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Social Connectedness and the Impact on Chronic Illness

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SOCIAL CONNECTEDNESS AND THE IMPACT ON CHRONIC ILLNESS

by

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in partial fulfillment of the requirements for the degree of

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Abstract

Having a chronic illness may feel alienating, yet examination of the literature shows limited research on social connectedness and health. In order to contribute to the understanding of this impact of illness, I examined perceived levels of social connectedness in persons with chronic diseases (CD), functional somatic syndromes (FSS) and medically unexplained symptoms (MUS). A major focus of this study was to investigate the association of social connectedness with depression, anxiety, and general health in patients with ongoing symptoms of illness. Data collection was obtained through the use of four online surveys collectively known as VOICE (*Verification of Coping, Illness and Experience*). For the purposes of this study, five measures were used: the Social Connectedness Scale, Short Form Health Survey (SF-36), Patient Health Questionnaire depression scale (PHQ-8), Hopkins Symptoms Checklist (HSCL) and the Social Impact Scale. Participants were recruited through announcements via online message boards and support groups, as well as through the distribution of brochures in local medical practices. A total of 148 participants (80% female) completed all four surveys. Results indicated that the chronic illness groups did not significantly differ in social connectedness, although there was some indication that the FSS group felt more social isolation. Regression analyses indicated that, while accounting for socio-cultural and health factors, social connectedness was the strongest predictor of depression ($\beta = -.43, p < .001$), anxiety ($\beta = -.48, p < .001$) and general health ($\beta = .34, p < .001$) in chronically ill persons. The independent and robust relationship of social connectedness with psychological and physical health in individuals with chronic illness suggests that this is an important factor deserving of future research with important clinical applications.

Social Connectedness and the Impact on Chronic Illness

There are many ways people stay connected with one another. Sending a letter through the mail, calling on the phone, email, text messages and social networks like *Facebook* and *Twitter* are just some of the ways people connect with others. Regardless of the method, however, the sole purpose of these different acts is to develop a sense of belongingness, to maintain relationships and ultimately, to stay socially connected.

Social connectedness is one facet of the multi-dimensional construct of belongingness developed by Kohut in 1984. Fiske (2004) identified belonging as a motive that “drives much of social behavior” (p. 536). In their early work, Lee and Robbins (1995) identified social connectedness as “one’s opinion of self in relation to other people” and suggested that it “focuses on the emotional distance or connectedness between the self and other people, both friends and society” (p. 239). Ultimately, Lee and Robbins (2000) defined social connectedness as a person’s “awareness of interpersonal closeness with the social world” (p. 484). In perhaps more simplistic terms, it is how we see and feel about ourselves in relation to the rest of the world, asking the question, “Do I belong?”

The importance of social connectedness is highlighted in research that shows those high in social connectedness are more socially dynamic and form new relationships easier than those who are low in the construct (Lee, Draper & Lee, 2001). Individuals simply appearing to be socially connected in pictures are preferred more often by others than those who appear alone (Milyavskaya, Reoch, Koestner & Losier, 2010). Meanwhile, those who have difficulty with connectedness may “feel different and distant” from others, leading them to feelings of loneliness and isolation (Lee & Robbins,

1995). Furthermore, those low in social connectedness tend to feel uncomfortable in social situations and more cut off from the world (Williams & Galliher, 2006). Our connections to others is important, even to the degree that feeling socially connected to someone can create shared emotions and physiology. In an experiment by Cwir, Carr, Walton and Spencer (2011), subjects were made to feel socially connected to a confederate who was to undergo a stressful task or made to run in place. Their results indicated that subjects displayed correlating increased stress or heart rate with the confederate due to this experimentally manipulated social connection.

Social connectedness has also been found to be associated with depression, anxiety, and adjustment. Hagerty, Williams, Coyne and Early (1996) found a moderate negative association between belonging and measures of anxiety and depression. Additional research by Sargent, Williams, Hagerty, Lynch-Sauer and Hoyle (2002) has also shown a negative correlation between depression and a sense of belonging. In college students, social connectedness has been identified as a predictor of adjustment difficulties (Duru, 2008) and depression (Armstrong & Early, 2009).

In their effort to establish that social relationships are not only a want, but a need, Baumeister and Leary (1995) found that those lacking social connectedness are more likely to have mental and behavioral problems, as well as physical illness. While there is a fair amount of research on social connectedness and mental health issues, the research is somewhat limited when it comes to social connectedness and physical health. The literature that is available, for example, shows that being more socially connected is associated with shorter hospital stays and postoperative pain, with individuals who are less socially connected more likely to experience more pain and have a hospital stay of

greater than or equal to seven days (Mitchinson, Kim, Geisser, Rosenberg & Hinshaw, 2008). People who are socially disconnected are more likely to rate their health as poor or fair as opposed to good, very good, or excellent (Cornwell & Waite, 2009). Kok and Fredrickson (2010) measured vagal tone¹ in adults and found a positive association between vagal tone and social connectedness.

Access to community centers (e.g., YMCA) and neighborhood connections may be important factors when it comes to social connectedness and health. For example, seniors who feel more connected to their neighborhood have better mental and physical health, less stress and are more physically active (Young, Russell & Powers, 2004). A twelve-month study that partnered local YMCA's and single-parent families indicated that when access to physical activities is made more readily available, social connectedness increases. Their results appear to indicate that activity, while beneficial to one's physical well-being, can also have significant effects on other aspects of one's life—their social connections.

Related to social connectedness is the concept of social isolation, which is defined as “an objective, quantitative measure of network size and diversity, and frequency of contact” (Shankar, McMunn, Banks, & Steptoe, 2011; p. 377). Individuals are considered to be socially isolated when they live alone, have a small number of friends, little-to-no family, and have restricted contact with others (Shankar et al., 2011). Social isolation has been recognized as detrimental to a person's health and well-being. Patients who reported feeling socially isolated in an interview were shown to have poor long-term outcomes and are more likely to have depression (Hawthorne, 2008). In addition, those

¹ Vagal tone is activity in the parasympathetic nervous system in which stress and stress vulnerability may be assessed. A low vagal tone indicates a disturbance of homeostatic processes – stress. (Porges, 1995).

who are more socially isolated have higher rates of chronic disease (Cloutier-Fisher & Kobayashi, 2009). The increased cardiovascular disease risk with isolation was tested in a laboratory study, revealing that social isolation was associated with cardiovascular longer recovery time to an acute stress task in both men and women and increased cholesterol responses in men (Grant, Hamer & Steptoe, 2009). In an effort to determine if social isolation had an effect on increasing left ventricular masses (a predictor of cardiovascular mortality), echocardiograms and self-report surveys were conducted on over two thousand tri-ethnic (White non-Hispanic, Black non-Hispanic and Hispanic) participants. The outcomes indicated that Hispanic participants who were more socially isolated were at higher risk for left ventricular mass (Rodriguez et al., 2011).

More research is needed to better understand the relationship of social connectedness with chronic illness. With this goal in mind, I examined the levels of perceived connectedness within three different categories of chronic illness: conventional/chronic disease (CD), functional somatic syndromes (FSS), and medically unexplained symptoms (MUS). According to the Centers for Disease Control and Prevention (2009), people with CD have a “noncommunicable illness that is prolonged in duration, does not resolve spontaneously, and is rarely cured completely” (e.g., diabetes and arthritis; p. 2). Those with FSS have “a physical syndrome without an organic disease explanation” (e.g., fibromyalgia; Manu, 1998; p.1). Patients with MUS have physical symptoms (typically chronic) with which no pathological or physiological cause can be found (e.g., pain, fatigue and nausea; Neimark, Caroff & Stinnett, 2005).

Though FSS and MUS are similar and overlap in many ways, those with MUS have not been given a clear-cut name or diagnosis for their condition. Patients with MUS

have difficulty receiving treatment due to its ambiguity and take exception to being labeled as someone with MUS. Some doctors have difficulty with the diagnosis of MUS because it “defines patient’s symptoms by what they are not, rather than what they are” (Creed et al., 2010; p. 5). Creed et al. (2010) has gone so far as to classify medically unexplained symptoms as a “negative statement” because it lacks the one thing a patient wants most – a diagnosis. Patients with MUS not only seek explanation for their symptoms, but also seek out more emotional support than other patients (Ring, Dowrick, Humphris, Davies & Salmon, 2005; Salmon, Ring, Dowrick & Humphris, 2005).

Left with the unknown and a clear desire for support, patients with MUS may feel more disconnected due to uncertainty and a lack of others understanding their experience. Without a way to label their illness, these patients may have difficulty finding others with which to connect (e.g., support groups), leaving them feeling isolated and alone. Faced with dealing with the unknown of ongoing symptoms may significantly affect patients with implications ranging from the inability to perform daily activities and maintain employment to depression, anxiety and social isolation.

The impact of an illness will vary from person to person. However, chronic illness and symptoms have been shown to affect a person both psychologically and physiologically. Hwu (1995) found that persons with chronic illness were primarily impacted by psychological functioning and secondly by physical functioning, with both diagnosis and duration of the disease being predictors of psychological and physiological outcomes in patients. With that in mind, one can deduce that a lack of diagnosis (such as those with MUS) would have an even greater psychological and physiological impact on a person.

One goal of this study was to examine the perceived levels of social connectedness within chronic illness groups (CD, FSS & MUS). Because of the limited research in this area, I first explored the levels of connectedness within each of the illness groups. Second, because those with MUS experience the most ambiguity with their illness, I hypothesized that they would perceive the lowest levels of social connectedness, compared to FSS and CD groups.

Based on the literature linking social connectedness with psychological and physical health outcomes, I hypothesized that patients reporting low levels of social connectedness would experience the greatest physiological and psychological impact of their illness. Specifically, low levels of social connectedness would be associated with higher scores on depression and anxiety scales, and lower scores on functional health and well-being scales.

Method

The *Verification of Illness, Coping & Experience* (VOICE) project and website were created in order to initiate the surveys used in the research, as well as to provide participants with information about the study, the researchers, privacy, and a means to contact the researchers with any questions or concerns. The four comprehensive surveys: *How You are Coping with Your Symptoms*, *Personal Views of Your Physical Symptoms*, *Relationships with Others and Support*, and *The Impact of Illness on Your Life* were listed separately leaving participants free to complete as many as they liked. Each survey was comprised of different scales that correlated with the survey topic. For example, the *How You are Coping with Your Symptoms* survey included the Brief-Cope scale as well

as open-ended questions and the *Personal Views of Your Physical Symptoms* survey included the Illness Perception Questionnaire-Revised scale.

To qualify for the study, the participants must have been at least 18 years of age, had physical symptoms from their illness lasting at least three months, and sought medical treatment for their condition. Each survey began with an informed consent page and a means to opt out at any time during the survey. The consent was followed by informational and categorical questions that enabled the researchers to determine if the participant fit the criterion required. Each survey was concluded with a debriefing page, addressing those who did not qualify, opted out or completed the survey in full.

Participants

Participants were recruited through two different methods: the internet and medical and alternative medicine practices. Recruitment via the internet included posting announcements on web sites of support groups, forums and blogs for people falling within each of the three illness categories (Appendix A). The recruitment announcement was posted on a total of 42 web sites, with several re-postings throughout the span of the study. Recruitment via medical and alternative practices was completed through the distribution of brochures (Appendix B). Over 70 clinics in the greater Jacksonville, Florida area were contacted and consented to distribute VOICE brochures.

Recruitment efforts were successful with well over 500 participants completing at least one of the surveys. However, due to different factors (i.e., attrition), only 148 participants completed all four of the internet surveys. The ages of the participants ranged from 18 to 76, with a mean age of 43.34 ($SD=13.69$). The majority of the

participants were female (80%), Caucasian (92%) and were involved in some form of romantic relationship (married, cohabitating or in a relationship) (69%). Based on the previously mentioned criterion, 23 (15.5%) of the participants were categorized in the MUS group by either reporting no diagnosis or selecting the option of “Medically Unexplained Symptoms”, 79 (53.4%) were categorized as FSS and 46 (31.1%) were categorized as CD. Nearly 86% of the participants reported experiencing their symptoms for one year or more. The most reported diagnosis within the FSS illness group (as well as all groups) was Fibromyalgia (46%), while Sarcoidosis (13%) was the highest reported diagnosis within the CD group. See Table 1 and Figures 1 and 2 for additional information.

Table 1. Demographics by Illness Group

	MUS	FSS	CD
Participants	23	79	46
Mean Age	37.52 <i>SD</i> =15.63	45.58 <i>SD</i> =12.80	42.07 <i>SD</i> =13.57
Gender	16 F 7 M	67 F 11 M 1 NA	36 F 10 M
Race ^a	87%	91%	76%
Illness Duration ^b	66%	95%	80%
In a Relationship ^c	52%	72%	72%
Unemployed	17%	33%	48%

^a White/Caucasian. ^b Symptoms lasting one year or more. ^c Reported being in a relationship, cohabitating or married.

Figure 1. *Chronic Diseases*

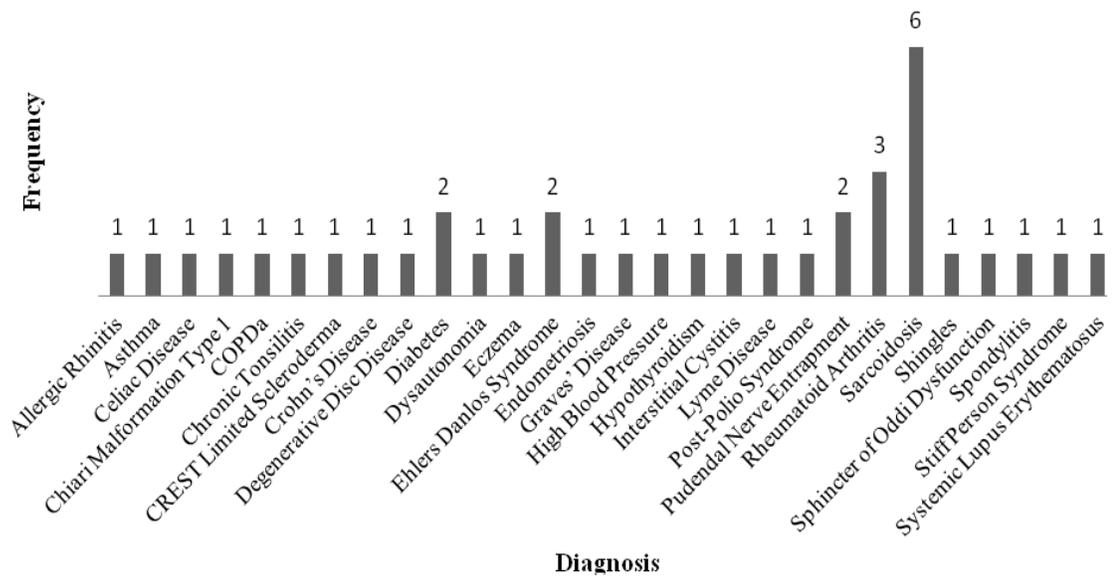
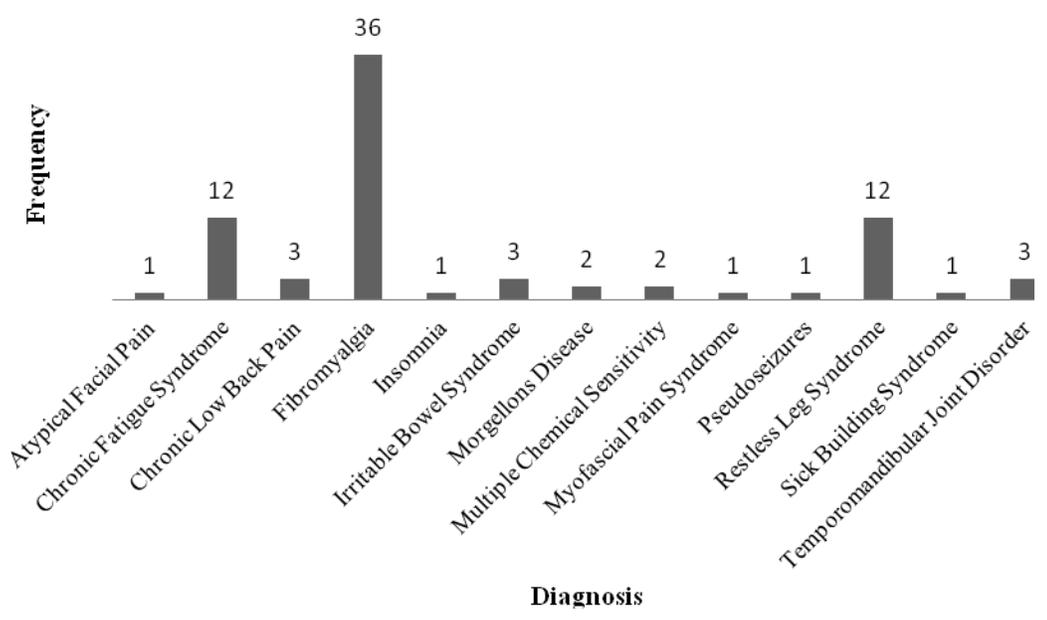


Figure 2. *Function Somatic Syndromes*



Measures

There were a total of twenty different scales used within the comprehensive surveys; for purposes of this research study, only five of the scales were used to analyze data (Appendix C):

Social Connectedness Scale: The social connectedness scale is an eight question survey, developed by Lee and Robbins (1995) assessing the participant's sense of connectedness to others and the world. Item examples include: "I feel disconnected from the world around me" and "I don't feel related to anyone". The survey is based on a six-point Likert scale, ranging from 1 (strongly agree) to 6 (strongly disagree), with a sum score ranging from 8-48. Higher scores indicate greater perceptions of connectedness expressed by the participant. Internal reliability of the social connectedness scale is measured at $\alpha = .91$ (Lee & Robbins, 1995). Additional analysis of the scale using the collected data revealed the internal reliability of this scale to be very high (8 items; $\alpha = .96$).

SF-36: The Short Form-36 is a health survey consisting of 36 questions divided into two measures: physical health and mental health. These measures are subdivided into four subscales within each, for a total of eight subscales. The physical health measure consists of the subscales: physical functioning (PF), role-physical (RP), bodily pain (BP), and general health (GH). The mental health measure consists of the subscales: vitality (VT), social functioning (SF), role-emotional (RE), and mental health (MH). The role-physical and role-emotional scales refer to difficulties dealing with day-to-day activities as a result of physical or emotional issues, respectively. Scoring on the survey

ranges from 0-100, with higher scores indicating a more favorable health state. The internal consistency of the measures range from $\alpha = .65$ to $.94$, with a mean reliability of $\alpha = .85$ (McHorney, Ware, Lu & Sherbourne, 1994). Additional analysis of the scale identified a mean internal reliability of $\alpha = .79$.

PHQ-8: The Patient Health Questionnaire-8 is an eight-question survey used to assess depression in the general population. The scores of the survey are based on a four-point Likert scale of 0 (“not at all”) to 3 (“nearly every day”); the scores of each item are summed to obtain a total score ranging from 0-24. Based on nearly 200,000 participants, Kroenke, Strine, Spitzer, Williams, Berry and Mokdad (2009) determined that a cumulative score of ≥ 10 typically indicated depression, with 88% sensitivity and 88% specificity. Data analysis indicated this eight-item scale to be highly reliable ($\alpha = .87$).

HSCA: The Hopkins Symptom Checklist is a self-report inventory of symptoms based on five separate dimensions: somatization, obsessive-compulsive, interpersonal sensitivity, anxiety and depression. The anxiety scale, consisting of six questions, was the only portion of the inventory included in the VOICE surveys. The anxiety scale is based on a four-point Likert scale ranging from 1 (not at all) to 4 (extremely) and is completed by participants to indicate the extent of their symptoms of anxiety (i.e. nervousness, racing heart, etc.) during the previous four weeks. Higher scores on the HSCA indicate greater anxiety. Derogatis, Lipman, Rickels, Uhlenhuth, and Covi (1974) measured the internal consistency of the anxiety scale at $\alpha = .84$. Additional analysis found the internal reliability of this six-item scale to be $\alpha = .84$.

Social Impact Scale: Fife and Wright (2000) developed a four part scale measuring stigma related to chronic illness. The four parts are: social rejection, financial insecurity, internalized shame, and social isolation. For purposes of this study, only the social isolation section was used in analysis. The social isolation portion consists of seven items rated on a four-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Scores for social isolation survey range from 7 to 28, with higher scores indicating greater feelings of isolation. The internal consistency of the social isolation scale is measured at $\alpha = .86$ (Fife & Wright, 2000). Data analysis indicated this scale to be highly reliable (7 items; $\alpha = .89$).

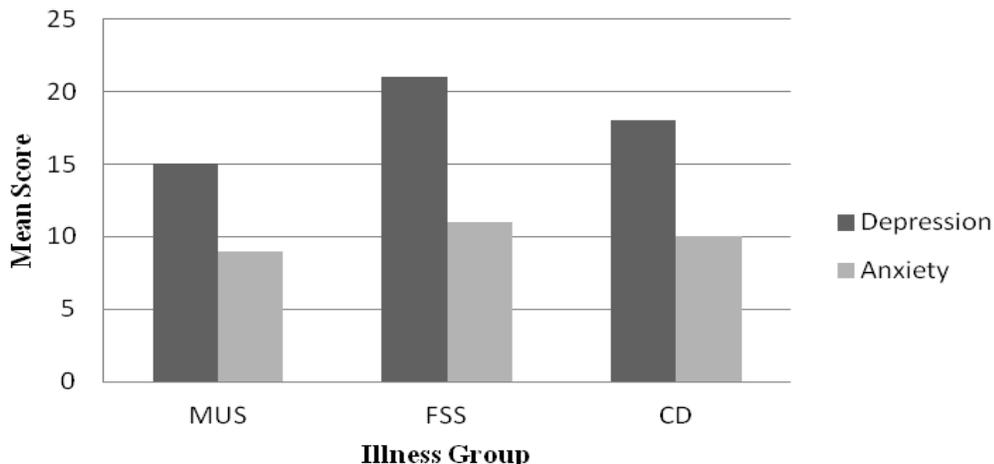
Results

Statistical analyses were completed through the use of the computer software program SPSS. Analysis of variance, correlational and linear regression analysis were conducted, as appropriate. All alpha levels were set at $\alpha=.05$ and when needed, post-hoc tests were completed using Tukey's HSD test. Additionally, Levene's test for equality was used to test for homogeneity of variances.

Social Connectedness & Isolation between Groups. To determine the levels of social connectedness within each of the three illness groups I used the mean summed scores on the social connectedness scale. With higher scores indicating higher levels of connectedness, those indicating they felt most connected were the MUS group and CD group ($M=26.74$, $SD=11.69$; $M=26.09$, $SD=10.99$, respectively), followed by the FSS group ($M=22.62$, $SD=10.11$). However, analysis of variance indicated that there were no significant differences between the three groups ($p>.10$).

Analysis of variance was used to analyze the social isolation scores. Results revealed a significant difference between groups, $F(2,145) = 4.36, p < .05$. Tukey's HSD showed that the FSS group ($M=19.67, SD=4.98$) reported feeling significantly more isolated than the MUS group ($M=15.87, SD=6.13$). There were no significant differences in feelings of social isolation between the FSS group and the CD group ($M=18.87, SD=5.83, p > .10$) or the CD group and the MUS group ($p > .05$).

Depression & Anxiety between Groups. The summed mean scores were used to determine the levels of depression (PHQ-8) and anxiety (HSCL) within each group with higher scores indicating higher levels of each. The FSS group had the highest scores on both measures ($M=20.89, SD=5.72$ and $M=10.90, SD=3.84$, respectively) followed by the CD group ($M=18.26, SD=6.13$ and $M=10.26, SD=3.95$, respectively) and lastly the MUS group ($M=14.83, SD=5.74$ and $M=8.74, SD=3.51$, respectively). There were no significant differences identified between groups on the anxiety measure ($p > .05$); however there were significant differences between groups on the depression measure, $F(2,145) = 10.28, p < .001$. Further analysis by means of Tukey's HSD indicated that the FSS group ($M=20.89, SD=5.72$) had significantly higher depression scores than both the MUS group ($M=14.83, SD=5.74$) and CD group ($M=18.26, SD=6.13$); conversely, there were no significant differences between the MUS group and the CD group ($p > .05$; Figure 3). However, based on previous research, all three groups appear to be depressed with mean scores well over 10 (Kroenke et al., 2009).

Figure 3. *Depression & Anxiety Mean Scores*

Physical & Mental Health between Groups. The results of the SF-36 were determined through the summed mean scores in each subgroup. Higher scores on the SF-36 indicated a more positive health status. Refer to Table 2 for mean scores and standard deviations. Analysis of variance revealed significant differences between groups on all of the subscales except for the General Health (GH) and Emotional Well-Being (EWB). Tukey's HSD revealed that on the Physical Functioning (PF) scale, $F(2,145) = 3.76, p < .05$, the MUS group had significantly higher scores than the FSS group indicating that the MUS group had greater physical functioning than the FSS group; however there were no significant differences between the MUS and CD groups ($p > .05$) and the FSS and CD groups ($p > .10$). The Role Physical (RP) scale, $F(2,145) = 12.54, p < .001$ showed the MUS group had significantly higher scores than both the FSS and CD groups, indicating that the MUS was less effected by the physical issues in their day-to-day activities. Additionally, the CD group had significantly higher scores than the FSS group on the RP scale. The Bodily Pain (BP) scale, $F(2,145) = 7.24, p < .01$ identified the FSS group as having significantly higher scores than both the CD and MUS groups, indicating that the

FSS group experienced more pain than the others. With the Vitality, $F(2,145) = 7.19, p < .01$ and Social Functioning (SF) scales, $F(2,145) = 5.24, p < .01$, the MUS and CD groups had significantly higher scores than the FSS group; though they were not significantly different from each other ($p > .10$). Results indicate the MUS and CD groups have more energy (vitality) and social functioning than the FSS group; however they do not differ from each other. The Role-Emotional (RE) scale, $F(2,145) = 5.53, p < .01$ indicated that the MUS group had significantly higher scores than the FSS group, however there were no significant differences between the MUS and CD group or the FSS and CD group ($p > .10$), indicating that the MUS group is less effected by emotional issues in their day-to-day activities.

Table 2. *SF-36 Mean Scores*

	Total	MUS	FSS	CD
Physical Functioning	48.87 (<i>SD</i> =30.07)	64.13 ^a (<i>SD</i> =30.14)	45.06 ^b (<i>SD</i> =28.56)	47.79 (<i>SD</i> =30.84)
Role-Physical	16.55 (<i>SD</i> =33.19)	42.39 ^a (<i>SD</i> =40.20)	6.65 ^b (<i>SD</i> =21.82)	20.65 ^c (<i>SD</i> =38.12)
Bodily Pain	7.47 (<i>SD</i> =2.45)	6.26 ^b (<i>SD</i> =2.62)	8.13 ^a (<i>SD</i> =2.14)	6.96 ^b (<i>SD</i> =2.55)
General Health	36.95 (<i>SD</i> =22.15)	43.48 (<i>SD</i> =20.42)	36.61 (<i>SD</i> =20.90)	34.27 (<i>SD</i> =24.74)
Vitality	24.56 (<i>SD</i> =20.79)	35.87 ^a (<i>SD</i> =21.67)	19.24 ^b (<i>SD</i> =18.61)	28.04 ^a (<i>SD</i> =21.33)
Social Functioning	39.10 (<i>SD</i> =27.8)	48.91 ^a (<i>SD</i> =33.05)	32.44 ^b (<i>SD</i> =23.73)	45.65 ^a (<i>SD</i> =29.25)
Role-Emotional	44.22 (<i>SD</i> =44.64)	69.70 ^a (<i>SD</i> =43.53)	35.44 ^b (<i>SD</i> =41.72)	47.10 (<i>SD</i> =45.85)
Emotional Well-Being	57.19 (<i>SD</i> =21.99)	63.04 (<i>SD</i> =18.99)	54.29 (<i>SD</i> =21.50)	59.24 (<i>SD</i> =23.81)

Means with a different superscript are significant at $p < .05$

Bivariate Analyses of Connectedness & Outcome Variables. Correlation analysis using Pearson's Product-Moment Correlation Coefficient was completed in order to determine the relationship between social connectedness and each of the following: depression, anxiety, general health and emotional well-being. There were significant relationships among each of the factors indicating as social connectedness increases, depression and anxiety decrease and emotional well-being and general health increase. See Table 3 for correlation coefficients.

Table 3. *Correlation Between Outcome Variables and Social Connectedness*

Variable	1	2	3	4
1. Social Connectedness				
2. Depression	-.530***			
3. Anxiety	-.434***	.641***		
4. Emotional Well-Being	.554***	-.641***	-.625***	
5. General Health	.414***	-.428***	-.314***	.330***

* $p < .05$ ** $p < .01$ *** $p < .001$

Multivariate Analyses of Connectedness & Outcome Variables. Hierarchical multiple regression analyses were performed to determine the relationship of social connectedness with depression, anxiety, and general health, while accounting for socio-cultural factors and illness category. Tests for multicollinearity indicated that it was not a concern in the analysis, with tolerance levels ranging from .66 to .96. In each regression analysis, socio-cultural-illness factors were entered into Step 1 (i.e., gender, age, race, relationship status, education, socio-economic status and length of symptoms), illness group into Step 2, and social connectedness into Step 3.

In the first analysis, the outcome variable was depression. Overall, the model was significant, $F(9,130) = 6.70, p < .001$. Socio-cultural factors accounted for 15.6% of variance, with illness groups adding 0.7% and social connectedness increasing variance accounted for in depression by 15.3% for a total model R^2 of .32. Social connectedness was identified as a robust predictor of depression in the chronically ill sample, and was the strongest predictor, with a $\beta = -.43, p < .001$.

In the second analysis, anxiety was the outcome variable and again social connectedness was revealed as the strongest predictor with a $\beta = -.48, p < .001$. The overall model was significant, $F(9,130) = 4.74, p < .001$ with socio-cultural factors accounting for 5.8% of variance and illness groups adding only 0.2%. Social connectedness increased the total variance by 18.7% for a total model R^2 of .25.

In the final analysis, the outcome variable was general health. Again, the overall model was significant, $F(9,130) = 4.28, p < .001$ and social connectedness proved to be the strongest predictor with a $\beta = .34, p < .001$. Socio-cultural factors accounted for 12.6% of the variance with illness group adding 0.5% to the variance and social connectedness increasing the variance by 9.7% for total model R^2 of .23. Refer to Table 4 for additional information on these analyses.

Table 4. Hierarchical Multiple Regression Analysis of Predictor Variables

	Depression		Anxiety		General Health	
	β	Partial r	β	Partial r	β	Partial r
Step 1						
Gender	.113	.119	.096	.095	.009	.009
Age (in years)	-.090	-.082	-.147	-.127	-.144	-.130
Race/Ethnicity	.065	.069	-.065	-.065	.061	.064
Relationship Status	.249**	.253	.055	.055	-.047	-.048
Education	-.078	-.079	-.018	-.017	.106	.105
Socio-Economic Status	-.112	-.113	-.147	-.140	.150	.148
Length of Symptoms	.298**	.269	.161	.141	-.174	-.158
R^2	.156		.058		.126	
Step 2						
Illness Group	.086	.092	.045	.046	-.073	-.076
R^2	.164		.060		.131	
ΔR^2	.007		.002		.005	
Step 3						
Social Connectedness	-.434***	-.428	-.479***	-.446	.344***	.334
R^2	.317		.247		.228	
ΔR^2	.153***		.187***		.097***	

Note: Standardized Beta coefficients were used

* $p < .05$ ** $p < .01$ *** $p < .001$

Discussion

Exploratory analyses revealed no significant differences between medically unexplained, functional, or conventional disease groups on social connectedness. The medically unexplained group did not report lower social connectedness compared to the other illness groups, which is contrary to what was predicted. However, the FSS group did report significantly greater feelings of social isolation than the MUS group.

Additionally, while all three groups appear to be depressed, the FSS group was identified

as significantly more depressed than both the MUS and CD groups. While social isolation can appear similar to social connectedness, one is objective (isolation) whereas the other is subjective (connectedness). One is based on actual physical presence and contact, or the lack thereof (isolation); whereas the other is based on our own perceptions of how we connect with those around us, even when they are not physically present (connectedness).

While testing indicated there were no significant differences in homogeneity of variance between the groups, the majority of the respondents to the surveys were in the FSS group. The abundance of support networks available online as well as the alternative medical clinics willingness to distribute our brochures perhaps allowed more advertising to this demographic and therefore most logically explains their majority. That being said, the findings indicating that they feel the most isolated and depressed, raises the question of, “why?” Perhaps online support groups provide anonymity and the ability to share freely without potential shame associated with the illness (Broom, 2005). The thought that a person can remain anonymous and still receive support from others experiencing the same thing may be beneficial, but it may also prevent them from connecting with others when they are incognito. Additionally, by participating online rather than in person, the chronically ill increase isolation from others. However, Broom (2005) identified that those who visited support groups online were more likely to be experiencing extenuating problems causing them to seek the support of others anonymously rather than attend a support group in person.

The fact that the MUS group was not significantly more disconnected than either the FSS or CD group is puzzling. Previous research (Ring, et al., 2005; Salmon, et al., 2005) suggests that the MUS group would have the most difficulty based on the

ambiguity surrounding their illness. Perhaps the idea that they actively seek out more support than others (Salmon, et al., 2005) plays a part in their feelings of connectedness. While there may be larger support networks available to those with FSS and CD, perhaps they are not as proactive in seeking support as those with MUS. Maybe their strong desire for an actual diagnosis (Creed, et al., 2010) leads them to maintain a more positive attitude in finding the connections they desire. One answer may lie in the length of time the patient has been experiencing their symptoms. The MUS group experienced their symptoms for much less duration in the current study. Only 66% of the MUS participants reported experiencing their symptoms of illness for more than one year, while nearly all of the FSS group (95%) and more than half of the CD group (80%) had been experiencing their symptoms for one year or more.

The most profound results from this study were the findings that social connectedness, after controlling for socio-cultural factors and illness group, was a significant predictor of depression, anxiety and general health. Specifically, individuals with lower social connectedness reported greater depression and anxiety, as well as poorer physical health. These results support our hypothesis and previous research indicating that patients who feel less connected to others suffer more with depression and anxiety and have a lower physical health status (Armstrong & Early, 2009; Baumeister & Leary, 1995; Cloutier-Fisher & Kobayashi, 2009; Hagerty, et al., 1996; Hawthorne, 2008; Hwu, 1995; Kok & Fredrickson, 2010; Mitchinson, et al., 2008; Sargent, et al., 2002; Young, et al., 2004). What is most revealing in the current study is the degree to which social connectedness was associated with psychological and physical outcome variables. Social connectedness individually accounted for an astounding amount of variance in

depression (15.3%), anxiety (18.7%), and physical health (9.7%). To give this some context, all other socio-cultural and health variables *combined* accounted for a range of 16.4% - 6% of variance in the same outcome variables. Social connectedness, as one variable, accounted for similar amounts of variance *alone!* Perhaps social connectedness has been overlooked as an important variable in health research, especially within the chronic illness population.

The findings suggest that when we are ill, one of the most important things we need is connection to others. Without that connection, a person is more likely to be depressed, anxious, and have poorer health. This does not appear to be associated with the type of illness they have, but rather due to losing touch with those they once believed they belonged with – friends, family, sports teams, clubs, and so on.

Additionally, these results are overwhelmingly relevant in our society with the proliferation of social media. With the advent of social media, the ability to belong has become much easier and possibly less stressful as the need to be face-to-face to connect has become unnecessary. The next step, however, may be finding a way to more efficiently address the chronically ill within the context of social media. While there are online support groups available, they tend to be limited to more conventional illnesses such as cancer and diabetes. Furthermore, and conceivably most important, the findings on social connectedness corroborate the idea that, as humans, we have a need to belong.

Future research, limitations, and conclusions. In addition to previously mentioned suggestions, future directions of research should focus on analyzing social connectedness in healthy controls along with illness groups. The addition of a physically

healthy control group will provide future VOICE researchers a baseline from which to measure their results as well as a means to rule out potential extraneous variables. For example, though insignificant, the MUS group had the highest level of connectedness of the three groups. How connected would they appear when compared to a healthy control? Because the three groups were not significantly different from each other, would they be considered significantly different from a healthy control? These are questions that can be better answered with the inclusion of a control group.

Other interesting directions would be to examine the relationships of social connectedness with coping strategies, stigma, and to more closely investigate the commonalities and distinctions of social support with social connectedness. Given that individuals with FSS have been found to have high levels of perceived stigma (Looper & Kirmayer, 2004), it would be interesting to see whether stigma plays a particular role in social connectedness within this cohort. Additionally, in-depth analysis of social connectedness in all facets of healthcare would prove beneficial as it has been shown in this study to be such a significant factor for those who are ill.

Results of this current study should be viewed with some caution as it is correlational and therefore directionality and cause-effect relationships cannot be discerned. Future research should include true experiments as well as longitudinal aspects to begin to decipher directionality of social connectedness and health.

Surveys were self-report and completed online with typical questions of reliability and validity of data. However, steps were taken in the current study to address these concerns. Rather than offering one very long online survey, four 10-15 minute surveys

were made available to participants. This was done to prevent survey fatigue, especially considering that the targeted population was dealing with ongoing symptoms from illness. Lengthy web surveys can result in participants simply clicking answers at random to finish. The efforts taken in this study were successful according to good reliability analyses findings, including those scales with necessary items reversed scored.

The use of online recruitment of individuals dealing with chronic illness was particularly successful in the current study, especially considering that this is a difficult population to access. The usage of the internet is a mainstay in the lives of many people these days, with over 2.2 billion users worldwide and over 270 million in the United States (Internet World Stats, 2012); this proliferation of the internet emphasizes the ease of not only soliciting to participants, but also the ease in which they were able to respond (i.e., the comfort of their own home). Also, the use of the internet to solicit and administer surveys allowed for access to a greater participant pool than those reached through brochure distribution alone.

Overall, this research reveals that social connectedness is a robust factor in physical and psychological health for individuals struggling with ongoing symptoms of chronic illness. The idea that social connectedness is such a key aspect for those dealing with chronic illness, suggests that physicians would benefit from addressing this facet of each patient's life. While there is certainly no "cure" for those who feel disconnected, having the knowledge that a person feels this way could prove beneficial to physicians and could provide opportunities for intervention. Knowing that their patient feels disconnected may allow for physicians to develop more individualized treatment plans, rather than simply focusing on their symptoms. Even something as simple as

encouraging participation in support groups or pairing newly diagnosed patients with those who are being successfully treated would surely be a positive start. These types of options may help open doors and build new paths for those who are dealing with illness to connect to others who are experiencing a similar illness. By focusing on each patient as a whole, better options for treatment can be established which may include both medical treatment as well as social belonging.

Appendix A

Internet Announcement

DO YOU EXPERIENCE PHYSICAL SYMPTOMS THAT INTERFERE WITH YOUR LIFE?

IF SO, WE WANT TO HEAR YOUR VOICE!

Dr. Lori Lange and a team of graduate researchers at the University of North Florida are currently conducting web survey study on the impact of ongoing physical symptoms in the lives of patients. Specifically, we are recruiting patients who:

- are at least 18 years of age.
- have experienced ongoing or intermittent somatic symptoms for more than 3 months.
- have an illness with ongoing symptoms (e.g., arthritis, lyme disease, eczema, COPD) **or** suffer from a chronic syndrome (e.g., fibromyalgia, IBS, CFS, MCS), **or** experience medically unexplained persistent symptoms (e.g., pain, fatigue, fever).

If you would like to participate or desire further information, please go to: www.unf.edu/~llange/voice

Sincerely,

The VOICE Research Team

Appendix B

Clinic Brochure



WHO WE ARE

VOICE is a project dedicated to understanding patients' experiences with ongoing physical symptoms. We are seeking honest and candid responses from patients who personally know about the impacts of living with symptoms of illness.

We recognize that symptoms of disease can be accurately diagnosed, but also can be misunderstood or remain mysterious. Therefore, we go directly to the source and ask you the patient about your illness, regardless of whether or not you have a diagnosis for your symptoms. Our goal is to document and share the collective voices of those who endure the challenges of living with chronic physical symptoms.

How you can help?
If you, or someone you know, have experienced chronic illness for more than three months, please complete an online survey at www.unf.edu/~llange/voice.




Feel free to contact us at
voice@unf.edu
Dr. Lori Lange
904-620-1638

Visit us online at
www.unf.edu/~llange/voice

University of North Florida
1 UNF Drive
Jacksonville, FL 32224



VERIFICATION OF ILLNESS, COPING, & EXPERIENCE

DO YOU EXPERIENCE PHYSICAL SYMPTOMS THAT INTERFERE WITH YOUR LIFE ?

IF SO, WE WANT TO HEAR YOUR VOICE !



WE WANT TO HEAR YOUR VOICE !

FREQUENTLY ASKED QUESTIONS

What are the benefits of participating in the online survey?
Currently, there is no known technology that can provide information on personal experiences of illness. Therefore, the advancement of understanding on this issue is dependent upon participation from people who live with ongoing physical symptoms. Understanding the personal impacts of ongoing physical symptoms will be an important step toward better care and support services for those suffering.

What should I expect?
The online survey contains various questionnaires and open-ended questions which can be completed at your convenience. All of your information is anonymous and kept confidential.

Who are the researchers?
Researchers at the University of North Florida are conducting an online study of personal experiences with ongoing symptoms of illness. Dr. Lori Lange and a team of committed students are collecting and analyzing the data, which will be reported in summary form to scientific and medical communities.



DO YOU?

Have a chronic illness, such as:

- Arthritis
- Lyme Disease
- Eczema/Dermatitis
- Chronic Obstructive Pulmonary Disease

Suffer from a chronic syndrome, such as:

- Multiple Chemical Sensitivity
- Fibromyalgia
- Chronic Fatigue Syndrome
- Irritable Bowel Syndrome

Experience unexplained symptoms, such as:

- Pain
- Fatigue
- Nausea
- Fever



DO YOU QUALIFY?

- Are you at least 18 years of age?
- Have your physical symptoms persisted or recurred for at least three months?
- Have you sought medical attention for your condition?

If you answered yes to these questions you are a candidate!

www.unf.edu/~llange/voice

Consent Form



VERIFICATION OF ILLNESS, COPING, & EXPERIENCE

<http://www.unf.edu/~llange/voice>

If you consent to us making information about our VOICE website and study available in your office via brochures, please sign below.

Date _____ Name of Office/Clinic _____

Address: _____

Phone: _____ Email: _____

Name & Signature of Authorized Representative (e.g. Doctor, Office Manager, etc.)

(print name)

(signature)

VOICE Research Team

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Appendix C

Measures***Social Connectedness Scale (Relationships with Others and Support Survey)***

Rated: 1 = agree, 2 = slightly agree, 3 = neutral, 4 = slightly disagree, 5 = disagree

1. I feel disconnected from the world around me.
2. Even around people I know, I don't feel that I really belong.
3. I feel so distant from people.
4. I have no sense of togetherness with my peers.
5. I don't feel related to anyone.
6. I catch myself losing all sense of connectedness with society.
7. Even among my friends, there is no sense of brother/sisterhood.
8. I don't feel I participate with anyone or any group.

Lee, R. M. & Robbins, S. B. (1995). Measuring belongingness: The Social Connectedness and the Social Assurance Scales. *Journal of Counseling Psychology, 42*(2), 232-241.

Social Impact Scale (Relationships with Others and Support Survey)

Think about your experiences over the last four weeks then, rate the following questions on a scale from "strongly disagree" to "strongly agree."

1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree

Social Isolation

- I feel set apart from others who are well
- I have a greater need than usual for reassurance that others care about me
- I feel lonely more often than usual
- Due to my illness, I have a sense of being unequal in my relationships with others
- I feel less competent than I did before my illness
- Due to my illness, I sometimes feel useless
- Changes in my appearance has affected my social relationships

Fife, B. L. & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior, 41*, 50-67.

Patient Health Questionnaire PHQ-8 (The Impact of Illness on Your Life Survey)

Over the last 4 weeks, how often have you been bothered by any of the following problems?

0=Not at all, 1 =Several days, 2=More than half the days, 3=Nearly every day

1. Little interest or pleasure in doing things
2. Feeling down, depressed, or hopeless
3. Trouble falling or staying sleep, or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual

Kroenke, K., Strine, T. W., Spitzer, R. L., Williams, J. B. W., Berry, J. T. & Mokdad, A.

H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders, 114*, 163-173.

Hopkins Symptom Checklist (HSCL), Anxiety Scale (The Impact of Illness on Your Life Survey)

How have you felt during the past 4 weeks, including today?

1 = Not at all, 2 = A little bit, 3 = Quite a bit, 4 = Extremely

1. Nervousness or shakiness inside
2. Trembling
3. Suddenly scared for no reason
4. Feeling fearful
5. Heart pounding or racing
6. Having to avoid certain places or activities because they frighten you

Derogatis, L. R., Lipman, R. S., Rickels, K., Uhlenhuth, E. H. & Covi, L. (1974). The

Hopkins Symptom Checklist (HSCL): A self-report symptom inventory. *Behavioral Science, 19*, 1-15.

Short Form-36 (SF-36) (The Impact of Illness on Your Life Survey)

1. In general, would you say that your health is:

- a. Excellent= 100
- b. Very good= 75
- c. Good= 50
- d. Fair= 25
- e. Poor= 0

2. Compared to one year ago, how would you rate your health in general now?

- a. Much better now than one year ago= 100
- b. Somewhat better than one year ago= 75
- c. About the same as one year ago= 50
- d. Somewhat worse now than one year ago= 25
- e. Much worse now than one year ago= 0

The following items are about activities that you might do during a typical day. Does your health now limit you in these activities? If so, how much?

3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports

- Yes, A Lot Limited= 0
- Yes, A Little Limited= 50
- No, Not At All Limited= 100

4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- Yes, A Lot Limited= 0
- Yes, A Little Limited= 50
- No, Not At All Limited= 100

5. Lifting or carrying groceries

- Yes, A Lot Limited= 0
- Yes, A Little Limited= 50
- No, Not At All Limited= 100

6. Climbing several flights of stairs

- Yes, A Lot Limited= 0
- Yes, A Little Limited= 50
- No, Not At All Limited= 100

7. Climbing one flight of stairs

- Yes, A Lot Limited= 0
- Yes, A Little Limited= 50
- No, Not At All Limited= 100

8. Bending, kneeling, or stooping

Yes, A Lot Limited= 0

Yes, A Little Limited= 50

No, Not At All Limited= 100

9. Walking more than one mile

Yes, A Lot Limited= 0

Yes, A Little Limited= 50

No, Not At All Limited= 100

10. Walking several blocks

Yes, A Lot Limited= 0

Yes, A Little Limited= 50

No, Not At All Limited= 100

11. Walking one block

Yes, A Lot Limited= 0

Yes, A Little Limited= 50

No, Not At All Limited= 100

12. Bathing or dressing yourself

Yes, A Lot Limited= 0

Yes, A Little Limited= 50

No, Not At All Limited= 100

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

13. Cut down on the amount of time you spent on work or other activities

Yes= 0

No= 100

14. Accomplished less than you would like

Yes= 0

No= 100

15. Were limited in the kind of work or other activities

Yes= 0

No= 100

16. Had difficulty performing the work or other activities (for example, it took extra effort)

Yes= 0

No= 100

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

17. Cut down on the amount of time you spent on work or other activities

Yes= 0

No= 100

18. Accomplished less than you would like

Yes= 0

No= 100

19. Didn't do the work or other activities as carefully as usual

Yes= 0

No= 100

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

a. Not at all= 100

b. Slightly= 75

c. Moderately= 50

d. Quite a bit= 25

e. Extremely= 0

21. How much bodily pain have you had during the past 4 weeks?

a. None= 100

b. Very mild= 80

c. Mild= 60

d. Moderate= 40

e. Severe= 20

f. Very severe= 0

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)

a. Not at all= 100

b. A little bit= 75

c. Moderately= 50

d. Quite a bit= 25

e. Extremely= 0

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks –

23. Did you feel full of pep?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

24. Have you been a very nervous person?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

25. Have you felt so down in the dumps that nothing could cheer you up?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

26. Have you felt calm & peaceful?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

27. Did you have a lot of energy?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

28. Have you felt downhearted & blue?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

29. Did you feel worn out?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

30. Have you been a happy person?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

31. Did you feel tired?

All of the time= 100

Most of the time= 80

A good bit of the time= 60

Some of the time= 40

A little of the time= 20

None of the time= 0

32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

a. All of the time= 0

b. Most of the time= 25

c. Some of the time= 50

d. A little of the time= 75

e. None of the time= 100

How TRUE or FALSE is each of the following statements for you?

33. I seem to get sick a lot easier than other people

Definitely true= 0

Mostly true= 25

Don't know= 50

Mostly false= 75

Definitely false= 100

34. I am as healthy as anybody I know

Definitely true= 0

Mostly true= 25

Don't know= 50

Mostly false= 75

Definitely false= 100

35. I expect my health to get worse

Definitely true= 0

Mostly true= 25

Don't know= 50

Mostly false= 75

Definitely false= 100

36. My health is excellent

Definitely true= 0

Mostly true= 25

Don't know= 50

Mostly false= 75

Definitely false= 100

McHorney, C. A., Ware, J. E., Lu, J. F., & Sherbourne, C. D. (1994). The MOS 36 item short-form health survey (SF-36): III. Tests of data quality, scaling assumptions, and validity among diverse patient groups. *Medical Care*, 32, 40-65.

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Vita

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Education

MA	University of North Florida, General Psychology Thesis: Social Connectedness and the Impact on Chronic Illness Advisor: Dr. Lori Lange	April 2012
BA	University of North Florida, Psychology	April 2009
BA	University of North Florida, Art History Minor: Anthropology	December 1998

Research Experience

Research Assistant	VOICE Study UNF Health Psychophysiology Lab Advisor: Dr. Lori Lange	2010-2011
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Conference Presentations

Hatchcock, T., Lange, L., & Eldred, K. (March 4, 2011). Social connectedness and coping with medically unexplained symptoms. Poster presented at the Southeastern Psychological Association Annual Convention, Jacksonville, Florida.

Eldred, K., Lange, L., & Hatchcock, T. (March 4, 2011). The impact of chronic illness experience on coping behaviors. Poster presented at the Southeastern Psychological Association Annual Convention, Jacksonville, Florida.

Distinctions

Delores A. Auzenne Fellowship	2010 – 2011
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Work Experience

Revenue Analyst	Mayo Clinic, Jacksonville, FL	Dec 2011 – Present
Financial Rep	Mayo Clinic, Jacksonville, FL	Jul 2005 – Nov 2011