

Identity integration in people with acquired disabilities: A qualitative study

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Abstract

Objective: This qualitative investigation focused on identity integration in a sample of individuals who acquired physical disabilities in adulthood. It also argues for the importance and ethics of these methods in the broader field of scholarship on personality change following adversity.

Method: Thirteen adults participated in the study. Participants engaged in an expanded Life Story Interview wherein they narrated the story of their life, including a section devoted to their story of acquiring a physical disability. In addition, participants completed questionnaires concerning their psychological well-being and maturity.

Results: We identified two dimensions of narrative themes participants used in grappling with identity integration: one represented active processing of one's life experiences and the other represented the extent to which participants described their identity as wholly transformed by the experience of acquiring a disability. When overlaid, these dimensions yielded four narrative strategies titled: Adapters, Wanderers, Drifters, and Resisters. We also observed that Adapters seemed to have better psychological well-being and maturity than the other groups.

Conclusions: This study offers a foundation for future scholarship on identity among people with disabilities. It also describes the contexts in which retrospective, qualitative methods are especially appropriate for research on personality change following adversity.

KEYWORDS

disability, identity integration, narrative identity, qualitative methods

1 | INTRODUCTION

Acquiring a physical impairment inevitably serves as a biographical disruption.¹ Not only does this experience entail physical, psychological, and economic challenges, but it also introduces a potential discontinuity in one's identity, rendering the person a member of a social minority group with which they had not previously been associated: people with disabilities.² And yet, the psychological literature on identity

development in the context of disability is remarkably thin. A recent systematic review of the literature identified only 41 empirical articles on the topic published between 1980 and 2017 (Forber-Pratt, Lyew, Mueller, & Samples, 2017). Of those, only a handful appear in the personality literature (Adler, 2018). Considering that one in five Americans lives with a disability (Centers for Disease Control and Prevention, 2015; Houtenville, Brucker, & Lauer, 2016)—making disability the largest minority group in the United States—this is

a striking disparity compared to empirical research on identity among other minority groups.

While the social scientific literature on identity among people with disabilities is nascent, the topic has been central to the thriving interdisciplinary field of disability studies (e.g., Davis, 2017; Garland Thomson, 2013). This field, deeply grounded in the humanities, has examined the development of identity, the dynamic dialectic between individual experience and social structures, and the economic, political, semiotic, literary, and artistic contexts for understanding disability identity.

Building on seminal work (Olkin & Pledger, 2003), Dirth and Branscombe (2018) outlined an agenda for bridging disability studies and psychological science. This agenda is grounded in an anti-individualist epistemology that regards the individual as embedded within dynamic and reciprocal social contexts that give rise to identity. Furthermore, it is an approach that prioritizes the perspectives of people with disabilities as insiders and experts who have historically been marginalized. Concurrently with Dirth and Branscombe's work, I (Adler, 2018)³ also offered recommendations for bringing together disability studies and personality science through narrative research grounded in the voices of people with disabilities, seeking to build theory inductively as a foundation for future scholarship. While there are some tensions between the details of Dirth and Branscombe's recommendations and my own (derived from their social psychological vs. personality psychological lineages), we see these approaches as fundamentally consonant and cumulative. The present study offers another step forward in establishing a foundation for psychological scholarship on disability identity.

Importantly, the challenges involved in bridging disability studies and psychological science produce demands for a high level of clarity about the epistemological foundation for scholarship and its methodological rationale. These requirements make the present paper well-suited to the broader special issue of *Journal of Personality* in which it is embedded. The special issue was developed in order to showcase methodologically innovative research on the broad topic of positive personality change following adversity, with a specific focus on the phenomenon known as “post-traumatic growth” (e.g., Tedeschi & Calhoun, 1996). The majority of contributions to this special issue will demonstrate methodological approaches and analytic strategies aimed at overcoming many of the shortcomings that have characterized the literature on post-traumatic growth and other positive personality changes in the wake of major challenges (Infurna & Jayawickreme, 2019; Jayawickreme & Infurna, this issue). In particular, the other contributions to this special issue offer alternatives to the retrospective, cross-sectional, self-report methods that have dominated the literature on this topic. Situated amongst these contributions is our study: a retrospective, cross-sectional, self-report design, and one with a small sample size.

Yet our study also represents the only contribution to this special issue that relies on qualitative methods aimed at addressing a descriptive question in an inductive way. While the epistemological foundation for this study and its methodological rationale set it apart from the other contributions in this special issue, we argue that there is a vital role for precisely this type of research in the field of personality change following adversity, and indeed, in the broader field of personality research. Identity represents one domain of personality (e.g., McAdams & Pals, 2006), but similar approaches might be applied to other domains as well. Thus, while making a substantive advance in the study of disability identity, we also hope this paper will make an important methodological contribution to the future of scholarship on personality change following adversity. Before returning to the content focus of this manuscript—identity among people with acquired physical disabilities—we will first offer an argument for our approach.

1.1 | One role for qualitative methods in the study of personality change following adversity

The literature on post-traumatic growth has conceptualized its central construct in a number of ways, with little consensus (Jayawickreme & Blackie, 2014). Each approach seems to point to a notion that some people experience not only a return to their pre-trauma position (whether that is an affective state, a degree of cognitive awareness, or an identity configuration), but a progression to an enhanced position following a challenging experience. For example, Tedeschi and Calhoun (2004) wrote, “posttraumatic growth is not simply a return to baseline—it is an experience of improvement that for some persons is deeply profound” (p. 4). Theorists construe the specific nature of this change differently. In recent work, scholars have begun to rigorously examine the optimal operationalization of post-traumatic growth by marshalling more sophisticated methodological and analytical approaches to studying it. Indeed, this special issue is intended to be a showcase for such methods. However, throughout the literature on post-traumatic growth over the past decade there runs a central thread focused on differentiating the objective nature of positive change following adversity from individuals' subjective reflections on it. For example, Frazier and colleagues (2009) wrote about the importance of disentangling “the relation between perceived growth and actual growth from pre- to post-trauma” (p. 916). Likewise, Infurna and Jayawickreme (2019) assert the importance of pursuing research that will shed light on “actual personality change” and “real growth following trauma,” compared to “coping strategies” or “the growth illusion” (p. 155). We assert that the central endeavor of distinguishing true change from illusory change following adversity is ethically fraught. We do not

want to suggest that individuals' self-knowledge is always well aligned with other criterion measures such as informant reports or objective measures, as high-quality scholarship has clearly proven this to be incorrect (e.g., Vazire & Wilson, 2012). Yet a respect for individuals who have experienced significant challenges demands that their perspectives on these experiences be elevated in striving to understand their impacts. As Pals and McAdams (2004) wrote, "the life story should not be viewed as just one piece of the complex puzzle of posttraumatic growth...but rather as the fundamental frame that holds the entire puzzle together" (p. 65). The stories individuals construct about their experiences serve as the foundation for change, however it is operationalized. We do not intend this assertion in a precious, romanticizing way that seeks to elevate the specialness of adverse experiences and those who have undergone them, but as a straightforward scientific argument: the ethical scientific pursuit of understanding post-traumatic growth ought to prioritize the perspectives of those who report experiencing it as the optimal way of conceptualizing this phenomenon. There is a tradition of scholarship that adopts this approach, such as research focused on meaning making (e.g., Janoff-Bulman, 2010; Pals & McAdams, 2004; Park, 2010; Roepke, Jayawickreme, & Riffle, 2014). However, much of the contemporary scholarship on post-traumatic growth continues to place meaning making in opposition to veridical change. Therefore, we assert that the continued pursuit of validating the construct of post-traumatic growth must not only advance in the service of substantive construct validity, but also in the service of ethical validation (e.g., Angen, 2000).

How might an ethical science of post-traumatic growth proceed? We argue that qualitative methods ought to make a vital contribution to the future of this literature, in conjunction with the many quantitative methods advocated by the other scholars represented in this special issue. Qualitative methods represent a broad and heterogeneous approach to psychological scholarship. In recent years, the Society for Qualitative Inquiry in Psychology (SQIP), a section of APA Division 5 (Quantitative and Qualitative Methods), as well as other organizations and scholars, have worked to articulate and advance the role of qualitative methods in psychology. Reviewing that broad agenda is well beyond the scope of the present manuscript, but several major publications summarize this work (e.g., Frost et al., in press; Gergen, Josselson, & Freeman, 2015; Levitt et al., 2018; Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017; Piccirillo, Beck, & Rodebaugh, 2019; Tracey, 2010). We intend to use our present work on identity among people with acquired disabilities to advance one role that qualitative methods ought to play in studying personality change.

As Schwab and Syed (2015) articulated, psychological approaches can largely be grouped into one of two epistemological traditions: positivist and social constructionist. These two traditions often get erroneously conflated with

quantitative and qualitative methodological approaches, respectively. Yet epistemology need not map so simplistically onto methodology. While the present study straightforwardly adopts a qualitative methodology, it emerges from a somewhat more complex epistemological foundation.

Elsewhere (Adler, 2012a), I have written about the ways in which the study of narrative identity often strives to sit at the nexus of epistemological traditions. While positivist narrative research has flourished in the past few decades (e.g., Adler, Lodi-Smith, Philippe, & Houle, 2016), many narrative scholars seek to embrace the strengths of both positivist and social constructionist traditions in their work. This effort is never simple, often fails to satisfy purists in each tradition, and necessarily involves compromises that warrant criticism. However, as I have argued (Adler, 2018, 2019), I believe it is possible and valuable to embrace the subjectivity, provisionality, and contextualized awareness of social constructionist approaches in the service of accumulating a foundation for scientific, positivist scholarship. Qualitative methods can do *much* more than serve this end (Levitt et al., 2018)—this is only *one* role among many for qualitative inquiry in the study of personality change—but this is the approach we have adopted in the present study. We do so with the moral and political conviction brought to bear on a great deal of qualitative research with minoritized people, which "is not simply to illuminate the subjective worlds of others, but to do so in ways that the boundaries separating peoples—ethnic, religious, race, class, gender, sexual orientation, ability, and the like—are diminished or even removed" (Gergen et al., 2015, p. 3). In other words, the present study strives not only to further theory about identity among people with acquired disabilities, but also to make a values-based methodological argument about the ethical obligation for researchers to listen rigorously to their research participants—especially, but not exclusively, those from historically minoritized populations—in the development of theory.

We will describe the specific methodological choices we have made in more detail in the Method section, below. However, it is important to state from the outset that we intend this contribution to the special issue to serve as an example of deploying qualitative methods in the service of theory generation. Qualitative methods are not only especially well-suited to this kind of descriptive scholarship, but also facilitate a vital ethical agenda in conducting research on minoritized, marginalized, and traumatized populations, who are often the focus of research on positive personality change following adversity (e.g., Angen, 2000). In presenting a new model for disability research production, Nasir and Hussain (2018) argue for an "emancipatory-inclusionary intention," one that is "politically committed, but rigorous" (pp. 41–42). Without a doubt, both quantitative and qualitative scholarship can be conducted in the service of social change, however qualitative methods may be

especially well-suited to elevating marginalized perspectives given their explicit grounding in participants' voices. Data of all types may be leveraged in an emancipatory agenda, but qualitative narrative approaches uniquely center scholarship on the *stories* of participants, a type of data that both remains close to participant experience, while providing potentially persuasive case material for advocacy. We have sought to embrace this approach in the present study.

1.2 | Narrative theory and narrative methods

Narrative offers an especially generative focus for scholarship on identity development. Narrative identity theory suggests that, beginning in adolescence, individuals begin to tell internalized, evolving stories about their lives that weave together their reconstructed past, perceived present, and imagined future (e.g., McAdams, 2001; McAdams & McLean, 2013). These stories, which continue to develop across the adult life span, synthesize life's many key moments and extended chapters into a coherent narrative, one that embraces the individual's efforts to make meaning of their experiences (Singer, 2004). These stories have utility as well, as individuals rely on them as a foundation for engaging with new experiences (Adler et al., 2015) and revise them to support their psychological well-being (Adler, 2012b). Narrative identity is a fundamentally cultural product, one that emerges as the result of dynamic and reciprocal social interactions (Hammack, 2008; McLean, Pasupathi, & Pals, 2007). Although narrative identity is often regarded as something each individual "has," it also serves as the point of connection between the individual and their cultural contexts, as individual identity is constructed through negotiation with social master narratives about how lives ought to unfold (Hammack, 2008; McLean & Syed, 2015). Therefore, narrative identity offers an opportunity to adopt a theoretical vantage point that straddles the positivist and social constructionist dichotomy. In this approach, "the subject is the site of competing and conflicting forms of embodied subjectivity, privately experienced, but which are relationally and collectively lived... [a subject] constituted in and through their social formations, yet still granted an agency and internality" (Aranda, Zeeman, Scholes, & Morales, 2012, p. 554). While still embracing the individual's subjective meaning making, this approach therefore ought to offer alignment with the anti-individualist epistemology advocated by Dirth and Branscombe (2018).

Narrative methods similarly offer a vehicle for operationalizing narrative identity that are suitable for both qualitative and quantitative inquiry. As the gold standard tool for collecting narrative identity, the Life Story Interview (McAdams, 2008) provides an opportunity to elicit data that prioritize the individual's meaning-making

processes and to ethically understand lived experiences in context (Fivush, 2010). As Schachter and Ben Hur (2019) explained,

Although we could ask directly "what does x mean to you?"...sometimes such a direct question is impossible or inadvisable. Part of the answer might not be accessible to an individual as an explicit explanation and yet can be implicit in narrative form. Furthermore, deliberately collecting an individual's broader life story can provide access to broad personal frameworks of meaning used also regarding other personal issues. (p. 5)

Narrative data may be examined in quantitative ways using established methods (Adler et al., 2017), or via inductive, qualitative methods, as in the present study. Operationalizing continuity and change in narrative identity in particular is a complex endeavor, one which qualitative methods might be especially well-suited to address (Adler, 2019). Thus, both narrative theory and narrative methods present a generative foundation for research on identity among people with disabilities.

It is important to note that the narrative approach employed in this study exists in a broader ecosystem of scholarship beyond personality psychology and disability studies. For example, classic work in sociology by scholars such as Bury (1982), Riessman (1990), and Frank (2013) focused on the biographical disruption caused by illness. Likewise, psychologists have examined the role of various autobiographical memory processes in the maintenance of self-continuity or production of self-change in the context of normal development (e.g., Conway, Singer, & Tagini, 2004; Prebble, Addis, & Tippett, 2013; Sani, 2010).

1.3 | A central theme in research on identity among people with disabilities

Across both psychological and disability studies literatures there is convergence on the merits of a positive disability identity. Synthesizing across psychological perspectives, Dunn and Burcaw (2013) suggest that disability identity includes a positive sense of self and a feeling of connection to and affinity or solidarity with other members of the disability community. This sense of disability identity guides people in what to do, what to value, and how to act in situations when their disability is salient, and it supports psychological well-being. Importantly, Dunn and Burcaw (2013) point to narratives of people with disabilities as the foundation for a future science of disability identity. Additional psychological work has further demonstrated the adaptive value of a positive disability identity in people with congenital (Bogart, 2014,

2015; Nario-Redmond, Noel, & Fern, 2013) and acquired disabilities (Chalk, Bartlett, & Bartlett, in press; Darling, 2019). Disability studies scholars also point to the benefits of a positive disability identity. As one example, writing in *The Disability Studies Reader (Fifth Edition)*, Siebers (2017) noted, "In almost every case, however, people with disabilities have a better chance of future happiness and health if they accept their disability as a positive identity and benefit from the knowledge embodied in it" (p. 326).

Perhaps unsurprisingly, when summing across scholarly literatures as diverse as these, there is little convergence on the precise definition of "disability identity." Social and rehabilitation psychological perspectives have tended to rely on questionnaires to operationalize identity (e.g., Hahn & Belt, 2004). Such approaches are efficient, but unsatisfying in their ability to describe the complexity of identity, sidestep the ethical imperative to conduct emancipatory scholarship with disabled people (Nasir & Hussain, 2018), and have not been subjected to rigorous construct validation methods (Forber-Pratt et al., 2017). Other efforts focus on stage models of development (e.g., Forber-Pratt & Zape, 2017; Gibson, 2006) which have been critiqued as proffering "triumphalist" view of identity formation (Shakespeare, 1996). Disability studies perspectives have generated a wide array of definitions for disability identity, from listing subcategories (Johnstone, 2004), to domains of disability identity salience (Putnam, 2005; Shakespeare, 1996), to critiques of the notion of identity as a neoliberal vehicle for supporting capitalist systems (Puar, 2015).

In our read of these diverse approaches, a central theme emerged: scholars across disciplines regard disability identity as fundamentally grappling with the issue of *identity integration*. Congenital disability serves as "an interruption in the continuity of sameness upon which familial solidarity is founded" (Garland Thomson, 2014, p. 4). Acquired disability serves as an interruption in the temporal coherence of one's unfolding life story. Resonating with psychological approaches that regard temporality as fundamental to identity (e.g., McAdams, 2001), Kafer (2013) wrote, "Time is foundational in the production of normalcy...normative narratives of time form the basis of nearly every definition of the human in almost all of our modes of understanding...disability is what ends one's future" (pp. 33–35). For Kafer the work of disability scholarship is therefore to restore "alternative temporalities that do not cast disabled people out of time" (p. 34). Indeed, across the spectrum of disability scholarship we reviewed, we found integration to be a core concern. Reflecting on her decades-long academic and clinical career, pioneering disability scholar Carol Gill (1997) wrote, "It is remarkable how many times the theme of integration emerges in the discourse of people with disabilities" (p. 42). This statement continues to resonate in the literature more than 20 years after Gill wrote it.

Scholars in different traditions regard the nature of identity integration, as well as its feasibility and merits, quite differently. Identity integration is central to developmental and personality psychological perspectives, tracing back to Erikson's foundational work on the topic. Erikson (1968) saw developing an integrated sense of self as the core developmental task of adolescence and the maintenance of integration in the face of disruptive life events as a major focus throughout the adult life span. If exploration and commitment are the fundamental mechanisms of identity formation in adolescence, integration is the fundamental mechanism of identity development and maintenance in adulthood, one that supports psychological well-being (Michell et al., under review). Erikson saw identity integration unfolding in a broader social context, but even contemporary scholars in the Eriksonian tradition have attended more to race, ethnicity, and culture than to disability (Syed & Fish, 2018). Nevertheless, the notion that acquired disability is a threat to identity integration would be deeply consonant with an Eriksonian perspective.

Social psychological perspectives grounded in the tradition of social identity theory (Tajfel & Turner, 1979) take a somewhat different perspective on integration. These approaches regard identity as emergent from specific contexts where one's group affiliation is made salient (Dirth & Branscombe, 2018) and examine different "disability identity management strategies" in specific contexts (Santuzzi et al., 2019, p. 847). As such, "social identities are neither preexistent in individual minds nor static entities in the social world; they are dynamic historical and cultural constructs that are creators of and responsive to collective action" (Dirth & Branscombe, 2018, p. 4). Thus, the notion of a centrally integrated identity is largely incompatible with social psychological perspectives. Instead, these approaches tend to emphasize integration between the individual and their social context. Nevertheless, social psychological perspectives do support some notions of identity integration within the individual. For example, Dirth and Branscombe (2018) wrote, "we would expect that attaining positive quality of life for [people with disabilities] will be predicated on successful individual-level strategies like integrating one's impairment/body into his or her personal self-concept" (p. 10).

Scholarship in disability studies is even more diverse than that within psychological approaches, yet here too the notion of identity integration looms large. Some emphasize the disintegration posed by disability. Kafer (2013) wrote "people with acquired disabilities are described as if they are multiple, a past and current self, like in before-and-after weight loss ads, but in the opposite direction," yet continued, "but such renderings are not so straightforward, as they deny the new aspects of the self that are added by disabling experience" (p. 43). For Kafer, disintegration yields possibility for expansion. Others see cultural imperatives for integration as serving political ends. Puar (2015) distinguished between "passing,"

the efforts of minoritized people to be read as coherent and valued by members of dominant social groups, and “piecing,” the tolerance of minoritized people for incoherence in how they are read by more powerful others. For example, piecing encourages people with physical disabilities to request readings of their brain’s intellectual or emotional capacities separate from readings of their body’s physical capacities, elevating one, while subjugating the other (the negative consequences of this strategy have been well documented (e.g., Smith & Bundon, 2018)). This disintegration of the body facilitates social integration. Puar (2015) asserted, “integration through piecing, rather than wholeness through passing, becomes a valued asset in control societies” (p. 57). The disabled person can be integrated into society—and therefore rendered a viable contributor to the capitalist state—based on a compulsory inward disintegration of brain and body.

Across these domains—personality psychology, social and rehabilitation psychology, and disability studies—the notion of identity integration emerged as a central theme. Whether embraced as vital or stridently rejected as a socially constructed fiction, “a latent coherence lurks” (Freeman, 2010, p. 167). We see convergence across perspectives that identity integration is a challenge that must be grappled with in the lives of people with acquired disabilities. As a result, we regarded identity integration as the necessary focus of our descriptive, inductive work. The scholarly literature offers many perspectives on integration in the context of disability. Our efforts were centered on describing the ways in which our participants—people who acquired physical disabilities in adulthood—grappled with integration in their own life stories.

It is worth briefly noting that scholarship on disability tends to distinguish between people with congenital versus acquired disabilities. While these groups are united by a shared disability identity in the face of societal ableism, they experience differing degrees of stigma and different developmental processes (e.g., Bogart, Rosa, & Slepian, 2019). We have chosen to focus on people who acquired physical disabilities in adulthood because they have experienced a change in their body that poses an important challenge for identity development (Michell et al., under review). It is also important to note that we have excluded people with other types of disabilities, such as cognitive and intellectual disabilities, from our investigation based on an assumption that those experiences are quite different than the experience of physical disability. Nevertheless, we acknowledge that this distinction may be somewhat arbitrary and based on untested assumptions.

The present study had two overarching goals. First, we sought to examine the role of identity integration among a group of people who acquired physical disabilities in adulthood and create a preliminary model for the ways in which integration manifests and develops. Using descriptive,

qualitative, and inductive methods, we sought to identify and explicate the ways in which our participants grappled with the acquisition of a physical disability and approached the challenge of integrating this experience into their narrative identity. We also wanted to examine the associations between different approaches to identity integration and psychological well-being. Second, we sought to use this study as an example of the role that descriptive, qualitative, inductive methods might play in future research on personality change following adversity, the focus of this special issue.

2 | METHOD

The study protocol was approved by the Internal Review Board of Brandeis University, which handles protocols from human subjects researchers at Olin College of Engineering, where this study was carried out (protocol #18101). The study methodology was preregistered on the Open Science Framework (<https://osf.io/rxdpq/>).

2.1 | Participants

Thirteen adults participated in this study. We recruited participants using a purposive sampling approach (Creswell, 2013). Rather than striving for a standard of representativeness, purposive sampling seeks to identify participants whose experience can speak directly to the phenomenon of interest. We also tapped personal contacts and posts with local disability-relevant organizations to yield the sample. Individuals were eligible for participation if they were (a) over age 21, (b) had acquired a major physical disability after the age of 18, and (c) were willing and interested in participating in a lengthy interview and completing questionnaires. The criteria for age and age at acquisition of disability were set because we were seeking a sample of participants who had already undertaken a great deal of identity development prior to acquiring a major physical disability so that we could examine identity integration (efforts to reconcile one’s disability acquisition with their existing identity), rather than identity formation (which would have been more relevant to people with congenital disabilities or disabilities acquired in childhood). In addition, we required that (d) disability acquisition had to be relatively discrete in time (occurring over the course of days to months, not gradually over years) to help distinguish the experience of disability from that of chronic illness. The criterion of “major physical disability” was left open to participants’ interpretation. Zero potential participants were excluded based on this criterion. Two potential participants were excluded due to acquiring a disability prior to age 18. Zero potential participants were excluded based on ability to participate in the interview or complete questionnaires. Every effort was made to minimize the burden of participation.

Interviews were conducted in a location of participants' choice, including personal homes, and assistance with the physical task of completing questionnaires was offered by the research team (some participants chose to have a family member or personal care attendant assist with completing questionnaires). However, the reliance on interview methods certainly excluded some potential participants, a problem that is common in disability research (Lester & Nusbaum, 2018). Furthermore, it is possible that some potential participants who might have informed our results may not have reached out to us because they did not identify as having a disability (Watson, 2002) or because they have a predominantly negative disability identity (e.g., Hihara, Sugimura, & Syed, 2018).

It is important to note that our practice of including participants with a wide variety of physical disabilities is quite common in disability scholarship from both social scientific and humanities based disciplines (e.g., Forber-Pratt et al., 2017; Siebers, 2017). While there are important and vital distinctions between the experiences of deafness, blindness, physical impairment, and other types of physical disabilities, each of which is deserving of specific inquiry, scholars have long noted that disability identity is unique relative to other marginalized identities; its lack of intergenerational continuity and heterogeneous membership requires rhetoric to cohere (Dirth & Branscombe, 2018). At its foundation, people with diverse disabilities are united by their shared experience of ableism (Bogart & Dunn, 2019; Nario-Redmond, 2019). Siebers (2017) wrote, "the ideology of ability is at its simplest the preference for able-bodiedness. At its most radical, it defines the baseline by which humanness is determined" (p. 314). It is this shared experience of being defined negatively in reference to a standard of personhood that gives rise to a communal category of "people with disabilities." Furthermore, studies asking people with disabilities about

this topic directly find that many individuals in this group find commonality (Dajani, 2001).

Table 1 lists demographic characteristics of the participants. The sample included five female-identified and eight male-identified people; two people of color (both identified as Black) and eleven White people; a mean age of 44.5 years old; and a mean of 16 years since the acquisition of disability (some participants acquired disabilities in a highly discrete way, such as in the context of an accident, allowing for a precise dating; for others we estimated an age based on their description of events).⁴ The appropriate sample size was determined using guidelines outlined by Guest, Bunce, and Johnson (2006), who concluded that a sample size of 12 was sufficient for qualitative approaches using purposive sampling procedures for assessing questions related to health and health behaviors. Like Guest and colleagues (2006), we are confident that additional participants would have helped us to further refine our insights, but with diminishing returns. Our sample size places this study in line with the majority of (the small extant body of) social scientific research on identity among people with disabilities, where the median sample size is 15 (Forber-Pratt et al., 2017).

2.2 | Research team

Qualitative methods espouse "an ethic of transparency" (Levitt et al., 2018). A common way this ethic is enacted in data analysis and presentation in many instances is by adopting a reflexive, open posture regarding the role of the research team in influencing the nature of the research findings. Our team of six scholars was assembled in part to recruit diverse perspectives to the research process. We are diverse along demographic characteristics such as age, gender identity,

TABLE 1 Demographic description of participants

	Gender identity	Racial identity	Age	Years since acquisition of disability	Type of disability
Adapter 1 (Layla)	Female (cis)	Black	24	6	Blindness
Adapter 2	Male (cis)	White	40	17	Spinal cord paralysis
Adapter 3	Female (cis)	White	34	5	Deafness
Adapter 4	Female (cis)	White	29	11	Deafness
Adapter 5	Male (cis)	White	37	15	Blindness
Wanderer 1 (Gerald)	Male (cis)	White	57	34	Spinal cord paralysis
Wanderer 2	Male (cis)	White	25	3	Spinal cord paralysis
Drifter 1 (Robbie)	Male (cis)	Black	44	20	Spinal cord paralysis
Drifter 2	Male (cis)	White	57	39	Spinal cord paralysis
Resister 1 (Carol)	Female (cis)	White	69	6	Amputation of legs and parts of hands
Resister 2	Male (cis)	White	63	30	Blindness
Resister 3	Male (cis)	White	43	6	Amputation of leg
Resister 4	Female (cis)	White	56	16	Amputation of legs

racial identity, and sexual orientation. We are also diverse with respect to disability status. One member of our research team has dealt with long-term physical impairment and has a thoughtful history of engagement with the label “disabled.” While different, several members of the research team also experience chronic illnesses that were actively influential during the research process. Despite this fact, is important to note the limitations in the research team's ability to fully empathize with participants' experiences. Writing elegantly about “researching while cisgender,” Galupo (2017) explained,

My own cisgender privilege is made more salient by the fact that, in the scientific community, training hasn't emphasized this type of introspection or put into place a process for rigorously addressing the biases that come with our collective and pervasive cisgender lens (p. 2).

Similarly, the personality and social scientific community has not emphasized rigorous examination of researchers' ableist biases and privileges (Petersen, 2011). Our entire research team had been engaged in research on disability identity for a year and a half prior to beginning the academic-year-long process of data analysis for this study and we have worked to identify and discuss ableism in ourselves. Nevertheless, we want to call out this issue, which certainly informed our work. In addition, while Jonathan Adler led the team, we developed a practice of regarding each other's voices as coequal contributors, seeking to diminish implicit power structures within the research team. Nevertheless, Jonathan Adler was the sole point of contact for participants and conducted all of the interviews, given his 15 years of experience conducting interviews for research and clinical purposes. In relation to our participants, we sought to embrace the emancipatory ethos of Nasir and Hussain's (2018) new model for disability research production, which encourages researchers to “recognize their participants as ‘expert-knowers,’... [positioning] him- or herself as a reporter who sought to bring the researched voices under the spotlight” (pp. 42–44). Nevertheless, we certainly fell short of their ideal for action research, in which scholarship focuses not just on the production of knowledge but on the creation of actual social change for those involved in research.

2.3 | Materials

2.3.1 | Interview

Participants took part in an expanded Life Story Interview (McAdams, 2008). The Life Story Interview begins by asking participants to divide their life into a series of chapters. Next, participants respond to a series of prompts about key

moments in their lives, such as the high point, low point, and turning point. The interview asks about major challenges, personal ideology, and for an overarching theme in the participant's life story. In the present study, the complete Life Story Interview protocol was used and an additional section was added in which participants were prompted to share the story of their experiences acquiring a disability. Interviews lasted between 1 hr, 50 min and 3 hr (average: 2 hr, 35 min).

The nature of the Life Story Interview poses challenges for anonymizing participants' identity. (This is one reason that the raw data have not been made publicly available.) Every participant quoted in this manuscript was given the opportunity to select their own pseudonym and to determine which details of their lives they wanted to have presented via direct quotes, versus further obfuscation (such as changing the names of cities, employers, relatives, etc.). Very few participants requested changes to obscure their identity and no modifications change the results of the study.

2.4 | Questionnaires

In addition to the Life Story Interview, participants also completed seven questionnaires. Given our sample of 13 participants, we did not include the questionnaires in the service of identifying quantitatively valid associations between narrative themes and the constructs assessed by these measures. Instead, the questionnaires were included for three reasons. First, we construed the data obtained from these questionnaires as providing an additional perspective on the participants' experiences. While we did not seek to examine quantitative associations between narrative and questionnaire data, we regarded the questionnaire data as an opportunity for further inductive interpretation. Second, we sought to adopt a personological approach (e.g., Alexander, 1988; McAdams, 2003), opening the possibility of connecting this study to broader work in personality psychology focused on domains of personality beyond narrative identity, such as dispositional traits and characteristic adaptations. Third, we wanted to offer our participants an opportunity to understand aspects of their experience beyond what would be possible based on providing them a transcript and/or audio of their Life Story Interview and the initial draft of this paper. The seven questionnaires were:

- Positive and Negative Affectivity Schedule (PANAS; Watson, Clark, & Tellegen, 1988). This 20-item measure asked participants to rate their trait-levels of positive and negative affect on Likert scales.
- Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). This 7-item measures asked participants to rate their life satisfaction on Likert scales.
- Psychological Well-Being (PWB; Ryff & Keyes, 1995). This 42-item measure asked participants to rate their

well-being along six dimensions (e.g., autonomy, positive relations, personal growth, etc.) using Likert scales.

- Beck Depression Inventory-2 (BDI-2; Beck, Steer, & Brown, 1996). This 21-item measure asked participants to rate depression symptoms along Likert scales.
- Penn State Worry Questionnaire (PSWQ; Brown, Antony, & Barlow, 1992). This measure asked participants to rate their dispositional worry along Likert scales.
- Washington University Sentence Completion Test of Ego Development (WUSCTED; Hy & Loevinger, 1996). The 18-item WUSCTED is the gold standard measure of ego development, or psychological maturity, which asks participants to complete standard sentence stems (such as “Being with other people...”). It was scored by a rater trained to the standards outlined by Hy and Loevinger (1996).
- International Personality Item Pool (IPIP; Goldberg, 2006). A commonly used 50-item questionnaire drawn from the IPIP to assess the Big Five dispositional personality traits, which asked participants to rate themselves along Likert scales.

For the purpose of this study, a composite measure of psychological well-being was created from participants' scores on the PANAS, SWLS, PWB, BDI-2, and PSWQ. These scales were highly intercorrelated and, when scales representing poor psychological well-being were reverse-scored, the Chronbach's alpha for this composite measure across all participants was .82.

2.5 | Procedure

2.5.1 | Data collection

Following a brief initial interaction (either over email, telephone, or both), participants completed informed consent forms and discussed the nature of participation. Interviews were scheduled at participants' convenience. Most participants completed questionnaires following the interview, though three completed the questionnaires first. Following the interview, all participants received transcripts, as well as audio files if desired. Participants received written feedback on their scores on the questionnaires, along with guidance about how to interpret them. We also shared a copy of this manuscript with all participants prior to initial submission. We incorporated feedback from participants into the version that was submitted.

2.5.2 | Data analysis

We employed a grounded theory method (e.g., Charmaz, 2006; Glasser, 1992) in approaching data analysis. This

widely used qualitative method involves iterative readings of the data, marked by increasingly specific descriptive codes, recorded in a set of memos, that shape subsequent readings. We undertook this process as a reading group of six members over the course of an academic year. We began with an initial read of each Life Story Interview transcript and open coding—the recording of anything seeming noteworthy for any reason, striving to remain as close to the data as possible (rich description of participants' stories, rather than theoretical interpretations). We brought these individual codes to a two-hour weekly discussion meeting where we compared codes and began to develop memos about possible emergent themes. Each meeting began with an in-depth discussion of the transcript under review, striving to remain focused on surfacing the key elements of that particular participant's narrative. As we consolidated memos about each transcript, we also began to devote the final section of each discussion meeting to comparing each new set of memos to the memos from prior meetings. This resulted in an emergent set of focused codes—those that require interpretive work to make connections across participants and determine which set of initial codes are most generative. Once this round of coding concluded, we were able to generate theoretical codes—those that forge connections across focused codes, beginning to produce an emergent theory about the data. Up to this point we worked to remain open to nascent concepts from the data, rather than looking for instances to support any preconceived ideas about what we might find. The set of theoretical codes that we generated was broad and diverse, pointing to insights about the data beyond what we will report in this manuscript. During the final stage of coding, we brought the literature review to the forefront and undertook a round of selective coding—we returned to the data in search of additional insights into the ways in which participants talked about grappling with identity integration. As with all prior rounds of coding, we did not seek data that would confirm any a priori hypothesis about identity integration, rather we sought to ensure that we had captured all data relevant to the topic of identity integration. This process resulted in the theoretical saturation—when returning to the data ceased to generate additional novel insights or connections—that is the point at which grounded theory analysis concludes. Only in preparing to write this paper did we examine the relationships between our emergent theory about identity integration and the results of the self-report data collected via questionnaire. In other words, the grounded theory work we conducted was appropriately considered “grounded”—only at later stages did we seek to incorporate the scholarly literature and only after we had consolidated our theory did we examine it in relationship to the additional data on psychological well-being.

One final note on our analytic approach: the method we have described hews closely to the specific recommendations for grounded theory analysis outlined by Charmaz (2006) and

others. This approach is one of the most widely used in the social sciences. To this process, we also brought our experience with tools developed in the field of human-centered design, a movement within engineering to democratize innovation by regarding the users of technology as key players in the development of technology (e.g., Saffer, 2010; von Hippel, 2005). For example, in our transition from focused coding to theoretical coding we used some of the framework models described by Saffer (2010), including Venn diagrams and two-by-two matrices, to advance the project of integrating insights across participants. This proved to be a highly productive and straightforward synthesis of interdisciplinary tools. Once the process of data analysis was complete we determined that identity integration was the topic most worthy of focus in this paper, based on its emergence as a central theme in the literature on disability identity across psychological and disability studies perspectives and its salience in our interviews. There is much more to say about this set of narratives, but we determined that their contribution to the study of identity integration was likely to be the most generative at this stage in the scholarship.

3 | RESULTS

Our analysis of the set of narratives indicated that identity integration was a major developmental task for our sample of adults who acquired disabilities. This grounded observation converges with the literature on disability identity to support the notion that reconciling one's identity prior to becoming disabled with one's current identity is a challenge that one must grapple with in the service of disability identity development (e.g., Bogart & Nairo-Redmond, in press; Dunn & Burcaw, 2013; Forber-Pratt et al., 2017). Acquired disability introduces a discontinuity into the life story, a disintegration, one which demands autobiographical attention. We will begin by describing the nature of this challenge across the whole sample. We will then present the primary results of our analysis, a set of two dimensions and four narrative strategies concerning identity integration that were pursued by our participants in response to acquiring a disability. We will provide more lengthy illustrations of these different narrative strategies to ground the results in the voices of some of our participants. Finally, we will discuss the results in relation to participants' psychological well-being.

3.1 | Acquired physical disability as a challenge to identity integration

Syed and McLean (2016) described four types of identity integration. We found evidence of disruption in each type among our participants. Temporal integration involves

seeing some continuity between past, present, and future selves (Syed & McLean, 2016). Many participants talked about the acquisition of their disability as a discrete break in the timeline of their life. One participant described returning to her house after months in the hospital and rehabilitation centers following the amputation of her legs this way: "It was a new start. Day 1." Another participant, also an amputee, said "For me, there was 'normal' prior to [the amputation], and now, this different reality." Other participants illustrated the disconnections between their past and present selves. One participant said, "So, in my mid-30s, I lost the rest of my vision. And, that kind of determined the rest of the course of my life." Becoming blind inserted a turning point in his life story. Even thirty years after becoming blind, he continues to grapple with this disconnect, saying, "You can never really put it behind you. You can never really throw it away. It's always there every single day. I'm still blind." Since the focus of Syed and McLean's approach to integration is on stories, temporality is endemic; temporality is one of the foundational aspects of stories (e.g., McAdams, 2001). It can therefore be difficult to disentangle temporal integration as the primary focus of a given story or excerpt, versus in service of other dominant types of integration. Indeed, this approach is not meant to be an empirical typology, but rather a generative framework.

Contextual integration involves the coordination of multiple personally meaningful aspects of the self that vary in salience from situation to situation. Our participants noted challenges to contextual integration both in the immediate wake of acquiring a disability and many years later. For example, one participant remembered being in the hospital in the weeks that followed his sudden, stroke-induced paraplegia.

I'm not supposed to be here. I'm supposed to be playing pick-up basketball right now. I'm supposed to be lifting weights right now. I'm supposed to be finishing my Master's right now. I'm supposed to be at the bar with my friends right now. But, instead, I'm in this hospital bed unable to move half of my body.

For this participant, the context of his hospitalized embodiment felt irreconcilable with how his life would look were he not paralyzed. The person he felt he was in the hospital was incompatible with the person he felt himself to be in other contexts. In another example, years after she had both legs amputated, one participant described the ways in which she and her husband were forced into unwanted roles in the context of their marriage by her acquired disability:

Being quite a dominant person, I had taken care of everything...I'm asking [my husband] to

switch and that's not his fort . There's a reason you fit. It was a total reversal...we both want our roles back because we were so good at them.

For this participant, her role as a wife lacked integration with her current self, more than a decade after her amputations.

In addition to temporal and contextual integration, which resonate strongly with the disability studies literature, Syed and McLean (2016) offered two additional types of identity integration. Striving to operationalize the Eriksonian meaning of identity integration, Syed and McLean (2016) proposed the term "ego integration" to represent an individual's overall sense of their self over time. More than the simple addition of contextual and temporal integration, ego integration represents the individual's holistic perspective on their identity development. The acquisition of a physical disability has ramifications not only for one's sense of self in different domains of life and for the cohesion of the past, present, and future selves, but also for a person's more generalized sense of self. For example, one participant described the "initial shock" of waking up in a hospital unable to move parts of his body, a feeling that evolved into "grief for my former life." He went on to say, "I was mad at my body and that kind of inherently separates you from your body. And so, I was separated. I was not whole. I was not whole." This participant described an overarching sense of disintegration following his injury.

Individual identity is a constant, dynamic negotiation between one's internal narrative and the broader cultural narratives in which one is situated (e.g., Hammack, 2008; McLean & Syed, 2015). Syed and McLean (2016) offered person-society integration as the fourth type of identity integration, one focused on the ways in which one's identity is embraced or problematized by one's social contexts. Given the stigma attached to disability (Bogart et al., 2019), it is not surprising that many participants spoke about the ways in which they felt socially fragmented. For some participants there were discrete moments when this experience of being shunned from a social group was made explicit. One participant recalled returning to college in a power wheelchair after becoming quadriplegic:

Got to the first class. The first day of class, they give a test. I didn't have a plan for taking a test, or maybe I did, but I had no setup. The professor took me in the hall and said, "maybe engineering is not right for you."

Another participant described returning to his longtime job after losing his vision by saying, "They didn't want to have a blind person around and I didn't want to be the blind person that they didn't want around." Others felt the burden of person-society disintegration in virtually any context. A blind participant said,

for the first few years, I didn't want to go anywhere with [my wife] because I didn't want to have to be the blind husband and have to have her explain. And, she didn't want to go anywhere with me either because she didn't want to have to explain either.

Still other participants internalized lessons about the relative worth of different aspects of their identity. After becoming deaf in her late-20s and deciding to switch to a different graduate program, one participant said, "I learned pretty early on that the one thing that I really have going for me in my life is my brain." This participant felt the pull to "piece," in Puar's (2015) terms, to elevate one aspect of her self to compensate for the denigration she felt society placed on other aspects of her self. In many ways, person-society integration is the narrative manifestation of ableism in our sample. It overlays the other types of integration and shows up in all domains, as individuals are always in dynamic and reciprocal interaction with their social context.

In introducing these four types of identity integration—contextual, temporal, ego, and person-society—we have recruited examples to illustrate the ways in which our participants narrated the acquisition of a physical disability as a point of *disintegration*. Some of the participants we have quoted above have since found ways to integrate this experience, while others have not. Yet regardless of the outcome of this developmental process, every one of our participants described the acquisition of a physical disability as a challenge to identity integration. In fact, in many cases they described it as the primary challenge posed by the acquisition of their disability.

3.2 | Two dimensions of narrative identity integration strategies in the context of acquired physical disability

With this foundational insight that acquired disability poses a challenge to all four types of identity integration, we were able to distinguish a spectrum of participants who seemed to have found an overall sense of integration to those who had not. As an illustrative comparison, here is how one participant described her deafness:

In some ways I think it's given me a lot more appreciation for my embodied self. I think now I see my body as more part of my total self, and more part of my identity than I saw it to be in the past... and I'm also coming into a sense of pride in myself as a deaf person, not just seeing deafness as a deficit but seeing it as this good thing shapes my world view. It's actually part of who I am.

In contrast, another participant spoke about her body after having her legs amputated as: “It’s equal to an Australian Shepherd that just can’t stop running after the ball. So, that Shepherd is still in me. But I can’t move. I haven’t been able to handle that.” The first participant has not only found unexpected benefits to her disability, but embraces her deafness as a part of her identity. The second participant cannot reconcile her present embodiment and the way she thinks about herself; she is still the Shepherd but cannot satisfy her need to move.

When we undertook a focal exploration of the differences between participants who seemed to have found a greater sense of integration from those who have found less, another dimension emerged as salient: the extent to which participants described themselves as actively engaged in a process of autobiographical reasoning in the wake of acquiring a physical disability. We observed a spectrum from a great deal of active processing in the life story to minimal processing or a more passive stance toward the development of the life story.

In some ways, these two dimensions—from high to low autobiographical reasoning and from high to low integration—tap the process and the outcome participants narrated. Although quite specific in content, the two dimensions we identified resonate with Pals’ (2006) work on narrative strategies for understanding difficult life experiences more generally. In her system, one dimension represents exploratory processing and the other represents coherent positive resolution. When displayed together, the two dimensions in our study yielded a two-by-two matrix that satisfactorily captured the narratives of every participant in the sample. This matrix and the resulting typology of strategies is pictured in Figure 1. The y axis of this matrix represents the degree to which participants engaged in active processing of their experience, with the top representing high processing and the bottom representing low processing. The x axis of this matrix represents the extent to which participants

described themselves as wholly changed as a result of their experience acquiring a physical disability, integrating their disability into a new sense of self. On the far right side are participants who described themselves as being “reborn” or “reinvented” (actual quotes) in the years since they became disabled. On the far left are participants who described themselves as “I’m still me” or as “fundamentally the same person” (actual quotes) that they were prior to becoming disabled. We have labeled the four quadrants in this matrix:

- *Adapters* included participants who described themselves as actively engaged in the process of autobiographical reasoning and who feel their identity has changed substantially since acquiring a disability.
- *Wanderers* included participants who described themselves as more passively engaged with the development of their narrative identity and who feel their identity is substantially changed since acquiring a physical disability.
- *Drifters* included participants who described a passive engagement with their life story and who feel their identity is fundamentally unchanged after acquiring a physical disability.
- *Resisters* included participants who described as actively engaged in a process of autobiographical reasoning and who felt their identity was largely unchanged since acquiring a disability.

Each of these quadrants represents a different narrative strategy for navigating identity integration. However, it is vital to remember that the quadrants themselves emerged from the two salient dimensions we observed in the data. We do not want to suggest that these narrative strategies actually represent wholly distinguishable categories. Indeed, when presented with this paper, several participants noted that they felt the quadrant to which they had been assigned resonated for them, but saw the potential that they might adopt a different strategy at some point in the future. For example, one participant said, “‘Wanderer’ seems very accurate to describe me. At least today.” He went on to note that the supportive context of our interview allowed him to express the genuine, if sometimes unflattering, aspect of being a Wanderer, but that in other contexts, such as in his political advocacy work, he could see himself adopting an Adapter strategy. The labels themselves somewhat overemphasize the active processing dimension over the identity change dimension, but our participants felt they were appropriate for capturing their experience. Narrative identity is a retrospective interpretation of one’s experience, constitutive of one’s sense of self in the present, and a tool that individuals use for making sense of new experiences (Adler, 2012b; Adler et al., 2015; McAdams, 2001). As such, these narratives reflect the process of meaning making that our participants engaged in and will serve as the foundation for their future meaning-making

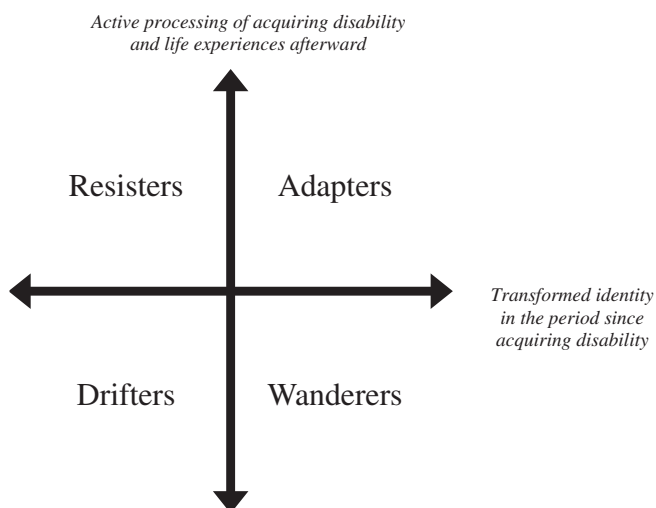


FIGURE 1 A matrix of narrative strategies for identity integration following acquired physical disability

processes. It is important that the four types of narrative strategies we have identified be used to understand the range of approaches adopted by our participants, but not reified as a definitive typology or used as such in clinical contexts.

We will describe these four narrative strategies of navigating identity integration by relying on a prototypical participant's story for each type. Each participant's life story is fundamentally unique and cannot stand in for others, but we selected these examples because they highlight the central themes of each narrative strategy. The length and amount of detail included in these case presentations is central to the overall goals of this project. In seeking to ground our findings in the voices of our participants, it was important for us to represent the individuals in as much rich complexity as possible. While each example speaks to the generalized observations we made about the sample, the particulars of each life story are not interchangeable. As such, we have strived to both evoke each exemplar as a full person, while illuminating the themes which transcend their specific experience.

3.2.1 | Adapters

The participants in our sample who adopted an Adapter strategy told life stories that were completely derailed by the acquisition of a physical disability, but they have worked hard to incorporate this experience and the changes it brought into a transformed sense of self. Adapters have engaged in purposeful and active efforts to make meaning of the changes they have experienced and to refashion a sense of self to fully integrate their disability status. As a group, they share few demographic characteristics (see Table 1) and represent a wide range in number of years since the acquisition of their disability, but share many elements of a common narrative.

Layla is an exemplary Adapter. She was born on the outskirts of Nairobi, Kenya, the middle child of an architect father and interior designer mother from two very different tribal backgrounds. She remembers the first chapter of her life as “the fun years,” with her close family. Layla always knew what she wanted and wasn't afraid to stand up for herself. She remembered her father getting pulled over for a traffic violation while he drove her to school one day when she was seven or eight years old. Layla knew that the police officer would try to extract a bribe from her father or threaten his arrest. When he leaned into the car, Layla

took off his hat and sat on it. And, I told him, “you either give my dad his driver's license and let him take me to school, or you're not getting your hat back.” He looked at me like, “what?” I was like, “yeah, you can't bully us like this”... and then he gave my dad back his license and just said “you just take your kid to school”...

So, I guess that's why I always like being able to decide things for myself.

This early memory would prove to be prophetic for Layla's life story.

When Layla was entering seventh grade she made another decision for herself: she wanted to go to boarding school. “I just wanted to do my own thing,” she said. Her parents sent her to a Catholic girls' school where Layla took her love of swimming to the next level of competition. When recounting one of the high points of her life, Layla remembered one swim meet when she convinced her coach to let her swim the butterfly stroke in a relay race, even though another team member was usually faster than her. “I remember, I did that butterfly and that was just the happiest moment because I went so fast. I went faster than everybody in the team. I was like, ‘oh my God, I have done this so well.’”

Secondary school was more challenging for Layla. She tested into a competitive public school closer to her home, which she had mixed feeling about. The school did not have a swimming pool, which felt like a big loss to Layla, and she began to struggle with body image.

I'm not a very skinny girl and, I mean, in my society, in my culture, I mean almost everywhere, skinny women are seen as beautiful... I would tell myself, this is not something important that I should start thinking about. I used to work out a lot, so I was like, as long as I'm keeping healthy, I mean, that should not be a huge thing that makes me who I am.

The active processing of her experience is emblematic of Adapters. Layla became captain of the field hockey team and was accepted to a competitive university program in actuarial science.

In the 6-month gap between the end of secondary school and university, Layla enrolled in a professional baking program, working long hours to master the art of cake baking. During this program, she began getting frequent headaches, which she attributed to the stress, long hours, and limited sleep. But a turning point came one day when she was at home. As if a metaphor for her life trajectory, Layla said, “I was just walking upstairs and then I collapsed.” Her family took her to the emergency room and Layla was plunged into several months of mystery.

Her headaches intensified to the point where she couldn't function. She was hospitalized at three different hospitals, none of which were able to get to the bottom of her affliction. Layla said,

I didn't feel like they were treating me like a human being. I just felt like I was this thing they

should be feeling sorry for...I wasn't thinking about the future, I was just thinking of the next hour and if I will still be in pain.

The pain dramatically reduced Layla's temporal self. One day, she collapsed in the hospital bathroom and remembers blacking out. She is not sure whether her vision ever returned or not, because she already felt wholly consumed with the pain. That night, she remembered having a dream that she was attending her own burial.

People were crying. And it's like I was looking at them and I'm trying to tell them, "you guys, I'm here," you know. But it's like I'm not there because they are thinking I'm in the coffin. So, when I woke up, I woke up crying, I remember, and I couldn't talk to anyone about that dream; I couldn't tell them. I felt like it was something very scary and if I said it, it would happen.

In her despair, Layla sensed that she was at a turning point.

Layla's sense of will resurged and she determined that she had to leave the hospital. "I'm the one who said 'nothing is happening.' I just told my parents, 'let's just go.'" She returned home, but could barely function, barely sleep.

I remember one day I was, like, oh my God, I want to sleep with all of you and they slept with me. We all slept in one bed. Five people. My brother, my dad, my mom, and my sister... Just, like, feeling their warmth and everything, just being there with them, it made me fall asleep. It was sweet.

Both of her parents had taken leave from their jobs to look into better medical care. The family decided to fly to India to see a specialized medical team.

The six hour plane ride was perhaps the nadir of Layla's suffering, as the air pressure made her pain intolerable. She remembered landing in the nighttime and being overwhelmed by the humidity. She now realizes that she has no visual memories of the trip.

I just thought I can't see because of the pain or because I'm closing my eyes... even when the doctors asked me I'd just say "it's blurry" or "I don't want to look at whatever you are telling me to look at."

An ambulance escorted her to a hospital and the testing began. By the end of the night, they identified the problem: advanced idiopathic intracranial hypertension, meaning intense swelling inside her skull without a clear cause. The next morning Layla underwent a nine-hour surgery. She remembers waking up from

the anesthesia and "feeling very weird. It's like it wasn't me." Her mouth was intensely dry, she had cotton swabs in her nose, and she felt like a different person, but the pain was gone for the first time in months.

Then I asked the doctor, "how come I can't see?" I don't know, but that is when I realized I can't see. So, I'm just asking "how come I can't see?" Then he started trying to explain, "for some people, with this kind of surgery, some people see immediately after the surgery. Some people take time. Some people take so many years. Other people don't see." Then I'm asking, "what about me? When am I going to start seeing?"... He just told me "we have to wait and see what happens." But, thinking about it later on, I think he knew that I would not see because of the way his voice, like, just his voice, he didn't sound very sure...But the pain was gone. My head was normal. It wasn't aching. I was, like, "okay, I feel like my head is there."

The family stayed in India for one month after the surgery and then returned home. Her parents prayed that her sight would return.

Arriving home was jarring for Layla. On the one hand, she felt perfectly comfortable navigating her house on her own, confident in her memory for where everything was. On the other hand, she felt tremendous guilt for having so dramatically altered her family's life. Medical care was incredibly expensive and had so consumed her parents' time that her siblings were largely left to fend for themselves. "I was thinking, 'how are we ever going to get back to normal?'" Layla felt the great distance between her current and past selves. She spent six months sequestered at home. During those days, her parents would often spend time with her, telling her stories from their own lives. Layla said, "I think it gave me the chance to heal and like, calm down, because I had been in so much confusion." This was also the time when Layla began to accept that her vision would not be coming back. "I think I'm the one who started accepting, before my whole family... I realized as soon as I started accepting it, I started becoming less frustrated and sad." Her family was slower to accept Layla's blindness as fact and Layla began to feel restless at home. "I have this feeling of being such a burden. I was getting tired of myself."

One day Layla was out to lunch with her parents when a stranger came up to their table, saying that she looked familiar and asked whether she had been one of his former students at a school for the blind. This moment crystallized Layla's blindness for the family. She felt offended, embarrassed, and also curious. "No one in my whole extended family was blind, so we had no idea what happens after you become blind." They took the man's business card and held onto it

for a few weeks, until Layla ultimately decided to call him to learn more.

The first day at the school for the blind was another turning point for Layla. She remembers that her family dropped her off and she was escorted into a classroom. But within a few minutes she retreated to the lobby and began to sob. She said,

subconsciously, I was crying because I think I had really accepted that I'm blind. And maybe because that was the first time my family had ever really left me alone when I was blind and I was just in a new place and I just felt helpless, like I can't do this on my own.

After a while, when Layla had calmed down, she began texting her brother to tell him how she was feeling. A man came and sat next to her and asked her what she was doing. She told him that she was texting and he asked her to show him how to do it on his phone. She remembered, "I was so happy because, like, oh my God, finally someone is asking *me* to show *them* something."

Then, he was like, "you want to go with me back to the computer lab?" I was like, "okay, let's wait for the lady, maybe she'll guide us." And he was like, "no, I'll take you." I was like, "no you won't take me, you're going to make me fall down because you're also blind." He was like, "no, you come, I'll take you." Then we just walked and he took me and I was like, "how do you know this place?" He's, like, "because I've been walking around here a lot and I know my way and I've practiced and everything." And he's like, "even you one day are going to know too."

After this experience, Layla threw herself into the school for the blind. She was especially interested in the technology courses, but more reticent to take on mobility classes, which felt scarier and more of a burden. She made a group of friends at the school and remembered another turning point. One night the group made plans to go out dancing. Layla told her parents that she would be sleeping over at one of the other women's houses (whose parents were on vacation) and they were out at the club until the early morning. "I think that's when it totally solidified," Layla said, referring to her identity as a blind person. She began dating a man "who was a total ninja at being blind," and although she later broke up with him, she said the relationship taught her "that I could trust someone."

Layla spent two years at the school for the blind before she felt that she needed a change. "All I knew is that I had

to be in school," meaning university, she said. She went to visit the actuarial science program she had planned to attend after secondary school, but they told her that they could not accommodate her blindness. She felt awful and this emboldened her further, saying, "I want to do great things." She decided to look into university programs in the United States, where she believed she would find greater accommodations. "I was like, if I stay here I'm always going to be fighting with these people in these schools." She got rejected from several American schools and began to despair, but was accepted to a major research university in a town not too far from where a close friend of her mother, an attorney, lived. Layla said, "At this time I had pretty much accepted I was blind. Like, I was happy. I was even, like, happy about being blind." Her narrative identity had shifted such that her blindness could be integrated into her new sense of self.

Layla's mother made the trip to the United States with her, connected Layla to her friend, and moved her into the residence hall. But the American university proved to be much more challenging than Layla had expected. "My first semester was just the worst." She found herself without accommodations in place when classes began and the school's Disability Coordinator was dismissive.

She asked me, "are you ready?" She asked me so many questions and was like, "I think if you're not ready for school you should go back home."...So I did what I did with the police officer [when I was a kid], I just told her, "you know you can't tell me that"... I just told her, "you just give me what the school requires you to help me with."

With the help of the attorney family friend, Layla did get accommodations after completing most of the semester without them. But Layla saw a lesson in this experience. She said,

I think my first semester is when I really learned how to advocate for myself as a blind person. I learned of so many other students who were not getting things for themselves and I was glad I was able to help them while I was helping myself.

Layla experienced distinctly American forms of racism, sexism, and ableism while in college, each of which made her more determined to advocate for others.

When I interviewed Layla, she was on the cusp of transferring to another college, the flagship campus of the state system she had started at, where they had a stronger program in computer science, her passion. At that turning point, Layla was especially reflective about the ways her blindness impacted her identity. She said,

some people really want their blindness to be everything about them. Which, I mean, it's not bad, but it's not the only thing, you know? For me it's not the only thing, it's one important part of who I am today.

Layla articulated how blindness altered her sense of self, but did not eclipse all other aspects of her identity. She is planning for a career in computer science, one where she intends to use her skills to help blind people in Kenya connect with each other and to advocate for more inclusive policies. Indeed, African master narratives of disability are even more extremely focused on dependency than American master narratives (Shakespeare, Mugeere, Nyariki, & Simbaya, 2019). Layla expressed gratitude for her blindness, saying,

I think my blindness is the best thing that ever happened to me. Like, even if a doctor came and told me they have a cure, I would not take it because I think it made me understand myself and it made me build a new identity. My blindness gives me these new challenges every single day and through those challenges I'm able to understand myself.

For Layla, becoming blind ushered in “a new identity,” but one in which her lifelong love of challenges could be focused toward a meaningful direction: helping others. As such, Layla represents the group of Adapters in our sample, who also demonstrated deep processing of their experiences and a new sense of self. Other Adapters' stories also contained key moments that demonstrate this sense of active engagement and identity transformation. For example, one participant said, “I've had to work really hard to create an identity for myself that's outside of my trauma” and another noted, “After working so hard at all this change, I finally feel more myself than I've ever felt.”

3.2.2 | Wanderers

The participants in our sample who adopted a Wanderer strategy were the participants who feel their identity to be substantially changed by the acquisition of a physical disability, but who have found their way to this change at the mercy of external forces. Wanderers differ from Adapters by virtue of their more passive orientation toward identity integration (even if they were quite active with other endeavors).

Gerald grew up in a devoutly Catholic family in Philadelphia, Pennsylvania in the 1960s and 70s. While he remembers his earliest years as “perfect, like out of a storybook,” by the time he was in elementary school the troubled

dynamics of his family became clear to him. His father was a physically abusive and alcoholic police officer who Gerald described as “a narcissist, borderline sociopath.” His mother looked to Gerald as “her surrogate husband” and caretaker of her and Gerald's three brothers. Gerald learned to put on a front, saying that “everyone just thought I had it all together. And then, [I'm] just crumbling inside.” He earned good grades and was accepted at a highly selective college. “My only goal in life was to get away... And fear doesn't lead to good choices and so I didn't make an active choice to go somewhere to do something... [College] wasn't fun. I spent the whole time getting away.”

Feeling lost, Gerald fell sway to a priest who had fallen in love with him and persuaded him to go on a social justice volunteer trip to Central America after graduation. Gerald recalled, “I thought I was in control and I thought that I could control him. But, meanwhile, I was totally out of my league.” As he would later discover, this priest would go on to a career of sexual abuse, but Gerald was his first attempt at the kind of coercive control he would later refine. The dynamics on the trip proved intolerable. Speaking about the priest and the nun who were running the trip Gerald said,

it was like a dynamic between my parents, where they're talking to me about their problems between each other. It's, like, she never listens and then he's just this patriarchal monster and just, like, I'm like, “seriously, help me someone, please”... I had no sense of agency. None whatsoever.

Five months into the trip, after a series of scary encounters, and feeling increasingly depressed, Gerald went to the beach to give a swimming lesson to some local children. He dove off a dock into the ocean, just as he had done many times on the trip, but he had misjudged how far the tide was out and hit the rocks just below the surface, shattering his fourth cervical vertebra.

I saw my whole life, past and future, in front of me. And, next thing you know, flipped over. [A friend] said “you all right?” And, I said “no, my life is over.” And, he said, “no, you're not going to die.” I said, “no you don't understand, my life is over.... You wasted 23 years of your life. It's gone.” Right in that moment.

The people around him took a door off of a nearby building and laid Gerald on it. He was soon airlifted to the capital city and ultimately to Houston. Gerald remembers the drive he felt to stay alert and alive until he was confident he would receive adequate medical attention. He recalled that once he arrived at the hospital in Houston, “My body just gave up... You're going

to be in the hospital, like they said, so now your family knows and now your job is done.”

Gerald spent a month in the ICU in Houston before being air lifted back to Philadelphia, where he spent another eight months in the hospital. “Existentially, I was nine months -- I was in the womb again,” Gerald said, “It was a rebirth.” Gerald dreaded leaving the hospital to return to his family's care: “I was horrified. I was petrified. I didn't want go. I did not want to leave.” They moved him into an apartment near their house and Gerald's mother and brothers took over most of his care. He found the lack of privacy intolerable. At one low point, “my big existential moment,” he remembers looking up at the cross on his wall and saying

“fuck you, big deal, I'm going to be like this for the rest of my life.” And, so at the moment it was sort of, oh my God, [Gerald], you just told God to fuck off and yet God didn't kill me, so God was fine. God helped me and loved me. And, so it was, like, wow. I can actually remember the conscious relationship with God, which is really an honest relationship with myself. It was neither acceptance nor resignation. It was what it is. This is what it is.

In this moment, Gerald came to terms with his traumatic experience and began to move on.

Gerald labeled the next 18-year chapter of his life “Wandering through the Desert.” He was able to live independently with the help of personal care attendants and his motorized wheelchair. He went back to school to earn a Master's degree in divinity and then a second one in counseling. He spent time working as a university chaplain and also working for the state Department of Public Health. When the sexual abuse scandal in the Catholic Church hit the national news, it sent Gerald into a tailspin.

It was an out-of-body experience. It was kind of like being in the ICU where I just wanted to crawl out of my skin. I couldn't deny my Catholic identity. All my Catholic identity was bad. And, I knew a really good priest, and yet were we supporting a culture that was...it was really just a lot of soul searching and a lot of just, like, it was just personally, I just didn't feel safe.

Today, Gerald still feels uncertain. He sees the federal and state agencies responsible for supporting people with disabilities to be crumbling: “the system's changing and I've lived in the system that they're moving toward and I know how bad it is....[it's] moving us from an advocacy-based social justice-run state, to a commercially-driven one.” He also sees his own personal care system shifting in uncertain ways. “I don't know

who's going to put me in bed some nights. And the people who I knew were in charge are no longer in charge. And, it's that sort of: ‘[Gerald] who?’” Gerald described. “I will survive. I'm trying to figure it out. Now I'm in the angry phase.”

Nevertheless, Gerald has really come to embrace his identity as a disabled person. This crystallized for him when he returned to Central America for the first time on a volunteer trip to serve people with disabilities. As Gerald said,

My big thing when I broke my neck was: I can never be a missionary. I can never go to another country. My goal was always to be outside and just try and make a difference. And, so, I was... so that, for me was a high point.

Gerald said, “I wouldn't say I thought of myself as a broken person waiting to be fixed, and I rejected that for so long...I came into my own disability.”

When I asked Gerald what he believed to be the central theme in his life, he replied, “I've been very lucky and not everyone is lucky.” Despite his many challenges and struggles, Gerald is able to find grace and fortune in his life. His strong investment in social justice made him aware of his privilege very early on—even during his time in Central America when he was in his 20s, he remembers feeling “lots of white, American guilt” about his great privilege compared to the people he was there to serve. And yet this pervasive sense of luck also captures Gerald's sense that the course of his life was largely influenced by external forces. His life story is not without moments of great agency—for example, Gerald remembers being in the hospital and his father telling him that he would never regain the use of his arms and Gerald thinking, “I'll beat you at your own game and you'll never win”—but Gerald narrates most of the major turning points in his life story as arising from circumstances out of his control. In this way, Gerald captures the core of the Wanderers strategy. For these individuals, their post-disability identity has been well-integrated, but their path to integration was largely directed by external forces. Other Wanderers narrate their lives in similar ways. For example, when I asked one participant how he relates to the notion of disability, he responded,

for a long time it was like, “No. I'm not disabled. Like, don't call me that. Like, I'm not in a wheelchair. I'm not using a cane. Like, I'm not disabled.” But, as I've grown more comfortable with being okay with my deficits, I finally realize that “no. Like, you are disabled and that's okay. Like, there's nothing wrong with being disabled.”

This integration was the result of a series of unexpected events which shaped this participant's self view.

3.2.3 | Drifters

The participants in our sample who adopted a Drifter strategy, like those who adopted a Wanderer strategy, also had life stories marked by the dominance of external forces. However, the Drifters do not seem to have experienced much change in their identity as a result of acquiring a physical disability. The Drifters narrate the acquisition of disability as an experience of identity disintegration, one that they have not really responded to, even after several decades in some instances. The Drifters seem to either have a diffuse identity or feel unequipped to integrate their pre- and post-disability selves. Both of these identity configurations are unpleasant for these participants—it is not that they feel satisfied with this situation—but they have not figured out a viable path toward integration.

Robbie provides a good example of the Drifters in our sample. Robbie was the first born son of Haitian immigrants living just outside of Boston. His father, a neurologist, left the family when Robbie was one year old and his mother quickly remarried and had a daughter. Robbie attended a Catholic boys' school until fourth grade, when he was approached by an administrator at a small, private choir school who noticed his promise as a singer. Robbie excelled at the school, which he attended from fifth to eighth grade. When he was 13, he was invited to be a soloist with the Boston Symphony Orchestra, which he remembers as both overwhelming and thrilling. He did media interviews and remembered meeting a fan who was moved to tears by his performance. He recalled thinking, “just knowing that I could impact people like that, I was like, wow, I want to do this type of stuff for the rest of my life.”

Robbie was accepted at a competitive, private Catholic high school, which was a hard transition for him.

So now I have an idea of who I am, I have all these accomplishments behind me, I feel strong, I'm ready to get into high school, you can't tell me anything right now... I thought I was on point. Go into my first week of school, I was torn down. Yeah, they took care of me...now I was in a huge pond and I'm a little fish now.

In response, Robbie said, “I usually went with the flow.” He tried to decipher the popular ways to dress, while finding a social niche with the artistic kids.

The transition between middle and high school was also the first time Robbie remembers being made aware of being Black, despite having been one of three people of color in his middle school (the other two were both Asian-American). Robbie remembers one student picking on his best friend, a biracial boy, stepping up to defend him, and being called “the N-word” for the first time. Robbie said,

I was shocked at the time. But, I wasn't going to do anything...And it was actually the other students of color who were like pushing me to fight him: “You've got to fight!” And so, we got into a fight, but I didn't want to fight him.

He remembers apologizing to his friend's mother—who “was basically my mom during that time,” as his own mother was working many hours and also beginning a relationship with the man who would become her third husband—and the talk she gave him about understanding what it would mean for him to be a Black boy in America. He joined his high school's “interracial awareness club” and began to explore his racial and ethnic identities more than ever before.

Robbie was accepted at a competitive, historically Black college, where he began to struggle academically for the first time. He felt immense pressure to pursue medicine: “my mom's side of the family kind of wanted me to show-up my dad's side of the family, and be like ‘we didn't need your help, he still became successful without you.’” But Robbie felt immense internal ambivalence about following in the footsteps of his father, who he had basically no relationship with at that point in his life. He said, “It was more that I was fighting myself, than it was difficult. If I was passionate about it, I'm sure I would have done well, but I knew I was fighting something else.” He minored in music, where he thrived, but he ended up failing too many courses to remain at the college.

Feeling shame and anger, Robbie returned home to live with his mother and her third husband. Robbie decided to confront his father about his absence throughout Robbie's life. Robbie called his father, who was living in Florida, and told him that he wanted to talk. When his father came to Boston that summer, they met for the first time in years. Robbie felt that his father shared more about his own experience of the marriage than Robbie had previously comprehended. He said,

for the most part, I understood, but I still wanted him to fight or something, or be around, or something like that. So, I finally got those questions answered, and I wasn't as angry as I was previously. And then I started to feel better about my direction in life, and finding my own direction, and not having to live up to something.

Robbie's new step-father was taking classes at a local community college and encouraged Robbie to join him. He earned an Associate's Degree and found a mentor who saw his potential and helped him get a scholarship to a flagship state university to finish his Bachelor's Degree. “I jumped on the chance and ended up going [there] for the next two years,” earning a

degree in education. Robbie remembers those years extremely fondly, saying, “that was the most in sync I ever felt. Like, I was on top of everything, I did great and I was in the Honors School, I was rewarded...if I wanted to stay in one point in my life, that's the spot.”

The period after graduation was “an all-time high” for Robbie. He said, “I graduated, I'm dating my dream girl, and this is where things start to speed up. I won't say turn for the worse, because it wasn't the worst at the time.” Robbie's girlfriend got pregnant and the couple was forced into making a decision about their future. They decided to get married and have the baby, moving to live closer to Robbie's family in suburban Boston. Robbie found himself pulled along by financial demands, working nights in a hospital intake department and DJ'ing at weddings, while his wife worked days as a high school guidance counselor. The stress began to mount and after a year Robbie felt that “I just need a quick vacation to just be able to stop and look around and see where I'm at, because I've been going, going, going since graduation.” He planned a few days in Montreal with some friends from his college acapella group.

His last night of vacation, Robbie and his friends went to a dance club and then got some fast food before beginning the drive home. Robbie was on the second shift as driver and at some point he nodded off. He remembered waking up as the car began to skid, saying “I was trying to regain control of the wheel and it [the car] flips over.” This sentence seems to capture the major shift in Robbie's life that was about to occur: he had taken the vacation in order to regain some control over his life and in doing so, his world was forever altered.

Robbie woke up in a local hospital and found himself paralyzed. At the time, he assumed it was temporary and was more concerned about his friends who were in the car—and who, mercifully, all received nothing more than scrapes and bruises. It was a week and a half before it became clear that Robbie's injury to the fourth and fifth cervical vertebrae left him with very little movement below his neck. In the local hospital and then the major trauma center in Boston where he was transferred, Robbie said, “I kind of just rolled with it.” The dominant emotion he recalls from the three months he spent in the hospital was feeling that he was disappointing others with his slow progress. When these words first came out of his mouth during the interview, Robbie found himself overcome with emotion and began to sob. He said,

I started feeling like: this is the most I can give right now, and I don't feel like it's going to change much....I kind of felt like, okay, maybe this is where I'm going to end up, you know. I didn't want to be too optimistic. I didn't want to put my hopes up too much.

He saw his own limitations, knew that others wished for more from him, but did not feel he could achieve more. This experience reminded him of the helplessness he felt as he began to fail out of his first attempt at college, fearing that he was disappointing his family but unable to do anything about it, as well as his years of conflicted feelings about his relationship with his father.

When he was discharged, Robbie moved into a converted storage room in his mother's house and she assumed much of his care. Robbie's wife and one-year-old daughter moved in for a time, but the arrangement was stressful for all of them. They ended up divorcing two years later, though remaining close and very well-coordinated as co-parents.

In many ways, Robbie's life seemed to have stalled after the accident, 16 years prior to our interview. He had experienced several ups and downs with his physical embodiment, with periods where he felt able to attend some graduate classes. He got very involved in a disability outreach and advocacy program and he began perusing the Internet for potential romantic prospects. But those times were offset by physical setbacks from pressure sores that required additional surgeries and a general feeling of directionlessness and poor body image. He said “I kind of just let it happen by chance, in terms of the things that I was involved in.”

Perhaps the best way to encapsulate Robbie's experience of identity since acquiring a disability is through the children's book that he wrote several years ago. His initial impulse to write the book was to explain his body to his daughter as she grew up. The protagonist of the book is a personified wheelchair. As Robbie described it: “a wheelchair who is looking at other chairs around him and seeing how they're useful, and he's wondering why does he look different and what is his use, what is his purpose.” While it seems likely that the character in this book does arrive at a sense of purpose, Robbie did not explain what the resolution of the book is. This very much mirrored the end of Robbie's interview. As he looked toward the next chapter of his life, he said “This is where I'm at: I'm still struggling with it.” Robbie's description of his life in the years since acquiring a disability is saturated with a sense that he has not integrated his disability into his identity and that he feels powerless to do so. He has made some active decisions in his life, but not with regards to his identity. Like the personified wheelchair in his book, Robbie just rolls with life.

Other participants in the Drifter group shared similar themes. For example, one participant says he feels “very much the same, I guess” about his sense of self, but his story is marked by a series of concessions to external forces shaping everything from his career path to his romantic life to his physical capabilities. His story is one of passive continuity and low exploration of what the disability has meant to his life story.

It is important to note the very real limitations some people with disabilities experience, both physical and social-structural, that constrain their lives and identities. The

Drifter strategy is not a comment on the objective reality of these individual's lives, but a characterization of the dominant narrative themes in their stories.

3.2.4 | Resisters

The participants in our sample who adopted a Resister strategy also describe strong continuity in their identity over their lives, but their stories are marked by an active engagement in maintaining their pre-disability sense of self. In most cases these efforts appear to be a refusal to grant the disability any power over their identity, despite its power over their daily lives.

Carol is an emblematic Resister. She recalled her childhood as wonderful, titling the first chapter of her life story "Everything's Good." That took a radical turn when both of her parents died within 15 months of each other during Carol's teenage years. Despite the challenges that came into Carol's life later on, this central loss remained the low point of her life and the experience she kept returning to as she told her story. After her parents' deaths, Carol was taken care of by her older sister and her boyfriend's family. She went to college, got married, had two daughters of her own, and worked in several jobs. But this loss cast a contaminative hew over everything. She said, "anything good that happens to me, there is always the sad thing that my parents weren't there... it's a sad thing that never goes away."

Carol's adult years were marked by important transitions in her sense of self. For example, she described the birth of her older child as a moment of transformation. As she put it, "the birth of the first child: when you change from the person you used to be to the person you're going to be forever." Carol was anxious about becoming a parent, given her own childhood experiences, but it was also something she knew she wanted, "and then it turned out I was great at it." She also had a professional low point, when she was abruptly laid off as a result of a reorganization from a job after working there for 13 years because the company decided to outsource the role she had filled, an injustice she "never really recovered from." Carol was therefore open to profound identity change in some spheres of her life and has experienced personal transformation.

Carol and her family spent time each summer on a lake in Maine. When Carol was 63, the period of "total relaxation" was interrupted by bad heartburn, a problem she had treated for years. She tolerated it, despite her usual medicine not working, until her husband finally convinced her to go to the local, rural hospital to get checked out. Carol described it this way:

At this point I had never been to an emergency room and I thought, you know, that's for drama. That's not, you don't just go there. But [my

husband] dropped me off at the hospital where there was nobody, nothing happening there... And then I said to the woman, "I think I'm having a heart attack," and I totally surprised myself. I didn't know I was going to say that. [My husband] was totally stunned. I don't know why I said it. I had no idea where that came from, and she said, "Okay," and took me back immediately and some man, I assume doctor, kind of lounging around the cubicle saying, "Well, we don't do cardiac events here, so we'll have to helicopter you to [a major city]." I said, "Oh, no, no, no, no, no, no, no. You don't, no, no, not causing that kind of drama here. We're on vacation; you don't get it. We're on vacation, and I just want someone to take a look just because the heartburn is just not getting better," and that's the last I knew. The last I knew, for months.

Carol was having a heart attack and she was taken to a major hospital in Maine. There, it turned out the situation was much more serious than previously understood and she was flown to a major hospital in Boston, where she stayed for the next six months, the first two in the intensive care unit, where the medical team undertook heroic efforts to keep her alive. Carol underwent seven surgeries and ultimately had amputations to both legs and parts of both hands. "I was a mess from head to toe," she summed it up. She remembered,

one night I was being taken for an x-ray and all the hospital lights were down low and for some reason the nurse was taking me, not a transport person, and at one point she looked over and she said, "Oh, it's you." And I looked at her and she said, "Look, the hair on my arms is standing up. I was one of the nurses that looked after you [when your helicopter landed at this hospital from Maine]." She said, "Nobody who was involved in your care at that point would believe me if I told them I was talking to you today."

That comment both stunned Carol and affirmed how dire her situation had been. She said, "psychiatrists cruised through and nurses would sit on the bed and say, 'Are you depressed?' And I would say, 'Pfft, of course.'" In her life story interview Carol titled this experience "The Catastrophic Medical Event," a phrase she used frequently.

After months of rehabilitation, Carol remembered, "Thinking: I can't believe this. I can't believe this happened. I can't believe this is my life." Her husband had retired just before their vacation and they found themselves having to create a wholly different chapter in their lives than the one

they expected to come home to. "It was so quiet here: no beeps, no buzzer. My main feeling was that it was so quiet." In that quiet, the couple renegotiated every aspect of their daily lives. When I asked her what was going through her mind during that period, she said:

When I was laying [in the hospital] I'm thinking to myself, "how am I going to do Christmas dinner?" Christmas dinner?! How am I going to go to the bathroom by myself tomorrow, you know? I mean, Every. Single. Thing. You know, I just read a book that had a sentence in it that stopped me totally in my tracks. It was: "I'm living a life I didn't agree to." And that really was it. I mean, this is totally not fair. At this point, I'm totally healthy. I mean, there's nothing wrong with me. Not bleeding, not on chemo, you know, I'm fine—just missing parts. So to need so much help when I'm fine is weird, you know?

Carol felt that her life had been fundamentally altered without her consent. So, when I asked her how she has made sense of that in the six years since the Catastrophic Medical Event, she said "I don't. I mean, I don't make sense of it. There's no way make peace with it. I'm trying, I'm trying, I'm trying. I'm trying and trying, yeah. But, I, I, I can't make sense of it. Can't." She compared it to a different experience in her past:

way, way back I was a smoker. It took me years to think of myself as a non-smoker; years. I don't know why. I didn't really believe I'd stopped or that I would have stopped and I'm finding this is similar. I don't think of myself as an amputee. You think, "well, how could you not?" But I am, I am surprised when that smacks me in the face.

Carol could not reconcile her body and her identity.

Nevertheless, as Carol demonstrated in these quotes, she is actively engaged in renegotiating her life. Those efforts are squarely focused on supporting her sense of identity continuity. After prolonged efforts on the part of her medical team, Carol qualified for a sophisticated prosthetic arm. Receiving it required her to travel to a special facility where it could be fitted and she could be trained to use it. She showed it to me: a large, black, robotic forearm that she called "The Darth Vader Hand." Carol used it for some time, but now it mostly sits in its box in her closet. "It wasn't me," she said. She found that it got in the way of her feeling connected to the activities that meant the most to her: putting on her own makeup and jewelry, writing thank you notes, and reading to her grandchildren. Carol came up with an impressive array of life hacks, involving very low-tech solutions that would facilitate her continuing to engage in these activities without

feeling mediated by a sophisticated prosthetic. Here, she does notice some change: "I would have said I wasn't clever before. Now, I would say I'm very clever and inventive, because you have to be."

In pursuit of identity continuity, Carol has also developed a distinctive perspective on common cultural depictions of people with physical disabilities. Living in Boston, she felt inundated by stories of people who had survived the Boston Marathon bombing and gone on to greatness.

The people who say, "Oh, you can do anything you did before if you just set your mind to it," Oh, pfft, please. And then, you know, there's the Dancing with the Stars, the snowboard star, you know, the fabulous amputees? Tired of all of them. You know, I feel like if, if I can do the regular things that is a major triumph... You know those people who say, "Oh, cancer made me a better person," I'm sorry. I'm sorry. I didn't need this in any way.

Carol resists dominant master narratives of redemption (McAdams, 2006) and the "super crip" (Goggin & Newell, 2004; Grue, 2016; Smith & Bundon, 2018), acknowledging how unfair and unwelcome her experience was.

When I asked Carol if there were *any* identity changes as a result of this experience that were positive, she drew some connections across the broad sweep of her life. She began, "I was a born worrier. I mean, I can picture myself in first grade, we were supposed to use a blue crayon and I didn't have a blue crayon, I mean, I was just distraught." She then connected this to the loss of her parents in adolescence, saying,

for a worrier to begin with, to suddenly have very dramatic things happen at 15 and at 16, I mean, it's a perfect storm for continuing to be a fabulous worrier...the "It'll be fine," people, they make me crazy and I think they're stupid, because it's not going to be fine a lot of the times. Being positive is one thing, but, "it'll be fine" doesn't help your finances, doesn't help you. So I'm not an "It'll be fine," person.

But then she continued, "When the medical catastrophe occurred, it's about the worst thing that could happen. So I actually became less of a worrier because, you know, what the hell else could happen?" Paradoxically, in her mid-60s, Carol found that experiencing a "catastrophe" quieted her lifelong worry. This is one way in which her sense of self did change.

Twice during the life story interview Carol used the phrase "I don't do change." As an example of the Resisters in our sample, Carol demonstrates a deep commitment to identity continuity in the face of major physical changes. Other

Resisters also shared Carol's active engagement in maintaining their pre-disability sense of self. For example, another participant in the Resister group said, "It's almost like I compartmentalize the handicap portion [of my body]. And it's almost like I'm simultaneously living in two separate worlds at the same time." He described the ways in which his life exhibits substantial continuity: "I've gone back to work. I'm more active than I've ever been in my life. I'm probably in the best shape I've ever been, physically, in my life." And yet, in the moments when he is without his assistive technology, "life changes drastically, dramatically." He demarcated his pre-disability life from his current life by saying, "You can lead a normal life. You say that, but, I mean, there's normal and there's normal. For me, normal was prior to [my disability]. And now, there's this reality." Like Carol, this participant actively works to create continuity in his identity despite major changes in his daily life.

3.3 | Strategies of identity integration and psychological well-being

Our primary goal with this study was to illuminate different narrative approaches to identity integration taken by our participants. The typology presented above, as a distillation of two dimensions that emerged from the data, represents the outcome of that effort. However, as noted in the Method section, we also collected a series of widely used self-report measures, one subset of which assessed the psychological well-being of our participants. In a sample of 13 participants divided into four uneven groups it would be wholly inappropriate to interpret observed trends in these self-report data to suggest that they generalize beyond the sample; that was neither our intention nor our goal. We did not even examine the self-report data until we had established the typology presented above. However, having developed this system for understanding participants' different narrative strategies, we looked to see if there were any apparent themes in the connections between participants' group and their overall well-being.

As described in the Method section, we conceptualized psychological well-being as comprised of a composite score of the following measures: PANAS, SWLS, PWB, BDI-2, and PSWQ (Chronbach's alpha: .82). In addition, we also explored the WUSCTED as an index of psychological maturity, one typically uncorrelated with measures of psychological well-being (in our sample the correlation was .03). Finally, we also explored associations between dispositional traits and narrative identity in an effort to bridge to other domains of the personality literature and to adopt a personological approach.

Generalizing across the sample, the Adapters seemed to have the highest levels of both psychological well-being and psychological maturity. In contrast, the Wanderers and

Resisters were low in hedonic well-being, but exhibited a range of psychological maturity. The Drifters did not demonstrate any discernable pattern. This set of insights suggests that Adaptation may be associated with better psychological well-being and maturity than other narrative strategies. In other words, responding to acquired physical disability by actively engaging with a major identity transformation may best support psychological well-being and maturity.

In terms of dispositional traits, the entire sample was notably high in the traits of Openness, Agreeableness, and Conscientiousness, which made variation in these traits hard to interpret. Nevertheless, the Adapters were especially high in Openness. No clear trends emerged with respect to Neuroticism or Extraversion. This overall lack of association with dispositional traits suggests that the narrative strategies adopted by our participants were not derivative of their dispositional traits, which aligns with other literature suggesting an incremental association between narrative identity and psychological well-being (Adler et al., 2016).

4 | DISCUSSION

The inductive process of grounded theory that our research team engaged in led us to understand identity integration following the acquisition of a major physical disability as unfolding along two dimensions (see Figure 1). First was the extent to which participants were actively engaged in processing their experience of acquiring a disability. Second was the extent to which participants integrated their acquired disability into their narrative identity, versus maintaining their pre-disability identity or remaining disintegrated years after the experience. When we overlaid these two dimensions, we produced a matrix with four quadrants of narrative strategies that we titled Adapter, Wanderer, Drifter, and Resister. We see these quadrant categories as emblematic of different narrative strategies for identity integration, but individuals' use of these strategies as dynamic and contextualized. When we examined psychological well-being and maturity alongside these four narrative strategies it appeared that only Adaptation was associated with trends of better well-being and maturity. Adapters also seemed to be higher in the dispositional trait of Openness, with no other traits demonstrating clear patterns. Taken as a set, our results suggest that there are four narrative strategies that our participants engaged in when telling their life story. A pattern that combined active processing and a fundamentally changed sense of self was most associated with psychological well-being and maturity.

Scholarly perspectives on disability identity, from both psychological science and disability studies, indicate that identity integration is a central challenge (e.g., Dunn & Burcaw, 2013; Garland Thomson, 2014; Gill, 1997; Kafer, 2013; Syed & McLean, 2016). Yet the broader literature

is unsettled as to whether identity integration is a desirable or even a possible task. The participants in our sample suggest that identity integration is not only feasible, but may be a psychologically productive, perhaps critical endeavor. Critiques of identity integration focus on the extent to which it is a fictional account that glosses over the shifting social dynamics that construct disabled selves and therefore deny the constitutive political forces which shape identity (e.g., Dirth & Branscombe, 2018) or the extent to which the pressure for an integrated identity is a tool of the modern capitalist state which demands and defines normalcy (Kafer, 2013; Puar, 2015). Such critiques have been lodged at the broader concept of narrative identity as well (e.g., Hyvarinen et al., 2010). Nevertheless, as McAdams (1997) wrote more than two decades ago in response to these critiques,

while the multiplicity of postmodern life renders it unlikely and perhaps undesirable...adults still seek to bestow upon the me a modicum of unity and purpose (i.e., identity) by constructing more or less coherent, follow-able, and vivifying stories that integrate the person into society in a productive and generative way and provide a purposeful self-history (p. 63).

Phenomenologically speaking, most Western adults *do* strive for a sense of unity in their life stories, and those who are unsuccessful in this pursuit often suffer as a result (Michell et al., under review). The specific nature of continuity in narrative identity is challenging to operationalize (Adler, 2019), but the inductive approach adopted in this study suggests that the content of participants' narratives construed their identity as transformed, stable, or diffuse from before acquiring a physical disability until after. The results of this study offer a framework for understanding the ways in which our participants approached the task of identity integration following the acquisition of a physical disability in adulthood. As such, the two dimensions and four strategies we have identified are both a set of conclusions in their own right and open up new avenues for future scholarship—both qualitative and quantitative—on disability identity development.

Schachter (2004) productively suggested that identity integration ought not be considered a binary, wherein one is either integrated or not. Our intention is not to offer the set of four narrative strategies we have identified as rigidly categorical. Indeed, this typology emerged from a two-by-two dimensional matrix, and the labels we have assigned to the four quadrants ought to be interpreted as “configurations” (Schachter, 2004), arrangements of diverse aspects of an individual's identity, woven together into a coherent narrative strategy at a given moment for a given reason, not discrete categories with clear boundaries. These narrative strategies

are emergent from the cultural embeddedness of individual development. These are four processes that our participants engaged in following a major, identity-threatening life experience. As such, they will certainly continue to unfold as the participants continue to age and may take on different thematic contours.

Tracey (2010) outlined eight criteria for assessing “excellent” qualitative research: We have strived to meet each of these criteria. We have argued that the study of identity in people with disabilities is a worthy topic (criterion a) and one that is understudied (criterion f). Furthermore, we have made every effort to be transparent about our rigor (criterion b), sincerity in undertaking this work (criterion c), the status of our credibility to investigate this topic (criterion d), and the ethics we have brought to bear on this study (criterion g). We hope that our Results section illuminates the experience of our participants with resonance (criterion e) and brings some meaningful coherence (criterion h) to the data.

4.1 | Limitations

Just as we have strived to be transparent about our epistemological orientation, our methodology, and our analytical approach, we also want to be clear about the limitations in the present study. Most important to us, while we have embraced an “emancipatory-inclusionary intention” in this project (Nasir & Hussain, 2018, p. 41), we have certainly fallen short of the ideals of participatory action research that not only describes a phenomenon but also leverages this new knowledge directly in service of the communities being studied. We have shared this paper with the participants and incorporated their feedback, and will continue to be supportive of them as individuals, but this project does not currently serve as the foundation for social activism. In addition, it is vital to remember that emancipatory approaches themselves offer a master narrative of disability, like all other approaches to research, and therefore risk silencing some voices (e.g., Danieli & Woodhams, 2005).

We have made every effort to stay focused on our participants as whole people, living embodied lives, and not as “an object of curiosity for theoreticians” (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019, p. 980). One strong critique of disability scholarship is its tendency to “describe disabled bodies using such an extreme level of abstraction” (Erevelles, 2014, p. 223) such that they fail to attend to the “physiological and psychological realities of an impaired body and mind” (Goodley et al., 2019, p. 983; also see Stephens, 2011). Nevertheless, we are confident that the constraints of this specific project have led us down this path further than we would like.

As noted in the introduction, this write-up of our study was far narrower in its scope than the rich dataset allows. Identity

integration rose to the forefront as a vital focus for our investigation, but other topics also surfaced in our inductive work. Given the space constraints, we particularly lament not having the ability to more deeply discuss the many nuances introduced by an intersectional analysis of our participants' life stories (e.g., Crenshaw, 1991). Race, gender, religion, sexual orientation, and socioeconomic class all explicitly intersected with disability status for our participants, which we have not done justice to in this paper. Issues of intersectionality are vitally important in the study of people with disabilities, yet continue to be underexamined (e.g., Bailey & Mobley, 2019; Bell, 2017; Devlieger & Albrecht, 2000; Erevelles & Minear, 2017; Johnson & McRuer, 2014). Perhaps most salient are the ways in which the relative financial security of our participants powerfully impacted their experiences with acquiring a disability. Many of them noted the extreme cost of their medical care and expressed both gratitude for and frustrations with the American health insurance system. While we did not collect socioeconomic data in this sample, we are aware of the ways in which their stories are filtered through this lens. In addition, we generated insights related to participants' engagement with social master narratives of ability (e.g., Goggin & Newell, 2004), the dynamic, reciprocal interaction between individual experience and familial and social context (e.g., Dirth & Branscombe, 2018), the role of adaptive technologies in shaping identity development (e.g., Feldner, 2019), and a more explicitly developmental reading of our participants' life stories (e.g., Adler, 2018) than we were able to present in this paper.

In addition, adopting a longitudinal study design would allow for an examination of the unfolding of these narrative strategies (and their association with psychological well-being and maturity) over time. While an emphasis on participants' retrospective personal narratives offers an optimal opportunity to examine different approaches to meaning making, collecting these same life stories again years in the future would add a layer of sophistication to our understanding of how participants' identity integration changes over time (e.g., Syed, 2010).

Finally, we want to again acknowledge our own biases as scholars and the ways in which those have shaped this paper. While one member of the research team has experienced long-term physical impairment, this project cannot appropriately be considered research about people with disabilities *by* people with disabilities. Relatedly, as a research team we bring potentially unexamined assumptions about what constitutes normalcy and resilience that may be ableist (Runswick-Cole & Goodley, 2013; Ungar, 2004). While we did not approach this project with an *a priori* hypothesis about the role of identity integration for our participants, we likely hold assumptions about the benefits of integration that overlook alternatives such as the “thrill of dissonance” (Schachter, 2004, p. 186) or the utility of “not making sense” (Noble, 2007, p. 171).

4.2 | Conclusion

As we noted in the introduction, we had two primary goals for this paper. First, we sought to offer an inductive, grounded understanding of the nature of identity integration among people with acquired physical disabilities. We hope that the set of narrative strategies we have described above serve as both a valuable set of insights in their own right as well as a foundation for future scholarship on this important and underexamined topic. In particular, we hope the two dimensions and four types of narrative strategies will offer a foundation for future scholarship on disability identity development and for positive narrative identity change in the wake of adverse experiences more generally. In the feedback our participants offered on this manuscript, many noted the ways in which it was generative to be exposed to a range of narrative strategies. For example, one participant wrote,

Reading it gave me a lot to think about regarding empathy for other disabled people who have approached their life changes differently than I have approached mine. I think this research is important for so many reasons—one being a challenge to the assumption of many that adult onset disability is always or almost always viewed as a tragedy.

Second, we sought to use this study to demonstrate one role for descriptive, qualitative, inductive methods in the examination of personality change following adversity, the focus of this special issue. This field of research is appropriately focused on correcting many of the methodological issues that have rendered the validity of post-traumatic growth difficult to decipher (e.g., Infurna & Jayawickreme, 2019). Against this landscape, we hope that our contribution will serve as a reminder to the broader field that the objective truth of post-traumatic growth ought not be the sole focus for future research. Whether or not people experience “true” personality change in the wake of adversity, many people make sense of challenging life experiences as both disintegrating and as transformative. The subjective meaning personified in life narratives therefore offers not only a vital emphasis for scholarship, but one that may have objective consequences (Adler et al., 2017), and one with an ethical mandate. Any scholar who seeks to understand others' responses to adversity has a duty to listen, rigorously, to those who are willing to share their experiences. Reflecting on her career as a pioneering psychologist, disability scholar, and activist, Michelle Fine (2019) recently wrote of “our obligation to animate a radically engaged, intersectional, critical, participatory, and provocative assemblage of research that is at once anti-ableist and crafted toward disability justice” (p. 972). Efforts to understand the truth of personality growth following adversity

can only be successful when the voices of those who have undergone such challenges are regarded as coequal with other sources of data and the ethical dimension of scholarship is seen as inextricable from its central pursuit.

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CONFLICT OF INTERESTS

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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ENDNOTES

¹The scholarly literature distinguishes between the terms “impairment” and “disability” (e.g., Dirth & Branscombe, 2018; Forber-Pratt et al., 2017; Siebers, 2017). *Impairment* is typically used to refer to a deviation from norms in body structure or function that confer a challenge to the individual. *Disability* is typically used to refer to a socially constructed marginalization as the result of an inaccessible social and built environment. It is important to note that neither term lives entirely in the body nor entirely in the social world (Runswick-Cole & Goodley, 2013), both live at the intersection of bodies and constructed worlds. Throughout this paper we have sought to use these terms consistent with these typical uses. Thus, when we refer to “acquired disability,” we refer to the psychosocial consequences of an environment that is no longer fully accessible to the individual.

²The American Psychological Association Style Guide recommends “person-first” language when writing on the topic of disability. We follow the examples of Bogart and Dunn (2019), Dirth and Branscombe (2018), and Dunn and Andrews (2015) who suggested that alternating between such person-first language (“people with disabilities”) and identity-first language (“disabled people”) is more inclusive of the breadth of self-identification used by people to describe themselves. Doing so may further support efforts to destigmatize disability.

³Following common practice in qualitative research, we have adopted a first-person voice in the present paper. Most often we use the first-person plural (“we”) to refer to the perspective of the whole research team. In certain instances, such as references to prior published work or when speaking about the identity of the interviewer,

first-person singular (“I”) was more appropriate, to refer to the first author, Jonathan Adler.

⁴This table may suggest a connection between type of physical disability and the type of narrative strategy adopted (for example, that blindness and deafness correspond to the Adapter strategy, while spinal cord paralysis corresponds to the Wanderer and Drifter strategies). This study was not designed to examine differences between disability type and narrative strategies. It is possible that certain kinds of disability experience either correspond to certain narrative strategies or make them more likely, or that these apparent trends are merely artifacts of our specific set of participants.

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