ARTICLE IN PRESS

Psychology of Sport & Exercise xxx (xxxx) xxx–xxx

Contents lists available at ScienceDirect

Psychology of Sport & Exercise

journal homepage: www.elsevier.com/locate/psychsport

A longitudinal examination of leisure time physical activity following amputation in England

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ARTICLE INFO

Keywords:
Qualitative
Generalizability
Rigour
Policy
Sport
Exercise

ABSTRACT

Objectives: There is a significant body of research on leisure time physical activity (LTPA) among people with physical disabilities. Yet, while this data set has been informative in identifying the social-relational factors that affect LTPA across disability groups, there is now a demand for context- and population-specific studies to provide a more nuanced understanding to better inform decision-makers and service-providers. This original study is the first to examine the barriers, facilitators, and benefits of LTPA among people with an amputation in England.

Methods: Multi-method, longitudinal research design (from April 2014 to May 2016). Participants were recruited using maximum-variation and criterion-based purposeful sampling. Data collection included two focus groups (> 4hrs), fieldwork observations (> 225hrs), and 44 formal interviews (> 50hrs). Practical strategies used to support or evidence the study's quality in terms of its credibility, rigour, generalizability, and significance included author self-reflexivity, member reflections from participants, and external reflections with key stakeholders before seeking publication. This large qualitative dataset was rigorously analysed using inductive thematic analysis.

Results: Ten themes were identified: personal wellbeing, social wellbeing, physical wellbeing, inspiration, self-presentation, experience of LTPA, knowledge of LTPA, environment, organisational functioning, and miscellaneous.

Conclusions: This article makes a novel and significant contribution to research by revealing the dynamic and relational nature of barriers, facilitators, and benefits. Practical implications for LTPA policies and practices are considered through a social ecological lens (i.e., intrapersonal, interpersonal, institutional, community, and policy).

1. Introduction

Between the 1st April 2007 and the 31st March 2010 there were 34,109 lower limb amputations in England, with the most prevalent cause being diabetes (Holman, Young, & Jeffcoate, 2012). Public Health England (2016) reported that there are 140 diabetes-related amputations per week. Yet, while the reduction of amputations is a major priority in England (see Healthier You: The NHS Diabetes Prevention Programme), the well-being of people with an amputation is also of critical importance. From a psychosocial perspective, there are numerous challenges for people following an amputation: threatened identity (Senra, Oliveira, Leal, & Vieira, 2011), elevated depression and anxiety (Horgan & MacLachlan, 2004), decreased social functioning from being in a ‘stigmatised’ group in society (Murray & Forshaw, 2013), and overall, a poorer quality of life (Sinha & Van Den Heuvel, 2011). One strategy that has been shown to enable people with an amputation to adjust to these challenges is being physically active (Bragaru, Dekker, Geertzen, & Dijkstra, 2011). Yet, many people with an amputation in England do not participate in sufficient physical activity to achieve health benefits, and more barriers than facilitators exist when striving to adopt and maintain a physically active lifestyle (Deans, Burns, McGarry, Murray, & Mutrie, 2012).

The United Nations Convention on the Rights of Persons with Disabilities (2006) enshrines the rights of disabled people to participate in recreational, leisure, and sport activities on an equal basis with others. However, people with an amputation face a plethora of barriers that prevent them from living an active life (Bragaru et al., 2013; Couture, Caron, & Desrosiers, 2010; Gallagher, O'Donovan, Doyle, &

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https://doi.org/10.1016/j.psychsport.2017.11.005
Received 30 June 2017; Received in revised form 7 November 2017; Accepted 7 November 2017

Please cite this article as: Wadey, R., Psychology of Sport & Exercise (2017), http://dx.doi.org/10.1016/j.psychsport.2017.11.005

Desmond, 2011; Kars, Hofman, Geertzen, Pepping, & Dekker, 2009). In Canada, Couture et al. (2010) identified that leisure activities decreased following amputation due to personal (e.g., functional constraints, affective constraints) and external constraints such as lack of accessibility (e.g., architectural barriers, transportation problems). The authors also reported in their results, "… many individuals stated that weather conditions were the main constraint on leisure participation following a lower limb amputation. In Canada, winter conditions include walking on ice and snow" (p. 61). In comparison, Bragaru et al. (2013) conducted a study in The Netherlands and identified other barriers. These were psychological factors such as self-presentation concerns, fear of injury, and feeling dependent on others. Other barriers included physical factors such as co-morbidities and phantom pain, and low social acceptance from abled-bodied individuals. Taken together, these findings demonstrate barriers to participation are not only intrapersonal (e.g., affect, phantom pain) and interpersonal (e.g., attitudes of others), but also contextual and prevalent in the environment (e.g., weather, architecture, transportation).

This original study aims to examine the barriers, facilitators and benefits of leisure time physical activity (LTPA) among people with an amputation in England. LTPA is defined as physical activity an individual engages in during their free time (Martin Ginis et al., 2011). Consistent with Williams, Smith, and Papathomas (2014), barriers are defined as reasons why people do not participate in LTPA, discontinue LTPA or negative experiences of LTPA. Benefits are positive responses and perceived advantages from participation in LTPA, whereas facilitators are factors that allow people to participate in LTPA. Yet, considering there is a sizable body of research on LTPA among people with physical disabilities (Martin Ginis, Ma, Latimer-Cheung, &Rimmer, 2016), do we really need yet another study on the factors that impact LTPA? From our perspective, it is a resounding *yes*. Our rationale is threefold. First, there is limited amputation-specific research. Indeed, Martin Ginis et al. (2016, p. 492) reported in their systematic review of review articles of LTPA in people with physical disabilities, "… it is important to acknowledge that some disability groups were more strongly represented in our synthesis than others (e.g., five reviews involving persons with spinal cord injury versus one review involving prosthetic users)." This study seeks to address this imbalance. Although previous researchers have included people with an amputation within their samples, Deans et al. (2012) reported that this approach makes it challenging to extrapolate data from specific disability groups.

Second, there is a dearth of amputation-specific research on LTPA conducted in England. To provide LTPA guidelines for decision-makers and service-providers, they need to be context-specific (e.g., England) and co-constructed with the intended user. Indeed, 'top down' approaches to health care design led by government initiatives have been criticised for undervaluing the exploration of genuine needs and problems (Jun, Morrison, & Clarkson, 2014). Therefore, it is critical that individuals with amputations become active-partners in informing policy, which aligns with the United Kingdom's (UK) National Health Service's (NHS) vision for person-centred care (NHS England, 2014). Third, the methodological choice by researchers examining LTPA in people with an amputation has been cross-sectional. Following a systematic review of research on individuals with an amputation and sports participation, Bragaru et al. (2011) reported, "The findings from this review should be interpreted cautiously because few studies had high methodological value" (p. 737). Heeding recommendations for longitudinal research (Horgan & MacLachlan, 2004) and rigorous qualitative research (Smith & McGannon, 2017), this study aimed to provide an original and rigorous account of LTPA among people with an amputation in England.

2. Method

2.1. Philosophical beliefs and sampling

This study was underpinned by interpretivism; that is, ontological relativism (i.e., reality is multiple, created, and mind-dependent) and epistemological constructivism (i.e., knowledge is constructed and subjective). Following procedural ethical approval from the University Ethics Committee, participants were recruited through maximum-variation and criterion-based purposeful sampling strategies (Sparkes & Smith, 2014). Maximum variation sampling was chosen to enhance the study's scope and represent the views of a diverse demographic across England. Characteristics accounted for were age, sex, time since surgery, type of amputation, and geographical regions (i.e., North-East, Yorkshire and Humberside, North-West, East-Midlands, West-Midlands, East of England, London, South East, and South-West). Criterion-based sampling was used to recruit participants who were aged 18 years and over and had an amputation. Potential participants enlisted on a charity's database of people with an amputation in England were asked if they would participate by sending them an email, which stated, "This study aims to understand the physical activity experiences among people with an amputation in England. What gets in the way of participation? What helps participation? What are you experiences of physical activity?" If an email recipient was interested in participating, they were requested to email one of the co-authors who would tell them about the study and what participation would likely entail.

A total of 22 participants were recruited; 14 were female and eight were male. The mean-age of the sample was 42 years ($SD = 10$ years). The participants reported a range of lower-limb amputations (i.e., congenital, acquired, transfemoral, transtibial, unilateral, and bilateral), and participated in diverse types of sport and exercise (e.g., badminton, volleyball, basketball, tennis, running, swimming, cycling, skiing) and hobbies (e.g., play with children, gardening, photography, carpentry, church bell-ringing, walking). Two participants reported having no interests in LTPA from the outset of the study. On average, participants were five years' post-surgery ($SD = 8$ years). No individuals with upper-limb amputations accepted our invitation to participate. The sample was diverse in income and employment status.

2.2. Data collection

Data was collected over 26 months using multiple qualitative methods to enhance the study's scope and construct a more nuanced understanding. Recognising that our sample of participants had experienced a significant event and that initial reflections on LTPA might induce emotive experiences, we elected to use focus groups as our first method of data collection. Focus groups have been shown to encourage disclosure and elicit a wide variety of different views (Krueger & Casey, 2000). We had also yet to develop sufficient rapport with our participants and the use of focus groups has been suggested to allow for safety in numbers (Connelly & Peltzer, 2016); meaning that participants only need to contribute to the conversation when they feel able. Two focus groups were conducted (11 participants in each group), resulting in > 4-h of data. Three questions were used to stimulate discussion: "What does physical activity *mean* to you?", "What *hinders* your participation in physical activity?" and "What *helps* your participation in physical activity?" Each author conducted one focus group and facilitated the discussion using curiosity-driven follow-up questions (Sparkes & Smith, 2014). Both were recorded and transcribed verbatim.

Following the focus groups, observations and informal-unstructured interviews were conducted at an annual two-day sporting event, which was organised by the same charity from whom the participants were recruited. The aim of our observations and interviews was to provide a contextual understanding of the participants' actions, interactions, and emotions, as well as further nurture the researcher-participant relationship that had been developed during the focus groups (Sparkes &