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Narrative identity among people with disabilities in the United States during the Covid-19 pandemic: The interdependent self

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1. Introduction

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This study examines narrative identity among a large, diverse sample of people with disabilities (PWDs) in the United States during the “second wave” of the Covid-19 pandemic (October-December 2020). The study relied on abductive analyses, combining a purely inductive phase of inquiry followed by two rounds of investigation that filtered inductive insights through three theoretical lenses: social-ecological theory, the theory of narrative identity, and perspectives from the interdisciplinary field of disability studies. The central result was the identification of a particular configuration of self, one that was demonstrably interdependent with both immediate interpersonal contexts and with broader cultural contexts. This interdependent self was interpreted in both positive and negative ways by PWDs. These findings invite future inquiry into commonplace conceptualizations of an independent self at the center of personality research and suggest that dominant conceptualizations of “the good life” may overly emphasize independence.

Keywords:
- Narrative identity
- Disability
- Social-ecological model
- Interdependent self

ARTICLE INFO

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especially among individuals from marginalized groups (McLean et al., 2017). That group connection, then, serves as the foundation for how one’s life is subjectively viewed as ‘good’... Accordingly, those who deviate from the master narrative of the good life have the opportunity to deviate into communion with an existing group, thereby achieving that belonging that was initially denied” (p. 11). Syed and McLean (this issue) further note that “this idea is admittedly speculative at this point” (p. 11). While our analyses of personal narratives of PWDs during the COVID-19 pandemic in the present study did not adopt an explicitly master narrative analytical approach (e.g., Syed & McLean, 2021), our findings provide support for the assertion that interdependence may be a vital aspect of “the good life,” perhaps especially for people from marginalized communities, like PWDs. Our findings offer an alternative narrative (McLean & Syed, 2015) to dominant psychological narratives of “the good life,” one that deemphasizes independence and elevates interdependence. Our approach in the present study was exploratory – we did not approach our qualitative analyses with specific hypotheses in mind, but rather adopted an abductive approach (e.g., Timmermans & Tavory, 2012), wherein our initial inductive analyses were subsequently filtered through theoretical lenses that seemed promising for making sense of the emergent themes. Yet the opportunity to engage with Syed and McLean’s paper (and McLean’s peer review of our manuscript) during the editorial process revealed generative connections between their contribution to this Special Issue and ours.

While we did not undertake this qualitative study with a priori hypotheses, our insights suggest that interdependence may be a vital aspect of “storying the good life” for PWDs. The importance of social connection is hardly a new insight, but our qualitative analyses suggest that PWDs in the United States during the COVID-19 pandemic not only emphasized social connection, but also presented a construal of self that is intertwined with others. In other words, their narratives did not only feature close connections with others (which they did feature), but an interdependent self, one wherein neither independence nor dependence was as salient as a blended self, grounded in reciprocal reliance. This insight expands upon approaches that emphasize the importance of social connection or a narrative of communion to suggest that narrating an interdependent self may be one strategic approach to “storying the good life” under conditions of marginality and existential threat.

The ongoing COVID-19 pandemic has been a challenging psychological experience for nearly every-one (e.g., Ongür, Perlis, & Goff, 2020, Pfefferbaum & North, 2020), yet emerging research has revealed significant disparities in the pandemic’s relative impacts across different social groups, including PWDs (e.g., Jesus et al., 2021; Lund et al., 2020). PWDs represent the largest minority group in the United States, comprising nearly 25% of the population (Okoro et al., 2018). Despite this, scholarship on all aspects of PWDs is subjectively viewed as ‘good’... Social-ecological approaches focus on the dynamic interplay between the developing individual and the many contexts in which they are embedded (Bronfenbrenner, 1979, 1997). These approaches have historically posited a developmental ecosystem in which the individual is placed at the center and is surrounded first by their proximal interpersonal context and then by successively more distal contexts, including their community (e.g., neighborhood and workplaces), and the broader society (e.g., cultural norms and public policies). These approaches also emphasize interactions between different social-ecological levels, for example how a person’s disability identity interacts with their interpersonal relationships, built environments, and cultural values. As such, they may be well-suited for understanding the multiple contexts of identity development. The social-ecological approach has been adopted by the Centers for Disease Control and Prevention (CDC) as a framework for advancing health and well-being (e.g., Dahlberg & Krug, 2002). Recent work by some members of our research team adopted a social-ecological approach to conceptualizing the range of healthcare workers’ experiences of the COVID-19 pandemic (Hennein, Mew, & Lowe, 2021). That study demonstrated the breadth of ways in which the pandemic experience impacted their participants and identified distinct connections between different social-ecological levels and psychological well-being. Prior research has also indicated that the meaning of social support (Dereue et al., 2015) and resilience (Tillier et al., 2019) among PWDs varies across levels in social-ecological models. Brutzman and colleagues (Brutzman et al., 2022) review contemporary applications of social-ecological approaches to social issues, highlighting the advantages of contextual complexity such approaches offer.
adequately capture the lived experience of marginalized populations. These critiques of social-ecological approaches align with Syed and McLean’s structural-psychological alternative to traditional psychological conceptions of “the good life” (this issue), in that both center systems of power rather than individuality. In the present study, we adopted a social-ecological lens in order to situate our current work alongside that of other scholars focused on well-being among PWDs, but also because adopting this lens offered an opportunity to reconsider the model with a different marginalized population than those that current critics of the model have examined. We believed that sorting PWDs’ narratives into the different systems in a social-ecological approach would be viable and might also surface new critiques of such models. (It is important to note that we adopted a generalized social-ecological model approach, as opposed to the specific Bronfenbrenner (1979) model.)

Narrative identity. The study of narrative identity focuses on the ways in which individuals reconstruct their past, interpret their present, and imagine their future in pursuit of coherence and meaning (McAdams, 1995, 2001; McAdams & McLean, 2013). Examining personal narratives about challenging life circumstances has a long tradition within the study of narrative identity in personality psychology. For example, prior research has examined narrative identity among: individuals working to maintain sobriety (Dunlop & Tracy, 2013), people undergoing major career changes or religious conversions (Bauer & McAdams, 2004), cancer patients (Thomsen & Jensen, 2007), parents of children on the autism spectrum (Mason et al., 2019), people with personality pathology (Lind, Adler, & Clark, 2020), psychotherapy clients (Adler, 2012), and veterans with difficulty adapting to civilian life (Mitchell, Frazier, & Sayer, 2020), as well as many others experiencing major challenges. Narrative identity serves as a tool for navigating adversity in multiple ways: retrospectively, concurrently, and prospectively (e.g., Adler et al., 2015).

The study of narrative identity among PWDs has tended to focus on identity development and in particular the importance of identity integration among people with acquired physical disabilities (Adler, 2018; Adler et al., 2021). Furthermore, the broader psychological literature on identity among PWDs has tended to focus on the construct of disability identity, or the extent to which someone considers themselves as a PWD (Bogart, Rottenstein, Lund, & Bouchard, 2017; Forber-Pratt et al., 2017). Drawing from social psychological approaches such as social identity theory, these approaches have examined the ways in which one’s identity as a disabled person or as a member of a disability community impacts their thoughts, emotions, and behaviors (Dirth & Branscombe, 2018; Nario-Redmond, Noel & Fern, 2013; Nario-Redmond & Oleson, 2016). Disability identity can be understood as a sub-component of narrative identity, comprising the stories related to one’s self-understanding as a PWD. The present study sought to deepen both traditions of scholarship, expanding the study of narrative identity among PWDs beyond samples of people who have acquired physical disabilities and incorporating the study of disability identity with the study of narrative identity more broadly.

Disability Studies. Social scientific approaches to disability, including those within psychology, have been rightly criticized for adopting an underlying medical model, one wherein disability is regarded as a deficit or deviation to be corrected (e.g., Dirth & Branscombe, 2018; Olin & Pledger, 2003; Rosa et al., 2016). In contrast, the interdisciplinary field of disability studies offers social or political/relational models that regard disability conditions as the effects of social structures that produce inaccessible built environments and relationships that marginalize or exclude (e.g., Davis, 2017; Garland Thomson, 2013; Kafer, 2013), and others have advocated for bridging disability studies and psychological science, which is a challenging task, given their different underlying epistemological orientations. Qualitative psychological science may offer a viable initial step in uniting these perspectives (Adler, 2018). In the present study, we sought to filter the emerging insights from our dataset through some of the foundational concepts in disability studies, both to foster a richer understanding of the data and to advance efforts to bridge these fields.

The Current Study. Social-ecological approaches, the theory of narrative identity, and perspectives from disability studies provided the three theoretical positions from which we sought to understand narratives of identity among PWDs in the context of the COVID-19 pandemic in the United States. By collecting and qualitatively analyzing personal narratives from PWD during the pandemic, we sought to build upon these theoretical understandings of identity among PWD.

2. Method

2.1. Positionality

Our 10-person research team is a diverse group, along multiple axes. As a set, we represent different genders, races, sexual orientations, life stages, career stages, academic training, expertise in the study of PWDs, and, importantly, disability identity. Two members of our team (KR and KW) identify as PWDs. We regard this diversity of the research team as a major asset in approaching abductive qualitative work, as it provided us with many lenses through which to understand the data and our approach to examining it. As described in more detail below, we regarded our positionality as researchers as centrally relevant to the questions we were asking of the data and, following typical qualitative methodological protocols, we discussed the ways in which our own perspectives informed our interpretations (e.g., Hall & Gallery, 2001). However, positionality extends beyond our demographic categories. Rather than explicating the motivations and intellectual contours of each member of our 10-person research team, our collective positionality is best summarized as one of socially-engaged scholars. While the contribution to knowledge is a shared goal among us, none of us is satisfied with producing knowledge that remains available primarily to other scholars. (Indeed, we almost decided not to pursue a contribution to this Special Issue because of the first author’s reservations about publishing in an Elsevier journal, a publisher who I view as having a poor track record with regards to disseminating scholarly contributions with people outside wealthy academic institutions willing to pay for access to pay-walled content (e.g., Tennent, 2018). We intend to pay the Elsevier Article Publishing Charge to make this manuscript open access. Our decision to contribute was driven primarily by my wish to be part of this Special Issue dedicated to Will Dunlop, a dear friend and collaborator of the first author (JMA), who died in 2021.) As a team, we are motivated by questions that might make a difference in the lives of marginalized people, especially PWDs. This motivation certainly influenced our perspectives on the narrative data by heightening our sensitivity to insights that might positively distinguish PWDs, casting them as a minoritized group with a deeply valuable perspective on “the good life.” We see this positionality as a positive bias, one that augmented our findings.

2.2. Participants and procedures

Data for the current study were taken from a larger online survey that investigated the psychosocial impacts of the COVID-19 pandemic on PWDs in the United States (Wang et al., 2022). There is only one prior publication based on this dataset, which reports exclusively on the quantitative data that were collected (Wang et al., 2022). Participants were eligible for the broader study if they 1) self-identified as disabled, 2) were 18 years of age or older, and 3) lived in the United States. Participants were recruited via disability-specific online communities.

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2 Data sharing was not detailed in the Institutional Review Board application or Consent Form for this study, so the data cannot be shared publicly. Furthermore, the study was not pre-registered.
and email listservs from national, regional, and local disability organizations, as well as through email blasts and social media posts aimed at audiences that included both PWDs and non-disabled people, between October and December 2020. During this period the United States saw a “second wave” of Covid-19 cases after an initial downward trend during the summer months (e.g., Johns Hopkins Coronavirus Resource Center, 2021). Participants contacted through the above outlets were given a web link to an online survey, administered anonymously via Qualtrics. Upon completion of the survey each participant received a $20 e-gift card. All study measures were approved by the institutional review board at Yale University. The final analytic sample consisted of 326 participants who responded to at least one of the three narrative prompts.

2.3. Materials

2.3.1. Demographics

Demographic data collected from participants included: age, gender identity, ethnicity, race, disability type, and age since primary disability onset. Table 1 provides descriptive statistics regarding demographic variables. In general, the sample was largely white, with 22% identifying as people of color. The sample was predominately composed of people with physical disabilities. The sample included 13.5% people reporting gender identity other than cisgender woman or man. Our sample over-represented people identifying as white, people identifying as female and as genderqueer, and those reporting physical disabilities, compared to the broader American population of PWDs (Varadaraj et al., 2021).

2.3.2. Narratives of the COVID-19 pandemic

Participants were asked to write (or use speech-to-text technology to produce) responses to three open-ended narrative prompts. They were encouraged to think about “stories of specific moments, with beginnings, middles, and endings, with characters, and maybe with lessons” pertaining to a low point, a high point, and a time their identity as a person with a disability was salient during the COVID-19 pandemic. The three open-ended narrative prompts used in this study were adapted from the Life Story Interview (LSI), which consists of a larger battery of narrative prompts inquiring about different life periods, specific “key moments” (i.e., important life memories), and projections of the future (McAdams, 2008). The LSI has been advocated as the “gold standard” for eliciting narrative data and has been used in dozens of empirical studies to provide information on how individuals make meaning from their life experiences (Adler et al., 2017). High points and low points are frequently used prompts in narrative research that does not include the full LSI (e.g., Cox & McAdams, 2014, Lilgendahl & McLean, 2020). In developing the study protocol, we discussed the potential challenge of recounting a high point of this challenging time but opted to include this prompt in order to elicit positive experiences alongside challenges. Zero participants commented that this prompt seemed inappropriate, and many offered moving positive experiences. The third prompt, concerning disability identity salience, was included to elicit narrative data concerning the unique experiences of disability during the pandemic, thereby allowing us to examine disability identity in the broader context of narrative identity. Appendix A provides the narrative prompts used in this study.

2.4. Data analysis

An abductive analytical approach was selected for investigating the present dataset. Abductive analyses strive to push inductive approaches towards the likelihood of identifying innovative theoretical insights (e.g., Timmermans & Tavory, 2012). In particular, abductive approaches elevate the positionalty of the researcher as a vital element in directing the inquiry. In this case, the diversity of the research team, both demographically (including disability status) and based on their scholarly traditions, alongside the invitation to contribute to this Special Issue on narrating “the good life,” made an abductive approach a strong fit. This approach provided a vehicle for filtering our initial inductive analyses through the lenses of social-ecological approaches, the theory of narrative identity, and perspectives from disability studies, maximizing the likelihood of producing novel analytical insights, not just rich descriptive summary. In addition, two members of our research team (RH, SL) have experience overseeing abductive approaches (Hennein & Lowe, 2020). Our abductive analytical strategy began with a purely inductive phase, relying on grounded theory methods. We then undertook a second phase of analysis filtering the insights from the initial phase through the lens of narrative identity. A third and final phase sought to integrate the insights from the first two phases with perspectives from disability studies.

2.4.1. Abductive analysis phase 1: Inductive grounded-theory analysis

A total of 862 responses were analyzed across 326 participants (individual narrative word count M = 86, SD = 110). We analyzed the open-ended responses using an abductive approach, sequencing both inductive and deductive coding (Tavory & Timmermans, 2014; Timmermans & Tavory, 2012). We began by using grounded theory to inductively characterize the lived experiences of people with disabilities during the pandemic (Charmaz, 2014). The analytic team for this step included four raters (RH, RM, JW, AB), and was led by a content expert in disability and stigma research (KW), and a content expert in clinical psychology (SRL). The raters included a cisgender woman doctoral student (RH), a cisgender man post-baccalaureate research assistant (RM), a cisgender woman masters of public health student (JW), and a cisgender woman undergraduate research assistant (AB). The demographic diversity of this coding team was seen as an asset in identifying divergent insights from the initial exploratory read of the data. After reading all responses, the analytic team met to develop the initial codebook by defining constructs present in the interviews. This initial phase focused on identifying the key content areas represented in the set

| Demographic variable | M (SD) | n  | %   |
|----------------------|--------|----|-----|
| Age                  | 35.5 (13.0) | 326 | 100 |
| Gender               |        |    |     |
| Cisgender woman      | 188    | 57.7
| Cisgender man        | 94     | 28.8
| Transgender man      | 5      | 1.5
| Transgender woman    | 2      | 0.6
| Gender queer, gender variant, or gender non-conforming | 32 | 9.8 |
| Other                | 5      | 1.5 |
| Race                 |        |    |     |
| White                | 256    | 78.5
| American Indian or Alaska Native | 14 | 4.3 |
| Asian                | 6      | 1.8
| Black                | 17     | 5.2
| Native Hawaiian or Pacific Islander | 3 | 0.9 |
| Multiracial          | 23     | 7.1
| Other                | 6      | 1.8
| Did not respond      | 1      | 0.3 |
| Ethnicity            |        |    |     |
| Hispanic or Latinx   | 45     | 13.8
| Years since disability onset | 19.3 (14.6) |
| Disability type†     |        |    |     |
| Physical Disability  | 166    | 27.6
| Emotional or Behavioral Disorder | 119 | 19.8 |
| Other Health Impairment | 96 | 15.9 |
| Hearing Loss or Deafness | 47 | 7.8 |
| Vision Loss or Blindness | 43 | 7.1 |
| Learning Disability  | 35     | 5.8
| Intellectual Disability | 5 | 0.8 |
| Autism               | 38     | 6.3
| Speech or Language Disability | 12 | 2.0 |
| Other                | 41     | 6.8 |

a – participants could select more than one disability type
of narratives, across all three prompts. None of the raters on this initial team had experience working with personal narratives, but they did bring experience identifying and classifying content in open text responses to surveys. Once an initial list of content areas was generated across raters, each rater independently coded the same random set of 50 responses and met to discuss discrepancies about classifying content areas until consensus was reached. The role of content experts in these group discussions was to refine coding constructs. Based on these discussions, the initial codebook for narrative content was iteratively developed during five additional rounds of coding sets of 100 responses each. After more than 50% of responses were coded and discussed in group meetings (N = 550), the raters divided the remaining responses to code independently. Once the remaining coding was complete, raters met to discuss all outstanding questions about responses and discuss the labeling of cross-cutting constructs. Data saturation, or the point at which no additional constructs emerged from the data, was reached after 550 responses; however, the team continued coding all responses to ensure every narrative was included in the analyses (Morse, 1995). The team used the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist to guide study reporting (Tong, Sainsbury, & Craig, 2007).

2.4.2. Abductive analysis phase 2: Deductive, exploratory narrative identity analysis

While the initial coding team had focused on classifying content, when they shared their coding notes with the broader research team, the first author (JMA), who was not involved in Phase 1, noted that they also seemed to have identified four emergent themes. The four themes represent the affective and motivational domain of narrative identity: redemption, contamination, agency, and communion (McLean et al., 2020). While these themes are common in the narrative identity literature, they became the focus of the second phase of coding because they had organically emerged in the inductive approach taken in Phase 1. Indeed, it was this organic emergence that led the research team to consider submitting this study for inclusion in this Special Issue on “storying the good life.”.

In order to deepen the connections between our emerging inductive understanding of the data and the narrative identity literature, we undertook a second round of deductive, exploratory qualitative analyses aimed at examining core concepts that might augment our insights. Two raters qualitatively coded the same 862 responses for these four themes. The analytic team for this phase included two raters (JMA, RM) one of whom also doubled as a content expert (JMA) in narrative identity. The raters included a cisgender man professor of psychology with over 15 years of experience in qualitative work (JMA) and a cisgender man post-baccalaureate research assistant (RM). In order to achieve a common understanding of the themes, each rater independently analyzed the same set of 50 responses and then raters met to discuss discrepancies until consensus was reached. Raters also discussed their positionalities during these group meetings to examine the influence of their own identities and experiences in the coding process (Hall & Gally, 2001). After three additional rounds of coding sets of 50 responses independently followed by group discussion, the raters divided the remainder of responses for analysis. Each of the coders was unaware of identifying information of participants.

Redemption and Contamination. Redemption and Contamination represent affective sequences in personal narratives (Adler et al., 2016; McAdams et al., 2001; McLean et al., 2020). Redemption sequences were identified as an explicit change in the narrative from a negative affective state to a positive affective state, whereas Contamination sequences were identified as an explicit change in the narrative from a positive affective state to a negative affective state (McAdams et al., 2001). For example, one participant described an experience of his shifting relationship with his parents using redemptive themes:

Because of the way they regard my disability, I have always been a little dissatisfied with my parents. This COVID-19 pandemic has cleared up this misunderstanding. Maybe for the first time in more than 30 years, I feel that my parents still love me.

In this story, the long-term challenges in his family are transformed for the better by the relational conditions of the pandemic. In a different example, a participant describes their experience in contaminative terms:

I’m a 4.0 student and do well in school but my disabilities combined with the fatigue of COVID life have made it extremely difficult to think. I could barely read/comprehend the questions on the exam, despite knowing the material well. I am not capable at this point of performing well in school due to my disabilities, despite being a great student under some circumstances. I feel like everything in school is working against me and that I have to work much harder than most students to achieve less than they do. I feel like the school system is designed to weed out people like me; there is almost no support for disabled students during the best of times and there is even less during COVID...It stands out because this has been a constant theme in my life in school while being disabled, but it has been even more pronounced now that quarantine has disadvantaged myself even further.

In this story, the participant who has been able to excel in school up to this point feels overtaken by the new pandemic challenges, in a way they have not experienced in the past. Thus, the prior history of overcoming challenges is contaminated by the school’s response to the pandemic. Raters approached the coding of these affective sequences in the narratives qualitatively, not deploying standard quantitative coding systems, but noting responses that seemed especially emblematic of the themes.

Agency and Communion. Agency and Communion represent motivational themes in personal narratives (Adler et al., 2016; McAdams et al., 1996; McLean et al., 2020). Agency in concerned with the portrayal of personal systems, but noting responses that seemed especially emblematic of the themes.

Agency and Communion. Agency and Communion represent motivational themes in personal narratives (Adler et al., 2016; McAdams et al., 1996; McLean et al., 2020). Agency in concerned with the portrayal of personal systems, but noting responses that seemed especially emblematic of the themes.

It is worth noting that the term “contamination” has a fraught history in the context of disability, as disgust or revulsion of PWDs has sometimes been ascribed to fears of contamination (e.g., Meloni, Federici, & Bracalenti, 2021). We have retained the use of the term “contamination,” given our efforts to ground this study in the literature on narrative identity that has long examined contamination sequences (McAdams et al., 2001).
turned the rest of the world upside down, I felt steady, skilled, and confident.

For this participant, the pandemic served primarily to highlight the strong sense of personal agency that they had cultivated. Their disability is framed as a mechanism by which their “skills, mindset, and knowledge” were fostered, empowering them for navigating future challenges.

The theme of communion is concerned with the quality of interpersonal relationships in the narratives and taps the extent to which the protagonist experiences connection, love, intimacy, belonging, and mutual care (McAdams et al., 1996). For example, one participant wrote,

My partner moved in with me during this time. I remember when they first walked into my place, once they had begun moving their things over. They stepped in the door and I kissed them. It was a beautiful moment. We are both disabled and trans and knew that without other disabled and trans people we both may not survive this time. We want to create a home space that feels secure, safe, and full of disability and trans wisdom and joy.

In this excerpt, this participant demonstrates deep, loving connection with their partner and also a sense of connection with the broader disability and transgender communities. The theme of communion in this narrative applies both to immediate interpersonal relationships and also to broader community connections. In light of our subsequent analyses, it is important to note that communion is not identical to an interdependent self. Communion focuses on the quality of interpersonal relationships, whereas the interdependent self focuses on inter-reliance as a core component of selfhood. An individual could have an independent, interdependent, or dependent self and be high (or low) in communion. Raters approached the coding of these motivational themes in the narratives qualitatively, not deploying standard quantitative coding systems, but noting responses that seemed especially emblematic of the themes.

2.4.3. Abductive analysis phase 3: integration of insights with disability studies

In the third and final phase of analysis, we sought to integrate the key insights from the first two phases with relevant perspectives from disability studies to allow our findings to speak to multiple literatures. This phase of analysis primarily relied on discussion among the research team (JMA, RM, KW, KRB, RH) about the ways in which the inductive and abductive insights both related to and advanced the psychological understanding of disability in light of critiques from the perspective of disability studies. Our discussion was focused on identifying key elements of our insights from the first two phases of analysis that either reinforced or expanded prior scholarship about identity among PWDs, embracing the critical lens of disability studies.

3. Results

While our analytical approach was sequenced in three phases, the insights it generated were cumulative and integrative. As such, while we generally present our results in the chronological order in which they were produced, we focus on a presentation that best represents their contribution to understanding narrative identity among PWDs in the context of the COVID-19 pandemic in the United States.

Building on prior exploratory research focused on health care workers’ experience of the pandemic (Hennein & Lowe, 2020), we sought to map the initial emergent insights about the content of PWDs’ narratives to the domains presented in the social-ecological model. This work, presented in Table 2, demonstrates the key content domains of participants’ narratives within the social-ecological model, along with exemplary quotes. Participants described a wide range of topics, from their personal health and hobbies, to social identities or group affiliations (such as racial groups or gender and sexual minority groups), to the

| Table 2 |
| --- |
| Socioecological mapping of narrative constructs. |
| | Socioecological level and construct | Example quote |
| Individual | Access | One of the high points of the pandemic for me has been the drastic and widespread acceptance of remote options for learning, working, and getting medical care. My low energy, fatigue, pain, immune deficiency, and other aspects of my chronic illness make it difficult for me to participate in many things in person. Having the opportunity to do these things remotely makes them much more accessible to me and saves me a lot of recovery time. I feel relieved that the remote options I’ve long been advocating for are finally available. Because of these changes, I feel my physical and mental health is better overall. |
| | Achievement | We returned to my home in a rural Northern California town. We had to decide immediately what to do with the annual conference in 3 weeks. We never considered canceling. We went all virtual in 3 weeks. Three of us worked continually and pulled off a live conference with 4 days of programming, and we smashed all records of number of attendees and also budget. I believe that being a [professional organization focused on people with disabilities] we had both more experience with virtual meetings and more importantly, more open minds about a virtual platform and its accommodation solutions. I know of no other group who managed to turn any size conference virtual in 3 weeks, let alone for 400 people with many different disability access needs. We rocked it. |
| | Advocacy | I live in low income housing due to poverty. When we moved here we were told it was a non-smoking complex, but the neighbors smoke and they had not stopped. Due to COVID, they were home all the time and kept smoking underneath my windows, which we had to open for heat reasons. I am *violently* allergic to cigarette/marijuana smoke and this made me very ill. Because of COVID, we could not leave the house (also because I have severe bursitis and Ehlers-Danlos Syndrome and live in an upstairs apartment), so I could not manage the stairs anyway but even if I could get out, we’d have no place to safely go. For my health we had to escalate this situation to the corporate office, and now all the neighbors hate us, which is especially difficult during a pandemic when we’re all trapped in the same building together. I don’t know if there is any lesson in this, but it’s the kind of problem I deal with all the time, as no one takes scent/smoke/etc. allergies seriously and they think I am just overreacting or trying to get attention. |
| | COVID-19 fear | I had a personal care attendant quit because the pay is too low. I had to find another one and I am not comfortable with the new one. I get scared about my health during the pandemic. I’m scared of getting COVID from people I don’t know and I worry about my family. I don’t feel safe going out and I’m really tired of being home all the time. I’m trying to find a replacement since I am paralyzed from the neck down and require assistance for everything. I’m forced to risk getting COVID from people I don’t know when I have the final interview in person. I’m really scared and feel like I have no control over my life and no one is helping me. |
| | Hobbies | One of the high points of the pandemic for me has been the drastic and widespread acceptance of remote options for learning, working, and getting medical care. My low energy, fatigue, pain, immune deficiency, and other aspects of my chronic illness make it difficult for me to participate in many things in person. Having the opportunity to do these things remotely makes them much more accessible to me and saves me a lot of recovery time. I feel relieved that the remote options I’ve long been advocating for are finally available. Because of these changes, I feel my physical and mental health is better overall. |

(continued on next page)
## Table 2 (continued)

| Socioecological level and construct | Example quote |
|------------------------------------|--------------|
| Individual health                  | don’t know what the pose was called) where you lay back on a bolster and spread your arms out—in my exhausted half-asleep state, I think my body was finally able to relax enough into a pose for it to be useful. I think I stayed there for 30 min, totally blissed out that my body was actually responding positively to something for once. We didn’t talk, but we were both so aware of how useful the session was for both of us—it was a beautiful moment both physically and emotionally. The scene that stands out to me was going to the eye doctor. I had to get a new prescription for my contacts and glasses. I had to wear a mask the whole time, and every-one else was, too, which made it hard for me to hear and lip-read. This in turn made my already high blood pressure spike, which triggered my anxiety, which caused a loop. I felt like I was unable to stim, which sometimes calms me down as an autistic person, because I didn’t want to be judged by the staff. Because my blood pressure and pulse were so high, they couldn’t dilate my eyes and I had to make another appointment to come back later. I made sure to bring my partner with me so they could help me understand things better. That was the first time I had to bring someone to the doctor to help me out and it definitely highlighted my disabled identity. |
| Loss                               | A low point was when my cousin, with whom I was close, died unexpectedly a few months ago at the age of 50. He had cancer, but seemed to be doing very well with his treatments so this came as a shock to all of us. What made this particularly hard was that I and many of my other family members were unable to travel to the memorial/service/funeral because of COVID risks. I was thinking about how he was someone who always “showed up” – all of my big life moments, like my graduations, my wedding, and was so supportive to me and my dad when my/our grandma passed away 5 years ago. He was such a wonderful dad and husband and friend. But I couldn’t be there for him and his family. I suppose I was feeling guilty about that in addition to feeling heartbroken by the loss. |
| Preparedness                       | I am already used to staying home a lot due to having low energy and lots of pain. The skills and lessons I’ve learned about staying home, have been useful during the pandemic, and therefore I feel that I’ve been coping with quarantine better than other people have. Seeing someone complain on Facebook about not being able to go to an event, makes me feel like a professional observing an amateur: there are many events I can’t go to, because of fatigue and pain, and I’ve gotten used to it. I’m an expert. |
| Interpersonal                      | I was criticized by a coworker after expressing my disappointment that he had failed for the 9th time to properly provide my required workplace accommodation. He not only blamed me for his mistake (s), but also accused me of failing to properly educate my coworkers on providing the accommodation. I felt incredibly sad, angry, frustrated, and disappointed. This feeling was prolonged because neither of our supervisors, HR representative, the disability support coordinator, and others on the email did not respond or defend me (at least not publically). I had to contact them individually to point out the inappropriateness of his response and respectfully express my frustration over how the matter was handled. |
| Advocacy                           | I have attended several job-related trainings related to virtual facilitation and teaching. Since I am disabled, I have pre-pandemic skills in these areas. I have also, at times, requested accommodations related to virtual/remote participation and/or work due to my disability. In these job-related trainings, I was able to demonstrate my pre-existing skills and explicitly remind my co-workers that disabled people have been experts about these things for a long time. I also used these trainings as moments to advocate for the continued common use of virtual/remote participation for employees (and in my setting, students as well). I’m emphasized that this is not something that should disappear whenever we reach post-pandemic life. Disabled people aren’t going anywhere and have so, so much to contribute across society. Let’s keep the channels for these contributions wide open. I think this scene speaks to my passion for advocacy and my desire to take opportunities to highlight where injustice has been perpetuated and how my workplace can do better in relationship to access, accommodations, and disability justice in the future. |
| Example quote                      | I was able to make some masks for people who wouldn’t otherwise be able to get them. I put a health sciences degree into application that wasn’t scaring people or parrotting the insanity from the media, and combined it with my sewing skills to produce something for people who often got forgotten about. |
| Giving                             | One high point was this summer, when my husband and I had great success in growing cherry tomatoes in our garden. We had much more than we could eat, so we started setting out little baskets of tomatoes for neighbors to take. They were very popular with folks around here, and it was nice to see them being used. People who often yell “thank you!” to us from the sidewalk although they couldn’t tell if we were even home or around to hear. One neighbor left a handwritten note on our doorstep to thank us. It felt good to imagine food we had grown being used and appreciated in other homes and families all around us. I think it helped to cultivate a sense of community among strangers. |
| Food                               | I stayed there for 30 min, totally blissed out that my body was actually responding positively to something — all of my big life moments, like my graduations, my wedding, and was so supportive to me and my dad when my/our grandma passed away 5 years ago. He was such a wonderful dad and husband and friend. But I couldn’t be there for him and his family. I suppose I was feeling guilty about that in addition to feeling heartbroken by the loss. |
| Racism                             | Because of my ethnicity, people started side-eyeing me whenever I sneezed or coughed (it was the start of Hay-fever season in Spring); if I were not Asian-American, this reaction would be likely nonexistent. |
| Social conflict                    | A difficult experience for me during the pandemic has been in seeing others choose not to listen to recommendations, even as COVID infections and deaths are rapidly increasing. For example, my sister drove to visit my grandparents for Thanksgiving. She hadn’t quarantined ahead of time or been tested, and my grandpa is currently sick with Lyme disease. It makes me very angry that people are choosing to behave in risky ways, seemingly careless about whether relatives or friends might catch COVID and potentially die. After I heard she was doing this, I spent several hours fuming (continued on next page)
Table 2 (continued)

| Socioecological level and construct | Example quote |
|-------------------------------------|---------------|
| Social health/wellbeing | One of the lowest points was at the beginning. Its hard to pinpoint a specific moment, but in April and early May, I was having really vivid nightmares about the Coronavirus. Particularly, people I love getting it, or me giving it to them. I pictured ventilators and lots of coughing and would wake up terrified and overwhelmingly anxious. I was more scared than that I would die, but mostly afraid that my selfish actions (hugging someone for example) would be what led to them getting sick. |
| Social support | I joined a disability support group and connected with others who are also experiencing numerous challenges, yet collectively work together to address them through advocacy, education, and collaboration. The first meeting I attended gave me a sense of belonging and support. It also helped me connect with people and make new friends for the first time all year. I felt happier, supported, valued, and respected. |
| Vocation | I slipped at work and hurt myself. I was very embarrassed and in a lot of pain. I had to take time off of work, go to physical therapy, and apply for temporary disability. The process was very difficult and upsetting. Work was unsupportive and made matters more difficult for me. It felt like they were out to get me and were intentionally making my life harder than it needed to be even though what happened was not my fault |
| Community | Ableism | One person told me that everybody needs to just contract COVID so we can have herd immunity and get past everything. When I mentioned that it would probably kill me, they just shrugged their shoulders and acted like it was a small price to pay, like my life is less valuable than theirs. It was an eye opening experience that confirmed what I already knew—able bodied people think that physically disabled people are seen as a burden to society, and nothing more. |
| Advocacy | I lost my job after asking for accommodations. This was the first time I went out in public was moderately scary for me. I was really worried about getting COVID and making sure I stay as far away as I could from other people. I feel like as a disabled person, I didn't belong in public during a pandemic, and was worried people would stare and say something nasty to me. |
| Employment/Finances | I lost my job after asking for accommodations. I decided to start a private practice, as I am a physician. It was hard to set up in a pandemic but I did it: I have a clinic and I'm seeing patients. I specialize in psychosomtics. The high point was being able to ask a disability nonprofit to co-locate with me rent free so they can start up an independent living center. The board voted yes on this and the are moving in next week, and we have some people lined up to help expand our peer support program. I feel so blessed we have the means to do this, even being out of work for so long. My profession feels very spiritual to me and being able to work with a disability rights organization is giving my life meaning and hope. |
| Guideline adherence | My guide dog doesn't know how to social distance. This situation happened repeatedly at my job before we were all working from home. I would be walking, and suddenly would be too close to someone. And the thing is, if they don't care, I may not notice we're too close. Masks make it very difficult for me to hear where someone is, especially if the location is kind of loud. Socially distancing has also made me feel even more isolated as a blind person: I know the world by touch, and I can't touch anything. |
| Loss | The low point has been that multiple friends of mine have died since March (not due to Covid) and our friend groups were not able to gather and grieve normally. A lot of grief is personal, but collective grieving is necessary as well. Covid severely hampers this. |
| | |  | | Government | Environment | Guideline adherence | Employment/Finances | Vocation | Social support | Social health/wellbeing | Socioecological level and construct | Example quote |

(continued on next page)
role of the government in their lives, and their experience of disability discrimination and ableism. As Table 2 makes clear, certain content topics mapped to multiple levels within the social-ecological model. For example, one participant described his experience of disability discrimination at the community level – interactions with people in his workplace. He wrote,

“I was criticized by a coworker after expressing my disappointment that he had failed for the 9th time to properly provide my required workplace accommodation. He not only blamed me for his mistakes, but also accused me of failing to properly educate my coworkers on providing the accommodation. I felt incredibly sad, angry, frustrated, and disappointed… I think this speaks to the many ways that being me has been incredibly difficult during the pandemic.”

In contrast, another participant wrote about his experience of disability discrimination at the societal level – ablest master narratives in the media by which he finds himself impacted. He wrote,

“Reading the news stories about doctors making quality of life decisions about ventilators and so on was disheartening, as people have thought me ugly and unintelligent based on whatever assumptions they have based on my body. So, I know that I am seen by others as ‘Less Important.’”

Both of these quotes illustrate the content domain of disability discrimination or ableism and both directly influence the participants’ lives and identity, but they operate in different domains of the social-ecological model.

Mapping the content of participants’ narratives to each level in the social-ecological model provided a descriptive foundation for understanding the distinctive concerns PWDs in the United States experienced during the height of the COVID pandemic. However, it was our attention to the difficulties that arose during the process of constructing this descriptive framework that led to our central analytical insight. When examining our process notes, the most salient theme was the blending of the individual level with the interpersonal and societal levels. This insight was bolstered by the particular configurations of themes of agency and communion in the dataset. Indeed, the self that emerged from our mapping of participants’ narratives to the social-ecological model was not the independent, autonomous self typically placed at the center of social-ecological models, one conceptually separable from the other systems. Instead, our participants described an interdependent self, one for whom agency is shared and mutually constituted and who is best understood as inextricable from broader cultural narratives about disability. We identified this configuration of selfhood at the nexus of the individual and interpersonal level and at the nexus of the individual and societal level, but less commonly between the individual and the community level. While this middle level clearly has ramifications for identity, the narratives participants shared highlighted an intertwine-ment between self and other proximal individuals and between self and master narratives.

The interdependent self – blending the individual and the interpersonal. For many participants, the upheaval in the rhythms of daily living caused by adapting to the pandemic offered an opportunity to reflect on the configuration of their identity in relation to others. Understandably, many participants highlighted their struggles with diminished independence and increased dependence, sometimes in contaminative terms. Several participants described the challenges they faced quite literally. For some, the conditions of pandemic life put them in an impossible bind. One participant wrote, “I can’t survive without help from others but those people may also end up killing me by bringing COVID into my home. I am in the high-risk category since I can’t even cough without someone helping me.” This participant is literally dependent on other people to support basic bodily functioning, a configuration that had been viable prior to the pandemic, but now introduced potentially lethal consequences. Many other participants in our sample – and many PWDs in general – were in a similar situation. Another participant described the dramatic shifts in what it felt like to be out in the world. Rather than relying on other people, this participant described the ways in which her interdependence with her service animal was now fraught: “My guide dog doesn’t know how to social distance.” Whereas she used to navigate the world as a cooperative unit with her guide dog, there was no opportunity to retrain her guide dog to adapt to the new and different social conditions. Multiple participants explicitly related these disruptions to their sense of self. For example, one participant wrote,

I think the pandemic has brought to light exactly how much my independence as a blind person relies on other people/services like grocery delivery, ride share services, etc… How could I independently and safely get a COVID test or medical care for myself or my son if we all got sick and my husband couldn’t drive us? Going places suddenly seemed much more risky as I couldn’t see where other people were in order to stay socially distant, and I couldn’t use tape markings, etc. on floors to stay in my proper place in lines. I also feel like I have to touch more surfaces as a blind person which also increased my risk. And I didn’t like that my choice seemed to be between dependence and increased risk to my and my family’s health.

This participant highlights the shift many described from an interdependent self, one whose independence is intertwined with both technological and human infrastructure, to a precariously dependent self. Another participant put it succinctly: “That was the first time I had to bring someone to the doctor to help me out and it definitely highlighted my disabled identity.” The conditions of the pandemic illuminated what it means to be a disabled person in a society built for able-bodied people.

Yet for many participants, the pandemic conditions offered a positive reinterpretation of their disabilities and sense of self, sometimes with a redemptive arc. For example, one participant wrote, “Because I’m single, I thought to arrange to check on four other single disabled gals on a daily basis. If I didn’t have disabilities, I might not have thought how close we are to the edge. e.g. if we got hurt, who would know. I feel proud to be doing this and thank my disabilities for giving me the empathy to think of it.” This participant construes her disabilities as the source of heightened empathy and communion. Another participant noted,

In non-pandemic times, I receive a good deal of support from friends, including helping me with chores or prompting, helping me get out of my apartment and go for walks, and helping make sure I am taken care of. When my friends couldn’t stop by to help me and I couldn’t

| Socioecological level and construct | Example quote |
|-----------------------------------|---------------|
| There has been many low points for me. I think it just seems to go on and on with no end in sight. I’m so frustrated by the lack of care from others and the extent of the misinformation! The day the Wisconsin Supreme Court overturned our Governor’s “lock down.” Everything just opened up in Wisconsin with no regulation at all. This was in part because the Tavern league wanted all the bars open. I live in a small college town and the day this was announced I was terrified because everything was going to open up. The bars were packed that entire weekend. I was crying and upset because I knew this was going to increase our COVID case numbers. |
| Racism | This doesn’t really require a story. Throughout the pandemic, the presidential administration has made it abundantly clear that my identity as a disabled black female is not valid to societal institutions such as law enforcement. This really has inspired me to advocate harder for people of color and people with disabilities. |
| Disability discrimination at the societal level | "I was criticized by a coworker after expressing my disappointment that he had failed for the 9th time to properly provide my required workplace accommodation. He not only blamed me for his mistakes, but also accused me of failing to properly educate my coworkers on providing the accommodation. I felt incredibly sad, angry, frustrated, and disappointed… I think this speaks to the many ways that being me has been incredibly difficult during the pandemic.” |
| Disability discrimination at the individual level | "Reading the news stories about doctors making quality of life decisions about ventilators and so on was disheartening, as people have thought me ugly and unintelligent based on whatever assumptions they have based on my body. So, I know that I am seen by others as 'Less Important.'" |
| Interdependence | "I think the pandemic has brought to light exactly how much my independence as a blind person relies on other people/services like grocery delivery, ride share services, etc… How could I independently and safely get a COVID test or medical care for myself or my son if we all got sick and my husband couldn’t drive us? Going places suddenly seemed much more risky as I couldn’t see where other people were in order to stay socially distant, and I couldn’t use tape markings, etc. on floors to stay in my proper place in lines. I also feel like I have to touch more surfaces as a blind person which also increased my risk. And I didn’t like that my choice seemed to be between dependence and increased risk to my and my family’s health."

Table 2 (continued)
This participant powerfully captured the interdependent self that many others described implicitly. For this participant, the pandemic heightened her awareness of interdependence as both a personal value and also a reality in her life. Participants like this one illustrate the broader trend we observed in a blending between the individual and the interpersonal. Importantly, these trends take on both contaminative and redemptive arcs. For some participants the elevation of their interdependence was seen as a negative consequence of the pandemic, whereas other participants narrated this shift as positive.

The interdependent self – blending the individual and the societal. In social-ecological theory, the societal level represents the particular configurations of the other levels within a cultural context. Factors at the societal level specify the consistent arrangements of the interpersonal and community levels and are often understood generally as “cultural factors” (e.g., Fish & Syed, 2018). While many people might narrate their lives with respect to broader cultural factors – such as using cultural-historical events as milestones or discussing cultural trends – the participants in our sample narrated their selves as interdependent with these broader cultural factors. For some, the ableism in their cultural context was especially salient. One participant wrote,

I have heard countless times ‘Only the sick and elderly will die. Why do we all have to be punished and stay home? Just make them stay home.’ As if our lives were meaningless and fodder to be extinguished, like we did not matter only the sick and elderly – ‘only, only.’ I heard and read this so many times from ones I had no idea felt that way about others like me, like my husband, like my children. It broke my heart to read and hear these words from people I loved and thought loved me, to know what I meant to them. I was a sacrifice they were willing to make if it meant they had their lives back.

The perceived disposability of PWDs in the United States (e.g., Andrews et al., 2021) was a common theme among participants’ stories. For these participants, the broader cultural narratives of ableism were not only painful but experienced as dehumanizing rejections of their personhood.

Yet for many participants, their interdependence with broader cultural narratives about disability actually produced profoundly positive experiences. For some, the pandemic opened up new opportunities for connection with other PWDs that participants had never experienced before. One participant wrote,

I remember the first few hours of the first Zoom session vividly. I sat alone in my living room, and listened to (the facilitator) and a cohort of mostly-Black, mostly-femme people share their experiences. I only sat and watched, but it was an intense experience. Attending that first session, I felt shocked and elated to find people who looked and acted like me, confidently and eloquently discussing ideas and questions that suddenly came to prominence. I finally had my voice, my presence, and my experiences were recognized as valuable. This participant experienced a redemptive revolution in his narrative identity, shifting from an internalized medical model of deficit to a social model of strength. He intends to leverage this internal shift to pursue broader social change.

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After working for years in advocating accessibility to education and technologies for people with disabilities, the pandemic has really forced a lot of people to see, and even experience for themselves, what it is like to be socially isolated, to have no access to work or education or social events, to have to worry that others around you are not taking precautions with your decreased immunity to illness. Also, while for years PWDs have been asking for virtual access to work and education and social activities, and being told that for one reason or another it was not feasible, suddenly we have a much more accessible, technologically and economically, virtual world. I refer to this as ‘the year we all became disabled.’

For this participant, the pandemic conditions forced able-bodied people to experience many of the accommodations that PWDs had already become accustomed to and expert at navigating. Many participants wrote about their existing facility with the technological adaptations that suddenly came to prominence for non-disabled people during the pandemic. Indeed, the “disabling” conditions everyone faced may reshape the non-disabled world to better accommodate PWDs. These shifts may prompt revisions to master narratives of ableism and disability identity. Indeed, while for years PWDs have been asking for virtual access to work and education and social activities, and being told that for one reason or another it was not feasible, suddenly we have a much more accessible, technologically and economically, virtual world. I refer to this as ‘the year we all became disabled.’

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4. Discussion

The COVID-19 pandemic introduced immense challenges for non-disabled people and PWDs in the United States alike. In our sample of
PWDs, the pandemic highlighted their interdependence with others and with cultural master narratives – for worse, and for better. The PWDs in our sample described experiences that map to each of the levels in social-ecological approaches (e.g., Bronfenbrenner, 1979, 1997). For example, participants described their experiences with ableism in both their immediate social and occupational contexts (the interpersonal and community levels) and in broad master narratives presented in the media (the societal level). Yet the process of mapping their narratives to these different levels highlighted a sense of self that does not neatly align with the independent self that is common to the individual core of social-ecological approaches. Instead, the self that emerged in our analyses of these narratives was best understood as interdependent with other individuals at the interpersonal level and with cultural narratives that unite the various other levels (and therefore understood as the societal level).

Participants in our sample noted the ways in which their interdependence with others was both a challenge and a benefit of being a PWD. Interdependence presented contaminative existential threats (such as a heightened risk of exposure to COVID-19) alongside profoundly meaningful, often redemptive connection. Interdependence also highlighted the devastating impacts of ableist master narratives as well as the unique opportunities for challenging master narratives that regard independence and dependence as the only two options for selfhood (Dirh & Adams, 2019). Without question, the pandemic posed immense disruption for the PWDs in our sample, but it also highlighted a generative narrative of oneself as interdependent and as part of a broader collective of disabled people as a disadvantaged minority (Nario-Redmond, 2019). As one participant in our sample noted, the pandemic and efforts to contain it “disabled everyone,” highlighting adaptations some PWDs had already developed, and implementing accessibility features long advocated for by PWDs (Bogart, 2021). Additionally, the pandemic highlighted the benefits of interconnection among PWDs to provide social support, foster disability identity, and promote advocacy (Bogart et al., 2017).

The notion of interdependence in conditions of disability is central to theories of disability identity from the humanistic traditions that inform the field of disability studies. For example, Arneil (2009) critiqued the dominant scientific paradigm that constricts personhood as a categorical construct, divided into independent and dependent persons. She cited legal categories of personhood that emerge from this scientific paradigm, such as those distinguishing minors from adults and those distinguishing people deemed to be “autonomous rational agents” from their opposites, as evidence of science-in-action that oversimplifies lived experience (p. 234). Arneil proposed a revision of scientific paradigms that would regard independence/dependence not as a categorical phenomenon, but a dimensional one, in which all people experience both independence and dependence in the course of their lives. Laying the roots of this perspective, Kittay (1999) suggested that dependence itself is a fundamental aspect of the human experience, not an artificial or undesirable condition. Childhood, old age, and illness are all inescapable human experiences that require dependence. For Kittay, any experience of independence or interdependence is grounded in these basic and universal experiences of dependence. As such, Kittay argued that the foundational principle of independence that shapes Western cultures is grounded in a denial of the fact of dependence in all human lives and therefore dependence itself demands a new understanding. In later writing, she concludes, “we are inextricably interdependent” (Kittay, 2001, p. 307). Kittay (2017) argues that we live with a „mismatch of disability, which locate the disabling condition in the misfit between the built physical/social environment and the individual person, sometimes reify an implicit privileging of independence. These approaches can imply that if only the physical/social environment would change, people with disabilities would enjoy independence. But Kittay (2017) suggests that these models deny the “residual dependencies that remain even when we have modifications in the social and physical environment intended to allow people with disabilities to function ‘independently’” (p. 309). These “residual dependencies” comprise the foundational caring for one another that our species requires for survival. Far from implying a one-directional service delivery in the context of disability, Fine and Glendinning (2005) suggest that “care,” in its most expansive state, offers mutual burdens and mutual benefits to those engaged. Sevenhuijzen (1998) termed this “caring solidarity” or the recognition of our mutual vulnerabilities and need for each other’s care. Pushing this construct further, Shakespeare (2000) wrote that “This notion of caring solidarity may perhaps offer some promise in the attempt to break down the dichotomy between disabled and nondisabled people, recognizing that everyone is variously dependent, that disabled people are themselves often carers, and that society is based on interdependence.” Disability justice scholar and activist Mia Mingus (2022) brings these notions directly into the COVID-19 pandemic, writing, “We should be framing this pandemic in terms of interdependence. This is the right political framing because it is the only moral and humane framing” (n. p.) and asserting that transformative justice for PWDs – and for all of American society – must necessarily be grounded in an interdependent construal of self.

These perspectives are largely absent from psychological research concerning PWDs. Indeed, in psychological theory and empirical inquiry, medical models that embrace an individualistic notion of the person and that construe disability as a condition of dependence and deficit continue to dominate (e.g., Bogart et al., 2020; Dirh & Branscombe, 2018; Rosa et al., 2016). Advocating within psychology for social models of disability that locate deficits in the built environment and social arrangement, not in the individual, promises to dismantle some of the implicit ableism in our field (e.g., Dirh & Branscombe, 2018; Olkin & Pledger, 2003). Contributing to this argument abductively by attending rigorously to the narratives of PWDs as the essential source of data extends the ethical foundations of this work. As the narratives described in this paper make clear, PWDs already articulate alternatives to the false dependence–independence dichotomy. Furthermore, this re-envisioning of the self as interdependent is far from a recapitulation of traditional individualistic versus collectivistic constrictuals of culture (i.e. Markus & Kitayama, 1991), but a more sophisticated description of individuals embedded in a U.S.-American cultural context for whom the self is more complicated than the independent self that dominates the personality and social psychological literature. Elevating the insights of PWDs about interdependence is vital to reforming our field and to broader social justice movements.

It is worth noting that PWDs are not the only population for whom placing the independent self at the center of social-ecological models is problematic. Fish and Syed (2018) elegantly articulate the ways in which Native American populations also upend a social-ecological model, centering both the societal level and the historical context in which the ecosystem operates. Rogers and colleagues (Rogers et al., 2021) also compellingly demonstrate the ways in which the centering of individuals, as opposed to cultural master narratives, perpetuates white supremacy and anti-Blackness in both social scientific and lay understandings of human development. Placing our work with PWDs alongside Fish and Syed’s (2018) work with Native Americans and Rogers’ (in press) work with Black Americans may suggest that conditions of marginality in the United States may highlight alternative narrative identities that challenge dominant models of selfhood. Rather than understanding these stories as exceptions, alternative narratives of identity reveal the contours of prevailing conceptions of narrative identity (Branscombe, 2003), complicating existing theory (e.g., McLean & Syed, 2015). This convergence of perspectives aligns with Vélez-Agostoso and colleagues’ (Vélez-Agostoso et al., 2017) revision of social-ecological models towards a “cultural microsystem model” that foregrounds the ways in which culture is instantiated in everyday life for individuals and which asserts the centrality of cultural understandings to the development of public policies aimed at improving daily conditions for marginalized people.

The Pew Research Center’s American Trends Panel (van Kessel et al.,
conducted about four weeks prior to our data collection, suggests that the insights our research generated with regards to PWDs may resonate with the broader U.S.-American population. Although the Pew survey did not include prompts about identity, it found that 67% of respondents noted both negative and positive impacts of the pandemic (though 89% of respondents noted primarily negative impacts). Furthermore, the relational domain was by far the most common focus in participants’ responses: “More than any other issue, Americans responded by bringing up how the pandemic has altered their ability to engage with friends and family. The single-most common category of comments (mentioned by 41% of those who answered the question) centered around missing family and friends and worrying about losing touch with people they used to see in person. Many described feelings of isolation...[While] a third (33%) of Americans mentioned positive impacts to their relationships” (van Kessel et al., 2021, n.p.). What differentiates our sample of PWDs from the general trends described in the Pew survey report is the interweaving of these relational concerns with participants’ narrative identity. Beyond noting the experiences of isolation and unexpected deeper connection with others, the PWds in our sample connected the conditions of their relationships to the configuration of their identity, highlighting their interdependency. While the Pew data do not offer insights into whether this is a general trend, it is possible that the pandemic elevated themes of interdependence for able-bodied U.S.-Americans as well.

It is important to note that the configuration of identity is not merely an academic topic or one that matters solely to individuals as they navigate their lives. Interdependence, as opposed to the independence/difference dichotomy, supports different societal responses to pandemics. Writing more than a decade before the COVID-19 pandemic, Wald (2008) examined cultural stories of outbreaks and identified a master narrative that has transcended global context and hundreds of years. According to Wald, this master narrative involves a villainous “alien” invader (the disease) that lays siege to a community (a village, a nation, the world) and is then combated and ultimately vanquished by leaders with specialized knowledge (doctors and scientists, religious figures). In this master narrative, lay people have little role, other than as passive victims and unwitting carriers of the disease; they are dependent on the vicissitudes of the invader and the strivings of the informed leaders. Speaking about her work as it applied to the COVID-19 pandemic, Wald (2020) suggested that this master narrative of outbreaks posed a particular challenge to many of the public health interventions rolled out in response to the pandemic, including wearing masks and, later, getting vaccinated. Such public health initiatives rely on a notion of interdependence that is in opposition to the dominant themes of dependence and independence in master narratives of outbreaks. In light of this insight, the interdependent self of the PWDs in our sample may offer a counter-narrative that not only proposes alternatives to ableist narratives of dependence/independence, but also better supports behaviors that will lead to a more effective curtailment of the COVID-19 pandemic (see also Doonan, 2021).

The study presented in this manuscript is an initial qualitative effort to understand narrative identity among PWDs under the conditions of the COVID-19 pandemic’s second wave in the United States. Despite relying on a large, diverse sample, it does not strive for representativeness or generalizability. Of particular note is that the study methods relied on participants’ engagement with digital platforms, thus prioritizing participation from people who are able to access these platforms and who could either type or speak their responses. This exclusion of PWDs who are non-verbal is pervasive in psychological research focused on disability (Forber-Pratt, 2020), and our study does not succeed in remedying this problem.

The Special Issue within which this article appears is focused on “narrating the good life.” Our contribution serves as a reminder that narrative identity always operates in dialogue with cultural master narratives (e.g., McLean & Syed, 2015). What counts as “good” is highly culturally contextualized. Whereas dominant U.S.-American narratives of selfhood tend to prioritize independence (e.g., McAdams, 2006), the stories of PWDs collected during this especially challenging chapter in U.S.-American (and global) history demonstrate that alternative narratives of interdependence confer considerable benefits. Pandemic narratives of PWDs suggest that “the good life” is ultimately an interdependent life, one of mutuality and negotiation, and of recognition that the self is both personal and intertwined with others, some of whom share disability as a group membership, and others who most likely will in the future. Furthermore, in producing this insight, these data implicitly call into question dominant notions of “goodness,” highlighting that defining a construct like this is a social process; one with real-world ramifications.

**Funding:**
This research was supported by funding from the Yale School of Public Health’s Covid-19 Rapid Response Pilot Grant. Preparation of this manuscript was in part supported by a NIH Mentored Scientist Development Award (K01DA045738) awarded to Katie Wang.

**Author Contributions:**
The following authors were involved in: study conceptualization (JMA, KRB, MRN, JMO, SRL, KW), data collection (KW, RBM, JW, AB), data preparation (RBM, RH, JW, AB, SRL, KW), data analysis (JMA, RBM, RH, JW, AB, SRL, KW), report writing (JMA, RBM, RH, KRB, MRN, JMO, SRL, KW).

**Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

**Appendix A.**

**Narrative prompts used in this study**

After all the questions we’ve asked, it’s time for you to share your experience in a richer, more personal way. As the last step in this survey, we’d like you to share three short stories about your experience of the COVID-19 pandemic. In answering the following questions, please share your experiences as stories of specific moments, with beginnings, middles, and endings, with characters, and maybe with lessons.

First, thinking back over your experience of the COVID-19 pandemic, please identify a scene that stands out as a low point. Even though this event is unpleasant, we would appreciate your providing as much detail as you can about it. What has the low point of the COVID-19 pandemic been for you? Please choose a specific moment and describe what happened, where and when, who was involved, and what were you thinking and feeling. Also, please share a bit about why you think this particular moment was so bad and what the scene may say about you or your life.

Second, we’d like you to share a high point. Although it may sound odd, there have likely been some positive moments in your life during the COVID-19 pandemic. What has the high point of the COVID-19 pandemic been for you? Please choose a specific moment and describe what happened, where and when, who was involved, and what were you thinking and feeling. Also, please share a bit about why you think this particular moment was so positive and what the scene may say about you or your life.

Finally, we’d like you to share a specific moment during the COVID-19 pandemic when your experience of yourself as a disabled person was especially salient or clear. The specific moment you choose may be positive, negative, or something else, but please choose a different moment than the low point and high point stories you just shared. Please describe what happened, where and when, who was involved, and what were you thinking and feeling. Also, please share a bit about why you think this particular moment stood out to you and what the scene may say about you or your life.
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