ABSTRACT

Title of Dissertation:	A SEQUENTIAL MIXED METHODS APPROACH TO IDENTIFYING AND UNDERSTANDING MOTIVATIONS FOR LEISURE TIME PHYSICAL ACTIVITY PARTICIPATION AMONG AMPUTEES
	Sara H. Olsen, Doctor of Philosophy, 2022
Dissertation directed by:	Dr. Donna E. Howard, Associate Professor, Department of Behavioral and Community Health

Physical inactivity contributes to increased risk for hypertension, coronary heart disease, diabetes, various cancers, and depression. Research shows small increases in leisure time physical activity (LTPA) level among the least active populations result in larger improvements in overall health than any increase in LTPA among more active populations. People with disabilities (PwD) are less likely to meet physical activity (PA) guideline recommendations than their counterparts in the general population (39.2% vs 53.8%). People with mobility disabilities, such as those with amputations, are less active than those with other disabilities. Amputees, however, are largely absent from physical activity-related and disability-related research. One step toward improving LTPA participation among amputees is understanding motivations to be active and the experiences influencing those motivations. Using Self-Determination Theory (SDT) as a framework, this dissertation employed a sequential explanatory mixed methods approach to integrate fitness app intervention data with interpretative phenomenological analysis

(IPA) findings. The quantitative component evaluated an app-based intervention with a waitlist control experimental design. Outcomes of motivations and PA level (Aim 1) were evaluated using linear mixed effect models. Amotivation, extrinsic motivation, and intrinsic motivation were evaluated as separate outcomes. Changes in amotivation and total activity level were significant during the intervention; there were no significant changes in extrinsic or intrinsic motivation. Amotivation (complete disinterest in LTPA) increased in both groups, but the increase was greater in the waitlist control group, suggesting use of the app staved off amotivation even though it did not contribute to increases in intrinsic motivation. Total activity increased in the waitlist control group only. Moderation was tested using SDT constructs of general causality orientation, a personality trait that represents a person's belief about behavioral change and reasons to change (Aim 2). Amotivation is moderated by general causality orientation. Results from intervention analyses, including attrition analysis, were used to develop interview guides and participant inclusion criteria for the qualitative phase. In-depth interviews with amputees (Aim 3) explored motivations to be active and embodied PA experiences. IPA resulted in the development of six superordinate themes. Data from both the intervention and interviews were integrated to develop a deeper understanding of amputees' experiences with motivations to be active (Aim 4). Participants identified barriers and facilitators to PA engagement that were unrelated to and unaffected by motivation to be active. These experiences disrupted the association between motivation and participation which added context to the intervention findings in which changes in intrinsic motivation over time did not parallel changes in PA over the same intervention period. Public health implications and suggestions for future research are discussed.

A SEQUENTIAL MIXED METHODS APPROACH TO IDENTIFYING AND UNDERSTANDING MOTIVATIONS FOR LEISURE TIME PHYSICAL ACTIVITY PARTICIPATION AMONG AMPUTEES

by

Sara H. Olsen

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Advisory Committee:

Associate Professor Donna E. Howard, DrPH, *Chair*
Assistant Professor Elizabeth M. Aparicio, PhD, *Committee Member*
Professor Robert S. Gold, PhD, DrPH, *Committee Member*
Associate Professor Xin He, PhD, *Committee Member*
Professor Paul T. Jaeger, JD, PhD, *Dean's Representative*

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No acknowledgement page would be complete without thanking my family. My extended family is so large, I can't possibly fit individual thanks on a single page, but know your love and friendship were felt and appreciated throughout this dissertation and beyond. I can't imagine finishing a PhD – or anything in life – without you. Dad you have been my friend and counsel for as long as I can remember. I appreciate your guidance and willingness to listen. Beka and Em, you keep me grounded and focused on life outside of books. So many of my favorite memories include us sitting around a table somewhere and connecting and laughing until we were crying.

There's a lot of beauty in ordinary things. Isn't that kind of the point?

~The Office

Table of Contents

List of Tables

List of Figures

List of Abbreviations

AC. Amputee Coalition.

ADL. Activities of Daily Living.

APHA. American Public Health Association.

BITZ. Being in the Zone.

BPN. Basic Psychological Needs.

BPNES. Basic Psychological Needs in Exercise Scale.

BPNT. Basic Psychological Needs Theory.

CDC. Centers for Disease Control and Prevention.

CET. Cognitive Evaluation Theory.

COT. Causality Orientations Theory.

COVID-19. Coronavirus Disease 2019, illness caused by SARS-CoV-2.

DoL. U.S. Department of Labor.

EMS. Exercise Motivation Scale.

GCOS. General Causality Orientation Scale.

GCT. Goal Contents Theory.

HHS. U.S. Department of Health and Human Services.

IOM. Institute of Medicine.

IPA. Interpretative Phenomenological Analysis.

IRB. Institutional Review Board.

ITAP. Intraosseous Transcutaneous Amputation Prostheses.

LTPA. Leisure Time Physical Activity.

MCAR. Missing Completely at Random.

MET. Metabolic Equivalent.

MS. Multiple Sclerosis.

NCDJ. National Center on Disability and Journalism.

NLLIC. National Limb Loss Information Center.

OIT. Organismic Integration Theory.

PA. Physical Activity.

PASIPD. Physical Activity Scale for Individuals with Physical Disabilities.

PT. Physical Therapy.

PwD. People with Disabilities.

SCI. Spinal Cord Injury.

SDT. Self-Determination Theory.

UCD. User-Centered Design.

UMD. University of Maryland.

WHO. World Health Organization.

uMARS. User Version of the Mobile Application Rating Scale.

Chapter 1 Introduction

1.1 Background

Physical activity (PA) participation is strongly related to improved health and well-being. Research into cognition and affect shows strong correlation of exercise to structural and functional changes in the brain that improve concentration, memory, and feelings of well-being (Crush & Loprinzi, 2017; Mandolesi et al., 2018). Moderate to vigorous PA improves muscular and cardiorespiratory fitness, and reduces the risk of chronic diseases such as hypertension, coronary heart disease, diabetes, various cancers, and depression (Martin & Whalen, 2012; Sothern et al., 1999; Warburton et al., 2006; WHO, 2018; Wilhite & Shank, 2009).

The Department of Health and Human Services (HHS) in their Physical Activity Guidelines for Americans recommends adults engage in at least 150 minutes per week of moderate-intensity or 75 minutes per week of vigorous-intensity aerobic PA (HHS, 2018). Moderate-intensity PA requires 3-6 metabolic equivalents (METs) to perform the activity; vigorous-intensity PA requires greater than 6 METs (HHS, 2018). As an illustration, a fast walk would be moderate-intensity, while running would be considered vigorous-intensity PA. These guidelines apply to adults over 18 years of age, older adults over the age of 65, and adults with disabilities and chronic conditions. PA refers to any movement that increases energy expenditure above basal level, including activity related to a person's occupation, transportation methods, household activities, and leisure time behavior (HHS, 2018). A person not meeting PA guideline recommendations is

considered inactive; while someone who habitually expends less than 1.5 METs is considered sedentary (Tremblay et al., 2017).

Leisure time physical activity (LTPA) provides greater health benefits and greater opportunities to meet PA guideline recommendations than do other forms of PA (Holtermann, 2018; Tsenkova, 2017; Vuillemin et al., 2005). Benefits of PA follow nonlinear dose-response curves with small increases in PA in the least active populations resulting in a much larger improvement in overall health than any increase in activity level in populations closer to achieving PA guideline recommendations (Erlichman et al., 2002; Everson-Hock et al., 2015; Minton et al., 2013; Thune & Furberg, 2001; Woodcock et al., 2011). People with disabilities (PwD) are less active and experience increased burden of disease compared to those without disabilities (Wilbur et al., 2002). Increases in PA by members of this population have the potential to greatly improve health and wellbeing.

This dissertation employed a sequential explanatory mixed methods research study design across three phases (Fig 1.1). Mixed methods combines elements of both quantitative and qualitative approaches to answer a central, primary question through examining multiple secondary questions and integrating and analyzing those results. The quantitative component evaluated an app-based intervention using the fitness tracking app BurnAlong as the intervention. The qualitative component used interpretative phenomenological analysis to understand amputees' embodied experiences of motivation for LTPA. The third phase integrated the results of both the quantitative and qualitative components. This dissertation is in the 3-manuscript format with each manuscript corresponding to the results in each of the three phases of the study.

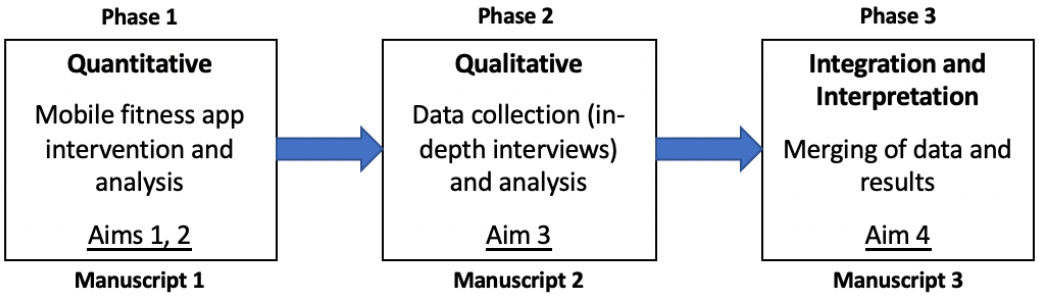

Figure 1.1 Study Phases

1.2 Problem Statement

Approximately 1 in 4 adults in the United States is living with a disability (Brault, 2012; CDC, 2017; Okoro et al., 2018). Disability is a broad term referring to the restriction of activity associated with physical or mental impairments. The restriction can be related to difficulty performing activities of daily living (ADL) or limitations in opportunities to take part in society on an equal level with limitations due to social and environmental barriers (CDC, 2019; DoL n.d.; WHO n.d.). The condition of disability involves three components: bodily impairment, activity limitation, and participation restriction (WHO, 2001). Impairments describe diagnosis of an injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function (CDC, 2019; WHO, 2001). Activity limitation is a difficulty performing a task; while a participation restriction is a limitation in involvement in life situations such as those related to work or social connection (WHO, 2001). Disability is categorized based on the impairment. For example, someone who is blind would be classified as having a visual disability.

The impairment is the primary diagnosis related to disability. Many impairments carry the risk of a person developing a secondary condition. A secondary condition is any additional physical or mental health condition that occurs as a direct result of having a

primary disabling condition (IOM, 1991). Secondary conditions are, to a large extent, preventable. PwD report, on average, five secondary conditions to their primary diagnosis (Wilbur et al., 2002). In addition to reported secondary conditions, PwD are at significantly greater risk of comorbidities associated with inactivity such as heart disease, stroke, diabetes, and cancer (Carroll et al., 2014; Martin Ginis et al., 2012).

PwD are less likely to meet PA guideline recommendations than their counterparts in the general population (39.2% vs 53.8%) and more likely to be sedentary (42.2% vs 24.3%) (CDC, 2017). PwD consistently experience poor physical and mental health, increased prevalence of disease, and fewer healthy days per month than adults without disabilities (CDC, 2008, 2017; Havercamp et al., 2004; McColl et al., 2010; Wilber et al 2002). These data consider PwD as a single population; however, PwD represent a diverse population with a wide range of needs and health concerns. Mobility- and ambulatory-related disabilities are the most common with a prevalence rate of almost 14% (13.7%) (Carroll et al., 2014; CDC, 2017; Erickson et al., 2016).

Those with mobility-related disabilities, defined as impairments that result in serious difficulty walking or climbing stairs without an assistive device, are less active than those with other disabilities (e.g. those related to cognitive, vision, or hearing impairments); 57% of people with mobility disabilities are inactive (CDC, 2014). Barriers to LTPA for people with mobility impairments are found at the intrapersonal, interpersonal, and environmental levels. PwD experience barriers related to motivation, lack of social support, absence of knowledgeable training staff, stigma, and physical barriers in the built or natural environment (Deans et al., 2012; Law et al., 2007; Malone et al., 2012; Martin Ginis et al., 2012; Rimmer et al., 2004). Despite the barriers to

participation, PwD who engage in LTPA show improvement in physical and emotional health, and strengthened social ties (Hicks et al., 2011; Martin Ginis et al., 2009). LTPA participation among PwD increases aerobic capacity, muscular power output, and functional performance (Hicks et al., 2011; Lui & Hui, 2009; Martin Ginis et al., 2012; Wilhite & Shank, 2009). Participation also improves a variety of factors associated with psychosocial well-being including increased coping skills, confidence, social connectedness, and belongingness, and decreased symptoms of depression (Martin Ginis et al., 2009, 2017; Nooijen et al., 2017; Prout & Porter, 2017).

Amputation is a subset of impairments associated with mobility-related disabilities. It is classified as a structural impairment in which there is a loss or difference in anatomical structure that results in mobility disability (WHO, 2001). There are approximately 1.7 million amputees living in the United States and, assuming no change in incidence rates, that number is expected to double before 2050, due in part to an aging population (NLLIC, 2008; Ziegler-Graham et al., 2008). Amputees experience disability differently than others with mobility disabilities. Prostheses are uncomfortable and painful at the socket-residual limb interaction, causing overheating and reduced integrity of the residual limb (Batten et al., 2019; Ghoseiri & Safari, 2014; Paternò et al., 2019). Prostheses are individually tailored to fit snugly over the residual limb and act as an extension of the body, but may twist on the limb or shift alignment vertically or horizontally from the fitted design. Residual limbs swell and decrease in size with activity, temperature, generalized post-operative edema, and muscle atrophy (Sanders & Fatone, 2011). Frequent prostheses displacements, limb volume fluctuations, temperature dysregulation, and phantom pains affect amputees' participation in ADL and inhibit

engagement in LTPA (Batten et al., 2019; Ghoseiri & Safari 2014; Littman et al., 2017; Paternò et al., 2019). In addition to physical function and medical reasons for not engaging in LTPA, amputees describe lack of knowledge of how to engage in LTPA with a prosthesis, inaccessible facilities, lack of motivation, and stigma as barriers to participation (Amtmann, 2015; Jaarsma et al., 2014; Littman et al .,2014; Wadey & Day 2018). Conversely, social support, social contact, reduced cost of participation, and goal setting opportunities are facilitators of LTPA for amputees (Batten et al., 2019; Jaarsma et al., 2014; Littman et al., 2014; Wadey & Day, 2018).

Research on LTPA among PwD is growing. Amputee-specific LTPA studies are beginning to explore barriers and facilitators to PA; however, much of the research with amputees to date focuses heavily on prosthetic design and function. There is a paucity of research on the design, implementation, and evaluation of interventions targeted to PwD, and amputees in particular, that focuses on increasing motivation to be active (Castro et al., 2018). This study will investigate the use of a fitness tracking app, with features specifically designed for amputees, on changes in type of motivation. It will provide a more nuanced understanding of how experiences influence motivation to be active among amputees.

1.3 Public Health Significance

PwD continue to be a population with unrecognized health disparities in the United States. For too long, public health research has focused on prevention of impairments associated with disability among various populations of interest, rather than the recognition of PwD as a population that exists on a health continuum (Krahn et al., 2015; Rimmer, 1999). Disability does not equate to illness; PwD can be active, health literate,

and be well or they can be sedentary, have limited health information and access, and be ill. Because having a disability has been researched as an outcome, PwD are generally absent in discussions of health promotion (HHS, 2005). In 2005, the Surgeon General issued a national call to action to elevate the health of PwD in areas of research, service delivery, education and health care policy (HHS). Four years later, the National Council on Disability (2009) found PwD continued to experience significant health disparities compared with those without disabilities; yet they are not included in federal health disparities research within the National Center on Minority Health and Health Disparities as mandated by the Minority Health and Health Disparities Research and Education Act (2000). *Healthy People 2020* identifies 20 objectives across four key domains of social determinants of health, all of which disproportionately affect PwD (HHS, 2014; Kraus, 2017). These are systems and policies, barriers to healthcare access, the built environment, and activities and participation. This is being reduced to six total objectives in the proposed Healthy People 2030, none of which are considered developmental or research objectives by HHS (HHS, 2019). The aim of public health is to promote and protect the health of all populations and to achieve health equity (APHA, n.d.; HHS, 2008). Federal research remains focused on disability prevention rather than on improving access to, and quality of, health care for PwD, or promoting healthy living of PwD. This research will be a step toward the vision of health equity for PwD by providing a comprehensive understanding of motivations among amputees to engage in PA that maximizes their health and well-being.

1.4 Theoretical and Philosophical Framework

This study will use Self-Determination Theory (SDT) to understand changes in amputees' motivation to engage in LTPA. SDT is a macro theory that incorporates five mini-theories (Deci & Ryan, 1985a; Ryan & Deci, 2017). The first two mini-theories address intrinsic and extrinsic motivations. SDT conceptualizes motivation along a continuum, with extrinsic or controlled motivation on one end and autonomous or intrinsic motivation on the other (Deci & Ryan, 1985a; 2000). Intrinsic motivation results in actions taken for their own sake – the activity is considered the reward. Extrinsic motivations, of which there are four types, have external sources of rewards. SDT associates intrinsically motivated behaviors with cognitive and social development. In order for psychological growth to occur, however, a person's basic psychological needs must be met. A third mini-theory of SDT defines the basic psychological needs as autonomy, competence, and relatedness and considers these universal human needs that transcend cultural differences. A fourth mini-theory incorporates individual trait differences in the way people orient toward environments and regulate behavior. This mini-theory identifies three causality orientations: autonomous, controlled and impersonal. Autonomy orientation is the tendency for a person to behave based on interest and awareness of one's own goals; control orientation involves a focus on rewards or perceptions of social norms; and the impersonal orientation characterized by the belief that behavior is a personal trait and beyond an individual's control (Deci & Ryan, 1985a). The last mini-theory describes how the type of goal setting is related to motivation. Table 2.1 illustrates which SDT constructs are incorporated into each mini-theory.

Experimental studies evaluating SDT-based PA interventions show autonomous motivation predicts engagement in exercise behaviors (Teixeira et al., 2012). Basic psychological need satisfaction is positively correlated with autonomous motivation (Martinez et al., 2013). BurnAlong, the fitness tracking app being used in this study, contains features to satisfy basic psychological needs associated with increasing autonomous or intrinsic motivation for PA. Autonomy reflects the need to have control over one's own behavior and the desire to choose behavior that is congruent with personal values. Competence refers to the ability to develop mastery of skills important to oneself and perception of effectiveness adapting to the environment in which the skill is attempted or influenced. Relatedness is the need to feel connected and understood by others. The app offers choice of workout, videos to improve exercise skills, and the ability to connect with others via live streaming. Use of the app may improve the degree to which basic psychological needs are met which should increase intrinsic motivation and PA engagement.

To contextualize the observed changes in motivation during app use, this study will incorporate theories of embodied knowing. Merleau-Ponty (and Smith 1966) challenged traditional accounts of humans who understand their environments solely through cognition, by positing they also experience the world around them through a corporeal process of knowing. He introduced embodiment as an epistemological framework in which the physical body influences how people know about and ascribe meaning to their social and built environments (Merleau-Ponty & Smith, 1966; Moya, 2014). This concept was further developed by Barnacle (2009) who described the body as a non-cognitive mode of knowing. Amputees describe barriers to PA such as illnesses,

poorly-fitting prostheses, low self-efficacy, insufficient resources, and lack of support (Batten et al., 2019; Littman et al., 2017; Malone et al., 2012). In some descriptions, amputees are reliving the bodily discomfort, "sweating really profusely, you know, trying to keep my leg straight…hot temperatures my leg sweats because it's encased…and because of sweat it's easy to turn" (Littman et al., 2017, p. 603). In-depth interviews with individual participants offer the opportunity to capture rich, descriptive data that will provide a deeper understanding of how an amputees' embodied knowledge impacts LTPA motivation.

1.5 Research Question, Specific Aims, and Hypotheses

Dissertation Primary Research Question: How do amputees' experiences of motivation to be active relate to changes in physical activity following exposure to a fitness app?

A sequential explanatory mixed methods study aimed to answer a central, primary question through examining multiple secondary questions and integrating and analyzing the results obtained from each. In this design type, quantitative data were collected and analyzed first. Using quantitative results, qualitative interview guides were developed and then data collected and analyzed. The final step was the connected integration of independent quantitative and qualitative components' data analyses to answer the primary research question (Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015).

1.5.1 Phase 1 Quantitative Component

Phase 1 Secondary Research Question: How does use of a mobile fitness app that includes features related to basic psychological needs for PA predict changes in

motivation to be physically active among amputees? Fig 1.2 shows the conceptual model that illustrates Aims 1 and 2.

Aim 1: Assess changes in motivation to be active and changes in PA among amputees exposed to a fitness app (BurnAlong) intervention that incorporates features to support basic psychological needs (workout autonomy, fitness competence, and relatedness).

Hypothesis 1a: Amputees who are exposed to the mobile fitness app are more intrinsically motivated to be active than amputees not exposed to the app.

Hypothesis 1b: Amputees who are exposed to the mobile fitness app engage in more LTPA than amputees not exposed to the app.

Aim 2: Test whether the relationship between mobile fitness app (BurnAlong) use and type of motivation differ by individual causality orientation of amputees.

Hypothesis 2: The relationship between mobile fitness app use and motivation to be active is stronger in amputees with an autonomy orientation and weaker in amputees with an impersonal orientation.

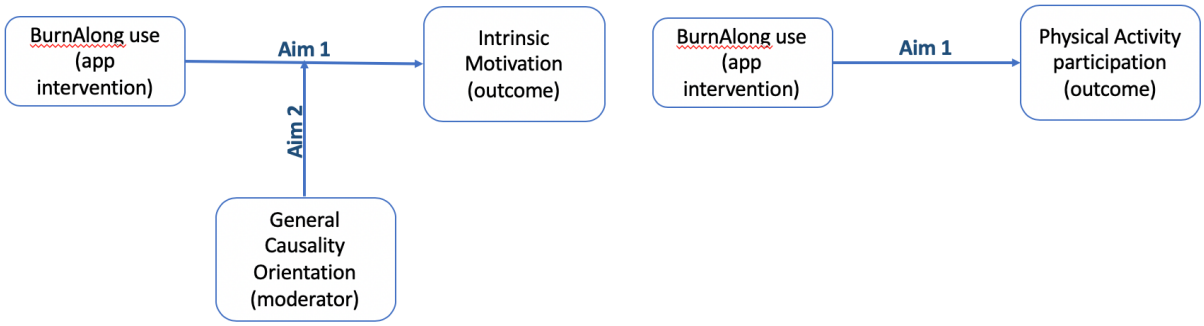

Figure 1.2 Phase 1 Quantitative Component Conceptual Model

1.5.2 Phase 2 Qualitative Component

Phase 2 Secondary Research Question: How do amputees experience motivation to participate in LTPA?

Aim 3: Using in-depth phenomenological interviews, explore the embodied meaning and lived experience of motivation to engage in LTPA among amputees.

1.5.3 Phase 3 Integration of Data

Phase 3 data integration serves to answer the primary dissertation research question by interpreting findings from both the quantitative and qualitative components together to answer the question: *how do amputees' experiences of motivation to be active relate to increases in physical activity following exposure to a fitness app*?

Aim 4: Evaluate, through connected integration, how the qualitative findings contextualize and provide more in-depth understanding of the quantitative findings; thus providing a more meaningful understanding of the phenomenon.

1.6 Key Terms

Acquired limb differences is also known as "amputation" and occurs when someone has a limb removed for medical reasons, or accidentally due to trauma (Smith et al., 2004).

Activities of Daily Living (ADL). Basic self-care tasks an individual does on a day-to-day basis. These activities are fundamental in caring for oneself and maintaining independence such as feeding, bathing, dressing, grooming, work, homemaking, and leisure time activity. The ability or inability to perform ADLs are often used as a practical measure of disability (Shiel, 2018).

Amputee. A person who is missing all or part of a limb (WHO, 2001).

Basic Psychological Needs. According to Self-Determination Theory (SDT), people have three basic psychological needs necessary for healthy development, engagement, motivation, and well-being. (Deci & Ryan, 1985a).

Comorbidity. A medical condition that exists simultaneously but is independent of the primary diagnosis (Valderas et al., 2009).

Congenital limb difference. Also referred to as "limb reduction" or "amelia" or amputation and occurs when someone is born missing all or part of their upper and/or lower limbs (Smith et al., 2004).

Disability. A broad term related to the restriction of activity resulting from physical or mental impairments. The restriction can be related to diminished body function or structure, difficulty performing activities of daily living, or limitations in opportunities to take part in society on an equal level with others due to social and environmental barriers (CDC, 2019; DoL, n.d.; WHO, n.d.).

Disarticulation. Separation of two bones at the joint.

Dysvascular Amputation. Amputation resulting from poor vascular status of a limb.

Embodiment. Epistemological framework in which the physical body influences how people know about and ascribe meaning to their social and built environments (Merleau-Ponty & Smith 1966; Moya, 2014).

Exercise. Planned, structured, and repetitive activity for the purpose of improving or maintain physical fitness (HHS, 2018).

Fitness. Set of attributes that are either health- or skill-related. For the purposes of this study, fitness refers to health-related physical fitness encompassing cardiorespiratory fitness, muscular endurance, muscular strength, body composition, and flexibility (HHS, 2018).

Impairment. An injury, illness, or congenital condition that causes, or is likely to cause, a loss or difference of physiological or psychological function (CDC, 2019; WHO, 2001).

Joint Contracture. Limitation in the passive range of motion of a joint secondary to shortening of the periarticular connective tissues and muscles (James, 2001).

Leisure Time Physical Activity (LTPA). Physical activities that are not required as essential activities of daily living or related to transportation or occupational activities and are performed at the discretion of the individual. These include activities such as sports, exercising, gardening, and recreational walking (Kirch, 2008).

Mechanism of Amputation. The process resulting in a person being an amputee. The amputation can be acquired or congenital. A congenital amputation is the result of birth malformation such as an absent or poorly developed limb. An acquired amputation is the loss of all or part of a limb. It can be the result of trauma, poor vascular status of a limb, or surgical in nature and unrelated to trauma.

Metabolic equivalent (MET). Refers to the energy expenditure required to carry out a specific activity, and 1 MET is the rate of energy expenditure while sitting at rest. This generally corresponds to an oxygen uptake of 3.5 milliliters per kilogram of body weight per minute. Physical activities frequently are classified by their intensity using the MET value as a reference (HHS, 2018).

mHealth. Component of eHealth supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices. **(**WHO Global Observatory for eHealth, 2011)

Mobility Disability. The CDC (2014) measures serious difficulty walking or climbing stairs to represent mobility disabilities but the classification is much broader. This type of disability affects speed and range of motion of the body, such as walking, manual

dexterity, and coordination. People with mobility disabilities often use assistive devices such as crutches, canes, wheelchairs and artificial limbs to obtain mobility.

Mobility Impairment. This type of impairment includes, for example, upper or lower limb loss, spinal cord injury, multiple sclerosis, and cerebral palsy.

Person with a Disability (PwD). Person with an impairment who experiences a restriction of activity resulting from physical or mental impairments.

Physical Activity (PA). Any bodily movement produced by skeletal muscles that requires energy expenditure. This type of activity is categorized into occupational, sports, exercise, household, transportation, or other activities (HHS, 2018).

Physical inactivity. Also referred to as inactivity; an insufficient physical activity level to meet present physical activity recommendations (Tremblay et al., 2017).

Prosthesis displacement. Slippage or movement of the prosthesis on the residual limb; may cause instability, discomfort, pain, or asymmetry in movement.

Reflexivity. Systematically attending to the context of knowledge construction at every stage of the research process, especially attending to the position or perspective of the researcher (Malterud, 2001).

Secondary Condition. Any additional physical or mental health condition that occurs as a result of having a primary disabling condition (IOM, 1991). Secondary conditions are, to a large extent, preventable.

Sedentary behavior. Any waking behavior characterized by a low level of energy expenditure (less than or equal to 1.5 METs) while sitting, reclining, or lying (HHS, 2018; Tremblay et al., 2017).

Self-determination Theory (SDT). Macro theory of motivation and personality encompassing five mini-theories (Deci & Ryan 1985a, 2000; Ryan & Deci 2017).

1.7 Statement on Disability Terminology

This dissertation uses person-first language throughout, i.e. people with disabilities (PwD). This was a decision based on experiences educating non-disabled populations and published approved practices among healthcare professions, journalism guides, and some peer-reviewed journals (Crocker & Smith, 2019; NCDJ, 2018). It is also the preference adaptive athletes I have worked with over the years and whose motivations related to exercise, in part, inspired this research. It is important to recognize that this practice is not used universally in academia nor is it universally preferred by PwD. Many scholarly fields and PwD prefer identity-first language, i.e. disabled person (Dunn & Andrews 2015). The terminology discussion among PwD, advocacy groups, and academics is ongoing (Ferrigon & Tucker 2019). As a best practice, I asked each person interviewed during the qualitative component their terminology preference. This dissertation uses person-first language, but reports results and analyses in alignment with participant preferences.

1.8 Reflexivity and Positioning

My first exposure to the disabled community was through a friend. He was training wounded warriors in his gym and decided to develop a competition. His idea was discouraged by others in the fitness community as being too difficult. His vision was to develop a competition that allowed all of his athletes to compete on an even playing field regardless of impairment. The argument against doing this was that people of differing

impairments had such different needs that there was no way to develop a functional fitness competition without classifying athletes similar to the process that occurs in the Paralympics. My friend was stubborn and defiant and knew he could find a sympathetic ear in me. We learned as much as we could about adapted sport for PwD – we read, we talked to expert sport-specific coaches, and we asked his athletes.

The result was far from perfect. People with the same or similar impairments experience disability very differently and they carry those experiences with them into sport and competition. Without this being the intent, people were excluded in the first competition we put together. We failed to effectively level the playing field across impairments. That failure, though, seemed secondary to the feedback we got from the competitors. Although imperfect and in need of much improvement, the competition offered an opportunity they had not found elsewhere; a place designed for the recreational athlete with a physical impairment to compete and interact with peers. That was transformative for me. I never thought about a local competition as being a unique opportunity to connect. As a white, able-bodied (a term that is problematic but none of my adaptive athlete friends or colleagues have a different, preferred word) woman, I have always found someone like me on my soccer and swim teams, at triathlons, or in the gym. It never occurred to me, when we first started, that we were doing anything other than putting on a competition.

The more I got to know the adaptive athletes that competed with us, the more I wanted to know and understand. They shared stories of stigma, isolation, their own body rebelling, struggles with access, and frustrations with trainers. Stories, that they had been told second hand or seen played out on TV would have felt like caricatures of real

experiences. I was so ignorant to their realties; the barriers they experienced I had never even had to consider before. How could I be an ally? What things could/should I do in my position to support inclusion? As a person outside of the community, when am I overstepping?

Since beginning this journey in 2011, I have become more and more involved and embedded in the adapted sporting community. Feedback from athletes led me to cofound a nonprofit whose mission is to increase inclusion of PwD into sport and fitness communities. I have had a unique experience during this process. I have been included by many in their adaptive communities and hold a level of credibility I did not have at the start. I have learned more about my role as a supporter and ally. I have become friends with so many of the adaptive athletes from that first competition and beyond. We trust each other. My credibility stemmed, I think, from sincere and genuine effort to enable the community to participate in greater levels of sport and fitness without trying to present myself as someone who has the same organic knowledge of what it means to be an adaptive athlete as they do. I know only what their stories, what I observe, and what research can tell me.

This gives me, and the nonprofit I helped to found, very unique access to an otherwise hard to reach group. The result of that has been outreach by other researchers wanting to gain their access. This felt wrong. My access was a result of years of vulnerability and trust building. There were a few times where the request of the researcher was minimal and clearly not harmful to the community. However, it always felt like they were asking not quite the right question about not quite the right population to make the most beneficial impact through research. Quite often, researchers generalized

PwD as wounded veterans, neglecting the material and social resources created and funded specifically for veterans that were not otherwise available, such as provisions for up to three prostheses for each missing limb to increase participation in multiple activities. There were other times when the studies focused on sport and fitness using instruments, definitions, and model designed for people without disabilities, again ignoring nuanced barriers and lived experiences of PwD that affect participation. In the multiple requests I received, the researchers never once included the voices of the adaptive athletes themselves. I realized one way I could help guide disability research in the United States, to ensure it included the perspective of the disabled community itself, was to become more involved. I started my PhD journey to do just that.

Now, several years later, I struggle with my role. Most athletes with disabilities, with whom I have worked, prefer to be called adaptive athletes. Part of that has to do with the definitions. Disability is a social or environmental limitation related to a physical impairment but the terms ‘disability’ and ‘impairment’ tend to be conflated such that anyone with an impairment is described or viewed as disabled. Many of my friends don’t feel disabled in sport. They acknowledge functional differences in the performance of sport based on their impairment, but those differences require modifications or adaptations, and are not seen as posing limitations. When I am in their presence, I don’t use the word disability. As a researcher, the term adaptive is not well used in the relevant published literature. Similarly, the more I write about the community, the more disconnected I feel. There are days I feel like I have turned friends into subjects and sacrificed community credibility for academic advancement.

As I moved forward in my studies, I have endeavored to be more intentional about remembering why I started. As an advocate and friend of the community, my role is to make space for athletes with disabilities to have a voice in research and policy, not to be their voice. In the months leading to my dissertation proposal, I struggled figuring out how to do that. How do I make sure research – my research – supports the removal of barriers and increases access to a healthy life for PwD without removing the people from the focus of the research? I continued and will continue to come back to this struggle throughout my dissertation, and my career. I will continue to seek ways to be a mechanism to amplify their voices and to hear their perspective on how well my research accomplishes that. Having worked with amputees and adaptive athletes for over 10 years, I have begun to see patterns in attitudes toward, and behaviors related to, leisure time physical activity (LTPA). As I reflected on interviews and transcriptions, I annotated when I am hearing components of those patterns, where I reflected upon whether I was inserting my experiences in the analysis, and considered even the origins of those assumptions to make sure my perspective augmented, and did not supersede the voice of the participant.

Chapter 2 Literature Review

This study aims to understand how the lived experiences of amputees affect motivations to participate in physical activity (PA). This chapter has three distinct sections: 2.1) literature related to PA among people with disabilities (PwD) including app-based interventions; 2.2) Self-Determination Theory (SDT) and its use in research to improve PA participation; and 2.3) reasoning for the use of phenomenology in embodied research. In section 2.1, amputees are identified as a unique subset of PwD who are largely absent from PA intervention literature but may benefit from research specific to their impairment and its relationship with PA. Section 2.2 provides a brief summary of SDT and describes how it has it has been applied to PA interventions and in populations of PwD. Finally, section 2.3 discusses the philosophy of phenomenology, providing justification for operationalizing the philosophy through embodied interpretative phenomenological analysis (IPA).

2.1 Physical Activity among People with Disabilities

The benefits of PA, and leisure time physical activity (LTPA) specifically, are well documented. Participation in PA has an inverse dose-response relationship with all-cause mortality and is an effective prevention of at least 25 chronic illnesses, including cardiovascular disease and depression (Arem et al., 2015; Dunn et al., 2001; Ekelund et al., 2019; Moore et al., 2012; Pedersen & Saltin 2015; Warburton & Bredin, 2016). A life-table model simulating the effects of PA among adults between the ages of 50 and 60 years showed health benefits from PA are greatest in those who are least active at baseline (Minton et al., 2013). The mathematical model used multiple data sources to

establish a baseline distribution of adult PA levels. The model then developed four simulations to estimate the impact of PA in the most active and least active adults: 1) no change in PA from baseline; 2) equal increase in PA from baseline; 3) greater increase in PA among least active adults; and 4) greater increase in PA among most active adults. Compared to the equal increase simulation, 10% fewer people died between the ages of 50 and 60 years in the simulation of low activity groups showing greatest PA increase; and 16% more people died in the simulation of highly active groups showing greatest PA increase (Minton et al., 2013). Similarly, findings from a meta-analysis of 22 cohort studies with greater than 10,000 participants, which estimated the relationship of PA to all-cause mortality, showed a non-linear dose-response relationship with greatest health benefits in the transition from inactivity to low levels of PA. Inactive populations that performed 2.5 hours per week of moderate intensity PA were shown to reduce mortality risk by 19% whereas engaging in 7 hours per week of PA reduced risk by 24% (Woodcock et al., 2011). These and other studies indicate smaller increases in PA in the least active groups may result in much larger improvements in overall health than does any increase in PA in the most active adults (Erlichman et al., 2002; Everson-Hock et al., 2015; Minton et al., 2013; Thune & Furberg 2001; Woodcock et al., 2011).

Forty-two percent of PwD in the United States are sedentary, which is much higher than the 24.3% of those without disabilities who are sedentary (CDC, 2017). The majority (57%) of people with mobility-related disabilities are inactive (CDC, 2014). Unilateral amputees have been shown to be less active than their non-amputee counterparts (Bussmann et al., 2008). Data collected through interviews, focus groups, and naturalistic observations among PwD show LTPA offers opportunities for personal

enrichment, challenge, autonomy, and physical health (Labbe et al., 2018). Greater LTPA is associated with lower biological risk factors for cardiovascular disease and type 2 diabetes among adults with spinal cord injury (SCI) (Buchholz et al., 2009). Not participating in exercise activities has been correlated ($r = -.426$, $p < .01$) with increased number and severity of secondary health conditions in people with SCI (Mashola & Mothabeng, 2019). The research related to people with SCI and PA or LTPA is extensive and shows a wide range of positive health effects (Hicks et al., 2011; Martin Ginis et al., 2012; van der Scheer et al., 2017; Wilhite & Shank, 2009); however, research related to people with amputations is less comprehensive, focusing more on gait improvement, the biomechanics of prosthesis use, and the physiology of limb loss than the physical and mental health effects of PA-related interventions (Bragaru et al., 2011; Castro et al., 2018; Lai et al., 2017). With the annual incidence of new amputations in the United States 8.9 times the incidence of SCI, it is unclear why this paucity of research among amputees persists (Jain et al., 2015; Ziegler-Graham et al., 2008). LTPA among amputees represents an important gap in both PA-related and PwD-focused research.

2.1.1 Amputees as a unique subset of People with Disabilities

The etiology of disability-related impairments, such as amputations, can be broadly categorized as congenital, or occurring in utero, and acquired, occurring any time after birth. Congenital amputees comprise less than 1% of the amputee population in the United States (Dillingham et al., 2002). The majority of acquired amputations are dysvascular; that is, they are the result of ischemia caused by diabetes or other peripheral vascular diseases (Dillingham et al., 2005; Esquenazi & Yoo, 2016; Ziegler-Graham et al., 2008). The second most prevalent cause of amputations is trauma, at about one eighth

the frequency of all dysvascular amputations (Varma et al., 2014). The majority of upper extremity amputations are the result of trauma while the majority of lower extremity amputations are dysvascular (Ziegler-Graham et al., 2008). Functionality among amputees is directly related to length of residual limb after amputation (McQuerry et al., 2019; Penn-Barwell, 2011; Raya et al., 2010). Although there is no medical definition for what is considered a 'major' amputation, there is general consensus is that loss of limb at or proximal to the wrist or ankle is a major amputation (Esquenazi & Yoo, 2016; Maduri & Akhondi, 2019). About 7.5% of upper extremity amputations and 60.7% of lower extremity amputations are classified as major (Ziegler-Graham et al., 2008). The risk of amputations, regardless of etiology, is higher for males and increases with age; Blacks have the highest risk for dysvascular amputation (Dillingham et al., 2002; Traven et al., 2020; Ziegler-Graham et al., 2008).

Dysvascular amputation removes diseased or dead tissues but does not remove the underlying cause or progression of disease that led to amputation. Within one year of dysvascular amputation, 24.4% of individuals undergo re-amputation on the same limb (ipsilateral amputation) and 11.9-15% undergo amputation of the limb on the opposite side of the body (contralateral amputation) (Czerniecki et al., 2019; Pasquina et al., 2014). In addition to recovery and rehabilitation post-surgery for those with acquired amputations, both upper extremity and lower extremity amputees experience secondary conditions related to amputation. Both groups report phantom limb pains and sensations, neuromata, heterotopic ossification, infections, back pain, and range of motion limitations in the joint nearest amputation (Coons & Franklin, 2013; Esquenazi & Yoo, 2016). Each of these conditions has the potential to affect initiation and sustainment of LTPA. They

result in chronic pain, stiffness in muscles and joints, impingement of muscles and nerves, skin irritations and lesions, re-hospitalization, and use of prescription drugs whose side effects include fatigue, blurred vision, nausea, and mood changes (Eisenstein et al., 2018; Mayo Clinic, n.d.).

Amputees are unique among PwD in their uses of assistive devices as well. Prostheses become a part of the body; literally, in the case of Intraosseous Transcutaneous Amputation Prostheses (ITAP). As the body interacts with the socket and attached components, the prosthesis may become displaced vertically or horizontally or may twist on the limb creating pain and discomfort. This movement can cause overheating and skin health issues that result in temporary inability to use their primary assistive device (Batten et al., 2019; Ghoseiri & Safari, 2014; Paternò et al., 2019). Prosthesis displacement, swelling of the residual limb, and infection or irritation of the skin reduce participation in LTPA and ADL in general (Batten et al., 2019; Ghoseiri & Safari, 2014; Littman et al., 2017; Paternò et al., 2019). When amputees participate in PA, studies show no statistical significance in improvement of cardiovascular fitness among amputees compared to non-amputee counterparts (Chin et al., 2002). In other words, amputation itself does not limit cardiovascular fitness.

2.2 Accessibility in Technology

Advances in technologies offer opportunities for independence and quality of life for PwD. Insulin pumps allow diabetics to monitor and control insulin levels away from healthcare facilities; elevators that have audible floor announcements improve navigation for people with visual impairments; closed captioning increases participation in online learning for the Deaf community. However, mainstream technologies that do not include

PwD in the design process result in barriers to participation and put the onus on the PwD to do without, to use products that pose shortcomings, or to buy specially designed products at a higher cost (Field et al., 2007). Barriers are created by everyday technologies, often taken for granted by people without disabilities, such as alarm clocks with only audible features, washing machines with touch screens, and mammography machines that are unable to adjust for women in wheelchairs. Introduction of electronic controls may impose further barriers; consider for someone with visual impairment the transition from a traditional stove in which the knobs click at each higher temperature level to one with a touchpad controls with no audible or tactile cues (Field et al., 2007).

Traditional product development processes treat accessibility as an edge case, only to be considered if the addition results in significant revenues, or is required to comply with regulations (Field et al., 2007; Shinohara et al., 2018). As internet use becomes ubiquitous, companies compete to develop software that improves the user experience. User-centered design (UCD) emphasizes the user experience in the design of both hardware and software technologies (Gould & Lewis, 1985). UCD is an iterative process that incorporates the end user, or target population for the product, in all stages of development (Sharp et al., 2007). This process improves adoption and usability. As part of the UCD process, the end user is defined and individuals matching the characteristics are recruited for evaluation and testing of the new technology. Although UCD practices should offer multiple opportunities for developers to include PwD into the design process, developers instead assume what PwD need or how they interact with technology and create products accordingly. This is as evidenced by the paucity of products that are

effectively accessible at point of sale (Sharp et al., 2007). Websites and apps in health and wellness industries are no exception to this (Stratton et al., 2020).

2.2.1 mHealth use in Physical Activity Interventions

With the vast majority (96%) of Americans owning a cell phone and 81% owning smartphones, app-based interventions are becoming more feasible across a wide variety of populations and health outcomes (Pew Research Center, 2019). The field of study that investigates mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices for improved health and well-being is called mHealth **(**WHO Global Observatory for eHealth, 2011). mHealth research on the impact of apps for influencing a wide variety of health behaviors has determined a set of features common to effective all apps that include feedback, goal setting, competition, and social sharing (Hosseinpour & Terlutter, 2019). BurnAlong offers fitness goal setting and tracking features, recognition of goal achievements through profile badges, the ability to interact with peers via live streaming and offline messaging, and opportunities to contact trainers with questions concerning workout performance.

A meta-analysis of 11 studies indicates mobile devices are a viable platform for delivering interventions to increase PA, but suggest that results could be improved with greater integration of theoretically-based designs (Fanning et al., 2012). Another meta-analysis of 45 studies aimed to quantify the impact of smartphone-based interventions to increase PA (Feter et al., 2019). Analysis determined app-based PA interventions resulted in an average of 12 more minutes per week of activity and 2000 more steps per day than a control group not using an app (Feter et al., 2019). One mHealth pilot study to improve PA through self-regulation recruited participants with impairments typically associated

with disability, but did not collect disability data. The study randomly assigned participants to three groups: mHealth-based self-management tool users, paper-based tracking tool users, and a control group. It showed mHealth significantly increased planned exercise and LTPA participation compared to both the control paper-based comparison groups (Plow & Golding, 2017).

Apps for PA promotion are not generally designed for, or with, PwD and require redesign or adaptations for PwD to gain full functional use of the app (Olsen et al., 2019; Stratton et al., 2020; Yu et al., 2019). This may explain why less than 20% of PA interventions for PwD in the last decade have used any interactive technology (Lai et al., 2017). When technology is used, communication tools are favored (Lai et al., 2017). Smartphones and web access enable counseling and peer support to be delivered remotely. An eight-week smartphone delivered counseling intervention, grounded in SDT, resulted in significant and large (Hedges' g=.85) increases in LTPA among people with SCI (Chemtob et al., 2019). In an mHealth delivered eight-week peer coaching pilot intervention among participants with Parkinson's disease, there was both acceptability of the intervention and clinically significant increases in steps generated per day (Colón-Semenza et al., 2018). An internet-based intervention, using social cognitive theory, to increase PA among people with a diagnosis of relapsing remitting multiple sclerosis (MS) significantly improved self-reported frequency and strenuousness of LTPA participation (p=.02) over the 12-week intervention (Motl et al., 2011). A review of 10 years of published literature among PwD pertaining to PA intervention characteristics, behavior change strategies, and types of technologies confirmed amputees are absent from research; 68% of all articles examined PA changes among people with MS, SCI, and

those that have experienced stroke (Lai et al., 2017). Even with the potential to extend recruitment reach through apps and the internet, the gap in research with amputees and PA extends to mHealth platforms.

2.3 Self-Determination Theory

Self-Determination Theory (SDT) is a complex macro theory framed in an organismic approach to understanding human motivation, emotion, and behavior (Fig 2.1; Gagné & Deci 2014). Organismic approaches attempt to look at the total human, taking into account interactions between the organism and the environment, human tendency toward growth, as well as toward unity or coherent sense of self (Deci & Ryan 2002). This theory suggests that when the environment supports fulfillment of needs for competence, relatedness, and autonomy, people will become more self-determined, which entails making decisions based on their own preferences and regulating their own actions. Self-determination is further supported or thwarted by an individual's natural tendencies to orient toward certain environments or behavior regulations. The theory was born of the hypothesis that type of motivation, not just amount, predicted health, well-being, and behavioral outcomes (Deci & Ryan, 2008). This was in opposition to existing theories emphasizing external rewards or punishments as primary sources for motivation; those were unable to explain a wide variety of behaviors, such as exploration or play (Ryan & Deci, 2007; Gagné & Deci, 2014). The first comprehensive introduction of SDT was in the mid-1980s (Deci & Ryan, 1985a). It encompasses five overlapping mini-theories to more clearly explain, isolate, and test the relationships of SDT constructs (see Table 2.1).

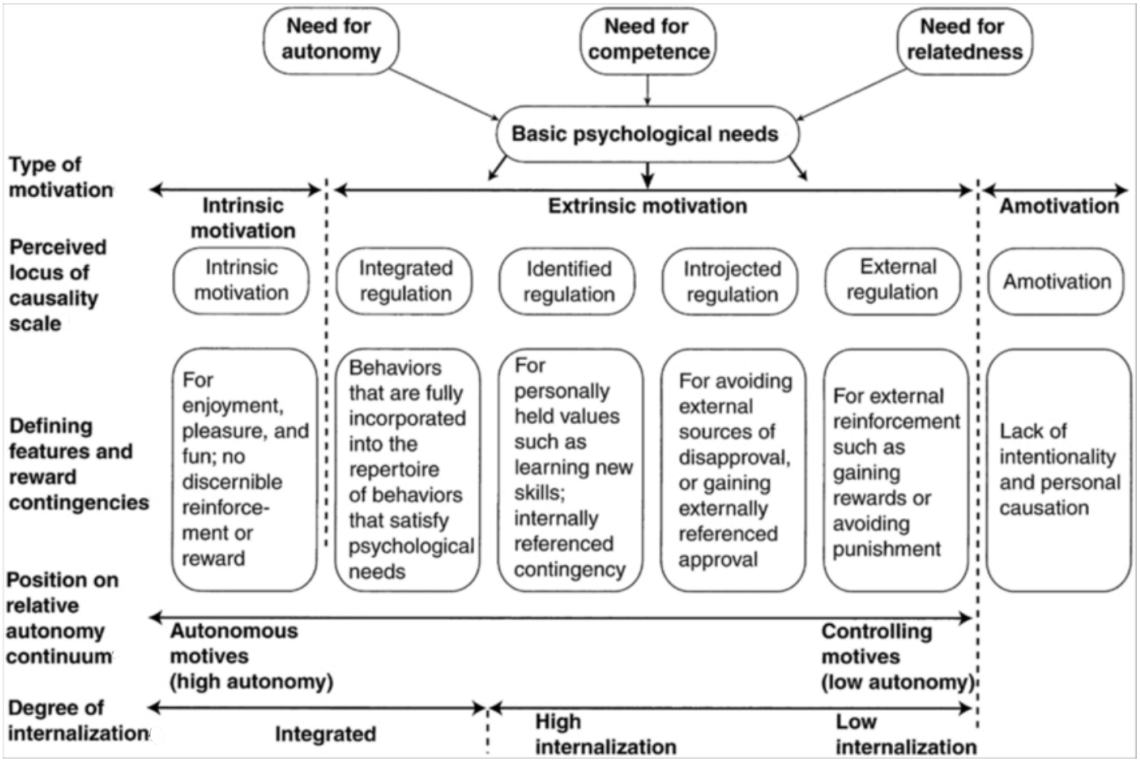

Figure 2.1 Self-Determination Theory Model (from Ryan & Deci 2007)

The first SDT mini-theory, Cognitive Evaluation Theory (CET) presupposes a dynamic interaction between external forces and individual interest (Vansteenkiste et al., 2010). Individual interest is not the pursuit of the behavior or activity but a result of full immersion in the activity; satisfaction is the outcome of the activity itself, with no other external rewards driving engagement (Vansteenkiste et al., 2010). CET differentiated intrinsic motivation from previously understood extrinsic motivations and begins to define the influence of social contexts, competence, and choice or autonomy in the fostering or support of intrinsic motivation (Vansteenkiste et al., 2010). In differentiating intrinsic from extrinsic motivation, CET describes how external influences that enhance perceived competence (e.g. optimal challenges that support growth) will also enhance intrinsic motivation, whereas events that diminish perceived competence will decrease intrinsic motivation (Deci & Ryan, 1985a). This becomes relevant when external rewards

are offered for tasks that appear to be their own reward. In line with organismic theory in which motivation is catalyzed, rather than caused, by environmental conditions conducive to expression, intervention focus on external rewards or punishments for behaviors otherwise performed for enjoyment or pleasure may actually reduce intrinsic motivation for that behavior (Ryan & Deci, 2000c).

The second SDT mini-theory sought to stratify external motivations. Organismic Integration Theory (OIT) places external motivation on a continuum in which external motivations can be considered controlling or can approach autonomy (Ryan & Deci, 2000a). Self-determined extrinsic motivations, i.e. those approaching autonomy, are described as integrated or highly internalized. An individual expressing extrinsic motivations on this end of the continuum endorses the value of the behavior (e.g. socially important) and believes they have choice in performance (Ryan & Deci, 2000a; Vansteenkiste et al., 2010). This is in contrast to extrinsic motivations on the controlled end of the spectrum which have low internalization. A person expressing low internalized motivation feels pressure or coercion to comply with external effects. Finally, OIT acknowledges the potential for complete amotivation, or lacking intent to act, based on low value of the activity, not feeling competent enough to perform the activity, and/or not expecting positive results from engaging in the activity (Ryan & Deci, 2000a; 2000c). In Figure 2.1, integrated regulated motivation and identified regulated motivation are the most self-determined of extrinsic motivations. The least self-determined or most controlled of the external motivations is externally regulated motivation. Behaviors that are externally regulated are motivated by reward, punishment, or compliance (Deci & Ryan, 1985a; Ryan & Deci, 2000a; 2000c). Introjected regulated motivations involve the

self but are driven by external results or expressions of reward and punishment. Such behaviors are motivated by ego, pride, anxiety, or guilt (Ryan & Deci, 2000a).

Causality Orientations Theory (COT), the third SDT mini-theory, defines three types of orientations that describes an individual's tendencies toward a specific way to regulate behavior based on how they interpret their environment (Vansteenkiste et al., 2010). Although people have display characteristics of all three orientations, causality orientations are considered relatively stable individual psychological traits (Deci & Ryan, 1985a; Deci & Ryan 2008; Gagné & Deci 2014; Ryan & Deci 2000a; Vansteenkiste et al., 2010). The three orientations are autonomy orientation, controlled orientation, and impersonal orientation (Deci & Ryan, 1985a). They influence locus of causality and position on relative autonomy continuum but are not visually present in most SDT graphic models (see Fig 2.1). People who are autonomy oriented perceive their environment as a source of information to make effective decisions. They tend to regulate their behavior toward their own interests and values, i.e. autonomously (Gagné & Deci, 2014; Ryan & Deci, 2000a; Vansteenkiste et al., 2010). Controlled orientation individuals interpret their environment as pressuring them toward particular ways of thinking, behaving, or feeling (Gagné & Deci, 2014). People high on control orientation scales tend to act based on external (rewards, punishments) or internal (approval, disapproval) contingencies (Gagné & Deci, 2014; Vansteenkiste et al., 2010). Impersonal oriented individuals are more likely to be amotivated, considering their experiences and environments to be outside of their control (Vansteenkiste et al., 2010).

Deci and Ryan (1985a) conceptualized the fourth mini-theory as a unifying principle of basic generalized needs that were psychological in nature rather than

physiological (see Maslow, 1943). Basic Psychological Needs Theory (BPNT) outlines three basic needs, which are growth-oriented, and operate across the life-span (Deci & Ryan 2014). BPNT describes the basic psychological needs of autonomy, competence, and relatedness as conducive to health and well-being, but if not met, as contributing to mental and physical illnesses (Ryan & Deci, 2000b). Studies have shown that fulfillment, or satisfaction, of basic psychological needs vary independently from each other and are individually able to predict fluctuations in physical and mental well-being, with greater levels of needs satisfaction directly correlating to well-being (Deci & Ryan, 2008, 2014; Ryan & Deci, 2000b). With autonomy, a person's behavior is considered of their own choice and in accordance with their values and interests; competence broadly refers to the a person's effectiveness of interactions with their environment that result in maximizing existing skills; relatedness is the need to feel connected with others and to experience care for and care from others (Deci & Ryan, 1985a; Vansteenkiste et al., 2010). Social environments can be described as needs supporting or needs thwarting and may effect motivation in a particular setting or social context.

The last SDT mini-theory is Goal Contents Theory (GCT). GCT describes long term or life goals as either intrinsic or extrinsic aspirations (Deci & Ryan, 2008). Intrinsic and extrinsic aspirations have different relationships to psychological needs (Vansteenkiste et al., 2010). Intrinsic aspirations (personal development, community engagement, physical health) are associated with greater health and well-being (Deci & Ryan, 2008). These life goals are developed over time as a function of needs satisfaction rather than a mechanism for basic needs to be met (Deci & Ryan, 2008). Extrinsic aspirations (fame, wealth, body image) are a substitute for basic psychological needs

satisfaction; they are adopted to achieve external measures of worth rather than support direct needs satisfaction (Deci & Ryan, 2008; Ryan & Deci, 2000b).

SDT and all of its five mini-theories have been empirically tested in a wide variety of settings, populations, and using a broad range of outcomes. One area extensively studied has been various aspects of sport, exercise, and competition discussed in section 2.2.1 (Hagger & Chatzisarantis, 2007).

Table 2.1 Self-Determination Theory constructs by Mini-Theory

→ Construct ↓Mini-Theory	**Intrinsic Motivation**	**Extrinsic Motivation**	**Amotivation**	**Locus of Control**	**Autonomy**	**Competence**	**Relatedness**	**Tendencies for Motivation type**	**Degrees of internalization**
Cognitive Evaluation Theory	internalized behavior performed for its own sake (inherently enjoyable, challenging, or significant)	in opposition to intrinsic motivation (e.g. external rewards reduce internalized interest in activity)			not a core construct but discusses role of environment in supporting or thwarting	not a core construct but discusses role of environment in supporting or thwarting			
Organismic Integration Theory	internalized behavior performed for its own sake	identifies multiple types	no drive to perform behavior	ties locus of control (behavior regulation) to motivation	defines relative autonomy continuum				level of autonomy in performing behavior
Causality Orientations Theory	relates individual tendencies to features of motivation type based on reliance of autonomous guides	relates individual tendencies to features of motivation type based on reliance of controlling or environmental guides						the way people orient to environments and subsequently regulate behavior; defined as autonomy, control, and impersonal	
Basic Psychological Needs Theory	as related to satisfaction of needs				experience of behavior as volitional and self-endorsed	experience of behavior as effectively enacted	feeling cared for and caring for others		
Goal Contents Theory					relationship of goals to needs satisfaction	relationship of goals to needs satisfaction	relationship of goals to needs satisfaction		

2.3.1 Self-Determination Theory in Physical Activity Interventions

PA has health benefits far beyond improved fitness but the majority of the country falls short of meeting Physical Activity Guidelines for Americans (HHS, 2018). Researchers have investigated a wide range of predictors related to initial engagement in PA and long term adherence to a PA routine. The proposed study presents SDT as an appropriate multilevel theory to understand motivations to be active. Previous research indicates environments conducive to needs satisfaction, actual satisfaction of basic psychological needs, and causality orientation predict PA participation (Eynon et al., 2017; Springer et al., 2013; Sylvester et al., 2016; Teixeira et al., 2012; Weman-Josefsson et al., 2015)

A systematic review of 53 studies investigating SDT constructs of motivation type and needs satisfaction on exercise initiation and maintenance found evidence of SDT to explain exercise behaviors (Teixeira et al., 2012). Motivation consistent with identified regulation was predictive of exercise initiation while intrinsic motivation more strongly predicted exercise maintenance (Teixeira et al., 2012). Satisfaction of basic psychological needs was associated with exercise; autonomy was positively associated with exercise, while competence and relatedness demonstrated positive or no association with exercise (Teixeira et al., 2012). No basic needs fulfillment were negatively associated with exercise. The review only considered direct effects and did not take into account potential mediating or moderating effects in its summary (Teixeira et al., 2012). In-depth interviews were conducted to better understand motivations to remain active among adults who had been regular exercisers for at least three years. Analysis revealed a strong association of basic psychological needs satisfaction and degree of internalized value of PA participation (Springer et al., 2013). How basic psychological needs satisfaction was

described by participants changed over time. Nearer the time of adoption of PA, relatedness, for instance, was marked by encouragement from an important other or presence of a workout partner. Over time relatedness evolved to connection with activity-minded individuals and being able to provide support and encouragement to others (Springer et al., 2013). Using the Basic Psychological Needs in Exercise Scale, Weman-Josefsson and colleagues (2015) demonstrated the mediating effect motivation on the relationship between needs satisfaction and amount of exercise. Identified regulation and intrinsic motivation had a positive mediating effect between needs satisfaction and exercise and controlled motivation had a negative indirect effect (Weman-Josefsson et al., 2015).

2.3.2 Self-Determination Theory among Populations with Disabilities

Few PA interventions studies among PwD have addressed motivation within a theoretical framework (Lai et al., 2017; Perrault & Vallerand, 2007). One study examined the role of peer mentorship on quality of life and participation-related outcomes, including LTPA, among people with SCI. Basic psychological needs of competence and relatedness were both found to mediate the relationship between peer mentorship and study outcomes of affect and participation (Sweet et al., 2018). Needs satisfaction was measured generally, as opposed to in relation to specific activities such as work or PA, using the Balanced Measure of Psychological Needs Scale (Sweet et al., 2018). In another study, comparison of wheelchair basketball players with and without disabilities showed no significant differences in motivation for sport (Perrault & Vallerand, 2007). This may indicate some transferability of SDT-related results in PA interventions to populations including PwD.

2.4 Phenomenology

Phenomenology describes both a philosophy and a methodology. Philosophically, phenomenology provides a way to think about how individuals become, and understand, their being in relationship to their social and physical environments – their world. Edmond Husserl (1859-1938) introduced phenomenology, "the science of pure phenomena" (Groenewald, 2004 p.43), as a philosophical means to reduce the realities people experience to their personal consciousness (Groenewald, 2004). Because the consciousness was of the world, Husserl believed there was no way to separate the individual from their connections within their world and that meanings are made based on the intentional relationship between the individual and the object being examined (Vagle, 2018). This was divergent from the current Western understanding, at the turn of the twentieth century, of an objective reality separate from self, described as Cartesian dualism (Crossley, 2012; Groenewald, 2004). Cartesian dualism describes mind and matter, specifically that of the body, to be completely separate from each other and to exist independently (Thibaut, 2018). Instead, Husserl argued that to truly understand the world, one must start with the thing itself – the experience within the world (Crossley, 2012; Vagle, 2018). He also understood that if realities are, at least in part, created by the individual experience, there is no way to be both the one experiencing and the one observing the phenomenon. Beyer (2018) provides the example of hallucination: if one is hallucinating, there is no object within the world with which to intentionally engage; however, the individual experiences the event the same as if the thing existed. Bracketing is Husserl's solution and one of the key features of transcendental or descriptive phenomenological methodologies. Bracketing, also called phenomenological reduction

and *epoche*, describes a reflective process used to actively suspend judgment about the natural world to instead focus on analysis of experience (LeVasseur, 2003). Husserl suggested that bracketing allowed one to transcend interaction with an experience, to actively set aside all biases, hypotheses, previous experiences and understandings and thus reveal the natural, essential lived experiences (Ashworth, 1999; Lopez & Willis, 2004; Tufford & Newman, 2012).

Martin Heidegger (1889-1976) was a student of Husserl. Heidegger was less interested in the epistemology of being in the world and more with the ontology of being, itself. His was an existential phenomenology (Groenewald, 2004; Kafle, 2011). He believed that people were constantly defining and being defined by their world; that being was a product of persistent intersubjectivity (Lopez & Willis, 2004; Smith et al 2009). Intersubjectivity is the two-way interaction between self and other used to construct shared meanings and interpret meanings of shared culture or experiences (Frie & Reis, 2001). Because a person's being is connected, temporal, and based on their point of view, the researcher's interpretation of meaning-making is integral to phenomenology (Smith et al., 2009). In Heideggerian-centered research how an experience is described and heard/interpreted is just as important as what the experience was. Language is an important part of how humans interact with and create meaning through their world. The focus on language is one of the reasons Heidegger is credited with the "grafting" (Vagle, 2018, p38) or permanent intertwining of phenomenology and hermeneutics. As such, the methodology that springs from Heideggerian philosophy is interpretative phenomenological analysis (IPA). As opposed to the reflective nature of bracketing,

researchers applying IPA to understanding a phenomenon are reflexive in all stages of research, deliberately contemplating one's own position in and to the subject matter.

2.4.1 Embodiment in Phenomenology

A contemporary and critic of Heidegger, Maurice Merleau-Ponty (1908-1961), argued that humans interact with their world both cognitively and bodily. Merleau-Ponty believed meaning-making was done both somatically and cognitively and that neither way of knowing had primacy (Crossley, 2012). Humans enter a world described as already in place – one present before birth with objects, cultures, and individuals that exists outside of the entering human; however humans continue the world's co-constructed meaning through their perceptions, relationships, and how they are being perceived by others (Sadala & Adorno 2001). Meaning is thus derived from and embedded in thoughts, feelings, and bodily (re)actions (Wilson, 2015). Finlay (2006) suggests bodily empathy, embodied self-awareness, and embodied intersubjectivity are all necessary components of phenomenological research. That is, the researcher must be aware of participant body movements, not as representations of emotion, but as the feeling itself; the body communicating beyond language or cognition. Finlay (2006, p. 23) offers this example, "a person's blush is not just an expression of embarrassment, it *is* embarrassment." Instinctively and immediately, before the cognition surrounding embarrassment occurs, observers understand and can empathize with reddening of cheeks and they know, in their body, the emotion that is occurring in front of them. In addition to knowing, the body can respond beyond conscious thought. Finlay (2006) describes an interview in which the participant's story elicited in her increased heart-rate, tunnel vision, and a sensation of skin crawling. Embodied self-awareness is necessary not only

to recognize the embodied reactions but to be able to use them reflexively in understanding the phenomenon in question. Both the participant and the researcher experience body-subject and body-object interactions. The body is being observed, evaluated and reacted to; it is the object of gaze and interpretation. Simultaneously, the body exists; it is a product of an individual's lived experiences and personal perspectives. There is a constant body-subject/body-object interplay in the way people move through the world and interact with others.

2.4.2 Disability in Phenomenology

Disability describes the loss of opportunity within an environment directly related to impairment (CDC, 2019; DoL, n.d.; WHO, n.d.). PwD experience the tension between having and being a body in way people without disabilities do not (Paterson & Hughes, 1999). PwD experience a paradox of the body being both ever-, and arguably extra-, present and invisible (Paterson & Hughes, 1999). PwD who have visible impairments frequently become the object of stares – leered at, probed, and investigated as a material, biological thing (Finlay, 2006). Their bodies are in greater focus to others as a result of visible impairments; however, PwD are ignored as separate from and not belonging to a world dominated by unimpaired bodies (Hughes, 2004). Phenomenological studies of PwD has focused on the impairment, the dysfunction, and the perceived loss often described in conjunction with the body as alien (Diedrich, 2001; Martiny, 2015). Martiny (2015) proposes a model that focuses on the person's experience being disabled to understand the lived experience outside of the constraints of a model aligned with illness and rehabilitation or the return to 'normal' – the bodily state before illness/impairment. Martiny's model does not ignore the history of impairment but focuses on how the body

exists within and interacts with the world now. The experience of disability is beyond the phenomenon of recovery; it is a complex intertwining of internal and external factors that affect how PwD engage with and move through the world (Martiny, 2015).

As opposed to making rehabilitation central to this research, the qualitative component of this study will allow participants to explore how embodied experiences helped them to understand and make meaning of PA motivation. This dissertation will attempt to contextualize motivations to be active among amputees through the first-person perspective of living with, and experiencing, disability.

Chapter 3 Motivation to be Active Among Amputees: Evaluation of A Fitness App Pilot Intervention based on Self-Determination Theory

3.1 Abstract

A small scale fitness app intervention that aimed to increase motivation to be active and total activity level among amputees is described and evaluated. Motivation is defined through Self-Determination Theory (SDT), ranging from amotivation through extrinsic motivation, to intrinsic motivation. Participants with single limb amputations, aged 18-65 years were enrolled and randomized into a two arm study. One group received access to BurnAlong, a commercially available fitness app, while the other group was designated as a waitlist control group and received access to the app at the completion of the 8-week intervention. The BurnAlong app contained specialized content consisting of workout videos both designed for, and taught by, amputees who were certified trainers. Several features of BurnAlong addressed SDT constructs of basic psychological needs (autonomy, competence, relatedness). In total, 257 single limb amputees enrolled in the intervention. Loss to follow-up was higher (36% after 4 weeks, 86% after 8 weeks) than other studies enrolling people with mobility disabilities. Using mixed effects modeling to evaluate the role of the intervention on outcomes over time, changes in amotivation and total activity level were significant during the intervention; there were no significant changes in extrinsic or intrinsic motivation. Amotivation increased in both groups, but the increase was greater in the in waitlist control group. Total activity increased in the waitlist control group only. Moderation was tested using SDT constructs of general causality orientation, a personality trait that represents a person's belief about behavioral change and reasons to change. Amotivation is moderated by all general causality

orientations. This study emphasizes unique needs of amputees in interventions related to physical activity. Several suggestions for future research and expansion are described.

3.2 Introduction

People with disabilities (PwD) are less likely to be active than their non-disabled counterparts; 42% of PwD are sedentary compared to 24.3% of non-disabled people (CDC, 2017). Amputees represent a subset of PwD who have mobility related impairments, as opposed to other impairment such as visual or developmental, for example. Focusing on PwD with mobility related impairments, 57% are inactive (CDC 2014) with unilateral amputees less active than non-amputee peers (Bussmann et al., 2008). Increased leisure time physical activity (LTPA) lessens the impact of high blood pressure, diabetes, and other chronic conditions in all adults and reduces severity of secondary conditions among PwD (Martin & Whalen, 2012, Mashola & Mothabeng, 2019, Wilhite & Shank, 2009).

To date, research related to people with amputations is limited, focusing more on the biomechanics of prosthesis use and the physiology of limb loss (Bragaru et al., 2011; Castro et al., 2018). Physical activity research among amputees centers the rehabilitative process rather than mental and physical benefits of LTPA (Lai et al., 2017). This is despite conditions unique to amputees that have the potential to affect both initiation and sustainment of LTPA, such as phantom limb pains and sensations, neuromata, heterotopic ossification, and range of motion limitations in the joint nearest amputation (Coons & Franklin, 2013; Esquenazi & Yoo, 2016). Amputees must also consider the impact of prosthesis use when engaging in LTPA. Prosthesis displacement, swelling of the residual limb, and infection or irritation of the skin reduce participation in LTPA and activities of

daily living, in general (Batten et al., 2019; Paternò et al., 2019). The opportunity to engage in LTPA that accounts for the unique aspects of being active as an amputee may improve overall activity.

Fitness apps are one way to engage with hard to reach populations, such as PwD. Feter and colleagues (2019) conducted a meta-analysis of 45 studies aimed to quantify the impact of smartphone-based interventions to increase PA. The study showed app-based PA interventions resulted in an average of 12 more minutes per week of activity and 2000 more steps per day than a control group not using an app, demonstrating the influence and efficacy of app-based interventions to improve LTPA engagement. Apps for LTPA and digitized fitness resources are not generally designed for, or with, PwD and require redesign for PwD to gain full functional use of the app (Olsen et al., 2019; Stratton et al., 2020; Yu et al., 2019). This may explain why less than 20% of PA interventions for PwD in the last decade have used any interactive technology (Lai et al., 2017).

Research on the effectiveness of apps to influence health behaviors has resulted in a set of core features common to all apps regardless of health outcome of interest. These features include feedback, goal setting, competition, and social sharing (Hosseinpour & Terlutter, 2019). BurnAlong, the app chosen for use in this study, offers fitness goal setting and tracking features, recognition of goal achievements through profile badges, the ability to interact with peers via live streaming and offline messaging, and opportunities to contact trainers with questions concerning workout performance. One of the critiques of fitness apps and app interventions is their failure to incorporate behavior change theories in development (Azar et al., 2013; Payne et al., 2015; Lai et al., 2017).

This study used self-determination theory (SDT) as a framework for operationalizing motivations to be active. SDT is a macro theory that aims to understand complex drivers and types of motivation through five mini-theories (Deci & Ryan, 1985a). This study integrates constructs of four mini-theories to evaluate the effect of a fitness app intervention among amputees. The constructs common among these theories include motivation, basic psychological needs, and general causality orientation. SDT describes three main type of motivation: amotivation, extrinsic motivation, and intrinsic motivation. Extrinsic motivation is further divided into four regulatory styles – external regulation, introjected regulation, identified regulation, integrated regulation – that drive action (Deci & Ryan, 1985a; Ryan & Deci 2000a; 2000c; Vansteenkiste et al., 2010). External regulation is based on rewards and punishments; introjected regulation may be described as ego-centric motivations; identified regulation is about challenges seeking and goal setting; and integrated regulation is consistent with internally held values. Basic psychological needs describe universal needs that operate across the life-span, and when satisfied, contribute to physical and psychological well-being, and ultimately intrinsic motivation (Ryan & Deci, 2000b). The needs are autonomy (person's behavior is considered of their own choice), competence (a person's effectiveness and confidence interacting with their environment), and relatedness (the need to feel connected with others) (Deci & Ryan, 1985a). General causality orientation describes an individual's tendencies toward a specific way to regulate behavior (Vansteenkiste et al., 2010). These are defined as autonomy orientation, controlled orientation, and impersonal orientation (Deci & Ryan, 1985a). Although people display characteristics of all three orientations, causality orientations are considered relatively stable individual psychological traits that

influence motivation type (Deci & Ryan, 1985a; 2008; Gagné & Deci, 2014; Ryan & Deci, 2000a; Vansteenkiste, et al., 2010).

The purpose of this study was to assess changes in motivation to be active and changes in actual PA among amputees exposed to a fitness app (BurnAlong) intervention that incorporates features to support basic psychological needs (workout autonomy, fitness competence, and relatedness). A secondary aim was to test whether the relationship between mobile fitness app use, and type of motivation, differ by individual causality orientation of amputees. We hypothesized that: 1) increases in intrinsic motivation and level of PA would occur with the use of BurnAlong as compared to the control group; and 2) intrinsic motivation to be active would be stronger in amputees with an autonomy orientation and weaker in amputees with an impersonal orientation.

3.3 Method

3.3.1 Design

This study used a randomized, 2-group experimental design in which the app-based intervention was provided to half the participants. The other half was a wait-list comparison control group that received access to the app at completion of the study. Throughout rolling enrollment, group assignment occurred through a Qualtrics (Qualtrics, Provo, UT) feature that randomizes participants into groups after they electronically signed the consent form. Institutional Review Board approval was provided by University of Maryland.

3.3.2 Participants

Participants were recruited through the Amputee Coalition (AC), one of the largest nonprofits in the United States dedicated to enhancing the quality of life for amputees and ensuring amputees have a voice in matters affecting their ability to live full lives (AC, n.d.). Advertisements in the AC sponsored periodical, *inMotion*, were placed in the May and July 2020 issues. The magazine has a reach of 30,000 subscribers. Additionally, AC registered support group leaders across the US were contacted by email and asked to share study information within their network. Participants were directed to contact the researcher via email for complete description of the study, time commitment, and incentives. The individuals' inclusion in, or decision (not) to participate in the study was not shared with the recruitment partners. Those interested in participating completed a short online questionnaire through Qualtrics to verify they met inclusion criteria for the study. Inclusion criteria included: adults between the ages of 18 and 65 years, single limb amputation at or above the wrist or ankle, internet and device access to be able to use the BurnAlong app, ability to read and respond to questionnaires in English, and initial willingness to commit to two BurnAlong workouts of their choice per week for eight weeks. Excluded from the study were those with multiple amputations and those under the care of a physician for conditions that precluded LTPA. Participants randomized into the intervention arm were provided immediate access to three months of BurnAlong app free of charge; participants in the waitlist control arm were provided three months of BurnAlong app access free of charge upon completion of the study. Participants in both arms were offered a $10 incentive for completion of all surveys.

The determination of the sample size (126 in total, 63 per study arm) is described in Appendix A. Previous LTPA interventions with disabled populations have recorded retention rates ranging from 49% to 91% (Kosma et al., 2012; Littman et al 2018; Wegener et al., 2009). With such a wide range of retention rates, I estimated 50% of the sample would be lost to follow-up. To account for loss to follow-up, the recruitment goals was at least 190 participants (95 per study arm).

3.3.3 Measures

Assessments were administered at baseline and at two follow-up assessment points: 4-weeks, 8-weeks (intervention endline) post-enrollment (Table 3.1). Demographic data and General Causality Orientation Scale (GCOS) data were collected at baseline. Demographic information included age, gender, race, education level, employment status, location of amputation (upper or lower extremity), mechanism of amputation (congenital or acquired), and length of time living with an amputation.

Intervention outcome measures of interest were motivation and PA level. The instrument that was be used to collect motivation data was the Exercise Motivation Scale (EMS) (Li, 1999). The EMS consists of 31 items assessing eight subscales measuring perceived locus of causality along the SDT motivation continuum: amotivation, external regulation, introjected regulation, identified regulation, integrated regulation, intrinsic motivation to learn, intrinsic motivation to accomplish task, and intrinsic motivation to experience sensations (Li, 1999). Although not previously reported in studies with disabled populations, internal consistency for all subscales have been measured at or above acceptable levels (Cronbach's alpha .75-.90) (Wininger, 2007). EMS has also been tested for temporal stability using a 1-week test-retest evaluation with scores ranging .78

to .88 (Li, 1999). The instrument response format is a 6-point Likert-style, ranging from strongly disagree to strongly agree with the item statement. Principal component analysis was used to reduce the number of motivation variables to three – amotivation, extrinsic or regulated motivation, and intrinsic motivation. Results were consistent with SDT.

The instrument used to evaluate PA was developed for measurement among populations with disabilities, the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Washburn et al., 2002). The instrument measures metabolic equivalents (METs) as a proxy for PA level. Most PwD samples used to develop and evaluate reliability and validity of PASIPD self-identified as having mobility disabilities (80%). Researchers did not further stratify the type of impairment to differentiate results of amputees from others with mobility disabilities (Washburn et al., 2002). The PASIPD showed temporal stability (ρ=.77) and criterion validity against an accelerometer (ρ=.30) equivalent or better than accepted measures used for the general population, such as the International Physical Activity Questionnaire and Stanford 7-Day Recall (van der Ploeg et al., 2007; van den Berg-Emons et al., 2011).

General causality orientations, hypothesized as moderating the relationship between app use and motivation, were measured using the General Causality Orientation Scale (GCOS). The instrument has shown internal consistency and temporal stability across all subscales among 1,116 adults (Deci & Ryan, 1985b). Test-retest reliability scores were .75 for autonomy orientation, .71 for control orientation, and .78 for impersonal orientation (Deci & Ryan, 1985b). Divergent validity testing confirmed little relationship ($r<.30$) among subscales; and no subscale correlated with measures of social desirability (Deci & Ryan, 1985b). Additional data related to app quality and basic

psychological needs were collected using the Basic Psychological Needs in Exercise Scale (BPNES) (Vlachopoulos & Michailidou, 2006) at each data collection point and the User Version of the Mobile Application Rating Scale (uMARS) at endline (Stoyanov et al., 2016). Based on the design of the intervention app, basic psychological needs satisfaction was expected to be correlated with perceived app quality. BPNES demonstrated adequate internal consistency for all three subscales (α=.84 for autonomy, α=.81 for competence, α=.84 for relatedness) (Vlachopoulos & Michailidou, 2006). uMARS internal consistency was very high (α=.90), and had good test-retest reliability (Stoyanov et al., 2016).

Table 3.1. Description of Measures used during intervention data collection

Variable	**Assessment**	**Sample Question**	0 Weeks	4 Weeks	8 Weeks
Motivation Level	Exercise Motivation Scale (EMS) (Li, 1999)	Reasons participants exercise. Likert scale from strongly agree to strongly disagree: For the pleasure it gives me to experience positive sensations from the activity	x	x	x
Physical Activity Participation	Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Washburn et al., 2002)	Participants indicated frequency and duration of listed activities: During the past 7 days, how often did you engage in moderate sport and recreational activities such as doubles tennis, softball, golf without a cart, ballroom dancing, wheeling or pushing for pleasure or other similar activities?	x	x	x
Basic Psychological Needs	Basic Psychological Needs in Exercise Scale	Statements with Likert scale responses from don't agree at all to completely agree: I feel I	x	x	x

	(BPNES) (Vlachopoulos & Michailidou, 2006)	have made a lot of progress in relation to the goal I want to achieve			
Causality Orientation	General Causality Orientation Scale (Deci & Ryan, 1985b)	Vignettes with 3 possible responses: You have been offered a new position in a company where you have worked for some time. The first question that is likely to come to mind is: a) What if I can't live up to the new responsibility? b) Will I make more at this position? c) I wonder if the new work will be interesting.	x		
App Quality	User Version of the Mobile Application Rating Scale (uMARS) (Stoyanov et al., 2016).	Series of indicators of quality with multiple choice responses: Is app content correct, well written, and relevant to the goal/topic of the app?			x
Age	Continuous variable		x		
Gender	Nominal variable		x		
Race	U.S. Census defined nominal categories		x		
Education level	Ordinal variable		x		
Employment status	Nominal variable		x		
Upper or Lower Amputation	Nominal variable		x		
Mechanism of amputation	Nominal variable		x		
Length of time living with amputation	Continuous variable		x		

3.3.4 Intervention

The independent variable in the intervention was use of a mobile fitness tracking app. The app, BurnAlong, contains a library of video classes delivered by certified fitness instructors in categories related to strength, aerobic conditioning, and mobility. BurnAlong is commercially available and not designed specifically for PwD. There are, however, specific in-app links to direct users to those videos designed for amputees and created by fitness professionals with experience working with adults with disabilities. Users could access BurnAlong from the app or the website using a smartphone, tablet, computer, or smart television. Although not designed using SDT as a framework, the app contains features to satisfy basic psychological needs associated with increasing autonomous or intrinsic motivation for PA. The app offers the user choice of workout (autonomy), videos to improve exercise skills (competence), and the ability to connect with others via private live streaming sessions where users can see and hear each other as well as the chosen workout video (relatedness). The amputee specific content and live streaming component set BurnAlong apart from other fitness tracking apps as uniquely situated for an intervention to increase intrinsic motivation among amputees. Evidence suggests PA interventions among disabled populations ranging from two to 10 weeks are sufficient to show both practical and statistically significant results related to motivation and PA participation (Arbour-Nicitopoulos et al., 2009; Chemtob, 2019; Jaarsma & Smith, 2018; Miller et al., 2017). Data to suggest an ideal intervention length for PwD are limited. This study included an eight week intervention with data collected at three time points: 0-weeks (baseline), 4-weeks, and 8-weeks (endline) (Table 3.1).

3.3.5 Analysis

The purpose of this study was to test the effects of fitness tracking app (BurnAlong) use on motivation and PA participation among amputees, over time. To examine the relationship between intervention and outcomes, linear mixed effects modeling was used, in part to account for the correlation among repeated measurements for an individual participant across three data points. Besides random intercepts, the study arm, time of measurements, and study arm by time interaction, were included as fixed effects in the model. Time of measurements was defined as a continuous time (in days) since the first survey. Separate models were developed for each outcome variable (amotivation, extrinsic motivation, intrinsic motivation, and PA). I controlled for race, level of education, employment status, location of amputation, mechanism of amputation, and time with amputation. GCOS variables (autonomy, control, and impersonal orientation) were assessed separately as potential moderating variables by including an interaction term to the linear mixed effects models. Bivariate correlations of app quality were performed with all outcome variables as well as BPNES variables.

3.4 Results

A total of 257 participants met inclusion criteria and were enrolled in the study (Table 3.2). There was a 36% loss to follow-up between baseline and week four and an additional 50% loss between weeks four and eight. All participants filled out demographic data in full. Missing data related to the other data collection instruments ranged from 0-1.6% across all data points. Little's Missing Completely at Random (1988; MCAR) test yielded non-significant results for all variables (p=.261-.999). Data are presumed to be missing completely at random. There were no significant differences in

characteristics between the wait list control and the intervention groups at any time point (Table 3.3). Compared to US demographics of the amputee population, several groups were over sampled: White participants, those with congenital amputation, and those with upper extremity amputations.

Table 3.2. Recruitment and retention/loss to follow-up information

		baseline	4-week	8-week
Intervention Group	Waitlist Control	129	83	16
	BurnAlong Intervention	128	81	19
	Total	**257**	**164**	**35**

Attrition analysis (Appendix A) showed significant differences ($p<.05$) in the characteristics of participants that completed the study and those lost to follow-up. Participants more likely to remain in the study included older participants, those who had been living longer with an amputation, Black or African-American identifying participants, and individuals with a congenital or lower extremity amputations. Additionally, in the intervention group, participants with more formal education were more likely to remain while control group participants with lower scores in Impersonal and Controlled orientations were more likely to remain.

At baseline, participants in both arms reported higher extrinsic motivation (15.35 out of 24 in control group; 16.30 in intervention group) than intrinsic motivation or amotivation toward exercise. At endline, intrinsic motivation (18.03 out of 24 in control group; 18.65 in intervention group) was highest in each group (Table 3.4). Means of all motivations types increased in both groups between baseline and endline. Total PA levels ranged from 0-66.5 METs per week in the control group and 0-76.4 METs in the intervention group at base line. At endline, total METs expended per week ranged from 21.13-39.80 in the control group and 0-35.32 in the intervention group.

Table 3.3. Characteristics of participants completing the baseline and 4-week & 8-week follow-up surveys. All data collected during baseline survey

	Waitlist Control mean (SD) or n (%)			**BurnAlong Intervention mean (std dev) or n (%)**		
	Baseline n=129	4-week n=83	8-week n=16	Baseline n=128	4-week n=81	8-week n=19
Age	35.84 (8.66)	37.76 (8.51)	42.44 (4.12)	35.73 (7.80)	37.16 (7.60)	39.89 (5.84)
Time with Amputation	9.13 (11.24)	11.77 (13.19)	30.44 (16.09)	8.96 (9.95)	11.02 (11.20)	28.79 (16.82)
Race						
White or Caucasian	74 (57.36)	36 (43.37)	1 (6.25)	65 (50.78)	25 (30.86)	4 (21.05)
Black or African American	40 (31.00)	32 (38.55)	15 (93.75)	42 (32.81)	35 (43.21)	15 (78.95)
All other races	15 (11.63)	15 (18.07)	0 (0.00)	21 (16.41)	21 (25.93)	0 (0.00)
Gender						
Man	83 (64.34)	51 (61.45)	9 (56.25)	77 (60.16)	49 (60.49)	10 (52.63)
Woman	42 (32.56)	29 (34.94)	7 (43.75)	49 (38.28)	31 (38.27)	9 (47.37)
All other genders	4 (3.10)	3 (3.61)	0 (0.00)	2 (1.56)	1 (1.23)	0 (0.00)
Education						
High school	24 (18.60)	21 (25.30)	0 (0.00)	25 (19.53)	19 (23.46)	0 (0.00)
Some college	22 (17.05)	12 (14.46)	4 (25.00)	21 (16.41)	18 (22.22)	11 (57.89)
Trade or vocational school	28 (21.71)	13 (15.66)	0 (0.00)	37 (28.91)	14 (17.28)	0 (0.00)
Undergraduate or Graduate degree	55 (42.64)	37 (44.58)	12 (75.00)	45 (35.16)	30 (37.04)	8 (42.11)
Employment						
Employed full time	28 (21.71)	18 (21.69)	6 (37.50)	34 (26.56)	23 (28.40)	7 (36.84)
Employed part time	49 (37.98)	37 (44.58)	10 (62.50)	39 (30.47)	26 (32.10)	11 (57.89)
Out of work or retired	36 (27.91)	16 (19.23)	0 (0.00)	41 (32.03)	21 (25.93)	1 (5.26)
Unable to work	16 (12.40)	12 (14.46)	0 (0.00)	14 (10.94)	11 (13.58)	0 (0.00)
Location of Amputation						
Upper – at or below elbow	33 (25.58)	25 (30.12)	0 (0.00)	32 (25.00)	25 (30.86)	2 (10.53)
Upper - above elbow	45 (34.88)	29 (34.94)	0 (0.00)	37 (28.91)	23 (28.40)	1 (5.26)

Lower – at or below knee	36 (27.91)	26 (31.33)	16 (100.00)	42 (32.81)	28 (34.57)	16 (84.21)
Lower - above knee	15 (11.63)	3 (3.61)	0 (0.00)	17 (13.28)	5 (6.17)	0 (0.00)
Mechanism of Amputation						
Congenital	13 (10.08)	13 (15.66)	11 (68.75)	11 (8.59)	10 (12.35)	13 (68.42)
Acquired Trauma	76 (58.91)	55 (66.27)	5 (31.25)	80 (62.50)	58 (71.60)	2 (10.53)
Acquired non-Trauma	40 (31.01)	15 (18.07)	0 (0.00)	37 (28.91)	13 (16.05)	4 (21.05)
Impersonal Orientation	4.44 (0.83)	4.67 (0.75)	3.73 (0.65)	4.54 (0.75)	4.58 (0.71)	3.96 (0.47)
Controlled Orientation	4.49 (0.76)	4.64 (0.69)	3.92 (0.27)	4.59 (0.68)	4.56 (0.65)	4.10 (0.41)
Autonomy Orientation	4.65 (0.81)	4.70 (0.73)	4.13 (0.73)	4.72 (0.81)	4.72 (0.77)	4.19 (0.57)

Note: no significant difference (p<.05) between intervention and control groups at baseline or 4- or 8-week follow-up time points using independent sample t-tests and Pearson's Chi square test for independence

Table 3.4. Comparison of baseline and endline outcome means (standard deviation) and ranges by intervention group

	WLC Baseline (n=129)	WLC 8-weeks (n=16)	BurnAlong Baseline (n=128)	BurnAlong 8-weeks (n=19)
Motivation				
Amotivation	12.51 (3.27) 3.50-21.00	15.47 (3.57) 3.50-18.50	12.96 (2.92) 3.50-20.00	14.66 (2.92) 3.50-18.00
Extrinsic Motivation	15.35 (2.66) 7.75-21.75	16.36 (3.79) 11.00-20.25	16.30 (2.18) 10.00-22.00	17.43 (2.07) 15.50-20.50
Intrinsic Motivation	15.32 (3.03) 8.00-24.00	18.03 (2.20) 14.50-20.50	15.93 (2.70) 9.50-22.00	18.68 (1.10) 16.50-22.00
Total Physical Activity	11.75 (12.71) 0-66.50	31.44 (6.79) 21.13-39.80	13.03 (12.57) 0-76.40	12.99 (14.46) 0-35.32

Separate linear mixed effects models were developed for each outcome measure: amotivation, extrinsic motivation, intrinsic motivation, and total PA (Table 3.5). There was no significant difference between groups in changes to extrinsic or intrinsic motivation level over time. There was no overall effect of intervention on amotivation level; however, the effect of time and the interaction effect of group by time were both significant factors in changes to amotivation level, demonstrating a crossover interaction effect. The effect of time on amotivation is different, depending on the intervention group. Although both groups reported increases in amotivation over time, the slope of increase in amotivation in the control group was far steeper than the slope of increase in amotivation in the intervention group over time, meaning the control group amotivation level increased faster than the intervention group. The PA model showed significant effects from group assignment, time, and the group by time interaction. The intervention group decreased total by .15 METs expended compared to control group for every day of the study. This represents less than the amount of oxygen consumed while sitting at rest, the definition of 1 MET.

Table 3.5. Mixed-effects models: Outcome variable Fixed Effect Estimates by Group over Time; control variables [a]

	Intervention (vs Waitlist Control)	Time (changes across surveys)	Interaction (Group X Time)
Motivation			
Amotivation	.56	.03**	-.02*
Extrinsic Motivation[b]	.62*	.02**	--
Intrinsic Motivation[b]	.42	.03**	--
Total Physical Activity	2.89*	.16**	-.15**

[a] Control variables: Race, Education, Employment, Location of Amputation, Mechanism of Amputation, Time with Amputation; [b]Interaction effect was not significant therefore removed from model
*p<.05; **p<.01

To test moderation, models with the interaction of group and each general causality orientation were developed independently. All general causality orientations significantly attenuated the relationship between group assignment and amotivation. The difference in the mean amotivation level between the intervention and control groups decreases with increase in the GCOS score. Controlled orientation had the largest moderating effect, while autonomy orientation affected the relationship between intervention group and amotivation level the least (interaction fixed effects estimates: impersonal orientation*group β= -1.02; controlled orientation*group β= -1.82; autonomy orientation*group β= -.90). No moderation effect was detected between intervention group and extrinsic motivation or intrinsic motivation for any of the three general causality orientations.

Participant opinion of overall app quality was collected at endline in the intervention group only. Only 15 of 19 participants not lost to follow-up completed the app quality questionnaire. Bivariate correlations were run using Pearson's Product-Moment Correlation (Table 3.6). There were significant correlations between app quality and all outcome variables, i.e. amotivation, extrinsic motivation, intrinsic motivation, and

total PA. There were also significant correlations between app quality and BPNES in autonomy and relatedness, but not exercise competence. Extrinsic and intrinsic motivations had a positive correlation with app quality, while amotivation had an inverse relationship. Autonomy and relatedness had positive correlations with app quality.

Table 3.6: App Quality (N=15) correlation with BPN satisfaction and outcome measures

	Amotivation	**Extrinsic Motivation**	**Intrinsic Motivation**	**Total Activity**	**Autonomy**	**Relatedness**	**Competence**
App Quality	-.572*	.583*	.644**	.739**	.626*	.549*	.400
p=value	.026	.023	.010	.009	.013	.034	.139

*p<.05; **p<.01

3.5 Discussion

This study examined the impact a brief intervention had on PA among amputees. Most PA interventions for amputees are designed as part of a rehabilitative protocol or one designed to understand the biomechanics of residual limb function (Bragaru et al., 2011; Castro et al., 2018; Lai et al., 2017). This study was unique in that it targeted motivation and activity levels of congenital amputees and amputees post-rehab to improve overall LTPA. The intervention leveraged a commercial fitness app with video content of workouts for PwD. Having access to video workouts focused on mobility, lifting, and functional fitness, led by amputees and other PwD that were certified trainers, added a component of peer modeling not available in other interventions.

The BurnAlong app has a wide variety of searchable activities from mindfulness training to high-intensity interval workouts. Those workout videos taught by amputee instructors, or with explicit modifications for amputees as part of the video, were tagged and searchable as well. This level of choice was expected to satisfy the basic psychological need for autonomy associated with intrinsic motivation. Similarly, the

ability to live stream a workout with another app user to virtually workout together was expected to satisfy the basic psychological need for relatedness. Several workout videos were focused on how to perform specific movements as an amputee. This was expected to satisfy the basic psychological need for competence. Although the intervention did not have significant effect on intrinsic motivation, there was evidence that how participants perceived app quality at the end of the intervention was positively correlated with BPNES. Reported app quality was also positively correlated with intrinsic motivation and negatively correlated with amotivation. SDT posits that when basic psychological needs are met, a person is more likely to be intrinsically motivated toward LTPA. App quality correlations imply use of BurnAlong should increase feelings of basic psychological needs satisfaction; increase intrinsic motivation level towards LTPA; and decrease amotivation related to LTPA. Mixed effects models results were not theoretically congruent with the bivariate results, suggesting some other factor influenced the relationship between app use and overall intrinsic motivation.

The entire study was conducted during the COVID-19 pandemic in which PA levels in all populations dropped significantly during the early months of the pandemic. There was a global 27.3% decrease in average steps per day with maximal national decreases as high as 48.7% (Tison et al., 2020). When stratified by pre-pandemic activity level, the greatest group decreases in activity were among younger groups and those most active pre-pandemic (Barkley et al., 2020; McCarthy et al., 2021). The range of METs expended in both the control and intervention groups was wider at baseline with much higher maximum reported activity (0-66.5 METs control; 0-76 METs intervention) than at endline (21-39 METs and 0-35 METs respectively). Although this study did not span

the pandemic, changes in maximum METs expended mirrored pandemic related decreases. All participants (n=21) who started with >30 METs expended weekly were lost to follow-up. It is also worth noting that the range of expended METs in the control group narrowed considerably. Of those participants who began the study with >30 METs expended weekly, 67% were in the intervention group.

3.5.1 Limitations

The loss to follow-up in this study was greater than the predicted 50% of all enrolled participants at baseline. Had the 36% loss to follow-up between baseline and week four remained consistent between weeks four and eight, the total loss to follow-up would have been 60% instead of the recorded 86%. Week eight data was expected to be completed at the end of December 2020 with a reminder sent to participants the first week of January 2021. This time period included Christmas, Hanukkah, Kwanzaa, New Year's Day, and the January 6 attack on the US Capitol. It was also during colder, winter months which historically reduces inclination to be active (Tucker & Gilliland, 2007). Developing a study with a longer rolling enrollment period may account for history bias in which events external and unrelated to the study influenced outcomes.

Data related to app quality was collected at the end of the intervention rather than throughout. With no baseline or midpoint app quality data for comparison purposes, there is no way to correlate app quality to loss to follow-up. One of the reasons for leaving the study may have been dissatisfaction with the app itself, meaning only those who had high opinions of the app remained in the study. The correlation of app quality to BPNES and intrinsic motivation may be influenced by the difference in app quality perception of those who remained in the study.

The baseline characteristics of participants differ greatly from the US amputee population. Nonwhite people are four times as likely to have an amputation as compared to white people; yet over 50% of each intervention arm at baseline identified as white (Ziegler-Graham et al., 2008). Congenital amputees make up about 1% of the amputee population, but congenital amputees accounted for more than 8% of participants at baseline (Ziegler-Graham et al., 2008). Lower extremity amputees are most prevalent, with upper extremity amputees representing only 3% of the amputee population (Braza & Yacub Martin, 2020). Sixty percent of this study's baseline participants reported being an upper extremity amputee. Such differences from the overall US amputee population limit generalizability and may also influence access to and psychology of LTPA. There may also have been a selection bias introduced by how the study was advertised. The clear interest in motivations to be active among amputees may have resulted in participants already interested in PA.

3.5.2 Future Research

Given the high percent of participants lost to follow-up, formative research related to app content desired by the amputee population may result in more intervention effect on both intrinsic motivation and total PA. A mixed methods study in which intervention participants are not anonymized and can be interviewed about app quality and other influences to motivation level may contextualize and explain the results more clearly. The amputee population is under-represented in LTPA behavior research. Understanding influences on LTPA engagement may improve intervention designs to increase LTPA. There is also little information among this population about the relationship between motivation or intention to be active and level of activity. As this study indicates, SDT

may not effectively capture amputees' experiences of motivation for LTPA; future studies should investigate multilevel environmental influences on the connection between motivation to be active and activity level.

Chapter 4 Exploring Motivations to be Active among Amputees: a Phenomenological Approach

4.1 Abstract

Leisure time physical activity (LTPA) participation is strongly related to improved health and well-being. People with disabilities (PwD) are less active and experience increased burden of disease compared to those without disabilities. Research with amputees focuses heavily on prosthetic design and function. Amputees are an under-represented population in research about LTPA and motivations to be active. The purpose of this study is to explore the lived experiences of motivations to be active among lower extremity amputees. The study employed an interpretative phenomenological analysis (IPA) approach, influenced by both understandings of embodiment and Self-Determination Theory (SDT). Six people with lower extremity, acquired amputations created a photo-diary of their motivations to be active and participated in two in-depth interviews. Data analysis followed IPA's structured six step approach of reading and re-reading, initial noting, developing emergent themes, and developing superordinate themes of each case, then developing final themes across the dataset. Participants described their motivations to be active as well as participation in LTPA. Barriers, facilitators, and processes associated with being an active amputee provided insight to the connection between motivation and participation. Embodiment was experienced in the form of muscle memory and as bodily integration of the prosthesis. Implications of the study inform policy actions to remove barriers to LTPA participation as well as considerations for LTPA intervention development.

4.2 Introduction

The benefits of leisure time physical activity (LTPA) are well documented. Participation in physical activity (PA) has an inverse dose-response relationship with all-cause mortality and is an effective prevention of at least 25 chronic illnesses, including cardiovascular disease and depression (Arem et al., 2015; Dunn et al., 2001; Ekelund et al., 2019; Moore et al., 2012; Pedersen & Saltin, 2015; Warburton & Bredin, 2016). Findings from a meta-analysis of 22 cohort studies with greater than 10,000 participants, which estimated the relationship of PA to all-cause mortality, showed a non-linear dose-response relationship with greatest health benefits in the transition from inactivity to low levels of PA (Woodcock et al., 2011). Among people with disabilities (PwD) in the United States, 47% are sedentary, which is much higher than the 24.3% of those without disabilities who are sedentary (CDC, 2017). The majority (57%) of people with mobility-related disabilities, such as wheelchair users and amputees, are inactive (CDC, 2014). The research related to people with spinal cord injury (SCI) and PA or LTPA is extensive and shows a wide range of positive health effects (Hicks et al., 2011; Martin Ginis et al., 2012; Wilhite & Shank, 2009; van der Scheer, 2017); however, research related to people with amputations is less comprehensive, focusing more on gait improvement, the biomechanics of prosthesis use, and the physiology of limb loss (Bragaru et al., 2011; Castro et al., 2018; Lai et al., 2017). With the annual incidence of new amputations in the United States 8.9 times the incidence of SCI, it is unclear why this paucity of research among amputees persists (Jain et al., 2015; Ziegler-Graham et al., 2008). LTPA among amputees represents an important gap in both PA-related and PwD-focused research.

Few studies among PwD have addressed motivation within a theoretical framework (Lai et al., 2017; Perrault & Vallerand, 2007). One study examined the role of peer mentorship on quality of life and participation-related outcomes, including LTPA, among people with SCI. Using basic psychological needs constructs of Self-Determination Theory (SDT), competence and relatedness were both found to mediate the relationship between peer mentorship and study outcomes of affect and participation (Sweet et al., 2018). In another study using motivational constructs of SDT, comparison of wheelchair basketball players with and without disabilities showed no significant differences in motivation for sport (Perrault & Vallerand, 2007). This may indicate some transferability of SDT-related results in LTPA interventions to populations including PwD.

This study integrated components of SDT as a framework for understanding and describing motivations (Fig 4.1; Gagné & Deci, 2014). SDT is a complex macro theory that incorporates five mini-theories (Deci & Ryan, 1985a; Ryan & Deci, 2017). Three of these mini-theories informed this study. The first two mini-theories, Organismic Integration Theory (OIT) and Cognitive Evaluation Theory (CET), combine to create a continuum of motivation ranging from low internalization, also called controlled or amotivation to the most autonomous motivation (intrinsic motivation), which represents full immersion in the activity with satisfaction of participation as its own reward (Vansteenkiste et al., 2010). Between amotivation and intrinsic motivation on the continuum are several type of extrinsic motivations, described as regulations. The third mini-theory used to understand motivation describes generalized basic psychological needs i.e., autonomy, competence, and relatedness. SDT suggests that when the

environment supports fulfillment of needs for competence, relatedness, and autonomy, people will become more self-determined, which entails making decisions based on their own preferences and regulating their own actions.

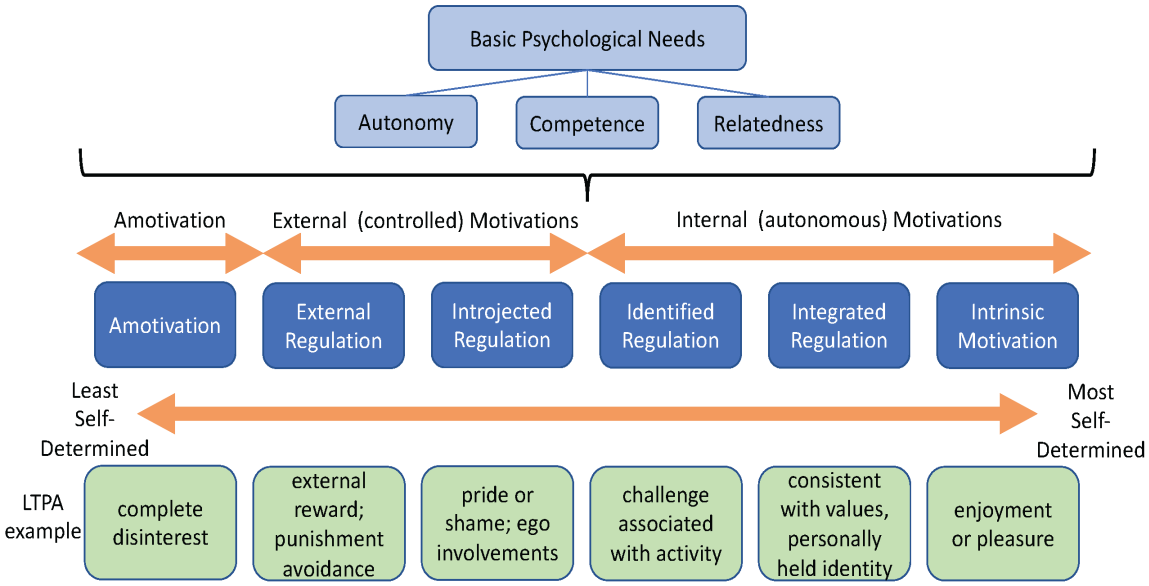

Figure 4.1 Self-Determination Theory (SDT) Model (adapted from Ryan & Deci, 2007)

Recognizing amputees are unique among PwD in their uses of assistive devices, this study aimed to incorporate Maurice Merleau-Ponty's concepts of embodied phenomenology into the data collection and analysis. Merleau-Ponty argued that humans interact with their world through both thought and body, making meaning both somatically and cognitively, with neither way of knowing holding primacy (Crossley, 2012). Prostheses become a part of the body for amputees; literally, in the case of Intraosseous Transcutaneous Amputation Prostheses (ITAP). The body interacts with the socket and attached components as a way of interacting with the environment and transmitting somatic knowledge. Meaning derived from and embedded in thoughts, feelings, and bodily (re)actions for amputees, therefore, may be different than for others (Murray, 2008; Wilson, 2015). This study incorporated embodied reactions and

understandings to better understand amputees lived experiences with motivations to be active.

4.2.1 Aim

This study aimed to explore the embodied meaning and lived experience of motivation to engage in LTPA among amputees through photo-diaries and in-depth interviews.

4.3 Method

4.3.1 Design

This study investigated the phenomenon of motivation to be active among amputees. Phenomenology describes both a philosophical movement and the methodological approaches that stemmed from it. Interpretative phenomenological analysis (IPA) methods were used to investigate, in detail, the significance of LTPA motivation, barriers, facilitators, and bodily reactions to those events and how amputees make sense of their experiences (Smith et al., 2009). The process requires both the participants and the researcher to engage in reflection, working through the cognitive, emotional, and embodied understanding of the experience's impact on the participants' lives. To capture the experiences of LTPA, participants created photo-diaries and the technique of photo-elicitation were incorporated within the in-depth interviews (Burke, 2005). During the second interview, participants were asked questions to try to take them back to the moment they took the picture e.g. Think back to the moment you took this photo. Tell me about the sounds and smells in the area. (Probes: normal sounds and smells, do they make you feel a certain way, can you hear/smell them now).

4.3.2 Participants

Accepted phenomenological research practices vary in terms of recommended and/or appropriate sample sizes but maintain the emphasis on small numbers to ensure qualitative rigor and depth of analysis (Creswell, 1998; Morse, 2003; Onwuegbuzie & Collins, 2007). Recommended sample sizes vary greatly e.g. 3-10 participants (Dukes, 1984; Reid et al., 2005), 5-25 participants (Polkinghorne, 1989), 2-10 participants (Groenewald, 2004). This study engaged with a sample of eight amputees; only six of whom chose to complete the photo-diary and second interview (Table 4.1). Recruitment was conducted through organizations and individuals trusted by, and with regular access to, the community of amputees in the U.S. The primary partner organization supporting recruitment was the Amputee Coalition (AC). AC advertised the study through listserv emails, social media posts, mailings, and peer support group leaders. Participant inclusion criteria included: being a single limb amputee, amputation at or above the ankle, aged 18 through 65 years, with access to the internet for Zoom™ meetings, and the ability to take digital photographs. Exclusion criteria included participation in a previous app-based motivation intervention, or currently under the care of a physician for anything other than routine purposes. All participants were lower extremity amputees whose amputation was acquired.

Table 4.1 Participant Characteristics (n=6)

Age	
Mean (SD)	53 (10.71)
Range	37-62
Gender	
Women	5
Men	1
Amputation	
Above the Knee (AK)	3
Below the Knee (BK)	3

Years Living with Amputation	
Mean (SD)	9.22 (5.77)
Range	4-21
Mechanism of Amputation	
Disease	2
Trauma	3
Infection Secondary to Trauma	1
Identified as Disabled[a]	
Yes	3
No	3

[a]Disability identity was not assumed. All participants were asked to define the term and describe how it related to their sense of self as an amputee

Potential participants were directed to the researcher for a complete description of the study, time commitment, and incentives. Potential participants underwent a phone screening to verify interested individuals met inclusion criteria. The phone screening provided a full explanation of the study. Participants were offered e-gift cards in the amount of $25 for the first interview and $35 for the second interview as incentives for participating in the study and to compensate them for their time. The individuals' inclusion in or decision (not) to participate in the study was not shared with the recruitment partners.

4.3.3 Data Collection

Data were collected through two in-depth, semi-structured interviews and included a participant developed photo-diary related to LTPA. The open-ended nature of the interview questions provided the participants with the freedom to use their own words and the researcher to allow the interview to go where the participant took it, modifying the questions as the interviews progressed (Daly, 2007; Miles & Gilbert, 2005). The interview guides were designed to explore 1) current motivations for LTPA, especially as they aligned with or contradicted SDT; 2) past experiences with LTPA; and 3) attitudes

and embodied understandings related to LTPA as an amputee. The interview guides were pilot tested with two amputees known to researcher and not drawn from the pool of eligible participants. The first interview explored participants' experiences and meanings of motivation to be active. Embodied research necessarily includes components of lived experiences within space and over time (Spatz, 2017). The second round of interviews were designed to elicit embodied experiences of being active. Accordingly, participants were asked not only to describe motivations and LTPA activities captured in their photo-diaries but to return to the moment through photo-elicitation interview techniques (Burke, 2005; Johnson-Glenberg & Megowan-Romanowicz, 2017; Magnat, 2011; Pink, 2011; Spatz, 2017).

Between the first and the second interview, participants were asked to create a photo-diary of anything that would help them describe their experiences related to motivation to be active. Participants were asked to take 4-8 pictures of any activity they regularly participated in or considered participating in. Participants were asked to represent their process to get ready for, participate in, and recover from their chosen activity. In the event they chose not to participate in the activity, they were asked to take pictures of things that influenced their decision not to participate. Once participants had taken photographs and provided them to the researcher, arrangements were made for the second interview. Participants determined the activity, the subject of the images, and which images to talk about during the second interview. Due to the ongoing COVID-19 pandemic, all interviews occurred via the video web app Zoom. The interviewer shared their screen for the second interview to allow both the participant and the interviewer to see the picture as questions were asked. This allowed participants to return to the moment

the picture was taken, both visually and as guided through the interview questions (Pink, 2011).

All interviews were audio recorded and subsequently transcribed verbatim for analysis. Participants chose pseudonyms before the recording began. Audio files were outsourced for initial transcription and cleaned by the researcher prior to analysis to ensure verbatim recording of the interviews.

4.3.4 Data Analysis

Data were analyzed from the perspective that the experience meant to be understood is the amputee's motivation to participate in LTPA and the experiences that influence that motivation. To facilitate this process, I relied on the method outlined by Smith and colleagues (2009). The analysis process incorporated peer debriefings throughout and member reflections to improve trustworthiness and credibility of results. Peer debriefing is the process of engaging colleagues who hold impartial views of the study. The impartial peers critically review methodology, implementation, and data analysis procedures (Spall, 1998). Member reflections involved sharing the study's findings with participants and providing opportunities for feedback and insight (Smith & McGannon, 2017). The six steps of IPA are:

1. Reading and re-reading. Verbatim transcriptions were read and reread to understand participant's narrative descriptions of LTPA motivation as an amputee. This was immersive in nature and offered the opportunity for prolonged exposure to the data as is necessary in phenomenological research.
2. Initial noting. This step was exploratory in nature and the most detailed of the analytical steps. Annotations were categorized as descriptive, linguistic, and

conceptual and were intended to focus on what is important to the participants (Smith et al 2009). Descriptive annotations represent events, relationships, and values through the eyes of participants. Linguistic annotations paid particular attention to the words, phrases, and expressions – the specific use of language – participants use. Conceptual annotations began to interpret participants' understandings and perceptions of their experiences.

3. Developing themes. Themes summarized individual participant stories, produced through integration of the data and theoretical assumptions brought into the process by the researcher. Notes and transcripts were reviewed to map interrelationships of ideas, connections between exploratory notes, and to reduce the volume of detail.
4. Searching for connections across themes within participant data. The themes were reviewed for grouping within a single participant's transcript. The themes that cluster into a single cohesive idea are combined to form superordinate themes. Lower order themes that described specific aspects of the superordinate themes are called subordinate themes. The transcripts were reviewed for oppositional relationships as well as complimentary ones, i.e. a participant may express the importance of close relationships in their LTPA participation in one section and the impact of stigma expressed by those individuals in another section. Both of these statements would be included in themes related to relatedness, but their connections to motivation would be organized very differently in this step.
5. Moving to the next participant. Steps 1-4 were repeated for each participant. The transcripts were read, noted, and themes compiled in isolation.

6. Looking for patterns across participants. Participant themes were not compared until all participants' data were independently analyzed through the first four steps. Each participant's interview transcriptions were completely coded and themes compiled separately before moving to this step. This is the step in which all themes discovered in each of the participant's interviews were compared to each other. The comparison results in the list of final superordinate themes and subordinate themes. Final themes were verified by returning to the data and research journals, as well as incorporating member reflections to ensure participants' experiences were accurately represented.

Although, themes in a single transcript may merit further investigation in another context, the essence of this process was to understand the phenomenon as it is presented among all amputees interviewed and focuses on overlaps of themes among participants.

4.3.5 Quality and Trustworthiness

Phenomenological methods such as reflexivity, member checking, and auditing are often among the most highly used procedures to maximize trustworthiness (Flynn & Korcuska, 2018). This study used member reflections instead of traditional member checking and incorporated peer debriefing as suggested by Smith and McGannon (2017) to ensure rigor in interpretative qualitative research. Member reflections offered iterative feedback from participants in the co-construction of the phenomenon with the researcher. Member reflections were, primarily, incorporated upon completion of study analysis. Participants were contacted via email and provided both a written and video described summary of findings with a request for a phone or Zoom conversation to discuss the findings and participant reactions to them.

Throughout the study, I engaged in peer debriefing (Smith & McGannon, 2017). The role of the peer debriefing process was to challenge my construction of knowledge through critical feedback that encouraged reflection upon, and investigation of, alternative interpretations emerging from the data. The peers were not directly involved in data collection or analysis and aided in probing my thinking around the research process and analysis (Given, 2008). The peer groups that provided regular debriefing sessions included a disability studies researcher, disabled scientists, experts in research within marginalized populations, and people with disabilities whose profession was not academic in nature.

An audit trail was developed which included: initial notes; step by step methods for recruitment, data collection and analysis; annotated transcripts; tables of themes that developed; the final report; and all field notes (Smith et al., 2009). Field notes recorded details of what was seen, heard, thought, and experienced throughout the course of data collection. Field notes were divided into three categories, each maintained in separate files (Groenewald, 2004). The first was observational notes i.e. objective recordings of what happened, who was involved, what activities occurred, and what was seen or heard. The second were theoretical or reflexive notes in which I recorded reflections on personal experiences related to the data and/or attempts to derive meaning through reflection on the data immediately after the conclusion of each. The final file contained research notes that summarizes procedures, events, and study progress.

4.3.6 Ethical Considerations

This study and all procedures involving human participant were reviewed and approved by the Institutional Review Board of the University of Maryland, College Park. Informed

consent was obtained from all individual participants included in the study prior to their participation. Information that was provided both verbally and in writing included: the aim of the study; the voluntary nature of participation; the confidential handling of participant photographs; what participants said and any background information they provided. Given the time between signing the consent form and interviews, before each interview participants were reminded of the voluntary nature of their participation and provided the opportunity to ask questions before recording started. All quotes have been de-identified and only pseudonyms are used throughout this study. Participants signed separate informed consent and photo-release forms.

4.4 Results

The main themes that were developed from interviews with participants, analysis, and member reflection feedback are outlined in Table 4.2. Two of the superordinate themes aligned with constructs present in SDT. The other three themes described facilitators to activity, barriers to activity, and the complex processes associated with being active. The influences on participation in LTPA are not described in SDT and are unrelated to participant descriptions of motivation to be active. Participants' embodied experiences were described throughout their interviews as ways in which the body remembered movements, protected itself from pain, and became integrated with their prosthesis as an extension of their body, rather than a medical device.

Table 4.2 Themes developed through IPA process

Superordinate Theme	**Subordinate Theme**
Motivation[a]	Goal setting related to specific LTPA and, separately, to increase functionality as interim step to LTPA participation and (identified regulation)[a]
	Pride and concerns about body image influenced motivation to be active (introjected regulation)[a]

Relatedness[a]	Amputee community offers connection not available in any able-bodied social network
	Relatedness enacted as participation in activities with others, directly and indirectly
Facilitators	Prosthesis fit
	Accessible environments
	Activities with intuitive or minimal adaptation requirements
Barriers	Healthcare/insurance system presents roadblocks for mobility devices, prosthesis components, and knowledgeable care
	Prosthesis causes pain or additional complications
	Fear of falling or risk of injury
Amputee Processes to Being Active	Anticipated effect of LTPA on body is necessary component of planning
	Daily use prosthesis is not conducive to LTPA and must be altered, removed, or adapted
Embodied Experiences	Body unconsciously helps participants perform
	Prosthesis and other mobility devices are described as extensions of body

[a]SDT construct

4.4.1 Motivation

Although participants described varying levels of enjoyment in, and integration with personal values associated with their chosen activities, intrinsic motivations and integrated regulation to be active were very personal, and not universal. Expressions of motivation to be active related to pride and body image and LTPA goal setting, however, were commonalities among participants. These motivations can be described as introjected and identified regulation, respectively. In figure 4.1, these motivations are in the center of the continuum of motivation.

4.4.1.1 Introjected regulation incorporates body image and pride

Participants experienced both pride and shame related to their identity as an amputee. Pride and shame provided ego-centric regulators that increased their motivation to participate in LTPA. Negative body image came across as participants described bodily changes occurring after their amputation. Participants gained weight, struggled with how

clothes fit over prostheses and felt the use of mobility devices beyond the protheses increased disability stigma. LTPA provided an outlet for controlling weight and improving function to reduce frequency of mobility device use. The following quotes are illustrative:

> When my former mother-in-law passed away and I was too embarrassed to go to her funeral because I was fat and on a walker. That was the day that I drew a line in the sand and said, "Girl, you got to get your act together. What, what if your sister dies? You know, you can't avoid that." And I was just kind of missing out on life. And I just ... I had to start all over. (Tiffany, 6.5 years living with amputation)

Michael, a 9-year amputee, explained how it also improved how they viewed their body aesthetically (Fig 4.2).

> Um, the other thing is, like, um, and I'll, and this is narcissistic one is when people say, "Wow, you know, um, your, you know, your arms look really good. You're, you've gotten bigger. Your shoulders are bigger, your chest is bigger." So that's my narcissistic ones, right? So as much as I, you know, don't wanna admit that, that's the other part.

Figure 4.2. Michael bench pressing his 5-rep max.

Pride also drove LTPA motivation. Several participants were able to draw on specific moments in which they described pride in their accomplishments. These ranged from familial praise to realizing, after the fact, that they didn't have to stop and focus before performing a specific activity. Roslyn, 6.5 years living with her amputation, described her face-saving in front of her children as a way to become more active and involved in a variety of LTPA after her amputation:

> Um, because there's so much to do and so much to see. Like, like when, before like my accident, like I worked, I took care of my kids. I really didn't think about much of anything. Like didn't really put thought into anything. Um, like I- like something like this drastic, it's, it's completely life changing. Like overall, like a whole 360. Like there is, my kids have never seen me fail at anything. Um, nor do

> I ever want them to see me fail at anything. So like my oldest daughter like, I kinda had to like push her out the door. I'm like, "Go." Like, "You need to go live your life." I said, "There's things that I need to do that I might fail at, at first." I said, "You don't need to see that."

4.4.1.2 Identified regulation as goal setting

All participants set goals related to LTPA. Several participants described the need to be able to perform certain functional skills, such as balanced walking using a prosthesis, in order to participate in their LTPA of choice. They set for themselves very specific milestones with the long term goal of becoming (more) active. This did not preclude them from setting specific LTPA goals such as more frequent participation or improved performance in their activity of choice.

Dawn, who has been living with her amputation for four years and was bedridden with infection for the first two, described her journey toward bike riding being buoyed by her ability to perform activities of daily living (ADL):

> Obviously I'm doing this stuff out of necessity, um, but super-duper excited to see and feel the change. I, um, honestly did not think, I, I honestly felt that I was doomed to be on my rear end the rest of my life. And the joy from realizing it don't have to be that way is tremendous…And every day's not perfect. There may be a day here or there that it hurts, but I just go in and do, um, additional therapy for myself. And I think that is helping, as a matter of fact, I'm sure it is.

Kristin, a 19-year amputee, used goal setting to motivate herself in the gym:

> It's really easy to get on the thing and just go real slow and you can do that for an hour and, you know, whatever. But if you're not pushing yourself to go further or

> faster or- or whatever, every time you don't, you don't get the workout that you really need. Um, so that's the determine... I mean, every time I go in, I'm- I have a goal of what I'm going to do and, you know, and- and try to achieve that.

In both types of goal setting, participants were motivated by the challenge the goal offered. They did not set milestones or goals they knew they could accomplish on the first attempt or even on subsequent attempts after the first success. Instead participants were eager to challenge themselves to accomplish something difficult, regardless of outcome.

4.4.2 Relatedness

The most universal and prominent basic psychological need being met among participants was relatedness. Individual participants described competence and autonomy in a wide range of settings, most unrelated to LTPA, but relatedness influenced their motivation to participate in LTPA in multiple ways. Connectedness to the amputee community offered a feeling of belonging not available through their able-bodied social networks. Relatedness was also enacted as participation in activities with others, both directly and indirectly.

4.4.2.1 Amputee community offers connection

As people with an acquired amputation, participants actively sought out other amputees for a sense of belonging. Fellow amputees provided a degree of relatedness that only comes from shared lived experiences. The amputee community offered ways to process grief and loss associated with amputation, empathy for physical and mental challenges, and general encouragement. Participants were adamant that this community offered emotional, informational, appraisal, and instrumental support that able-bodied people did

not and were not able to provide. As Roslyn declared, “100%. Like, your family, your friends, they can give you the best support in the world, but they don't actually know, like, what you're feeling, but, yeah, what you're thinking, so yeah. I think that is, like, a, a must have.”

From a LTPA perspective, relatedness to the amputee community gave access to innovations that enabled activity. Kristin, who doesn’t wear a prosthesis in water, found that her kayak immediately flipped due to the weight imbalance. Her online network of amputees gave her a wide variety of inexpensive way to adapt. She said, “that's one of the great things about our community is if you, you can go on any, not any but many of the amputee Facebook pages. And there are several that are athletic inclined and get, you know, 14 different ways people are doing it. And then you can just kind of figure out what is the, the easiest for you.”

Participants actively sought out relationships with other amputees through support groups, online forums, healthcare options, and through chance encounters. When a participant’s prosthetist was also an amputee, they expressed greater satisfaction with fit and socket options. In public, participants recognized other amputees and introduced themselves. Summer, who has been living with her amputation for 21 years, talked about meeting another amputee while traveling. “And I'm in touch, I know amputees and anytime I meet an amputee on the street, I always accost them. I met one on our recent road trip and, uh, we took photos together and it was really nice to meet her. So I- I love meeting amputees, and I always give them resources.”

4.4.2.2 Relatedness enacted as participation in activities with others

Throughout each interview with participants, they talked about activities in terms of who else was involved. The involvement could be direct interaction as with Michael's lifting partners or Summer's dancing husband; or indirect involvement such as the person Roslyn designed and developed her woodworking projects for. In multiple cases, the who was a dear pet. Dawn's bike was outfitted with a basket and bedding to allow her dog to ride along (Fig. 4.3). Regardless of who or in what way, being with others was central to LTPA. In Tiffany and Summer's case the who was the impetus for trying a new activity. Tiffany tried seated water skiing for the first time with two other friends who were also amputees attempting the sport for the first time. Summer started Krav Maga lessons based on a family interest, "Sometimes I was having someone there to do it depending on how challenging the concept was. Like Krav Maga I sort of always wanted to do and like I did kickboxing at home, kickboxing videos and stuff, you know, but Krav Maga, my husband, uh, and his son expressed interest too, [he] was the one who instigated."

Figure 4.3. Dawn showing off the basket built for her dog to ride with her while biking.

4.4.3 Facilitators

Participants identified factors that made LTPA easier. These facilitators, unique to amputees and PwD, did not affect motivation but did support engagement in LTPA once the interest in a particular activity or event arose. These facilitators were: the prosthesis fit, which was heavily influenced by the prosthetist; the accessibility of the built environment surrounding the activity; and the ease at which activities or activity-related equipment were adaptable for participant use.

4.4.3.1 Prosthesis fit

When the socket fit well around the residual limb without slipping, causing pain, or irritating the skin, participants engaged in LTPA more frequently. Prosthetists' knowledge, experience and ability to empathize greatly influenced the socket fit.

Participants described long journeys to find the right prosthetist, changing providers multiple times until they felt they were receiving appropriate care. In several cases, one of the deciding factors was the prosthetist also being an amputee. Participants felt an amputee prosthetist was more attune to the difficulties and pains of an ill-fitting socket and were more aware of advances in technology that would improve fit and function of prostheses. Tiffany's relationship with her prosthetists have been critical to her function; while Summer only uses an amputee prosthetist for specialized equipment, like her running leg.

> My prosthetist now, I don't know if I told you before or not, but she's also, and both of my prosthetists, my last two prosthetists have been female and they've been AK [above the knee] amputees. But, um, my current prosthetist is congenital. So that's all she knows, but still, uh, you know, I just, I don't ... I guess that's, uh ... What am I being? Um, what's the word I'm looking for? I just, I don't want a able-bodied prosthetist because they can't relate. They can't put themselves in my shoes. I want, I want an amputee for my prosthetist because they know what the heck I'm going through, you know. (Tiffany)

Michael, who works in the physical therapy field, was, on the other hand, looking for someone willing to take a person-centered approach to his needs:

> So my socket fits well. Um, I have an experimental socket that I developed with my prosthetist and I that's adjustable with ratchet straps. So it fits tight, snug every day which allows me to do over 10,000 steps a day and to stay at what I would call a high level of exercise for an amputee. Um, at night I take, I put my

leg on it around seven o'clock, 7:30 in the morning. I take it off at 10 o'clock at night. It stays on all day. I don't take it off.

4.4.3.2 Accessible environments

Activities held in environments that were accessible made participation easier. For the participants, an accessible environment was simply about taking into account people with a wide variety of mobility needs. They described even, solid ground, close parking, and event toilet facilities that didn't require walking through soft ground to access. Although all participants used multiple mobility devices, e.g. wheelchairs, cane, and walkers, most preferred to use their prostheses during LTPA. They found an environment that made mobility less of a challenge encouraged participation in the activity. Dawn was in the process of getting a new socket when we spoke, but was eager to be more active again. She described one of her favorite places to walk, "I just said to my mom's husband today, um, when we were getting, going to get the pedal for my bike, um, that I wished we could go to [redacted]. It's a little park, has water, ducks, but all around it has sidewalk with benches and tables and, uh, where I could try to walk. It's, it's an even ground."

4.4.3.3 Activities with intuitive or minimal adaptation requirements

Convenience and ease of inclusion into an activity facilitated LTPA participation. As described below, there are additional process considerations with any activity, so for study participants, activities that required minimal additional adaptation made engagement easier. Kristin, a life-long athlete, looked for facilities that would make it easier to get a workout in the gym. She found the recumbent elliptical to be ideal. The rower was too hard to get on an off and stationary bikes required additional equipment, changes to her current prosthesis, or willingness to cycle one-legged. She said, "Um, they

have a lot of recumbent equipment because as you get older, that's just easier for you to do. But when I saw that machine, I told my husband, I said, 'Oh no, we're gonna move here because they have my thing.'"

4.4.4 Barriers

Just as facilitators make participation more likely regardless of motivation, barriers made participation harder, regardless of interest in LTPA. Barriers specific to amputees aiming to be more active included: the healthcare system puts up roadblocks for obtaining appropriate components, devices, and care; prostheses cause pain and other complications when being active; and fear of falling or injury prevents activity.

4.4.4.1 Healthcare/insurance system presents roadblocks

The complex, intertwined healthcare and insurance systems in the country present an overly burdensome obstacle to amputees seeking to maintain health while being active. Prostheses are considered durable medical equipment rather than an extension of an amputee's body. This lowers the limit on spending. As a result, prostheses that can be used in water as well as for ADL were not approved for Kristin. Dawn waited over two years, using a wheelchair for mobility in an inaccessible home, for her insurance to approve a prosthesis. Summer was required to get a prescription to protect her skin from rubbing against her prosthesis:

> I needed some new liners because the silicone started hardening, so I put in the request with my prosthetist and then a couple weeks later they were like, 'Oh, by the way, we need you to go get a new prescription and new medical stuff from your GP'…So then I had to schedule time, go to my GP, then try and get them to get the paperwork to the prosthetist in the correct way…I'm sitting here with my

leg off right now because the liner started hardening, so it's starts ripping the very sensitive skin.

All participants felt counseling for acquired amputees was limited. Some felt their mental health was not part of their pre- or postoperative engagement. Others experienced ableist comments from providers, such as being told not to consider themselves disabled or that they should not rely on assistive technology as a younger amputee. Most turned to peer and role models found in the community to understand what to expect as an amputee. None of the participants received counseling prior to surgical amputations that addressed expectations of grief or loss, or the physical process and tolls for regaining mobility post amputation. This was mentioned as a barrier to becoming active post-amputation, and even identified as a contributor to depression.

When asked what would support amputees in becoming more active, every participant pointed to removal of barriers erected by the healthcare and insurance systems. They felt insurance companies had the power to deny mobility devices based on arbitrary or ableist understanding of how they would be used. One participant was told she didn't need a wheelchair that could be easily folded for rideshares because the measure of need for a wheelchair ended at the individual's place of residence. Another was denied a prosthesis with a specialized knee because of her age and the insurance company's assumption that people of her age with limb loss are not active enough to require the device. Michael expressed his frustration knowing he was coming from a place of privilege. By working in physical therapy, in a medical department of a university, he had access to experts and devices that many others do not. He comments,

> No matter your financial or social economic condition, that you could get the best prosthesis…And the biggest thing I see mostly is pain from the socket and people think it's normal and it's not normal because my prosthesis is so good, I really don't have any pain at all…So prosthetic fit and be able to afford any, um, prosthetic, uh, items that they can, if they can't afford, they still can get it. To me that would make people become more active and more social and work out more.

Prosthesis causes pain or additional complications

Chronic pain caused by prostheses affected participation in LTPA. Dawn explains that pain associated with her amputation is actually two-fold – the pain from the prosthesis and the pain in her sound leg from compensatory movement.

> Being an amputee, there is extra wear and tear on your good parts, your, your good leg, your good knee, uh, your good hip, um, your back. So there's seems like always, um, something that you're really having to stop and say, 'Okay, h- how do I do this with this being like that?' So it's a, it, it, it's a struggle. Every day, honestly, every day is not hard, it depends on how active I am…And it is so painful that in all honesty I have, whether I'm sitting or I'm in my room or whatever, I have been taking it off just for the pain to stop.

Prostheses also cause discomfort. Michael's socket becomes very sweaty when biking. This affects the suction and his ability to keep his leg on. There is no pain associated with this but he limits his bike rides to cool weather, evenings, and shorter mileage in order to be able to bike without losing his leg.

4.4.4.2 Fear of falling or risk of injury

As lower-extremity amputees with acquired limb loss, participants had to relearn how to maneuver using mobility devices. In general, participants preferred wearing a prosthesis for mobility. Wearing a prosthesis added a layer of relearning to walking, having to balance on the device while manipulating it through movement. Participants expressed concern over falling and associated complications. Dawn was not concerned with the fall so much as her inability to get up off the ground after a fall. Others expressed concern about injury to their anatomical leg that would further limit mobility. Roslyn described a hiking outing with family that nearly wasn't completed because of the additional care she wanted to take to prevent injury or falls.

> And like being an amputee walking on uneven terrain is a challenge within itself, okay? Um, walking on steep inclines, and rocks, and you know, a little stream going through it, with grass. I mean, that was even more of, you know, a challenge. Um, it's little stuff like that. I mean, and that's stuff that I grew up doing.

4.4.5 Process

Participants described multi-layered processes for participating in both ADL and LTPA that, in their opinion, didn't rise to even a level of awareness for non-amputees. The processes stretched from various methods of self-care and bodily preparation days in advance of an activity to recovery post-activity. Participants anticipated the effect of LTPA on their bodies and prepared accordingly to minimize that effect; they also had to consider their prosthesis functional design and how it may not be conducive to the planned LTPA.

4.4.5.1 LTPA impact on body as component of planning

In addition to the processes described for an activity that required time and energy not expended by non-amputees, participants described additional processes specific to LTPA engagement. Participants considered the environment they were about to enter. For instance, Tiffany made sure she had a portable chair for her adaptive waterskiing event because she didn't know if there would be a long, fatiguing walk from the parking lot to the dock or if there would be any place to rest between ski runs. Summer plans her events in terms of days. If she knows she will be especially active, she stays out of her prosthesis in the day or so leading up to the activity to prevent skin irritation and builds in recovery the day after, making sure she can meet all her work or other tasks in a wheelchair. Dawn said conducting the photo-diary exercise highlighted the extra steps she takes to participate in LTPA, "Um, it's just showing what I have to do, uh, to bike ride. So I guess the challenges that are faced, uh, as an amputee trying to ride a bike." Each participant detailed the steps they took, mentally and physically, to prepare for LTPA. They outlined the extra time it took them to prepare, setting out clothes, socket liners and socks the night before an early workout so as not to delay their gym partner; making sure there was a seat set up at the end of a bike ride to be able to recover their shaking leg before putting their prosthesis back on; preparing a space for recovery to minimize movement. Summer describes her recovery environment from one of her pictures: "And, um, do I have all my sodas right here? Did I pee, so I don't have to stand up for three hours? So, so there's a lot of sort of prep that goes into just being able to sit there…Um, so it looks very calm and chill, uh, but it's very controlled and planned."

4.4.5.2 Removal or modification of daily use prosthesis to enable participation

Some amputees have the benefit of multiple prostheses to accommodate multiple types of activities. Many, however, must learn to adapt their everyday leg to an LTPA they wish to do. For some, simply removing the prosthesis makes the most sense. The weight of the metal and carbon fiber leg become a hindrance to the activity. Roslyn prefers to do most of her woodworking without her prosthesis. She says that after she has prepped her area, much of the physical activity of sanding and carving can be done sitting down, allowing her to leg to rest. Tiffany has found the need to wear orthotics in her anatomical leg's shoes to add cushioning and protect her knee. She wears the same pad in the shoe on her prosthesis to maintain similar leg length and reduce compensatory injury. This is a method she discovered on her own after several changes in her prosthetic ankle. There is a lot of trial and error associated with determining the modifications necessary to enable safe LTPA. Kristin (Fig 4.4) used to lift without her prosthesis because it got in the way for some movements. She had to determine her workouts based on whether she was going to wear her leg that day or not. After attempts with different techniques, she was able to adapt her prosthesis to the movement without having to remove it. She talked about her troubleshooting to use the machine, "I tried to do it like a normal person the first time, but that was, like I said…it's um, just annoying, I guess, for lack of a better word. And so then I said, oh, I can just flip it up and get it out of the way…And so I've been doing it like this for 18 years."

Figure 4.4. Kristin holding her prosthesis out of the way in order to keep it on while using a hamstring curl machine.

4.4.6 Embodiment

The body and somatic experiences were in the forefront of participants' descriptions of LTPA. In many cases, the body was primary in how they participated in, reacted to, and experienced LTPA. Embodiment was expressed by some as related to muscle memory, or 'being in the zone', while for others, it was how their body took on the prosthesis as part of them.

4.4.6.1 Body unconsciously helps participants perform

Two ways in which the body improved LTPA performance were a level of focus, often called 'being in the zone', and muscle memory. During interviews, participants enacted a version of muscle memory when describing how they performed certain movements.

While talking about the movements, participants performed them, not as a way of demonstrating the movement to the interviewer but as how their body informed recall and articulated the process. Participants also talked about feeling their way into the proper position for lifting or cross-training. They said that it took a long time to determine the best position for their body in a specific movement; that it took professional trainers to watch and correct their movements when they were first learning. After years of participation, their body let them know if they were in a position of imbalance or potential injury. Kirstin talked about the full body engagement required for an overhead press, “I can usually tell within the first one or two, because it doesn't feel the same when I'm pressing down. Um, but that's from years of doing this.”

‘Being in the zone’ was highlighted by a detachment from pain and other sensory messages. Michael described a combination of aural focus in which all noise, except his training partner’s voice, was blocked out and his near-constant phantom pain disappeared. Summer had similar experiences in which she did not feel pain while cross-training despite the constant pounding of her prosthesis on her residual limb that would result in abrasions and swelling.

4.4.6.2 Prosthesis and other mobility devices are described as extensions of body

For all participants, their mobility devices, specifically, their prostheses were considered an integrated extension of their own organic body, essentially making them a cyborg being, with both organic and biomechatronic body parts. Michael was very clear in how he embodied his cyborg-ness, “So I do, I am aware of my residual limb. I actually aware of my whole leg, even though I don't have it from the knee down, but I'm- I'm aware of it.” This connection, not in thought, but in bodily reaction to the prosthesis and LTPA in

the prosthesis helps understand how the body communicates emotion to participants. For Summer, her body reacted to regular workouts, "[by] taking care of myself, then I feel like I can start every step with power, and that's very healthy for me and my mentality. So largely, I work out because of that.

4.5 Discussion

This study aimed to better understand amputees' lived experiences of motivation to be active, within the framework of SDT. According to SDT, basic psychological needs satisfaction supports autonomous or intrinsic motivation; motivation then leads to behavior. Yet, physical activity interventions among PwD have not addressed motivation within a theoretical framework such as SDT (Lai et al 2017; Perrault, Vallerand 2007). Research not involving PwD have shown evidence that SDT explains exercise behaviors, i.e., identified regulation had a positive effect on exercise participation and relatedness was positively associated with exercise (Teixeira et al 2012; Weman-Josefsson et al 2015). Participants in the present study experienced relatedness as the most strongly met psychological need and described introjected and identified regulations toward LTPA; however, this study also revealed concepts that influence the relationship between motivation and LTPA not addressed by SDT (Fig 4.5). Amputees in this study described facilitators and barriers to being active that did not affect their motivation level but did change their activity level. They also discussed the processes required for them to be active that prevented casual participation in LTPA, adding important nuance and contextualization to our understanding of engagement in LTPA

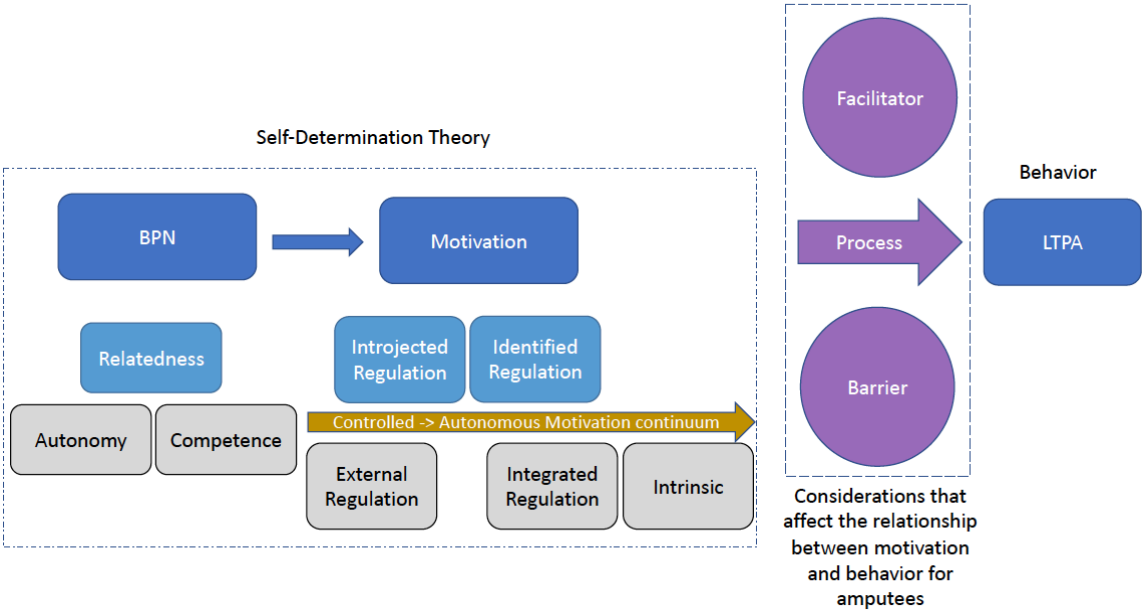

Figure 4.5. Considerations raised by amputees in the present study (purple shapes) that impact the relationship between motivation to be active and LTPA participation

Research in exercise and LTPA with amputees seeks to understand facilitators and barriers to LTPA participation absence an understanding of motivation (Batten et al., 2019, Littman et al., 2017). Alternatively, motivation itself or lack of motivation are identified as facilitators and barriers, respectively (Deans et al., 2010, Lui & Hui, 2009). This study suggests the relationship between motivation, external facilitator and barriers, and participation in LTPA is more complex for amputees than previously understood. The process to become active or recover from activity is also suggested to play a significant role in the relationship between motivation and participation.

Participants' motivations to be active ranged from experiences of amotivation associated with depression and loss through intrinsic motivations involving pure joy in the activity itself. These extremes of the motivational continuum represented personal experiences that occurred adjacent to the overall phenomenon revealed in this study. Amputees' collective experiences in motivation to be active were experienced toward the

center of the spectrum – ego-centric motivations and challenge-based motivations – introjected and identified regulations. These findings are supported by studies interested in specific body image or goal setting outcomes. Holzer and colleagues (2014) identified amputation as a source of lower body image. LTPA participation improved body image in amputees and generated pride in the way they looked (Galli et al., 2016, Wetterhahn et al., 2002). Inadequate or absent goal setting has been shown to pose a barrier to LTPA among lower extremity amputees (Batten et al., 2019).

Another key finding of this study was the importance of satisfying the basic psychological need of relatedness. As with motivation, participants found unique and personal ways to meet the needs of autonomy and competence, but there was a common experience in satisfying relatedness, specifically the connection to the amputee community. While participants did not necessarily interact with other amputees at any regular interval, they felt a strong bond with other amputees that was not replicable in other relationships. Fellow amputees provided informational support in terms of LTPA adaptations not available through physical therapists or non-amputee activity partners. Amputees traded reviews and recommendations for mobility devices and component upgrades; they supported navigation of the healthcare and insurance systems. Most importantly, fellow amputees provided a deep understanding of lived experiences and emotional journeys that offered a sense of belonging.

4.5.1 Somatic Knowledge as Central to Experiences of LTPA

Without using the term, participants embodied a cripborg nature (Nelson et al., 2019). Cripborg, in contrast to other cyborg descriptions of disability (see Howe, 2011; Howe & Silva, 2017; and Meyer & Asbrock, 2018), does not equate the bodily integration of

technology with an attempt to normalize or superhumanize the disabled body. Howe (2011), for instance, describes the advancements of assistive technology as "help[ing] create a legion of cyborg bodies that is manifest in the image of the sporting supercrip." Participants used the mobility devices that fit the needs of their activity and their body, moving from prosthesis to wheelchair to walker. Some had preference for their prosthesis but most acknowledged a sort of transmobility (Nelson et al., 2019) created through the use of multiple devices, each an extension of and, fully incorporated with, their body. Merleau-Ponty described the integration of prostheses with the body as more than a physical extension, but one that becomes part of the body's realm of knowledge, its sensorium (Merleau-Ponty & Smith, 1966).

In addition to their prostheses' role in embodied cognition, participants discussed embodied experiences of 'being in the zone' (*bitz*) during LTPA (Wellard & Pickard, 2017). During times of *bitz*, participants described a sort of detachment from pain and other sensations not directly related to their LTPA. Summer, Roslyn, and Michael frequently described not feeling pain in the moment of activity, despite awareness of what pain the prosthesis, movement, or phantom sensations should or could be eliciting. Wellard and Pickard's research (2017) delve into the complex relationship between physiological, psychological, and social influences that lead to *bitz* experiences and cannot be explained by Cartesian body-mind understandings. In *bitz* there is a sense of being able to close out thoughts and environmental influences to allow enjoyment of LTPA movement; as sort of 'going into one's own world' (Wellard & Pickard, 2017). For lower extremity amputees in this study, *bitz* allowed them to be enveloped in the activity, in both body and mind, without feeling pain, or hearing external distractions.

Shusterman (2011) outlines six types of muscle memory that describes the way in which the body unconsciously influences movement. One of these types, experienced by participants in this study, has to do with the body's reaction to place. In muscle memory influenced by place, the body's interactions with location, previous movement patterns, and social environment create a memory of how to move when the place is encountered again. For participants in this study, the fitness environment provided a bodily memory trigger that influenced how LTPA was performed. Participants instinctively knew if their body was in a position to safely and effectively perform the movement required for LTPA and adjusted accordingly.

4.5.2 Study Limitations

The phenomenon being described must be understood as the experiences of motivation to be active among lower extremity amputees whose amputations were acquired after youth. There are many differences in the lived experiences of lower and upper extremity amputees in how they use, or do not use, prostheses, as well as how those protheses may be integrated into ADL or LTPA. There are also discussions about how embodied prosthesis use is among congenital amputees who do not have the somatic memory of ever having a limb in the place where the prosthesis currently is (Murray, 2008). There may be selection bias in the recruitment of participants. Information about the study described interest in motivation to be active. Participants who were less active may have chosen not to respond to recruitment efforts. All participants in this study were currently active and had some level of motivation to be active beyond external regulation.

4.5.3 Study Strengths

Researchers were committed to transparency and rigor in this study. Throughout the development, recruitment, data collection, and data analysis, detailed reflexive and procedural journals were maintained. Member reflections were offered to enable participants' voices to clearly be heard within the interpretations of the phenomenon. I tried to provide clear descriptions of methodology and study aims to participants and answer any questions they had. The result is a study that has potential impact for policy makers, LTPA interventionists, and researchers. Prior to this study, there were no post-rehabilitative, theory-based qualitative studies done on the lived experiences of amputees with motivations to be active.

4.6 Recommendations and Future Research

Study findings suggest motivations to be active among amputees are influenced by connections and relationships. There is also evidence that the relationship between motivation and participation is not direct, but influenced by facilitators, barriers, and processes undertaken by amputees. The embodied experiences of participants in this study parallel experiences of embodiment described by other researchers, with nuances specific to active lower extremity amputees (Murray, 2008). Each of these have the potential to impact strategies to increase activity among amputees and to expand research with the population for deeper understandings of lived experiences.

4.6.1 Recommendations for healthcare providers

The complexity of the healthcare system and how insurance companies perceive necessary costs for ADL erected barriers for participants at all stages of diagnosis,

surgery, recovery, and post-rehabilitative LTPA participation. Simplifying the process and focusing on patient-centered care plans may reduce barriers and lead to better recovery. By treating the whole person, and not just the limb that requires or has been amputated, health care providers have the opportunity to influence longer term mental, physical, and social well-being. The focus on the whole person may also reduce reliance on the medical model of disability that discourages a disabled identity or reliance on mobility devices. Recommendations offered by participants included mental health counseling before and after amputation procedures, offering amputee peer visitors before surgery, and considering a comprehensive resource list post-surgery of physical and mental health support.

4.6.2 Recommendations for policy

Recognizing that the prosthesis is not, functionally or emotionally, separate from the body for participants, there is opportunity to integrate mobility devices as part of medical insurance, rather than listing it as a durable medical device. The change in classification, practically, increases coverage amount and may offer more opportunities for mobility devices that enable activity and participation in a wider variety of both LTPA and social activities. Participants also mentioned the built environment as a barrier to participation. Considering paved or solid pathways, including in beach environments, widens the opportunities for people using mobility devices for ADL or LTPA. Policies for new construction, especially of public spaces, should require incorporation of universal design principles, to ensure accessibility and use to the greatest extent possible.

4.6.3 Future research

The relationship between motivation and participation being influenced by facilitators, barriers, and processes creates opportunity for exploring how SDT may be modified for amputees or other PwD to more accurately reflect the experiences of LTPA and motivations to be active in these populations. The experiences of intrinsic motivation were not part of the overall phenomenon described by participants. Research of the lived experiences of amputees early in their life with limb loss and, separately, after decades of living as an amputee may better describe motivations to be active at various stages in the life-course of an amputee. There may also be differences in the lived experiences of those that identify as being disabled and those that don't. Neither time since amputation or disability identity were explored through this study. Building on embodiment findings of this study, further research in how the body is centered in experiences of amputees beyond LTPA.

Chapter 5 When Motivation Isn't Enough: A Sequential Explanatory Mixed-Methods Approach to Understanding Experiences of Motivation to be Active among Lower Extremity Amputees

5.1 Abstract

Physical activity (PA) participation is strongly related to improved health and well-being with leisure time physical activity (LTPA) providing greater health benefits and increased opportunities for engagement. People with disabilities (PwD) are less active and experience increased burden of disease compared to those without disabilities. Although, research on LTPA among PwD is growing, much of the research with amputees to date focuses heavily on prosthetic design and function. There is a paucity of research on the design, implementation, and evaluation of interventions targeted to PwD, and amputees in particular, that focuses on increasing motivation to be active. The aim of this study was to better understand the relationship between motivations to be active and LTPA participation among lower extremity amputees. Using Self-Determination Theory (SDT) as a framework, this study employed a sequential mixed methods approach to integrate fitness app intervention data with interpretative phenomenological analysis (IPA) findings. The intervention employed a two-group, randomized waitlist control design to evaluate the impact of app usage on motivation level and total PA. The IPA study aimed to understand the experiences of motivation to be active among amputees. Connected integration (using quantitative results to define the sampling frame for qualitative data collection) was used to evaluate how the IPA findings contextualized and provided more in-depth understanding of the intervention results. Participants described barriers and facilitators to participation that were unrelated to and unaffected by motivation to be

active. These experiences disrupted the theorized association between motivation and participation in which increased intrinsic motivation leads to increased LTPA participation. These results added context to the intervention finding in which statistically significant changes in PA over time did not parallel changes in intrinsic motivation over the same intervention period. In-depth interviews with amputees showed that LTPA participation was facilitated by prosthesis fit and an accessible environment. Chronic pain and impediments created by a complex healthcare and insurance system posed barriers to participation. Theory-based interventions for PwD may benefit from separating facilitators and barriers to LTPA from motivation to participate in order to retain participants and affect long term changes in activity level. There are also implication for accessible design for the built environment to improve the ability for amputees to engage in LTPA in a wide variety of settings and activities.

5.2 Introduction

More than 185,000 people experience lower extremity amputation each year in the US (Dillingham et al., 2005; Ziegler-Graham et al., 2008). Lower extremity amputees have increased risks of comorbidities and death and report lower quality of life as compared to the general population (Fortington et al., 2013; Sinha et al., 2011). Physical activity (PA) improves or prevents at least 25 chronic illnesses, including cardiovascular disease and depression (Arem et al., 2015; Dunn et al., 2001; Ekelund et al., 2019; Moore et al., 2012; Pedersen & Saltin, 2015; Warburton & Bredin, 2016). Research suggests leisure time physical activity (LTPA), i.e. PA performed at the discretion of the individual and not associated with work, transportation, or activities of daily living, provides greater health benefits and greater opportunities to meet PA guideline recommendations than do other

forms of PA (Holtermann, 2018; Tsenkova, 2017; Vuillemin et al., 2005). The majority of lower extremity amputees, however, are inactive or sedentary (CDC, 2017; Pepin et al., 2018).

Self-Determination Theory (SDT) provides a framework for understanding motivations to be active and motivations' link to LTPA participation. SDT proposes that people have basic psychological needs (BPN) that, when satisfied, lead to psychological health and overall wellbeing (Deci & Ryan, 1985a; 2000; 2002; 2008). These BPN are autonomy, competence, and relatedness. Autonomy refers to feeling one's choice makes a difference in situational outcomes; competence refers to feeling capable in the face of challenging tasks; and relatedness is feeling close with others. BPN satisfaction is necessary to experience autonomous or intrinsic motivation; that is, a sense of enjoyment congruence with personal values related to LTPA (Ryan & Deci, 2017). When BPN are not fully satisfied, people experience amotivation (disinterest in LTPA) or various levels of regulated or extrinsic motivations; that is, engaging in LTPA for some external reward. Studies have repeatedly shown BPN satisfaction predicts intrinsic motivation to exercise, and intrinsic motivation predicts activity level (Chatzisarantis & Hagger, 2009; Kalajas-Tilg et al., 2020; Teixeira et al., 2012).

Much research related to people with amputations focuses on rehabilitation, gait improvement, the biomechanics of prosthesis use, and the physiology of limb loss rather than the physical and mental health outcomes of interventions to increase LTPA (Bragaru et al., 2011; Castro et al., 2018; Jamieson et al., 2020; Lai et al., 2017). Recent PA-related research tends to be related to organized sport, and often elite athletes (Gunaydin, 2020; Lamberg & Pierre-Glaude, 2021). Therefore, understanding and improving underlying

drivers for motivation to be active among lower extremity amputees may be critical for affecting several long term health benefits and positively impacting their quality of life.

The purpose of this mixed methods study was to implement a fitness app based intervention among lower extremity amputees to improve BPN satisfaction, motivation, and PA levels; and, to contextualize those changes through interpretative phenomenological analysis that integrated in-depth interviews. Primary outcomes of interest in the intervention were motivation and PA level; secondary outcomes were BPN satisfaction as it related to exercise. The qualitative study aimed to understand experiences of motivation to be active among lower extremity amputees.

5.3 Methods

5.3.1 Overall Study Design

This study used a mixed methods intervention design to understand experiences of motivation to be active among lower extremity amputees (Fig 5.1). This approach is a specific use of a sequential explanatory mixed methods study in which the quantitative data were collected through an intervention and the qualitative data were used to contextualize or enrich the quantitative experimental results (Creswell & Clark, 2018). The intent was to provide personal experiences of the population to better explain the intervention results and to understand how setting or context may have influenced outcomes (Creswell & Plano Clark, 2018). Integration through connection occurred by using the quantitative data to inform the sampling frame of the qualitative data collection and through analyses of findings across both quantitative and qualitative phases (Fig 5.1; Fetters at al., 2013).

This study drew from a intervention to increase motivation to be active and physical activity level among amputees in which loss to follow-up was least pronounced among lower extremity amputees. This study reports on the results from only lower extremity amputee participants. The intervention employed a waitlist control experimental design in which the intervention group received unlimited access to a mHealth app. The app was commercially developed by BurnAlong to enable on-demand physical activity classes and skills building sessions with a feature to live stream a remote partner while working out. These features operationalize the BPN constructs of SDT by offering choice of activity (autonomy), improving exercise techniques (competence) and allowing on-demand videos to be viewed simultaneously by friends and workout partners (relatedness).

To explain the intervention results and retention rate of lower extremity amputees, in-depth interviews were conducted following interpretative phenomenological analysis (IPA) guidelines (Smith et al., 2009). Six participants completed two interviews and a photo-diary of their physical activity. The semi-structured, in-depth interview guides were designed to explore motivations to be active, experiences as an amputee, and concepts of relatedness, competence, and autonomy.

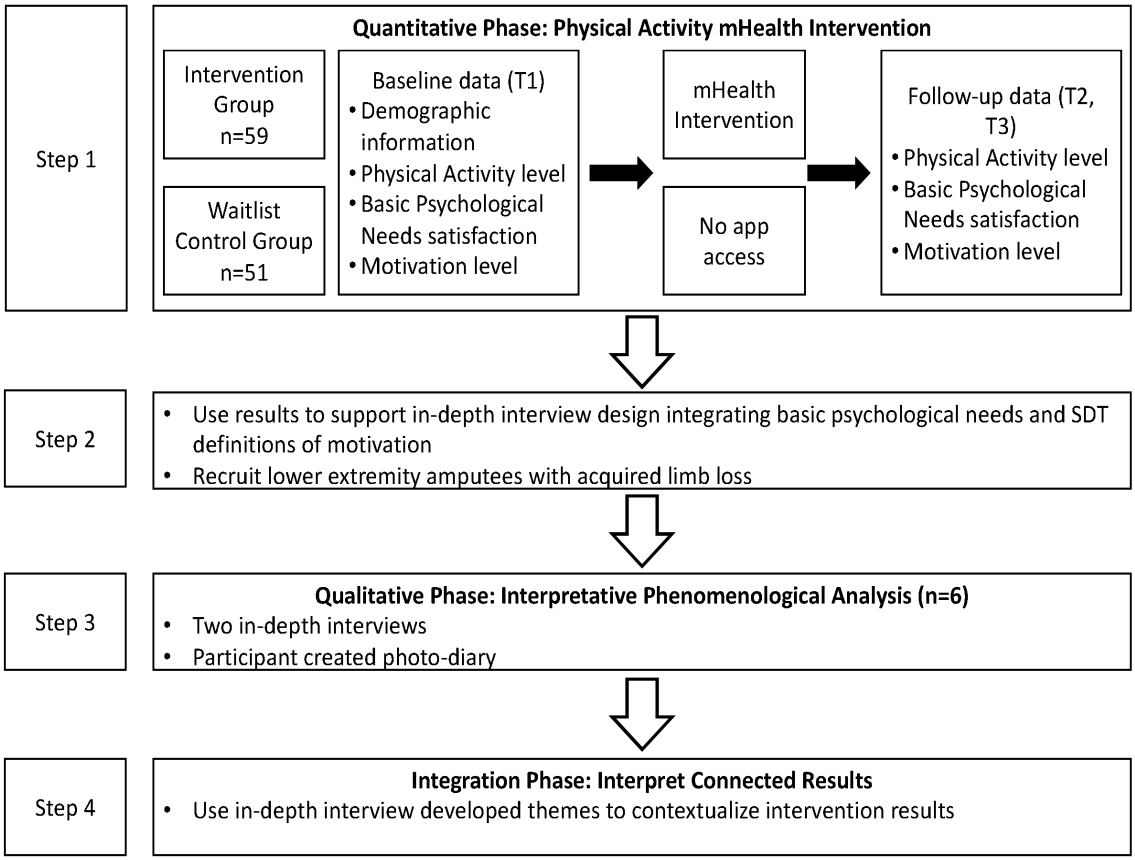

Figure 5.1. Explanatory sequential mixed methods research flowchart.

5.3.2 BurnAlong Intervention Design (Quantitative Phase)

This phase was a randomized, 2-group experimental design in which the app-based intervention was provided to half the participants. The other half was a waitlist control group that received access to the app at completion of the study. Group assignment occurred through a Qualtrics (Qualtrics, Provo, UT) feature that randomizes participants into groups after they electronically signed the consent form. Primary outcome variables were motivation levels and physical activity level. Secondary outcome variables were basic psychological needs satisfaction.

5.3.2.1 Participants

Single-limb amputees (Table 5.1) were recruited through amputee-specific publications (i.e, *inMotion* from Amputee Coalition) and peer support groups. Participants were enrolled on a rolling basis from July through October 2020. Inclusion criteria included: adults between the ages of 18 and 65 years; single limb amputation at or above the ankle; internet and device access to be able to use the prescribed mHealth app; ability to read and respond to questionnaires in English; and initial willingness to commit to two workouts of their choice, per week, for eight weeks. Excluded from the study were those with multiple amputations and those under the care of a physician for conditions related to their amputation or that precluded physical activity (PA). Participants randomized into the intervention arm were provided immediate access to three months of the app free of charge; participants in the waitlist control arm were provided three months of app access free of charge upon completion of the study. This study examines the intervention effect among lower extremity amputees.

5.3.2.2 Data Collection

During the eight week intervention data were collected from both groups at three time points: 0-weeks (baseline), 4-weeks, and 8-weeks (endline). Questionnaires that had previously been tested for reliability and validity among people with disabilities (PWD), or in PA settings, were used for primary data collection related to motivation type (Li, 1999), basic psychological needs in exercise satisfaction (Vlachopoulos & Michailidou, 2006), and activity level (Washburn et al., 2002). Demographic information was collected at baseline.

The instrument used to collect motivation data was the Exercise Motivation Scale (EMS). The EMS consists of 31 items in a response 6-point Likert-style format, ranging from strongly disagree to strongly agree with the item statement. Internal consistency for all subscales has been measured above acceptable levels (Cronbach's alpha .75-.90) (Wininger, 2007). The Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) was developed for measurement among populations with disabilities (Washburn et al., 2002). Most PwD participant groups used to develop and evaluate reliability and validity of PASIPD self-identified as having mobility disabilities (80%). Researchers did not further stratify type of impairment to differentiate results of amputees from others with mobility disabilities (Washburn et al., 2002). The PASIPD showed temporal stability (ρ=.77) and criterion validity against an accelerometer (ρ=.30) equivalent or better than accepted measures used for the general population, such as the International Physical Activity Questionnaire and Stanford 7-Day Recall (van der Ploeg et al., 2007; van den Berg-Emons et al., 2011). PAPSID results in an estimation of metabolic equivalents (METs) expended by the participant during the previous seven days. The Basic Psychological Needs in Exercise Scale (BPNES) was used to collect data on how well participants felt their basic psychological needs were being met with respect to exercise participation (Vlachopoulos & Michailidou, 2006). BPNES consists of 12 items with four items per subscale: autonomy, competence, and relatedness. The instrument was designed to specifically address basic psychological needs necessary to be motivated to participate in exercise activities. The instrument demonstrated adequate internal consistency for all three subscales (α=.84 for autonomy, α=.81 for competence, α=.84 for relatedness) (Vlachopoulos & Michailidou, 2006) as well as discriminant

validity of the subscales with the three-factor model of BPNES demonstrated to be statistically superior to the single-factors and all of the two-factor models (Vlachopoulos, 2008).

5.3.2.3 Data Analysis

To examine the relationship between intervention and primary (motivation) and secondary (PA) outcomes, linear mixed effects models were developed, controlling for race, level of education, employment status, mechanism of amputation (congenital or axquired), and time with amputation. Besides random intercepts, the study group, time of data collection, and group by time interaction were included as fixed effects in the model. Separate models were developed for each outcome variable (amotivation, extrinsic motivation, intrinsic motivation, PA, autonomy, relatedness, and competence).

Table 5.1. Integrated table showing characteristics of intervention participants completing the baseline and 8-week follow-up surveys, as well as IPA participants completing two in-depth interviews.

	BurnAlong Intervention mean (std dev) or n (%)		**Waitlist Control mean (std dev) or n (%)**		**In-Depth Interviews**
	Baseline n=59	8-week n=16	Baseline n=51	8-week n=16	n=6
Age	36.71 (8.14)	41.44 (4.96)	36.76 (9.24)	42.44 (4.12)	53 (10.71)
Time with Amputation (years)	11.90 (12.84)	33.75 (13.17)	13.53 (14.25)	30.44 (16.09)	9.22 (5.77)
Race					
White or Caucasian	28 (47.46)	2 (12.50)	27 (52.94)	1 (6.25)	6 (100.00)
Black or African American	26 (44.07)	14 (87.50)	17 (33.33)	15 (93.75)	0 (0.00
All other races	5 (8.47)	0 (0.00)	7 13.73)	0 (0.00)	0 (0.00
Gender					
Man	32 (54.24)	8 (50.00)	35 (68.63)	9 (56.25)	1 (16.67)
Woman	25 (42.37)	8 (50.00)	16 (31.37)	7 (43.75	5 (83.33)
All other genders	2 (3.39)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)
Employment[a]					
Employed full time	16 (27.12)	5 (31.25)	12 (23.53)	6 (37.50)	2 (33.33)
Employed part time	18 (30.51)	10 (62.50)	20 (39.22)	10 (62.50)	1 (16.67)
Out of work or retired	17 (28.81)	1 (6.25)	10 (19.61)	0 (0.00)	1 (16.67)
Unable to work	8 (13.56)	0 (0.00)	9 (17.65)	0 (0.00)	2 (33.33)
Mechanism of Amputation					
Congenital	9 (15.25)	13 (81.25)	10 (19.61)	11 (68.75)	0 (0.00
Acquired Trauma	34 (57.63)	2 (12.50)	26 (50.98)	5 (31.25)	3 (50.00)
Acquired non-Trauma	16 (27.12)	1 (6.25)	15 (29.41)	0 (0.00)	3 (50.00)

[a] Significant difference ($p<.05$) between intervention and control groups at 8-week follow-up time point

5.3.3 Interpretative Phenomenological Analysis Design (Qualitative Phase)

This phase investigated the phenomenon of motivation to be active among lower extremity amputees. The sampling plan and interview guides for data collection were developed after the quantitative phase data were analyzed. Interpretative phenomenological analysis (IPA) methods were used to investigate, in detail, current motivations for leisure time physical activity (LTPA), especially as they aligned with or contradicted constructs of SDT; past experiences with LTPA; and attitudes related to LTPA as an amputee to understand how amputees make sense of their experiences (Smith et al., 2009). To capture the experiences of LTPA, participants created photo-diaries and the technique of photo-elicitation were incorporated with the in-depth interviews (Burke, 2005).

5.3.3.1 Participants

Because loss to follow-up was least pronounced among lower extremity amputees in Phase 1, this study focuses on the experiences of lower extremity amputees only. This population also makes up more than 75% of all amputees in the US (Ziegler-Graham et al., 2008). Purposive recruitment of lower extremity amputees for Phase 2, the qualitative phase, (Table 5.1) was conducted through organizations and individuals trusted by, and with regular access to, the community of amputees in the US. The primary partner organization supporting recruitment was the Amputee Coalition. Participants were enrolled on a rolling basis from June through August 2021. Participant inclusion criteria were: single limb, lower extremity amputee; amputation at or above the ankle; aged 18 through 65 years, with access to the internet for Zoom meetings; and, the ability to take

digital photographs. Exclusion criteria included participation in Phase 1 of this study, or currently under the care of a physician for anything other than routine purposes.

5.3.3.2 Data Collection

Data were collected through two in-depth, semi-structured interviews and included a participant developed photo-diary related to LTPA. The open-ended nature of the questions provided the participants with the freedom to use their own words and the researcher to allow the interview to go where the participant took it, modifying the questions as the interviews progressed (Daly, 2007; Miles & Gilbert, 2005). The first interview explored participants' experiences and meanings of motivation to be active. The second round of interviews asked participants not only to describe movements and LTPA activities but to return to the activities through photo-elicitation (Burke, 2005; Johnson-Glenberg & Megowan-Romanowicz, 2017; Magnat, 2011; Pink, 2011; Spatz, 2017). Participants were asked questions to take them back to the moment they took the picture and describe the environment, their feelings, and what information their senses were providing them. The interview guides were pilot tested with two amputees known to me and not drawn from the pool of eligible participants. The pilot test was used to clarify questions and framing; answers were not collected nor used in study analysis.

5.3.3.3 Data Analysis

Data were analyzed from the perspective that the experience meant to be understood is the amputee's motivation to participate in LTPA and their experiences that influence that motivation. To facilitate this process, I relied on the IPA method outlined by Smith and colleagues (2009). The six steps are: reading and re-reading; initial noting; developing themes; searching for connections across themes; repeating the first four steps with each

individual participant's data; and looking for patterns across participant data. The analysis process incorporated peer debriefings throughout and member reflections. Peer debriefing engaged colleagues who hold impartial views of the study to critically review methodology and analysis (Spall, 1998). Member reflections involved sharing findings with participants and providing opportunities for feedback (Smith & McGannon, 2017).

5.3.4 Ethical Considerations

This study and all procedures involving human participants were reviewed and approved by the Institutional Review Board of the University of Maryland, College Park. Informed consent was obtained from all individual participants included in the study. Additional informed consent, in the form of a photo release, was obtained from all individual participants for whom identifying information is included in this dissertation. Where applicable, all quotes have been de-identified and only pseudonyms are used throughout this study: Dawn, Tiffany, Michael, Summer, Roslyn, and Kristin.

5.4 Results

5.4.1 BurnAlong Intervention (Quantitative Phase)

There were no significant differences in demographics between groups at baseline. At the 8-week mark, employment status was significantly different between groups with the intervention group retaining more out of work or retired participants than the waitlist control group (Table 5.1).

At baseline, participants in both arms reported higher extrinsic motivation (16.31 in control group out of 24 possible in the EMS scale; 16.30 in intervention group) than intrinsic motivation or amotivation toward exercise (see Figure 5.2; Table 5.2). At

endline, intrinsic motivation (18.03 in control group out of 24 possible in the EMS scale; 18.72 in intervention group) was highest in each group. Means of all motivations types increased in both groups between baseline and endline. Total mean PA increased in both groups, with the largest change occurring in the control group (10.88 to 31.44 METs in control group; 12.54 to 15.39 METs in intervention group). Figure 2 illustrates the means of each outcome variable by group over time. The only time point or variable in which the 95% CI does not overlap between groups is the 8-week mean PA in which the control group is significantly higher than the intervention group.

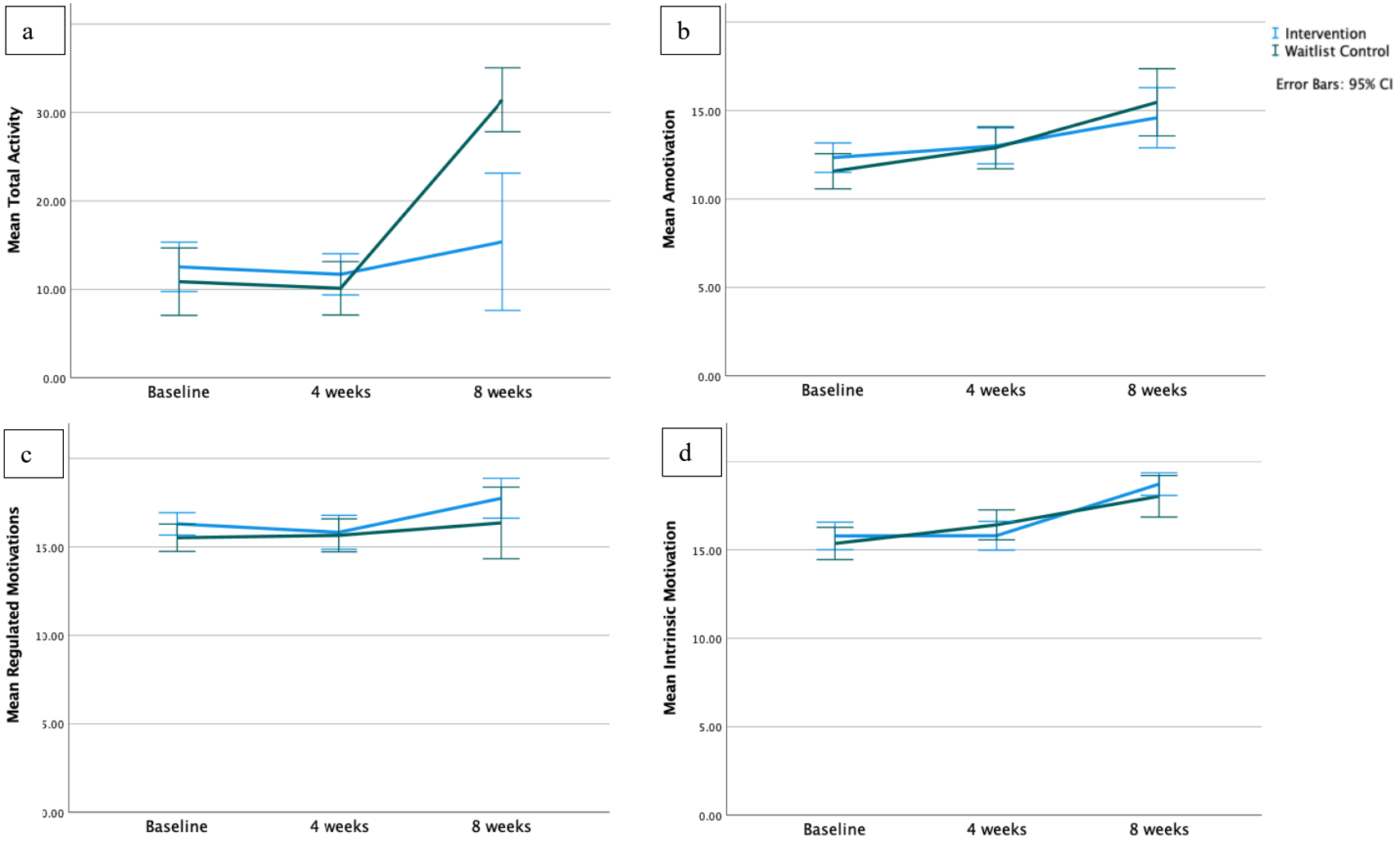

Figure 5.2. Changes in primary outcome patterns: a) activity level; b) amotivation; c) extrinsic (regulated) motivation; and d) intrinsic motivation

Separate linear mixed effects models were developed for each primary outcome measure: amotivation, extrinsic motivation, intrinsic motivation, and total PA (Table 5.2). There was no significant difference between groups in changes to extrinsic or intrinsic motivation level over time. There was no overall effect of intervention on PA level; however, the effect of time and the interaction effect of group by time were both significant factors in changes to PA level, demonstrating a crossover interaction effect (Fig 5.2). The effect of time on physical activity is different, depending on the intervention group. Although both groups reported increases in PA over time, the rate of increase in PA in the control group was far greater than the rate of increase in PA in the intervention group over the intervention. The amotivation model showed significant effects from intervention, time, and group by time interaction. The mean amotivation level of both groups increased over time; however, the increase in the control group was faster than in the intervention group.

Secondary outcome variables (autonomy, relatedness, competence) were analyzed using separate linear mixed effects models (Table 5.2). The mean satisfaction level of autonomy and competence increased in the waitlist control group over the 8-week study. Both groups relatedness levels decreased between baseline and endline. There was no significant difference between groups in any of the basic psychological needs outcomes. The effect of time and the interaction effect of group by time were both significant factors in changes to relatedness, demonstrating a crossover interaction effect. Both groups' level of relatedness satisfaction decreased over time, but the decrease in the intervention group was more pronounced.

Table 5.2. Mixed-effects models: Outcome variable Fixed Effect Estimates by group over time[a]

Outcome Variables		**Baseline**	**8 weeks**	**Linear mixed effects model results**		
		Mean (SD)	Mean (SD)		Fixed Estimates	CI 95%
Amotivation	Intervention	12.34 (3.19)	14.59 (3.19)	Group	1.14	(.06, 2.17)*
	Control	11.57 (3.53)	15.47 (3.57)	Time	.03	(.01, .04)*
				Group*Time	-.03	(-.05, -.001)*
Extrinsic Motivation	Intervention	16.31 (2.43)	17.50 (2.12)	Group	.97	(.01, 1.93)*
	Control	16.30 (2.18)	16.36 (3.79)	Time	.01	(-.01, .03)
				Group*Time	-.003	(-.03, .02)
Intrinsic Motivation	Intervention	15.79 (2.98)	18.72 (1.20)	Group	.35	(-.67, 1.36)
	Control	15.93 (2.70)	18.03 (2.20)	Time	.04	(.02, .05)**
				Group*Time	-.007	(-.03, .02)
Physical Activity	Intervention	12.54 (10.69)	15.39 (14.56)	Group	3.32	(-.75, 7.41)
	Control	10.88 (13.54)	31.44 (6.79)	Time	.29	(.23, .36)**
				Group*Time	-.20	(-.30, -.11)**
Autonomy	Intervention	13.75 (2.36)	13.95 (2.30)	Group	-.07	(-.67, .54)
	Control	13.93 (2.75)	15.25 (2.24)	Time	.01	(-.001, .02)
				Group*Time	-.01	(-.03, .005)
Relatedness	Intervention	14.16 (2.24)	12.16 (3.76)	Group	.51	(-.14, 1.16)
	Control	13.55 (2.56)	12.44 (3.83)	Time	-.001	(-.01, .01)*
				Group*Time	-.02	(-.04, -.01)*
Competence	Intervention	13.28 (2.40)	15.05 (2.17)	Group	-.54	(-1.13, .05)
	Control	13.71 (2.42)	15.75 (1.61)	Time	.02	(.01, .03)*
				Group*Time	-.02	(-.03, .002)

[a] Control variables: Race, Education, Employment, Mechanism of Amputation, Time with Amputation

* $p < .05$; ** $p < .001$

5.4.2 Interpretative Phenomenological Analysis (Qualitative Phase)

The main themes are outlined in Table 5.3. The strongest association participants made to LTPA participation was the relationships surrounding the activity, i.e. dynamics of relatedness. The other three themes affecting LTPA participation were facilitators to activity, barriers to activity, and the complex processes associated with being active that are unique to amputees. Illustrative quotes throughout the results use participant preferred pseudonyms.

Table 5.3: IPA Themes

Theme	**Subordinate Themes**
Relatedness	Role of others in LTPA participation
	Peer connection within amputee community
Facilitators	Prosthesis fit
	Accessible environments
Barriers	Residual limb pain
	Combined healthcare and insurance systems impede LTPA
Processes	Recovery is necessary part of LTPA planning
	Competing demands on body dictate timing of LTPA participation

5.4.2.1 Relatedness

Relationships were paramount to LTPA engagement. In every activity, participants described the role of others. Study participants either engaged in LTPA with those whom they had strong relationships or were enabled and encouraged to participate through their relationships with the broader amputee community.

Michael has a very active life, teaching physical therapy, lifting, bike riding, and walking historical sites, but he was very clear about the importance of others in his activities. When asked about what motivated him to do the historical walks, he said, “First off with who I'm with…So since I enjoyed it so much, I'm not afraid to do sightseeing by myself. So, but obviously doing it with my children and friends is much

more fun but I will do by myself." He also centered his students in his activities, involving them in his first 5k post-contralateral knee surgery and sharing lifting techniques as part of his teaching. For Michael, "they're [students] my extracurricular activity. So I would say it's student driven." Roslyn, on the other hand, was limited in her activity options as a result of multiple revisions and the associated recovery process. Revision surgery is shortens the length of the residual limb to address complications associated with a traumatic amputation. Her primary physical activity was woodworking, which gave her a creative outlet, exercised her upper body, and allowed her to rest her leg without a prosthesis. Despite this being an individual activity, she designed each woodworking piece for important people in her life. Describing one of the pieces from her photo diary (Fig 5.3), Roslyn spoke more about the recipients than the piece itself, "I never want them to forget, like, how much they mean to me. And, like, that they are the reason why I keep going on, like. I mean, life can be hard enough as it is and I just try to instill in them, like, every day, like, truly how much they mean to me." Dawn discussed the importance of having support from close relations and the value of those people willing to just be present.

Figure 5.3. Roslyn's woodworking piece for her daughter.

Additionally, participants emphasized the importance of their relationships with the amputee community, specifically their reliance on peer modeling and peer support. Kristin was emphatic that she preferred to learn from someone with similar lived experiences because they often had different understandings of needs. Soon after her amputation, she found peers gave her solutions that improved independence and function: "I was taught how to get up from the floor one way by my physical therapist. And while I can do it, it's, uh, it's not an easy way. I went to a support group meeting and…he showed me what he did. It was completely different from what the physical therapist had told me. And it was a hundred percent easier, you know." Kristin continues to reach out through social media to the online amputee community when adapting a new LTPA. Summer and Tiffany feel the community connection is so important, they actively reach out to other amputees to make sure they know a community is available. Both Summer and Tiffany

described recent instances in which they approached strangers. Tiffany said “you know, I'm, I'm not a shy person. So, I was like, if I see another amputee, I'll go up and start a conversation. And, uh, one of the guys that I saw when I was at fireworks, I was telling him about this support group...So, he was at the last meeting that I was at.” Similarly, Dawn and Roslyn described depression in the months and years immediately following amputation. They both talked about the influence of peers within the amputee community as part of their recovery process. Dawn was treated by a mental health professional, but felt that the support from fellow amputees was more transformative. She said, “And through that and the dealing with other people that knew exactly where I was, you know, and how I could get out of where I was, because they've been there, um, is really the, the only reason that I am trying, you know, to make the changes.”

5.4.2.2 Facilitators

During interviews, participants discussed facilitators that supported their LTPA but were not directly related to their motivation to be active. Facilitators were related to the quality of prosthesis fit and the accessibility of the built environment.

When participants felt their prosthesis was properly fitted, they were able to concentrate on their LTPA of choice. Michael is able to frequently challenge his body in a variety of LTPA, in part, because he considers his prosthesis comfortable. After his 5k, he admitted having some pain, but said that was a result of pushing himself, “obviously the pounding of residual limb, and it's not made to take that pounding…but my fit, my residual limb pain is only when I overuse it, 'cause I don't have any, ‘cause I have a great fit in my socket.” Kristin, who has a high above the knee amputation, tried several different socket and liner combinations over the years until she found one that supported

her active lifestyle. She said, “I've worn everything, you know, from those sealing liners to the-I mean everything…the guy that I worked for, he said- he said, ‘Let's just try straight carbon fiber.’ Because I- I had lots of skin issues and I just thought…it's gonna be so painful, but I've never had an issue since.”

Participants also described aspects of their built environment that facilitated activity. Michael and Kristin specifically addressed fitness equipment and the benefit to finding adaptive equipment in a gym. When they find machines or equipment designed for use by a wide variety of athletes, they spend less time figuring out how to make their body fit the environment and more time using the machines to improve their fitness. Tiffany, whose amputation challenges her balance, especially on uneven ground, appreciates the places that consider visitors with mobility challenges. As someone who lived most of her life near water, she searches for way to continue to enjoy it, “There's one particular beach access…it's like, you know…a drive…But it is so neat because, uh, of just the way the beach is down there. The concrete gets you so close to the water that you can hear the waves.”

5.4.2.3 Barriers

Similar to the influence of facilitators, participants discussed barriers that were not related to overall motivation but did affect LTPA engagement. Pain as a result of use, phantom sensations, nerve damage, and skin ulcerations prevented or limited LTPA. The complexity of the healthcare and insurance systems created barriers to being more active.

Chronic pain manifested as pain at the site of amputation and as compensatory pain in joints distal to the amputation or in the anatomical leg. Summer’s traumatic amputation from a bombing affected how the residual limb healed and complicated

prothesis fit. She frequently experienced skin ulcerations and nerve pain from contact. She explained, “I think I would definitely be more active if I didn't have to worry about my stump and how it was doing or things like that, you know? Uh, yeah, I mean even just the fact that I'm in the wheelchair today so that I can stand tomorrow.” Dawn’s pain is exasperated by standing for long periods of time. Not only does this reduce her LTPA options, but it affects activities of daily living, such as cooking and cleaning. Tiffany experienced an unexpected change in frequency and intensity of pain when her prosthesis began to press against a nerve at the end of her amputated leg. Even when the prosthesis was removed, the pain lingered, affecting sleep, concentration, and planned LTPA until she was able to have the socket adjusted.

The complexities of the interconnected healthcare and insurance systems often imposed barriers that affected LTPA participation. Dawn, a hiker, fisher, and gardener pre-amputation was limited by the speed at which a prosthesis was authorized, “so once I was released from him [surgeon], I pretty much sat in my wheelchair waiting on insurance approval for a leg for almost two and a half years.” In that time, her strength atrophied, her weight increased, and it took another two years to be able to walk for any extended time using her prosthesis. Summer’s prosthesis liner began to harden near the beginning of the COVID-19 pandemic. To get a replacement through her prosthetist required a prescription from her primary care physician and several forms, putting sensitive skin at risk of tearing. Tiffany struggled with a disconnect between providers. After her amputation, the team performing the surgery and aftercare was unable to provide advice for choosing a physical therapist resulting in a lot of trial and error to find a facility able to support an above the knee amputee. As she put it, “and so, I as a brand

new amputee, not knowing anybody or anything, I had to get on the phone and call all of the, the people that were physical therapists in my area."

5.4.2.4 Processes

Amputees have planning and process considerations that others do not have to account for as part of their LTPA participation. Participants planned their time leading up to LTPA to ensure they were able to participate, and they planned significant time for recovery after LTPA participation to ensure they would still be able to perform usual activities of daily living. Participants also described competing demands on their bodies and how that affected their LTPA planning.

LTPA participation for amputees required extensive preparation and recovery processes. For Tiffany, the effort it takes to maintain balance while walking can result in a large amount of expended energy. She has to consider this when planning LTPA, often taking into account the distance from parking to the activity, the type of ground she will be walking on, bathroom facility access, and availability of seating. To ensure she has the energy to participate, she may carry a foldable chair with her as she did when learning adaptive water skiing, or have friends drop her off before parking for events like bowling. Summer was very detailed in the processes that she had developed to be able to enjoy her LTPA of choice. In preparation for an activity, she minimized time in her prosthesis to avoid aggravating sensitive skin or nerves. After a day of elevated activity, she spent time stretching instead of a workout (Fig 5.4). She talked about how she felt getting ready for a night dancing with her husband, "And, uh, that was the culmination of that prep and right then I felt great. By the end of the night absolute shattered, lots of pain…like difficulty walking the next day…But yeah, it just, it'd be nice if that, if that was easy."

Figure 5.4. Summer stretching her back and leg to account for LTPA.

In choosing to participate in LTPA, the participants in this study often had to consider competing demands on their body. Just before the start of this study, Dawn had started cycling using a new trike. After years being sedentary, she placed importance on regular LTPA, but found her body was not always able to match her motivation, “it makes you feel guilty for not getting on when you, when you usually do, you know, which has been 7:00, 7:15, um, but on physical therapy days, it's impossible for that.” Roslyn had trouble planning her LTPA because “it, uh, basically, it depends whether, when I get up if my leg goes on without any problems or if I have problems.” Michael also understands high intensity workouts affect his ability to perform activities of daily living or teaching classes all day. He recognizes the energy and effort to be active may compete with what he needs his body to be able to do in other settings, “before used to be, what can I, what can my body do? And now I'm more so what can have my body safely do?…it's gotten easier for me to say: I need to keep moving; so I can't do this anymore.”

5.5 Discussion and Integrated Findings

This mixed methods study was designed to understand motivation to be active among lower extremity amputees. It utilized a combination of experimental quantitative design research and IPA qualitative investigation to amplify and contextualize the experimental results. The intervention study evaluated a fitness app's impact on motivation and PA. The app incorporated features that operationalized SDT constructs of autonomy, relatedness, and competence. The effect of the intervention over time on all primary and secondary variables is weak, with narrow confidence intervals. I can say with relative certainty that the intervention was not the driver in changes in motivation or physical activity level among lower extremity amputees. Increases in intrinsic motivation, PA level, and feelings of exercise competence were more strongly attributed to time rather than being randomized into the intervention group.

Interviews with lower extremity amputees revealed facilitators and barriers to LTPA that affected overall activity level, regardless of motivation. Pain and difficulties receiving assistive technology or associated components may have influenced PA level more than the fitness app. Moreover, the intervention took place in 2020, during the first year of the COVID-19 pandemic. The National Association for the Advancement of Orthotics and Prosthetics (2020) recommended orthotics and prosthetic providers triage care to only those with the most urgent needs. During the first year of the pandemic, assistive technology providers described supply chain issues that affected the availability and cost of mobility devices, as well as travel restrictions for both patients and staff preventing service delivery (Puli et al., 2021). Instances like Summer's exemplify these challenges, in which she was required to make multiple appointments weeks apart for

signatures on forms and to process prescriptions in order to receive a silicon liner constitutes routine, not urgent or essential services.

Intervention study participants may have been without some facilitators for LTPA. Reduced access to healthcare facilities would prevent adjustments to socket fit in an effort to reduce pain or improve experiences participating in LTPA. In an effort to contain the spread of disease, many local, State and National Parks were closed (Schroeder, 2020; Slater et al., 2020). Gyms and community centers also shuttered their doors. Effectively, what accessible environments participants may have used for LTPA were no longer available. Increases in barriers and decreases in facilitators may have influenced changes in measured PA during the qualitative phase of this study.

The most prevalent and important influence on LTPA participation among IPA study participants was their relationship with others. Relatedness is a strong predictor of motivation for LTPA (Divine et al., 2019; Sylvester et al., 2018). While the fitness app had features designed to increase virtual social interactions, average relatedness scores decreased in both intervention study groups. This may also been influenced by COVID-19 associated restrictions. COVID-19 precautions limited the ability to connect with others in person. Kirstin talked about continuing a new activity after some restrictions had lifted: “actually learning maybe a side effect because I learned how to do this without anybody. It was during COVID[-19] and watching the computer. So I guess I could learn on the computer if I wanted to, but, um, I guess probably is more the, you know, just, you know, having somebody to talk to.” Tiffany also lamented reduced LTPA social interactions, “So, um, you know, one of, one of the things that I do for, um, recreation or that type of thing is, um, go to, uh, amputee support groups when they're in session...The

one that I had been going to the last few months, they stopped having in-person meetings again because of this new round of COVID[-19]."

5.5.1 Study Limitations

This study was developed before the pandemic began. Given the virtual nature of the intervention component, the quantitative phase was implemented as designed in May of 2020. The history bias associated with implementing an intervention during a pandemic may have had a greater effect on participants' motivation to be active, activity level, and basic psychological needs satisfaction than the intervention, especially if restrictions or rate of contagion were different geographically or at the time of participant enrollment. There was also a 71% loss to follow-up among intervention participants, higher than other studies among disabled populations with 51% retention rates or better (Kosma et al., 2012; Littman et al., 2018; Wegener et al., 2009). The intervention anonymized all data upon collection. This prevented a change in study protocol to use intervention participants as a sampling frame for the IPA study. Such a change may have provided more insight about the effects of the pandemic on study variables or the reasons for study drop-out. Finally, all IPA participants identified as white, and all but one as female. This is different from the demography of lower extremity amputees in the US, which tends to be male and Black or African American. Black males may have very different lived experiences of motivation to be active as an amputee.

5.5.2 Future Research

This study suggests the relationship between LTPA participation is more complex than is able to be explained by SDT. Facilitators, barriers and the processes to be active

contribute to overall level of LTPA, outside of the influence of motivation. Future studies should consider ways to operationalize and quantify the influence of those barriers and facilitators, specifically as mediators between motivation to be active and LTPA. Theory-based interventions for PwD may benefit from separating facilitators and barriers to LTPA from motivation to participate in order to retain participants and affect long term changes in activity level. Recognizing that participants in the IPA study placed great value on relatedness in their LTPA experiences, refining and understanding how relatedness can be reinforced or developed within a fitness app warrants study. Leveraging a user-centered design framework would inform features, content, and use cases for amputees.

In addition to research implications, this study offers insight into policy change that would influence LTPA among amputees. In-depth interviews with amputees showed that LTPA participation was facilitated by prosthesis fit and an accessible environment. Policy encouraging universal, accessible design for the built environment could improve the ability for amputees to engage in LTPA in a wide variety of settings and activities. Healthcare policy designed to reduce complex authorization paperwork would increase autonomy, decrease recovery time, and lead to increased LTPA. Healthcare policy should also be written to center the importance of mental health services in amputation surgery recovery.

5.6 Conclusion

The present study provides insight into motivations to be active among amputees. The mixed methods results offered a rich context to intervention results. Interviews provided clearer understanding of facilitators and barriers to LTPA that were not captured through

intervention motivation data. Amputees experience a wide variety of influences on their LTPA participation that cannot be explained by motivation to be active alone. These results suggest that improving connectedness and removing barriers may be just as important to activity level as motivation. Multilevel interventions across policy, environment, and community are needed in addition to individual interventions to address LTPA participation among amputees.

Chapter 6 Summary

This dissertation explored experiences of motivation to be active among amputees through a sequential mixed method study design. Chapter 3 evaluated the impact of BurnAlong, a commercially available fitness app, on motivation to be active and total activity level among amputees. BurnAlong is an industry innovator in two key ways that made it the preferred fitness app for this intervention. First, the company designed their app to improve social connectedness in a virtual fitness environment. The app allows users to choose prerecorded workout videos with video overlay of a partner live streamed. The allows for real-time interaction with friends and family while working out together, virtually. Second, the BurnAlong content management team has been energetic in maximizing the variety of fitness options, including adaptive workouts led by certified instructors with apparent disabilities. The presence of near peers as trainers, as well as descriptions for adapting workouts or movements within workouts, improved the quality of the app for amputees. This was demonstrated in the significant bivariate correlations of app quality with motivation and basic psychological needs satisfaction (see Table 3.6). Despite positive correlation between app quality and intrinsic motivation and relatedness, the intervention group did not experience increases in motivation or total activity level based on BurnAlong exposure over time. Some lack of diversity in app content, large loss to follow-up, pandemic restrictions, or some other confounders may have influenced results.

Chapter 4 describes the interpretative phenomenological analysis (IPA) to explore the embodied meaning and lived experience of motivation to engage in LTPA among amputees. Interview guides for use in the IPA study were developed based on the

intervention study results, integrating Self-Determination Theory (SDT) concepts and photo-diary data collection methods. Participant inclusion criteria were updated to recruit lower limb amputees only, based on those who remained through the completion of the intervention. All participants had acquired amputations and identified as white (see Table 4.1). None of the participants had acquired their amputation as a result of dysvascular conditions, the most common cause for lower extremity amputations in the US (Dillingham et al., 2005; Esquenazi & Yoo, 2016; Ziegler-Graham et al., 2008). Two in-depth interviews were conducted with each participant. Participants also maintained a photo-diary of a leisure time physical activity (LTPA) of their choosing that was discussed during interview two. Themes included the importance of valued relationships in LTPA, the complex and often time consuming processes employed to participated in LTPA, and facilitators and barriers to LTPA regardless of motivation level.

Finally, Chapter 5 integrates the findings from lower extremity participants in the intervention and from the IPA study. Using self-determination theory (SDT) as a framework, this study employed a sequential mixed methods approach to integrate fitness app intervention data with interpretative phenomenological analysis (IPA) findings to better understand the relationship between motivations to be active and LTPA participation among lower extremity amputees. IPA themes contextualized intervention changes in relatedness, amotivation and activity level (see Table 5.2). Interview participants described ways in which the COVID-19 pandemic disrupted contact with others. Decreases in relatedness may have influenced increases in amotivation and decreases in activity level. Additionally, intervention participants may have experienced increased barriers to LTPA engagement as a result of their environment or restrictions

associated with pandemic precautions. Together, these results provide insight to the complex influences on motivation to be active and LTPA participation among lower extremity amputees. As the COVID-19 pandemic becomes endemic, discovering physically distanced mechanism to maintain and grow relationships will be critical for both researchers and practitioners interested in improving LTPA among amputees.

6.1 Public Health Implications

Health is physical, mental, and social wellbeing; not just the absence of disease (WHO, 1947). The healthcare and public health fields must overtly acknowledge that PwD are not unhealthy by virtue of their disability, but can be healthy and can live healthy, active lives. Regular LTPA improves physical and mental health and is protective against many chronic illnesses. Results of this study suggest a comprehensive, wholistic approach to increasing LTPA among amputees is needed. The high rate of inactive and sedentary PwD cannot be reduced through individual level motivational interventions alone. Increased LTPA may need to be approached from a multilevel perspective to be effective. Some government funding opportunities, such as NIH's Notice of Special Interest: Developing and Testing Multilevel Physical Activity Interventions to Improve Health and Well-Being (NIH, 2021), are beginning to recognize the importance of enabling interventions that address multiple domains of influence to affect change. Disability, however, continues to be referred to as an outcome to be "managed" along with disease.

Participants made clear that healthcare policies, both those promulgated by government entities and insurance carriers, prevent access to prosthetic equipment and mental health care necessary to fully rehabilitate after surgery and impede an active lifestyle among PwD. The disconnect between surgical teams and physical therapy (PT)

teams was troubling to many participants for whom the responsibility fell to both find and subsequently educate clinicians/therapists on their individual needs. For Roslyn, this disconnect resulted in reinfection; Tiffany, went through a litany of PTs until she found one with experience working with amputees; for Dawn, it was a prolonged period of depression as mental health impacts were not discussed prior to her amputation. A healthcare-related facilitator of LTPA was prosthesis fit. Michael, who trains future PTs recognized he had access to professionals and medical education many other amputees do not. In describing his satisfaction with his prosthesis, he said "having the best prosthesis is a number one way for you to become more active. And the biggest thing I see mostly is pain from the socket and people think it's normal and it's not." Person centered care practices improve the integration of care, patient recovery outcomes and patient education, and should be considered in addressing a wide variety of amputee healthcare needs (Rathert et al., 2013).

The built environment also influenced LTPA engagement. Participants experienced difficulty accessing events designed for participants with disability because of the location of the events. Water events near beaches or lakes without paved or level approaches introduced barriers to participation. Traversing uneven ground results in higher energy expenditure for amputees than nondisabled people and increases the risk of falls for amputees (Paysant et al., 2006; Sturk et al., 2019). Universal design principles were initially developed and defined by architects to address the need for the built environment to serve the most people possible. The seven key principles (equity, flexibility, intuitive use, perceptible information, minimizes impact of unintended actions, low effort, size and space for use) have since been adapted and adopted for

developing curricula, online platforms and software (Center for Universal Design, 1997). The US Federal Government endorses universal design to increase inclusion of PwD and for businesses be more competitive (DoL, nd.b), but further steps can be taken to tie incorporation of universal design principles to federal grant eligibility. Implementing universal design requires forethought, but not additional resources on the part of the planner or developer and makes neighborhood- and city-level spaces functional for all users (Health and Places Initiative, 2015). Consider, for instance, planning for curb cuts and audible beaconing at crosswalks. These innovations serve more of the population, address otherwise unmet user needs, and do not add to the cost of urban planning.

In addition to institutional and environmental barriers, participants experienced social barriers in the form of stigmatization and ableism from healthcare providers, who told individuals not to identify as disabled or, in Tiffany's case, not to rely on mobility devices: "…she's like, 'You're too, you're too, uh, young for a cane. And it's like, you know what? I'm not trying to attract a man. I'm trying not to break my hip, you know." Medical providers are influenced by the medical model of disability in which they view their role as 'fixing' the disability. Consequences of this model are unconscious biases against disability that comes through in treatment of PwD (Anderson et al., 2019; Smeltzer, 2007). Implementing education that recognizes disability as an identity and community of people rather than a medical outcome can ameliorate some of these biases or at least bring them to the level of consciousness so providers can begin to combat those biases (Sabatello, 2019; Smeltzer, 2007). Training should be implemented throughout formal education as well as being integrated with professional development.

6.2 Limitations

There are some limitations that should be acknowledged regarding this dissertation. First, BurnAlong is new to adapted sport and fitness; therefore, the library of workouts for amputees is limited. The autonomy associated with choice may have been constrained by the limited library and have affected changes in motivation over the 8-week app-based intervention. Second, BurnAlong was originally designed, as are most programs in the larger health and fitness app industry, for people without disabilities. The needs and interests of amputees were not part of the original design and even though specific content has since been added, it may not be sufficient for people with amputations to feel included and enticed to use the app (Olsen et al., 2019; Stratton et al., 2020). Similarly, BurnAlong contains features that can be mapped to basic psychological needs for exercise but it was not designed with any theory in mind nor has it been tested against theory prior to this dissertation.

Pre-amputation activity is a predictor of PA participation post-amputation (Kahle et al., 2016). This may have impacted who expressed interest and participated in the study and may have resulted in selection bias. Data related to pre-amputation activity was not collected because Phase 1 recruitment was not limited to those with acquired amputations. The choice not to collect this information prevented controlling for or analyzing pre-amputation LTPA level.

Loss to follow-up was much higher than other studies among disabled populations, which reported 51% retention rates or better (Kosma et al., 2012; Littman et al., 2018; Wegener et al., 2009). The intervention anonymized all data upon collection, preventing implementation evaluation to improve this dissertation study or inform future

research. Sample characteristics were very different from population characteristics. Intervention participants were disproportionately white and all IPA participants were white; there were an even number of men and women enrolled in the intervention while the majority of IPA participants were women (see Tables 3.3 and 4.1). People who identify as Black or African American in the US are four times as likely to experience amputations as compared to other races; men outnumber women in new amputation two to one (Dillingham et al., 2002; Ziegler-Graham et al., 2008). Black men may have very different lived experiences of motivation to be active as an amputee as other demographics and those experiences are not captured in this dissertation.

Finally, there may be selection bias in the recruitment of participants. Recruitment information for both phases of the first two phases of this dissertation described interest in motivation to be active. Participants who were less active may have chosen not to respond to recruitment efforts.

6.3 Strengths

The mixed methods approach to answering this dissertation's primary research question gave a unique perspective on motivation to be active among amputees, which would not have been possible with either method alone. This approach also elevated and gave voice to an underrepresented population in public health research. Throughout the qualitative phase, member reflections were solicited to enable participants' voices to clearly be heard within the interpretations of the phenomenon. Member reflections, with regular peer debriefing, supported triangulation of data to uphold the rigor of the IPA research (Henry, 2015). Additionally, an audit trail was maintained, consisting of detailed reflexive and procedural journals.

This dissertation incorporated theory at all stages of research. SDT is a well-tested theory. Relationships among SDT variables in practice align with the theoretical relationships among SDT constructs, demonstrating positive association of basic psychological need satisfaction and autonomous motivation (Fortier et al., 2012; Ng et al., 2012; Teixeira et al., 2012). Primary SDT constructs of basic psychological needs and the continuum of motivation were central to the intervention design as well as interview guide questions. Prior to this dissertation, there were no post-rehabilitative, theory-based studies done focused on motivations to be active among amputees.

The quantitative phase of this dissertation centered on BurnAlong, a fitness app, as the intervention. The app had content designed for amputees and workouts lead by certified instructors with apparent disabilities. PwD are often left out of or not considered as potential users in innovations and technological advances of fitness resources, especially digitized and virtual opportunities to be active (Stratton et al., 2020). This study leveraged a fitness app in the early stage of developing and including its adaptive fitness content.

6.4 Future Directions

Results from this dissertation have implications for future research and interventions. With the limited BurnAlong library and large loss to follow-up, formative research related to app content desired by the amputee population may result in larger effect sizes of fitness app interventions. In conjunction with testing intervention outcomes, process outcomes should be evaluated to better understand the influence of app quality and intervention implementation. There is little information among this population about the relationship between motivation or intention to be active and level of activity. As Chapter

4 indicates, SDT may not effectively capture amputees' experiences of motivation for LTPA. There are factors that influence the association between motivation and behavior that are not well explained using SDT. Future studies should investigate multilevel environmental influences on the connection between motivation to be active and activity level. Similarly, there may be opportunities to develop a modification of SDT for PwD.

Facilitators, barriers and the processes to be active contribute to overall level of LTPA. Future studies should consider ways to operationalize and quantify the influence of those barriers and facilitators, specifically as mediators between motivation to be active and LTPA. Recognizing that participants in the qualitative phase placed great value on relatedness in their LTPA experiences, refining and understanding how relatedness can be reinforced or developed within a fitness app warrants study. Leveraging a user-centered design framework could inform features, content, and use cases for amputees. The Ecological Model of Four Domains of Active Living may offer a framework for intervention or app design (Sallis et al., 2006). This model includes advocacy organizations, peer modeling and activity partners, as well as the built environment.

All participants in the qualitative phase of this dissertation had acquired amputations. Research of the lived experiences of amputees early in their life with limb loss and, separately, after decades of living as an amputee may better describe motivations to be active at various stages across the life-course of an amputee. There may also be differences in the lived experiences of those that identify as being disabled and those that do not. Neither time since amputation or disability identity were explored in detail through this dissertation. The intersection of race and amputee identities as it

related to physical activity was not explored. The study disproportionately enrolled white participants despite the number of new amputees in the US who identify as Black being nearly four times that of white amputees. There is opportunity to better understand how multiply marginalized identities may influence opportunity or motivation to be active. Finally, building on embodiment findings, research should explore how the body is centered in experiences of amputees beyond LTPA.

Appendices

Appendix A Methods and Supplemental Results

A.1 Methods

Mixed methods research combines elements of both quantitative and qualitative approaches, for "broad purposes of breadth and depth of understanding" (Johnson et al., 2007 p.123). A mixed methods study aims to answer a central, primary question through examining multiple secondary questions and integrating and analyzing those results (see Chapter 1 detailed descriptions). This dissertation employed a sequential explanatory mixed methods design (Fig A.1) to develop a deeper understanding of amputees' motivations to be physically active. This is one of the three basic mixed methods research design types (Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015). In this design type, the qualitative component will be used to contextualize the results from the quantitative component. Quantitative data will be collected and analyzed first. Using those results, qualitative instruments will be developed and then data collected and analyzed. The final step is the integration of quantitative and qualitative components' data to answer the overarching mixed methods primary research question (Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015). This can be done in one of two ways for a sequential explanatory mixed methods study: embedded integration, in which the secondary research questions and methods are nested within the framework of the primary question; or connected integration, in which one data set is used to explain the other (Curry & Nunez-Smith, 2015). This dissertation analyzed the two components together through connected integration to emphasize the voices of participants to contextualize and explain the data from the quantitative component. Sequential

explanatory mixed methods design was ideal for this study because the results from the quantitative analysis helped shape the qualitative sampling, data collection, and analysis focus (Creswell & Plano Clark, 2018). It provided a deeper understanding of amputees' motivations to be active than either research methodology alone could address.

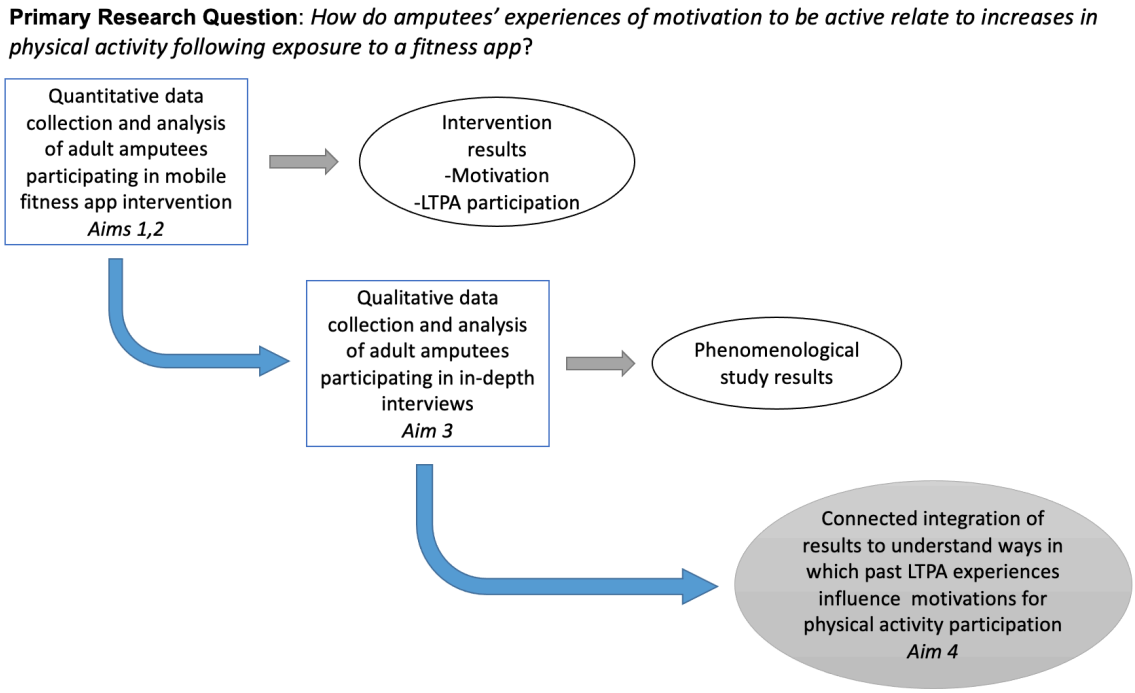

Figure A.1 Mixed Methods Study Design (adapted from Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015)

A.2 Description of Population

All participants were adults between the ages of 18 and 65 years with a major amputation – one that is at or proximal to the wrist or ankle. This age range was more likely to capture congenital and traumatically acquired amputations as well as those whose amputations were acquired through dysvascular causes, which happens later in life. In alignment with interdependent mixed methods sampling procedures, quantitative component results informed additional inclusion criteria to identify a purposive sample for the qualitative component. This maximized the explanatory findings from the

quantitative component (Creswell & Plano Clark, 2018; Curry & Nunez-Smith, 2015). The recruitment messaging used plain language and was direct, with details for where potential participants could seek further study information (Kenealy et al., 2015).

A.3 Phase 1: Quantitative Component

Phase 1 attempted to answer the secondary research question: How does use of a mobile fitness app that includes features related to basic psychological needs for physical activity (PA) predict changes in motivation to be physically active among amputees?

Qualtrics was used to randomize participants into intervention or comparison arm before showing the questionnaires for baseline data collection. Those randomized into the intervention arm received an instruction screen and follow-up email for accessing BurnAlong free of charge. Those randomized into the comparison arm were given a timeline to expect follow-up surveys and a date to expect BurnAlong access information. Participants were enrolled on a rolling basis to reduce the time between meeting inclusion criteria and accessing the app; however, all 257 participants were enrolled within one week of beginning outreach to Amputee Coalition support group leaders.

Previous studies have shown small to moderate effect sizes in interventions using SDT to promote PA (Ng et al., 2012; Silva et al., 2009). For the purposes of calculating the sample size required (α=.05; β=.2), a small effect size (d) of .20 was used (Cohen, 1977). Because there is no population data for amputees involved in PA interventions, Cohen's d, instead of difference in means divided by population standard deviation, was used to develop the intervention hypothesis used for sample size calculations: H_0: $d < .20$ and H_A: $d \geq .20$. Using G*Power to estimate the sample size for repeated measures ANOVA to detect an effect size of .20 or greater, the total required number of

participants for this study would be 126, 63 per study arm. Data analysis for Aim 1 was conducted using linear mixed effects model, a higher powered statistical test than ANOVA; however, sample size estimation for these statistical tests requires detailed knowledge about the sample characteristics to perform simulation studies so ANOVA estimates were used (Jung & Ahn, 2003; Liu & Liang, 1997). Previous LTPA interventions with disabled populations have recorded retention rates ranging from 49% to 91% (Kosma et al., 2012; Littman et al., 2018; Wegener et al., 2009). With such a wide range of retention rates, I estimated higher end of the range or total dropout of 50% of the sample. To account for dropout and loss to follow-up, my goal was to recruit at least 190 participants, 95 per study arm. Institutional Review Board (IRB) approved enrollment of 325 people, including the 38 people recruited prior to IRB amendment approval to recruit participants over the age of 45 (see Appendix L). Data from those 38 people are not included in this dissertation.

Initial quantitative data collection included a post intervention follow-up 12 weeks from the start of the intervention to assess retention of changes in motivation and PA level. A user error associated with scheduling email reminders resulted in participant IDs being reassigned at week 12. Because data were anonymized, there was no way to associate the week 12 data with previously collected data. Thirteen week 12 responses, six from the intervention group and 7 from the control group, were discarded and only data from the first three surveys were analyzed.

A.3.1 Additional information informing measure selection

The instrument that was used to collect motivation data was the Exercise Motivation Scale (EMS). A description of EMS can be found in Chapter 3 and the full instrument is

available in Appendix E. Convergent validity of EMS established by Li (1999) has been confirmed by Wininger (2007), showing largest correlations among subscales on the diagonal in an intercorrelations table of all subscales; that is, types of motivation were most highly correlated to other types of motivation nearest to them on the SDT motivation continuum (e.g. amotivation and externally regulated motivation). The analysis of simplex patterns in this table confirmed face validity such that adjacent subscales along the SDT motivation continuum correlated more positively than those most distant from each other on the continuum (Wininger, 2007). Discriminant validity has been examined for all subscales in relation to scores of social desirability bias. Seven of the eight subscales lacked any significant correlation with social desirability. The introjected regulation subscale had a correlation coefficient of -.20 at significance level p=.02. (Wininger, 2007). There were significant gender differences in motivation noted during EMS validation testing. Females reported higher levels of motivation on the autonomous end of the SDT motivation continuum (intrinsic motivation, integrated regulation, and identified regulation) and lower levels of motivation on the controlled end of the SDT motivation continuum (external regulation and amotivation) than their male counterparts (Li, 1999). It is worth noting that the EMS is designed to measure motivation toward exercise, not LTPA in general. BurnAlong provided opportunities for exercise as well as other form of LTPA such as mobility and yoga sessions.

The instrument used to collect data related to activity level was developed for measurement among populations with disabilities, i.e., the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Washburn et al., 2002). Principal component analysis resulted in five latent factors: (1) home repair and lawn and garden;

2) housework; 3) vigorous sport and recreation; 4) light sport and recreation; and 5) occupation and transportation). These explained 63% of total variance in physical activity self-reports (Washburn et al., 2002). PASIPD, as a self-report data collection tool, overestimates activity level when compared with accelerometers and other objective activity monitors (van den Berg-Emons et al., 2011). This is consistent with accepted physical activity measures based on recall in which the participant recalls greater levels of activity than objective instruments record. It is most useful for measuring change in activity rather than actual activity level.

The instrument used to measure general causality orientation was the General Causality Orientation Scale (GCOS) (Deci & Ryan, 1985b). This is a 12-vignette questionnaire in which each vignette offers three possible responses to the scenario. The responses are associated with the three subscales related to general causality orientation: autonomy, control, and impersonal (see Table 2.1). Participants will rank their likelihood to respond to the vignette scenario for each response option independently. Vignette responses will be ranked in a 7-point Likert-style format ranging from very unlikely to very likely; therefore, each subscale will have a 7-84 point range. The instrument has shown internal consistency and temporal stability across all subscales among 1,116 adults (the study identifies students, mothers, corporate employees, and cardiac patients as some of the participant groups) (Deci & Ryan, 1985b). Cronbach's alpha for the subscales were .74 for autonomy, .69 for control, and .74 for impersonal (Deci & Ryan, 1985b). Compared with other validated instruments measuring emotions, attitudes, and behaviors, GCOS showed construct validity as well (Deci & Ryan, 1985b).

A.3.2 Supplemental quantitative results

The dissertation examined data for 257 participants, randomized into two arms. Univariate analysis was run to examine the characteristics of the sample. Demographic variable categories (e.g. race, gender, education, employment, location of amputation; mechanism of amputation) were consolidated into fewer categories to facilitate statistical analyses. Equal distribution between groups were verified on age, gender, race/ethnicity, education level, employment status, extremity of amputation, mechanism of amputation, and length of time living with amputation using independent sample t-tests and χ^2 tests. As described in Chapter 3, there were no significant differences between groups at baseline or endline. At the conclusion of the study, baseline characteristics of dropouts were compared with those of completers to identify potential factors associated with attrition. To conduct attrition analysis, I created a binary variable for study drop out. T-tests and χ^2 tests were conducted to compare characteristics of those that left and those that remained. Table A.1 shows characteristics affected by differential loss to follow-up. In both groups, those with fewer years as an amputee, Black participants, below the knee amputees, congenital amputees, and individuals with impersonal or controlled orientations were less likely to remain.

Table A.1. Significant difference in demographic characteristics, within groups, due to loss to follow-up

	Waitlist Control mean (std dev) or n (%)		**Burnalong Intervention mean (std dev) or n (%)**	
	Baseline n=129	8-week n=16	Baseline n=128	8-week n=19
Age	35.84 (8.66)	42.44 (4.12)*	35.73 (7.80)	39.89 (5.84)
Time with Amputation	9.13 (11.24)	30.44 (16.09)*	8.96 (9.95)	28.79 (16.82)*
Race				
White or Caucasian	74 (57.36)	1 (6.25)*	65 (50.78)	4 (21.05)
Black or African American	40 (31.00)	15 (93.75)*	42 (32.81)	15 (78.95)*
All other races	15 (11.63)	0 (0.00)	21 (16.41)	0 (0.00)
Gender				
Man	83 (64.34)	9 (56.25)	77 (60.16)	10 (52.63)
Woman	42 (32.56)	7 (43.75)	49 (38.28)	9 (47.37)
All other genders	4 (3.10)	0 (0.00)	2 (1.56)	0 (0.00)
Education				
High school	24 (18.60)	0 (0.00)	25 (19.53)	0 (0.00)
Some college	22 (17.05)	4 (25.00)	21 (16.41)	11 (57.89)
Trade or vocational school	28 (21.71)	0 (0.00)	37 (28.91)	0 (0.00)*
Undergraduate or Graduate degree	55 (42.64)	12 (75.00)	45 (35.16)	8 (42.11)
Employment				
Employed full time	28 (21.71)	6 (37.50)	34 (26.56)	7 (36.84)
Employed part time	49 (37.98)	10 (62.50)	39 (30.47)	11 (57.89)
Out of work or retired	36 (27.91)	0 (0.00)	41 (32.03)	1 (5.26)*
Unable to work	16 (12.40)	0 (0.00)	14 (10.94)	0 (0.00)
Location of Amputation				
Upper – at or below elbow	33 (25.58)	0 (0.00)	32 (25.00)	2 (10.53)
Upper - above elbow	45 (34.88)	0 (0.00)*	37 (28.91)	1 (5.26)
Lower – at or below knee	36 (27.91)	16 (100.00)*	42 (32.81)	16 (84.21)*
Lower - above knee	15 (11.63)	0 (0.00)	17 (13.28)	0 (0.00)
Mechanism of Amputation				
Congenital	13 (10.08)	11 (68.75)*	11 (8.59)	13 (68.42)*
Acquired Trauma	76 (58.91)	5 (31.25)	80 (62.50)	2 (10.53)*
Acquired non-Trauma	40 (31.01)	0 (0.00)*	37 (28.91)	4 (21.05)
Impersonal Orientation	4.44 (0.83)	3.73 (0.65)*	4.54 (0.75)	3.96 (0.47)*
Controlled Orientation	4.49 (0.76)	3.92 (0.27)*	4.59 (0.68)	4.10 (0.41)*
Autonomy Orientation	4.65 (0.81)	4.13 (0.73)	4.72 (0.81)	4.19 (0.57)*

* indicates significant ($p<.05$) within group difference between baseline and 8 week surveys

Basic psychological needs (BPN) satisfaction data were evaluated as secondary outcomes. At baseline, there were significant differences between groups in level of relatedness satisfaction. There were no differences between groups in autonomy or competence satisfaction. Both groups had significant increases in mean level of competence satisfaction between the start and the end of the intervention. The intervention also showed significant decreases in mean relatedness satisfaction level.

Table A.2. Secondary outcome means comparison

	WLC Baseline (n=129)	**WLC 8-weeks (n=16)**	**BurnAlong Baseline (n=128)**	**BurnAlong 8-weeks (n=19)**
Basic Psychological Needs				
Autonomy	13.93 (2.75)	15.25 (2.24)	13.75 (2.36)	13.95 (2.30)
Competence	13.71 (2.42)	15.75 (1.61)**	13.28 (2.40)	15.05 (2.17)**
Relatedness*	13.55 (2.56)	12.44 (3.83)	14.16 (2.23)	12.16 (3.76)**

Note: t-test used to compare pre- and post-intervention means
* diff at baseline between groups
**significant change from baseline within groups

Separate linear mixed effects models were run using each of the BPN as outcomes, and controlling for race, education, employment status, location of amputation, mechanism of amputation, and time with amputation. There were no significant differences between groups for any BPN. Only change in relatedness in groups over time was statistically significant. The fixed effect estimates were small in nature and indicated relatedness among intervention group members decreased more than in the control group.

Table A.3. Mixed-effects conditional models: Secondary outcome variable Fixed Effect Estimates by Group over Time[a]

	Intervention (vs Waitlist Control)	**Time (changes across surveys)**	**Interaction (Group X Time)**
Basic Psychological Needs			
Autonomy	-.06	.01	-.01
Competence	-.50	.02**	-.02
Relatedness	.53	<-.01	-.02*

[a] Control variables: Race, Education, Employment, Location of Amputation, Mechanism of Amputation, Time with Amputation
*p<.05; **p<.01

The intraclass correlation coefficient (ICC) is used in mixed models to give a sense of how much variance is explained by a random effect (Table A.4). The ICC quantifies the degree of homogeneity of the outcome within individuals; that is the same person will have scores that are related to each other. The ICC represents the proportion of the between-group variation in the total variation of outcome variables. ICC was calculated first in an unconditional model; that is, a model with no predictor in the equation. Then models were built with only the intervention group as a predictor and no control variables included. This is the conditional model. Finally, control variables were added to the conditional models. The only random effect in these models is intercept; therefore, increases in ICC represent less variance explained by intervention and more by random effects.

Table A.4. Changes in ICC using final models

Variables	Unconditional Model	Conditional Model	Conditional Model w/controls	Difference
Motivation				
Amotivation	.49	.50	.50	.01
Extrinsic Motivation	.18	.50	.50	.32
Intrinsic Motivation	.01	.50	.50	.49
Physical Activity				
Total Activity	.12	.50	.50	.38
Total Exercise	.13	.50	.50	.37
Total LTPA	.11	.50	.50	.39
Basic Psychological Needs				
Autonomy	.06	.50	.50	.44
Competence	.02	.50	.50	.48
Relatedness	<.01	.50	.50	.49

A.4 Phase 2: Qualitative Component

Embodied phenomenology, as pioneered by Merleau-Ponty has been variously ascribed to descriptive or transcendental, interpretative or hermeneutic, and existential perspectives to understanding the body's role in a specific lived phenomenon (Kafle,

2011; Skea & Cert, 2016). Merleau-Ponty describes the embodied way in which people are able to interact and understand the world and objects within it as also a "normal means of knowing other bodies" (Gallagher, 2007, p.257). From this perspective, it is impossible to bracket my own experiences of training amputees, my participation in LTPA, and my interactions with adaptive athletes both socially and professionally. Instead, regular and thorough reflexive journal entries recorded how my experiences defined the lens through which this dissertation was conducted and data analyzed. The intentional evaluation and acknowledgement of my relationship to the study topics resulted in a more critical analysis and ensured member reflections were taken into account.

A.4.1 Data Collection COVID-19 Modifications

Institutional Review Board approval for Phase 2 was received in May of 2020, amidst the early months of the COVID-19 global pandemic. Phase 2 approval was received in June of 2021 as a surge of COVID-19 infections and hospitalizations began in the US. As a result of CDC recommendations to remain physically distanced, University of Maryland (UMD) restricted in-person data collection. My original plan was to conduct two in-person interviews to collect data for an embodied phenomenological analysis. The first interview would have been to better understand experiences as an amputee and as an amputee engaged in physical activity. The second would have incorporated participant observation, and engaging in activity with the participant to capture the embodied nature of preparing to and engaging in physical activity. After additional literature review, I proposed Zoom interviews augmented by a participant photo-diary of a single physical activity. The first interview purpose remained unchanged. Between the first and the

second interview, participants were be asked to document a leisure time physical activity of their choice, from decision to participate through end of activity or subsequent decision not to engage. The second interview integrated photo-elicitation interviewing to better understand the images captured and how motivation to be active was embodied by the participant. Proposed incentives and sample size did not change. It was important to me to find a method that would not make participants the object of my gaze, but remained as close to the original participatory observation as possible. PwD are frequently othered, objectified, and researched upon rather than being part of the co-construction of research and findings (Cork et al., 2019; Ouellette, 2019; Richards, 2008). I felt having them share a video of them being active would preserve ableist research norms. In the photo-diary plus photo-elicitation method, participants have control of what I see of them and we could revisit the experience together through photo-elicitation interview techniques.

A.4.2 Expansion on Quality and Rigor

In qualitative research, dependability and credibility are used in place of quantitative measures of reliability and internal validity. Dependability is the degree to which researchers record, account for, and describe the changing circumstances that may influence participant responses or reactions (Curry & Nunez-Smith, 2015). Credibility describes the degree to which the findings present a true picture of the phenomenon and includes alternative explanations and degree of correspondence between researcher and participant portrayal of the phenomenon (Curry & Nunez-Smith, 2015; Shenton, 2004).

It is impossible to achieve theory-free knowledge; that is, to separate researchers' experiences from the data (Smith et al., 2009; Smith & McGannon, 2017). However, it is

possible to increase awareness of the influence of the researcher on the research through deliberate and in-depth reflexivity. Before research began, I started the reflexive notes journal, spending time contemplating and recording personal and professional relationship with the topic, participants, and research.

Prolonged engagement with the phenomenon being studied and the group experiencing it enhances rigor of IPA. For this study, prolonged engagement was achieved through interviewing participants multiple times and by including a prolonged analysis period to immerse myself in the audio recordings, transcripts, and my own journals. The audit trail is the final strategy used to promote dependability and credibility and enable future process and data verification. The audit trail includes: initial notes; step by step methods for recruitment, data collection and analysis; annotated transcripts; tables of themes that developed; the final report; and all field notes (Smith et al., 2009).

A.4.3 Supplemental qualitative results

Although not reported in Chapter 4, an additional theme was developed during IPA related to disability identity. Participants were evenly split as to whether they identified as disabled or not. They all acknowledged their amputation would result in others seeing them as a person with a disability, but they did not all see themselves as disabled. Identity was directly tied to how they themselves perceived disability. Those that focused on loss of function or ability in the definition did not identify as disabled. Those that viewed disability as a condition that required adaptation, interpersonal support, or accessibility accommodations were more comfortable identifying as disabled. This distinction is a basis for future research related to internalized ableism, disability stigma, and implications for identity.

Table A.5 IPA developed Themes not previously reported

Superordinate Theme	Subordinate Theme
Relationship to disability identity is directly related to definition of disability	Those who do not identify as disabled regard disability as an inability to perform ADL regardless of adaptation options
	Those who do identify as disabled regard disability as a continuum of limitations related to reduced autonomy

A.5 Phase 3: Integration of Data

The motivation to be active among amputees is a multifaceted phenomenon. The in-depth interviews enhanced interpretation of longitudinal survey results and captured amputees' experiences related to LTPA motivation. The mixed methods approach also incorporated the voices of amputees in the collection and interpretation of data. The study was integrated at the design level; this dissertation was conceptualized from the start as an explanatory sequential design (Fetters et al., 2013). It was integrated at the methods level through connected integration in which quantitative data were linked to qualitative data through sampling (Creswell & Plano Clark, 2018; Fetters et al., 2013). Finally, data were integrated in their interpretation and reporting using a contiguous approach to integration through narrative in Chapter 5 (Fetters et al., 2013).

A.5.1 Supplemental results

App quality data for lower extremity amputees were analyzed but not reported in Chapter 5. Participant perception of overall app quality was collected at endline in the intervention group only. Thirteen of 16 participants completed the app quality questionnaire. Bivariate correlations were run using Pearson's Product-Moment Correlation (Table A.6). There were significant correlations between app quality and total PA, extrinsic, and intrinsic motivation, but not with amotivation. There were also significant correlations between app quality and the basic psychological needs of

autonomy and relatedness, but not exercise competence. All significant correlations were positive. The degree of loss to follow-up makes it difficult to draw conclusions based on these analyses. The results may suggest the app is well designed and contains content for amputees that satisfies choice and connection with others while increasing motivation; or it may suggest that only those who had positive perceptions of the app remained in the study.

Table A.6 App Quality (n=13) correlation with BPN satisfaction and outcome measures

	Amotiva-tion	**Extrinsic Motiva-tion**	**Intrinsic Motiva-tion**	**Total PA**	**Auton-omy**	**Related-ness**	**Compe-tence**
App Quality	-.526	.746**	.553*	.769**	.621*	.649*	.516
p=valu e	.065	.003	.050	.002	.023	.016	.071

*$p \leq .05$; **$p < .0$

In addition to unreported app quality, a visual display of IPA themes was created to support integration. The word cloud in Figure A.2 represents key words associated with the themes developed in Chapters 4 and 5. The size of the word is correlated to the frequency used by participants in the interviews. The color of the word represents the theme context in which the word was used rather than any unrelated connotation. For instance, disability was used to describe the need for adaptations as part of the process to be active while disabled was most used to describe a barrier to LTPA. At a glance, there are numerous orange words, visually representing the influence of processes on participant's engagement in LTPA. The relative size of "friend", "people", and "daughter" (all participants with living children had daughters) represent the importance of relatedness in LTPA participation.

Figure A.2. Word cloud of thematic related terms used by participants during in-depth interviews. Colors connote context in which the term was most frequently used. Purple words are relatedness terms; dark blue = body terms; green = activity; orange = process; pink = positive or intrinsic motivation; red = barriers; light blue = prosthesis / mobility device

A.6 Protection of Human Subjects

People with amputations are not only a hard-to-reach population, but as persons with likely disabilities, these participants also fall into the research classification of vulnerable populations. IRB approval of the study, incentives and consent wording were obtained before recruitment began (Appendix L). Informed consent detailed the option to stop participating at any point without repercussions. Even though Amputee Coalition facilitated recruitment, no chapter, support group, or national leaders were informed of an individual's decision to participate. The decision to participate or remain in the program had no bearing on future relationships or benefits of partner organization offerings.

Participants in both the first two phases of the study were offered incentives. Phase 1 participants were provided 3-month subscriptions to BurnAlong ($44.97 value) - at no cost to them - to be used during the study or after, depending on the group they were randomized into. They were also offered a $10 for completing all surveys. Phase 2 participants were compensated for their time: $25 for the first interview (~ equivalent of two hours highest minimum wage in the geographic area where recruitment occurred) and $35 for the second interview, to account for possible local travel to participate in PA during the interview. Compensation was offered in the form of an e-gift card to Walmart, Target, or Amazon, based on the participant's preference. Both phases began with tailored informed consent forms.

Identifiable data for both phases were kept separate from data used in analysis. During the screening survey collecting baseline data in Phase 1, all participants were assigned a participant ID which used for the remainder of survey-based data collection. All survey data was collected through the Qualtrics tool and password protected. Phase 2 required the collection of contact information for follow-up interviews. Participants selected their own pseudonym for the interviews such that transcriptions of audio recordings did not identify the participant. Interviews audio recordings were outsourced for transcription to Rev, then cleaned, and stored in a password protected folder on my computer. The contracted transcription company (Rev) has mechanisms in place to protect data and agrees to remove all audio and text files from their servers at the request of the researcher. Identifying data collected during both phases were stored in a standalone, password protected file on my computer, which is biometrically protected, and destroyed at the completion of the study.

Appendix B: Phase 1 Quantitative Component Inclusion Screening Survey

Study Description Thank you for agreeing to participate in this study. The next several pages will gather demographic information about you as well as some baseline activity and motivation information. This should take you about 25 minutes.
Once complete the survey, you will either be directed to a website to set up your fitness app account or you will be provided information about the next survey date and when you will get app access.

How old are you?

Are you of Hispanic, Latino, or of Spanish origin?

- ○ Yes
- ○ No

How would you describe yourself?

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White or Caucasian
- ☐ Other

To which gender identity do you most identify?

- ○ Man
- ○ Woman
- ○ Transgender Man
- ○ Transgender Woman
- ○ Gender Non-Conforming
- ○ Not Listed
- ○ Prefer Not to Answer

What is the highest degree or level of school you have completed? If currently enrolled, highest degree previously received.

- ○ Grade school
- ○ Some high school
- ○ High school graduate, diploma, or equivalent (e.g. GED)
- ○ Some college
- ○ Trade, technical, or vocational training
- ○ Bachelor's degree
- ○ Master's degree
- ○ Professional degree
- ○ Doctorate degree

What is your employment status?

- ○ Employed full time
- ○ Employed part time
- ○ Out of work and looking for work
- ○ Out of work and not looking for work
- ○ Unable to work
- ○ Student
- ○ Military
- ○ Retired

Do you have an upper or lower limb amputation?

- ○ Upper - below the elbow
- ○ Upper - above the elbow
- ○ Upper - elbow disarticulation
- ○ Upper - shoulder disarticulation
- ○ Lower - below the knee

- ○ Lower - above the knee
- ○ Lower - knee disarticulation
- ○ Lower - hip disarticulation

What was the mechanism or cause of amputation?

- ○ Congenital - I was born without my limb
- ○ Acquired - The amputation was caused by trauma (e.g. car accident or injury)
- ○ Acquired - The amputation was the result of surgery (e.g. infection or tumor in bone or muscle)
- ○ Acquired - The amputation was secondary to another underlying health condition (e.g. diabetes or vascular disease)

What is the length of time, in years, you have been living with an amputation? (If the amputation is congenital, please type your age)

Do you currently experience pain or discomfort during exercise?
***Reminder: If experience pain or your health changes cease exercise and tell your health professional. Ask them whether you should change your physical activity plan. Regardless, you may continue with this study.

- ○ Yes
- ○ No

At any point in your life, have you experienced an exercise-related injury that resulted in medical care or reduction in physical activity?

- ○ Yes
- ○ No

In the last 4 weeks, have you experienced an exercise-related injury that resulted in medical care or reduction in physical activity?
***Reminder: If experience pain or your health changes cease exercise and tell your health professional. Ask them whether you should change your physical activity plan. Regardless, you may continue with this study.

- ○ Yes
- ○ No

Appendix C: General Causality Orientation Scale

These items pertain to a series of hypothetical sketches. Each sketch describes an incident and lists three ways of responding to it. Please read each sketch, imagine yourself in that situation, and then consider each of the possible responses. Think of each response option in terms of how likely it is that you would respond that way. (We all respond in a variety of ways to situations, and probably most or all responses are at least slightly likely for you.) If it is very unlikely that you would respond the way described in a given response, you should circle answer 1 or 2. If it is moderately likely, you would select a number in the mid-range e.g. 4, and if it is very likely that you would respond as described, you would circle answer 6 or 7.

1	2	3	4	5	6	7
very unlikely			moderately likely			very likely

1. You have been offered a new position in a company where you have worked for some time. The first question that is likely to come to mind is:
a) What if I can't live up to the new responsibility?
b) Will I make more at this position?
c) I wonder if the new work will be interesting.

2. You have a school-age daughter. On parents' night the teacher tells you that your daughter is doing poorly and doesn't seem involved in the work. You are likely to:
a) Talk it over with your daughter to understand further what the problem is.
b) Scold her and hope she does better.
c) Make sure she does the assignments, because she should be working harder.

3. You had a job interview several weeks ago. In the mail you received a form letter which states that the position has been filled. It is likely that you might think:
a) It's not what you know, but who you know.
b) I'm probably not good enough for the job.
c) Somehow they didn't see my qualifications as matching their needs.

4. You are a plant supervisor and have been charged with the task of allotting coffee breaks to three workers who cannot all break at once. You would likely handle this by:
a) Telling the three workers the situation and having them work with you on the schedule.
b) Simply assigning times that each can break to avoid any problems.
c) Find out from someone in authority what to do or do what was done in the past.

5. A close (same-sex) friend of yours has been moody lately, and a couple of times has become very angry with you over "nothing." You might:

a) Share your observations with him/her and try to find out what is going on for him/her.
b) Ignore it because there's not much you can do about it anyway.
c) Tell him/her that you're willing to spend time together if and only if he/she makes more effort to control him/herself.

6. You have just received the results of a test you took, and you discovered that you did very poorly. Your initial reaction is likely to be:
a) "I can't do anything right," and feel sad.
b) "I wonder how it is I did so poorly," and feel disappointed.
c) "That stupid test doesn't show anything," and feel angry.

7. You have been invited to a large party where you know very few people. As you look forward to the evening, you would likely expect that:
a) You'll try to fit in with whatever is happening in order to have a good time and not look bad.
b) You'll find some people with whom you can relate.
c) You'll probably feel somewhat isolated and unnoticed.

8. You are asked to plan a picnic for yourself and your fellow employees. Your style for approaching this project could most likely be characterized as:
a) Take charge: that is, you would make most of the major decisions yourself.
b) Follow precedent: you're not really up to the task so you'd do it the way it's been done before.
c) Seek participation: get inputs from others who want to make them before you make the final plans.

9. Recently a position opened up at your place of work that could have meant a promotion for you. However, a person you work with was offered the job rather than you. In evaluating the situation, you're likely to think:
a) You didn't really expect the job; you frequently get passed over.
b) The other person probably "did the right things" politically to get the job.
c) You would probably take a look at factors in your own performance that led you to be passed over.

10.You are embarking on a new career. The most important consideration is likely to be:
a) Whether you can do the work without getting in over your head.
b) How interested you are in that kind of work.
c) Whether there are good possibilities for advancement.

11. A woman who works for you has generally done an adequate job. However, for the past two weeks her work has not been up to par and she appears to be less actively interested in her work. Your reaction is likely to be:
a) Tell her that her work is below what is expected and that she should start working harder.
b) Ask her about the problem and let her know you are available to help work it out.
c) It's hard to know what to do to get her straightened out.

12. Your company has promoted you to a position in a city far from your present location. As you think about the move you would probably:
a) Feel interested in the new challenge and a little nervous at the same time.
b) Feel excited about the higher status and salary that is involved.
c) Feel stressed and anxious about the upcoming changes.

KEY:
A = Autonomy; C = Control; I = Impersonal

1. a. I	2. a. A	3. a. C	4. a. A
b. C	b. I	b. I	b. C
c. A	c. C	c. A	c. I
5. a. A	6. a. I	7. a. C	8. a. C
b. I	b. A	b. A	b. I
c. C	c. C	c. I	c. A
9. a. I	10. a. I	11. a. C	12. a. A
b. C	b. A	b. A	b. C
c. A	c. C	c. I	c. I

Appendix D: Basic Psychological Needs Satisfaction Scale

Instructions. The following sentences refer to your overall experiences in exercise as opposed to any particular situation. Using the 1-5 scale below, please indicate the extent to which you agree with these statements by circling one number for each statement.

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

1. I feel I have made a lot of progress in relation to the goal I want to achieve.

2. The way I exercise is in agreement with my choices and interests.

3. I feel I perform successfully the activities of my exercise program.

4. My relationships with the people I exercise with are very friendly.

5. I feel that the way I exercise is the way I want to.

6. I feel exercise is an activity which I do very well.

7. I feel I have excellent communication with the people I exercise with.

8. I feel that the way I exercise is a true expression of who I am.

9. I am able to meet the requirements of my exercise program.

10. My relationships with the people I exercise with are close.

11. I feel that I have the opportunity to make choices with regard to the way I exercise

12. I feel comfortable with the people I exercise with

Key.
Autonomy: items 2, 5, 8, 11;
Competence: items 1, 3, 6, 9;
Relatedness: items 4, 7, 10, 12

Appendix E: Exercise Motivation Scale

Instructions: The following is a list of reasons why people exercise. Please read each of the statements listed below. Considering your primary sport/exercise, indicate how strongly you agree or disagree with each statement as it pertains to you.

1	2	3	4	5	6
Strongly Disagree					Strongly Agree

___ 1. For the pleasure it gives me to experience positive sensations from the activity.
___ 2. For the satisfaction it gives me to increase my knowledge about this activity.
___ 3. Because other people believe that it's a good idea for me to exercise.
___ 4. Because I must exercise to feel good about myself.
___ 5. Because I believe that regular exercise is a good way to enhance my overall development.
___ 6. Because it is consistent with what I value.
___ 7. I can't understand why I am doing this.
___ 8. Because I feel pressure from others to participate.
___ 9. Because I think that exercise allows me to feel better about myself.
___ 10. For the pleasure I experience while learning about this activity.
___ 11. For the satisfaction I feel when I get into the flow of this activity.
___ 12. Because I feel I have to do it.
___ 13. To satisfy people who want me to exercise.
___ 14. Because exercising is an important aspect of how I perceive myself.
___ 15. For the pleasure of understanding this activity.
___ 16. I have no idea.
___ 17. For the pleasure of mastering this activity.
___ 18. Because I think it is a good thing for my personal growth.
___ 19. For the pleasure I experience when I feel completely absorbed in the activity.
___ 20. For the satisfaction I feel while I try to achieve my personal goals during the course of this activity.
___ 21. Because I would feel guilty if I did not take the time to do it.
___ 22. Because I value the way exercise allows me to make changes in my life.
___ 23. It is not clear to me anymore.
___ 24. Because I think exercise contributes to my health.
___ 25. To comply with expectations of others (e.g., friends).
___ 26. For the enjoyment that comes from how good it feels to do the activity.
___ 27. Because I enjoy the feelings of discovering more about this activity.
___ 28. Because I enjoy the feelings of improving through participating in this activity.
___ 29. Because I feel that changes that are taking place through exercise are becoming part of me.

___ 30. For the pleasure I experience while trying to become the person I want to be.
___ 31. Because I would feel ashamed if I was not doing anything to improve my current situation.

Key:
Amotivation: 7, 16, 23
External regulation: 3, 8, 13, 25
Introjected regulation: 4, 12, 21, 31
Identified regulation: 5, 9, 18, 24
Integrated regulation: 6, 14, 22, 29
Intrinsic Motivation to Learn: 2, 10, 15, 27
Intrinsic Motivation to Accomplish Tasks: 17, 20, 28, 30
Intrinsic Motivation to Experience Sensation: 1, 11, 19, 26

Scoring: Items are summed for each subscale to provide three separate scores for individual psychological needs satisfaction. Subscales are related based on SDT construct of a continuum of motivation. A participant would be expected to score high on one subscale and progressively lower on those subscales at further distance along the continuum.

Appendix F: Physical Activity Scale for Individuals with Physical Disabilities

Instructions: This questionnaire is about your current level of physical activity and exercise. Please remember there are no right or wrong answers. We simply need to assess your current level of activity.

Leisure Time Activity

1. During the past 7 days how often did you engage in stationary activities such as reading, watching TV, computer games, or doing handcrafts?
    a) Never (Go to question #2)
    b) Seldom (1–2days)
    c) Sometimes (3–4days)
    d) Often (5–7days)

What were these activities? _____

On average, how many hours per day did you spend in these stationary activities?
    a) Less than 1hr
    b) 1 but less than 2hr
    c) 2–4hr
    d) More than 4hr

2. During the past 7 days, how often did you walk, wheel, push outside your home other than specifically for exercise. For example, getting to work or class, walking the dog shopping, or other errands?
    a) Never (Go to question #3)
    b) Seldom (1–2days)
    c) Sometimes (3–4days)
    d) Often (5–7days)

On average, how many hours per day did you spend walking, wheeling or pushing outside your home?
    a) Less than 1hr
    b) 1 but less than 2hr
    c) 2–4hr
    d) More than 4hr

3. During the past 7 days, how often did you engage in light sport or recreational activities such as bowling, golf with a cart, hunting or fishing, darts, billiards or pool, therapeutic exercise (physical or occupational therapy, stretching, use of a standing frame) or other similar activities?
    a) Never (Go to question #4)
    b) Seldom (1–2days)
    c) Sometimes (3–4days)

d) Often (5–7days)

What were these activities? _____

On average, how many hour per day did you spend in these light sport or recreational activities?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

4. During the past 7 days, how often did you engage in moderate sport and recreational activities such as doubles tennis, softball, golf without a cart, ballroom dancing, wheeling or pushing for pleasure or other similar activities?

a) Never (Go to question #5)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

What were these activities? _____

On average, how many hours per day did you spend in these moderate sport and recreational activities?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

5. During the past 7 days, how often did you engage in strenuous sport and recreational activities such as jogging, wheelchair racing (training), off-road pushing, swimming, aerobic dance, arm cranking, cycling (hand or leg), singles tennis, rugby, basketball, walking with crutches and braces, or other similar activities

a) Never (Go to question #6)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

What were these activities? _____

On average, how many hours per day did you spend in these strenuous sport or recreational activities?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

6. During the past 7 days, how often did you do any exercise specifically to increase muscle strength and endurance such as lifting weights, push-ups, pull-ups, dips, or wheelchair push-ups, etc?

a) Never (Go to question #7)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

What were these activities? _____

On average, how many hours per day did you spend in these exercises to increase muscle strength and endurance?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

Household Activity

7. During the past 7 days, how often have you done any light housework, such as dusting, sweeping floors or washing dishes?

a) Never (Go to question #8)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend doing light housework?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

8. During the past 7 days, how often have you done any heavy housework or chores such as vacuuming, scrubbing floors, washing windows, or walls, etc?

a) Never (Go to question #9)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend doing heavy housework or chores?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

9. During the past 7 days, how often you done home repairs like carpentry, painting, furniture refinishing, electrical work, etc?

a) Never (Go to question #10)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend doing home repairs?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

10. During the past 7 days how often have you done lawn work or yard care including mowing, leaf or snow removal, tree or bush trimming, or wood chopping, etc?

a) Never (Go to question #11)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend doing lawn work?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

11. During the past 7 days, how often have you done outdoor gardening?

a) Never (Go to question #12)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend doing outdoor gardening?

a) Less than 1hr
b) 1 but less than 2 hr
c) 2–4hr
d) More than 4hr

12. During the past 7 days, how often did you care for another person, such as children, a dependent spouse, or another adult?

a) Never (Go to question #13)
b) Seldom (1–2days)

c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend caring for another person?

a) Less than 1hr
b) 1 but less than 2hr
c) 2–4hr
d) More than 4hr

Work-Related Activity

13. During the past 7 days, how often did you work for pay or as a volunteer? (Exclude work that mainly involved sitting with slight arm movement such as light office work, computer work, light assembly line work, driving bus or van, etc.)

a) Never (Go to END)
b) Seldom (1–2days)
c) Sometimes (3–4days)
d) Often (5–7days)

On average, how many hours per day did you spend working for pay or as a volunteer?

a) Less than 1hr
b) 1 but less than 4hr
c) 5 but less than 8hr
d) 8hr or more

Scoring: PASIPD Item multipliers

1. Not scored
2. 2.5
3. 3.0
4. 4.0
5. 8.0
6. 5.5
7. 1.5
8. 4.0
9. 4.0
10. 4.0

11 4.0

12. 1.5
13. 2.5

Average Hours Per Day Calculation for Items 2–12

Category	Reported (hr/d)	Average (hr/d)
Seldom (1–2d)	<1	.11

	1–2	.32
	2–4	.64
	>4	1.07
Sometimes (3–4d)	<1	.25
	1–2	.75
	2–4	1.50
	>4	2.50
Often (5–7d)	>1	.43
	1–2	1.29
	2–4	2.57
	>4	4.29

Average Hours Per Day Calculation for Item 13

Category	Reported (hr/d)	Average (hr/d)
Seldom (1–2d)	<1	.12
	1–4	.64
	5–8	1.39
	>8	1.93
Sometimes (3–4d)	<1	.28
	1–4	1.5
	5–8	3.11
	>8	4.5
Often (5–7d)	<1	.49
	1–4	2.57
	5–8	5.57
	>8	7.71

Appendix G: Mobile Application Rating Scale: user version (uMARS)

Circle the number that most accurately represents the quality of the app you are rating. All items are rated on a 5-point scale from "1.Inadequate" to "5.Excellent". Select N/A if the app component is irrelevant.

SECTION A

1. Entertainment: Is the app fun/entertaining to use? Does it have components that make it more fun than other similar apps?
    a. Dull, not fun or entertaining at all
    b. Mostly boring
    c. OK, fun enough to entertain user for a brief time (< 5 minutes)
    d. Moderately fun and entertaining, would entertain user for some time (5-10 minutes total)
    e. Highly entertaining and fun, would stimulate repeat use

2. Interest: Is the app interesting to use? Does it present its information in an interesting way compared to other similar apps?
    a. Not interesting at all
    b. Mostly uninteresting
    c. OK, neither interesting nor uninteresting; would engage user for a brief time (< 5 minutes)
    d. Moderately interesting; would engage user for some time (5-10 minutes total)
    e. Very interesting, would engage user in repeat use

3. Customization: Does it allow you to customize the settings and preferences that you would like to (e.g. sound, content and notifications)?
    a. Does not allow any customization or requires setting to be input every time
    b. Allows little customization and that limits app's functions
    c. Basic customization to function adequately
    d. Allows numerous options for customization
    e. Allows complete tailoring the user's characteristics/preferences, remembers all settings

4. Interactivity: Does it allow user input, provide feedback, contain prompts (reminders, sharing options, notifications, etc.)?
    a. No interactive features and/or no response to user input
    b. Some, but not enough interactive features which limits app's functions
    c. Basic interactive features to function adequately
    d. Offers a variety of interactive features, feedback and user input options
    e. Very high level of responsiveness through interactive features, feedback and user input options

5. Target group: Is the app content (visuals, language, design) appropriate for the target audience?
    a. Completely inappropriate, unclear or confusing

b. Mostly inappropriate, unclear or confusing
c. Acceptable but not specifically designed for the target audience. May be inappropriate/ unclear/confusing at times
d. Designed for the target audience, with minor issues
e. Designed specifically for the target audience, no issues found

SECTION B

6. Performance: How accurately/fast do the app features (functions) and components (buttons/menus) work?

a. App is broken; no/insufficient/inaccurate response (e.g. crashes/bugs/broken features, etc.)
b. Some functions work, but lagging or contains major technical problems
c. App works overall. Some technical problems need fixing, or is slow at times
d. Mostly functional with minor/negligible problems
e. Perfect/timely response; no technical bugs found, or contains a 'loading time left' indicator (if relevant)

7. Ease of use: How easy is it to learn how to use the app; how clear are the menu labels, icons and instructions?

a. No/limited instructions; menu labels, icons are confusing; complicated
b. Takes a lot of time or effort
c. Takes some time or effort
d. Easy to learn (or has clear instructions)
e. Able to use app immediately; intuitive; simple (no instructions needed)

8. Navigation: Does moving between screens make sense; Does app have all necessary links between screens?

a. No logical connection between screens at all /navigation is difficult
b. Understandable after a lot of time/effort
c. Understandable after some time/effort
d. Easy to understand/navigate
e. Perfectly logical, easy, clear and intuitive screen flow throughout, and/or has shortcuts

9. Gestural design: Do taps/swipes/pinches/scrolls make sense? Are they consistent across all components/screens?

a. Completely inconsistent/confusing
b. Often inconsistent/confusing
c. OK with some inconsistencies/confusing elements
d. Mostly consistent/intuitive with negligible problems
e. Perfectly consistent and intuitive

SECTION C

10. Layout: Is arrangement and size of buttons, icons, menus and content on the screen appropriate?

a. Very bad design, cluttered, some options impossible to select, locate, see or read

b. Bad design, random, unclear, some options difficult to select/locate/see/read
c. Satisfactory, few problems with selecting/locating/seeing/reading items
d. Mostly clear, able to select/locate/see/read items
e. Professional, simple, clear, orderly, logically organized

11. Graphics: How high is the quality/resolution of graphics used for buttons, icons, menus and content?

a. Graphics appear amateur, very poor visual design - disproportionate, stylistically inconsistent
b. Low quality/low resolution graphics; low quality visual design – disproportionate
c. Moderate quality graphics and visual design (generally consistent in style)
d. High quality/resolution graphics and visual design – mostly proportionate, consistent in style
e. Very high quality/resolution graphics and visual design - proportionate, consistent in style throughout

12. Visual appeal: How good does the app look?

a. Ugly, unpleasant to look at, poorly designed, clashing, mismatched colors
b. Bad – poorly designed, bad use of colour, visually boring
c. OK – average, neither pleasant, nor unpleasant
d. Pleasant – seamless graphics – consistent and professionally designed
e. Beautiful – very attractive, memorable, stands out; use of color enhances app features/menus

SECTION D

13. Quality of information: Is app content correct, well written, and relevant to the goal/topic of the app?

a. N/A There is no information within the app
b. Irrelevant/inappropriate/incoherent/incorrect
c. Poor. Barely relevant/appropriate/coherent/may be incorrect
d. Moderately relevant/appropriate/coherent/and appears correct
e. Relevant/appropriate/coherent/correct
f. Highly relevant, appropriate, coherent, and correct

14. Quantity of information: Is the information within the app comprehensive but concise?

a. N/A There is no information within the app
b. Minimal or overwhelming
c. Insufficient or possibly overwhelming
d. OK but not comprehensive or concise
e. Offers a broad range of information, has some gaps or unnecessary detail; or has no links to more information and resources
f. Comprehensive and concise; contains links to more information and resources

15. Visual information: Is visual explanation of concepts – through charts/graphs/images/videos, etc. – clear, logical, correct?

a. N/A There is no visual information within the app (e.g. it only contains audio, or text)
b. Completely unclear/confusing/wrong or necessary but missing
c. Mostly unclear/confusing/wrong
d. OK but often unclear/confusing/wrong
e. Mostly clear/logical/correct with negligible issues
f. Perfectly clear/logical/correct

16. Credibility of source: does the information within the app seem to come from a credible source?
a. N/A There is no information within the app
b. Suspicious source
c. Lacks credibility
d. Not suspicious but legitimacy of source is unclear
e. Possibly comes from a legitimate source
f. Definitely comes from a legitimate/specialized source

SECTION E

17. Would you recommend this app to people who might benefit from it?
a. Not at all I would not recommend this app to anyone
b. There are very few people I would recommend this app to
c. Maybe There are several people I would recommend this app to
d. There are many people I would recommend this app to
e. Definitely I would recommend this app to everyone

18. How many times do you think you would use this app in the next 12 months if it was relevant to you?
a. None
b. 1-2
c. 3-10
d. 10-50
e. >50

19. Would you pay for this app?
a. Definitely not
b.
c. Maybe
d.
e. Definitely yes

20. What is your overall (star) rating of the app?
a. ★ One of the worst apps I've used
b. ★★
c. ★★★ Average
d. ★★★★

e. ★★★★★ One of the best apps I've used

SECTION F

21. Awareness – This app has increased my awareness of the importance of addressing the health behavior

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

22. Knowledge – This app has increased my knowledge/understanding of the health behavior

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

23. Attitudes – The app has changed my attitudes toward improving this health behavior

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

24. Intention to change – The app has increased my intentions/motivation to address this health behavior

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

25. Help seeking – This app would encourage me to seek further help to address the health behavior (if I needed it)

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

26. Behavior change – Use of this app will increase/decrease the health behavior

1	2	3	4	5
I don't agree at all	I agree a little bit	I somewhat agree	I agree a lot	I completely agree

27. Please provide any further comments about the app

Scoring
A: Engagement Mean Score = _____
B: Functionality Mean Score = _____
C: Aesthetics Mean Score = _____
D: Information Mean Score* = _____
App quality mean score = A + B + C + D / 4 = _____
* Exclude questions rated as "N/A" from the mean score calculation.

Appendix H: Phase 2 Phone Screener Script

Date:_____

Introduction:
Thank you for agreeing to talk with me today. I will take notes as we talk but will not be recording this session.

This is a phone screener prior to more in-depth interviews about your experiences being active and motivation to be active. This conversation should take between 5 and 10 minutes.

The purpose of our time today is to verify you meet the pre-determined inclusion criteria for the study and your interest in participating. If there is a fit with the study and you remain interested, we will schedule two longer interviews using zoom that will take 60-90 minutes.

Do you have any questions before we get started? Please feel free to stop me and ask questions at any time as well.

Demographics:
We will start with basic information about you and your amputation.
Age:_____ (must be 18-65)
Are you currently under the care of a physician?_____ (**if yes, thank and dismiss**)
Are you a single limb amputee?_____ (**if no, thank and dismiss**)
Is your amputation qualified as "major"?_____ (**if no, thank and dismiss**)
[define "major" for individual; major = above the wrist or above the ankle]
This is an extension of a fitness app study conducted last fall. Did you participate in that study?
_____ (**if yes, thank and dismiss**)

Activity:
The next set of questions will ask about your regular leisure time physical activity. When I say leisure time physical activity, I am talking about physical activities that are not required as essential activities of daily living or related to transportation or occupational activities. These would include organized sports, exercising, gardening, recreational walking or biking.

Do you participate in any leisure time physical activity?_____
If so, how frequently?_____
[prompt for daily, a few times per week, weekly, monthly, infrequently]

Whether or not you are regularly active, do you find yourself motivated or interested in participating in leisure time physical activity?_____

(must have yes to first or second question; **if no to both, thank and dismiss**)

Rich Description screener:
For the last question, please tell me about a recent grocery shopping experience.
[looking for 2-3 detailed sentences without needing prompting]

Invitation and Research description:
Thank you; it would be my honor to include your experiences in this study. This study will involve 2 interviews. Both interviews will be hosted through zoom and recorded so the transcripts can be analyzed. The first one will be focused on your experiences as an amputee as well as your experiences being active. The second interview will be scheduled for a week or two later. In between the interviews, you will be asked to create a photo diary of one experience being active. During the second interview, we will use a method called photo elicitation that will allow you to take me back to the activity in your pictures and describe your experience. Participants will be offered $25 for the first interview and $35 for the second interview as incentives for participating in the study and to compensate them for their time and efforts. I have a few more logistics questions about participating in this study.

Do you have access to a computer with a camera and internet connection for later interviews?
_____ **(if no, thank and dismiss)**
Do you have access to a camera and the ability to email pictures for discussion during later interviews?
_____ **(if no, thank and dismiss)**
Are you interested in participating in this study?_____ **(if no, thank and dismiss)**
Are you able and willing to participate in both interviews and the photo diary?_____ **(if no, thank and dismiss)**

Name:_____
Phone (H/C):_____
Email:_____

Closing And Next Steps
Thank you for your time. I'm looking forward to learning about your experiences.

I will follow up soon with a confirmation email and instructions for completing electronic consent and photo release form.

Would you like to schedule our first interview now or would you prefer I follow-up after you have signed the electronic consent?

Again, thank you for your time and responses. I look forward to talking with you again.

Appendix I: In-depth Interview Guides

I.1 Interview 1

Hello, and thank you for meeting with me today. As indicated in the Informed Consent, this session will be video recorded and then transcribed. Throughout the interview, you will be asked about your personal experiences. The interview will take approximately 60 minutes. Per the Informed Consent you signed, I just want to remind you that your participation is voluntary. You can stop the interview at any time, if you no longer want to participate. You also do not need to answer any questions which make you feel uncomfortable. During the interview, my main job is to listen to you and your stories. I look forward to hearing about your experiences.

I will let you know when I will start recording. If your name happens to come up in the interview, it will be removed when the interview is transcribed and replaced with a pseudonym. Do you have any questions for me before we start? I am now going to start recording.

I would like to start the interview by thanking you for your participation. It is greatly appreciated. The purpose of this interview is to explore and gain a deeper understanding of your experiences and motivations, as an amputee, with leisure time physical activity. It would be great to start with a little background information just to get to know you and then we'll talk more about living as an amputee and what it is like for you to be or think about being active.

General Background:

1. Before we start, so I use the same terms you do, how do you refer to your residual limb?

2. Please tell me a little bit about how your life right now.
a. Probes: Living situation, employment, education, friends, significant other, what's going well, what struggles you have

3. What was a typical day like for you?

Disability Background

4. Let's shift to understanding your life as an amputee. Would you describe your amputation please?
a. Probes: congenital or acquired, if acquired – how, location, prosthetic use or not, surgeries

5. How does your amputation affect or integrate into your daily activities?

a. Probes: pain, prosthetic use or not, fatigue, stigma, planning time, connection with other amputees

6. What is your definition of the word disability?
a. Probes: impairment, difficulty in performing daily activities, inability, Medicaid, SSD, legal classification

7. How do you feel your identity as an amputee aligns with or contradicts your definition of disability?
a. Probes: difficulty in performing daily activities, accessibility challenges, does not equate to inability, how I view others, label that provides support, identity

Follow-on. If you identify with a disability identity, do you prefer the term disabled person or person with a disability, or some other reference to your disability identity?

8. If you were to use two or three words to describe yourself as a an amputee, what would they be?
a. Probe: Please tell me about an experience that demonstrates why you chose those words

<u>Physical activity</u>
9. Physical activity is anytime you use skeletal muscles to create movement and expend energy. This study is interested in leisure time physical activity – or activity you choose to do that is not related to your job, maintaining your home, or transportation. These can be hobbies like gardening or yoga, or fitness activities like walking or lifting, or more traditional sports like golf or tennis. Thinking back at least 2 years, what sort of leisure time physical activities have interested you in the past?
a. Probes: as a child/adolescent, before amputation if acquired, pre-COVID-19, school activities

Follow-on. Were you interested in participating or did you also participate? What got you to participate?
b. Probes: friends participating, meet new people, good at the activity, challenge, interesting, freedom of choice, health

10. More recently, what activities have interested you or have you participated in?
a. Probes: same as a child/adolescent, differentiate between interest and participation, no difference from past, how/why different from past

11. What two or three words would you describe yourself as an athlete or active person?

a. Probe: Please tell me about your experiences in physical activity that demonstrates why you chose those words.

Motivation

12. In your more recent activities, what do you think drives your interest or participation?
a. Probes: friends participating, meet new people, good at the activity, challenge, interesting, freedom of choice, health

Follow-on: If interest only or if not participating as much as you would like, what barriers affect participation?
b. Probes: time commitments, pain, weather, transportation, stigma, don't know others, not skilled

13. Think about other things you do outside of work. What motivates you to participate in those activities?
a. Probes: fun, easy, no pain, can do at home, friends also participate, low risk (of mocking, injury, challenge, etc)

Demographic questions (asked at the end of the interview to avoid creating a pattern of short responses before the in-depth interview)

14. The last set of questions are basic demographics. I know you answered some of these during the phone screener, but that was not recorded for study purposes:

- Date of Birth
- Gender
- Race
- Location of amputation (limb and nearest joint)
- Time living with amputation (if congenital, age)
- Mechanism of amputation (acquired or congenital)

Thank you for your time today! Before we discuss next steps, do you have any questions for me?

In preparation for our next interview, you are going to be asked to take several photographs related to a leisure time physical activity that you regularly participate in or wish to participate in. You will be emailed these instructions after this interview so you have a written copy for your reference. This study is interested in how you "experience" motivation to be active as an amputee.

By this, I mean I want to better understand all the things that affect whether you want to participate in leisure time physical activity as well as whether you end up participating, regardless of interest. To do this effectively we will use pictures you take that represent something important to you related to a current activity interest. These pictures can be related to deciding to participate, the process of preparing to participate, the activity itself, or your recovery process. There are no right or wrong pictures as long as they represent how you feel – in body and mind – about your own motivation or participation.

After you email the pictures of your activity, we will schedule the next interview.

Do you have questions about next steps or anything else discussed today?

Thank you!

I.2 Interview 2

Hello, and thank you for meeting with me again. I also appreciate you sending your pictures ahead of time. As indicated in the Informed Consent, this session will be video recorded and then transcribed. Throughout the interview, you will be asked about your personal experiences. The interview will take approximately 60 minutes. Per the Informed Consent you signed, I just want to remind you that your participation is voluntary. You can stop the interview at any time, if you no longer want to participate. You also do not need to answer any questions which make you feel uncomfortable. During the interview, my main job is to listen to you and your stories. I look forward to hearing about your experiences.

I will let you know when I will start recording. If your name happens to come up in the interview, it will be removed when the interview is transcribed and replaced with a pseudonym. Do you have any questions for me before we start? I am now going to start recording.

I would like to start the interview by thanking you for your participation. It is greatly appreciated. Before we move into this interview, I'm wondering if you had any other thoughts that came up after we met last time. The purpose of this interview is to explore and gain a deeper understanding of your experiences and motivations, as an amputee, with leisure time physical activity. We will be using your pictures to start the interview.

Activity

1. Let's begin with a description of the activity you chose to capture in your photo-diary.
a. Probes: what was the activity; participate alone or with others; regular participation; actual participation or only interest

2. What made you choose this activity?
a. Probes: motivation to participate

Photo-Diary

3. I would ask you next to walk me through the pictures you took. I am going to let you tell the story of each image, but will insert questions throughout to try to take you back to the moment you took the picture and how your senses were informing your experience at that time.

Let's start with this first picture (*share screen*). Please describe this image and why you took it.

Follow-on questions:

a. Where were you when you took this picture?
b. How does this image relate to your activity?
c. Think back to the moment you took this photo. Tell me about the sounds and smells in the area. (Probes: normal sounds and smells, do they make you feel a certain way, can you hear/smell them now)
d. What does your body feel like in this environment (muscle engagement, weather – heat rain etc, weight of clothing against skin)
e. As you are present in this moment, what does your *residual limb [use preferred term from Interview 1]* feel like? (Probes: sweaty, painful, same as always, throbbing, not noticed, how does this influence your emotions about the activity?)

4. *Move through each image in chronological order to elucidate bodily reactions to LTPA and how those influence motivation to be active*.

5. If you could change or improve things for amputees to make leisure time activity more interesting or fun, what changes would you do?
a. Probes: motivation changes from skill, relatedness, choice

6. What do you think is the best way of supporting amputees toward being active?
a. Probes: social, financial, structural barriers that could be removed

7. Is there anything else you would like to say?

Thank you for your time today! Before we close our time together today, do you have any questions for me?

Appendix J: Photo-Diary Instructions

Motivations for Leisure Time Physical Activity Study

Information for Photo-Diary

Thank you for agreeing to take some photos as part of our study to better understand how being an amputee influences your interests and motivations for physical activity.

Please take photos of any aspect of your chosen activity that you think is important.

Some things to consider:

- √ Things you have to do as an amputee to prepare for your activity
- √ Things that make your activity more or less enjoyable
- √ Things that represent why you chose your activity
- √ People who help you or participate with you in your activity
- √ Recovery process
- √ Anything else you think we should know about

Things to remember:

- √ Please make sure anyone you take a picture of knows you are taking their photo and why. If they have not signed a photo release, their likeness will be blurred or the image removed from any publications or presentations about this project.
- √ Only take photos of what you want to share. We will be using these during the second interview to help tell a story about you and your activity.

Instructions:

The pictures we will ask you to provide for this next interview will be used for this study and associated publications or presentations. Outside of reporting results, the pictures will be used solely for the purpose of our next interview to elicit responses to questions that we have and navigate through the interview.

1. Choose an activity that you regularly participate in or consider participating in.
2. Decide when you want to do that activity
3. Please take at least 4 pictures (although you may use as many as 8) that represent your process to get ready for, participate in, and recover from your chosen activity.
    a. If you change your mind about participating in your activity, please take pictures of things that influenced your decision not to participate.
4. Email the pictures to solsen@umd.edu with your first and last name and short descriptions (about a sentence) so chronology is clear
    a. If you prefer, you may send the images via the Signal app to 757-615-3538
    b. Note: the photos will be moved to a password protected computer in a protected file and all email or Signal copies will be permanently deleted

5. After the pictures are received, I will reach out to schedule our next interview.

If you have any questions throughout the process, please contact Sara at solsen@umd.edu

Appendix K: e-Consent Forms

K.1 Phase 1 Consent

What is the purpose of this study?
We want to understand how using a fitness app with content designed for amputees changes motivation to exercise or amount of time exercising

Study Procedures

- The study begins with this survey. You will be asked a series of questions to ensure you meet study criteria. If you do, you will then be asked baseline questions. This survey will take about 25 minutes.
- After you complete this baseline survey, you will be randomly assigned to the app intervention or the waitlist group. Both groups will receive access to the fitness tracking app for 3 months at no cost to you. The intervention group will get immediate access, the waitlist group will get access in 12 weeks.
- If you are in the intervention group, you will receive instructions to download and use the app. You will be asked to log on at least twice a week. Access to the app includes a wide variety of workouts and mobility sessions. You can sign up for as many of these sessions as you want. There are no study incentives for trying harder workouts or for the number of workouts you complete.
- Both groups will be asked to complete 3 sets of follow-up surveys every 4 weeks. These follow surveys should take 10-15 minutes each to complete.

Risks

- As with any exercise routine, you may experience some physical discomfort like muscle strain or soreness.
    - All app-based workout videos are developed by certified personal trainers and you may choose workouts that fit your pace and skill level to protect against injury.
    - There are no incentives for attempting difficult workouts and no penalties for starting but not completing a workout.
- Risk of exercise-induced injury.
    - You may select your own workouts. Workouts beyond current skill, strength, or endurance level may result in injury. You are encouraged to begin slowly and build up gradually
    - Contact a health professional if your health status changes at any point
    - Signing up for the meditation and mindfulness options in the app may provide an option to support gradual physical activity build up.
- Some questions may be personal or upsetting. You can skip them or quit the survey at any time.
- Anytime you share information online there are risks. We're using a secure system to collect this data, which is only available to approved University of Maryland researchers and the system administrators.

Possible benefits: There are no direct benefits from participating in this research. However possible benefits include improved physical fitness. We hope that in the future, other people may benefit from this study through improved understanding of motivations to exercise among amputees.

Confidentiality: There is a chance your data could be seen by someone who shouldn't have access to it. We're minimizing this risk in the following ways:

- We'll store all electronic data on a password-protected, encrypted computer.
- We'll keep your identifying information separate from your research data. We'll destroy this link after we finish collecting and analyzing the data.

Costs: None

Compensation: You will receive 3 months of free access to the fitness app; a $44.97 market value. All participants who complete all 4 surveys will also receive $10 after the last survey.

Questions about the research, complaints, or problems; or if you would like an emailed copy of the consent form:
Sara Olsen
solsen@umd.edu
+1 240-716-8768

Questions about your rights as a research participant, complaints, or problems:
University of Maryland College Park
Institutional Review Board Office
E-mail: irb@umd.edu
Phone: 301-405-0678

Please print or save this screen if you want to be able to access the information later.
IRBNet Package ID #: 1599600-2
IRB Approval Date: Oct 16, 2020

ELECTRONIC CONSENT:
Your participation is completely voluntary, and you can withdraw at any time.

To participate, you confirm you are:

- 18-65 years old
- A single limb amputee with amputation at or above the wrist/ankle
- Able to participate in exercise activities
- Able to read and write in English
- Have internet access and a phone, tablet, computer, or smartTV to use the fitness app

Clicking on the "agree" button below indicates that:

- you have ready the above information
- you understand the risks associated with beginning a physical activity program
- you will follow safety recommendations to gradually build up in frequency and difficulty of workouts
- you understand there are no incentives for attempting difficult workouts and no penalties for not completing a workout
- you will notify your health professional if health conditions change or you suspect injury
- you voluntarily agree to participate

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

K.2 Phase 2 Consent

Please read below with care. You can ask questions at any time, now or later. You can talk to other people before you sign this form.

Study: Understanding the Experiences of Motivation to be Active Among Amputees: an Embodied Phenomenology (IRB-1599600-5)

Why is this study being done (study purpose)? We are doing this study to explore the experiences of motivation to be active among amputees. This study is designed for adults ages 18-65 who have a single limb amputation above the wrist or ankle, and have the ability to take and send digital photographs to the research team. If you participate in this project, you will be asked to take part in project focused on your experiences with physical activity, what motivates you to be active, and what prevents physical activity.

What will happen while you are in the study (study procedures)? Approximately 6 amputees will participate in this research project. If you agree to participate, here is what you will be asked to do. First, we will set up a zoom call for an interview to help me better understand your experiences, in general, as an amputee, and any engagement in physical activity throughout your life. At the end of this interview we will discuss the next part of the project. You will be asked to create a digital photo-diary that represents your motivations and feelings about a physical activity of your choice. After you send me the photos, we will return to a zoom interview that incorporates questions about your photos. No pictures of other people will be used in this project unless they consent as well.
Participation in this study is completely voluntary, and you may drop out of the study at any time. Whether or not you participate in the study will never impact other services you receive with the agency who may have referred you to the study.

Time: Each interview will take 60-90 minutes. It is expected taking the photographs and emailing them to the researcher will take an additional 15-30 minutes.

Costs: None

Risks: The researchers believe that there is little to no risk in participating in this study. There may be a small risk that talking about some of the pictures you have taken or your experiences related to barriers to physical activity as an amputee may make you feel uncomfortable. You may choose to not share anything if you do not want to. Please let us know if you do not understand what you're being asked to do at any point during the study. If you become upset during any of the sessions you may seek out counseling services or other health services as you wish. A list of referrals for such services is being emailed with this consent form.

Benefits: A possible benefit of this study may be that it would be helpful to you to reflect on your experiences and provide suggestions about supports and services that may help other people like yourself. Otherwise, there are no direct benefits to participants.

Compensation: To compensate you for the time you spend in this study, you will receive a $25 e-gift card following the completion of the first interview and a $35 e-gift card following the completion of the second interview. You will be able to choose between an Amazon, Target, and Walmart gift card. Compensation will be given only to those participants who agree to be recorded. However, you may choose to not answer certain questions during the interviews without any impact on your compensation.

Who will know that you are in this study? The research team is the only party that will be allowed to see the demographic data or interview transcriptions, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, we will use a pseudonym instead of your real name when describing study findings. All data will be kept on a secure computer in a password protected folder.

Confidentiality: There is a chance your data could be seen by someone who shouldn't have access to it. We're minimizing this risk in the following ways:

- We'll store all electronic data on a password-protected, encrypted computer.
- We'll keep your identifying information separate from your research data. We'll destroy this link after we finish collecting and analyzing the data.

Do you have to be in the study? You do not have to be in this study. You are a volunteer! It is okay if you want to stop at any time and not be in the study. You do not have to answer any questions you do not want to answer. Nothing will happen to you. You will still get the compensation that you were promised. Your payment will not be affected if you decline to answer specific questions.

Questions about the research, complaints, or problems; or if you would like an emailed copy of the consent form:

Sara Olsen
solsen@umd.edu
+1 757.615.3538

Questions about your rights as a research participant, complaints, or problems:

University of Maryland College Park
Institutional Review Board Office
E-mail: irb@umd.edu
Phone: 301-405-0678

Please print or save this screen if you want to be able to access the information later. You may also email Sara for an emailed copy of the form

IRBNet Package ID #: 1599600-5
IRB Approval Date: Jun 15, 2021

Study Summary
I would like to get a summary of this study:
Please select: Yes No

As part of this study, it is okay to record my Zoom Interview (required for participation):
Please select: Yes No

As a part of this study, it is okay for the researchers to publicly share the photographs I take (required for participation – separate release on next page):
Please select: Yes No

Name:

Emil address:

Phone number:

Preferred contact method
Please select: email phone

ELECTRONIC CONSENT:
Your participation is completely voluntary, and you can withdraw at any time.

To participate, you confirm you are:

- 18-45 years old
- A single limb amputee with amputation at or above the wrist/ankle
- Able to participate in exercise activities
- Able to read and write in English
- Have internet access and a phone, tablet, computer, or smartTV to use the fitness app

Clicking on the "agree" button below indicates that:

- you have ready the above information
- you voluntarily agree to participate

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

K.3 Phase 2 Photo-Release

University of Maryland, and Sara H. Olsen, PI
Video/Photo Release

Study: Understanding the Experiences of Motivation to be Active Among Amputees: an Embodied Phenomenology

I, (typed name) _____, give my permission to he University of Maryland, and the study principal investigator (PI) Sara H. Olsen (collectively, "Parties") to use the photograph(s) taken as part of this project, film/video, voice recordings, and/or demographic information, in its media relations, publications, displays, advertisements, websites, social media platforms, and for any purpose related to public education and information.

I understand that the Parties may retouch and/or modify the images or recordings for such limited purposes as protecting the privacy of participants or other people in the picture.

By participating in this study, I authorize the Parties to use the images without my review or final approval, and I waive my rights against the Parties, its successors or assigns, for invasion of privacy, defamation, or any other reason relating to this Release.

I HAVE READ THIS DOCUMENT AND UNDERSTAND ITS CONTENTS. I AM AWARE THAT THIS IS A CONTRACT TO RELEASE CERTAIN LEGAL RIGHTS, AND I SIGN IT OF MY OWN FREE WILL.

Electronic Signature: _____

Date: _____

Appendix L: IRB approval

The initial Institutional Review Board (IRB) submission outlined the entire sequential mixed methods stud but only provided procedures and protections of participants for Phase I. The IRB Chair approved recruitment for participants age 18-45 years instead of the requested 18-65 years. This age range excludes the amputees below 40 who are not as likely to identify as disabled. The narrowing of age range also introduce age-related sampling bias that had the potential to affect generalizability among the amputee population and result in a sample that no longer reflected the whole amputee community.

- Approximately 50% of all new amputees each year are over the age of 50. Age of amputation is associated with mechanism of amputation. Limb loss secondary to diabetes and other vascular diseases are most common in those over the age of 50, while traumatic and cancer-related amputations are most common below the age of 40.
- Upper extremity limb amputation is most commonly congenital or related to trauma, whereas 93% of all amputations related to peripheral vascular disease are of the lower extremity. The change in age will likely result in oversampling of upper extremity amputees.

Amendment 1 reflected the change in inclusion criteria to account for enrollment of participants age 18-65 years.

Amendment 2 requested an increase in quota.

Amendment 3 submitted procedures, participant protections, and supporting documentation for Phase 2.

L.1 Initial submission

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	May 27, 2020
TO:	Sara Olsen, MS, MPH
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1599600-1] A Sequential Mixed Methods Approach To Identifying And Understanding Motivations For Physical Activity Participation Among Amputees
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	APPROVED
APPROVAL DATE:	May 27, 2020
EXPIRATION DATE:	May 26, 2021
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # 7; Waiver of Written Consent, 45CFR46.117(c)(1).

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of May 26, 2021.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

L.2 Amendment 1

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	October 16, 2020
TO:	Sara Olsen, MS, MPH
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1599600-2] A Sequential Mixed Methods Approach To Identifying And Understanding Motivations For Physical Activity Participation Among Amputees
REFERENCE #:	
SUBMISSION TYPE:	Amendment/Modification
ACTION:	APPROVED
APPROVAL DATE:	October 16, 2020
EXPIRATION DATE:	May 26, 2021
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # 7

Thank you for your submission of Amendment/Modification materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of May 26, 2021.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

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All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

L.3 Amendment 2

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	November 2, 2020
TO:	Sara Olsen, MS, MPH
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1599600-3] A Sequential Mixed Methods Approach To Identifying And Understanding Motivations For Physical Activity Participation Among Amputees
REFERENCE #:	
SUBMISSION TYPE:	Amendment/Modification
ACTION:	APPROVED
APPROVAL DATE:	November 2, 2020
EXPIRATION DATE:	May 26, 2021
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # 7

Thank you for your submission of Amendment/Modification materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of May 26, 2021.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

L.4 Amendment 3

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	June 15, 2021
TO:	Sara Olsen, MS, MPH
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1599600-5] A Sequential Mixed Methods Approach To Identifying And Understanding Motivations For Physical Activity Participation Among Amputees
REFERENCE #:	
SUBMISSION TYPE:	Amendment/Modification
ACTION:	APPROVED
APPROVAL DATE:	June 15, 2021
EXPIRATION DATE:	May 26, 2022
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # 7

Thank you for your submission of Amendment/Modification materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of May 26, 2022.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

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