Loss of resources and demoralization in the chronically ill

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ABSTRACT

Objective: The study examined whether the association between the severity of physical symptoms and demoralization is mediated by loss of resources in individuals with chronic conditions including conventional diagnoses, functional somatic syndromes, and medically unexplained symptoms.
Method: This cross-sectional study evaluated $N = 194$ patients (mean age = 46, 83.5% female) who reported at least 3 months of persistent physical symptoms using the following self-report instruments: PHQ-15 (modified), Loss of Resources Inventory, Psychosocial Questionnaire – Demoralization Subscale, and PHQ-8. The mediation hypothesis was tested by multiple regression analyses controlling for age, race, employment status, income, educational attainment, and depression.
Results: Participants experienced $M = 9.3$ out of 16 possible health-related losses ($SD = 4.4$). Average to severe demoralization scores were indicated by 59.1% of individuals, of which only 17.1% experienced high demoralization. Loss of resources fully mediated the effect of symptom severity on demoralization, explaining 56% of the variance of demoralization and inhibiting the initially significant effect of symptom severity on demoralization to nonsignificant levels [from $b = 0.67$, 95% CI (0.26, 1.07) to $b = 0.03$, 95% CI (−0.27, 0.32)].
Conclusion: Early recognition of the loss of resources phenomena and interventions to reduce its progression through the introduction of resource gains may diminish, or even prevent, the installation of demoralization in individuals with chronic symptoms.

1. Introduction

According to recent estimates, 60% of all adults in the United States (US) have at least one chronic health condition [1], and this phenomenon contributes to 7 in 10 deaths per year [2,3]. Additionally, treating chronic diseases and conditions is a substantial expense for the US health care system, consuming 86% of its total yearly expenditure, which equals 17.9% of the US gross domestic product (GDP) [2]. Chronic conditions also tend to demand rich social resources, for instance, family members of a chronically ill patient are the first individuals to experience the distress of being constantly involved in caretaking [4,5].

Demoralization is a syndrome of existential distress that can emerge from living with persistent bodily symptoms [6,7]. An increasing number of studies have demonstrated the significance of demoralization and its association with physical symptom burden in patients with cancer [8]. When physical symptoms become chronic and difficult to treat, individuals may become demoralized due to loss of integrity, which challenges the performance of their social roles, capacity to feel pleasure, and sense of competence and morale [9,10]. Demoralization is a joint phenomenon where an individual may experience distress and subjective incompetence from being "bound" to an illness and the attempts to treat it. In addition to the pervasive self-perceived lack of capacity, subjective incompetence can be characterized as a sense of entrapment resulting from an illness, which, when increasing in intensity and duration, can lead to feelings of hopelessness and helplessness [11]. Other occurrences linked with demoralization are loss of meaning, disheartenment, dysphoria, and sense of failure [12].

More specifically, sociodemographic factors of individuals with chronic conditions associated with an increased risk for demoralization are being single, being unemployed, feeling isolated, and experiencing poor management of their symptoms [8]. Although chronic conditions have been associated with a higher risk of demoralization [13],[14], limited knowledge is available on the precise mechanism that relates chronic conditions to demoralization.

An increasing number of physical symptoms has been positively associated with demoralization [15–17]; thus, we adopted the concept of *loss spirals*, essential to Conservation of Resources (COR) theory [18]. According to COR theory, any stressful event could disturb an individual's pool of resources (e.g., financial assets or marriage), and

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logically, the multiplicity and accumulation of such events could affect this pool of resources to the extent where the resources become scarce due to the absence of recovery periods, in which resources are typically replenished [19] [20]. To illustrate the loss spirals phenomena, studies have indicated that previously traumatized individuals who experience re-traumatizing events (e.g., individuals who have cancer recurrence or populations whose resources become scarce after natural disasters) are prone to deleterious outcomes, which is possibly due to an already diminished pool of resources [21–23] [24].

In the context of chronic illnesses, persistent physical symptoms can trigger such loss spirals, which may increase the risk of demoralization. In this study, we examined the following hypothesis: higher levels of physical symptom severity are associated with higher demoralization levels, and this association is mediated by the loss of resources.

2. Methods

2.1. Participants and procedures

This cross-sectional study was a subset of a larger study titled VOICE (Verification of Illness, Coping, and Experience), whereby individuals with ongoing symptoms of chronic illness were recruited through two approaches: in-person and over the internet. To collect a diverse sample, brochures of the VOICE study survey were available in 72 health clinics/practices in the greater Jacksonville area (Florida, US) that provided access to a variety of health practitioners, including primary care physicians, specialists, and alternative health care practitioners. This same strategy was adopted for the online recruitment, and 42 websites/discussion boards for a variety of chronic physical conditions were used. After the recruitment phase, participants completed an online survey through a website created for this project, where data was collected and recorded.

The participants reported whether they were diagnosed by a physician and which chronic condition(s) the diagnosis comprised. The participants' chronic condition diagnoses were then subcategorized as Conventional Diagnosis (CD), Functional Somatic Syndromes (FSS), or Medically Unexplained Symptoms (MUS) [25]. CD includes medically explained symptoms congruent with diagnostic criteria and physiological markers, which include diseases that could be rapidly and precisely diagnosed and treated (e.g., type I diabetes) [26]. FSS are physical symptoms and impairments related to everyday life that are generally not attributed to verifiable, conventionally defined diseases despite similarities regarding diagnostic criteria, etiology, pathophysiology, neurobiology, psychological mechanisms, patient characteristics, and treatment responses that have been documented (e.g., fibromyalgia or chronic fatigue syndrome) [27]. MUS are best characterized as symptom-based disorders where the cause (or causes) of symptoms is not completely explained or understood either by current diagnostic markers (physiological exams) or medical community (e.g., dizziness or headache) [28].

Eligibility criteria were having at least 3 months of persistent physical symptoms and an age older than 18 years. Exclusion criteria were self-reported primary diagnoses of somatoform disorders, and psychiatric and neurologic conditions linked to severe cognitive incapacitation (e.g., psychosis or dementia). Participants were informed regarding the main aspects of the project, namely the goals, privacy policy, time for completion, potential scientific benefits, and contact information for the researchers, the Institutional Review Board and mental health resources, after which informed consent was obtained. This study was approved by the Research Ethics Board of the University of North Florida.

2.2. Measures

Demographic and symptom-related data were collected from participants by using a self-report questionnaire.

We assessed symptom severity using the self-report *Patient Health Questionnaire (PHQ-15)* [29], which was expanded through the addition of certain items from both *Screening for Somatoform Symptoms - 7 (SOMS-7)* [30] and *Revised Illness Representations Questionnaire (IPQ-R)* [31], resulting in a comprehensive 63-item symptom list (available online). In the pool of participants, the *PHQ-15* alone achieved a very good reliability rating, Cronbach's $\alpha = 0.86$, a rating similar to the original instrument rating (Cronbach's $\alpha = 0.80$). Scores were obtained by averaging participants' rating for intensity of symptoms (e.g., fever, rashes, and trouble sleeping) on a 3-point scale ranging from *"not bothered at all"* to *"bothered a lot,"* over the past 4 weeks.

The *Demoralization Subscale* of the Psychosocial Questionnaire is a 22-item self-report measure based on the conceptual framework developed by Mohr et al. [32]. The scale originally assessed psychosocial consequences of multiple sclerosis; however, Katz, Flasher, Cacciapaglia, and Nelson [33] replicated Mohr et al.'s [32] study by pooling two populations–one diagnosed with lupus and one diagnosed with cancer–and achieved results similar to Mohr [32] . The 22-item demoralization subscale contains items such as *"I feel like my family is just waiting for me to die or go away"* and *"I am embarrassed to be seen in public because of my health condition."* Respondents specified on a 5-point scale (1 = *strongly disagree*, 2 = *disagree*, 3 = *neutral*, 4 = *agree*, 5 = *strongly agree*) the rating that best described their situation. Moderate and high demoralization is defined by mean item scores of ≥ 3 and ≥ 4, respectively. The demoralization subscale in Mohr's [32] sample had a Cronbach's $\alpha = 0.90$. In our sample, reliability analysis resulted in a Cronbach's $\alpha = 0.95$, suggesting high internal validity.

We assessed loss of resources by creating a 16-item inventory for gauging the amount of losses participants experienced due to health symptoms. Loss of resources is at the center of COR stress theory [18] [34]; thus, the inventory included items that represented objective and subjective losses (see online supplement). Survey participants were instructed to select as many losses as they thought were consonant with their health situation. The answers were based on a yes/no response, and the total score was computed by summing all items [35]. Higher scores indicate more losses. The internal consistency was Cronbach's $\alpha = 0.88$.

Depression was measured by the *Patient Health Questionnaire* (PHQ-8) [36]. The instrument assesses how often an individual is bothered by any of the presented problems, and answers follow a 4-item scale ranging from *"not at all"* to *"nearly every day,"* with the total score varying from 0 to 24. The questionnaire assesses DSM-IV depression criteria, except suicidality. Scores of 5, 10, 15, and 20 represent cutoffs for mild, moderate, moderately severe, and severe depression, respectively. The participants reliability score was very good (Cronbach's $\alpha = 0.86$).

2.3. Statistical analysis

We used the SPSS software package (IBM - version 25) to perform the statistical analyses. In a preliminary set of analyses, correlations were conducted to understand the associations between variables. Next, we examined patterns of association between the predictor variables and outcome variables by using hierarchical linear regressions. In the hierarchical linear regression analyses, scatterplots of residual values did not indicate violations in linearity or homoscedasticity.

The mediation model was tested following the nonparametric bootstrap approach employed in PROCESS [37,38]. In all of the analyses, different levels of a predictor (e.g., racial–ethnic categories, levels of income) were dummy coded. When estimating the indirect effect of symptom severity through the hypothesized loss of resources mediator, bias-corrected bootstrap confidence intervals (CIs; OLS) around the indirect effect of symptom severity were calculated with the number of bootstrap samples set to 5000 and with the inclusion of race, education, work, income, age, and depression as covariates. As a result of missing data, the number of participants' responses for specific items was less than the total participant count in the sample ($N = 194$).

Table 1
Demographic and disease-related sample characteristics and descriptive statistics for study variables ($N = 194$).

Variable	N	%
Age, mean (SD), years		46.2 (12.9)
Gender		
Female	162	83.5
Male	32	16.5
Stable relationship	129	68.3
Education		
≤High school	12	6.6
Some bachelor's degree	87	48.1
≥bachelor's degree	82	45.3
Type of diagnosis		
Conventional diagnosis (CD)[1]	64	33
Functional Somatic Syndrome (FSS)[2]	110	56.7
Medically Unexplained Symptoms (MUS)[3]	20	10.3
Illness chronicity, in years		
CD[1], mean (SD)		9.8 (11.1)
FSS[2], mean (SD)		14.1 (13.1)
MUS[3], mean (SD)		8.2 (8.6)
Total, mean (SD)		12.1 (12.2)
Physical symptom count, mean (SD)[a]		30.5 (13.7)
Physical symptom severity, mean (SD)[b]		0.7 (0.4)
Loss of resources, mean (SD)[c]		9.3 (4.4)
Demoralization, mean (SD)[d]		3.2 (0.9)
Depression, mean (SD)[e]		10.53 (6.78)

[a] Possible range: 0–63.
[b] Possible range: 0–3.
[c] Possible range: 0–16.
[d] Possible range: 1–5.
[e] Possible range: 0–24.
[1] CD: Conventional diagnosis of a chronic condition.
[2] FSS: Functional Somatic Syndrome.
[3] MUS: Medically Unexplained Symptoms.

3. Results

3.1. Sample characteristics and descriptive statistics

Demographic characteristics of the sample are presented in Table 1 and descriptive statistics in Table 2: 33% were diagnosed with a conventional chronic disease (most frequently sarcoidosis, ankylosing spondylitis, and rheumatoid arthritis), 56.7% with a functional somatic syndrome (most frequently fibromyalgia, restless leg syndrome, and chronic fatigue syndrome), and 10.3% had MUS (not specified).

While demoralization was present in 59.1% of participants (scores between 3 and 5), only 17.1% of these participants exhibited high demoralization levels (scores 4 or 5). The mean score on the demoralization subscale was $M = 3.15$ ($SD = 0.93$). On average, participants experienced $M = 9.35$ out of 16 possible health-related losses ($SD = 4.41$). The most frequent health-related losses were "reduced participation in activities" (88.1%), "lack of participation in activities I enjoy" (85.6%), and "fewer pleasures" (79.9%). The most frequent and severe physical problem was "feeling tired/having low energy" ($M = 1.67$, $SD = 0.62$, 91.3%), followed by "unrefreshing/unrestorative sleep" (90.2%) and "trouble sleeping" (89.6%).

3.2. Preliminary analyses

Table 2 presents group differences regarding demographic variables. Analyses revealed that demoralization was significantly higher among Caucasian, less-educated individuals, and individuals not working due to disability or sickness. Marital status, illness type, and sex did not differ significantly in the participants' means for any of our tested variables.

Product-moment correlations were computed among symptom severity, loss of resources, demoralization, depression, and age. Symptom severity presented a positive correlation with loss of resources ($r = 0.56$, $p \leq 0.001$), demoralization ($r = 0.43$, $p \leq 0.001$) and depression ($r = 0.32$, $p \leq 0.001$). Loss of resources was positively correlated with demoralization ($r = 0.76$, $p \leq 0.001$) and depression ($r = 0.38$, $p \leq 0.001$). Demoralization was positively correlated with depression ($r = 0.34$, $p \leq 0.001$). Age was positively and only slightly associated with loss of resources ($r = 0.17$, $p = 0.02$).

3.3. Mediation analyses

Analyses indicated that loss of resources is a statistically significant full mediator of the relationship between symptom severity and demoralization ($\beta = 0.26$, 95% CI: 0.15, 0.37) (Table 3 and Fig. 1).

Table 2
Association of demographic and disease-related characteristics with demoralization, symptom severity, loss of resources, and depression.

Variables		Demoralization		Symptom severity		Loss of resources		Depression	
		n	M(SD)	n	M(SD)	n	M(SD)	n	M(SD)
Race	Caucasian	166	3.22[a]*(0.90)	163	0.74(0.38)	167	9.71[a]**(4.21)	147	10.75(6.77)
	Non-Caucasian	23	2.72[b](1.06)	20	0.61(0.36)	23	6.91[b](5.27)	19	9.19(6.89)
Education	≤High school	12	3.72*[a1](0.54)	12	0.86(0.37)	12	11.17[1](2.33)	12	12.25(9.25)
	Some bachelor's degree	86	3.01[b](0.99)	84	0.72(0.35)	87	8.72[1](4.48)	76	10.75(6.82)
	≥Bachelor's degree	82	3.17[b](0.88)	79	0.72(0.37)	83	9.54[1](4.43)	70	9.65(6.30)
Income	< $20 K	47	3.38(0.90)	46	0.82***[b](0.41)	48	10.54 *[a](4.33)	44	11.60(6.94)
	$20-50 K	59	3.13(0.97)	58	0.78 ***[b](0.38)	59	9.54 [ab](4.68)	54	11.52(6.75)
	$50-100 K	51	3.20(0.85)	49	0.74 **[b](0.33)	51	9.41 [ab](3.72)	44	10.04(6.39)
	> $100 K	25	2.85(0.99)	25	0.47 [a](0.28)	25	7.36 [b](4.68)	19	7.43(6.73)
Work	Working	70	2.85 [b](0.92)	67	0.62 [b](0.34)	70	7.68 [b](4.45)	56	10.00(6.66)[ab]
	Disabled/Sickness	67	3.44***[a](0.79)	64	0.87***[a](0.35)	67	11.09***[a](3.57)	63	12.15(6.38)[a]*
	Retired/Other	56	3.20 [ab](0.99)	52	0.71 [ab](0.40)	57	9.35 [ab](4.53)	51	9.09(7.10)[b]
Sex	Female	162	3.12(0.95)	154	0.75(0.38)	162	9.12(4.44)	140	10.18(6.63)
	Male	31	3.36(0.83)	29	0.63(0.37)	32	10.50(4.13)	30	12.12(7.37)
Marital status	Committed	129	3.24(0.93)	125	0.74(0.37)	129	9.50(4.34)	113	10.40(6.42)[1]
	Non-committed	59	3.00(0.94)	57	0.73(0.40)	60	9.10(4.68)	52	11.18(7.45)
Illness type	CD[2]	64	3.07(1.0)	60	0.67(0.35)	64	8.75(4.80)	56	9.53(6.97)
	FSS[3]	109	3.23(0.90)	103	0.76(0.39)	110	9.90(4.03)	97	11.12(6.57)
	MUS[4]	20	3.02(0.93)	20	0.72(0.41)	20	8.25(4.88)	17	10.40(7.38)

Note: Means with different letters were significantly different from each other at: * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$. The racial categories used by the US Census (African-American, Asian American, Latinos/-as, Native-American, and Pacific Islander) have been collapsed into the category "non-White." Means with 1 superscript were calculated using Brown-Forsythe and Games-Howell tests; All other post-hoc comparisons were calculated using the Bonferroni test. 2: CD-Conventional Diagnosis. 3: FSS-Functional Somatic Syndrome. 4: MUS-Medically Unexplained Symptoms.

Table 3
Mediation Model Coefficients.

Outcome variable (Y)	Mediator variable (M)	Independent variable (X)	a	b	c'	c	ab	ab_cs
Demoralization	Loss of Resources	Symptom severity	4.25***	0.15***	0.03	0.67***	0.64 [0.38, 0.96]	0.26 [0.15, 0.37]

Note: 95% confidence intervals shown in square brackets; a = effect of X on M; b = effect of M on Y; c' = effect of X on Y controlling M (direct effect); c = total effect on Y; ab = indirect effect of X on Y through M; ab_{cs} = completely standardized indirect effect.
* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$.

The direct effect of symptom severity on demoralization (path c) was $b = 0.67$, $p \leq 0.001$ (95% CI: 0.26, 1.07). After considering the indirect effect of symptom severity on demoralization, through loss of resources as a mediator (path c'), the unstandardized beta changed to $b = 0.03$ ($p = 0.87$, 95% CI: −0.27, 0.32). Path c' provides no evidence that symptom severity influences demoralization scores independent of its effect on loss of resources. These results suggest that individuals who report more severe symptoms also suffer increased loss of resources due to these symptoms, making them feel demoralized.

4. Discussion

The lives of the participants in this study have been constantly altered by their close experience with physical contingencies such as pain, discomfort, and movement limitation, in addition to the psychosocial consequences of such manifestations. Although research on demoralization has primarily based its results on accounts of oncologic patients' experiences, either in remittance or in a terminal stage [8,14,39], our results show that demoralization is also highly relevant in individuals with chronic physical problems (noncancerous), as demonstrated by almost two-thirds of our sample being at least moderately demoralized. Additionally, although differentiating demoralization levels according to participants' diagnoses subgroups (CD, FSS, and MUS) was beyond the scope of this study, assessed demoralization levels did not differ among them; thus, demoralization could be a very pervasive syndrome, irrespective of the diagnosis classification. In this study, we attempted to examine a potential mechanism underlying demoralization in a chronically ill population, and the results indicate that loss of resources elucidates its occurrence.

We observed that loss of resources fully mediated the association between physical symptom severity and demoralization. A strong, statistically significant effect emerged for the association between higher symptom severity and increased loss of resources. This phenomenon can be explained by the second corollary of COR theory [20], often referred to as *loss spirals*. More specifically, respondents may have experienced symptom severity comprising an initial degree of distress (i.e., recurrent body symptoms) and its consequential disturbance (i.e., being bothered by these symptoms). According to the second principle of COR theory, becoming distressed demands a surplus of resources either for protecting an individual's resource pool or for recovering from lost resources in order to maintain the resource reservoir

homeostasis [20]. Therefore, being bothered by persistent symptoms causes disturbances in an individual's resource reservoir, either by the use of resources for neutralizing such a disturbance (use of resource = loss of resource) or by acknowledging that there are no available resources for ameliorating such a stressful event (lack of resource = reallocation of another key resource = loss of resource). For instance, being both a full-time professional and a parent while having to manage a chronic condition can impose strenuous and limiting time schedules that can prevent or make it almost impossible to participate in revitalizing activities such as social gatherings, regular exercise, or balanced nutrition.

Our results further showed a significant positive association between loss of resources and demoralization. From the perspective of loss spirals, the initial loss of resources in a certain domain (e.g., sickness) leaves an individual's pool of resources in a state of instability, which demands the use of other key resources (e.g., money for treatment) as an attempt for remediation. If the source of resource consumption (i.e., sickness) is not eradicated, the depletion of other key resources (e.g., self-esteem, professional performance, or interpersonal relationships) will be continuously instigated, leading to the dilapidation of total resource reserve. This process of sequential losses may underlie the high levels of demoralization among patients with high physical symptom severity.

According to Jerome Frank [40], helplessness in demoralization is experienced whenever the usual fight or flight defense mechanisms are pointless in the face of potential harm in which both confidence in authority and survival skills are jeopardized. Additionally, along with helplessness, other feelings such as inadequacy, confusion, sadness, and hopelessness arise. Considering that the participants were experiencing ongoing symptoms without definite solutions (86% of the sample reported having symptoms for at least 3 years), with many stating that their symptoms were received with skepticism by close friends and health care providers (66% felt that others doubted their illness), this uncertainty about illness and perceived disregard may have exacerbated their demoralization symptoms.

Our results suggest that countering such circumstances of delegitimation, lack of understanding, and a sense of desolation in the absence of solutions to physical symptoms may reduce or prevent demoralization in patients with chronic conditions. Patients may be supported by an early assessment of change in resources (e.g., loss of job or failing intimate relationships) to indicate specific interventions, such as
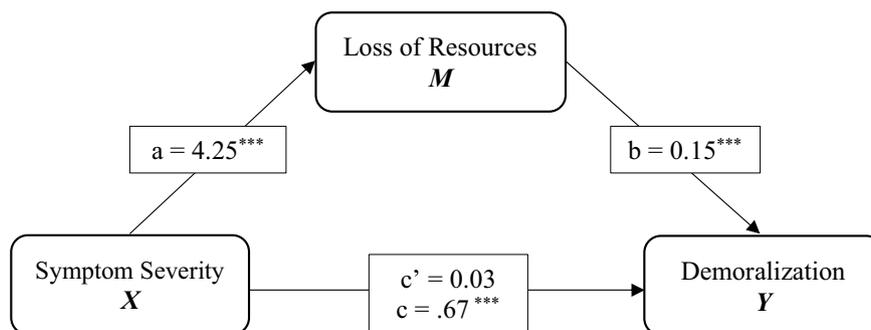

Fig. 1. Mediation diagram
Note: * $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$. Covariates: Age, race, education, work, income, and depression.

resiliency-promoting psychotherapy or social services, because resource loss has been demonstrated to be a strong predictor of PTSD symptoms and depression [41] [42]. If none of these services are available, clinicians can encourage patients to adopt self-efficacy thought patterns for its modulating effect on negative feelings, non-adaptive cognitions, and self-sabotaging actions [43] [23]. Because patients with chronic conditions are not likely to have had the opportunity to regain resources by themselves in a timely fashion, healthy communities can be a source of resource influx by providing a venue for social cohesion and support, emotional exchange, and structure; thus, ecological approaches are also highly recommended [44–48].

Finally, due to the high prevalence of demoralization in the present sample, the development of tailored therapeutic approaches would be warranted to treat installed demoralization in these patient groups. Thus far, and according to our review of the literature, no intervention studies have assessed the effectiveness of treatment approaches for demoralization tailored to the needs of patients with persistent physical symptoms. However, the literature has presented existential therapies focused on cancer patients that are effective in ameliorating loss of meaning [49] [50]. Furthermore, individuals with chronic conditions [51] may present a degree of existential crisis similar to those with cancer, as persistent physical symptoms, some of which may be disabling and/or without a clear medical explanation, result in delegitimization and poor societal understanding and support, mostly due to the lack of a definite illness etiology and treatment.

This study has limitations because of the cross-sectional design and preponderance of white females in the sample (75%). To placate the potential threats to validity, we included race, education attainment, age, income, work status, and depression as covariates in the mediation analyses. Despite the inclusion of depression as a covariate, our study did not assess suicidality because we used PHQ-8 instead of PHQ-9; notably, we could have used a more comprehensive approach because many studies have highlighted this prevalent association between suicidality and demoralization in cancer patients [52,53] and among patients with advanced progressive disease [54]. Therefore, further research could consider suicidal thoughts and plans, given such prevalence. Additionally, a replication of the observed mediation effect in a longitudinal study would be necessary to substantiate the alleged directions of the causal relationships.

5. Conclusion

The findings of this study provide support for the junction of demoralization syndrome and resource theories (i.e., COR theory). Our proposed conceptual model enlightens the still limited body of knowledge regarding populations with both difficult-to-diagnose and conventionally diagnosed chronic conditions by unveiling, testing, and suggesting one mechanism (loss of resources) that explains the incidence of demoralization. The results indicate that patients should be evaluated for changing resources through early triage to encourage the adoption of resource-targeting interventions, such as the Information-Motivation-Behavioral Skills model [55]. Future research may possibly assess patients' previous traumatic occurrences because these may act as a compounding factor on deleterious outcomes due to current resource losses [45,56,57].

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Ethics approval

The study was approved by the Research Ethics Board of the University of North Florida.

Declaration of competing interest

The authors declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.genhosppsych.2019.08.002.

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