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Associations Among Decisional Autonomy, Fatigue, Pain, and Well-Being in Long-Term Physical Disability

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Objective: Decisional autonomy—or sense of one's ability to make independent choices about one's life—is especially relevant to individuals who may feel their autonomy is limited due to physical challenges. Past work has found associations between measures of autonomy and quality of life (QoL) in individuals with disability and in older adults. However, it is less clear how *decisional* autonomy influences the impact of pain and fatigue severity on QoL, especially in adults aging with physical disability. This study examined the relationship of decisional autonomy to QoL and the extent to which autonomy moderates the association between symptom severity and QoL. ***Method:*** We used hierarchical linear regression models to examine the associations between autonomy, pain and fatigue, and quality of life in a sample of individuals with long-term disability. In 2 sets of models, we examined individuals reporting some level of fatigue (n = 1,060, M_{age} = 62.66, SD = 11.88) and some level of pain (n = 964, M_{age} = 62.79, SD = 11.69). ***Results:*** We found that decisional autonomy significantly predicted QoL over and above other measures related to social participation. Decisional autonomy also weakly moderated the associations between fatigue and QoL and the associations between pain and QoL. ***Conclusions:*** The findings indicate that levels of decisional autonomy may be important to QoL in individuals aging with physical limitations.

Impact and Implications
The findings add to the literature by indicating the possibility that increasing decisional autonomy may help individuals with long-term disability increase well-being, potentially through improved management of symptoms such as pain and fatigue. This work provides a basis for further research that examines the role of choice and decisional autonomy in maintaining quality of life for individuals aging with long-term physical disability. The findings also suggest that in working with adults aging with long-term disability, a focus on choice and decisional autonomy may be another method to improve well-being.

Keywords: autonomy, well-being, long-term disability, aging, physical disability

Introduction

For individuals with long-term physical disabilities, having a strong sense of decisional autonomy may be especially important to maintaining well-being. Decisional autonomy has been described as a way to maintain choice in one's life despite experiencing physical challenges (Cardol, De Jong, & Ward, 2002). Clark (1988) noted that when examining autonomy and quality of life (QoL) in long-term care, that the concept of QoL was related to but distinct from personal autonomy (p. 283–284). This suggests that the construct of autonomy is distinct from the construct of QoL and is not merely a proxy for QoL.

According to Ryan and Deci's theory of self-determination, autonomy is one of three elements key to self-motivation and well-being (Ryan & Deci, 2000, 2006). The concept of autonomy has been defined in multiple ways but generally relates to the idea of being able to independently make decisions and choices for oneself (Cardol et al., 2002). In the context of long-term disability, *decisional autonomy* has been defined as "the ability to make decisions without external restraint or coercion" (p. 972).

There is support in both the rehabilitation and aging literatures for associations between autonomy and well-being-related outcomes. For example, in older adults with a history of stroke, researchers have found evidence for an association between an individual's perceived ability to make choices and lower levels of

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depression (Castellucci, 2004). Kasser and Ryan (1999) found that endorsing more autonomy was positively correlated with vitality, and perceived autonomy support from friends and family predicted life satisfaction, in older adults. Another study found that a measure of perceived autonomy was positively associated with life satisfaction in a sample of older adults (Hertz & Anschutz, 2002). Findings from a qualitative study in nursing home residents (Choi, Ransom, & Wyllie, 2008) indicated that a lack of perceived autonomy was associated with negative psychosocial outcomes. In a study of old-old adults, environmental mastery (conceptualized as a sense of choice and control over one's environment) predicted life satisfaction, positive affect, and negative affect, whereas higher autonomy (conceptualized as mental independence from others' expectations) predicted lower negative affect (Neubauer, Schilling, & Wahl, 2017).

Autonomy is also an important element of participation in everyday life for individuals with long-term physical disabilities and has been shown to be distinct from social support-related indicators of participation, such as satisfaction with participation or level of participation. For example, Heinemann and colleagues (2013) examined indicators of participation for individuals with disabilities and found evidence distinguishing evaluation (whether individuals are satisfied with their level and type of participation), engagement (how often they participate), and enfranchisement (what they value in their participation and why they participate; p. 2158). According to Heinemann et al., one component of enfranchisement is the sense of control over participation, also described as individuals' sense that they are able to make decisions about how they live their life. This concept of sense of control over participation is closely related to decisional autonomy.

Hammel and colleagues (2008) also found in a qualitative study that experiencing decisional autonomy was important for participation in adults with disabilities, separately from social support. In addition, they noted that social support can have positive or negative effects on well-being, depending on whether the relationship was perceived as supportive or draining. This finding provides further support for the idea that decisional autonomy has effects on QoL that are distinct from social indicators of participation.

Researchers have also examined the relationship between other personal factors believed to be related to an individual's sense of autonomy, such as self-efficacy, and QoL-related outcomes in individuals with long-term physical disability. Warner et al. (2011) found a positive correlation between perceived self-efficacy and perceived autonomy in a sample of older European adults with multiple conditions, indicating that autonomy and self-efficacy are related, and Shnek and colleagues (1997) found that low levels of self-efficacy were correlated with higher levels of depression in a sample of individuals with multiple sclerosis (MS) and spinal cord injury (SCI). However, it remains less clear how autonomy may relate to QoL over and above social indicators of participation or other measures related to autonomy, such as self-efficacy.

Autonomy may be particularly relevant to the well-being of those aging with long-term physical disabilities; recent qualitative work on adults aging with long-term physical disabilities (Molton & Yorkston, 2017) found that autonomy is considered an important element of successful aging in this group. However, little research has been conducted on autonomy, especially decisional autonomy, in adults aging with long-term physical disabilities. Well-being and autonomy have been examined in individuals with postpolio syndrome (Atwal et al., 2015) and spinal cord injury (Larsson Lund, Nordlund, Bernspång, & Lexell, 2007). Researchers have also examined well-being–related outcomes and medical decision-making autonomy in patients with MS, finding decisional autonomy is valued in the treatment process (Heesen, Kasper, Segal, Köpke, & Mühlhauser, 2004), and Köpke, Kasper, Mühlhauser, Nübling, and Heesen (2009) developed a program to increase sense of patient autonomy in MS-treatment decisions.

However, it is still not clear how autonomy contributes to well-being. For example, little research has examined how decisional autonomy affects the relationship between symptoms such as fatigue or pain and well-being in adults aging with disability. van de Ven, Post, de Witte, and van den Heuvel (2008) noted that for individuals with SCI, fatigue and pain are related to participation. This finding suggests that experiences of pain and fatigue may be connected to an individual's sense of their decisional autonomy. Past work on the relationship between autonomy and pain has found associations between pain interference and the psychosocial construct "mental defeat" (Tang, Goodchild, Hester, & Salkovskis, 2010, p. 550). Individuals who are managing chronic symptoms such as pain may therefore show a weaker relationship between symptom severity and QoL if they perceive a sense of more control over their choices about how and when they participate in everyday activities, which could allow them to participate in ways that mitigate or control symptom severity.

The Current Study

As noted previously, although past research has found associations between autonomy and well-being-related constructs in older adults and people with disabilities, it is less clear how decisional autonomy affects QoL in adults aging with long-term disability. In addition, symptoms such as pain and fatigue are common in adults aging with long-term disability, and it is not known whether and how decisional autonomy moderates the effects of these symptoms on quality of life.

The goal of this study, therefore, was to determine whether decisional autonomy was associated with QoL, and to examine how decisional autonomy may affect the impact of common symptoms on well-being, in individuals aging with long-term physical disability. Specifically, we sought to (a) determine whether decisional autonomy, measured as an individual's sense of control over participation (COP), predicted QoL-related outcomes in those aging with long-term disabilities, over and above satisfaction with participation in social roles and self-efficacy, and (b) determine whether decisional autonomy moderated the association between fatigue severity and QoL, and between pain intensity and QoL, over and above satisfaction with participation in social roles, ability to participate, and self-efficacy. Based on findings from previous research that found a higher sense of perceived control over life was related to higher QoL in a group of low-functioning older adults (Bowling, Seetai, Morris, & Ebrahim, 2007), we hypothesized that COP (our measure of decisional autonomy) would significantly and uniquely predict QoL over and above satisfaction with participation and self-efficacy. We predicted higher COP would be associated with higher perceived QoL. We also hypothesized that COP would show a buffering effect on the associations between symptom (pain and fatigue) severity and QoL, such that the association between symptoms and QoL would

be weaker as COP scores increased. In this study, we used measures from the Patient-Reported Outcomes Measurement Information System (PROMIS) item bank to examine demographic variables, social indicators of participation, and predictors of interest.

Method

Participants and Procedure

Participants were recruited as part of the seventh wave of data collection in an ongoing longitudinal study on healthy aging in individuals with long-term physical disabilities. Participants with multiple sclerosis (MS), spinal cord injury (SCI), neuromuscular disease (NMD), or postpolio syndrome (PPS) were recruited through disability specific registries, participant pools from universities, ongoing studies at the University of Washington, word of mouth, and web and print advertisements. All participants were 18 years of age or older; able to read and understand English; and self-reported a physician's diagnosis of MS, NMD, SCI, or PPS. Participants were screened for eligibility over the telephone and provided oral consent.

Participants received questionnaires by mail and were provided $25 as compensation for their participation in the study. All study procedures were reviewed and approved by the University of Washington Institutional Review Board. Participants were mailed a reminder letter to complete the survey 1 month after the survey was mailed and were called 2 weeks after the reminder letter was mailed as an additional follow-up. If a survey was received with data missing, the participant was contacted up to three times, once per week, via a combination of phone and e-mail messages to obtain the data. Reimbursement was mailed to participants after the missing data were received or the staff had failed to reach the participant after three attempts. Of 1,551 surveys mailed, 1,396 surveys were completed and returned to the researchers. Demographic information about the sample is presented in Table 1. The mean age of the total sample (N = 1,396) was 63.17 years (SD = 11.85).

Measures

Demographic variables. Age was computed using the participants' reported date of birth subtracted from the date the survey was completed. Education level was assessed using a categorical variable; a binary variable was created where participants were classified as those with a college degree or higher (n = 804) and those with less than a college degree (n = 592). Income was assessed by asking participants to estimate their annual household income. For data analysis purposes, annual income was dichotomized into being greater than or equal to $52,000 or less than $52,000, using a median split (Mdn = $51,500). Gender was assessed by asking participants to indicate whether they were male or female. Marital status was assessed using a categorical variable, with the options being *Married, Registered domestic partnership/civil union, Separated, Divorced, Living with significant other, Never married,* or *Widowed.* Participants were asked to choose only one response. A binary variable was created by classifying participants as being (a) married or in a registered domestic civil partnership or civil union (n = 800) and (b) those who were separated, divorced, living with a significant other, never married, or widowed (n = 596).

Race was assessed using a categorical variable asking participants to select the response that best described their race or ethnic background. A binary variable was created classifying participants as either White (n = 1,250) or non-White–unknown (n = 138).

Table 1
Descriptive Characteristics of Full Sample of Participants

Variable	*N*	*M* (*SD*)	%
Age at Time 7	1,396	63.17 (11.85)	
Duration of condition (years since diagnosis for PPS)	1,373	22.45 (10.54)	
Diagnostic group	1,396		
PPS			25.6
NMD			19.1
MS			31.7
SCI			23.6
Gender (female)	1,396		64.8
Education (≥college graduate)	1,396		57.6
Annual income (≥$52,000)	1,188		50.0
Marital status (married or domestic partnership–civil union)	1,396		57.3
Race (White)	1,388		90.1
Urban status (living in urban area)	1,396		78.9
PROMIS Physical Function *t* score	1,390	35.61 (10.54)	
PROMIS Ability to Participate in Social Roles *t* score	1,378	44.50 (8.81)	
PROMIS Satisfaction w Participation in Social Roles *t* score	1,381	45.07 (9.31)	
UW Short Form Self-Efficacy Scale *t* score	1,392	47.45 (10.08)	
ES Control over Participation normed score	1,384	59.11 (14.25)	
PROMIS Fatigue *t* score	1,392	55.54 (10.38)	
Pain intensity raw score	1,394	3.34 (2.50)	
PROMIS Global Quality of Life raw score	1,394	3.52 (1.03)	

Note. PPS = postpolio syndrome; NMD = neuromuscular disease; MS = multiple sclerosis; SCI = spinal cord injury; PROMIS = Patient-Reported Outcomes Measurement Information System; UW = University of Washington; ES = Enfranchisement Scale.

Location was assessed as a categorical variable (urban, rural or isolated rural location based on 2016 Centers for Medicare & Medicaid designations of zip codes). A binary variable classifying participants as either urban (n = 1,101) or nonurban (n = 295) dwellers was created. Participants were classified as being in one of four diagnostic groups: MS, NMD, PPS, or SCI. Duration of condition was operationalized as years since the original diagnosis. Duration of condition for participants with postpolio syndrome was measured as years since postpolio syndrome diagnosis, rather than years since initial polio diagnosis.

Physical function. Physical function was measured using a custom 12-item short-form measure for mixed mobility aid users with items from the PROMIS Physical Function item bank. The PROMIS item bank was developed by the National Institutes of Health (NIH) and contains measures of multiple health-related domains. Measures from PROMIS are appropriate for populations with long-term disability. PROMIS measures are scored through creating a summed score of individual items in the measure and then converting the raw summed score into a t score centered at 50, with a standard deviation of 10. A t score of 50 represents the mean of the sample used to create the measure. Higher PROMIS t scores indicate higher levels of the domain being measured (e.g., higher satisfaction with participation in social roles and activities, higher fatigue). The PROMIS measures were developed using item response theory in community-based samples of adults from the United States. The measures show construct validity and reliability and have shown validity for usage in populations with physical disability. The sample for developing the Physical Function item bank was taken from a U.S.-based population that included both a general population and individuals with at least one chronic condition, and was normed to a U.S. general population (Rose et al., 2014). On a scale of 1 (*Unable to do*) to 5 (*Without any difficulty*), participants rated their difficulty, on average, in doing various daily tasks (e.g., "get in and out of bed," "reach and get down an object [such as a can of soup] from above your head"). In the sample, Cronbach's alpha for the eight items measuring physical function was .93, and Cronbach's alpha for the three items measuring mobility-related function was .87. (The final item was a categorical screener item asking individuals, "Can you walk 25 feet on a level surface [with or without support]?").

Ability to participate in social roles and activities. Ability to participate in social roles and activities was measured using the four-item PROMIS Ability to Participate in Social Roles and Activities measure. On a scale of 1 (*Always*) to 5 (*Never*), participants rated their ability to participate in multiple types of activities by answering questions such as "I have trouble doing all my regular leisure activities with others" and "I have trouble doing all of the family activities that I want to do." The measure was normed to a U.S. population (Hahn et al., 2010). Cronbach's alpha for the sample was .94.

Satisfaction with participation in social roles and activities. Satisfaction with participation in social roles and activities was measured using the four-item PROMIS Satisfaction with Participation in Social Roles and Activities measure. On a scale of 1 (*Not at all*) to 5 (*Very much*), participants rated their satisfaction with their ability to participate in multiple types of activities. Example items include "I am satisfied with my ability to do things for my family" and "I am satisfied with my ability to perform my daily routines." The measure was normed to a U.S. population (Hahn et al., 2010). Cronbach's alpha for the sample was .93.

Fatigue. Fatigue was measured using a four-item PROMIS short-form measure. Participants were asked how often they felt fatigued and how much fatigue prevented them from performing activities over the past 7 days in four separate life domains. Questions were answered on a scale from 1 (*Not at all*) to 5 (*Very much*). The measure was normed to a U.S. population (Junghaenel, Christodoulou, Lai, & Stone, 2011). Cronbach's alpha for the sample was .95.

Quality of life. Quality of life (QoL) was measured using a single item from the PROMIS Global Health measure. This item asked participants to answer the question "In general, would you say your quality of life is . . ." on a scale of 1 (*Poor*) to 5 (*Excellent;* Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). The measure was normed to a U.S. population. A single-item quality of life measure has been examined in previous work on adults with cystic fibrosis (Yohannes, Dodd, Morris, & Webb, 2011).

Pain intensity. Pain intensity was measured using a single item Numerical Rating Scale. Participants rated their pain at its average in the past week on a scale from 0 (*No pain*) to 10 (*Pain as bad as you can imagine*). Numerical rating scales of pain intensity have shown "positive and significant correlations with other measures of pain intensity" (Von Korff, Jensen, & Karoly, 2000, p. 3144) and have been recommended by the IMMPACT Initiative for use in chronic pain trials (Dworkin et al., 2005).

Self-efficacy. Self-efficacy was measured using the six-item University of Washington Short Form Self-Efficacy Scale. On a scale of 1 (*Not at all*) to 5 (*Completely*), participants rated their confidence in their ability to keep their health condition from interfering with their ability to live their lives (Amtmann et al., 2012). Cronbach's alpha for the sample was .93. The measure was developed using a population with MS and SCI.

Decisional autonomy. Decisional autonomy was measured using a 13-item version of the Control over Participation subscale of the Enfranchisement Scale (Heinemann et al., 2013). This subscale measures individuals' sense of control and choice over abilities and decisions that affect their everyday life. Example items include "I have control over how I spend my time," "I have the freedom to make my own decisions," "I have choices about the activities I do," and "I live my life the way that I want." Participants were asked to rate how closely each statement corresponded to their opinion on a Likert scale ranging from 1 (*Almost never*) to 5 *(All the time*). A normed decisional autonomy measure was created by summing the items and then converting raw scores to a 0–100 scale. The scale was developed with participants experiencing long-term physical disability (Heinemann et al., 2013). Cronbach's alpha for the sample was .94.

Data Analysis

The study hypotheses were tested using regression analyses. In the analyses, QoL was the criterion variable, and COP, the measure of decisional autonomy, was a predictor. We used hierarchical linear regression to examine predictor and outcome variables and created two sets of models to test the hypothesized associations between COP and QoL. The first set of models, which included fatigue as a predictor, used data from individuals who reported at least some fatigue (i.e., a level of fatigue greater than 0; n =

1,060). The second set of models, which included pain intensity as a predictor, used data from individuals who reported at least some pain intensity (i.e., a level of pain intensity greater than 0; n = 964).

The first set of regression models examined fatigue. In Step 1, we created a model that included demographic variables (age, duration of condition, diagnostic group, gender, education, income, marital status, race, urban status, and physical function) to examine their potential relationships to COP and QoL. Continuous demographic variables were mean-centered, and categorical demographic variables were entered as binary variables. In Step 2, we added measures of social participation: satisfaction with participation in social roles, ability to participate in social roles, self-efficacy. These measures were mean-centered. In Step 3, we entered the COP variable. In Step 4, we entered mean-centered fatigue severity. An interaction term was created by multiplying the centered fatigue measure and COP variables. This interaction term was entered in Step 5. The second set of regression models, examining pain intensity, was like the first, except that the mean-centered measure of pain intensity was entered instead of fatigue, and the Pain Intensity × COP interaction term was entered in the final step.

Results

Assumptions Tests

The independent (decisional autonomy, fatigue, pain) and dependent (QoL) variables of interest were assessed as continuous. To evaluate linearity, we created scatterplots of the relationship between fatigue and QoL, and between pain and QoL, at low (below 1 *SD* of the mean), midlevel (between −1 and +1 *SD* of the mean), and high (above 1 *SD* of the mean) values of COP. These graphs did not indicate a nonlinear relationship between fatigue and QoL or between pain and QoL. To evaluate normality, we examined Q-Q plots for the standardized residuals of fatigue and pain; both graphs indicated normality. To evaluate homoscedasticity, we graphed standardized residuals against standardized predicted values and observed some heteroscedasticity for fatigue and pain, but it was not significant enough to apply transformations. We also examined the variance inflation factor (VIF) and tolerance statistics for multicollinearity. Tolerance values were above .2 for all variables. VIF was below 10 for all coefficients. No outliers were less than 1 or greater than 5 (the range of our dependent variable). Therefore, the assumptions for multiple linear regression were found tenable.

Zero-Order Associations Between the Study Variables

The zero-order Pearson correlation coefficients for the study variables examining the overall sample are presented in Table 2. Fatigue, pain, and COP were all associated with QoL. We found significant positive correlations between COP and physical function, ability to participate, satisfaction with participation, self-efficacy, and QoL; we found negative correlations between COP and fatigue, and between COP and average pain. However, age and duration of condition were not significantly associated with COP.

Next, we examined mean differences between demographic study variables, QoL, and COP in subsets of individuals reporting some fatigue or some pain. Descriptive statistics are presented in Table 3, and mean differences for education level and marital status were examined. Using t tests, we found that for individuals reporting some fatigue (n = 1,294), individuals in the high-education group reported significantly higher mean levels of autonomy (M = 59.19, SD = 13.11) than did those not in the high-education group (M = 56.68, SD = 13.80), $t(1292) = -3.33$, $p = .001$. Individuals who were married or in a domestic partnership also reported a significantly higher mean level of autonomy (M = 58.99, SD = 14.11) than did those who were not (M = 56.96, SD = 12.46), $t(1292) = -2.70$, $p = .007$. For individuals reporting some pain (n = 1,178), those in the high-education group also reported higher mean levels of autonomy (M = 58.66, SD = 12.53) than did those not in the high-education group (M = 56.80, SD = 13.49), $t(1176) = -2.44$, $p = .015$. Individuals who were married or in a domestic partnership also reported a significantly higher mean level of autonomy (M = 58.76, SD = 13.39) than did those who were not (M = 56.64, SD = 12.36), $t(1176) = -2.78$, $p = .006$.

After controlling for continuous descriptive variables and fatigue, we found a significant correlation of .31 ($p < .001$) between COP and QoL in the subsample reporting some fatigue (df = 1236). Similarly, controlling for descriptive variables and pain intensity, we found a significant correlation of .32 ($p < .001$) between COP and QoL in the subsample reporting some pain (df = 1125).

Table 2
Bivariate Correlations Between Control Variables, Fatigue, Pain, and Quality of Life (Listwise N = 1,325)

Variable	1	2	3	4	5	6	7	8	9	10
1. Age	—									
2. Duration of condition	.26**	—								
3. PROMIS Physical Function *t* score	−.09**	−.25**	—							
4. PROMIS Ability to Participate in Social Roles *t* score	−.18**	−.12**	.55**	—						
5. PROMIS Satisfaction with Participation in Social Roles *t* score	−.11**	−.09**	.50**	.73**	—					
6. UW Short Form Self-Efficacy Scale *t* score	−.05	−.05	.37**	.60**	.65**	—				
7. ES Control over Participation normed score	.01	−.01	.32**	.53**	.62**	.71**	—			
8. PROMIS Fatigue *t* score	.02	−.01	−.11**	−.48**	−.45**	−.49**	−.45**	—		
9. Pain intensity raw score	.03	.05*	−.31**	−.39**	−.35**	−.34**	−.29**	.44**	—	
10. PROMIS Global Quality of Life raw score	−.03	−.06*	.35**	.50**	.58**	.69**	.66**	−.42**	−.35**	—

Note. PROMIS = Patient-Reported Outcomes Measurement Information System; UW = University of Washington; ES = Enfranchisement Scale.
* $p < .05$. ** $p < .01$.

Table 3
Scores for Control Over Participation (COP) and Quality of Life (QoL) Variables by Categorical Demographic Characteristics

Variable	Fatigue				Pain				Total			
	COP		QoL		COP		QoL		COP		QoL	
	M (*SD*)	*n*	*M* (*SD*)	*n*	*M* (*SD*)	*n*	*M* (*SD*)	*n*	*M* (*SD*)	*n*	*M* (*SD*)	*n*
Diagnostic group		1,294		1,304		1,178		1,188		1,384		1,394
PPS	59.04 (11.96)		3.61 (.95)		59.23 (12.14)		3.62 (.94)		59.54 (12.28)		3.66 (.96)	
NMD	55.56 (13.14)		3.39 (1.06)		54.86 (11.26)		3.31 (1.05)		56.23 (13.78)		3.42 (1.06)	
MS	59.25 (14.05)		3.50 (1.03)		58.08 (12.94)		3.40 (1.02)		60.37 (15.11)		3.54 (1.05)	
SCI	57.68 (14.21)		3.35 (1.04)		58.20 (14.74)		3.38 (1.04)		59.28 (15.14)		3.43 (1.06)	
Education		1,294		1,304		1,178		1,188		1,384		1,394
≥College graduate	59.19 (13.11)		3.61 (.97)		58.66 (12.53)		3.57 (.97)		60.02 (13.75)		3.65 (.98)	
<College graduate	56.68 (13.80)		3.29 (1.07)		56.80 (13.49)		3.28 (1.05)		57.87 (14.83)		3.34 (1.08)	
Marital status		1,294		1,304		1,178		1,188		1,384		1,394
Married or in domestic partnership–civil union	58.99 (14.11)		3.60 (1.02)		58.76 (13.39)		3.58 (1.01)		60.07 (14.90)		3.66 (1.03)	
Not married or in domestic partnership–civil union	56.96 (12.46)		3.29 (1.00)		56.64 (12.36)		3.25 (.99)		57.81 (13.24)		3.33 (1.02)	
Annual income		1,105		1,109		1,005		1,009		1,182		1,186
≥$52,000	60.38 (13.94)		3.75 (.96)		60.04 (13.49)		3.72 (.96)		61.41 (14.61)		3.80 (.97)	
<$52,000	56.07 (12.34)		3.26 (1.04)		55.83 (11.72)		3.22 (1.02)		56.75 (12.95)		3.29 (1.04)	
Gender		1,294		1,304		1,178		1,188		1,384		1,394
Male	57.97 (13.38)		3.35 (1.05)		58.12 (13.63)		3.35 (1.04)		58.94 (13.98)		3.41 (1.06)	
Female	58.20 (13.51)		3.54 (1.00)		57.68 (12.63)		3.49 (1.00)		59.20 (14.41)		3.58 (1.02)	
Race		1,287		1,296		1,172		1,181		1,377		1,386
White	58.13 (13.39)		3.50 (1.01)		57.78 (12.78)		3.46 (1.00)		59.06 (14.12)		3.55 (1.02)	
Non-White	57.74 (13.84)		3.20 (1.12)		58.10 (14.38)		3.23 (1.16)		59.29 (15.29)		3.26 (1.14)	
Urban status		1,294		1,304		1,178		1,188		1,384		1,394
Living in urban area	58.23 (13.61)		3.46 (1.03)		57.99 (13.17)		3.42 (1.02)		59.28 (14.41)		3.51 (1.04)	
Not living in urban area	57.73 (12.90)		3.52 (1.00)		57.29 (12.33)		3.49 (1.00)		58.46 (13.64)		3.56 (1.01)	

Note. PPS = postpolio syndrome; NMD = neuromuscular disease; MS = multiple sclerosis; SCI = spinal cord injury. Means and standard deviations are presented separately for the subsample reporting some fatigue, the subsample reporting some pain, and the full sample of participants.

The Association Between COP, Fatigue, and Quality of Life

The mean age of the subsample reporting some fatigue (n = 1,060) was 62.66 years (SD = 11.88). The regression model including COP as a unique predictor of QoL, Model 1c, was statistically significant, $F(16, 1043) = 93.24$, $p < .001$. The change in F from the model including demographic variables and social participation–related variables (Model 1b) was significant, $F(1, 1043) = 120.58$, $p < .001$; the adjusted R^2 changed from .53 to .58. COP significantly predicted QoL ($\beta = .33$, $p < .001$), over and above satisfaction with social roles, ability to participate in social roles, and self-efficacy (see Table 4). The model including COP and a Fatigue × COP interaction (n = 1,060), Model 1e, was statistically significant (adjusted $R^2 = .60$), $F(18, 1041) = 88.88$, $p < .001$. Moreover, there was a significant Fatigue × COP interaction effect ($\beta = .11$, $p < .001$; see Table 4).

Graphing the equation indicated that at low values of COP (−.5 SD from the mean), there was a weak negative association between fatigue and QoL, and at high values of COP (+.5 SD), there was a nonsignificant association between fatigue and QoL (see Figure 1). When restricting the subsample to individuals who reported COP values of .5 SD or greater below the total sample mean (n = 354), there was a negative association between fatigue and QoL ($\beta = -.13$, $p = .014$). Individuals who reported values of COP within .5 SD of the sample mean (n = 468) showed a significant negative relationship between fatigue and QoL ($\beta = -.12$, p = .01). Individuals who reported COP values of .5 SD or higher than the sample mean (n = 238) showed a nonsignificant relationship between fatigue and QoL ($\beta = -.11$, $p = .090$).

The Association Between COP, Pain, and Quality of Life

The mean age of the subsample reporting some pain (n = 964) was 62.79 years (SD = 11.69). The regression model including COP as a unique predictor of QoL, Model 2c, was statistically significant, $F(16, 947) = 81.44$, $p < .001$. The change in F from the model including demographic variables and social participation–related variables (Model 2b) was significant, $F(1, 947) = 113.44$, $p < .001$, and the adjusted R^2 changed from .52 to .57. COP significantly predicted QoL ($\beta = .34$, $p < .001$), over and above satisfaction with social roles, ability to participate in social roles, and self-efficacy (see Table 5). The model including COP and a Pain × COP interaction (n = 964), Model 2e, was statistically significant (adjusted $R^2 = .58$), $F(18, 945) = 75.78$, $p < .001$. Moreover, there was a significant Pain × COP interaction ($\beta = .08$, $p = .001$; see Table 5).

Graphing the equation indicated that at low values of COP (−.5 SD), there was a weak negative association between pain and QoL, and at high values of COP (+.5 SD), there was a trend toward a nonsignificant association between pain and QoL (see Figure 2). When restricting the subsample to individuals who reported COP values of .5 SD or more below the total sample mean (n = 328), there was a negative relationship between pain and QoL

Table 4
Regression Models Examining Predictors of Quality of Life in a Subsample of Participants Reporting Some Fatigue (n = 1,060)

Variable	Model 1a			Model 1b			Model 1c			Model 1d			Model 1e		
	b	*SE*	β	*b*	*SE*	β	*b*	*SE*	β	*b*	*SE*	β	*b*	*SE*	β
Constant	3.05**	.13		3.00**	.10		3.00**	.09		2.98**	.09		3.04**	.09	
Duration of condition (centered)	<.01	<.01	.05	<.01	<.01	.01	<.01	<.01	−.003	<.01	<.01	−.003	<.01	<.01	−.001
PROMIS Physical Function *t* score (centered)	.03**	<.01	.33	−.001	<.01	−.01	<.01	<.01	−.004	<.01	<.01	.01	<.01	<.01	.01
Age at T7 (centered)	−.004	<.01	−.05	−.004	<.01	−.04	−.01*	<.01	−.06	−.01**	<.01	−.07	−.01**	<.01	−.07
NMD	−.19*	.09	−.07	.03	.07	.01	.07	.07	.03	.08	.07	.03	.08	.06	.03
MS	−.21*	.09	−.10	.06	.07	.03	.04	.07	.02	.08	.07	.04	.07	.06	.03
PPS	.14	.10	.06	.27**	.08	.11	.25**	.07	.10	.28**	.07	.12	.26**	.07	.11
Education	.14*	.06	.07	.12*	.05	.06	.11*	.04	.05	.11*	.04	.05	.10*	.04	.05
Annual income	.28**	.07	.14	.14**	.05	.07	.11*	.05	.05	.11*	.05	.06	.11*	.05	.05
Gender	.18**	.06	.08	.17**	.05	.08	.18**	.05	.08	.20**	.05	.09	.20**	.05	.09
Marital status	.11	.07	.06	.06	.05	.03	.09	.05	.04	.08	.05	.04	.08	.05	.04
Race	.23*	.10	.07	.27**	.08	.08	.28**	.07	.08	.27**	.07	.08	.28**	.07	.08
Urban status	−.11	.07	−.04	−.11*	.05	−.04	−.10	.05	−.04	−.10	.05	−.04	−.10*	.05	−.04
PROMIS Ability to Participate in Social Roles and Activities *t* score (centered)				<.01	<.01	.03	<.01	<.01	.02	−.002	<.01	−.01	−.002	<.01	−.01
PROMIS Satisfaction with Social Roles and Activities *t* score (centered)				.02**	<.01	.20	.01**	<.01	.11	.01**	<.01	.10	.01**	<.01	.11
UW Short Form Self-Efficacy Scale *t* score (centered)				.05**	<.01	.52	.04**	<.01	.35	.03**	<.01	.33	.03**	<.01	.31
ES Control over Participation normed score (centered)							.03**	<.01	.33	.02**	<.01	.32	.03**	<.01	.35
Fatigue *t* score (centered)										−.01**	<.01	−.09	−.01**	<.01	−.07
Fatigue × ES Control over Participation													<.01**	<.01	.11
Adjusted R^2	.17**			.53**			.58**			.59**			.60**		
ΔF	19.23**			273.21**			120.58**			14.74**			30.43**		

Note. PROMIS = Patient-Reported Outcomes Measurement Information System; T7 = Time 7; NMD = neuromuscular disease; MS = multiple sclerosis; PPS = postpolio syndrome; UW = University of Washington; ES = Enfranchisement Scale. SCI (spinal cord injury) status was used as the diagnosis reference group. Education reference category: less than college graduate. Annual income reference category: less than $52,000. Gender reference category: male. Marital status reference category: not married or in domestic partnership-civil union. Race reference category: non-White. Urban status reference category: not living in urban area.
* $p < .05$. ** $p < .01$.

(β = −.17, p = .001). Individuals who reported values of COP within .5 *SD* of the sample mean (n = 437) showed a significant negative relationship between pain and QoL (β = −.13, p = .005). Individuals who reported COP values of .5 *SD* or more above the sample mean (n = 199) showed a nonsignificant relationship between pain and QoL (β = .002, p = .979).

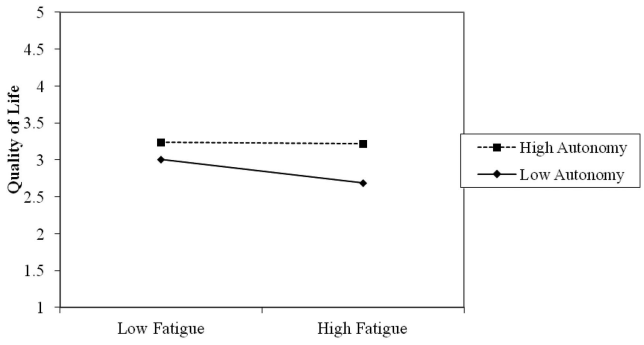

Figure 1. Illustration of the relationship between fatigue and quality of life at lower (−.5 *SD*) and higher (+.5 *SD*) levels of autonomy from the total sample mean, in the subsample reporting some fatigue. Low fatigue = −1 *SD* of total sample mean, high fatigue = +1 *SD*.

Discussion

Effects of Decisional Autonomy on Quality of Life

In line with the study hypotheses, we found a significant association between a measure of decisional autonomy and a measure of QoL in a sample of adults aging with long-term disability. This relationship was significant even after controlling for the effects of social indicators of participation (ability to participate and satisfaction with participation in social roles) and self-efficacy. This relationship also held after controlling for level of physical function. This finding supports the idea that individuals' sense of freedom to make their own decisions (i.e., decisional autonomy) is important to well-being. These findings also suggest the possibility that increasing individuals' sense of choice and ability to make independent decisions is a potential way to improve well-being in adults with long-term physical disability; research to examine this possibility is warranted.

These results build upon past literature on autonomy and physical disability to show that decisional autonomy is associated with well-being. Most research on autonomy in physical disability has examined medical decision-making autonomy (e.g., Heesen et al., 2004), has focused on autonomy in the context of participation (e.g., Heinemann et al., 2013), or is qualitative work examining how lack of autonomy is associated with negative outcomes (e.g., Choi et al., 2008). Consequently, few empirical studies have exam-

Table 5
Regression Models Examining Predictors of Quality of Life in a Subsample of Participants Reporting Some Pain (n = 964)

Variable	Model 2a			Model 2b			Model 2c			Model 2d			Model 2e		
	b	*SE*	β	*b*	*SE*	β	*b*	*SE*	β	*b*	*SE*	β	*b*	*SE*	β
Constant	3.09**	.13		3.00**	.10		2.98**	.09		3.05**	.09		3.07**	.09	
Duration of condition (centered)	<.01	<.01	.04	<.01	<.01	.01	<.01	<.01	−.003	<.01	<.01	<.01	<.01	<.01	<.01
PROMIS Physical Function *t* score (centered)	.03**	<.01	.28	−.001	<.01	−.01	−.001	<.01	−.01	−.003	<.01	−.02	−.002	<.01	−.02
Age at T7 (centered)	−.004	<.01	−.04	−.005	<.01	−.05	−.01**	<.01	−.07	−.01**	<.01	−.07	−.01**	<.01	−.08
NMD	−.23*	.10	−.09	.06	.07	.02	.08	.07	.03	.06	.07	.02	.05	.07	.02
MS	−.29**	.10	−.13	.06	.07	.03	.05	.07	.02	.05	.07	.02	.04	.07	.02
PPS	.10	.10	.04	.31**	.08	.13	.28**	.07	.12	.28**	.07	.12	.27**	.07	.12
Education	.13	.07	.06	.10*	.05	.05	.10*	.05	.05	.08	.05	.04	.08	.05	.04
Annual income	.29**	.07	.14	.12*	.05	.06	.10*	.05	.05	.09	.05	.05	.10	.05	.05
Gender	.19**	.07	.09	.17**	.05	.08	.18**	.05	.08	.19**	.05	.09	.18**	.05	.09
Marital status	.18**	.07	.09	.10*	.05	.05	.13**	.05	.06	.13**	.05	.06	.13**	.05	.06
Race	.18	.10	.05	.26**	.08	.08	.29**	.07	.09	.24**	.07	.07	.24**	.07	.07
Urban status	−.12	.07	−.05	−.13*	.06	−.05	−.12*	.05	−.05	−.12*	.05	−.05	−.11*	.05	−.05
PROMIS Ability to Participate in Social Roles and Activities *t* score (centered)				.01	<.01	.05	.01	<.01	.04	<.01	<.01	.03	<.01	<.01	.02
PROMIS Satisfaction with Social Roles and Activities *t* score (centered)				.02**	<.01	.19	.01**	<.01	.10	.01**	<.01	.10	.01**	<.01	.11
UW Short Form Self-Efficacy Scale *t* score (centered)				.06**	<.01	.51	.03**	<.01	.32	.03**	<.01	.32	.03**	<.01	.31
ES Control over Participation normed score (centered)							.03**	<.01	.34	.03**	<.01	.34	.03**	<.01	.33
Pain intensity raw score (centered)										−.04**	.01	−.09	−.03**	.01	−.08
Pain × ES Control over Participation													<.01**	<.01	.08
Adjusted R^2	.15**			.52**			.57**			.578**			.583**		
ΔF	14.91**			248.31**			113.44**			14.91**			11.79**		

Note. PROMIS = Patient-Reported Outcomes Measurement Information System; T7 = Time 7; NMD = neuromuscular disease; MS = multiple sclerosis; PPS = postpolio syndrome; UW = University of Washington; ES = Enfranchisement Scale. SCI (spinal cord injury) status was used as the diagnosis reference group. Education reference category: less than college graduate. Annual income reference category: less than $52,000. Gender reference category: male. Marital status reference category: not married or in domestic partnership-civil union. Race reference category: non-White. Urban status reference category: not living in urban area.
* $p < .05$. ** $p < .01$.

ined how decisional autonomy relates to QoL. Our findings build upon the current literature by showing that a measure of decisional autonomy is significantly associated with QoL in a disabled population, over and above social support-related indicators of participation, suggesting the importance of decisional autonomy for QoL in this population. These findings are in line with qualitative work (Hammel et al., 2008; Molton & Yorkston, 2017) that finds freedom to make choices is important to individuals living with long-term disabilities.

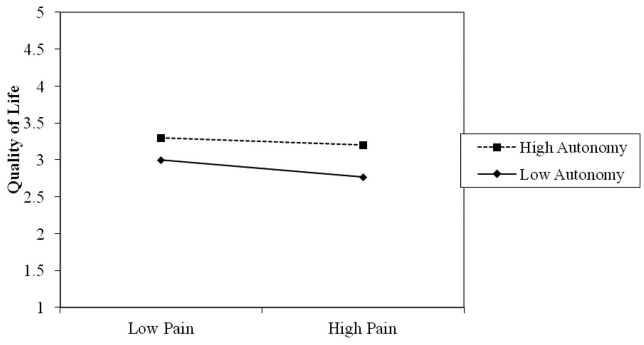

Figure 2. Illustration of the relationship between pain intensity and quality of life at lower (−.5 *SD*) and higher (+.5 *SD*) levels of autonomy from the total sample mean, in the subsample reporting some pain. Low pain = −1 (*SD*) of total sample mean, high pain = +1 *SD*.

We also found in exploratory analyses that individuals with higher levels of education, and individuals who were married or in a domestic partnership, reported higher mean decisional autonomy compared to individuals with lower levels of education or those who were not married. Future research should further evaluate the reliability of these findings. If the findings replicate, and having lower levels of education and living alone are found to be risk factors for reporting lower levels of decisional autonomy, it may be useful to develop interventions that facilitate higher levels of decisional autonomy for these individuals in particular.

This study also found some evidence for a weak buffering effect of decisional autonomy on the associations between symptom severity (fatigue and pain) and QoL, where the relationship between symptom severity and QoL was weaker at higher levels of decisional autonomy. These findings suggest that decisional autonomy may buffer the impact of these symptoms on QoL, at least for some individuals. This finding builds upon past literature that found participants with long-term disabilities such as MS valued opportunities to participate in choices about their treatment (Heesen et al., 2004). These findings also extend the literature by demonstrating associations between decisional autonomy and pain intensity, which to our knowledge have not yet been examined. Although the buffering effects are weak, these effects suggest that the role of decisional autonomy may be important for a subset of individuals with long-term physical disabilities, and further research to identify individuals with long-term physical disabilities

that may find decisional autonomy especially important is warranted.

Study Limitations

This study has limitations that should be considered when interpreting the results. First, we did not include measures that would allow us to assess the mechanism(s) by which decisional autonomy may affect fatigue and pain. We were not able to measure the extent to which decisional autonomy may be associated with symptom coping choices, for example, and whether those coping choices are related to QoL. Individuals with higher levels of autonomy may be able to make choices about how to cope with fatigue or pain that are in line with their own preferences, and therefore they experience a weaker effect of fatigue or pain on QoL. Future work could examine whether individuals with higher decisional autonomy are more likely to report using different types of coping behaviors, or a wider range of coping behaviors, than are those with lower autonomy.

Second, as a cross-sectional correlational study, it was not possible to evaluate whether there was a causal relationship between decisional autonomy, fatigue and pain, and QoL. We were not able to evaluate whether pain and fatigue directly influence decisional autonomy or whether there was a bidirectional, causal relationship between these variables. Research involving longitudinal designs or true experiments (e.g., where participants are randomly assigned to treatments that could impact decisional autonomy) would be needed to evaluate the directionality of the relationship between autonomy, symptom severity, and QoL.

Finally, both the measure used to assess QoL and the measure used to assess pain intensity were single-item scales. Single-item scales tend to be less reliable than are multiple item scales. Because low reliability can limit the strength of associations between variables, it is possible that the study underestimated the true associations between QoL, pain intensity, and the other study variables. Future research in this area should use multiple-item scales of QoL and pain intensity when possible, to provide more reliable estimates of the strength of the associations between decisional autonomy and these criterion variables.

Conclusions

Overall, the study findings provide important new information regarding the role that decisional autonomy plays as a predictor of QoL for individuals aging with long-term physical disability. We found that decisional autonomy—individuals' sense that they are able to make choices independently—is directly related to QoL. These findings indicate that a sense of ability to make choices may be an important element of maintaining well-being in individuals with long-term disability and is distinct from social support–related indicators of participation. We also found evidence that decisional autonomy buffers the association between symptom severity and QoL in this population. Although the effect of the buffering relationship was weak, our findings provide the basis for further examination of a potential relationship between decisional autonomy and symptoms such as fatigue and pain. These findings are consistent with the possibility that decisional autonomy may influence QoL in populations aging with long-term physical disability and extends the literature to show that individuals aging with disability vary with respect to their decisional autonomy. Specifically, we found that some individuals with long-term physical disability can experience high levels of decisional autonomy despite physical limitations. Interventions that increase decisional autonomy could possibly contribute to successful aging in these individuals.

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