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Secondary Health Conditions and Social Role Satisfaction in Adults with Long-term Physical Disability

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Abstract

Objective: Individuals living with physical disability due to early-acquired or traumatic conditions often experience a range of psychological and physical health problems that are associated with their condition, but are not directly caused by it. Known as “secondary health conditions,” these problems can interact with existing functional limitations and other medical comorbidities to limit social participation. The current study assessed the concurrent and longitudinal associations between secondary health conditions, chronic medical comorbidities, and functional limitations, with a PROMIS measure of social role participation.

Methods: A longitudinal survey study of community-dwelling adults with one of four chronic physical conditions (multiple sclerosis, muscular dystrophy, spinal cord injury, postpoliomyelitis syndrome). The baseline survey (T1) was mailed to 2041 individuals, and 1862 baseline surveys were completed and returned (91% response rate). The follow-up survey (T2) was mailed roughly three years later; 1594 completed and returned the T2 survey (86% of T1 survey completers).

Results: Multiple linear regression analyses revealed that secondary health conditions, functional impairments, and chronic medical comorbidities accounted for 52% of the variance in satisfaction with social roles concurrently at T1. The amount of variance of change in satisfaction with social roles over the ~3 year period accounted for by these variables was 3%. Functional limitations and more psychologically oriented secondary conditions were the strongest predictors of satisfaction with social roles.

Conclusions: Findings suggest that, for people with disabilities, addressing psychologically oriented secondary health conditions may be as important as functional impairment in predicting long-term social health.

Keywords

Social Participation; Secondary Health Conditions; Multiple Sclerosis; Muscular Dystrophy; Spinal Cord Injury

As healthcare for individuals with disabilities has transitioned from an emphasis on acute management to overall health promotion, the domains of health outcomes deemed important have expanded to include those related to social health (Marge, 1988; Rimmer, 1999;

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conflict of interest

Dijkers, Whiteneck, & El-Jaroudi, 2000). In particular, social participation – commonly defined in the literature as one’s ability to engage with social activities and to enact one’s socially constructed role (i.e., spouse, parent, friend, etc.) – is strongly related to functional outcomes and quality of life in individuals with physical disability (Levasseur, Desrosier, & Noreau, 2004; Fier, Barnett, Devine, & Barker, 2016; Wallack, Wiseman, & Ploughman, 2016; Barclay, McDonald, Lentin, and Bourke-Taylor, 2016; Yorkston, Baylor, & Amtmann, 2014; Kwiatkowski et al., 2014).

Unfortunately, living with a chronic disability often means dealing with multiple barriers to social participation and satisfaction, including environmental barriers that limit social access (for example, to adapted recreational activities) and managing relational complexities associated with caregiving among family members (Hakim et al., 2000; Gagnon et al., 2008; Barclay, McDonald, & Lentin, 2015). Given the importance of social health in disability, it is critical that researchers and policy makers understand the factors that influence social health and participation in this population.

For people with chronic physical disability, health-related factors are complex and interrelated, and the specific role of different health factors in predicting social health and participation is not entirely clear (Frier et al., 2016). For example, individuals living with physical disability due to early-acquired or traumatic conditions (such as spinal cord injury or multiple sclerosis) often experience a range of psychological and physical health problems that are associated with their condition, but are not directly caused by the pathophysiology that underlies their disability. These are known as secondary health conditions (SHCs; Rimmer, Chen, & Hsieh, 2011; Jensen et al., 2012; Molton et al., 2014). Despite an understanding of the importance of SHCs in general, precisely defining this concept an ongoing challenge to the disability research field. Rimmer and colleagues (Rimmer et al., 2011) provided a theoretical framework of SHCs that distinguishes between a “comorbidity” (i.e., a medical condition that may not be directly or indirectly related to the disability, such as diabetes), an “associated condition” (a condition that is *directly* associated with the etiology, such as paralysis), and a “secondary condition” (i.e., a medical or health problem that is not *directly* related to the disability diagnosis, occurs after the onset of the primary disability, and is more prevalent in people with disability, such as pain, fatigue, or weight gain). A large number and variety of SHCs have been identified as being common in individuals with physical disabilities (Rimmer, Chen, & Hsieh, 2011; Jensen et al., 2012). The presence and severity of these SHCs is associated with increased health care costs (Gabbe & Nunn, 2016), lower employment rates (Marti, Boes, Lay, Escorpizo, & Trezzini, 2016), poorer treatment adherence (Marrie & Hanwell, 2013), difficulty engaging in activities of daily living (Piatt, Nagata, Zahl, Li & Rosenbluth, 2016; Callaway, Barclay, McDonald, Farnworth, & Casey, 2015; Wagner et al., 2015; Cobb et al., 2014), worse subjective quality of life (Marrie & Hanwell, 2013; Adriaansen et al., 2016), and increased risk of mortality (Krause & Saunders, 2011). Some preliminary research has also demonstrated a connection between SHCs and poorer social outcomes (Yorkston, Baylor, & Amtmann, 2014; Piatt et al., 2016). Taken together, research indicates that addressing SHCs is essential for health promotion in populations with physical disabilities (Adriaansen et al., 2016; McNalley et al., 2015; Adriaansen et al., 2013; Newland, Jensen, Budhathoki, & Lorenz, 2015; Jensen et al., 2013).

In one study from our group (Molton et al., 2014), we found that patient-reported SHCs could be statistically grouped into three domains: (1) SHCs relating to bodily symptoms (e.g., numbness, spasticity, balance problems, infections, speech problems); (2) SHCs relating to mood and somatic complaints (depression, anxiety, sleep disturbance, fatigue) and (3) pain (including pain severity and pain interference). These domains are related to but separate from chronic medical comorbidities (CMCs, e.g., diabetes, hypertension) and functional impairments (e.g., problems with ambulation and activities of daily living). These data also suggested that SHC domains influenced functional impairment differently, such that SHCs related to bodily symptoms created more activity of daily living (ADL) interference than did those associated with mood, sleep, and energy problems. SHCs in general were more strongly associated with ADL impairment than were CMCs (Molton et al., 2014).

Research has also suggested that age may influence the health consequences of SHCs in those with chronic physical disabilities (Hitzig, Campbell, McGillivray, Boschen, & Craven, 2009; Molton et al., 2014; Jensen et al., 2013). As expected, the incidence and severity of SHCs (particularly physical SHCs) appear to increase as one grows older (Molton et al., 2014; Hitzig et al., 2009). However, these relationships are not always linear, and preliminary findings indicate that certain SHCs (psychosocial distress, fatigue, sleep disturbance, pain) exhibit more complex, curvilinear relationships with age (Cook et al., 2011; Molton et al., 2014). For example, in the general population, fatigue tends to peak at middle age and decrease following retirement age; this does not appear to be true for people with long-term disabilities, who maintain high levels (Cook et al., 2011). Further, while all adults may experience problems like chronic pain or fatigue, these symptoms arrive earlier and are more severe for people with early-acquired disability. In addition, due to their timing in the life-course, these symptoms can also create additional problems, such as involuntary early retirement (Denton, Plenderleith, & Chowhan, 2013). Given that SHCs and their impact appear to change dynamically across the lifespan, researchers have identified the need for additional longitudinal research on SHCs to better understand their impact over time and as people age (Jensen et al., 2013; Hitzig et al., 2009).

Taken together, there is now a substantial body of research demonstrating the importance of social health and participation among individuals with chronic disabilities, and the associations between SHCs and social participation. However, available research has been limited to studying only a narrow subset of the many SHCs that are common in individuals with chronic physical disabilities. In addition, there is a lack of prospective or longitudinal research investigating both SHCs and social outcomes in individuals with chronic physical disabilities. Ultimately, longitudinal research that incorporates a comprehensive variety of SHCs is necessary to better understand social outcomes.

Further, understanding the role of SHCs in influencing long term social health could inform how social outcomes might be most optimally impacted by biomedical and psychosocial treatments, as well as by changes in public policy. Recently, there has been a paradigm shift among rehabilitation research and public policy efforts to emphasize the importance of a multidisciplinary approach to clinical care (Ehde et al., 2018; Derakhshanrad, Vosoughi, Yekaninejad, Moshayedi & Seberi, 2015). A central component of this approach is an

emphasis on viewing the patient in terms of the biopsychosocial model, placing equal weight on biological (i.e., physical symptoms, physical illness), psychological (i.e., depression), and social factors (i.e., satisfaction with social roles, social participation). Thus, understanding the relative importance of each of these SHC domains in influencing long term social health could inform future directions for research and treatment in the field of rehabilitation medicine as it begins to embrace this multidisciplinary approach.

Given these considerations, the aim of this study was to better understand the associations between three broad domains of SHCs on satisfaction with social roles in adults with chronic physical disabilities. We also sought to determine whether these SHCs domains were more or less impactful than other separated, but related areas of health (functional limitations and CMCs). We hypothesized that higher levels of SHC severity would be negatively associated with satisfaction with social roles, even after considering the effects of functional limitations and the presence of other chronic conditions. Further, given that past research has indicated that pain and physical SHCs are more strongly associated with general function than psychosocial factors and comorbid chronic medical conditions, we hypothesized that these domains will also be more robustly associated to satisfaction with social roles here. We also sought to address important questions regarding the role of chronological age in moderating the impact of SHCs on social participation.

This work is based on the same baseline data as those previously reported by our group (Molton, 2014). However, those analyses did not include or address social variables such as satisfaction, and did not include a longitudinal component.

Methods

Participants

The study used data from an ongoing national longitudinal survey tracking persons aging with spinal cord injury (SCI), multiple sclerosis (MS), muscular dystrophy (MD), or postpolio syndrome (PPS) in the United States. These four conditions were selected because each is associated with physical impairment and/or disability, and each represents a unique trajectory in terms of onset and course. Inclusion criteria were: being able to read and understand English (assessed via self-report; “Can you read and understand English?”), self-reporting a physician’s diagnosis of multiple sclerosis (MS), spinal cord injury (SCI), muscular dystrophy (MD), or postpolio syndrome (PPS), and being at least 18 years of age. A total of 2202 individuals expressed interest in participating and, of those, 2041 were eligible. The 2041 eligible participants learned about the study through advertisements in organization newsletters and websites (661; 33%), involvement in a previous survey study at University of Washington (473; 23%), a University of Washington disability registry (398; 20%), disability specific registries (375; 18%), referral from a friend or relative (90; 4%), and other sources (44; 2%).

Procedures

The baseline (T1) survey and a consent form were mailed to eligible participants between July 2009 and March 2010. A total of 1862 T1 surveys were returned with a signed consent

form. Additional surveys were mailed roughly each year for the following 3 years. The second and third surveys did not include data relevant to the current study. The fourth survey (labelled T2 for purposes of this manuscript) was administered between August 2012 and March 2013, roughly 3 years after the T1 survey. The T2 survey was completed and returned by 1594 participants (86% of T1 survey completers). T1 responders who did not complete the T2 survey included: 135 participants who did not return the survey, 48 who asked to withdraw during previous time points, 47 who were deceased, 20 who could not be located at their address on file, and 18 who declined to complete the additional survey.

Each returned survey was examined by research staff for completeness; if missing data were identified, staff attempted to call the participant and obtain the missing data. If a survey was not received within 4 to 6 weeks of the initial mailing, a reminder letter was sent. If a survey was still not received after 6 weeks, research staff made reminder phone calls. Participants were reimbursed \$25 for completing each survey. All study procedures were approved by the University of Washington's Human Subjects Division.

Measures

Demographic/descriptive data.—Measures of demographic variables, including age, ethnicity, diagnosis, and gender, were administered for descriptive purposes.

Satisfaction with social roles.—Satisfaction with social roles was assessed using the Patient-Reported Outcomes Measurement Information System (PROMIS) Satisfaction with social roles short-form at T1 (Cella et al., 2007; Cella et al., 2010). At T2, satisfaction with social roles was assessed using the corresponding questions from the PROMIS-29 (Craig et al., 2014). PROMIS is a measurement system, developed by the National Institutes of Health, designed for use in both the general population and populations with chronic conditions. Each PROMIS measure is derived and validated from a central item bank. The PROMIS measures used here have been validated across a wide variety of representative samples, including those with physical disabilities (Cook, Bamer, Amtmann, Molton, & Jensen, 2012; Hahn et al., 2010). Although the PROMIS-29 does not include three of the specific social role items used in the T1 survey, the scores obtained from both sets of items are directly comparable, as both sets of items were derived and validated from the same item bank and then normed into their t-score equivalents (such that a score of 50 represents the general U.S. population average). The items from the PROMIS Social Role Satisfaction item bank assess satisfaction with social roles by asking respondents the degree to which social role statements (e.g., “I am satisfied with my ability to meet the needs of those who depend on me”) are true for them in the past seven days using a 5-point Likert scale ranging from “*Not at all*” to “*Very much*.” The internal consistencies (Cronbach's Alpha) for satisfaction with social roles were .94 (T1) and .93 (T2) in our sample, indicating excellent reliability.

Health Domains.—To assess the effect of SHCs and related constructs on social role satisfaction, we measured SHCs (in three categories), as well as functional impairments and chronic medical comorbidities (CMCs).

SHC variables.—SHCs were chosen based on meeting three criteria that describe SHCs in previous work, i.e. a medical or health problem that 1) is not *directly* related to the condition associated with disability, 2) occurs after the onset of the primary condition, and 3) is more prevalent in people with disability. We further chose to divide SHCs into three broad categories (1. bodily symptoms and problems; 2. mood, sleep, and energy problems; and 3. chronic pain) in order to determine which of these categories most strongly predicted social role satisfaction. Previous work from our group has demonstrated that these categories are statistically reliable in people with disability (Molton, 2014).

It is important to acknowledge that any SHC definition is imperfect, because the distinction between what is “secondary” versus what is “primary” or “associated” depends in large part on the specific medical condition causing disability. In order to include as wide a range of disability conditions and individual experiences as possible in these analyses, we describe many potential symptoms and conditions as “secondary” (although some may be “associated” in particular cases).

Bodily symptoms and problems.: Nine individual items were used to assess a broad variety of disability-related physical health symptoms. Seven of these items assessed the average severity of physical health symptoms (weakness, imbalance, numbness of body, numbness of hands or feet, vision loss, shortness of breath, spasticity) over the past week using a 10-point Numerical Rating Scale (NRS), ranging from “None” to “Very severe.” The remaining two items asked respondents to rate how problematic two of the symptoms are (difficulty with speech and swallowing) in general, using a 5-point Likert scale ranging from “Not at all” to “Very much.”

Mood, sleep and energy problems.: This domain contained PROMIS short-forms of sleep disturbance and fatigue (Cella et al., 2007; Cella et al., 2010) and the Patient Health Questionnaire-9 item measure of depressive symptoms (PHQ-9; Kroenke, Spitzer, & Williams, 2001). These measures have been extensively validated across a wide demographic, including populations with chronic physical disabilities (Cook et al., 2012; Pilkonis et al., 2011; Kroenke, Spitzer, & Williams, 2001). The internal consistencies (Cronbach’s Alpha) were .84 (PHQ-9), .93 (PROMIS-Sleep Disturbance short-form v1.0), and .85 (PROMIS-Fatigue short-form v1.0) in our sample, indicating good to excellent reliability.

Pain.: The Pain SHC category was assessed using the average value of four pain intensity items. These items assessed pain intensity by asking respondents to rate how much they hurt (1) currently, (2) on average during the past week, (3) at their worst during the past week, and (4) at their least during the past week, using an 11-point NRS ranging from 0 “No pain” to 10 “Pain as bad as it could be.” We chose to assess pain with measures of pain intensity, as opposed to other common measures of pain (i.e., pain interference), to minimize the potentially biasing effects of multicollinearity among the study predictors. Pain intensity numerical rating scales such as these have a great deal of support for their validity and reliability (Jensen & Karoly, 2011).

In addition to these 3 groups of SHCs, we also created domains of functional impairment and CMCs, in order to test their effects on social role participation alongside SHCs.

Functional Impairment.—The PROMIS physical function item bank was used to assess functional impairment (Cella et al., 2007; Cella et al., 2010). 12 items were selected from the item bank that assessed capability to perform a variety of essential daily activities with a physical component, such as housework, bathing, dressing, and preparing food. PROMIS physical function measures have been validated for use across a wide demographic, including those with physical disabilities (Jensen et al., 2015). The PROMIS physical function item bank is a measure of positive physical function; a higher score on the PROMIS physical function short-form indicates less functional impairment. The internal consistency (Cronbach's Alpha) for the PROMIS physical function item bank questions was .94 in our sample, indicating excellent reliability.

Chronic Medical Comorbidities (CMCs).—Presence of CMCs was assessed by totaling the number of four health conditions endorsed by each respondent. Using questions from the National Health Interview Survey (NHIS; <https://www.cdc.gov/nchs/nhis/>), respondents indicated whether or not they had ever been told by a doctor that they had hypertension, coronary heart disease, diabetes, and arthritis. These chronic diseases were selected because they are among the most prevalent and impactful chronic diseases in the United States (Centers for Disease Control and Prevention [CDC], 2009; CDC, 2015; Ogden, Carroll, Fryar, & Flegal, 2015; Ward, Schiller, & Goodman, 2014).

Computation of health domain scores.—For analytic purposes, a single score was computed for each of the 3 health domains described above (i.e., SHCs in three categories, functional impairments, and CMCs). The Pain category score was calculated by computing a mean of the component items. The CMC score was calculated by totaling the number of the four specific chronic medical conditions (hypertension, coronary heart disease, diabetes, arthritis) endorsed. The Functional Impairment domain score was represented by the PROMIS Physical Function scale t-score. To represent the bodily symptoms and problems SHC category, the component items or measures were converted into their z-score equivalents, and the mean values of these z-scores were then computed. The same approach was taken for the mood, sleep and energy SHC domain. The end result was five single scores which represented the amount or severity in each of three health domains (three SHC categories, plus functional impairment and CMCs).

Data Analysis

To describe the sample, we computed the means and standard deviations (continuous variables) and percentages (categorical variables) of the demographic variables. We then performed two regression analyses to evaluate the associations among SHCs, functional impairments, CMCs, and satisfaction with social roles. Prior to performing the regression analyses, we assessed the study variables for potential skew and multicollinearity (by computing the variance inflation factor for each predictor), to ensure that the variables met the assumptions for the planned analyses. To detect problematic skew and variable inflation

factor (VIF), we used cutoff values of three or higher and 10 or higher (respectively) (Tabachnick & Fidell, 1996; Hair, 2010).

In the first (concurrent) regression analysis, T1 social role satisfaction was the criterion variable. Age, gender, and diagnosis (dummy coded such that 1 indicates the presence of the condition) were entered as control variables in step 1. Entering these demographic and diagnostic variables as controls is common practice and serves to ensure that the main effect is isolated from extraneous sources of variance. Each of the five scores reflecting SHCs, functional impairments and CMCs were entered as a block in step 2.

In the second (longitudinal predictive) analysis, T2 social role satisfaction was the criterion variable. We entered T1 social role satisfaction in step 1. Next, we entered the participant demographic and descriptor variables (age, gender, diagnosis) in the second step. Finally, we entered the five health domain scores as a block in step 3.

To assess the potential moderating effect of age on associations between each health domain and satisfaction with social roles, we conducted additional regression analyses separately for each health domain. In the concurrent regression analyses, T1 satisfaction with social roles was the criterion variable. We entered gender and diagnosis as control variables in step 1, five health domain scores (three SHCs, CMCs and functional impairments) and age in step 2, age² (to assess a curvilinear age effect) in step 3, the term representing the Age X each domain score interaction in step 4, and the term representing Age² X domain score term in Step 5. The regression models assessing age interactions longitudinally were structured in the same way as the concurrent models, but T2 satisfaction with social roles was the criterion and T1 satisfaction with social roles was entered in the first step, prior to demographic controls.

Results

Participant Characteristics

After removing cases with missing values for the variables studied here, the final sample consisted of 1540 participants. We used this sample for both the concurrent and longitudinal analyses to ensure that results would be directly comparable. Table 1 presents descriptive statistics (means and standard deviations for continuous variables, number and percent for categorical variables) for the demographic and diagnostic variables of the final sample. As can be seen, the sample was predominantly white (91%), and the majority were women (64%) and highly educated (56% completed college, and 25% went on to complete post-collegiate education). Participants also reported an average of 15.23 (SD = 11.49) years since being diagnosed with their condition. Table 2 presents the means and standard deviations for the study variables.

To determine whether there were any systematic differences between those with and without missing data at T2, we conducted a series of t-tests comparing each primary study measure at T1 in those with and without missing data. There were statistically significant differences between individuals with and without missing data in terms of their T1 Functional Impairment (missing mean, 32.86±10.21; non-missing mean, 36.85±10.16; $t_{1860} = 6.41$; P

= .000), number of CMCs (missing mean, 1.14 ± 1.07 ; non-missing mean, 0.99 ± 0.99 ; $t_{431.54} = 2.29$; $P = .023$), bodily SHCs (missing mean, 0.09 ± 0.58 ; non-missing mean, -0.02 ± 0.57 ; $t_{1860} = 3.20$; $P = .001$), pain (missing mean, 3.86 ± 2.53 ; non-missing mean, 3.42 ± 2.40 ; $t_{1855} = 2.92$; $P = .004$), and satisfaction with social roles (missing mean, 42.91 ± 8.29 ; non-missing mean, 45.39 ± 8.26 ; $t_{1820} = 4.64$; $P = .000$), but not mood and energy related SHCs (missing mean, 0.07 ± 0.82 ; non-missing mean, -0.01 ± 0.82 ; $t_{1859} = 1.56$; $P = .120$). These findings suggest that those T1 completer's who did not continue on to complete the T2 survey were slightly worse off at T1 with regard to their physical symptoms, physical function, and social role satisfaction.

The concurrent and longitudinal associations between health domains and satisfaction with social roles

There was no evidence of significant skew with or multicollinearity among the study variables used in the regression analyses. Among the predictors, the highest VIF value was 2.12 and the highest bivariate correlation coefficient was .47, both of which are well below the commonly used cutoffs for these statistics (<10 and <0.70 , respectively). The results of the concurrent and longitudinal multiple linear regressions predicting satisfaction with social roles are reported in Tables 3 and 4.

As expected, both the concurrent and longitudinal regressions revealed significant inverse relationships between symptom severity or functional impairment and satisfaction with social roles. Combined, the SHCs, functional impairment and CMCs accounted for 52% of the variance in satisfaction with social roles concurrently; the amount of variance of change in satisfaction with social roles over the ~3 year period accounted for by these domains was 3%.

Looking at the individual variables concurrently, functional impairment accounted for the largest amount of variance in satisfaction with social roles ($\beta = .53$, $p < .001$, 95% CI [.40, .47]), followed by the mood and energy related SHCs ($\beta = -.39$, $p < .001$, 95% CI [-4.29, -3.44]). In the regression analyses predicting change in satisfaction with social roles, the measure representing mood and energy related SHCs made a larger individual contribution ($\beta = -.18$, $p < .001$, 95% CI [-2.55, -1.36]) than did functional impairment ($\beta = .07$, $p < .05$, 95% CI [.01, .12]), although both were statistically significant.

None of the interaction terms involving age were significant (all p 's $>.05$ and $R^2 < .02$), in either the concurrent or longitudinal analyses. Age did not appear to moderate the relationship between health domain scores and satisfaction with social roles, either cross-sectionally or longitudinally. Full results of these additional analyses assessing the moderating effect of age are reported in tables 4 through 14 (available as online resources).

Discussion

We hypothesized that higher levels of SHC severity would be negatively associated with satisfaction with social roles both concurrently and longitudinally, even after considering the effects of functional limitations and the presence of other chronic health conditions. Additionally, we hypothesized that pain and SHCs that were primarily physical (e.g.,

numbness, spasticity) would exhibit the strongest associations with satisfaction with social roles, relative to other domains. Generally, these findings were consistent with study hypotheses, as the combination of SHCs, CMCs, and functional limitations predicted large amounts of variance in social role satisfaction. However, contrary to the hypothesis that pain and physical SHCs would exhibit the strongest associations with satisfaction with social roles, only functional impairment and SHCs related to mood, fatigue, and sleep were significantly associated with social role satisfaction. These findings existed even after controlling for gender and diagnosis, and ultimately suggest that psychological or psychosocial SHCs (such as depression and fatigue) are as or more important than functional impairment in predicting satisfaction with one's social activity.

While past research has also shown associations between some specific SHCs and functional outcomes (Callaway et al., 2015; Wagner et al., 2015; Cobb et al., 2014), including social participation (Yorkston, Baylor, & Amtmann, 2014; Piatt et al., 2016), these studies are limited by small sample sizes, narrower selections of SHCs, and cross-sectional designs. The current study makes several methodological advancements when compared to past research that has assessed the relationship between SHCs and function. To our knowledge, the current study is the first to investigate the associations between SHCs and social function using a longitudinal design (albeit a short-term one). The current study is also among the first to allow for a comparison of various different kinds or categories of SHCs, as well as functional impairment and CMCs, in their unique associations with social function.

Our findings demonstrate that various different areas of health and SHCs may be important in regard to one's satisfaction with social roles. In the concurrent model, functional impairment was the individual domain with the strongest association with satisfaction with social roles, followed closely by SHCs that focused on mood and mood-related issues. However, in the longitudinal model, these "psychosocial" SHCs emerged as the strongest predictor of satisfaction with social roles, while the role of functional impairment weakened considerably. These results suggest that, while one's ability to complete activities of daily living (such as dressing, bathing, and eating), may have the strongest immediate impact on one's social health, one's psychosocial health (i.e., degree of depressive symptoms, fatigue severity, and sleep quality) may be more important long term in terms of social participation. Further, CMCs, bodily SHCs, and pain did not significantly contribute to one's satisfaction with social roles, either concurrently or longitudinally, when the other domains were controlled for in the same model (for uncontrolled results, consult supplemental tables). Considering that past research has suggested that these factors may play a key role in functional outcomes (Molton et al., 2014; Yorkston, Baylor, & Amtmann, 2014; Piatt et al., 2016), at least when examined individually, the lack of a significant association found in the current study suggest the possibility that the associations between these domains and satisfaction with social roles may be primarily accounted for by one's degree of functional impairment and by psychosocial health.

Contrary to our expectations, analyses did not support a moderating role for chronological age on associations between health domains and satisfaction with social roles. Past research in geriatrics has suggested that while increasing age is generally associated with worsening symptom severity, it may also be associated with decreased symptom impact on mood and

quality of life, due to aging related psychosocial processes (such as increased mastery; Bierman, 2011). In our data, this was not true in the case of social role satisfaction, where the impact of SHCs remained relatively stable across age. This highlights the importance of targeting psychological SHCs and functional impairments to promote social function in people with disability, regardless of age or timing of onset.

Altogether, the findings highlight the complexity of health-related factors in populations with chronic disabilities, and the need for additional research to compare different theoretical categories of SHCs and their influence on health outcomes. The study findings support a biopsychosocial approach to treatment of individuals with chronic physical disabilities that targets more than just management of the immediate consequences of one's disease or disability, but also the varied secondary health complications as well. While traditional biomedical treatments, like occupational therapy or physiotherapy, may be most effective for addressing issues related to physical functional impairments (Steultjens et al., 2003), these traditional biomedical approaches, most often medication (Pöhlmann & Feneberg, 2008), are largely insufficient for other types of secondary health factors, such as pain (Truini, Barbanti, Pozzilli, & Cruccu, 2013), fatigue (Ledinek, Sajko, & Rot, 2013), and depression (Ehde et al., 2008). Evidence suggests that psychological treatments, such as cognitive behavioral therapy, group psychotherapy, self-hypnosis, and mindfulness meditation training, are effective treatments for these secondary health factors that are not adequately treated with the more traditional, biomedical approach (Mohr et al., 2000; Mohr & Cox, 2001; Patterson & Jensen, 2003; Zangi et al., 2012). A multidisciplinary approach that incorporates psychological treatments in conjunction with the traditional biomedical approach should be emphasized for treatment of individuals with chronic physical disabilities.

The study findings also have implications for public policy. Research has demonstrated that low-cost programs that promote self-management skills are effective for treatment of varied chronic diseases of aging (Lorig et al., 2001; Bodenheimer, Lorig, Holman, & Grumbach, 2002). Future public policy research should investigate the possibility of tailoring such self-management programs for health and wellness promotion in individuals with chronic physical disabilities, by incorporating self-management techniques and teaching self-management skills that address specific SHCs.

Study Limitations.

The current study has important limitations which should be considered when interpreting results. The study sample is predominantly white (91%), and highly educated (56% completed college and of those, 25% went on to receive a graduate degree). The extent to which the results generalize to populations that are non-white or less educated is not known. Further, the study used a convenience sample of individuals which was subjected to a response bias. In addition, missing data appeared to be somewhat systematic, as those with missing data at T2 were slightly worse off with regard to their physical symptoms, physical function, and social role satisfaction. Thus, there is a need to replicate these findings in additional sample of individuals with disability in order to evaluate their reliability. Further, there are other potential factors, such as socioeconomic status and social integration or

primary disease severity, which were not accounted for in the current study and could also influence one's satisfaction with social roles. Although we used a short-term longitudinal approach to evaluate the ability of SHCs to predict subsequent change in social role satisfaction, the design used was a correlational predictive design. We cannot conclude from these results that systematic changes in psychosocial SHCs or functional impairment will necessarily cause changes in social role satisfaction. Experimental research (e.g., an RCT where individuals are randomly assigned to treatment conditions that target these SHC domains for change) is needed to evaluate causal relationships.

Conclusions

Despite the study's limitations, the findings provide important new information regarding the role that SHCs play in affecting social participation. We found that, among individuals with chronic physical disability, functional limitations and SHCs with strong psychological components (e.g., depression, sleep disturbance and fatigue) were most strongly associated with both current and future satisfaction with social roles. This was true across the lifespan. These findings emphasize the importance of a multidisciplinary approach to treatment of individuals with chronic disabilities that is based on a biopsychosocial model of function. Further, the findings suggest that public policy efforts supporting self-management training programs could be tailored for use in populations with chronic physical disabilities by targeting issues related to these SHCs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Demographics.

Measure	N	Mean (SD) or Percent
Age	1540	56 (13)
Gender		
Men	562	36%
Women	978	64%
Marital Status		
Married	917	60%
Separated	26	2%
Divorced	244	16%
Living with significant other	84	5%
Never Married	177	11%
Widowed	90	6%
Missing	2	<1%
Household Composition		
Number of individuals in household	1521	2.21 (1.11)
Socioeconomic Status		
Annual household income (in US\$)		
<25,000	318	20%
25,000–40,000	250	16%
41,000–55,000	201	13%
56,000–70,000	179	12%
71,000–85,000	138	9%
86,000–100,000	144	9%
>100,000	239	16%
Missing	71	5%
Hours per week of assistance		
Paid assistance	1532	5.24 (19.94)
Unpaid assistance (from family or friends)	1494	9.02 (26.64)
Education Level		
9 th grade or less	4	<1%
Some high school	19	1%
High school graduate or GED	188	12%
Vocational or technical school	91	6%
Some college	366	24%
College graduate	481	31%
Professional/Graduate School	391	25%
Ethnicity/Race		
White/Caucasian	1404	91%
Black/African American	52	3%
Native American/Alaska Native	9	<1%

Measure	N	Mean (SD) or Percent
Asian	12	1%
Hispanic	19	1%
More than one race	33	2%
Unknown	2	<1%
Missing	9	<1%
Diagnosis		
Muscular Dystrophy	275	18%
Multiple Sclerosis	492	32%
Post-Polio Syndrome	371	24%
Spinal Cord Injury	402	26%
Years since diagnosis	1481	15 (11)

Abbreviation: GED, General Educational Development.

Table 2.

Descriptive statistics of study variables.

Measure	Mean (SD) or Number (Percent)
Satisfaction with Social Roles *	
T1 T-score	45.40 (8.26)
T2 T-score	45.42 (9.18)
T1 raw score	11.75 (4.44)
T2 raw score	12.03 (4.75)
T2 – T1 raw change score	0.28 (4.07)
Mood and energy related SHCs	
PHQ-9	6.25 (5.04)
PROMIS Sleep Disturbance *	52.25 (9.57)
PROMIS Fatigue *	56.23 (8.24)
Functional Impairment	
PROMIS Physical Function *	37.85 (10.16)
Chronic Medical Comorbidities	
Coronary Heart Disease	105 (7%)
Diabetes	213 (14%)
Arthritis	591 (38%)
Hypertension	620 (40%)
0 CMCs	588 (38%)
1 CMC	516 (33%)
2 CMCs	323 (21%)
3 CMCs	85 (6%)
4 CMCs	28 (2%)
Pain	
Composite 0–10	3.42 (2.40)

* General U.S. population mean is 50 and SD is 10 on all PROMIS measures

Abbreviation: SHCs, Secondary Health Conditions; PROMIS, Patient-Reported Outcome Measurement Information System; PHQ-9, Patient Health Questionnaire-9 item; CMC, Chronic Medical Conditions

Table 3.

Summary of regression analyses predicting satisfaction with social roles at T1 (n=1540)

Step & Variable	R ²	R ²	F	β (Unstandardized)	β SE	β
1. Control Variables	.02		7.23 ***			
Age				-.08	.02	-.13 ***
Gender				-.54	.48	-.03
MD Diagnosis				.85	.66	.04
MS Diagnosis				.31	.61	.02
PPS Diagnosis				-.20	.70	-.01
2. Health Domains	.54	.52	342.94 ***			
Physical Function (Functional Impairment)				.43 ***	.02	.53 ***
Chronic Medical Comorbidities				-.18	.17	-.02
Bodily Secondary Health Conditions				-.61	.32	-.04
Mood and energy related Secondary Health Conditions				-3.86 ***	.22	-.39 ***
Pain				.08	.07	-.02

* $P < .05$ ** $P < .01$ *** $P < .001$

Table 4.
Summary of regression analyses predicting change in satisfaction with social roles from T1 to T2 (n=1540)

Step & Variable	R ²	R ²	F	β (Unstandardized)	β SE	β
1. T1 Satisfaction w/ Social Roles	.36		874.23***			
2. Control Variables	.37	.01	5.16***			
Age				.01	.02	.01
Gender				.40	.43	.02
MD Diagnosis				-2.90***	.59	-.12***
MS Diagnosis				-.96	.54	-.05
PPS Diagnosis				-.94	.63	-.04
3. Health Domains	.40	.03	12.55***			
Physical Function (Functional Impairment)				.06*	.03	.07*
Chronic Medical Comorbidities				-.28	.22	-.03
Bodily Secondary Health Conditions				-.18	.41	-.01
Mood and energy related Secondary Health Conditions				-1.96***	.30	-.18***
Pain				.00	.09	0.0

* P<.05

** P<.01

*** P<.001