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Resilience, age, and perceived symptoms in persons with long-term physical disabilities

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Abstract

Resilience may mitigate impact of secondary symptoms such as pain and fatigue on quality of life in persons aging with disability. This study examined resilience in a large sample of individuals with disabling medical conditions by validating the Connor–Davidson Resilience Scale, obtaining descriptive information about resilience and evaluating resilience as a mediator among key secondary symptoms and quality of life using structural equation modeling. Results indicated that the measure's psychometric properties were adequate in this sample. Resilience was lowest among participants who were middle-aged or younger, and participants with depression. Resilience mediated associations between secondary symptoms and quality of life.

Keywords

age, chronic illness, disability, model, protective factors

Introduction

Consistent with the aging of the general population (Werner, 2011), the average age of individuals with disabling conditions such as multiple sclerosis (MS) and spinal cord injury (SCI) is increasing (Lin et al., 2012). This is in part due to increased incidence of new disabling medical conditions in later adulthood (Centers for Disease Control (CDC), 2013) and also improvements in early survivorship and life expectancy for those who acquired disability early in life (DeVivo et al., 1999; Minden et al., 1993). As persons with physical disabilities enter older adulthood, many contend not only with the health changes associated with aging but also with conditions associated with chronic physical disability. For example, pain, fatigue, and depression are more common among those with physical disabilities than the general population (Amtmann et al., 2012), and age is a risk factor for these conditions in people with disabilities (e.g. Cook et al., 2011; Molton et al., 2013a). These "secondary conditions" contribute to physical and psychological dysfunction beyond the effects of the disability itself and represent significant barriers to

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community participation, employment, and general quality of life (QoL) (e.g. Bombardier et al., 2010; Mitchell et al., 2006).

Despite increased risks for secondary conditions associated with aging, the majority of individuals, regardless of disability status, adapt well to age-related declines in health and function (Bombardier et al., 2010; Jeste et al., 2010). This tendency is described in the gerontology literature as "healthy" or "successful" aging (Palmore, 1979). Although previous conceptualizations of successful aging focused on remaining free of medical conditions and disability (Rowe and Kahn, 1987), more recent conceptualizations promote the inclusion of psychological and social components such as maintaining QoL and engaging in meaningful activities (Depp et al., 2007). As such, elements including psychological well-being, social connectedness, and ability to adapt to aging-associated changes are regarded as important indicators of successful aging (Young et al., 2009).

Given that aging successfully requires an ability to adapt to declines in health and function associated with growing older, recent attention has sought to identify factors that predict positive responses to negative life events. One such factor is *resilience.* Resilience refers to the human capacity to persist, bounce back from, and flourish in the face of stressors or adversity (Bonanno, 2004). Resilience is considered to be a dynamic process consisting of cognitive, behavioral, and interpersonal skills, many of which may be learned and practiced. Individuals with greater resilience have been shown to maintain more stable emotional well-being when challenged with serious stressors, including traumatic injury (Ehde, 2010), cancer diagnosis (Costanzo et al., 2009), or natural disaster (Pietrzak et al., 2012).

The concept of resilience may be useful in understanding why some people are able to develop adaptive competence and coping skills regardless of their exposure to adversity (Bonanno et al., 2007; DeRoon-Cassini et al., 2010). Although resilience is often described in response to acute stressors, it may also play a key role in maintaining well-being when faced with losses associated with aging. Resilience may be particularly relevant to successful aging by accounting for some older individuals' propensity to view their lives and health as satisfactory in spite of age-related disease and disability (Montross et al., 2006). In a recent study, Jeste et al. (2013) found that higher resilience, lower depression, better physical health, and older age were all associated with greater self-rated successful aging, with resilience and depression effects being equal to or greater than physical health effects.

Interventions have been developed to promote resilience across a diverse range of populations (e.g. Brunwasser et al., 2009; Loprinzi et al., 2011; Reivich et al., 2011), with results supporting efficacy in improving various outcomes. However, empirical research on resilience in individuals aging with a physical disability is limited, and further investigation into factors contributing to resilience could provide valuable insight to inform the development of clinical interventions to promote resilience in the context of aging with a physical disability.

Current study

The aim of this research was to examine resilience in a large sample of individuals aging with long-term physical disabilities associated with muscular dystrophy (MD), MS, post-polio syndrome (PPS), or SCI. Primary study goals were to (1) examine psychometric properties of a measure of resilience in a sample of persons with physical disability; (2) describe levels of resilience in this population, and determine whether they differed by demographic or medical variables; and (3) evaluate the mediating role of resilience in the relationships among key secondary symptoms (pain, fatigue, and depression) and QoL, using a structural equation modeling (SEM) approach.

Methods

Participants and procedures

Participants were a large sample (n = 1862) of people with SCI (n = 492), PPS (n = 446), MD

(n = 340), or MS (n = 584) who participated in a longitudinal study of secondary health conditions in people with disabilities (see, for example, Alschuler et al., 2012; Cook et al., 2011; Molton et al., 2013b). A total of 2446 individuals responded to invitations sent to the University of Washington Disability Registry and Web/print advertisements. Eligible individuals were required to be at least 18 years of age and have a self-reported definitive diagnosis of MS, SCI, MD, or PPS. Surveys were sent to all eligible participants, along with a consent form and postage-paid return envelope. Reminder letters were sent to nonresponders 4 weeks after surveys were mailed, and an additional reminder call was made to nonresponders 6 weeks after surveys were mailed. Of the 2041 surveys that were mailed to interested and eligible respondents, 1877 surveys were completed (91% response rate) and 1862 were included in the final dataset. There were two versions of the survey: a primary survey assessing core variables and a second version that also contained additional measures of pain, coping, and QoL. All study participants completed the primary survey questions, and a randomly selected subset of these participants (n = 926) completed the second version with the additional measures. This subsample of participants was included in our SEM analyses.

Completed surveys were checked for missing data upon return, and participants were called by phone up to three times to collect missing data. All participants received US$25. All participants were consented prior to participation, and all study procedures were approved by the Human Subjects Division of the University of Washington.

Measures

Demographic and basic medical information was collected, including age, sex, race/ethnicity, education, type of disability condition, and years of disability.

Resilience was measured using the 10-item Connor–Davidson Resilience Scale (CD-RISC; Campbell-Sills and Stein, 2007), a brief, unidimensional measure of resilience. Participants rated items such as "Able to adapt to change," "Can deal with whatever comes," and "Tend to bounce back after illness or hardship," on a 5-point Likert scale from "Not true at all" to "True nearly all the time." The 10-item CD-RISC was based on the 25-item CD-RISC (Connor and Davidson, 2003), and highly correlates with the original instrument (Campbell-Sills and Stein, 2007).

Depression was measured using the Patient Health Questionnaire–9 item version (PHQ-9) and the Patient-Reported Outcomes Measurement Information System (PROMIS) Depression–Short Form (PRO-D-SF). The PHQ-9 is a measure that was developed for primary care patients and is based on *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) criteria for Major Depressive Disorder (Kroenke et al., 2001). Participants rated the presence of symptoms as occurring not at all (0) to nearly every day (3) over the past 2 weeks. The PHQ-9 has been extensively used in medical and rehabilitation populations (e.g. Fann et al., 2011). The PRO-D-SF is a 7-item measure of depression on which participants rated presence of depressive symptoms over the past week on a 5-point Likert scale from "never" to "always." PROMIS depression items have been validated for use in this population (Cook et al., 2012).

Pain was measured using a numeric rating scale (NRS) for pain severity and items from the PROMIS Pain Interference–Short Form (PRO-PI-SF). The NRS for pain severity is a widely used measure and has demonstrated adequate concurrent validity with other pain measures (Jensen, 2010). The PRO-PI-SF is a 6-item scale that assesses the extent to which pain interferes with functioning (from "not at all" to "very much"), including the ability to enjoy life and participate in everyday activities. PROMIS pain items have been validated for use in populations with disabilities (Cook et al., 2012).

Fatigue was measured using a 0–10 NRS of fatigue severity and the PROMIS Fatigue–Short Form (PRO-F-SF). The PRO-F-SF is a 7-item measure that assesses the extent to which fatigue interferes with functioning (from

"never" to "always"), including limiting ability to work or showering. PROMIS fatigue items have been validated for use in this population (Cook et al., 2012).

QoL was assessed using a 1-item scale on which participants were asked to rate their overall QoL on a Likert scale from 1 ("life is very distressing; it's hard to imagine how it could get much worse") to 7 ("life is great; it's hard to imagine how it could get much better"). Similar 1-item measures have been used in populations with disability and chronic illness (Yohannes et al., 2011).

Data analysis

Validation and descriptive statistics of the CD-RISC. Because the CD-RISC has (to our knowledge) never been validated in a sample of persons with long-term physical disabilities, we first evaluated the psychometric properties of this measure in our sample. Confirmatory factor analysis (CFA; Muthén and Muthén, 2007) was used to examine whether a unidimensional structure of the CD-RISC can be supported, specifying a 1-factor solution. Second, we used descriptive statistics, analysis of variances (ANOVAs) and t-tests to determine if CD-RISC scores varied as a function of disability or demographic variables. We also examined whether individuals who were depressed were lower on resilience (e.g. Southwick and Charney, 2012).

Global model fit for the CFA was evaluated using the χ^2-test, comparative fit index (CFI), the root mean square error of approximation (RMSEA) and its 90 percent confidence interval (CI), and standardized root mean square residual (SRMR). Each fit index provides different types of information and when considered as a group they provide a reliable and conservative evaluation of model fit. Good model fit was defined as follows (Hu and Bentler, 1999): CFI > .95 (CFI > .90 is conventionally considered adequate; Hooper et al., 2008); RMSEA < .06; SRMR < .08. The χ^2-test was reported, but not relied on to evaluate model fit due to its oversensitivity to sample size. Instead, the χ^2/degrees of freedom (df) ratio was used, which is an index intended for use in large samples. $\chi^2/df < 5$ indicates adequate fit (Taylor and Todd, 1995).

Modeling the relationship between resilience, secondary symptoms, and QoL. To evaluate relationships among resilience, secondary symptoms, and QoL, we utilized an SEM approach (Mplus v5.2; Muthén and Muthén, 2007). SEM is a statistical technique that allows for both exploratory and confirmatory modeling of a large number of variables simultaneously, making it well suited for testing theoretical models. This approach allows for the creation of "latent" variables, which are conceptual variables that are not measured directly but estimated from measured variables.

Prior to testing the structural model, CFA was used to assess goodness of fit for the measurement model (as recommended by Kline, 2005). Both the measurement and structural regression models used maximum likelihood estimation. Initially, separate models were evaluated for age and duration of disability; however, because no significant effects were found for duration and any of the criterion variables in the model, only the model containing age will be presented. Acceptance or rejection of SEM models was based on the same global fit criteria outlined for the CFA.

Results

Participant characteristics

Participants were primarily middle-aged or older adults (median = 57 years); however, ages ranged from 20 to 94 years (M = 56.13, standard deviation (SD) = 13.31). The mean duration of disability condition was 15.45 years (SD = 10.65), with a range of 0 to 79 years. Participants were predominantly women (63%), Caucasian (91%), and generally well educated, with 86% of participants having some education beyond high school. Participant characteristics for the subsample used in the SEM analyses were comparable to the entire sample.

Evaluation of the CD-RISC

Global fit for the 1-factor CFA was borderline ($\chi^2(35) = 646.55$, $p < .001$; $\chi^2/df = 18.47$; CFI = .938; RMSEA = .097, 90% CI = .090−.103; SRMR = .035). Several of the CD-RISC items had overlapping content (e.g. *able to adapt to change, can deal with whatever comes*). Lagrange modification indices suggested several areas where model fit could be improved by allowing the residuals of the following items to correlate to account for their high degree of overlap: item 1 with item 2, 3 with 4, 5 with 6, 6 with 7, 6 with 9, 7 with 8, 8 with 9, and 9 with 10. After allowing for correlation of residuals, global fit for the modified CFA improved to acceptable levels: $\chi^2(27) = 111.77$, $p < .001$; $\chi^2/df = 4.14$; CFI = .991; RMSEA = .041, 90 percent CI = .033−.049; SRMR = .016. All items had significant and substantial loadings on the factor, ranging from .63 to .77 (standardized loadings, all *p*s < .001).

Resilience descriptives

Mean resilience score for the sample was 28.07 (*SD* = 7.18). One-way ANOVA indicated significant differences in resilience among disability types, $F(3, 1843) = 8.74$, $p < .001$. Participants with MD or MS ($M = 27.94$, $SD = 7.85$; $M = 27.37$, $SD = 6.74$) scored significantly lower on resilience than participants with SCI or PPS diagnoses ($M = 28.46$, $SD = 7.24$; $M = 28.65$, $SD = 6.99$). Resilience did not vary by sex ($t(1845) = 1.79$, $p = .07$) but there were significant differences between age groups, $F(2, 1844) = 9.81$, $p < .001$. Middle-aged participants (45–64 years) scored significantly lower on resilience than those 65 or older ($M = 27.83$, $SD = 7.14$ vs $M = 28.95$, $SD = 7.03$). The youngest group (<45 years) did not significantly differ from middle-aged or 65 or older groups ($M = 27.74$, $SD = 7.28$). There were no significant differences between duration of disability condition groups, $F(2, 1767) = 0.44$, $p = .64$.

Scores for depressive symptoms for the sample ranged from 0 to 27 on the PHQ-9, with a mean of 6.39 (*SD* = 5.14). Based on DSM-IV clinical diagnostic criteria, 172 (9.2%) of participants met criteria for Major Depressive Disorder. Participants who met criteria for Major Depression were statistically significantly lower in resilience ($M = 18.57$, $SD = 6.69$) than those who did not ($M = 29.03$, $SD = 6.47$), $t(1828) = 20.07$, $p < .001$.

Evaluation of the structural regression model

Measurement model. The following four latent constructs were created using items from the self-report measures described above: *Pain* (included NRS for Pain Severity and PRO-PI-SF items), *Fatigue* (NRS for Fatigue and PRO-F-SF items), *Depression* (PHQ-9 and PRO-D-SF items), and *Resilience* (CD-RISC items) (see Figure 1). Following creation of these four latent variables, CFA was used to test the overall measurement model. Latent variables were allowed to covary without specified structural relationships and manifest variables were restricted to load onto their corresponding latent variables. Global fit for the measurement model was acceptable; however, some fit indices were somewhat problematic. Global fit for the measurement model: $\chi^2(889) = 4788.49$, $p < .001$; $\chi^2/df = 5.38$; CFI = .862; RMSEA = .069, 90 percent CI = .067−.071; SRMR = .066. All parameter loadings in the measurement model were meaningful (close to .7; Brown, 2006) and statistically significant ($p < .001$). All of the factor correlations were less than .85; therefore, the model had reasonable discriminant validity (Brown, 2006).

Lagrange modification indices suggested several areas where fit for both models could be improved by allowing residuals of items to correlate. The revised model provided a good fit for the data, $\chi^2(858) = 3090.56$, $p < .001$; $\chi^2/df = 3.60$; CFI = .921; RMSEA = .053, 90 percent CI = .051−.055; SRMR = .061. Furthermore, it provided superior fit compared to the original model, $\chi^2_{diff}(31) = 1697.93$, $p < .001$.

Structural regression analysis model fit. The structural regression model showed adequate global

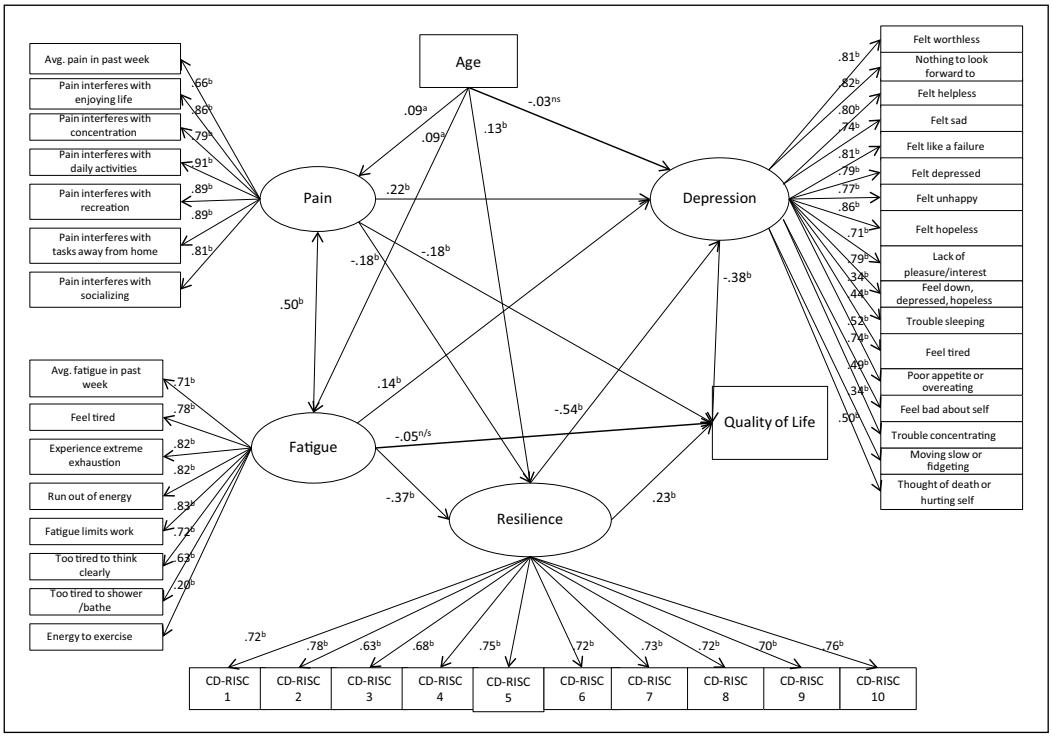

Figure 1. Resilience mediation model.
CD-RISC: Connor–Davidson Resilience Scale.
Standardized values, [a]$p > .01$, [b]$p > .001$.

fit: $\chi^2(859) = 3091.14$, $p < .001$; $\chi^2/df = 3.60$; CFI = .921; RMSEA = .053, 90 percent CI = .051−.055; SRMR = .061. The model accounted for 55 percent of variance in depression and 25 percent of variance in resilience (ps < .001).

Model parameters. Analysis results indicate that older age was associated with statistically significant more pain (.09, $p = .007$), greater fatigue (.09, $p = .006$), as well as greater resilience (.13, $p < .001$). Age was not significantly associated with depression (−.03, $p = .18$).

Analysis results also indicated that fatigue and pain were positively correlated ($r = .50$, $p < .001$), and higher levels of each were associated with greater depression (pain: $\beta = .22$, $p < .001$; fatigue: $\beta = .14$, $p < .001$). Pain and fatigue were negatively associated with resilience (pain: $\beta = -.18$, $p < .001$; fatigue: $\beta = -.37$, $p < .001$). Both greater pain and depression were associated with statistically significant lower QoL (pain: $\beta = -.18$, $p < .001$; depression: $\beta = -.38$, $p < .001$). There was no significant association between fatigue and QoL ($\beta = .05$, $p = .18$). Higher resilience was associated with lower depression ($\beta = -.54$, $p < .001$) and higher QoL ($\beta = .23$, $p < .001$).

Analysis results also indicated a significant summed indirect effect for pain on QoL via its effects on resilience and depression ($\beta = -.17$, $p < .001$). Therefore, resilience partially mediated the effect of pain on QoL. Indirect effects were also significant for fatigue on QoL via its effects on resilience and depression ($\beta = -.22$, $p < .001$), indicating that the relationship between fatigue and QoL was fully mediated by resilience and depression. Resilience accounted for the larger mediation effect ($\beta = -.09$ vs $-.05$, $p < .001$).

Discussion

The results of this study suggest that the 10-item CD-RISC is an appropriate measure of resilience for individuals with long-term physical disabilities. The 10-item CD-RISC performed well in our sample: the measure's hypothesized unidimensional structure was supported by good fit to data for the 1-factor CFA model, and all item loadings were substantial and statistically significant. Compared to mean resilience scores on the same measure, our sample mean was lower than resilience scores among a community sample of adults (M = 31.8; Campbell-Sills et al., 2009), community-dwelling adults 50 years and older (M range = 30.8−32.1; Jeste et al., 2013), and primary care patients (median = 34; Wingo et al., 2010). This suggests that having a chronic physical disability may be negatively associated with a person's resilience. In comparison, mean resilience scores in our sample were similar to 10-item CD-RISC scores reported for HIV-positive older adults (M = 27; Mascolini, 2012) and non-treatment-seeking trauma survivors (28.1, Hammermeister et al., 2012).

Individuals with MD or MS had lower mean resilience scores than individuals with PPS or SCI. Differences may be attributable to clinical course (sudden onset in SCI versus progressive disease in MD and MS; previous contraction of illness followed by recovery and renewed symptoms at a later age in PPS), personality characteristics (Rohe and Krause, 1999), or the traumatic nature of SCI onset that may interact with resilience (Bonanno et al., 2012).

The finding that participants who were depressed were significantly less resilient than those who were not depressed is consistent with larger literature (e.g. Catalano et al., 2011; Gooding et al., 2012) and suggests that further investigation of the resilience–depression relationship is warranted. Although resilience is sometimes conceptualized methodologically as the absence of depression (e.g. Alim et al., 2008; DeRoon-Cassini et al., 2010), others conceptualize it as the presence of psychological thriving (Bonanno, 2012; Jeste et al., 2013; Ryff and Singer, 1996). Whether lower resilience predisposes someone aging with a disability to depression is unknown; if it does, interventions aiming to increase resilience may decrease risk for depression.

Older age in our sample was associated with higher resilience, which is similar to other findings reported in the aging literature (Gooding et al., 2012). This finding could be explained by the possibility that managing a physical disability may be more challenging when the disability is an "off-time" life event, that is, an event that is not typical for younger-aged individuals (Neugarten and Hagestad, 1976). Furthermore, it may be that middle/younger ages are times when there are greater demands with regard to work or family roles and fewer coping resources, which may make managing a physical disability and secondary conditions more taxing. Interestingly, duration of disability was not associated with resilience. This suggests that resilience may be more related to lifespan experience than one's specific length of experience with disability. Higher resilience with greater age also may reflect a change in expectations and self-acceptance (Windle et al., 2008), and attitude toward disability.

Older age was associated with more pain and fatigue, in addition to higher resilience. Similar to findings across the literature, pain and fatigue were positively associated, and higher levels of each predicted more depressive symptoms (Bombardier et al., 2010; Widerstrom-Noga and Finlayson, 2010). Higher levels of pain and depression were directly associated with lower QoL; however, fatigue did not directly predict lower QoL. Rather, the relationship between fatigue and QoL was fully mediated by its prior effects on depression and resilience. Furthermore, resilience was a stronger mediator than depression on QoL, which points to resilience being particularly important in ameliorating the detrimental effects of fatigue.

Overall, the study findings have important implications for researchers and clinicians alike, most notably that resilience should be considered as an important factor for healthy aging in individuals with long-term physical disabilities. Increasing resilience may mitigate detrimental effects of pain and fatigue on depression and QoL. Middle age may be particularly difficult for individuals with disabling conditions, as life

demands are typically high and impact of secondary symptoms and emotional distress peaks during this time. Our findings also suggest that middle age may be a time when individuals have significantly lower resilience and may therefore be particularly vulnerable. This represents an opportunity for targeted intervention to increase resilience in an at-risk group.

Limitations

This study had several limitations. Our study had a large proportion of non-Hispanic Whites, who were on average well educated. Therefore, our results may not generalize to other populations. Furthermore, we did not compare to population-based reference groups and/or demographically matched (e.g. age, education) groups without physical disability. Having better comparison groups could improve our understanding of resilience in the context of aging with a physical disability. Furthermore, data were cross-sectional, thus limiting our ability to examine directionality of these effects. In addition, correlating errors between items in CFA creates a unique scoring that is not representative of how the instrument is typically scored (i.e. a summary or simple total sample score) and may not replicate to other samples. Model fit was not optimal and may be improved with inclusion of other variables. Identifying these factors should be considered an important next step. To address these limitations, replication in a different sample of individuals aging with disability along with future longitudinal investigations is warranted.

Conclusions and future directions

More research is needed to examine the construct of resilience within specific disability groups, particularly those for whom resilience may be lower, such as individuals with MS and MD. There may be other factors that contribute to or are affected by resilience that were not measured in this study but warrant investigation, including cognitive functioning, spirituality, and social well-being. A closer examination of the qualities, circumstances, or behaviors of people who are resilient would also be useful in understanding the role of resilience in aging with a physical disability and in developing interventions specific to this cohort.

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