaires will measure their athletic identity, how often they exercise in a week, how long they have done exercise, their type of amputation, time since amputation, how much social support they have, how the person feels about their body, how they feel other people view them, and how much importance they place on appearance and other personal variables (age, gender). Preliminary analyses will be completed to determine how the variables are related to one another. If the data meets the assumptions required for mediation, mediation analysis will be completed to test whether perceived social stigma mediates the relationship between physical activity level and reported athletic identity.

### **Participants**

An a priori power calculation using G\*Power (Faul, Erfelder, Bucnhner, & Lang, 2014) for multiple regression analysis, assuming a medium effect size of .15, power of .8, with an alpha level of .05 for 2 predictors, suggested a total sample of around 68 participants would be required.

Participants will be recruited online. Online advertisements will be posted on various platforms, including Twitter, Facebook, and a Lancaster University hosted webpage (http://www.lancaster.ac.uk/shm/study/doctoral\_study/dclinpsy/). Specialist amputation and prosthesis organisations and support groups, such as the Amputee Coalition and the Limbless Association, will be contacted by telephone, Twitter 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.

### **Inclusion Criteria**

Participants will;

- Have had an acquired amputation (upper or lower surgical limb removal due to disease of trauma).
- Be aged 16 years and over.

### **Exclusion Criteria**

Participants will not;

- Have a limb absence from birth.
- Use a prosthesis to aid a congenital limb difference (e.g. to help support a poorly developed limb).
- Have a physical disability other than amputation.

Participation will not be determined by age, ethnicity, gender or nationality, although this information will be collected as part of the study to understand the demographics of the sample population and to be entered into the analysis. The study will be advertised in English language, which may impact the demographics of the sample completing this study.

### Design

The study will adopt a quantitative approach to test a statistical model with numeric data as the variables being tested. Data will be collected via a series of self-report questionnaires. Questionnaires will be hosted online by Qualtrics online survey software or provided as hardcopy participant survey packs.

### Materials

Online participants will have access to an electronic participant information sheet before being asked to read a series of consent statements before completing the online questionnaires. Participants who request a hard copy of the questionnaires will be asked to read a hard copy of the consent form which will be sent via post with the questionnaires.

Participants will be asked to provide some personal information, including age, gender, ethnicity and nationality. They will also be asked to complete a series of questions regarding their amputation, including the cause, type, and time since amputation. Participants will then be asked to answer questions on their participation in sport, including how long they have taken part in sport (years/months) and how often they take part in sport per week (minutes). Participants will be asked to complete six questionnaires, including;

• Athletic Identity Measurement Scale (AIMS; Brewer, Van Raalte, & Linder, 1990): This 10-item scale was developed to assess the strength and exclusivity with which an individual identifies with an athletic role. Subsequent research identified nine of the items loaded on four subscales; self-identity, social identity, exclusivity, and negative effectivity (Martin, Mushett, & Eklund, 1994). The items require response on a seven-point scale whereby seven represents strongly agree and one strongly disagree. Although this measure is not amputation specific, it has been validated in a sample of people with Cerebral Palsy (Martin, Eklund, & Mushett, 1997), and a study including three people with amputations (Van de Vliet, Van Biesen, & Vanlandewijck, 2008).

• Perceived Social Stigma Scale (PSSS; Rybarczyk et al., 1995):

The 22-items included in this measure were originally derived from a generated pool of common negative stereotypes of people with a disability. The final 22-items were validated in a sample of people with leg amputations (Rybarczyk et al., 1995), indicating good internal consistency.

### Analysis

Data collected by Qualtrics online survey software and surveys returned by post will be entered into the Statistical Package for the Social Sciences (SPSS) Version 22 for analysis. Kolmogorov-Smirnoff tests will be conducted on all continuous variables to assess for normality of the distribution. Non-normal variables will affect how the results of the regression are interpreted and will be corrected using the most effective transformation for that data set (e.g. logarithmic transformation). It is hoped that the likelihood of missing data will be reduced by setting Qualtrics to identify questions not completed and to prompt the participant to complete them before moving on. However, if this option is not available missing data will be addressed with the appropriate procedure and software on SPSS depending on the nature of the missing data (random or not random). Incomplete data sets (i.e. partial completion of the questionnaires) will be entered into the analysis providing the participant has not contacted the researcher to request removal of the data.

Descriptive statistics will be reported and analysed for all variables. Correlations (Pearson r: two-tailed) will be used for descriptive purposes to identify significant patterns between the predictor, mediator and outcome.

Model parameters will be assessed by a series of statistics. VIF, tolerance and eigenvalues will be calculated to assess collinearity within the dataset. The Durban-Watson test will be applied to check for autocorrelation of residuals. Casewise diagnostics will be examined to check for bias within the residuals. Standardised residuals will be plotted against standardised predicted values to check for heteroscedasticity and non-linearity-Finally, mediation-as outlined by Hayes (2018) will be completed using the PROCESS macro for SPSS (version 3; Hayes, 2018). This will be performed in two mediation models: model one will examine whether perceived social stigma mediates the relationship between physical activity and social athletic identity, and model two will explore the same indirect relationship on the outcome of self- athletic identity. Analysis will be completed by the principal researcher and reviewed by a member of the research team.

### **Practical Issues**

All aspects of the study can be accessed, completed and collated for analysis via the Qualtrics software. Participants will first be directed to the participant information sheet and consent form. Participants will be advised that by completing the questionnaires they thereby consent to the statements included in the consent form. Identifiable information (names, contact details) will not be collected which will ensure the data remains anonymous. The study advertisement and information sheet will include the principal researcher's email address so participants can request further details or a hardcopy survey pack. Surveys returned via post will be manually entered into an excel spreadsheet by the principal researcher.

All electronic data will be stored securely on the principal researcher's Lancaster University box storage facility, a secure electronic file storage and transfer system. Hardcopy surveys will be destroyed immediately after the data has been uploaded onto the excel spreadsheet. Data will be encrypted following completion of the research study for transfer to long-term storage. The data will be sent to the university Doctorate of Clinical Psychology Research Coordinator via box, and stored under password protection on the university server. Data will be stored for 10 years, when it will be the responsibility of the Research Coordinator to delete the data.

Lancaster University will be approached to fund the costs of involving amputation organisations in the involvement of this study (e.g. for advertising the study), however individual participants will not be reimbursed for taking part.

### **Ethical Concerns**

It is not anticipated that any risk will occur during completion of this study. However, it is possible that participants may become distressed whilst filling out the questionnaires. To minimise potential distress, participants will be provided with general advice (i.e. contact general practitioner) and suitable support group contact details prior to beginning the questionnaires. If participants contact the principal researcher via email to disclose a concern for their welfare, they will be advised to contact their general practitioner. If the research team is concerned for the safety of a participant, the participant will be informed that their personal email may be forwarded onto a health professional or support service in their area.

Participants will be informed prior to starting the questionnaires that they are able to

opt out at any time during the completion of the questionnaires. However, participants will be informed that data entered up until the point they stop completing the questionnaires will be used in the analysis. Participants will be able to contact the lead researcher to request removal of all their data. This process will require participants to enter a four-digit code as part of the completion of the online survey/return of the hardcopy survey. Participants will be informed that this code should be unique to them and not likely to be entered by someone else, and that this code will be used by the lead researcher to identify their responses should they wish to withdraw their data at a later date. The option to remove their data will be available to participants up until the study analysis period expected to begin on 1<sup>st</sup> January 2017.

As members of the research team will not be meeting one-to-one with participants, it is not anticipated that they will come to any harm during the completion of this study. The principal researcher may attend support group organisation meetings and events to discuss the study and disseminate hard copy survey packs. Whilst attending meetings of this nature 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/lc ft\_lone\_working\_policy.pdf ).

While every effort will be taken to ensure the research process is satisfactory, it is possible that participants will disagree with some aspects of the study. Participants will be provided with the contact details of an independent member of the Lancaster University staff team to be able to lodge a complaint should they wish.

### Timescale

The principal researcher will submit an application to the Faculty of Health and Medicine Research Ethics Committee for ethical review in June 2017, with a view to starting recruitment by August 2017. It is expected that recruitment will run from August - December 2017, with all data analysed by the end of January 2018. The study will be written and submitted as part of a doctoral thesis to Lancaster University by May 2018. The study will be suitably amended and submitted for publication by the researcher by September 2018, at this time the Ethics Committee will be notified of the study completion.

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# Appendix 4-A: Participant Information Sheet Version 3, July 2017



# **Participant Information Sheet**

# Exploring physical activity and feelings about appearance following amputation

My name is Kimberley Keegan and I am conducting postgraduate research at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore physical activity and feelings about appearance in people who have had an amputation.

Why would you like me to take part?

I am interested in gathering information from individuals who have had an amputation. To clarify, you do not need to take part in exercise or sport to contribute to this study. If you fit the following criteria for inclusion in the study, then I would be extremely grateful if you would complete the survey.

Inclusion criteria:

- Participants will have had in the past an acquired amputation (upper or lower surgical limb removal due to disease or trauma).
- Participants will be aged 16 years and over.

Exclusion Criteria:

- Participants will not have limb absence from birth.
- Participants will not use a prosthesis to aid a congenital limb difference (e.g. to help support a poorly developed limb).
- Participants will not have a physical disability other than an amputation.

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 online questionnaires asking about you and about your level of physical activity. You will not be asked for any personal identifying information, such as your name or any contact details.

Alternatively, you can request paper versions of the questionnaires by contacting me. In this instance I will require your address to send the pack out to you. Once the pack has been sent I will destroy the email with your address provided. The questionnaires can be sent back to me using the stamped and addressed envelope provided. The length of time to complete the questionnaires will vary from person to person, but it should take no longer than 15 minutes.

# Do I have to take part?

No. It's completely up to you whether you decide to take part. If you do decide to take part and change your mind, you can choose to opt out. If you are completing the survey online, you can stop at any point. Your responses up until the point you choose to stop will be used in the analysis unless you contact me to request the removal of all your data. Similarly, if you return partially completed questionnaires via post they will be used in the analysis unless you instruct me otherwise. To do this you just need to email me and provide me with the four-digit code you are asked to enter at the beginning of the survey. Please choose a code unlikely to be entered by another participant and keep your code safe. This code will be used to identify your data. You will have up until the 1<sup>st</sup> January 2017 to request the removal of your data.

# Will my data be identifiable?

The information you provide will be pooled with other participants' responses for analysis, and will therefore be confidential. I will not ask for your name or contact details and the questionnaires will not ask for any direct comments or quotes. The only way to identify your responses will be via the four-digit code of your choice. The data collected for this study will be stored securely and only the researchers conducting this study have access to this data:

- Hard copies of questionnaires will be destroyed immediately after the data has been uploaded onto a computer file.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, electronic files will be kept securely for ten years. At the end of this period, they will be destroyed.

There are some limits to confidentiality: if information shared via email (e.g., when requesting additional information) makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

# What will happen to my data?

Your data will be pooled with data from other participants. The data will then be analysed and written up as part of my 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 been completed. It is expected that summaries will be available from August 2018. If you would like a summary of the results, please contact me by email; k.keegan@lancaster.ac.uk.

# Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during completion of the questionnaires you may wish to exit the survey.

If you feel you need support, 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.

# MIND [https://www.mind.org.uk/]

- "We won't give up until everyone experiencing a mental health problem gets support and respect."

The Amputee Coalition [http://www.amputee-coalition.org]

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

Befrienders Worldwide [http://www.befrienders.org]

- "Providing emotional support to prevent suicide worldwide. We listen to and help people without judging them".

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 quality of life for people with an amputation in order to aid improved healthcare provision. However, there are no direct gains to taking part in the study. Who has reviewed the project?

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

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: Kimberley Keegan, by email: k.keegan@lancaster.ac.uk

Alternatively you can contact

Dr Craig Murray Tel: (01524) 592730

Research Supervisor Email: c.murray@lancaster.ac.uk

Doctorate of Clinical Psychology

Division of Health Research

Lancaster University

Lancaster

LA1 4YG

### 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 Roger Pickup Tel: (01524) 593746 Email: r.pickup@lancaster.ac.uk

Associate Dean for Research

Faculty of Health and Medicine (Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YD

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.

If you do wish to continue, the survey can be found at: [insert link]

# Appendix 4-B: Online Consent Form Version 2, July 2017



By proceeding to the survey you confirm that:

- You have read the information sheet and understand what is expected of you within this study
- You have had the opportunity to contact the research team to ask any questions and to have them answered
- You confirm that you understand that any responses/information you give will remain anonymous
- Yourparticipation is voluntary and you can optout at any point during completing the questionnaires
- You agree for any responses completed to be used in the analysis unless you contact the researcher to request the removal of all data
- You consent for the information you provide to be shared and discussed with my supervisors at Lancaster University
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished
- You consent for your responses to be pooled with other participants' responses for analysis and for the results to be written up as part of a doctoral thesis and published.
- By progressing on to the next page, you consent to taking part in the current study.

# **Appendix 4-C: Hardcopy Consent Form Version 2, June 2017**



## **Consent Form**

# Study Title: Exploring physical activity and feelings about appearance following amputation

I am asking if you would like to take part in a research project exploring physical activity levels following amputation and feelings about appearance.

Before you consent to participating in the study I ask that you read the participant information sheet and consider fully before reading the below consent statements and completing the questionnaires. If you have any questions or queries please contact me, the principal researcher, on <u>k.keegan@lancaster.ac.uk</u>.

- 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.
- 2. I confirm that I have had the opportunity to contact the research team to ask any questions and to have them answered.
- 3. I understand that my participation is voluntary and that I am free to withdraw at any time during the completion of the survey.
- 4. I understand that once I have completed and sent the survey I can contact the principal researcher up until 1<sup>st</sup> January 2017 to optout of the study and they will remove my data from the analysis.
- 5. I understand that the principal researcher will share and discuss data with the supervisors of the study.
- 6. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with health or support services.
- 7. I give consent for my responses to be pooled with other participants' responses for analysis and for the results to be written up as part of a doctoral thesis and published.
- 8. I consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished.
- 9. I consent to take part in this study.

By completing and returning the questionnaires you thereby agree with the above statements and consent to taking part in this study.

# **Appendix 4-D: Participant Survey Pack**

To enable to retrieval of your data at a later stage should you request it, please enter a four-digit code below. This code should be unique to you and unlikely to be entered by another participant. Please keep this code safe.

Unique code:

What gender do you	u identify as?
Male	Female
Other gender, please s	pecify:
How old are you?	
Where do you current	y live? Country:
What ethnic group of Choose one option the	<b>do you identify with?</b> nat best describes your ethnic group or background.
White English/Welsh/Scott Gypsy or Irish Travel American Other White backgroun Mixed/Multiple ethnic White and Black Cari White and Black Afric White and Asian Black Asian Any other Mixed / Multi Asian	ish/British ler id, <i>please describe:</i> <b>2 groups</b> ibbean an ble ethnic background, <i>please describe:</i>
Indian Pakistani Bangladeshi Chinese Any other Asian backgr	ound, <i>please describe:</i>
Black / African / Ca	ribbean
Caribbean	
Any other Black / Africa	n/Caribbean background, please describe:
Other ethnic group	
Arab	

Any other ethnic group, please describe:

# If the boxes above do not capture your chosen ethnicity please insert your own description: -

How long ago did	you have your amputation?					
Length of time:	YearsMonths					
How much do you currently wear your prosthesis?						
I wear my prosthes	sis, on average:days per monthhours per day					
What type of amputation do you have?						
Below-knee	Below-elbow					
Through-knee	Through-elbow					
Above-knee	Above-elbow					
Other	Other amputation, please specify;					
What was your amputation a result of? (Please tick any that apply)						
Peripheral Vascula	ar Disorder 🔲 Diabetes 🗌 Military trauma 🗌					
Cancer	Accident					
Other, please specify:						
How often do you	take part in sport/complete physical activity each week? (This can					
includeallformof	activity, e.g. walk, game of rugby, as long as it exerts some degree of					
physical exertion	on your body)					
Amount of time:	HoursMinutes					
How long have you been involved in sport/doing physical activity?						
Length of time:	Years Months					

Please mark an "x" in the space that best reflects the extent to which you agree or disagree with each statement in relation to your own sports participation.

1. I consider myself an athlete.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

2. I have many goals related to sport.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

3. Most of my friends are athletes.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

4. Sport is the most important part of my life.

Strongly Agree :\_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

5. I spend more time thinking about sport than anything else.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

6. I need to participate in sport to feel good about myself.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

7. Other people see me mainly as an athlete.

Strongly Agree : \_\_\_\_\_: \_\_\_\_: \_\_\_\_: Strongly Disagree

8. I feel bad about myself when I do poorly in sport.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

9. Sport is the only important thing in my life.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

10. I would be very depressed if I were injured and could not compete in sport.

Strongly Agree : \_\_\_\_: \_\_\_: \_\_\_: Strongly Disagree

As a person with an amputation, others see me as:

	Not at all	Somewhat	Mostly true	Very much
	true	true		true
a burden	1	2	3	4
different	1	2	3	4
unhappy	1	2	3	4
clumsy	1	2	3	4
slow	1	2	3	4
pitiful	1	2	3	4
noticeable	1	2	3	4
weird	1	2	3	4
strange	1	2	3	4
worthless	1	2	3	4
dependent	1	2	3	4
handicapped	1	2	3	4
shameful	1	2	3	4
defenceless	1	2	3	4
intelligent	1	2	3	4
attractive	1	2	3	4
friendly	1	2	3	4
worth knowing	1	2	3	4
confident	1	2	3	4
normal	1	2	3	4
healthy	1	2	3	4
able-bodied	1	2	3	4



# Have you had an amputation?

# If so we would like to hear from you...

- I am conducting a study on how physical activity might affect a person's feelings about appearance following an amputation.
- I am interested in gathering information from individuals who have had, in the past, an amputation. You do not need to take part in exercise or sport to contribute to this study. If you fit the following criteria, then I would be very pleased for you to complete the survey.

Inclusion criteria:

- Participants will have had in the past an acquired amputation (upper or lower surgical limb removal due to disease or trauma).
- Aged 16 years and over.
- Exclusion Criteria:
- · Participants will not have limb absence from birth
- Use a prosthesis to aid a congenital limb difference (e.g. to help support a poorly developed limb).
- Have a physical disability other than amputation.
- The survey should take around 15 minutes to complete.
- You can find some more detailed information about the study via this link (link provided). Please take adequate time to consider this information before proceeding to the survey provided below.

# • Toaccess the survey please follow this link (link provided).

• Alternatively if you would like to receive a paper copy of the survey, or would like to ask any questions, please contact the researcher on k.keegan@lancaster.ac.uk





Applicant: Kimberley Keegan Supervisors: Craig Murray and Jane Simpson Department: Health Research FHMREC Reference: FHMREC16107

17 July 2017

**Dear Kimberley** 

Re: Athletic identity as a predictor of appearance concerns in people with amputation

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

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

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

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

Yours sincerely,

Dione Havis

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



Applicant: Kimberley Keegan Supervisors: Craig Murray and Jane Simpson **Department: Health Research** FHMREC Reference: FHMREC17087

17 May 2018

**Dear Kimberley** 

Re: Athletic identity as a predictor of appearance concerns in people with 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 Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained:
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

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

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

Yours sincerely,

Diane Havis

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