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CARE Scale - 7: Development and preliminary validation of a measure to assess factors impacting self-care in chronic pain

Maisa Ziadni, PhD,

Stanford University School of Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, 1070 Arastradero Road, Suite 200, MC5596, Palo Alto, CA 94304, Phone: (650) 736.5494

Dokyoung Sophia You, PhD,

Stanford University School of Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, 1070 Arastradero Road, Suite 200, MC5596, Phone: (650) 736.5494

Anna C. Wilson, PhD, and

Associate Professor, Department of Pediatrics, Institute on Development & Disability, Oregon Health & Science University, 3181 Sam Jackson Park Road, CDRC, Portland, OR 97239

Beth D. Darnall, PhD

Clinical Professor, Stanford University School of Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, 1070 Arastradero Road, Suite 200, MC5596

Abstract

Objectives—Social and interpersonal factors may impact chronic pain self-care and self-management; however, no integrated measure exists to assess the interplay of these factors. We developed and tested a measure designed to assess salient interpersonal factors, including relationship guilt and worry, and difficulty prioritizing self-care in chronic pain.

Methods—We tested self-report items broadly relevant to locus of care, limit-setting capacity, and worry/guilt about relationships in 3 discrete chronic pain samples (total N=1,452): (1) online sample of chronic pain clinic patients (N=729; 21 candidate CARE items, sociodemographics, and measures of psychological and physical functioning). Analytic results supported a final 7-item CARE Scale which was next tested in (2) an anonymous online sample of 578 adults with chronic pain. (3) Finally, preliminary validation of the CARE Scale was performed in a tertiary pain clinic sample (N = 145).

Results—Exploratory factor analysis revealed a 7-item, 2-factor solution (difficulty prioritizing self-care and guilt/worry) that accounted for a combined total of 58% of the variance. CARE Scale-7 had modest convergent validity with pain intensity, pain-related interference, and emotional distress. Extreme difficulty with both factors was reported by about one-third of the total sample, suggesting that relationship factors significantly impact pain management and self-care.

Discussion—Social factors are gaining attention for their influence on the trajectory of chronic pain. The CARE Scale is a brief, integrated measure that may be used to reveal specific interpersonal and personal impediments to self-care, and identify important therapeutic targets to optimize self-management behaviors.

Keywords

self-care; chronic pain; relationships; guilt; worry; behavior; self-management

INTRODUCTION

Social and interpersonal factors influence the experience of pain. Individuals with less social support or more interpersonal stress report greater pain after surgery (1) and higher levels of pain intensity (2). Additionally, the effect of social isolation on pain has been directly examined in a laboratory study, demonstrating that individuals in a social support condition report less laboratory pain (3). The interpersonal context of pain has also been identified as a factor that influences not only the experience of pain, but also disability and distress (4, 5). For example, solicitous and/or punishing responses from a partner have been shown to associate with greater pain intensity (6), reduced acceptance of pain (7), and greater use of opioids (8, 9) lending further evidence to suggest that one's relationships may influence the trajectory of pain.

Among individuals with chronic pain, relationship concerns are reported as the most frequent theme of non-pain related worry (10). About 73% of individuals with chronic pain endorse high levels of perceived partners' burden (11) and this proportion is comparable to stroke survivors (70%) (12). Perceptions of being a burden to others is found to be associated with greater pain intensity, functional disability, depressive symptoms, and reduced pain self-efficacy compared to those who do not feel like a burden (11). However, it is not known how relationship worry may impact self-care behavior. The influence of relationship worry on self-care behavior is particularly salient given that most individuals with chronic pain do not live in isolation. Indeed, the majority of people with chronic pain (63 – 70%) are either married or partnered (11, 13, 14). Despite having chronic pain and associated-limitations, people have dependents and may even be the primary caretaker of the household. For example, a study found that 46% of adults with complex regional pain syndrome have at least one dependent (15). Therefore, adults with chronic pain adopt a dual role of caretaker and care receiver and may need to negotiate or adjust their roles within the family structure (16).

Through the role negotiation process, some individuals may ameliorate their relationship worry and find a balance between care for self and others, whereas others may have difficulty prioritizing and practicing chronic pain self-care. For instance, an individual with dependents may experience guilt about how pain limits their ability to provide care to others, and therefore defer self-care in favor of meeting the needs of others. Similarly, worry about how pain impacts a partner or family members, in addition to the fear of failing to meet others' expectations, may shape emotions, choices, and behaviors that serve to facilitate pain.

Self-care is a foundational element of behavioral management of chronic pain taught in cognitive behavioral and self-management treatment programs (17). While acquisition of pain management knowledge and skills are critical, social factors may moderate or mediate application of skills and self-care behaviors. As such, assessment of interpersonal factors and their influence on one's ability to deliver self-care in the context of chronic pain is important, yet no integrated measure exists to specifically tap the interplay of these factors.

The primary goal of this study was to develop and validate a measure of interpersonal factors and their influence on self-care behaviors (the CARE Scale) for adults with chronic pain. This was conducted in three distinct samples and using two formats; an online survey and a paper-pencil survey administered during a pain clinic visit. The specific objectives were to (1) examine the factor structure and psychometric properties of the CARE Scale; (2) examine convergent validity of the CARE Scale by examining the relationship of the CARE scale to other measures for pain, pain-related interference, and emotional distress; (3) examine gender differences on the CARE total and subscale scores to investigate whether the CARE Scale is a gender-invariant measure.

METHODS

The study procedures were approved by the Human Subjects Committee of the Institutional Review Boards of Oregon Health & Science University and Stanford University; informed consent was obtained from all participants.

Procedures and Participants

The study involved administering self-report surveys to patients seeking treatment at a chronic pain clinic, or online to individuals who endorsed having chronic pain. The study was conducted in two phases, exploratory and confirmatory, involving three discrete adult chronic pain samples as follows (see Figure 1).

Phase I (Exploratory): Patients receiving care at a tertiary pain clinic who had agreed to be contacted for research purposes and met study criteria were sent a link to the study survey. Inclusion criteria were 18 years of age, pain for 3 months, and able to complete an online survey. Twenty-one CARE Scale candidate items (18), demographic variables, pain characteristics, pain-related interference and emotional distress were assessed.

Phase II (Confirmatory): the selected items from the Phase I study were re-tested in two samples: an online sample, and a new pain clinic sample. The online sample was recruited via email. Information about the study and links to the online survey were emailed to previous participants of fibromyalgia research who had consented to being contacted for future studies. The initial page of the online survey page invited anyone with pain for 3 months to take the voluntary and anonymous survey. The pain clinic sample was recruited from patients seeking new evaluation from a pain physician at an academic multidisciplinary pain clinic.

Measures

Demographics—Participants in Phases I and II completed questions related to gender, age, marital status, and having dependents. Participants in Phase I were asked to provide additional information about race/ethnicity, income, education level, employment status, number of dependents, and pain characteristics.

Self-Care Behaviors and Relationship Worry (CARE) scale—A group of pain psychology specialists proposed candidate items designed to assess a broad domain and inform the impact of relationships and caregiving on pain and self-management. Proposed items captured domains related to locus of care, capacity to set limits with self and others, and emotional response to the impact of pain on relationships. Twenty-one candidate items were refined and selected for the initial CARE scale. Sample items include: “I tend to put other people’s needs ahead of my own” and “I worry that my pain will disconnect me from family and /or friends”. Participants rated each item on a 0–4 numeric rating scale (0 = Not at all/Not applicable, 1 = Slightly, 2 = Somewhat, 3 = To a moderate degree, 4 = To an extreme degree). Four items were reverse-scored to indicate higher scores as being related to greater difficulty in self-care.

The following three measures were selected as they have been widely utilized in pain research, and are expected to be related to the CARE Scale. They were administered in Phase I to examine the convergent validity of the CARE Scale.

The **Brief Pain Inventory-Short-Form (BPI)** (19) was administered in the Phase I sample. The BPI asks respondents to rate average pain intensity on a 0–10 numeric rating scale (0=no pain, 10=extreme pain) for the past week. Additional questions assess the level of pain-related interference across the following 7 domains: mood, general activity, normal work (inside and outside the home), enjoyment of life, relations with other people, walking ability, and sleep (0=does not interfere, 10=completely interferes). Cronbach’s alpha for the BPI in this sample was excellent ($\alpha = .90$).

The **Patient-Reported Outcomes Measurement Information System (PROMIS)** has been successfully applied in pain research (20–23). PROMIS was used in Phase I to assess multiple variables to examine convergent validity of the CARE scale such as Pain Intensity, Physical Function, Depression, Anxiety, Anger, and fatigue using short-forms in the Phase I sample (24). Higher scores on PROMIS depression, anxiety, fatigue, and pain intensity signify greater severity of these symptoms. However, higher scores on Physical Function reflects a greater level of physical functioning. Cronbach’s alpha for the PROMIS measures in this sample was very good ($\alpha s = .89-.93$).

The **Pain Catastrophizing Scale (PCS)** [1] was administered in the Phase I sample. The PCS is the most widely used empirical and clinical measure of pain catastrophizing (13-items). This scale assesses domains of rumination, magnification of the negative consequences of pain, and helplessness related to pain that have been associated previously with enhanced physical and mental pain and response to treatment. Cronbach’s alpha for the PCS in this sample was excellent ($\alpha = .94$).

Analyses

SPSS version 21.0 was used for exploratory factor analysis and IBM SPSS AMOS 25 was used for confirmatory factor analysis. Explorative Factor Analysis (EFA) was conducted with Phase I clinic sample. First, Cronbach's alphas were calculated to examine the internal consistency of the 21 CARE Scale items prior to factor analysis and to exclude items with poor psychometric properties. Next, EFA was conducted to identify the underlying factor structure of the scale. EFA was conducted using the Phase I clinical data. It should be noted that the Phase I sample size was sufficient to satisfy at least 10:1 subject to item ratios. The principal axis factoring extraction method was used to derive initial eigenvalues, and oblique rotation with Kaiser normalization was used to derive rotated sums of squared loadings for the 21 items. Eigenvalue was set at one and mean substitution was used for missing data. Item values were retained if the primary factor loading was $\geq .50$. Items that loaded on two factors were retained if the primary loading was twice the value of the secondary factor loading. Oblique rotation of the factor matrix initially revealed 3 factors. Items were removed one at a time based on fit on the factor loadings, and analyses were repeated. Item 21 loaded on both factors; however, it fell below retention threshold for Factor 2 and thus was retained in Factor 1. A final superior and parsimonious solution was attained when 2 clean factors emerged comprised of a total of 7 items. All items loaded $\geq .50$. Cronbach's alpha was used to determine the internal consistency of items in each factor.

Convergent validity between the 7-item CARE measure total score and other measures were assessed with Spearman Rho's correlation coefficient due to non-normal distribution of data. Because no self-care measures are available, the relationship of the CARE scale scores to pain ratings, pain-interference, and the PROMIS-health outcome measures were examined.

In Phase II, Confirmatory Factor Analysis (CFA) was conducted with two additional samples: an online and clinic sample. Model-fit was evaluated using the traditional chi-square statistics with degrees of freedom and p -value, root-mean-square error of approximation (RMSEA), root-mean-square residual (RMR), Comparative Fit Index (CFI), and Goodness-of-Fit (GFI). A good fit would be indicated by $RMSEA < .08$, $RMR < .05$ (acceptable $< .08$), $CFI > .95$, and $GFI > .90$. (25)

Missing data—Individuals who missed or did not answer three or more items on the original 21 CARE-scale items were excluded from analysis (8.1% in Phase I). All remaining participants had two or fewer missing items on the scale and were included in the study ($N=729$). For the remaining participants in Phase I, any missing values on the CARE Scale items (two or less), in addition to missing values on other self-report measures (7.1% at most) were then replaced with the overall mean of the final sample. Missing values on the CARE scale were minimum for Phase II online (1.0% at most) and clinic (2.8% at most) samples and were replaced with the overall means; a conservative approach typically used for data with small percentages of missing values (26).

RESULTS

Descriptive statistics

Table 1 describes the sample characteristics. All three samples were predominantly female (66.9~83.6%), middle aged (mean ages = 47 ~ 51), and married (30.7–58.1%). About 32.5% to 46.5 % of participants in Phase I and II studies endorsed having dependents. Phase II participants were asked to report a primary caretaker status and more than half endorsed having a primary caretaker role at home.

Phase I clinic sample—The majority were Caucasian (84.2%), followed by Hispanic/Latino (8.9%) and other ethnicity (6.9%). About half of the sample endorsed having at least a bachelor's degree (58.3%). The most frequently endorsed employment status was working full- or part-time (45.6%), followed by unemployed or homemaker (21.6%), retired (19.6%), and other (13.2%). The top three most frequently endorsed pain conditions were chronic low back pain (63.4%), fibromyalgia (26.7%), and migraines (20.2%). Most participants reported a chronic pain duration longer than a year (97.5%).

Phase II samples—The Phase II online sample was comprised of individuals with fibromyalgia, whereas the Phase II clinic sample had heterogeneous pain conditions. Of participants in Phase II clinic sample, the top three most frequently endorsed chronic pain conditions were back pain (62.1%), neck pain (30.4%), and headache (15.2%). Information about pain duration, race/ethnicity, education, and employment status was not collected in the Phase II samples.

Internal consistency of the CARE scale with initial 21 items

With the initial 21 items, Cronbach's α was .86, suggesting a good internal consistency. No bad items were identified, as Cronbach's α s remained at .85 ~ .87 even if items were deleted one at a time. The Kaiser-Meyer-Olkin (KMO) Test Measure of sampling adequacy and Bartlett's Test of Sphericity were examined. The KMO value of 0.892 and the significant Bartlett's test ($p < .001$) suggest that the data were suitable for factor analysis.

Explorative Factor Analysis with Phase I sample

The initial solution of the EFA with the 21 items revealed four factors with an Eigen value of >1 . After selecting items with the primary factor loading of $\geq .50$ and the secondary factor loading of at least twice difference from the primary loading, two factors with 10 items were identified. Then, the stepwise procedure was done by removing an item with the lowest factor loading until the percent of explained variance reached to an acceptable level (at least 50%). A final superior and parsimonious solution was attained when two factors emerged with a total of 7 items: a factor associated with difficulty prioritizing self-care (Eigen value = 2.86) and the other factor associated with relationship worry/guilt (Eigen value = 1.17). All seven items were loaded $>.60$ on each factor and accounted 57.6% of variance (Table 2).

With the final seven items, Cronbach's α was .81, suggesting a good internal consistency. No bad items were identified, as Cronbach's α s remained at .77 ~ .80 if items were deleted one at a time.

Convergent validity of the 7-item CARE scale

The distributions of the total and subscale scores were non-normal (Shapiro-Wilks tests of normality = .94–.98, $p < .001$) and negatively skewed. The means (SDs) were 17.1 (6.1) for the total CARE score and 9.9 (3.9) for the difficulty prioritizing self-care and 7.2 (3.6) for the worry/guilt subscale scores.

Spearman rhos were computed to examine the relationship of the CARE scale scores to pain intensity, pain-related interference, and other emotional distress measures (Table 3). All spearman rho's results were significant at p level of .001. The total CARE scale scores were correlated with higher average pain intensity, pain-related interference, pain catastrophizing, and emotional distress ($r = .31 \sim .46$) and with lower physical functioning ($r = -.31$). Between the two subscale scores, the worry/guilt subscale scores were more strongly correlated with pain-interference, pain catastrophizing, and depression ($r = .50 \sim .55$) than the difficulty prioritizing self-care scores ($r = .17 \sim .26$). Overall, the results of the spearman rhos suggest the CARE scale has a modest degree of convergent validity with measures of average pain intensity, pain-interference, and emotional distress.

Confirmatory Factor Analysis with Phase I and II samples

A CFA was conducted to fit the two-factor structure model to the data. The results of the model-fit were presented in Table 4. With the Phase I sample, all the fit indices suggested a good fit except that RMR result was an acceptable fit. With the two Phase II samples, GFI and CFI suggested a good fit and RMR and RMSEA suggested an acceptable fit. Overall, the model showed an acceptable fit to all three data sets. Therefore, the two factor structure can be considered as stable across the three different samples: the online survey completed by clinic patients with heterogeneous pain conditions (Phase I) and by individuals with fibromyalgia (Phase II), as well as the paper-and-pencil survey by clinic patients with heterogeneous pain conditions (Phase II). Figure 2 shows the factor structure of the CFA model with the Phase I sample.

Gender differences on the CARE scale

Mann-Whitney U tests were used to examine gender difference in the total and subscale scores for Phases I and II combined samples because the data was not normally distributed (Shapiro-Wilk statistics = .976, $p < .001$, Figure 3). The results indicated there were gender differences in the total scores ($U = 138821.0$, $Z = -6.3$, $p < .001$) and subscale scores of difficulty prioritizing ($U = 148972.0$, $Z = -4.8$, $p < .001$) and relationship worry/guilt ($U = 143288.5$, $Z = -5.6$, $p < .001$). Women had higher levels of difficulty in practicing their self-care than men, as indicated by a higher total CARE median score (IQR) for women such as 19 (14–22) than men such as 15 (12–20). The quartiles on the CARE scale total were presented for the combined group in Table 4-1 as well as men and women, separately in Table 4-2. The Table 4-1 and 4-2 include quartile score ranges with descriptors, which will help clinical interpretation of an individual CARE score. It should be noted that the number of male participants were less than a third of the total sample ($n = 322$). Therefore, male clinical norms are provisional and should be further evaluated in the future study with a large sample size.

DISCUSSION

The goal of this study was to develop and evaluate the validity of a measure designed to quantify interpersonal factors that impact self-care behaviors among patients with chronic pain. We followed a rigorous protocol to adapt the original 21 candidate items of the CARE Scale across three validation samples. Expert pain psychologists proposed the initial items based on their clinical experience, which ensured the communication validity of the intrusions and item content of the original item pool. Internal consistency of the original items ensured suitability for subsequent factor analyses.

Factor analysis of relevant items revealed a concise, 7-item, 2-factor structure that comprised the final CARE Scale measure (see Appendix 1). Factor 1 measures difficulty prioritizing self-care and taps the construct of “externalized” care (i.e., having a tendency to focus on the needs of others rather than one’s own self-care). Such a construct is particularly salient in chronic pain, an ongoing condition that requires a behavioral focus on ongoing, daily self-management. The average score for this factor in our sample was 2.5 on a scale ranging from 0–4, suggesting an overall moderate difficulty to externalize self-care. Stated differently, study participants report an overall moderate level of difficulty for maintaining a focus on self-care. Furthermore, 27% of the total sample endorsed more difficulty with prioritizing self-care needs, thereby underscoring the clinical utility of the CARE Scale and potential value in identifying important cognitive, emotional, and behavioral therapeutic targets. Factor 1 subscales were modestly related to BPI average pain intensity and pain interference, PROMIS measures of emotional and physical functioning, and pain catastrophizing. These modest associations were expected given that factor 1 assesses one’s ability to prioritize self-care-- a new construct that is distinct, yet related to other pain-related variables. Overall, findings suggest that difficulty prioritizing self-care factors may significantly impact pain self-management, and that the CARE Scale may be a useful screening tool for identifying people who may be at risk for abdication of self-care to tend to the needs of others. Future studies using the CARE Scale can examine whether patients who endorse greater externalization of care (and abdication of self-care) may have poorer pain outcomes.

Factor 2 taps the emotional construct of Guilt/Worry about the impact of one’s pain on significant relationships, and limitations on one’s ability to provide care to others (i.e. I worry a great deal about how my pain impacts my partner and/or family). For instance, guilt regarding how pain impacts one’s family may push people with chronic pain to exceed their current physical limitations, thus compromising self-care. The average score for this factor was 2.4, out of a possible 0–4, suggesting an overall moderate tendency to externalize self-care. Stated differently, study participants report an overall moderate level of difficulty for maintaining a focus on self-care. Almost one-third of the total sample endorsed extreme difficulty with relationship worry and guilt. In addition, consistent with research (13, 14), the majority of our participants were married or partnered and reported moderate to severe worry or guilt about how pain impacted their primary relationships. Factor 2 subscales showed strong associations with pain-interference, pain catastrophizing, and depression ($r = .50 \sim .55$), and was significantly related to all other pain-related measures, confirming convergent validity of our factor structure. Notably, these findings suggest a conceptual

overlap between relationship worry and the concept self-perceived burden (11) which has been widely studied in medical populations (e.g. 12), and the emerging factor structure reveals an association between this emotional construct and self-care behavior among patients with chronic pain. Finally, Total CARE Scale scores were significantly related to the total BPI pain-related interference scores ($p < .001$), thus providing further convergent validity of the measure. Results from factor 2 underscore the importance of assessing relationship worry and guilt in the context of chronic pain, as these may be driving behaviors that contribute to pain and disability.

Individuals living with chronic pain are faced with numerous social dilemmas that may center around attempts to preserve existing social roles and relationships. Overall, our findings suggest that for some individuals the motivation to reduce daily social pain (e.g., distress related to feeling like a deficient parent or partner) may impede or even outweigh one's motivation to deliver self-care. Viewed in this light, knowledge about self-care and self-management may have limited benefit if potential perceived interpersonal barriers to self-care are not assessed and addressed. Our findings underscore that the social environment impacts self-care and pain self-management, as well as broader constructs in chronic pain, and may have particular salience for patients who have dependents. Indeed, about half of the study sample reported having dependents; for many individuals, chronic pain may force an uncomfortable shift away from a caregiving role and identity. The extent to which a patient is able to delicately navigate and balance the personal and interpersonal roles of caregiving, self-care, and care receiving may play an important role in adaptation and adjustment to chronic pain, and may shape the trajectory of outcomes. Some previous qualitative work has examined the impact of chronic pain on parenting among parents with chronic pain conditions, and found that parents frequently report that pain negatively impacts perceived ability to care for their children, and 37% reported experiencing guilt related to this (27). The CARE-7 offers a validated tool for quantitative assessment of this experience in populations with dependents, including parents.

Accordingly, identifying perceived relationship factors and self-care behaviors that impact function may be important therapeutic targets. Notably, across samples, participants were predominantly female, middle aged, and married or partnered. There were no differences across pain conditions, as participants in Phase II had a homogenous pain condition (i.e. fibromyalgia), which shows that the scale is applicable across diverse pain condition groups. Preliminary gender differences emerged in total and subscale scores, with women showing higher levels of difficulty in practicing self-care than men. This is potentially related to primary caretaking roles that are predominantly endorsed by women, and consistent with catastrophizing research (28). This is also aligned with research suggesting that social variables are more predictive for pain outcomes in women than in men (9). We underscore the preliminary nature of the gender effect given the substantially smaller cell sizes for men ($n = 322$) versus women ($n = 1120$). As overall fewer men participated in the studies, replication is required with a greater male census.

The results of this study should be viewed in light of several limitations. First, presence of chronic pain was self-reported and medical diagnoses were not confirmed. To ameliorate these concerns, we conducted the validation in two distinct tertiary pain clinics, and

administered it in two formats; two online survey and a paper and pencil clinic survey. Second, demographics for both studies revealed that both samples were predominantly female and middle-aged, and in Phase I predominantly Caucasian and college-educated; results reported here may not be representative of populations with greater diversity and we highlight this as a necessary topic of future research. Third, results from this work may not extend to settings involving acute pain and specific validation is needed for research involving such populations (e.g., post-surgical studies). Another limitation of the study is self-report design; however, we included two distinct clinic samples, two administration formats, and examined associations between the CARE Scale and BPI as well as other psychosocial and physical indices to enhance convergent validity.

Despite the aforementioned limitations, this research has several noteworthy strengths. First, we found strong evidence for the 2-factor 7-item CARE Scale; the first psychosocial measure in chronic pain to assesses the impact of socio-relational factors on self-care. Self-care is an important construct in psychosocial research. Prior work suggested that depression and other psychopathology are inversely related to self-care and self-management behaviors (29–31). Surprisingly, social and environmental factors that impact and impede self-care behaviors are understudied, despite their clear relevance to clinical care.

The CARE Scale-7 may facilitate measurement of this important construct in pain registries and in psychosocial diary research that seeks to elucidate the interplay between relationship roles, self-care, adaptation and recovery. Furthermore, the CARE Scale may facilitate standardized measurement in research and clinical contexts, which may serve to inform a comprehensive treatment focus that integrates individualized self-care planning with a clear focus on negotiating relationship roles and adjustment within and without the family structure. Helping patients with chronic pain live richer, more functional lives requires that clinicians help patients negotiate and optimize to the balance between caring for self and others, and address the underlying cognitive and emotional factors that may facilitate imbalance and abdication of self-care. Rarely does pain exist in isolation. Further study of socio-relational factors that impact self-care and wellness behaviors in chronic pain may lead to treatment pathways that are optimized to facilitate positive adaptation and therefore reduce social and sensory pain.

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Appendix 1: CARE Scale-7

Please select a number to indicate your response to each question below.

- 4 To an extreme degree
- 3 To a moderate degree
- 2 Somewhat
- 1 Slightly
- 0 Not at all
- 0 Not applicable

Response	Item
_____	(1) I tend to focus on taking care of others and think of myself last.
_____	(2) I tend to put other people's needs ahead of my own.
_____	(3) I have difficulty prioritizing my needs first.
_____	(4) I often find that I meet the expectations of others at the expense of myself.
_____	(5) I feel guilty about how my pain impacts my spouse/partner/children/dependents.
_____	(6) I worry a great deal about how my pain impacts my partner and/or family.
_____	(7) I worry that my pain will disconnect me from family and/or friends.

Appendix 2: CARE Scale scoring metric

Factor 1: Difficulty Prioritizing Self-Care

$$\frac{\quad}{1} + \frac{\quad}{2} + \frac{\quad}{3} + \frac{\quad}{4} = \frac{\quad}{\text{F1: SUM}}$$

Factor 2: Relationship Guilt/Worry

$$\frac{\quad}{5} + \frac{\quad}{6} + \frac{\quad}{7} = \frac{\quad}{\text{F2: SUM}}$$

Total CARE Scale Score

$$\frac{\quad}{\text{F1 SUM}} + \frac{\quad}{\text{F2 SUM}} = \frac{\quad}{\text{TOTAL SCORE}}$$

Figure 1.
An outline of study phases and procedures.

Figure 2.

Path diagram for the two factor model of the confirmatory factor analysis with standardized regression weights (Phase I sample).

Figure 3.
Distribution of the total CARE Scale scores

Table 1

Clinic and Online Sample Characteristics

	Phase I		Phase II	
	Clinic Sample n = 729	Online Sample n = 578	Paper and Pencil Clinic Sample n = 145	
	n	(%)	n	(%)
Gender [*]				
Female	540	(74.1)	483	(83.6)
Male	189	(25.9)	87	(15.1)
Age: <i>M (SD)</i>	50.8	(14.4)	47.2	(12.2)
			49.8	(15.5)
Marital status [*]				
Single	120	(16.5)	84	(14.5)
Married	383	(52.5)	336	(58.1)
Widowed	19	(2.6)	10	(1.7)
Divorced/Separated	122	(16.7)	97	(16.8)
Domestic Partnership	56	(7.7)	50	(8.7)
			8	(5.5)
Have dependents [*]				
Yes	238	(32.6)	269	(46.5)
No	491	(67.4)	305	(52.8)
			54	(37.3)
Primary caretaker of home [*]				
Yes	-	-	400	(69.2)
No			171	(29.6)
			44	(30.3)

^{*} Totals <100% due to missing data

Table 2

Factor loadings for individual items

		Factor	
		1	2
No.	Item	Difficulty Prioritizing self-care	Worry/Guilt
1	I tend to focus on taking care of others and think of myself last	.876	.195
2	I tend to put other people's needs ahead of my own	.798	.141
3	I have difficulty prioritizing my needs first	.617	.124
4	I often find that I meet the expectations of others at the expense of myself.	.607	.096
5	I worry a great deal about how my pain impacts my partner and/or family	.100	.894
6	I feel guilty about how my pain impacts my spouse/partner/children/dependents	.170	.759
7	I worry that my pain will disconnect me from family and/or friends	.175	.617
% Variance		40.8	16.8

Table 3

Convergent Validity: Correlations of the CARE scale scores with other measures

		Total	Subscale 1 Difficulty Prioritizing self-care	Subscale 2 Worry/Guilt
Brief Pain Inventory				
Pain Intensity:	Average pain for the past week	.31	.20	.32
Pain Interference:	General	.44	.20	.55
	Activity	.32	.12	.44
	Walking	.26	.12	.34
	Work	.35	.08	.46
	Relationships with others	.43	.21	.51
	Sleep	.37	.22	.39
PROMIS				
	Depression	.46	.26	.51
	Anxiety	.41	.22	.47
	Anger	.40	.25	.42
	Fatigue	.42	.23	.46
	Physical Function	-.31	-.09	-.44
	Pain Behaviors	.39	.13	.51
	Isolation	.42	.26	.44
PCS	Total	.40	.17	.50
	Rumination	.32	.13	.41
	Magnification	.37	.20	.41
	Helplessness	.39	.15	.51

Note: Spearman rho's were used, all p 's < .001.

Table 4-1

Quartiles on the CARE Scale Total and Subscale scores (n = 1,452)

CARE QUARTILE	Total Scores	Subscale 1	Subscale 2
		Difficulty Prioritizing Self-care	Worry/Guilt About Relationships
1 (Low Level of Difficulty)	0–13	0–7	0–5
2 (Mild Difficulty)	14–18	8–10	6–8
3 (Moderate Difficulty)	19–22	11–13	9–10
4 (High Level of Difficulty)	23–28	14–16	11–12

Note: The combined group included those who did not endorse their gender and therefore, the total number of participants (n = 1,452) were greater than the sum of the men and women combined presented in Table 4-2 (n = 1422).

Quartiles on the CARE Scale Total and subscale scores by gender (n = 322 for men, n = 1120 for women)

Table 4-2

CARE QUARTILE	Total Scores		Difficulty Prioritizing Self-care				Worry/Guilt About Relationships	
	Men	Women	Men	Women	Men	Women	Men	Women
1 (Low Level of Difficulty)	0–12	0–14	0–7	0–7	0–3	0–5	0–3	0–5
2 (Mild Difficulty)	13–15	15–19	8–9	8–10	4–7	6–8	4–7	6–8
3 (Moderate Difficulty)	16–20	20–22	10–11	11–13	8–9	9–11	8–9	9–11
4 (High Level of Difficulty)	21–28	23–28	12–16	14–16	10–12	12	10–12	12