Psychological Adjustment to Disability: Heterogeneous Trajectories of Resilience and Depression Following Physical Impairment or Amputation

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Abstract

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Adjustment to disability is a foundational concept within rehabilitation psychology and constitutes an important public health problem given the adverse outcomes associated with maladjustment. While the disability literature has highlighted depressive elevations in response to functional impairment, resilience and alternative patterns of psychological adjustment have received substantially less empirical inquiry. This dissertation is comprised of three papers, the first two of which are longitudinal studies utilizing distinct samples of individuals with acquired disabilities: a population-sample of physically impaired older adults, and a convenience sample of individuals with newly acquired amputations. The third paper summarizes current data science and statistical findings regarding disability adjustment for patients and their providers. The two longitudinal studies share a common statistical methodology, latent growth mixture modeling (LGMM), allowing for the identification of distinct subgroups (classes) of individuals who share similar symptom profiles over time. LGMM is well-poised to resolve fundamental questions about whether psychological functioning after disability is best described by a population-level archetypal response (i.e., distress and depression that remits over time), or alternatively, whether the data suggest a variety of definable subgroups with distinct psychological trajectories. Results of empirical papers 1 and 2 provide strong empirical evidence that the process of disability adjustment is heterogeneous, with multiple pathways of symptom development and remission. The third paper demonstrates how findings from current rehabilitation science can be utilized to inform psychoeducational materials for practitioners and their patients with recent limb loss. This chapter addresses gaps in dissemination of knowledge by describing various patterns of psychological outcomes encountered by individuals following amputation surgery, as supported by Study 2 and the broader resilience literature.

Keywords: Disability onset, depression, trajectories, Latent Growth Mixture Modeling (LGMM)

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Dedication

- Dedicated to those who inhabit different bodies and different minds – may we continue to lay claim to wholeness, even amidst a world that is constrained by the artifice of normality

- And to the Pearl, the Wolf, and to my wife Megan Elizabeth, my three undeserved treasures

- And lastly, to Jane and Jim – for all that they were and for all that they continue to be that lives on in a heart and mind.

Chapter 1: Introduction

Psychological Adjustment to Disability: Heterogeneous Trajectories of Resilience and Depression Following Physical Impairment or Amputation

The onset of a physical disability is a challenging life event that requires adaptation across the biological, psychological, and social realms. The process of adapting to a new disability is marked by numerous challenges that may vary substantially across the initial and long-term phases of adjustment. The primary aim of this dissertation is to examine trajectories of psychological functioning following Physical Impairment or Amputation (PIA), and to identify meaningful predictors of these trajectories that may have scientific, clinical, or policy implications. The current dissertation also explores the relevance and translational value of these findings to the field of rehabilitation psychology and the broader science of resilience.

The processes of adaptation and adjustment to disability are foundational concerns in the field of rehabilitation psychology, which seeks to help individuals preserve a meaningful life in the context of disabilities, irrespective of severity and societal constraints (Dunn et al., 2016; Jennings, 1993). This dissertation will examine whether the course of disability adjustment is similar for individuals with shared disability characteristics, or whether adjustment is a heterogeneous process, best characterized by multiple trajectories of functioning with a variety of important predictors of who will do well, and who will do poorly when challenged by a PIA.

This section provides a brief overview of the history of empirical research on adjustment to disability, beginning with the first systematic studies conducted in the aftermath of World War II. Prevalent theoretical and methodological problems with early empirical research will be addressed that pervaded the theoretical and clinical vantage points for much of the 20th century.

This review will be followed by an overview of advances within the field of trauma research, especially the emergence of research on resilience and other non-pathological profiles of adjustment to aversive life events (Bonanno, 2004). Related methodological advances that facilitated the scientific acceptance of resilience as a distinct and valid profile of adjustment in response to aversive life events are outlined, including select studies that have previously addressed acute injury and disability. The section ends with discussion of the rationale for the application of latent variable modeling to the two empirical studies contained herein.

The body of this dissertation consists of three chapters intended as separate standalone articles (Chapters 2, 3 & 4). Chapters 2 and 3 are individual empirical studies with separate samples of distinct disability subtypes. Both studies utilize LGMM to identify trajectories of depression following disability. Study 1 (Chapter 2) utilized a large prospective data set on a population sample of older adults with broadly defined new-onset impairments in physical functioning. Study 2 (Chapter 3) utilized a longitudinal data set derived from a convenience sample of individuals following surgical amputation. Study 2 used different measures of the same primary outcomes as in Study 1 and, in an extension of latent variable modeling, utilized the identified trajectories to predict incidence of posttraumatic stress disorder (PTSD) at 6-months post-amputation. The final article (Chapter 4) addresses dissemination of knowledge based on current data science (both Study 2 and other work), representing a psychoeducational guide for individuals with recent limb loss and their care providers. This article is an adaptation and extension of a previous paper developed for use at Mount Sinai Hospital's acute inpatient medical rehabilitation unit in accordance with Commission on Accreditation of Rehabilitation Facilities (CARF) standards, for distribution to all individuals with new amputations post-discharge from Mount Sinai's medical rehabilitation facility. Designed and written as part of a multi-faceted psychoeducational intervention, it provides a comprehensive overview of the empirical science on psychological adjustment to limb loss, including a range of possible reactions for patients to be aware of and when to consider seeking help. It emphasizes that resilience is common after amputation based upon current data science and other similarly aversive life events, while validating the occurrence of alternative patterns of adjustment that represent periods of psychological difficulty. In addition, the paper will compare trajectories of resilience and dysfunction following disability with similar trajectory analyses following other types of aversive events. This will involve tests for heterogeneity between studies and the calculation and comparison of weighted pooled prevalence rates (see: Galatzer-Levy et al., 2018).

Literature Review

> *Almost all people are at some time faced with the necessity of adjusting to loss. In investigating the problems of injured people, therefore, we are dealing not only with special problems of a special group but with problems important to all* (Dembo et al., 1956, p. 2)

Definition of Disability

A comprehensive definition for what constitutes a disability became the topic of vigorous debate during the latter half of the 20th century. Prior to the social revolutions of the 1960s-70s, the prevailing "medical model" defined disability solely in terms of impairments in human anatomy or bodily functioning, resulting in activity limitations (Chan et al., 2009). During the civil rights era, this deficit-based view became contested as disability advocates increasingly drew attention to institutional and structural aspects of society that were discriminatory to persons with disabilities (PWDs). The "social model" of disability articulated this counterview to the medical model by decentralizing bodily functioning, highlighting instead systemic discrimination (e.g., in the job market) and lack of access (e.g., to buildings, institutions, and enhancing health services) as primary determinants of the limitations experienced by PWDs (Andrews, 2019; Chan et al., 2009). In response to substantive critiques of both models, the World Health Organization (WHO) recently developed *The International Classification of Functioning, Disability and Health* (ICF) using a biopsychosocial approach to integrate the two perspectives:

> Disability is the umbrella term for *impairments, activity limitations* and *participation restrictions,* referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (i.e., environmental and personal factors; World Health Organization, 2011, p. 4).

The WHO ICF has been widely adopted by the rehabilitation field as an adequate compromise between the medical and social models (MacLachlan & Mannan, 2014), because it adresses the interaction between altered bodily functioning (i.e., *impairments*) and social-contextual factors (e.g., discrimination, lack of accessible transportation; World Health Organization, 2011, p. 5).

The ICF refers to *impairments* in general terms as inclusive of physical, emotional, and neurological conditions. However, this dissertation primarily addresses disability as defined by decrements in physical functioning (e.g., inability to perform one or more activities of daily living; ADLs) or a bodily injury or alteration (e.g., limb loss); this definition can be contrasted with disabilities related to primary cognitive or emotional disorders[1]. Furthermore, the data presented in empirical studies 1 and 2 address *new-onset* disabilities, defined as demonstrable changes in anatomy or physical functioning incurred during adulthood. Individuals with

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[1] Although the criteria for chronic disability onset in Study 1 are physical in nature (i.e., based upon ADLs), the specific etiology of disability in Study 1 is largely unknown. Thus, the possibility of physical limitations being caused by conditions that are primarily neurological in nature (e.g., stroke) cannot be ruled out (McGiffin et al., 2019).

congenital or life-long disabilities form an alternate but unique subset with differential risk and resilience factors that are outside the scope of the current manuscript (Andrews, 2019, p. 101).

Prevalence of Disability

> Almost everyone will be temporarily, or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning (World Health Organization, 2011)

The WHO ICF has adopted a "universalist" perspective that describes disability as an intrinsic part of the "human condition," thereby bolstering arguments in favor of increasing access and participation for PWDs. In 2011, approximately 38 million Americans qualified as disabled, constituting roughly 12.2% of the overall U.S. population (Houtenville & Ruiz, 2011; Ma et al., 2014). Estimates of the global prevalence of disability are slightly higher than in the U.S., due to wealth-health disparities and the impact of poverty, ranging from 15% (World Health Organization, 2011) to 15.3% (Mathers et al., 2008). Approximately 2-4% of individuals globally have a disability that meets criteria for "severe" within the ICF classification system (World Health Organization, 2011). Underscoring the importance of rehabilitation outcomes in the U.S., over 50% of disabled Americans are estimated to be in their working years, between the ages 18-64 (Houtenville & Ruiz, 2011).

Disability Adjustment

The process of accommodating to changes in physical, social and occupational functioning has been referred to in the academic literature as adaptation or adjustment to disability (Chan et al., 2009; Livneh & Antonak, 1997). The current manuscript uses the terms *adjustment* and *adaptation* flexibly to refer to the broad collection of processes involved in coping with a newly acquired disability over time. The processes of adjustment to disability dates back to the inception of rehabilitation psychology as a field in the aftermath of World War

II, when clinical psychologists first began to systematically study recovery from serious injuries, including amputation and spinal cord injury (SCI; e.g., Dembo et al., 1956, 1975; Reznick et al., 2009). Early researchers were aware that veterans with noticeable physical injuries encountered unique psychosocial challenges during the adjustment process, above and beyond the challenges of coping with war-related trauma. For many, their identities, sense of self, and interactions in the world had been dramatically altered, and their social, vocational, and family lives were often irrevocably altered.

Adjustment to disability is a foundational concept and cornerstone within the field of rehabilitation psychology (Dunn et al., 2016), where clinicians regularly work with patients on initial acute adjustment issues, and in later stages help patients develop long-term coping strategies to support adaptation. Yet, much of the literature regarding adjustment to disability has focused on maladjustment, including a disproportionate emphasis upon depression and other reactive psychopathologies.

Rationale for the Studies

Depression has a long history of study in the disability literature. With some exceptions (e.g., Dembo et al., 1956, 1975), the early empirical literature widely asserted the disability onset was universally depressing for all individuals (e.g., Wittkower, 1947; Wittkower et al., 1954). In addition, stage models were prevalent that typically outlined a process of linear, sequential phases of adjustment following disability, purportedly adhered to by all individuals (for an early example see: Cohn, 1961). By the early 1980's, however this cannon of early research began to be challenged (Frank et al., 1987; Wortman & Silver, 1989). In a broad review, Silver and Wortman (1980) systematically evaluated a range of data on aversive life events, including grief and bereavement, cancer diagnosis, SCI, and other difficult health events. They identified broad methodological flaws in the early corpus of research, including: subjective interpretation of interview data, lack well-operationalized definitions of depression and other psychopathologies, lack of standardization of measurement across studies, and sparse methods sections limiting the interpretation and replicability of results (Silver & Wortman, 1980). By the end of the 20th century, interest in alternative patterns of adaptation to disability began to receive increasing amounts of attention, including resilience following disability (Dunn, 1996).

Since then, a growing body of research has documented heterogeneous trajectories of adjustment following a range of aversive life events, including potentially traumatic events (deRoon-Cassini et al., 2010; Bonanno et al., 2002; Bonanno, et al., 2012) but also onset of serious medical conditions (Burton et al., 2015; Galatzer-Levy & Bonanno, 2014). Importantly, many people facing aversive life events have exhibited resilient outcomes, as well as other non-pathological patterns (for a review see: Bonanno et al., 2011). Though a small but growing literature has emerged documenting resilience as a common outcome following disablement (for a review, see: Dunn, Uswatte, & Elliott 2009), few studies have emphasized resilience in samples of disabled older adults or individuals with new-onset amputations (i.e., PIAs). However, there is reason to believe resilience may be common in the face of serious functional impairment based on the findings from adjacent research of specific acute injury, including spinal cord injury (Bombardier, Adams, Fann, & Hoffman, 2016; Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfström, 2012), acute traumatic injury (deRoon-Cassini et al., 2010), multiple physical trauma (Quale & Scahnke, 2010), and traumatic brain injury (Hanks, Rapport, Perrine, & Millis, 2016; Juengst et al., 2015).

Even as interest in alternative profiles of adjustment has increased across rehabilitation psychology and the rest of the field, researchers remained unable to address the heterogeneity in outcome profiles, and groups of disability subtypes were often modeled together using assumptions of homogeneous adjustment profiles over time. In spite of mounting evidence and growing acceptance that not all individuals with disabilities evidenced prolonged psychopathological responses, statistical paradigms for the study of longitudinal data that allowed for the appropriate modeling of individual differences have yet to be widely applied to psychological recovery after disability onset. As recently as 2019, an modeling longitudinal depression trajectories with multilevel modeling, suggested that depression scores were flat and unchanging over the course of the first year following limb loss (Roepke et al., 2019). Thus, the methods described and utilized herein present significant statistical advantages to understanding adjustment to disability, that have heretofore been obscured by reliance upon group-level average responses for individuals with shared disability subtypes.

In line with this, the purpose of Studies 1 and 2 is to apply novel statistical modeling techniques for longitudinal data (i.e., LGMM, described below) to unique disability populations: Study 1 presents the first application of LGMM to disability onset in later life, and Study 2 presents the first application of LGMM to post-amputation psychological recovery. To our knowledge, these studies represent the first empirical studies using LGMM with these specific populations. Together, these two studies identify trajectories of psychological functioning, previously assumed to be homogeneous and depressed on the whole and allow for the examination of the development (and remission) of psychopathology over time in these samples. The purpose of utilizing these newer data driven methodologies is to relax a priori assumptions about homogeneity in favor of a bottom-up (i.e., data-driven) approach to understanding psychosocial adjustment to disability.

The second goal of empirical studies 1 and 2 is to understand whether the patterns of adjustment identified utilizing these methods conform to previously identified prototypical patterns of adjustment after aversive life events. Third, given the high prevalence of disability, these two studies aim to identify meaningful predictors of depression following disability, given the well-known adverse health outcomes associated with depression in populations of individuals with medical conditions (e.g., decreased activity and wellness behaviors, poorer treatment compliance, etc.). Finally, in study 3, utilizing inferential statistics and a broad literature review, I suggest ways in which the current findings and others from the empirical rehabilitation literature can inform psychoeducational materials for patients and their practitioners, to update current treatment paradigms and better inform clinicians' allocation of treatment resources. Notably, building awareness for both patients and practitioners regarding the prevalence of resilience across all types of disabilities, can reduce the risk of iatrogenic injury due to over-attribution of depression and other psychopathologies during initial consultations with recently injured patients.

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Chapter 2 : Socioeconomic Resources Predict Trajectories of Depression and Resilience Following Disability

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BRIEF REPORT

Socioeconomic Resources Predict Trajectories of Depression and Resilience Following Disability

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Objective: Adjustment to chronic disability is a topic of considerable focus in the rehabilitation sciences and constitutes an important public health problem given the adverse outcomes associated with maladjustment. While existing literature has established an association between disability onset and elevated rates of depression, resilience and alternative patterns of adjustment have received substantially less empirical inquiry. The current study sought to model heterogeneity in mental health responding to disability onset in later life while exploring the impact of socioeconomic resources on these latent patterns of adaptation. ***Method:*** Latent growth mixture modeling was utilized to identify trajectories of depressive symptoms surrounding physical disability onset in a population sample of older adults. Individuals with verified disability onset (n = 3,204) were followed across four measurement points representing a 6-year period. ***Results:*** Four trajectories of depressive symptoms were identified: resilience (56.5%), emerging depression (17.2%), remitting depression (13.4%), and chronic depression (12.9%). Socioeconomic resources were then analyzed as predictors of trajectory membership. Prior education and financial assets at the time of disability onset robustly predicted class membership in the resilient class compared to all other classes. ***Conclusion:*** The course of adjustment in response to disability onset is heterogeneous. Our results confirm the presence of multiple pathways of adjustment surrounding late-life disability, with the most common outcome being near-zero depressive symptoms for the duration of the study. Socioeconomic resources strongly predicted membership in the resilient class compared with all other classes, indicating that such resources may play a protective role during the stress of physical disability onset.

Impact and Implications

The current analysis helps to establish that the course of adjustment to disability onset in later life is heterogeneous, with the most common trajectory being resilience, followed by alternative patterns of adjustment that indicate more significant depressive burden. Socioeconomic variables strongly predicted membership in the resilient class compared to other classes, suggesting that such resources may buffer against the psychological stress of functional decline. Current findings suggest that older adults with lower socioeconomic status are most at risk for elevated depressive symptoms following disability onset. Socioeconomic factors may thus be important predictors of adjustment difficulty, which has important policy implications for the guidance and targeted distribution of treatment resources.

Keywords: adjustment, depression, latent growth mixture modeling, Heath and retirement study, socioeconomic resources

Introduction

The onset of a physical disability is an undeniably challenging and difficult life event. Empirical evidence has linked physical disability with a high prevalence of depression as well as a range of other mental health outcomes (Ormel et al., 1994). The association between physical disability and depression has been detected across the life span (Aneshensel, Frerichs, & Huba, 1984; Brenes et al., 2008) but is especially prominent in later adulthood as risk

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Socioeconomic Resources Predict Trajectories of Depression and Resilience Following Disability

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Abstract

Objective**:** Adjustment to chronic disability is a topic of considerable focus in the rehabilitation sciences and constitutes an important public health problem given the adverse outcomes associated with maladjustment. While existing literature has established an association between disability onset and elevated rates of depression, resilience and alternative patterns of adjustment have received substantially less empirical inquiry. The current study sought to model heterogeneity in mental health responding to disability onset in later life, while exploring the impact of socioeconomic resources on these latent patterns of adaptation. ***Methods***: Latent Growth Mixture Modeling (LGMM) was utilized to identify trajectories of depressive symptoms surrounding physical disability onset in a population sample of older adults. Individuals with verified disability onset (*n* = 3,204) were followed across four measurement points representing a 6-year period. ***Results***: Four trajectories of depressive symptoms were identified: resilience (56.5%), emerging depression (17.2%), remitting depression (13.4%), and chronic depression (12.9%). Socioeconomic resources were then analyzed as predictors of trajectory membership. Prior education and financial assets at the time of disability onset robustly predicted class membership in the resilient class compared to all other classes. ***Conclusion***: The course of adjustment in response to disability onset is heterogeneous. Our results confirm the presence of multiple pathways of adjustment surrounding late-life disability, with the most common outcome being near-zero depressive symptoms for the duration of the study. Socioeconomic resources strongly predicted membership in the resilient class compared with all other classes, indicating that such resources may play a protective role during the stress of physical disability onset.

KEYWORDS: Adjustment to Disability; Disability; Depression; Latent Growth Mixture Modeling; Health and Retirement Study; HRS; Socioeconomic Resources

Impact

- The current analysis helps to establish that the course of adjustment to disability onset in later life is heterogeneous, with the most common trajectory being *resilience*, followed by alternative patterns of adjustment that indicate more significant depressive burden.
- Socioeconomic variables strongly predicted membership in the resilient class compared to other classes, suggesting that such resources may buffer against the psychological stress of functional decline.
- Current findings suggest that older adults with lower socioeconomic status (SES) are most at risk for elevated depressive symptoms following disability onset. Socioeconomic factors may thus be important predictors of adjustment difficulty, which has important policy implications for the guidance and targeted distribution of treatment resources.

Socioeconomic Resources Predict Trajectories of Depression and Resilience Following Disability

The onset of a physical disability is an undeniably challenging and difficult life event. Empirical evidence has linked physical disability with a high prevalence of depression as well as a range of other mental health outcomes (Ormel, 1994). The association between physical disability and depression has been detected across the lifespan (Aneshensel et al., 1984; Brenes et al., 2008), but is especially prominent in later adulthood as risk for functional impairment increases (Regan et al., 2013). Some estimates of clinically significant depression in samples of physically disabled older adults are above 35% (Ormel et al., 2002; Turner & McLean, 1989; Turner & Noh, 1988). Despite these elevations, it is clear that not all who become disabled will develop depression or other psychopathologies. This raises crucial questions about the longitudinal course of adjustment to physical disability in later life, and whether there are alternative “latent” patterns of adaptation. Furthermore, if the course of adjustment to disability is indeed heterogeneous, are there important determinants of these differential pathways?

To address these questions, the current study identified trajectories of depressive symptoms using Latent Growth Mixture Modeling (LGMM) in a population sample of older adults with verified physical disability onset. We utilized true prospective data that covered a six-year period, beginning two years before disability onset and continuing four years after. Given evidence suggesting socioeconomic factors play a protective role in the disability onset stress-adaptation process (Kavanagh et al., 2015; Mandemakers & Monden, 2010; Smith et al., 2005), we targeted two socioeconomic variables as predictors of trajectory membership.

Method

Data

The current study used data from the Health and Retirement Study (HRS; University of Michigan), a nationally representative research initiative funded by the National Institute on Aging. Data were analyzed in accordance with approval from the NYU Medical Center Internal Review Board. The HRS was designed to explore socioeconomic, physical, and mental health factors relevant to aging and retirement in the United States, and participant data was gathered every two years (see: Sonnega et al., 2014 for HRS sampling methods). Ten biennially sampled waves were used for the current analysis (1994-2012), extracted from the HRS RAND data files version N (Chien et al., 2014). We centered data around the wave of disability onset using a *floating-baseline* methodology (Galatzer-Levy et al., 2010; Galatzer-Levy & Bonanno, 2014), aligning participants from different HRS cohorts to the same four measurement points: T1 (baseline), T2 (disability onset), T3 (2-yrs. Post), and T4 (4-yrs. Post).

Participants and Procedure

Physical disability

Physical disability onset was defined as the change from no impairment in activities of daily living (ADLs) to difficulty in at least one domain. HRS respondents were asked whether they currently experience difficulty in any of five ADL domains: walking across a room, getting dressed, bathing, eating, and getting out of bed. All respondents included in the current sample reported no difficulties with ADLs in the year of baseline measurement (T1, ADL = 0), followed by a subsequent two waves of ADL impairment (T2-T3, ADL ≥ 1). Thus, all individuals in the current sample transitioned from no impairment (T1) to chronic disability, defined as two consecutive waves of functional disability (T2-T3). To facilitate model convergence, the sample was restricted to participants with at least two available depression measurements across the four waves. The final sample was comprised of 3,204 participants, predominantly female (65%), and Caucasian (77.4%), with a mean age at time of disability onset of 72.6 years (SD = 11.68).Sample demographics are summarized in Table 1.

Depression

Depression was assessed using a brief 8-item version of the Center for Epidemiological Studies-Depression scale (CES-D, Radloff, 1977). The 8-item CES-D has been validated for use with older populations, with adequate reliability ($\alpha = 0.84$; Karim, Weisz, Bibi, & ur Rehman, 2014). The HRS suggests a cutoff score of 4 for clinically significant depression (Steffick, 2000).

Table 1. Sample Demographics (*n* = 3,204)

	n	Percentage % (SD)		*n*	Percentage %
Gender			Marital status		
Male	1117	34.9	Married	1693	52.8
Female	2087	65.1	Unmarried	1502	46.9
Race/Ethnicity			Education		
White	2478	77.4	High school or below	2308	72.0
Non-white	726	22.6	College or above	896	28.0
Mean Age	72.6	(11.68)			

Data analysis

Trajectories of depressive symptoms were identified using LGMM (Mplus 8.1; Muthén & Muthén, 2017). Successive models of increasing complexity were tested, comparing k vs. k-1 model-fit statistics. We allowed the variance of the slope and the intercept to be freely estimated but fixed the quadratic parameter. Final unconditional model selection was guided by fit statistics, interpretability, and theoretical coherence (Bonanno, 2004; Muthén, 2004). We explored a range of demographic and situational covariates (age, gender, education, wealth, marital status, race, ethnicity) for possible inclusion in the conditional model based on their theoretical relevance to the question of disability adjustment in later life. Three variables were entered successfully into the conditional model and influenced class membership in a multinomial logistic regression: age, participant education (coded 0 = high school or less, 1 = some college or more) and wealth (total household financial savings at the time of disability onset, including the value of home ownership and other property, minus debt). We normalized the financial variable by first shifting the distribution to remove negative asset values (i.e., adding a constant to each score), and then conducting a natural logarithmic transformation.

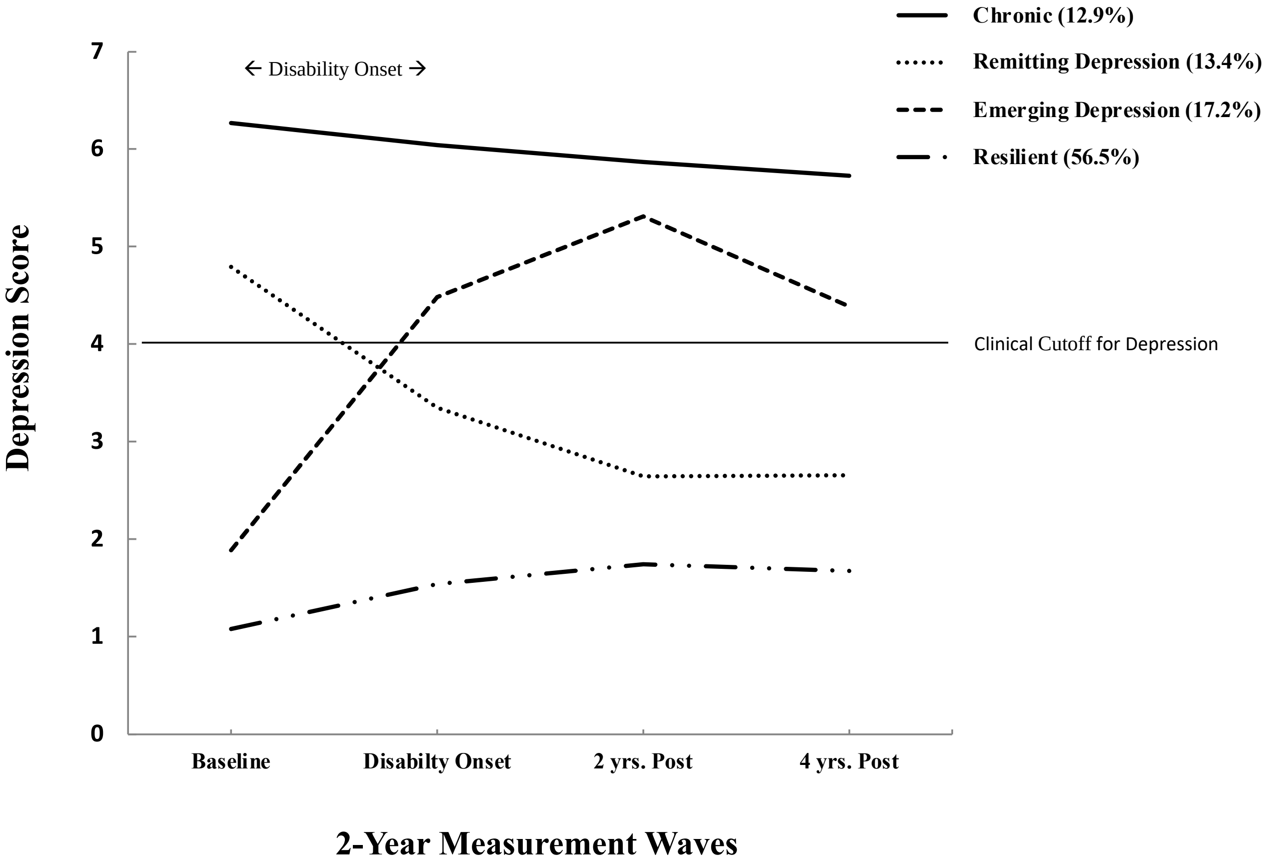
Results

Unconditional Model

We tested 1-5 class unconditional solutions and observed continued improvement in model fit through 4 classes (Table 2). Although the 5-class solution also resulted in improved fit, it was theoretically and practically less interpretable. The proportion of resilience was identical in both the 4- and 5-class solutions (56%), however the 5-class solution split the emerging trajectory into two smaller trajectories, adding little new useful information to the model. For this reason, the 4-class model was selected as the optimal solution (Figure 1).

Figure 1. Final 4-class unconditional model (*n*=2,204)

Figure 1. Final 4-class model of depression trajectories across four time points (*n* = 3,204). Vertical gray bar represents window of disability onset.



The largest class was *Resilient* (56.5%) exhibiting consistent low levels of depressive symptoms across 6 years (low intercept, *b* = 1.05, *SE* = 0.05, *p* < .001, a flat but significant linear slope, *b* = 0.62, *SE* = 0.06, *p* < 0.001, and a significant negative quadratic parameter, *b* = –0.13, *SE* = 0.02, *p* < .001). An *Emerging Depression* group was characterized by low initial depression that increased after disability onset (low intercept, *b* = 1.94, *SE* = 0.11, *p* < .001, a significant increasing linear slope, *b* = 3.49, *SE* = 0.21, *p* < .001, and a significant negative quadratic parameter, *b* = –0.90, *SE* = 0.07, *p* < .001). A *Remitting Depression* trajectory (13.4%), demonstrated high initial depression followed by decreases over subsequent waves (high intercept, *b* = 4.72, *SE* = 0.18, *p* < .001, significant decreasing linear slope (*b* = –1.77, *SE* = 0.29, *p* < .001, and a significant quadratic parameter, *b* = 0.37, *SE* = 0.08, *p* < .001. Finally, a *Chronic Depression* class (12.9%) demonstrated high levels of depressive symptoms across the 6-year study (high intercept, *b* = 6.30, *SE* = 0.14, *p* < 0.001, a flat non-significant linear slope, *b* = –0.27, *SE* = 0.15, *p* = 0.08, and a non-significant quadratic parameter, *b* = 0.03, *SE* = 0.06, *p* =0.64).

Table 2. Fit Indices for two- to five-class latent growth class analyses of depression

Statistic	1 class	2 class	3 class	4 classes	5 class
AIC	48854.65	48151.16	47920.21	47672.22	47541.98
BIC	48915.37	48236.17	48029.51	47805.80	47699.86
SSBIC	48883.60	48191.69	47972.32	47735.90	47617.25
Entropy	–	.83	.78	.78	.77
VLM LRT	–	711.49	238.95	256.00	138.23
(p-value)		(.0000)	(.0000)	(.0000)	(.001)
LMR LRT	–	690.11	231.77	248.31	134.08
(p-value)		(.0000)	(.0000)	(.0000)	(.001)
BLRT	–	711.49	238.95	256.00	138.23
BLRT p-value	–	(.0000)	(.0000)	(.0000)	(.0000)

Note: AIC = Akaike Information Criterion; BIC = Bayesian Information Criterion; SSBIC = Sample Size Adjusted Bayesian Information Criterion; LMR LRT = Lo-Mendell-Rubin Likelihood Ratio Test; VLM LRT = Vuong-Lo-Mendell_Rubin Likelihood Ratio Test; BLRT = Bootstrap Likelihood Ratio Test.

Conditional Model

The addition of age, education and wealth covariates to create a conditional model did not significantly alter the shape of the trajectories and resulted in only minor alterations of proportional trajectory membership (entropy = 0.78, was comparable). One participant was excluded from covariate analyses due to missing data (final sample *n* = 3,103).

We examined predictors of class membership in a multinomial logistic regression (Table 3). Compared to the resilient class, all other classes had significantly lower financial assets, less education, and younger age. Compared with the chronic group, the emerging and remitting depression groups had significantly greater assets and older age, and the emerging group had significantly greater education. The emerging and remitting depression groups did not significantly differentiate on socioeconomic predictors or age.

Table 3. Multinomial logistic regression predicting class membership (n = 3,203)

Reference Class	Resilience vs.					
	Emerging Depression		Remitting Depression		Chronic Depression	
	Est	*SE*	*Est*	*SE*	*Est*	*SE*
Wealth	–2.26***	0.62	–1.32*	0.57	–4.40***	0.83
Education	–0.51***	0.15	–0.67***	0.16	–0.95***	0.17
Age	–0.03***	0.01	–0.02**	0.01	–0.05***	0.01
Reference Class	Chronic vs.				Remitting Depression vs.	
	Emerging Depression		Remitting Depression		Emerging Depression	
	Est	*SE*	*Est*	*SE*	*Est*	*SE*
Wealth	2.14*	0.96	3.08**	1.02	–0.94	0.81
Education	0.47*	0.21	0.28	0.23	0.17	0.20
Age	0.02**	0.01	0.03***	0.01	–0.01	0.01

Note : $p \leq .05$* ; $p \leq .01$**; $p \leq .001$***.

Discussion

A growing number of studies have mapped the physical process of functional decline, modeling trajectories of ADL impairment (e.g., Gill, Gahbauer, Han, & Allore, 2010; Liang et al., 2010; Nusselder et al., 2006; Wolf, Freedman, Ondrich, Seplaki, & Spillman, 2015), and at least one study has modeled psychological functioning using Hierarchical Linear Modeling (HLM; Lucas, 2007). In the current study, we used LGMM to identify four trajectories, confirming the course of disability adjustment is heterogeneous. The majority of our sample (56.5%) demonstrated resilience: Low depressive symptoms pre- and post-disability onset. We also identified a chronic-depression group (12.9%), characterized by high pre-disability depression that remained elevated throughout the study, a remitting-depression trajectory

(13.4%) characterized by high pre-disability depression that decreased over time, and an emerging depression trajectory (17.2%) characterized by low pre-disability depression levels that increased sharply in response to the event and remained elevated for a 2-year period.

Although a majority of our sample evidenced resilience, two of the identified classes – the chronic, and emerging depression classes – depicted clinically significant depressive elevations for a substantial period of time post-disability onset. Importantly, however, a significant segment of our sample was depressed in the wave *prior to* disability onset (both the chronic and the remitting-depression trajectory). This fact highlights the utility of true prospective data, which helps to demarcate pre-existing clinically significant depressive symptoms from depression in response to the event. Only one trajectory – the emerging depression class – depicted a clinically significant depressive reaction that was temporally related to disability onset. This is consistent with prior research that highlights disability onset as a stressful life event (Turner & Noh, 1988; Turner & Beiser, 1990). Individuals with clinically significant depression in response to acute health events have been shown to be at increased risk for distal adverse health outcomes (e.g., myocardial infarction and attendant risks for early mortality; Bower, 2001; Galatzer-Levy & Bonanno, 2014) highlighting the need for further exploration of the emerging depression profile.

Socioeconomic variables were consistent predictors of resilience. Compared with all other classes, resilient individuals were more likely to have greater wealth, suggesting that financial assets play a protective role with respect disability onset. This effect has been demonstrated in previous research on disability. Smith et al. (2005) showed that increased financial assets buffered against the stress of new disability onset in a sample of HRS respondents: Net assets 2-years prior prospectively predicted smaller decrements in subjective well-being at the time of disability onset. Likewise, in an Australian sample of newly disabled individuals, Kavanagh et al. (2015) showed that declines in mental health were the largest for individuals in the bottom tertile of the wealth distribution. In the current analysis, participant's level of education also strongly predicted membership in the resilient class, again extending prior studies (e.g., Mandemakers & Monden, 2010). Although education and wealth covary in important ways, our data suggest that these are *unique and independent* predictors of disability adjustment. Together, our findings and previous research support resource-model theories of stress-resistance (e.g., Hobfoll, 2001, 2002), which propose that access to resources (e.g., social, material, etc.) can mitigate the deleterious impact of stressful life events.

Limitations

There were several limitations in our study worth noting. The biennial spacing of the HRS sampling waves prevents the capture of short-term fluctuations in both ADL-impairment and depressive symptoms. Given that the temporal onset of disability can technically occur anywhere between the first two measurement waves (see onset window, figure 1), we were unable to precisely model acute depressive reactions contemporaneous to the onset. To minimize this limitation, we employed stringent inclusion criteria (i.e., selecting only chronic cases), to ensure that the trajectories identified would reflect broad patterns of responding to chronic disability onset over time. However, the wide spacing of the HRS may be less ideal with respect to the study of disability (Wolf & Gill, 2009), given that whole episodes and recoveries may occur within smaller measurement windows (e.g., Cronin-Stubbs et al., 2000).

Second, while depression represents a critical target variable, other important outcomes are relevant to the disability adjustment process (e.g., anxiety, general distress), and at least one paper has modeled trajectories of subjective well-being using HLM (Lucas, 2007). In cases of sudden or traumatic disability, posttraumatic-stress symptoms are of particular relevance. Thus, future trajectory studies might examine alternative (or multiple) disability adjustment measures. Finally, our data lacks specific information about the etiology of disability. While this is typical of population-based studies that utilize panel data (e.g., Cronin-Stubbs et al., 2000; Regan et al., 2013), future studies should seek to prioritize the relationship between trajectory membership and the etiology of disability (e.g., chronic health conditions vs. normal aging vs. trauma).

Conclusion

The course of depression surrounding late-life disability onset is heterogeneous. We observed multiple pathways of depression symptoms, with the most common trajectory (56.5%) being resilience, or stable low depressive symptoms across a 6-year measurement period. We also observed that disability onset intensified mental-health related challenges for many individuals, as a segment of our sample (17.2%) endorsed clinically significant depressive elevations in response to disability onset (emergent-depression). However, as with other findings that utilize true prospective data, we identified a substantial number of individuals who were depressed prior to becoming disabled (chronic depression 12.9%; remitting depression 13.4%), underscoring the fact that depressive elevations previously cited in the disability literature may be confounded by a lack of pre-event data. Finally, we found that socioeconomic factors robustly predicted these trajectory patterns. Our findings thus dovetail with prior research demonstrating that financial and educational resources play a protective role in the stress-adaptation process for those individuals who experience functional decline. It will be important for future research to more thoroughly examine the mechanism behind this association.

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Chapter 3: Heterogeneity in Adaptation to Limb Loss: Trajectories of Resilience, Depression, and Posttraumatic Stress

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Abstract

Objective**:** Limb Loss (LL) is a significant and disabling physical impairment with important health, mobility, and psychological consequences. Nevertheless, individuals can adapt and lead happy and healthy lives. The empirical literature has historically focused upon elevated rates of depression and other psychopathologies after limb loss, while resilience and other alternative patterns of adaptation have received substantially less empirical inquiry. ***Methods***: Individuals (*n* = 203) were followed across 3 measurement points representing a 6-month period following the onset of new limb loss. Trajectories of depression symptoms beginning directly after amputation were identified using Latent Growth Mixture Modeling (LGMM) and then explored as potential predictors of the development of posttraumatic stress (PTS) as a distal outcome. ***Results***: Four trajectories of depression were identified: resilience (73.2%), chronic depression (11.2%). emerging depression (8.9%), and recovery (6.7%). A chronic depression trajectory predicted significantly elevated PTS symptoms compared to all other classes in post hoc comparisons; the resilient class predicted significantly less PTS burden than the emerging depression class but did not differentiate from the recovery trajectory. ***Conclusion***: The current analysis confirms that psychological adaptation following amputation is a heterogeneous process, with varying pathways of symptom development and remission. Further, the derivation of latent classes of mood symptoms in longitudinal data (performed here using LGMM), may prove useful as a risk surveillance tool, especially with respect to clinical outcomes like PTS with unique time course requirements. Identifying predictors of resilience and other longitudinal profiles is a crucial goal above and beyond the monitoring of risk, in order to advance the scientific understanding of the complex process of adaptation to limb loss.

KEYWORDS: Amputation; Disability; Depression; Latent Growth Mixture Modeling; PTSD

WORD COUNT: 265

Adaptation to Limb Loss: Heterogeneous Trajectories of Resilience, Depression, and Posttraumatic Stress

Limb Loss is a significant and disabling physical injury with important mobility, health, and psychological sequelae. The prevalence of limb loss has been estimated at greater than 1.6 million individuals in the U.S. (Ziegler-Graham et al., 2008), a number that is expected to double by 2050 due to the obesity epidemic and related health conditions (e.g., diabetes). Within rehabilitation psychology, empirical and clinical efforts have long been focused on supporting amputees during the adjustment process, especially identifying individuals at risk for depression or other acute adjustment difficulties (Kashani et al., 1983). The development of depression following acute illness or injury has been associated with suboptimal treatment adherence and greater morbidity and mortality risk (e.g., Galatzer-Levy & Bonanno, 2014).

The foundational principles of rehabilitation psychology (see: Dunn et al., 2016) are closely related to several early empirical studies of amputation (e.g., Dembo et al., 1956, 1975), and subsequent theories based upon these observations now form the cornerstone of the field's psychosocial approach (Wright, 1960, 1983). Successful adjustment to limb loss typically requires adaptation in multiple arenas, with changes to physical functioning or mobility, vocational and social roles, self-concept and body image, and stress related to pain or other medical sequelae (Dunn, 1996; Unwin et al., 2009).

Until recently, the empirical literature focused primarily on the association between limb loss and elevated rates of depression or other mood disturbance (Dunn, 1996). As with other disability classes (e.g., Wittkower et al., 1954), early psychological accounts of individuals with limb loss asserted a near-universal period of depression or psychological dysfunction. Wittkower (1947) studied a sample of wartime veterans with amputations (n=200) and concluded that "the amputation… is followed by a second spell of depression which is almost universal" (p. 21). Likewise, Caplan and Hacket (1963) reported that 100% of patients (*n*=12) following lower extremity amputations (n=12) developed "postoperative depression characterized by feelings of hopelessness and by preoccupation with impending death" (p. 1171), and Ewalt and Blair (1945) reported that 60% of veterans with wartime amputations (*n*=100) demonstrated "serious psychopathologic conditions."

While these early empirical studies were rife with methodological flaws that have largely been addressed,[2] other prominent sources of bias have persisted in the rehabilitation literature. Beginning in the 1980's, researchers started highlighting the overtly negative vantage point of research on adjustment to disability (Shontz, 1982), which had disproportionately focused upon depression and reactive mood disorders, and largely treated disability from within the 'disease-model' of medicine (Dunn & Dougherty, 20050829). This was especially the case with research on adaptation to limb loss (Dunn, 1996), which continued to publish estimates of depression at rates as high as 35% (Kashani et al., 1983) even after the adoption of standardized instruments based on DSM-III depression criteria. Overall, an overreliance on cross-sectional data and the neglect of individual differences in favor of group-level means prohibited a more complex and comprehensive understanding of the process of adaptation to limb loss, as did the use of cut-points to establish depression 'caseness' (e.g., (Singh et al., 2007).

In the time since the early empirical work cited above, only select studies have endeavored to offer a more complex and nuanced view of the process of psychological adaptation to limb loss. For example, Kratz et al. (2010) examined longitudinal symptoms of depression, PTSD, and anxiety over time, with the specific aim of characterizing variation in

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[2] These included overinterpretation of interview data, lack of operational definitions for depression, use of unstandardized psychometric instruments (e.g., the Rorschach Test).

these areas across subsets of amputation etiology (i.e., dysvascular vs. traumatic). Others have examined larger groups over time, in predominantly cross-sectional but some longitudinal designs. Of particular note is a recent study of depression post-amputation endeavored to use a multilevel (nested) modeling approach (Roepke et al., 2019). In spite of visual depictions of significant heterogeneity in spaghetti plots[3], the authors found a group-level initial decrease in depression, followed by negligible changes in symptoms over time (Roepke et al., 2019). Thus, current statistical approaches to modeling adjustment post-amputation have yet to address what is likely substantial heterogeneity in adjustment patterns.

By contrast, a growing corpus of research from the broader stress response literature has increasingly confirmed the presence of resilience and alternative pathways of adjustment following a variety of aversive life events (Bonanno, 2004; Galatzer-Levy et al., 2018), including serious injuries and disabilities like SCI (Bombardier, Adams, et al., 2016; Quale & Schanke, 2010), traumatic brain injury (TBI; Bombardier et al., 2016), and cancer diagnosis (Burton et al., 2015). Many of these studies have utilized advancements in statistical modeling, that allow for the exploration of individual differences and group heterogeneity in adjustment patterns across time. Rather than requiring homogeneity as a basic assumption, methods such as latent growth mixture modeling (LGMM) and latent class growth analysis (LCGA) allow for the parsing of distinct subgroups of individuals who share similar patterns of change across time (i.e., intercepts and slopes; Jung & Wickrama, 2008; Muthén, 2004; Nagin & Odgers, 2010). Utilizing these methods, latent classes (often referred to as growth trajectories), are derived from the data using the expectation-maximization (EM) algorithm and provide important advancements over the use

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[3] As with other types of modeling, visual inspection of *k*-level spaghetti plots is suggested as an important step when modeling longitudinal data.

of *a priori* groups (a requirement for popular statistical methods such as analysis of variance; Jung & Wickrama, 2008; Muthén, 2004).

Longitudinal research is essential to the social sciences to understand how psychological states develop and change over time, and more importantly, what predicts this change and for whom. LGMM as a methodology is well-suited for answering these types of questions, and can explore the influence of covariates as predictors of trajectory membership, in order to determine what factors are most closely associated with differential patterns of adjustment. Based upon prior research, we posited the impact of demographic predictors (e.g., age, gender, education level, ethnic/racial minority status, etc.) would be negligible (Darnall et al., 2005), whereas we hypothesized that elevated pain would be a significant predictor of trajectory membership.

The current study sought to apply LGMM to a sample of recent amputees, to explore trajectories of depression following amputation. In addition, we sought to explore the association between trajectories of depression and the development of posttraumatic stress symptoms at the 6-month timepoint. Amputation is associated with increased risk for posttraumatic stress disorder (PTSD), although incidence is slightly lower than other serious injury classes such as SCI and serious burns (Martz & Cook, 2001). We hypothesized that: (1) PTSD scores would vary significantly across the latent classes, and (2) that PTSD scores would be greatest in the trajectory with the most depressive symptoms (i.e., the chronic trajectory, if identified), given previously identified overlap between depression and PTSD in populations with limb loss.

Method

Data

The current analysis utilized archival data from two sequential longitudinal studies conducted by a collaborative research group at a large academic medical center. Both stages of data collection sought to explore factors impacting the adjustment of individuals with new onset limb loss, and gathered data about participants’ mood, level of pain, and behavioral health factors. Given commonality across data sets with respect to psychometric measurement of mood and psychological symptoms (e.g., depression and PTSD), no data harmonization methods were required for the current study. Significance tests were conducted to rule out systematic differences in demographics, pain, and depression scores across the data collection waves. These were negative with the exception of age ($F_{1,194}=8.29$, $P<.05$); the average age of participants was slightly higher in wave 1 of data collection (52.3 years, *n*=98) versus wave 2 (46.4 years, *n*=98). Data for the present analysis were first sorted (ascending) and merged by participant ID using SPSS syntax (version 27). Study protocols and data collection procedures (described below) were approved by the University of Washington Human Subjects Division and the VA Puget Sound Health Care System Institutional Review Board.

Participants and Procedure

Participant recruitment and procedure have been partially described elsewhere (see: Kratz et al., 2010; Phelps et al., 2008). For both studies, participants were recruited from consecutive cases of amputation surgery within a large metropolitan hospital system (a Level 1 trauma center and a Veterans Health Administration Medical Center)[4] over a period of approximately four years (2002-2007). Participants were identified via the medical records system and evaluated for eligibility prior to being approached for consent. Participant inclusion criteria were: (1) Age 18 or older; (2) no previous amputations; and (3) ability to speak English. Etiologies of limb loss were not constrained, and included trauma, vascular disease, cancer, and others (e.g., infection).

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[4] Harborview Medical Center and VA Puget Sound, Seattle, WA.

To capture variation in the outcomes of interest in response to newly acquired amputations, individuals with a previous history of amputation surgery (greater than one digit) were excluded from the current study. Data for both studies were obtained following informed consent and included measurements at initial, 1, 3, and 6-month follow-ups. Data for initial interviews were conducted in person whereas follow-ups were primarily conducted over the phone. To facilitate model convergence, the present analysis utilized only three measurement waves for trajectory analyses: T0 (initial), 3-month, and 6-month timepoints. Final sample (*n* = 203) was predominantly male (78.8%) and Caucasian (83.3%) with an average age of 49.4 years (*SD* = 14.58) at the time of amputation. Sample demographics are summarized in Table 1.

Table 1. Overall sample demographics (*n* = 203)

	ns=197	Percentage % (SD)		*ns=196*	Percentage %
Mean Age	49.4	(14.6)			
Gender			Education		
Male	160	78.8	High school or below	76	37.4
Female	37	18.2	Some college or above	120	59.1
Marital status			Race/Ethnicity		
Married	65	32	Caucasian	161	79.3
Divorced/separated widowed	61	30	Other	35	17.2

*Note***:** percentages represent demographic proportions of overall sample (*n*=203).

Measures

Depression

Depression symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9; (Spitzer et al., 1994), a 9-item self-report module from the Primary Care Evaluation of Mental Disorders (Arroll et al., 2010; Kroenke et al., 2001). Symptoms within the past 2-weeks are rated on a 4-point likert-type scale ranging from 0 (“not at all”) to 3 (“nearly every day”), with an absolute range of 0-27. Previous meta-analyses have suggested a cutoff score of ≥ 10 as having sufficient sensitivity (78%) and specificity (87%; Moriarty et al., 2015), corresponding to qualitative descriptors of ‘moderate’ or greater. Chronbach’s alpha coefficients for the initial, 3-, and 6-month measurement waves were .78, .87, and .86 respectively.

Posttraumatic stress symptoms

Symptoms of posttraumatic stress were assessed at the 6-month timepoint using the PTSD checklist – Civilian Version (PCL-C; Weathers et al., 1993). The PCL-C asks respondents to rate 17 PTSD symptoms within the past month on a 5-point likert scale ranging from 1 (“not at all”) to 5 (“extremely”). Total PCL-C scores were calculated by summing the answers to all 17 items, yielding a total score range between 17-85. Although valid cutoff scores for probable PTSD vary depending on population prevalence rates (Norris & Hamblen, 2004), a range of 30-44 has been suggested to indicate *moderate to moderately high* scores, and 45-85 corresponds to *high severity*. Chronbach’s alpha coefficient for the PCL-C at the 6-month timepoint was .93. Full information maximum likelihood estimation was used to impute missing data for the PTSD variable at missing

Pain Intensity

Pain intensity was assessed using a composite of two items: current level of pain (at the time of interview), and average pain during the past month. The window of inquiry for the average pain item was shorter for the initial interview only, with slight variation across data collections: “average pain during the past 24 hours” (data set 1, *n*=104); “average pain during the past week?” (data set 2, *n*=99). Average pain intensity for the 3- and 6-month surveys referred to average pain during the past month across both data sets. Pain items were rated by participants on an 11-point scale ranging from 0 (“no pain”) to 10 (“pain as bad as could be”). A composite score was created by averaging the two pain items together, yielding a total pain score ranging from 0-10 for each timepoint. Chronbach's alpha coefficients across the 0, 3-, and 6-month measurement waves were .90, .84, and .88, respectively.

Predictor Variables

Demographic and situational covariates were examined for inclusion in the final conditional model, including age, gender education level (dichotomized as 0=high school or less, 1=some college or more), and ethnic/racial minority status (dichotomized as 0=white, 1=non-white/other) and marital status (dichotomized as 1=married/partnered, 0=other). Demographic and situational covariates were aggregated from self-report data and medical records.

Data analysis

In order to identify the best-fitting trajectories of depressive symptoms, Latent Growth Mixture Modeling (LGMM) was performed using M*plus* (Version 8.1; Muthén & Muthén, 2017). The best-fitting class solution was determined by testing successive models of increasing complexity and comparing k vs. k-1 model-fit statistics for each model iteration. All models tested included the estimation of intercept, slope, and quadratic parameters. We allowed the variance of the intercept and slope parameters to be freely estimated across classes, whereas the quadratic parameter was fixed to facilitate model convergence. Our selection of the final model was made using Akaike (AIC), Bayesian (BIC), and sample-size-adjusted Bayesian (SSBIC) information criterions, entropy values, and the Vuong-Lo-Mendell-Rubin (VLRT) and bootstrap likelihood-ratio tests (BLRT). In addition, interpretability, model parsimony, and theoretical coherence were considered in the selection of the final unconditional model (Bonanno, 2004; Jung & Wickrama, 2008; Muthén, 2004; Nagin & Odgers, 2010). Following identification of the final unconditional model, we examined a conditional model that included demographic covariates, using multinomial logistic regression to assess the impact of predictors upon class assignment. PTSD as a distal outcome was analyzed using the auxiliary function in M*plus* using the BCH method (Asparouhov & Muthén, 2014b). Full information maximum likelihood estimation (FIML) was used to handle missing data for the 6-month PCL-C scores and depression across the 3 timepoints.

Results

Unconditional Model

We tested 1-5 class solutions and observed good model convergence and continued improvement in information criteria (AIC, BIC, SSBIC) through 4 classes (see Table 2). The addition of a 5th class yielded an increased BIC, suggesting the 4-class model as optimal (Jung & Wickrama, 2008; Nylund et al., 2007; van de Schoot et al., 2017). Entropy improved to above .80 for the 3- and 4-class models indicating strong classification confidence (Muthén, 2004; Ram & Grimm, 2009), before decreasing to a value of .74 with the addition of a 5th class. Likelihood ratio tests (VLM LRT, BLRT) were significant through 4 classes with the exception of a marginally nonsignificant VLM LRT for the 4-class model (p=.07). The addition of a 5th class yielded clear non-significance on the VLM likelihood ratio test, which in concert with information criteria and entropy signals indicated the 4-class model. Thus, subsequent analyses compared differences across the identified 4-class model, which was theoretically coherent and interpretable.

Table 2. Fit Indices for one- to five-class latent growth mixture models of depression (unconditional model, N=203)

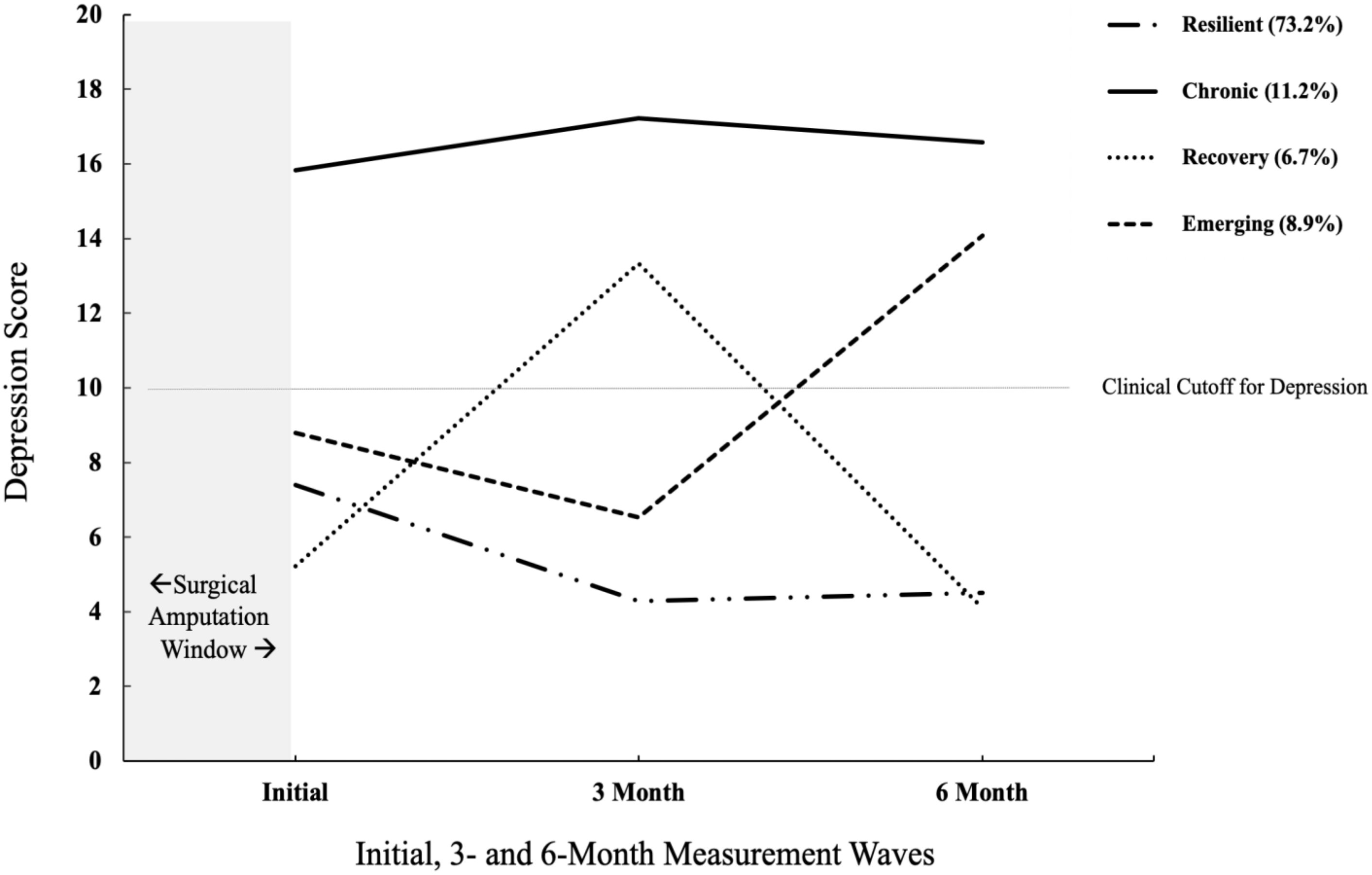
	Model				
Statistic	One class	Two class	Three class	Four class	Five class
AIC	2660.80	2615.24	2601.07	2587.36	2575.03
BIC	2683.99	2651.65	2650.77	2650.31	2651.24
SSBIC	2661.81	2616.80	2603.25	2590.12	2578.37
Entropy	–	.79	.85	.81	.74
VLMR	–	53.59	22.13	21.71	20.33
VLMR p-value		(<.05)	(<.05)	(.07)	(.51)
BLRT	–	53.59	22.13	21.83	20.33
BLRT p-value	–	(<.001)	(< .001)	(<.001)	(.03)

Note: AIC = Akaike Information Criterion; BIC = Bayesian Information Criterion; SSBIC = Sample Size Adjusted Bayesian Information Criterion; VLMR = Vuong-Lo-Mendell-Rubin Likelihood Ratio Test; BLRT = Bootstrap Likelihood Ratio Test.

The final unconditional model describes 4 unique depression trajectories (see Figure 1). The largest class was *Resilient* (73.2%) exhibiting low levels of depression throughout the 6-month study. The resilient class was characterized by a low intercept (b = 7.40, SE = 0.50, p < .001), a significant negative slope (b = -1.60, SE = 0.21, p < 0.001), and a significant positive quadratic parameter (b = 0.19, SE = 0.03, p < .001). Next largest was a *Chronic Depression* trajectory (11.2%), with consistently high levels of depression symptomatology across the 6-month study. This class was characterized by a high intercept (b = 15.83, SE = 1.18, p < 0.001), a non-significant linear (b = 0.81, SE = 0.43, p = .06), and a non-significant quadratic parameter (b = – 0.11, SE = 0.06, p = 0.07). The third largest class was an *Emerging Depression* class (8.9%), characterized by mildly elevated initial and 3-month depression scores, followed by a significant increase in depression at the 6-month measurement wave. This class had a significant intercept (b = 8.79, SE = 1.38, p < .001), a significant negative slope (b = –2.39, SE = 0.80, p = .003), and a significant quadratic parameter (b = 0.55, SE = 0.09, p < 0.001). Finally, a *Recovery class* (6.7%) was defined by low initial depression that increased to moderate during the middle wave, followed by a return to baseline at the conclusion of the study. This trajectory was characterized by a low intercept (*b* = 5.23, *SE* = 1.25, *p* < .001), a significant linear (*b* = 5.59, *SE* = 1.01, *p* < .001), and a significant quadratic parameter (*b* = –0.96, *SE* = 0.13, *p* < .001).

Figure 1. Final 4-class unconditional model (n=203)

Figure 1. Final 4-class model of depression trajectories across four time points (*n* = 203). Horizontal gray line represents cutoff for clinically significant depression.



Conditional Model

Following identification of the unconditional model, the impact of continuous predictor variables on class membership was explored in a conditional model. Predictor variables selected for inclusion in the final conditional model were: pain (reported intensity at time of initial interview) and participant age. The addition of covariates to the unconditional model resulted in a reduction in sample size (*n*=155) due to missing predictor data. Results are presented in Table 3 and reveal that pain at the time of initial interview was an independent predictor of membership in the resilient class compared to the chronic and emerging depression classes, but that pain did not predict membership in the resilient versus the recovery trajectory. Age was treated as a control variable in these analyses but did not statistically predict class membership. The addition of covariates to the unconditional model did not significantly alter the shape of the trajectories and resulted in only minor alterations of proportional trajectory membership. Entropy for the conditional model was comparable (.79).

Table 3. Multinomial logistic regression predicting class membership (n = 203)

Reference Class	Resilience vs.					
	Chronic Depression		Emerging Depression		Recovery	
	Est	*SE*	*Est*	*SE*	*Est*	*SE*
Age	– 0.05	0.03	–0.022	0.027	–0.04	0.03
Pain	0.38**	0.17	0.37*	0.17	0.22	0.13

Reference Class	Chronic vs.				Recovery vs.	
	Emerging Depression		Recovery		Emerging Depression	
	Est	*SE*	*Est*	*SE*	*Est*	*SE*
Age	0.03	0.03	0.00	0.04	0.02	0.04
Pain	–0.00	0.19	–0.16	0.15	0.16	0.19

Note: $p \leq .05$* ; $p \leq .01$**; $p \leq .001$***.

In addition to the primary conditional model, an auxiliary logistic regression analysis was conducted to explore categorical demographic covariates as predictors of class membership. Because the distribution of categorical covariates resulted in small cell sizes for certain classes (e.g., counts < 2 for race and gender within emerging depression class), demographic predictors were analyzed using the 3-step auxiliary method in M*plus* (R3STEP; Asparouhov & Muthén, 2014a, 2014b).[5] Demographic variables used as predictors of the latent classes were first dichotomized and included education, race, marital status, and gender. Results of the multinomial logistic regression of class membership on demographic covariates were nonsignificant for all four predictor variables: gender, education, racial/ethnic minority status, and marital status (see table 4).

PTSD as Distal Outcome

In order to assess whether trajectory membership was associated with increased risk for the development of PTSD, we conducted a distal outcome analysis regressing class assignment on 6-month PCL-C scores using the auxiliary command in M*plus* (BCH method; Asparouhov & Muthén, 2014). The result of the omnibus equality of means test was significant $\chi^2(3, N = 203) = 77.19$, $p < .001$, confirming our original distal outcome hypothesis that PTSD would vary significantly across trajectories. In general PCL-C estimated means by class were highest in the chronic trajectory and lowest in the resilient class (see table 3), descending by class as follows: chronic depression **(***M*=59.15, *SE*=4.03, *severe range*), emerging depression **(***M***=** 41.95, *SE*=4.16, *moderate range*), recovery class (*M*=31.46, *SE*=8.9; subclinical), resilient (*M*=24.65, *SE*=1.12; subclinical). The chronic depression trajectory revealed significantly greater PTSD symptoms compared to all other classes in subsequent pairwise chi-square significance tests, confirming our follow-up hypothesis that PTSD scores would be highest for the class with the greatest depressive burden. The emerging depression trajectory demonstrated significantly

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[5] This method ensures that predictor variables with alternative distributions or direct effects on the indicator variables (i.e. depression scores) do not exert undue influence on the shape or distribution of the classes, thereby rendering the trajectories uninterpretable (Asparouhov & Muthén, 2014a).

greater PTSD symptoms compared to the resilient class but not the recovery trajectory. The resilient trajectory had the lowest degree of PTSD symptom burden overall, although did not statistically differentiate from the recovery trajectory.

Table 4. Results of pairwise equality of means tests of class membership predicting 6-month PCL-C scores.

	PCL-C			
Classes	*Est. Mean*	*SE*	$\chi^2(3)$	*p*
Compared to Chronic Depression	59.15	4.03		
Emerging depression	41.95	4.16	8.32	0.004
Recovery	31.46	8.90	7.84	0.005
Resilient	24.65	1.12	67.32	0.000
Compared to Resilient	24.65	1.12		
Chronic depression	59.15	4.03	67.32	0.000
Emerging depression	41.95	4.16	14.21	0.000
Recovery	31.46	8.90	0.57	0.451
Compared to Emerging Depression	41.95	4.16		
Recovery	31.46	8.90	1.09	0.30

Note: Omnibus test comparing all classes was significant $\chi^2(3, N = 203) = 77.19, p < .001$.

Discussion

Although rehabilitation psychology has long recognized that some individuals are able to cope resiliently after incurring serious injuries and disabilities, this has largely been presumed to be the minority response (Dunn & Dougherty, 2005). In the current study we applied LGMM to model heterogeneity in sequential depression scores across initial, 3-, and 6-month measurements. Our study revealed four prototypical patterns of symptom development over time – resilient, recovery, emerging depression and chronic depression – providing strong evidence that the course of psychological adaptation following limb loss is heterogeneous.

. The majority of our sample was characterized by stable, low levels of depression that decreased from the initial interview across the 6-month study (i.e. resilience, 73.2%). We identified a significant chronic depression group (11.2%), characterized by chronically elevated depression scores in the ‘severe’ range for the duration of the 6-month study window. An emerging depression trajectory (8.9%) was characterized by mild initial and 3-month depression levels that increased sharply by the conclusion of the study. Finally, the recovery trajectory (6.7%) was characterized by low initial depression levels, a significant rise to the moderate range at 3-months, and then a return to baseline sub-clinical depression by the conclusion of the study.

Based on the current findings, the majority of individuals with recent limb loss evidenced stable, low-levels of depressive symptoms over time, and were at relatively low risk for the development of elevated posttraumatic stress at 6-month follow-up. However, a significant proportion of the current sample demonstrated chronically elevated depression symptoms for the duration of the study (*chronic depression* trajectory, 11.2%) , which was also associated with the highest risk for PTS symptoms (estimated mean PCL score = 59.15, *severe range, n* = 23). This suggests that for a substantial minority of individuals, amputation presents prominent psychological difficulties during the acute adjustment period. Importantly, however, we do not know what segment of our sample was depressed prior to the event, reinforcing the necessity for prospective data in future studies.

While depressive reactions have received widespread attention in the amputee literature resilience has been a less common emphasis. Our findings provide substantial evidence that a majority of individuals who undergo limb loss do not report significant difficulties with depression during a 6-month recovery window, converging with a limited selection of previous literature (Dunn, 1996; Ladlow et al., 2015). Notably, resilient individuals in our sample were also at least risk of developing clinically significant posttraumatic stress symptoms by the end of the 6-month study (Estimated mean PCL-C score, *resilient class,* 24.65, mild/subclinical range).

This lack of disruption in mental health raises crucial questions about the determinants of resilience, including the need for identifying important mediators and moderators of resilience following limb loss. Our study was able to identify pain as a meaningful predictor of resilience – resilient individuals had lower pain scores than the emerging and chronic depression classes while controlling for age. Unfortunately, our ability to identify demographic predictors of trajectory membership was curtailed by relatively small sample size limiting statistical power.

The current study explored the relationship between depression trajectories and the development of posttraumatic stress symptoms at 6-months. This type of analysis could ultimately provide a foundation for the identification of at-risk individuals following amputation. While LGMM and LCGA are increasingly common in the behavioral sciences as a modeling tool for longitudinal data, the clinical utility of these methods has been somewhat less clear. Yet recent research has demonstrated the application of latent variable modeling to the medical setting to identify at-risk groups of individuals with similar vulnerability factors. Castillo et al. (2018) employed latent class analysis (LCA) at 6-weeks to predict psychological functioning at 12-month follow-up in a sample of individuals with orthopedic injuries (N=352) at 12-months. In a similar fashion, our study found that early identification of latent classes can successfully classify those at risk for downstream negative traumatic stress.

Limitations and Future Directions

There are several important limitations to acknowledge with respect to current findings. First, although the current study meets gross benchmark criteria for sample size sufficient to perform LGMM, constraints related to sample size limited statistical power for identifying predictors of trajectory membership, especially in smaller classes. Future studies with larger sample sizes will be necessary to identify meaningful predictors and determinants of trajectory membership. In addition, the 6-month timeframe of the current study prevented the consideration of alternative patterns of adjustment following, including the identification of a second recovery trajectory (i.e., whether some portion of the chronic and emerging depression trajectories would improve over a longer time course. 6-months has been identified as a potential “node” of adjustment difficulty for individuals with new-onset disabilities, given that pressure to resume previous activity levels and responsibilities (e.g., financial, vocational, familial) may increase after the acute recovery period, all in the context of new physical challenges and limitations, which may provoke additional adjustment stress. Future research should explore additional timepoints (e.g., 12-, 18-, and 24-months) in order to better understand the course of trajectories. Finally, although the association between the emerging and chronic classes and greater PTSD symptoms offers a novel contribution to the literature, it is important to note that this finding is based exclusively upon self-report data. Thus, it remains possible that the association between PHQ-9 trajectories and 6-month PCL-C scores is a statistical artifact of symptom over-endorsement (i.e., ‘yay-saying’). Future research should consider the use of symptom validity indices to improve diagnostic certainty, as well as adjuvant data modalities (e.g., clinical interview, collateral ratings, neurobehavioral correlates), which would substantially strengthen conviction in the association between depression trajectories and elevated PTS.

Conclusion

While trajectories have previously been conducted with mixed linear models of functional impairment after amputation (e.g., Vogel et al., 2014), to our knowledge the current study is the first published work that utilizes LGMM to identify trajectories of mood symptoms in individuals with recent limb loss. Our findings confirm that the course of depression following amputation is indeed heterogeneous, with a variety of prototypical patterns of symptom development over time. The modal outcome was resilience, a finding that converges with a large corpus of research on adaptation to stressful life events (see: Galatzer-Levy et al., 2018). The findings offer a substantial contribution to the extant literature, which has previously obscured heterogeneity with mean effects in cross-sectional data (for an excellent review of the 'problem of heterogeneity' in case-control designs see: Feczko et al., 2019), or in the case of longitudinal studies, upon group-level averages of depression over time (Singh et al., 2007, 2009), with only select exceptions (Dembo et al., 1956, 1975; Kratz et al., 2010)

Future studies with larger sample sizes are needed to properly identify and understand the determinants and predictors of trajectory membership, especially the role of demographic factors. In particular, recent studies of disability have identified socioeconomic factors as significant predictors of mental health trajectories following disability onset (Kavanagh et al., 2015; McGiffin et al., 2019; Smith et al., 2005), which if replicated in samples of individuals with limb loss would represent crucial targets to help guide public health policy and treatment recommendations. Nevertheless, our study advances the scientific understanding of the impact of self-reported pain by demonstrating heightened pain as a risk factor for membership in the emerging depression and chronic depression classes.

Lastly, an important qualifier to our finding that the majority of individuals are resilient following limb-loss. In spite of the fact that the resilient class' average depression was in the sub-clinical range at the 3- and 6-month timepoints, the class average at the initial time-point was decidedly in the mild depression range. This indicates that during the initial post-surgical phase, a majority of individuals endorsed mild but clinically significant mood disruption, underscoring the challenging nature of undergoing the amputation of a limb. Future studies should continue to address the acute adjustment period, to increase options for brief intervention and to improve our basic scientific understanding of the psychological challenges inherent in the loss of a limb.

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Chapter 4: Adjusting to Limb loss: A Guide Based on the Science of Resilience

(For Patients, Families, and Medical Practitioners)

Limb loss is an undeniably challenging and difficult life event. Regardless of the cause of your amputation, the experience of losing a limb presents a new set of physical and emotional challenges that may at times seem overwhelming. However, one of the biggest myths about recovery from limb loss, is that all individuals will inevitably become hopeless or depressed after their amputation.[1–3] ***This is simply not the case***. Most individuals find that they are able to adapt successfully and cope well with the challenges presented by amputation, especially over time. From studies of human psychology, we now have compelling evidence that human beings are resilient across a broad range of difficult life events, including physical disability and serious injury.[4–8] As an individual recovering from limb loss surgery, there is every reason to expect that you will adjust quite well over time.

While resilience and successful adaptation are common, it is important to acknowledge a range of other emotional responses that may arise during your recovery process, including grief, anger, sadness, loss, and worry.[9] These experiences are a *normal* part of the adjustment process – what you are going through is tough! – and you may find yourself feeling irritable, tearful, frustrated, or emotionally overwhelmed after your amputation. Research shows that for most individuals, these periods of emotional upheaval tend to fade in intensity over time.[1] However, if symptoms intensify or begin to get worse over time, it may be important to consult your healthcare provider to explore possible treatment options. These options include talking with a psychologist or other care provider to help support your adjustment, consulting with a psychiatrist or other MD to explore the possibility of medication, and peer support from other individuals with limb loss.

As part of your discharge plan from acute rehabilitation here at Mount Sinai Hospital, you will leave with an understanding of these types of psychological resources, as well as appropriate referrals, should you wish to continue psychological consultation after leaving the hospital. In addition, we have a once-monthly peer support group (information below) that we hope you will attend!

Beyond these broad trends of adjustment to limb loss, there are some important differences that may be specific to the primary cause of your amputation. In general, amputations are caused by three main categories of life events – **traumatic injury, cancer**, and **vascular disease –** although in rare cases there are other causes. These unique contexts for limb loss may present their own psychological recovery patterns.

Amputations from Vascular Disease and Diabetes

Vascular disease, including diabetes mellitus and peripheral arterial disease, is the most common cause of amputation worldwide. Each year, over 50% of amputations nationwide are related to vascular disease.[10] Importantly, amputations from vascular disease typically occur in the context of a pre-existing health condition (e.g., diabetes), which may itself be challenging or difficult to manage. As an individual with vascular disease, you may have already encountered a lengthy struggle with chronic skin infections, difficulty healing wounds, previous vascular surgeries (such as an arterial bypass), and even previous amputations. Thus, you may have been suffering for a long period of time prior to your amputation with both chronic pain and reduced mobility. Because of this, some individuals may be surprised to experience relief after their amputation, as a long and drawn out process comes to an end[11]. Although many people will still experience grief and loss, the amputation can also mark a turning point, and an opportunity for a fresh start. One of the most sensitive psychological processes that individuals may undergo after amputation due to vascular conditions are questions about whether or not there was more they could have done to manage their own health effectively and prevent amputation. For some individuals there may be feelings of guilt or remorse as they wrestle with negative health behaviors they may regret. For others, amputation may truly have been unavoidable. Either way, we encourage you to be gentle during this process of self-inquiry, and to discuss your thoughts and feelings with your rehabilitation psychologist. As a possibility, consider that many individuals with vascular disease use the experience of limb loss to renew their commitment to their own health, self-care, and wellbeing.

Traumatic Amputations

A traumatic amputation is one that results from an accident or serious injury. Because these events are often sudden and potentially life-threatening, they may be accompanied by a unique set of psychological responses, including: frequent memories of the accident, nightmares related to the event, feeling more anxious than usual, feeling watchful or vigilant to further threat of injury, and being jumpy or easily startled. As with other emotional responses to extreme life stressors, mild versions of these symptoms are generally considered to be a normal part of the adjustment process. However, if these symptoms don't go away with time, it would be important to seek help, as you may be experiencing posttraumatic stress disorder (PTSD). Your rehabilitation psychologist can help you to create an open dialogue with your healthcare team should any of these difficult feelings arise, as well as to make recommendations for your care following discharge. There are many effective treatments for these types of responses to traumatic events.

Another unique aspect of traumatic amputation, is that individuals may have sustained other injuries during the course of their accident, including internal injuries, skin wounds, damage to other limbs, and even additional amputations. As a result, the healing process for traumatic amputees may include numerous surgeries during the acute hospitalization period, especially if lifesaving therapies are necessary immediately following the accident. In spite of these added challenges, traumatic amputees generally recover quite well, even while dealing with additional injuries.

Individuals who encounter sudden injury or traumatic accidents, may also feel that their world view or basic belief systems have been fundamentally challenged. For instance, you may no longer feel as though you live in a safe and predictable world, or perhaps your religious beliefs have been called into question ("Why did God let this happen to me?"). Individuals who experience this disruption may have very different approaches to resolving this conflict with their belief. Some may find a new relationship of acceptance to the unpredictable nature of life; others may go more deeply into reliance upon their spiritual beliefs; and still others may find themselves relying upon relationships with family and friends to rediscover their sense of stability and purpose.

Amputations from Cancer

Amputations from cancer are the third most common cause of amputation in the United States. The types of cancer that may lead to amputation are usually bone or soft tissue cancers but include a range of other malignancies. As with amputations from vascular disease, individuals with amputations from cancer typically have some time to prepare for the possibility of amputation. For some people this may be a period of weeks or a few months, as it becomes apparent that amputation is the most effective treatment for their cancer. For others, amputation may come many years after the initial diagnosis of cancer, after other treatments have failed, or after the limb has had difficulty healing from previous surgeries to remove a tumor. Individuals with cancer may have also experienced a long road of difficult treatments, including chemotherapy, radiation, prior tumor resections, and even experimental treatments. Thus, as is the case with vascular disease, amputations from cancer may be the endpoint in an already long road of medical treatments, suffering, and psychological or physical pain. In addition to grief and loss, some individuals may feel relief after their surgery, given that it may come at the end of a long process of decision making.

Adaptation to limb loss after cancer will inevitably be related to each person's feelings about the diagnosis of cancer itself. A diagnosis of cancer can be a frightening, life-altering event, that for many people seems to come out of the blue. In particular, many of the cancers that result in limb loss commonly occur in teen-agers or young adults; coping with cancer at an age when one's peers are healthy and having fun can bring its own set of challenges. It is common to ask, "Why me?" or to feel intense anxiety or even anger. That said, once it becomes clear that amputation is the most effective treatment for halting the progression of a given cancer, many people are strongly in favor of the amputation, as it may be understood to be a life-saving therapy (this is sometimes referred to as the choice between “life or limb”). Sometimes this can lead people to a different type of grieving process: the loss arising from the amputation occurs in the context of saving their own life.

Common Experiences Following Limb loss

Post-Amputation Pain

Nearly all amputees experience some form of pain following amputation. Although estimates may vary, a recent national survey of amputees found that 95% had experienced amputation-related pain during the past month.[12] In general, post-amputation pain falls into three categories: residual limb pain (pain originating at the site of amputation or “stump”), phantom pain (pain experienced as if were originating in the part of the limb that is no longer there), and phantom sensations. There are many effective therapies for phantom pain, including medication, stimulation (such as rubbing the affected limb), and even mirror therapy. It is strongly suggested that you discuss your pain with your rehabilitation doctor, to let them know what you have found helpful for your pain. The rehabilitation doctor may be able to recommend other specialists should your pain become intolerable. Phantom pain is an active area of scientific research, and there are regularly new therapies emerging from this active research.

Body Image

Nearly all individuals with physical disabilities are confronted with issues related to body image and physical appearance. Our society places heavy emphasis upon a narrow definition of physical beauty, which is only now beginning to include bodies of all different shapes, sizes, and ability levels. As you venture out into the community for the first time following your amputation, you may be surprised to find people that people may look at you differently, and you will likely experience “staring” behaviors for the first time. This can often come from children, who are less inhibited about their curiosity than adults. For new amputees, this process can sometimes be jarring or upsetting, and is an important topic to discuss with your support system or rehabilitation psychologist. Over time, some amputees who are regular prosthetic users may be able to conceal their amputation with clothing or prosthetic covers, which enables them to control how the world sees them. Sometimes, amputees choose not to conceal their disability; they may wear a prosthetic without a cosmetic cover or chose to ambulate with a wheelchair or crutches depending on their mobility level and amputation type. This is another process of discovering your own comfort level with revealing your amputation to the world, and like many processes of adjustment will likely evolve over time. Many amputees eventually come to accept staring behaviors as originating mostly from curiosity in others, or from a place of concern or caring.

You may be surprised to find that your relationship to your new body may be colored by your own ideas and preconceived notions about disability prior to your amputation. For instance, you may suddenly realize that you think of people with disabilities as weak, ugly, or unattractive. If this is true, you may now be confronted with this harsh and unloving tone turned inwards upon yourself, leading to shame about your amputation, and an inability to think of your new body as attractive. For some people, it may be difficult to feel strong and secure again. For others, it may be difficult to feel delicate or beautiful again. Experiencing your new body as beautiful and attractive may take time, but you can begin the important work of trying to love yourself and be self-compassionate right away.

Sexuality

Many people experience difficulty feeling confident in their physical appearance and body image, even prior to amputation. Of course, losing a limb may present an entirely new set of complicating factors related to body image. "How will I be attractive to other people in this new body?" "If I do become romantically involved with someone, how will I possibly have sex in this new body?" "If I show someone what's underneath my clothes, will they still love me?" "Can I *myself* love this new body?" "Are "stumps" beautiful or ugly?" This process, like many others in adjusting to amputation, usually *takes time*. However, most amputees report a process of coming to love and accept themselves in their new physical form, and report being able to have open and loving relationships of all kinds.

Beyond the experience of attractiveness, sexuality will also be experienced differently in this new body, and not just because of your body image. There may also be difficulty with moving physically in the ways that you used to, or difficulties stemming from underlying health problems related to the amputation, such as cardiovascular issues. Learning to be secure in your sexuality after amputation will necessitate an open mind and creative approach to physical encounters that may take some getting used to. Some people are eager to try engaging in sexual behaviors again after amputation, whereas others choose to take their time, and engage when the time is right.

Peer and Family Support

One of the most important resources during any difficult life event is the presence of ***social support***. This social support often comes from friends, family, and loved ones, who may be intricately involved in your plans for discharge from the inpatient rehabilitation environment. Especially during the early stages of reintegration back into your community, these may be important figures for you to rely upon while you are regaining your independence and continuing with your rehabilitation on an outpatient basis.

Another important source of social support during the period following your amputation, is the option of meeting an ***amputee peer visitor*.**[13] There is perhaps no one better equipped to understand the challenges of adjusting to limb loss than another individual who has been through the process. While here at Mount Sinai, you may have already met with other amputees at our Mount Sinai Limb Loss Support Group, or you may have had a visit in your hospital room from one our Mount Sinai Amputee Peer Mentors. This is an important resource moving forwards, and we encourage you to continue to build relationships with other amputees during your adjustment process; they can provide important informational and emotional support during this crucial time. Even further, many amputees discover over time, that *becoming* a peer visitor and supporting other amputees can become a vital part of their own recovery process and ongoing mental health. Below are some community resources where you will find support from other amputees, including the amputee coalition of America which offers access to peer visitors as well as its own certified peer visitor training program.

Local Community Resources for Amputees:

- **Mount Sinai Limb Loss Support Group,** meets every third Wednesday of the month at 1450 Madison Ave. (at approximately 99th St.), 2nd floor, room 269.
    - In addition to our own Peer Support group, there are numerous groups that meet monthly around the city at other hospitals, including **NYU Rusk Institute, Harlem Hospital, Columbia Medical Center**, and others.

- **Amputee Coalition of America** is non-profit organization that works tirelessly on behalf of amputees nationwide. Their website https://www.amputee-coalition.org is an excellent resource for information on everything from pain management to prosthetic care.
    - The ACA has a Certified Peer Mentoring (CPA) program, where you can gain access to a network of other amputees. Over time, you may have interest in giving back to the amputee community, and becoming certified as a peer-mentor to visit new amputees in the hospital setting is an excellent way of getting involved. You can access their Peer Support resources here: https://www.amputee-coalition.org/support-groups-peer-support/certified-peer-visitor-program/

    - The ACA also has a network of peer support groups already identified and validated on their website. This can be an excellent resource for local peer-support groups, as well as when traveling to get in touch with amputees from the local community: https://www.amputee-coalition.org/support-groups-peer-support/certified-peer-visitor-program/

    - The ACA sponsor's an annual conference, which includes amputees from all over the country and the world, who gather to participate in activities, classes, and gatherings (including dancing!) for a period of days. Many new amputees report this experience is profoundly transformational, because you are surrounded by caring and positive people with the same disability.

- **Recreational and Sports:** Physical activity is a crucial component of well-being and has been shown to be associated with resilience in individuals with limb loss.(Silverman et al., 2015) There are a growing number of sports and recreational teams for amputees who are interested in becoming physically active again. Several good examples are listed below:

- **Adaptive Climbing Group of New York:** This group is open to individuals of all disability types who want to learn how to rock climb. The group meets regularly at “Brooklyn Boulders,” a climbing gym in Brooklyn, but also hosts outings in greater New York. http://www.adaptiveclimbinggroup.org

- **Achilles International:** A national group dedicated to getting people of all disability types active and participating in running events. The group has an active New York chapter, which meets regularly in Central Park and across the city. For amputees that are not yet mobile or able to walk on a prosthesis, the organization has handcycles, which are powered by arms alone. Contact your local chapter through the national website: https://www.achillesinternational.org

Figure 1. Data from a recent study[1] show that most individuals are resilient following amputation (yellow line representing 81% of individuals over 6 months).

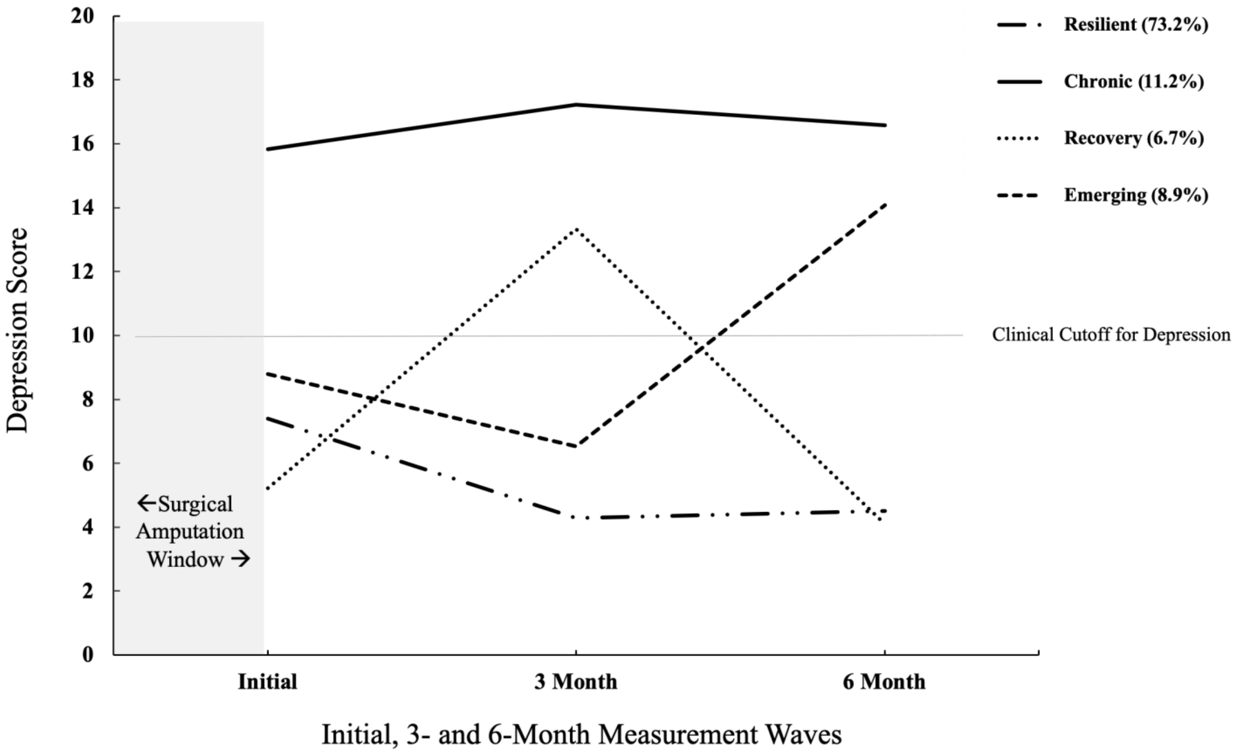

Figure 1. Final 4-class model of depression trajectories across four time points (*n* = 203). Horizontal gray line represents cutoff for clinically significant depression.

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Chapter 5: Discussion

The onset of a physical disability is a life-changing event that often impacts people's lives on biological, psychological, and social levels. The process of adapting to such a major life change is marked by numerous challenges that often vary substantially at different phases of adjustment, both initially and over the longer term. Empirical research has disability had historically emphasized its demanding nature and primarily on dysfunctional outcomes, such as reactive mood disorders or other psychopathologies, particularly depression and posttraumatic stress disorder (PTSD). The literature on disability has generally linked the acute stress of disability onset with elevations in mood or trauma-related symptoms, and subsequent decrements in quality of life related to social-role changes, identity disruption, and decreased participation in work and society (Rybarczyk et al., n.d., 2000; Turner & Beiser, 1990; Turner & Noh, 1988).
In spite of the prevailing emphasis upon psychopathology in this literature, however, it is also clear that not all disabled individuals experience persistent emotional dysregulation or permanent disruption in social and vocational functioning (Dembo et al., 1956, 1975; Dunn, 1996; Dunn et al., 2009). While the period of initial adjustment often includes transient emotional upheaval, with a variety of physical and emotional challenges that intensify at the outset of the acute adjustment period, many individuals are able to return to baseline levels of psychological and socio-emotional functioning(Dunn et al., 2009). Yet surprisingly little is known about how common resilience and other latent patterns of psychological adjustment are following disability onset. However, evidence across a broad swath of studies now supports the conclusion that resilience is the modal outcome after a diverse range of acute life events (Bonanno, 2004; Bonanno et al., 2011; Galatzer-Levy et al., 2010), including a small but growing selection

subclasses of illness and disability as well (Bombardier, Adams, et al., 2016; Bombardier, Hoekstra, et al., 2016; Burton et al., 2015; McGiffin et al., 2019; Quale & Schanke, 2010).

The current dissertation explores essential questions about the course of psychological adaptation to disability, including the basic question of whether adjustment over time can be captured by one prototypical response (such as a set of sequential adjustment stages more or less conformed to by everyone who shares a common disability type), or whether adjustment to disability is a heterogenous process, with multiple prototypical responses that have unique developmental time courses, symptom onset and remission patterns, and differential predictors and associated outcomes. The answer to this question is important at the level of scientific understanding but also suggests critical policy and treatment implications.

Studies 1 and 2 of this dissertation used cutting-edge computational methodologies that were well-poised to adjudicate these questions, more specifically whether adjustment to disability is best characterized by a single group-level average over time, or whether there are discrete (statistically discernable) subgroups of individuals who share similar patterns of adaptation. Moreover, empirical studies 1 and 2 suggest important conclusions about who might become depressed and why, which has important treatment implications. This discussion will review the contemporary science of resilience to potentially traumatic events, and how this can inform our understanding of psychological adjustment to disability. Findings from the current empirical studies will be reviewed and contextualized in the broader resilience literature, clinical implications will be explored, and directions for future research will be considered.

Resilience and Disability

Both culturally and scientifically, biases have prevented the advancement of the understanding of the “human capacity to thrive after extremely aversive life events” (Bonanno, 2004). A range of preconceptions have been shown to be at play, including the pervasive notion that acquired disabilities are uniformly psychologically damaging (Dunn, 2000). For one, research suggests there is a significant discrepancy between self-rated quality of life for individuals with disabilities (i.e., “insiders”), versus quality of life ratings made of the very same individuals by non-disabled observers (i.e., “outsiders”; Andrews, 2019; Dunn, 2000; Dunn et al., 2016). This discrepancy has come to be referred to as the “disability paradox” (Albrecht & Devlieger, 1999; Ubel et al., 2005). A number of mechanisms have been proposed for the disability paradox, including widely held cultural stigmas about disability, and the pervasive “ableism” if our culture (i.e., discriminatory beliefs that individuals with typical abilities are superior, and disability is stigmatized as something broken that requires fixing; Andrews, 2019). But while sociology and social psychology have been challenging the cultural and systemic prejudices that impact the lives of individuals with disabilities for many years (see also: somatopsychology and the Lewinian school), the literature on adjustment to disability has only recently begun to accommodate alternative patterns of adaptation, including resilience (Dunn, 1996; Dunn et al., 2009). In part, this is due to the slow advancement of statistical models that can handle longitudinal data beyond mean effects. Empirical studies 1 and 2 provide examples of how these statistical modeling tools can be applied to novel populations of interest, thus increasing the complexity and nuance of our understanding of the course of adjustment.

Empirical Findings

Review of Study 1

Study 1 sought to model heterogeneity in psychological adjustment to late-life disability onset and to explore the impact of socioeconomic resources on patterns of adaptation. Individuals with verified disability onset (n=3,204) were sampled from a large population level data set (The Health and Retirement Study, HRS) and followed for a 6-year period during which depression was measured at 4 timepoints. Latent Growth Mixture Modeling was used to identify four distinct trajectories of depression: resilience (57%), emerging depression (17%), remitting depression (13%), and chronic depression (13%). These trajectories provide strong confirmatory evidence that the course of adjustment in response to late-life disability onset is heterogeneous, with the most common pattern characterized by low levels of depression across the 6-year study (i.e., resilience).

One of the strengths of Study 1 results from the use of the HRS data set which provided access to true prospective data. The first wave of data represented in these analyses was gathered *before* the reported onset of disability, ensuring that individuals with elevated depression prior to the event were not misidentified as becoming depressed in reaction to the advent of functional impairment. A substantial number of individuals in the final 4-class model evidenced depression prior to disability onset, and one class revealed scores that remained elevated throughout the duration of the 6-year study (chronic depression group, 12.9%; class average CES-D at intercept = 6.3 out of a maximum range of 8). In addition, a remitting depression group (13.4%) also revealed elevated depression in the wave prior to disability onset (average CES-D at intercept = 4.7, *SE* = 0.14), although the pre-disability average for this class was only slightly elevated above the suggested cutoff for clinically significant depression. Our findings indicate that prior estimates of elevated depression post-disability (as high as 35% in some samples; Ormel et al., 2002; Turner & Noh, 1988) may be confounded by lack of pre-event data.

One caveat to this assertion should be noted, however. There is now a significant literature on the reciprocal relationship between disability onset and depression that is *bidirectional* - the presence of mood symptoms increases the likelihood of impairments in physical functioning (through proposed mechanisms of both direct and indirect effects; Ormel, 2002), in addition to the well-established causal pathway of impairments in physical functioning increasing risk for depression. The latter effect, however, was demonstrated to be stronger than the former in a seminal study utilizing cross-lagged panel methodology (Ormel et al., 2002), but the presence of both mechanisms was noted and described to create a mutually reinforcing feedback loop (or “downward spiral” effect). Thus, it is theoretically possible to overstate the assertion that the temporal primacy of depression in the chronic group in our study, leads to the conclusion that depression is therefore causally unrelated to subsequent disability. This is distinct from other prospective research on aversive life events (Bonanno et al., 2007; Tracy et al., 2011), where the presence of true prospective data represents access to a relatively “clean” pre-event measurement of psychological functioning, less hindered by selection bias. Another complicating factor of disability onset research - especially in elderly populations - is the fact that many conditions that result in functional impairment do not have discrete onsets, but rather are an endpoint of an emerging or chronic disease process that escalates over time into disabling physical sequelae.

Nevertheless, prospective data is essential to the study of depressive reactions surrounding disability onset and accumulating empirical evidence will continue to increase our nuanced understanding of this process. Without these data, the goal of targeted treatment interventions for those who become depressed contemporaneous to onset will be difficult to achieve. Moreover, it remains likely given current evidence that individuals with chronic, pre-existing depression vs. emergent depression post-disability have unique and discernable characteristics in both the development and maintenance of mood symptoms, requiring differential clinical sensitivity and care. Phenotypic differences in the chronic vs. emergent trajectories has been shown in samples of individuals with myocardial infarction as well as individuals who undergo a divorce, with the emergent trajectory demonstrating increased mortality risk in comparison to individuals with chronic depression (Galatzer-Levy & Bonanno, 2014; Malgaroli et al., 2017).

In terms of predictors of trajectory membership, study 1 revealed a strong impact of socioeconomic resources on class membership. Prior education and financial assets at the time of disability onset robustly predicted membership in the resilient class compared to all other classes. These findings dovetail with prior research demonstrating that financial and educational resources play a protective role in the stress-adaptation process (Hobfoll, 2002; Kavanagh et al., 2015; Mandemakers & Monden, 2010). It will be important for future research to thoroughly examine the mechanism behind this association. Notably, current research across broad swaths of neuroscience and developmental psychology have identified health and economic disparities as primary targets for intervention. Promising advances in the neuroscience of socioeconomic inequality (Noble & Giebler, 2020) are now poised to inform policy and evidenced-based interventions (Farah, 2018) adding to the mounting evidence in support of universal healthcare and universal basic income (UBI; Ruckert et al., 2018). Advancing our understanding of the protective role of SES factors in the process of disability adjustment will provide similarly important directions for future research.

Review of Study 2

Study 2 sought to model trajectories of depression symptoms in a sample of individuals with new-onset amputations (*n*=203). Individuals were followed for a 6-month period, with depression symptoms measured in three separate post-amputation interviews (initial, 3-month, and 6-month timepoints). Trajectories of depression were identified using LGMM and then explored as potential predictors of the development of PTSD as a distal outcome. Four trajectories of depression were identified: resilience (73.2%), chronic depression (11.2%), emerging depression (8.9%), and recovery (6.7%). A chronic depression trajectory evidenced significantly elevated posttraumatic stress (PTS) symptoms compared to all other classes; the resilient class was associated with significantly less PTS burden than the emerging depression class but did not statistically differentiate from the recovery trajectory.

Like Study 1, Study 2 also provides strong confirmatory evidence that psychological adaptation to disability is a heterogeneous process, although in this case with a more specific disability subset comprised of individuals with recent amputations. These data suggest varying pathways of symptom development and remission described by the trajectories, but also concord with Study 1 and the broader stress response literature to substantiate resilience as the modal response profile. It deserves mention that the resilient trajectory in this sample demonstrated an intercept (i.e., class average depression score at the initial measurement wave) technically in the "mild range" (PHQ = 7.4, *SE*=0.50), suggesting at least some variation across the resilient class inclusive of individuals with mild depression endorsements. Importantly, these symptom endorsements appear transient, as on the whole the resilient trajectory presents with sub-clinical average depression scores for the duration of the study (i.e., 3- and 6-month follow-up). However, the mild elevation in intercept for the resilient class is noteworthy, because it diverges slightly from findings in previous work, where it is rather rare for the resilient trajectory to have symptom ranges that are above the low or subclinical range. However, these findings might be understandable from another perspective – that individuals captured early in the post-amputation phase are likely very close to the disruptions of surgery, post anesthesia recovery, pain, and so on. This finding poses interesting questions for the future of resilience research and suggests there may be more variation at the minute level during the first month of recovery post-amputation. Experience sampling methods may be a way to capture this short-term fluctuation and are likely an important avenue to furthering our understanding of early heterogeneity in response to potentially traumatic events.

Finally, Study 2 explored the relationship between depression trajectories and the development of posttraumatic stress symptoms at 6-months, revealing that classes with chronic or increasing depression were also the classes with the highest average PTSD symptoms at 6-months. This finding is significant for a number of reasons. While LGMM and LCGA are increasingly common in the behavioral sciences as tools for modeling of longitudinal data, the clinical utility of these methods has been somewhat less clear. Recently, however, research has demonstrated how latent variable modeling might be employed in the medical setting to identify at-risk groups of individuals with similar vulnerability factors. Castillo et al. (2018) employed latent class analysis (LCA) at 6-weeks to predict psychological functioning at 12-month follow-up in a sample of individuals with orthopedic injuries (N=352). In a similar fashion, our study found that early identification of latent classes could successfully classify those at risk for downstream traumatic stress.

Finally, Study 2 provides preliminary support that the derivation of latent classes of mood symptoms in longitudinal data using LGMM may prove useful as a risk surveillance tool, especially with respect to clinical outcomes like PTSD that have unique time course requirements. However, many questions remain, including the validity of the association (see: Chapter 3, discussion, for limitations regarding self-report data). More importantly, however, should an association between depression trajectories and downstream traumatic stress be verified in future research, important questions about the range of psychological disturbance predicted by depression trajectories, as well as methodological considerations (e.g., the possibility that LGMM with a single indicator across time reduces measurement error by accounting for change over time, and thus is better poised to parse general mental health from dysfunction). Nevertheless, results suggest that similar analyses could ultimately provide a foundation for the early identification of individuals who are at-risk for the development of downstream psychological difficulty.

Clinical Implications

The findings from empirical studies 1 and 2 have relevant policy and clinical implications, when considered alongside complementary evidence from the rehabilitation sciences and the broader stress response literature. Identifying individuals with mood symptoms is important in populations of PWDs for several key reasons: (1) the development of clinically significant mood symptoms has been shown to be associated with accelerating functional decline for individuals with acquired disabilities (Aneshensel et al., 1984; Cronin-Stubbs et al., 2000; Stuck et al., 1999); (2) targeted treatment interventions are a primary goal of current rehabilitation and psychological science, consuming fewer resources and decreasing the risk of iatrogenic injury; and (3) ethical considerations inherent in the provision of healthcare to populations of PWDs, especially mental health treatment.

Depression increases the rate of functional decline for PWDs

Globally, depression is a leading cause of morbidity and mortality (Mathers et al., 2008). The risks of functional decline in individuals who both acquire disabilities and then subsequently develop depression have been outlined in numerous studies (Aneshensel et al., 1984; Cronin-Stubbs et al., 2000; Stuck et al., 1999). Moreover, accumulating evidence from longitudinal studies has shown that newly emerging depression symptoms following an aversive health event are associated with increased morbidity and mortality. In a prospective study of depression trajectories surrounding myocardial infarction, the emergent depression trajectory was associated with increased risk for mortality as a distal outcome, which was not the case for the chronic, improved, or resilient classes (Galatzer-Levy & Bonanno, 2014).

Targeted Intervention in Disabled Populations

Targeted treatment interventions are a primary aim for most modern clinical science endeavors. This is especially the case for rehabilitation psychology, which has been seeking to open up the "black box" of treatment to better understand the mechanisms of effective change and treatment (Hart & Ehde, 2015). One crucial feature of a properly matured clinical science program is limiting unnecessary intervention (especially provision of clinical interventions for those who would otherwise recover on their own; e.g., remitting or recovery trajectories).[6] Reserving treatment for those who really need it has a two-pronged effect, including preserving limited resources and spending, while also curbing the likelihood of causing iatrogenic injury by

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[6] Of note, it is important to highlight the crucial role of timing in the identification of cases for whom targeted intervention might be helpful. For one individuals on a recovery trajectory might look resilient or depressed depending on when they were sampled, which also underscores problems with cross-sectional research, and the necessity for better identification of early predictors to identify probability of belonging to recovery vs. resilient. Vs. emerging depression.

treating people who don’t need treatment. Evidence suggests that people who receive unnecessary treatments, especially after potentially traumatic events, may do worse.

Ethical Considerations in the Mental Health for PWDs

Closely related to the considerations above, are the ethical implications of verifying that the course of disability adjustment is heterogeneous and can be described by a number of prototypical pathways of symptom development and remission. As our understanding of these prototypical patterns becomes more fine-grained, it is possible to begin to predict whether individuals will improve, decline, relapse and remit – or moreover start low, and remain low without ever evidencing significant mood disruption.

Most plainly, these findings underscore the importance of not overtreating individuals with newly acquired amputations, due to the fact that most individuals across samples seem to be doing just fine. Does this mean that nobody needs or wants treatment? Certainly, this would be an overreaction and a misread of the data. In spite of not being depressed, an individual in a rehabilitation hospital who recently awoke from a traumatic accident and must now learn to walk with crutches for the first time -- while concurrently adjusting to pain, wound dressing changes, and profound alterations to body image and physical functioning – might have a few things to talk about with a well-trained rehabilitation psychologist who drops by to check in.

However, the current findings do put a check on the notion that newly disabled individuals need psychological professionals to come to their aide and fix them (this has undertones of the history of rehabilitation psychology, which has been criticized for a lengthy period of overdependence upon an “ableist” medical model during the latter part of the 20th century). In general, the philosophical questions provoked by the idea of the “well” medical practitioner or mental health provider treating the “sick” patient have been challenged by the disability rights movement with a profound and growing sense of clarity (see: Andrews et al., 2020 for a compelling discussion about medical rationing for PWDs during the Covid-19 pandemic). Contributions to the field of medical ethics by the disability rights movement and disability studies is ongoing, and individuals with disabilities will continue to exercise an important voice in the mission for an egalitarian health care system and a more just society.

Future Directions

Where does this leave us? The data and analytic methods presented in the current manuscript via empirical studies 1 and 2 ultimately support the humanistic viewpoint of early pioneers in the field of rehabilitation psychology and somatopsychology (Wright, 1960, 1983). It is not enough to simply group individuals by shared physical characteristics (e.g., PIAs) and study subsequent population-level adjustment. Rather, where psychological adjustment is concerned, individuals with disabilities appear largely the same as those with comparatively able bodies: heterogenous with a high degree of individual variability in their response to life stressors, their employment of coping and regulatory strategies, and their ability to access and use the resources available to them – not only to survive adverse life circumstances, but to thrive in the face of significant challenges. The path forward to understanding this heterogeneity rests in part with advancing the complexity of our scientific understanding of the process of human adaptation to disability, which can be supported by utilizing novel statistical methods to examine the most potent predictors of optimal and poor adjustment, especially in large samples. In this way, we will ultimately continue to identify ways of targeting these predictors in intervention research and public health policy. Finally, the field of rehabilitation must continue to listen to individual voices and support the lives of each person whose resources may falter. Although these difficulties are now indisputably known to arise in a minority of cases, they are no less important or crucial to address.

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