

Meaning in Life in Individuals with Dysautonomia

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The present mixed-methods study investigated the role of various predictors of meaning in life (MIL) in individuals with dysautonomia, a condition growing in prevalence with increasing reports of long-COVID (LC), Postural Orthostatic Tachycardia Syndrome (POTS), Chronic Fatigue Syndrome (CFS), and similar manifestations. Specifically, this study examined total autonomic symptom count, duration of symptoms, religious practice status (yes/no while living with the condition), and age as predictors of Search for and Presence of MIL. In the sample, 50.8% reported LC or a similar post-viral syndrome as at least one contributing factor. Participants ($N = 305$), aged 18–68 years ($M = 34.09$, $SD = 10.98$), were members of online dysautonomia support groups internationally. Symptom duration and active religious practice were positively associated with Presence of MIL, whereas higher symptom count was negatively associated. This suggests that those who have lived with the condition longer and those who practiced a religion while living with dysautonomia may have a greater capacity to find MIL. Critically, higher symptom count was associated with less meaning. Age was the only significant predictor of Search for meaning, with older participants reporting a lesser need to search. Importantly, associations between the predictors and Presence of MIL did not differ significantly between etiological subgroups, indicating that these predictors relate to Presence of MIL similarly across groups with different etiological and symptomatic profiles. Qualitative responses were analyzed thematically to contextualize and enrich quantitative findings.

Keywords: meaning in life, dysautonomia, long-COVID, religion, existential

Dysautonomia (also known as autonomic dysfunction) broadly refers to impaired functioning of the autonomic nervous system (Hovaguimian, 2022) and has become prevalent in recent years because of the emergence of Long-COVID (LC), which has been defined as a form of dysautonomia (DePace & Colombo, 2022). Generally, dysautonomia presents as a multi-organ disorder with wide-ranging symptoms including but not limited to tachycardia, chest pain, near fainting, syncope, brain fog, exercise intolerance, fatigue, depression, anxiety, chronic pain, constipation, and diarrhea (Colombo et al., 2022; DePace & Colombo, 2022). Additionally, both autoimmunity and mast cell activation have been associated with dysautonomia (Theoharides et al., 2024; Vernino & Stiles, 2020).

Causes of dysautonomia can be genetic and non-genetic. In genetic cases, patients often suffer from connective tissue disorders, such as Hypermobile Ehlers-Danlos Syndrome (hEDS/EDS), a heritable connective tissue disorder associated with joint hypermobility and musculoskeletal complications, often involving Craniocervical Instability (Gensemer et al., 2020; Lohkamp et al., 2022). Symptoms of autonomic dysfunction have been reported at rates as high as 78% in hEDS and EDS cohorts (Ruiz Maya et al.,

2021). The latter population – categorized by non-genetic pathogenesis – acquire dysautonomia because of chronic viral infections, such as COVID-19, acquired brain injuries, such as TBI, and various other mechanisms that contribute to chronic inflammation and oxidative stress (Bellin et al., 2015; DePace & Colombo, 2022; Wirtz et al., 2020). Common manifestations of dysautonomia, such as Postural Orthostatic Tachycardia Syndrome (POTS) and Chronic Fatigue Syndrome (CFS), are being increasingly reported in patients diagnosed with LC. POTS is defined as an abnormal autonomic response to an upright posture, resulting in tachycardia and orthostatic hypotension, whereas CFS is debilitating fatigue that does not improve with rest (Davis et al., 2023; Mallick et al., 2023; Yancey & Thomas, 2012).

Dysautonomia is individualized, and demographic differences may play a role in how the disorder presents. Studies have found that 85% of POTS patients are female and are of childbearing age (Boris et al., 2024; Bourne et al., 2021; Shaw et al., 2019; Thieben et al., 2007). Although there is some existing research on race and autonomic functioning, the current research lacks data from individuals of traditionally marginalized and underrepresented backgrounds. While POTS predominantly affects White females, one study found that heart rate variability (HRV) was lower in African Americans and individuals of lower social class, suggesting that the negative effects of minority race and lower social class on cardiovascular testing may be heightened by autonomic dysfunction (Lampert et al., 2005).

Critically, the Centers for Diseases Control (CDC) defines LC as a chronic condition that occurs after being infected with the SARS-CoV-2 infection and is present for at least three months (Centers for Disease Control, 2024). With the increasingly reported incidence rates of autonomic dysfunction in individuals with LC (Seeley et al., 2025), there is a pressing need for further research to investigate the impact of dysautonomia on psychological and existential well-being.

Psychological Well-Being and Dysautonomia

Prior research points to associations between hEDS/EDS, POTS, CFS, and LC with negative psychological outcomes. Berglund and colleagues (2015) found individuals with EDS reported lower health-related quality of life (HQoL) and higher levels of anxiety and depression compared to a control group. Similarly, existing research has examined quality of life among those with POTS. In a study with 624 adults reporting physician-diagnosed POTS where 607 were females (compared to only 15 males), individuals with POTS reported decreased HQoL and nearly half (47.6%) of the sample was at high risk for suicide (Pederson & Brook, 2017). This is a drastic comparison to the 4.3% of adults in the United States suffering from suicidal ideation (Ivey-Stephenson et al., 2022). Further, the relationship between post-viral origins of dysautonomia, such as LC, and psychological outcomes has gained attention with the recent rise in reported cases. Moreover, a review of the mental health impact of LC shows that individuals with the condition report new and worsening symptoms including depression, anxiety, posttraumatic stress disorder (PTSD), and insomnia (Saltzman et al., 2024).

The association between dysautonomia and negative psychological outcomes aligns with findings concerning existential concerns within this population. In a qualitative study Fang et al. (2023) demonstrated that LC sufferers experience a sense of existential loss of identity, feeling disconnected from their previous selves and struggle to make sense of living in the circumstances of their illness. In another qualitative study examining meaning in life (MIL) in LC participants lost an existing understanding of life and arrived at a new sense of meaning, partially due to social isolation and loss of physical and cognitive abilities associated with LC (Lieberwerth & Niemeijer, 2024). Given these findings, participants in our study may have also arrived at a new sense of meaning from their experiences with dysautonomia. Corroborating evidence that individuals can arrive at a new sense of meaning post-illness aligns with existing research demonstrating that higher levels of meaning are associated with higher levels of posttraumatic growth in individuals who have experienced traumatic or adverse situations, such as cancer (Almeida et al., 2022). The present study aims to further investigate predictors of meaning within this population.

While numerous psychological outcomes have been explored in relation to dysautonomia, MIL remains underexplored beyond the qualitative studies. Although MIL has been examined in the context of the COVID-19 pandemic, it has yet to be explored quantitatively in those suffering the deleterious effects of the chronic form of the infection. To our knowledge, this is the first study to examine the relationship between dysautonomia and MIL.

Meaning in Life

Victor Frankl, known for the development of Logotherapy, suggested that the primary driving force for individuals is to find and cultivate meaning (Frankl, 1963). In the contemporary literature, a

commonly used definition for MIL exists as “the extent to which people comprehend, make sense of, or see significance in their lives, accompanied by the degree to which they perceive themselves to have a purpose, mission, or overarching aim in life” (Steger, 2009, p. 682). This view consists of two dimensions: the Presence of Meaning and the Search for Meaning (Steger et al., 2006). The Presence of Meaning maintains the above definition, whereas Search is “the strength, intensity, and activity of people’s desire and efforts to establish and/or augment their understanding of the meaning, significance, and purpose of their lives” (Steger et al., 2008, p. 200). MIL is a known contributor to well-being in healthy populations (Zika & Chamberlain, 1992; Brassai et al., 2011). Specifically, MIL is strongly associated with positive psychological well-being dimensions and is inversely related to depression (Debats, 1996; Mascaro & Rosen, 2005).

Moreover, MIL has generally been explored in relation to chronic pain/illness, demonstrating that concerns with life’s meaning are prevalent in individuals dealing with significant medical stressors (Dezutter et al., 2010, 2013; Sherman & Simonton, 2012). In a study exploring existential issues in patients with chronic pain and multiple sclerosis, patients experienced existential despair by way of struggling to identify and relate to themselves with their new illness (Andersen et al., 2021). The authors also documented a continuous struggle of failed attempts to return to their previous way of being. Such findings corroborate the themes demonstrated in the recent LC studies (Fang et al., 2023; Lieberwerth & Niemeijer, 2024). Critically, Dezutter and colleagues (2013) found that individuals low in Presence of and high in Search for MIL demonstrated low levels of acceptance and well-being, while the opposite was true for those with high Presence of MIL. Unsurprisingly, experiencing MIL is an established predictor of well-being in patients with chronic pain and chronic illness (Dezutter et al., 2013; Dezutter et al., 2015). Furthermore, existing research suggests that MIL allows for improved coping with chronic illness. Adaptation to chronic conditions requires a re-evaluation of life goals and expectations, forcing individuals to question the role of MIL (Dezutter et al., 2013; Pinquart et al., 2009). Unsurprisingly, deRoon-Cassini et al. (2009) demonstrated that MIL was related to higher psychological well-being in a sample of individuals living with spinal cord injury.

Total Symptom Count

Across numerous health conditions, the number of symptoms an individual reports has been used as a clinically meaningful indicator of the impact of one’s illness. One study found that menopausal symptom burden, operationalized by summing total number of symptoms, was associated with decreased cognitive functioning and increased behavioral impairment (Crockford et al., 2025). Similarly, in a study examining patients treated for hypertension, total symptom count was associated with poorer HQoL even when symptom intensity was considered separately (Erickson et al., 2024). Greater psychological symptoms also have negative implications. Specifically, Park et al. (2016) found that greater depressive symptoms were associated with increases in severity across multiple psychological outcomes. Building on this work, we predict that symptom count will negatively predict MIL.

Symptom Duration

Symptom duration generally refers to how long an individual has lived with an illness and experienced symptoms. Duration of dysautonomia may depend on its genesis and contributing factors. However, the relationship between duration of autonomic dysfunction and MIL has yet to be explored. Despite this gap, researchers have generally examined the relationship between duration of chronic illness and quality of life. For instance, one study demonstrated a loss of HQoL was associated with longer duration of chronic illness in stroke and mental illness and differed across age groups (Busija et al., 2017). Contrary to these findings, Arat et al. (2012) found that there was no association between HQoL and disease duration in systemic sclerosis.

More relevant to the current issue of dysautonomia is LC and the unpredictable nature of symptom duration. According to the Centers for Disease Control, LC symptoms may range weeks, months, or even years (Centers for Disease Control, 2024). It is not surprising that Fang et al. (2023) found that individuals with LC faced existential concerns including hindered resilience because of the uncertainty associated with their symptoms. Critically, they also showed that those with LC felt disconnected from their narrative identity, disrupting their perception of both the past and the future. Therefore, this study explores the role of duration of symptoms in relation to MIL in individuals with dysautonomia.

Active Religious Practice and Chronic Illness

Religiousness has been shown to predict MIL by serving as a source of well-being in people's lives (Steger & Frazier, 2005). Additionally, religion has been identified as a source of meaning in individuals experiencing LC. Lieberwerth and Niemeijer (2024) showed that participants who considered themselves religious demonstrated a lesser need to adjust their understanding of MIL than those who were not. Similar findings have been observed in relation to other types of chronic illnesses. In a study on individuals with multiple sclerosis, religion served as a meaning system and was positively related to the Presence of MIL (Wilski et al., 2024). On a similar thread, a study examining how 40 women with chronic conditions (e.g., rheumatoid arthritis, osteoporosis, multiple sclerosis, etc.) used religious beliefs to help cope found that women who identified as coping well reported stronger religious beliefs, while those who coped poorly reported having no religious practice (Gordon et al., 2002). While the role of practicing a religion has been explored in relation to chronic illnesses and qualitative in LC, it has not yet been investigated quantitatively in the population. Therefore, the present study examines the role of practicing a religion on MIL in those with dysautonomia. Specifically, we expect those who practice a religion while living with their condition will report greater levels of MIL.

Age

Research investigating MIL throughout the lifespan shows that individuals at later life stages tend to report greater levels of Presence of meaning, while those in earlier life stages tend to report higher Search for meaning (Steger et al., 2009). Individuals tend to develop more positive coping strategies with age but may regress to maladaptive coping when faced with traumatic events (Aldwin et al., 2023). There is limited research concerning MIL and age in the context of chronic illness. Most of the existing research focuses on older adults given the propensity for illness to arise during later

stages of life. However, one study examining age differences in coping with chronic illness found that older adults were less likely to use emotional expression or information seeking when compared to middle-aged adults (Felton & Revenson, 1987). The researchers also revealed that when older adults perceived their illness as highly serious, they were less likely to make positive coping efforts and were more likely to minimize the illness' threat. The present study aims to help resolve the ambiguity of how meaning and age may be related in the context of dysautonomia.

Current Study

We examined whether autonomic symptom count, symptom duration, religious practice status, and age served as predictors of MIL in individuals suffering from dysautonomia. Building on the summarized research, we maintained the hypotheses that total symptom count would negatively predict Presence of MIL, whereas practicing a religion would positively predict Presence of MIL. We did not maintain specific hypotheses for variables age and symptom duration; instead, they were included for exploratory purposes. For these same purposes, we assessed how symptom count, symptom duration, active religious practice, and age served as predictors of Search for MIL. Additionally, qualitative data was collected to provide context to the quantitative findings. Despite the rise in reported cases of dysautonomia and LC, research examining the relationship its association with MIL is lacking. The present study is intended to help resolve this ambiguity.

Methods

Participants

The participants in the sample included members of online dysautonomia support groups across various social media platforms (primarily Facebook and Reddit). The total sample of participants included 316 individuals, but 11 were deemed ineligible for not meeting criteria (i.e., answering "No" to "Have you been diagnosed with Dysautonomia by a physician"). After the screening process, the final sample size was 305 and included 85.2% females, 7.2% males, 6.6% non-binary individuals, and 1% who preferred not to say. The age of participants ranged from 18 to 68 ($M = 34.09$, $SD = 10.98$). Participants reported experiencing their condition from the first month of its onset up to 49 years ($M = 121.25$ months, $SD = 116.41$). See Table 1 for additional demographic characteristics. Additionally, participants reported potential contributing factors to their condition, with 50.8% endorsing LC or a similar post-viral syndrome, 40% EDS or another genetic cause, 31.8% MCAS or histamine disorders, 15.1% autoimmune disorders, 7.2% traumatic brain injury or spinal cord injury, 0.3% a neurodegenerative disease, 24.6% a traumatic life event, 16.4% "other", and 18.7% "unknown." These categories were not mutually exclusive overlapped, and many participants selected multiple contributing factors. See Table 2 for commonly reported symptoms of LC, POTS, and CFS within the sample.

Materials

Demographics. Participants were asked a series of questions pertaining to their race/ethnicity, age, their country of residence, employment status, marital status, and gender identity.

Religious Practice Status. We operationalized religious practice status by asking participants: 'Do you practice a religion

while living with dysautonomia?" and dummy coded 1 = yes and 0 = no.

Table 1. Additional demographic characteristics (N = 305)

Characteristic	Category	Frequency	Percentage
Country of Residence	United States	250	82
	Canada	10	3.3
	Europe	36	11.8
	Australia	7	2.3
Race/Ethnicity	Other	2	0.6
	White	274	89.8
	Hispanic/Latino	13	4.3
	African American	5	1.6
Employment status	Other	13	4.3
	Full-time	99	32.5
	Part-time	42	13.8
	Unemployed	132	43.3
	Students	19	6.2
Other/missing	Other/missing	13	4.2

28-Item Autonomic Symptom Checklist. Autonomic symptom count was assessed using a 28-item checklist derived by an autonomic and cardiovascular clinic on the East Coast of the United States and was used by Colombo et al. (2022), in which respondents indicated whether they experienced each autonomic symptom (yes/no). In the present study, responses were summed to produce a total autonomic symptom count ranging from 0 to 28, with higher scores indicating that individuals were experiencing a greater number of autonomic symptoms. Consistent with prior research treating symptom counts as indicators of illness impact, this total is interpreted as reflecting the amount and complexity of autonomic symptoms. Because this questionnaire does not assess intensity, frequency, or functional impairment, and has not been fully validated as a severity scale, findings are interpreted as total autonomic symptom count. Despite this, the 28-item autonomic checklist is continually used in the abovementioned clinic to guide symptom management, which suggests the measures' ecological validity. In the present study, the autonomic checklist showed good reliability $\alpha = .84$. Examples of symptoms on the autonomic questionnaire can be found in Table 2.

Origin and Contributors. Participants were then asked to indicate known causes and contributors to their condition. Possible answers included: a) EDS or another genetic cause; b) Long-COVID, chronic Lyme disease, or another post-viral syndrome; c) Traumatic Brain Injury or Spinal cord injury; d) Histamine issues like Mast Cell Activation Syndrome (MCAS) or histamine intolerance; e) Autoimmune disease (autoimmune autonomic ganglionopathy (AAG), paraneoplastic autonomic neuropathy, etc.); f) Neurodegenerative diseases (Parkinson's, Multiple Sclerosis, etc.); g) Traumatic life event; h) Other; and i) Unknown.

Symptom Duration. To assess the duration of participants' experiences with dysautonomia, we asked how long respondents had been living with the condition. Participants were instructed to enter the number in months and years. We then operationalized symptom duration by summing symptom duration to total number of months.

Meaning in Life Questionnaire (MLQ; Steger et al., 2006). The MLQ is a 10-item measure that assesses Presence of and Search

for MIL and is rated on a seven-point Likert scale where 1 represents "Absolutely True" and 7 represents "Absolutely Untrue." However, the ninth item, "My life has no clear purpose," is reverse coded. The Presence subscale measures the degree to which participants feel their lives have meaning. Example statements relating to the Presence of meaning are "I have a good sense of what makes my life meaningful" (item five), and "I have discovered a satisfying life purpose" (item six). The Search subscale assesses how engaged and motivated participants are in efforts to find and deepen their understanding of meaning within their lives. Example statements relating to the Search for meaning are "I am always looking to find my life's purpose" (item three), and "I am searching for meaning in my life" (item ten). Items on the Search subscale indicate the degree to which participants are searching for meaning in their lives. The MLQ has established temporal stability, factor structure, and validity as demonstrated by Steger et al. (2006). Both subscales have shown good internal consistency and test-retest reliability. The MLQ has been widely used in chronic pain/illness population research. Within the present study, both subscales demonstrated strong reliability: Presence subscale $\alpha = .91$ and Search subscale $\alpha = .90$. The present study was concerned with the predicting variables on both subscales.

Table 2. Symptom frequencies and percentages per the 28-item autonomic checklist

Variable	N	%
Fatigue	299	98.8
Brain Fog	294	96.4
Lightheaded	288	94.4
Bothered by hot/cold weather	288	94.4
Hypersensitivity to light, touch, sound	273	89.5
Difficulty finding words	268	87.9
Shortness of breath	266	87.2
Cold hands and feet	265	86.9
Tension headaches	263	86.2
Chest palpitations	263	86.2
Difficulty standing	260	85.2
Sleep issues	255	83.6
Depression and anxiety	253	83.0
Diarrhea/constipation	247	81.0
Chronic pain	241	79.0
Coat hanger pain	240	78.7
Short term memory loss	234	76.7
Sweat too little/too much	233	73.1
Migraine	222	72.8
Nausea and vomiting	220	72.1
Dimmed hearing	220	72.1
Tingling in arms/legs	219	71.8
Fainting/near fainting	212	69.5
Numbness in hands/feet	198	64.9
Hands/feet turn colors	198	64.9
Dimmed vision	160	52.5
Hypermobile: joint popping	169	55.4
Salivate too little/dry mouth	153	50.2

Exploratory Qualitative Questions. Given the exploratory nature of this study, we included the following optional qualitative questions to capture the lived experience of individuals with dysautonomia: (a) How has your condition impacted your

experience of meaning in life? (b) How did religion affect your experience of meaning in life while living with your condition? The latter question was included only for participants who reported practicing a religion.

The qualitative responses were intended to help contextualize the quantitative findings. As such, we utilized Braun and Clarke's (2006) method of thematic analysis within an experiential, essential/critical-realist framework, treating participants' responses as reflections of their lived experiences with dysautonomia. We subjected the data to familiarization, coding, theme development and refinement. Given that participants responded directly to specific to questions concerning the lived experience with dysautonomia, we applied theoretical (vs. inductive) thematic analyses during the coding process for both qualitative questions.

Procedure

With approval from the dysautonomia online support groups moderators, we made posts providing a description of the study, the chance for potential reimbursement, and a link to the Qualtrics survey. To prevent automated bot responses and ensure participant validity, we utilized CAPTCHA verification checks at the start of the survey.

All participants encountered the Qualtrics survey in the following sequence: (a) CAPTCHA verification; (b) informed consent; (c) eligibility questions (e.g. age 18 or older, physician-diagnosed dysautonomia); (d) demographic questions; (e) a question assessing religious status while living with their condition; (f) the 28-item autonomic checklist; (g) the Meaning in Life Questionnaire; (h) a question about perceived causes and contributing factors to their condition; (i) about duration of symptoms; and (j) qualitative questions inviting participants to elaborate on their experiences with dysautonomia.

Following completion of the survey, participants were given the option to enter their email addresses to be randomly selected for reimbursement with twenty-dollar e-gift cards. Survey answers and email addresses were recorded separately, maintaining confidentiality. Forty-eight email addresses were randomly selected and reimbursed. It was explained that the option of providing one's email addresses was voluntary and not required. The researchers reimbursed the 48 randomly selected participants the first week of April 2025. The entire Qualtrics survey took approximately 15 minutes to complete. The study was approved by the Institutional Review Board of a university on the East Coast of the United States (IRB: IRB-FY2025-68; Date: 18.2.2025).

Results

Quantitative Analyses

Descriptive Statistics

Means, standard deviations, and bivariate correlations for all primary quantitative variables are presented in Table 3 and Table 4.

Multiple Linear Regressions

We conducted a multiple regression to predict Search for MIL from age, symptom duration, symptom count, and religious practice status. The model accounted for 4.3% of the variance in Search for MIL, indicating a statistically significant yet small contribution, $R^2 = .043$, $F(4, 300) = 3.39$, $p = .01$. Age was the only significant

predictor, indicating that older participants reported less Search for meaning than younger participants. Symptom duration, symptom count, and religious practice status were not significant predictors of Search for meaning. See Table 5 for coefficients.

A second multiple regression was conducted to predict Presence of MIL from age, symptom duration, symptom count, and religious practice status. The Presence model was significant but only accounted for 9.4% of variance, reflecting a relatively small effect, $R^2 = .094$, $F(4, 300) = 7.83$, $p < .001$. Symptom duration, symptom count, and religious practice status were significant predictors of Presence of MIL, while age was not (see Table 5 for coefficients). Longer symptom duration and active religious practice while living with the condition were associated with greater Presence of MIL, whereas greater symptom count was associated with lower Presence of MIL.

Predictors of Presence of MIL by Etiological Subgroup

To determine whether predictors of Presence of MIL functioned differently across etiological subgroups, mutually exclusive dummy-coded groups (LC/post-viral only $N = 55$, EDS/genetic only $N = 15$, other/mixed etiology $N = 79$) and their interactions with age, symptom count, symptom duration, and religious practice status were entered into hierarchical regression models predicting Presence of MIL. In the main-effects model, Presence of MIL was predicted from age, symptom count, symptom duration, religious practice status, and the two etiological dummies, accounting for 9.8% of the variance, $R^2 = .10$, $F(6, 298) = 5.42$, $p < .001$. Neither the LC/post-viral only group nor the EDS/genetic only group significantly differed from the remaining etiological profiles in Presence of MIL, (LC/post-viral only: $B = -1.36$, $SE = 1.19$, $t = -1.14$, $p = .25$; EDS/genetic only: $B = -.36$, $SE = 2.00$, $t = -.18$, $p = .86$). Adding the etiology x predictor interaction terms did not significantly improve model fit $R^2 = .02$, $F(8, 290) = .84$, $p = .57$, and none of the individual interactions were significant (all $p > .05$). This indicates that the association between the included predictors and Presence of MIL were similar across etiological subgroups.

Qualitative Analyses

Q1: How has your condition impacted your experience of meaning in life?

Using Braun and Clarke's (2006) reflexive thematic analysis, three central themes were developed from 239 participants' responses about how dysautonomia impacted their experience of MIL.

Theme 1: Uncertain futures and narrowed worlds.

The experience of dysautonomia greatly impacted people's ability to plan for routine aspects of daily life, including career and family plans, largely in part due to the disabling symptomatology. Many responses include a contrast between the person's experience before and after developing symptoms. They contrasted an earlier life where they could plan and feel excited about the future with a present dominated by the unpredictable nature of their condition and frequent flares. Existential concerns were evident in this unpredictability, as many questioned the meaning of the future that lay ahead.

Additionally, many described their lives as now restricted and greatly narrowed. Respondents described having to give up passions

like sports, careers, and social roles and activities since these were no longer feasible in the face of their disabling symptoms. Unable to do the things they once relied on for meaning, many respondents reported greater social isolation, more time at home alone, and more time recovering from flares.

Table 3. Means and standard deviations for primary quantitative variables

Measure	Min.	Max.	<i>M</i>	<i>SD</i>
Age (years)	18	68	34.09	10.98
Symptom Duration (months)	0	588	121.25	116.42
Symptom Count	8	28	21.94	4.73
Search for Meaning	5	35	23.47	6.97
Presence of Meaning	5	35	22.38	7.78

One participant described the difficulty of maintaining their career while also questioning the purpose of their future:

"I had a very clear purpose and found significant meaning in my life through my job as a music teacher prior to my diagnosis, but now it is physically so hard to keep doing the job I love... I've missed time from work, I feel physically crappy while working... and it's utterly exhausting. I have no social life outside of work because work takes every last bit of energy. So now, I have no idea what my new purpose will be."

In fewer words, another participant wrote:

"Before I got sick with this, I was so driven and ambitious. I lived what some would even have called an adventurous life. Now, I struggle because this condition has taken from me the ability to do nearly all the things I loved so much. What is left of me? I'm unsure."

The provided examples highlight the unpredictability and shrinking worlds of those living with dysautonomia. The uncertainty associated with disabling symptoms was experienced as an existential threat, undermining any sense of a secure or meaningful future.

Table 4. Bivariate correlations between primary quantitative variables (*N* = 305).

	1.	2.	.3	4.
1. Age				
2. Symptom Duration	.27**			
3. Symptom Count	-.14**	.12**		
4. Search for MIL	-.18**	-.08	.11	
5. Presence of MIL	.06	.15**	-.16**	-.25**

*Correlation is significant at the .01 level (two-tailed).

**Correlation is significant at the .001 level (two-tailed).

Theme 2: Loss of meaning, identity, and self-worth.

Unsurprisingly, dysautonomia contributed to a loss of meaning, identity, and self-worth by undermining previous sources of meaning and fulfillment. Many individuals lost sources of meaning (e.g., employment, relationships, activities) due to their disabling symptoms and came to feel that their lives were meaningless. Some reported feelings of uselessness and confusion about their identity, especially when examining the self prior to and during illness.

One participant described feelings of shame, uselessness, purposelessness, and most critically, a longing for death, while pointing to the stark change in their quality of life before the onset

of symptoms:

"I am so sick I am not able to do many of the things I love such as working and hiking... I can't even shower alone now because I am a fall risk. I feel ashamed and wish MAID (medical assistance in dying) was available. I feel like I am a waste of air and have no purpose. My life before becoming disabled was amazing."

This sense of meaninglessness and worthlessness was echoed across many responses, highlighting the depth of existential distress associated with dysautonomia.

Table 5. Coefficients for Model Variables

	B	B	<i>t</i>	<i>p</i>
Search for Meaning Model				
Age		-.096	-.150	-2.513 .012
Symptom Duration		-.003	-.048	-.806 .421
Symptom Count		.137	.093	1.604 .110
Religious Practice Status		-.096	-.150	-2.513 .420
Presence of Meaning Model				
Age		-.019	-.027	-.462 .644
Symptom Duration		.011	.168	2.900 .004
Symptom Count		-.318	-.193	-3.428 <.001
Religious Practice Status		3.181	.203	3.681 <.001

Theme 3: Acknowledging loss and finding new meaning

Critically, an existentially positive theme emerged in a subset of respondents. These individuals acknowledged various forms of loss while adopting new sources of meaning. While previous themes highlighted the unpredictable nature of the condition, the present theme highlighted respondents' experiences of losing prior meaning sources and turning to inward, controllable, and advocational forms of meaning. Many described shifting from career or achievement-based meaning to finding joy in small daily experiences, creative pursuits, relationships, advocacy, or helping others in similar situations.

One participant described their efforts to find joy in the little things and purpose through advocacy:

"My condition has altered my life significantly to the point [sic] I can barely get out of bed some days... I've learned I have to find joy in the little things and find purpose in advocating for the people who can't and find purpose in the people around me."

Another participant wrote:

"My priorities have completely changed; I can no longer really be ambitious or strive for external validation; I've had to work very hard to be satisfied with inward purpose/meaning/validation instead... I have to find meaning that works for me and no one else. I have to learn to be satisfied with very little because I have no control over the quality of my life, only how I feel or think about it."

Across these accounts, participants emphasized finding meaning sources that work specifically for them in their current circumstances, often contrasting pre-illness meanings centered on ambition or activity with new, more internally or relationally focused meanings.

Q2: How did religion affect your experience of meaning in life while living with your condition?

We again used reflexive thematic analysis (Braun and Clarke, 2006) to analyze how active religious practice affected participants' experience of MIL while living with dysautonomia. A total of 101 responses were analyzed, from which core themes were constructed.

Theme 1: Religion as a source of meaning, comfort and hope.

Many participants found religion to be a source of sustained meaning, comfort, and hope in the face of suffering. Specifically, they described religion as providing a reason for their suffering, an avenue to turn to when feeling existentially isolated, and a source of hope that their suffering would ultimately end. Furthermore, many respondents explained the calming nature of prayer when health anxiety is high, describing religion as "one of the only things that brings me peace or meaning a lot of times."

One participant described their experience of turning to religion for meaning and comfort during worsening of symptoms: "I was an atheist for a very long time, and then when my symptoms got very bad and I was painfully alone. I turned to God because I didn't know what to do."

Similarly, another participant reported:

"I had to wrestle with my faith and my image of God more than ever during this process, but ultimately my faith is the one source of continual hope and purpose for me. It's hard to accept my new life/disability, but I trust I can still do the work of God with it."

These responses illustrate how, for some participants, religion became a key framework for sustaining meaning, comfort, and hope when other sources felt unavailable.

Theme 2: Feeling cheated by God.

In contrast to Theme 1, many individuals reported a deterioration of faith because of their condition. Some felt that if God exists, he is cruel; others recall being told they 'just need to pray more,' which intensified feelings of abandonment or blame. Unsurprisingly, several participants described giving up their beliefs altogether because their ongoing suffering felt fundamentally unfair.

Such characteristics can be observed by the following person's account:

"I feel as though my religion has not affected my life as much as my condition has affected my view on religion. I feel cheated by God."

Another individual reported their felt sense of cruelty while suffering with the condition:

"It feels as though there is an inherent cruelty in the condition. If there is a god, they are beyond cruel; if this is just nature, it's also meaningless."

Another participant wrote:

"My faith was everything but as I have lost more & more physical abilities and independence, I honestly have given up my beliefs. Becoming disabled has changed me."

Together, these accounts capture a pattern of deteriorating faith, in which participants felt cheated or even actively harmed by God, and struggled to find meaning within their previous religious frameworks.

Theme 3: Spiritual practices, rather than religion itself, as coping strategies.

Many individuals described the utility of engaging in spiritual - - and not necessarily religious -- practices as strategies for coping, regulation, or acceptance rather than primarily as way of enhancing or explaining meaning. In other words, participants often found comfort in certain practices without holding their focus on a God-figure. Participants contributing to this theme often described the calming benefits of such practices.

One participant wrote:

"It has helped calm my soul and accept that all things die. Then we are reconnected with the universe."

Another individual reported:

"Meditation helps my nervous system."

Another participant said:

"Massively. When my limitations became more severe it was the only way I could find to create some sense of still being able to be of benefit through dedicating my life to meditation practice and retreat."

Numerous individuals found benefits in spiritual, not necessarily religious, practices and frequently described meditation, contemplation, and their calming effects. Moreover, these responses suggest that spiritual practices may help some participants sustain a sense of MIL even when traditional religious beliefs are strained.

Discussion

In examining the relationship of MIL in individuals with dysautonomia, over half (50.8%) of whom reported experiencing LC and similar post-viral syndrome, we found that active religious practice, symptom duration, and symptom count predicted Presence of MIL. Specifically, active religious practice and longer symptom duration were associated with greater Presence of meaning, whereas greater symptom count was associated with less Presence of MIL. Meanwhile, age was the only significant predictor of Search for MIL and did not predict Presence of MIL. These findings confirm our hypotheses that religious practice status and symptom count served as predictors of Presence of MIL within the sample. We did not maintain specific hypothesis for symptom duration and age on Presence of MIL, nor did we for any of the variables on Search for MIL. Instead, these predictors were included for exploratory purposes. Importantly, the association between the predictors and Presence of MIL did not differ to a significant degree between etiological subgroups, indicating that these predictors relate to Presence of MIL similarly across groups with varying symptomatic profiles.

Existing research has shown active religious practice serves as a source of meaning for individuals experiencing LC and helps coping with other chronic illnesses, such as multiple sclerosis (Gordon et al., 2022; Lieberwerth and Niemeijer, 2024; Wilski et al., 2024). Consistent with this work, the present study found that participants who actively practiced a religion while living with dysautonomia reported higher Presence of MIL. Similarly, prior studies indicate that higher symptom count is associated with poorer health outcomes, including cognitive functioning, behavioral impairment, and HQoL (Crockford et al., 2025; Erickson et al., 2024; Park et al.,

2016). In line with these findings, our results showed that greater autonomic symptom count was linked to lower Presence of MIL, suggesting that experiencing a broader range of symptoms may undermine individuals' capacity to sustain meaning.

Furthermore, research examining symptom duration and HQoL shows mixed findings. While there is evidence of impaired HQoL with greater symptom duration in individuals with chronic illness and mental illness, this relationship differs across age groups (Busija et al., 2017). On the other hand, Arat et al. (2012) found no association between HQoL and disease duration in systemic sclerosis. It is worth restating that individuals with LC experience existential concerns during their experience with chronic illness (Fang et al., 2023). While our findings may help resolve the ambiguity concerning symptom duration and MIL, we cannot make any conclusions regarding symptom duration and quality of life. Additionally, a perplexing finding within the present study was that symptom duration positively predicted Presence of MIL, whereas symptom count showed the opposite relationship. One possible explanation is that, over time, some individuals gradually adjust to their condition and reconstruct a sense of meaning, whereas a higher number of concurrent symptoms may still overwhelm coping resources and undermine meaning. This interpretation is supported by the qualitative theme "Acknowledging loss and finding new meaning," in which participants described accepting long-term limitations and developing new, more sustainable sources of meaning despite ongoing symptoms.

On another note, the themes that emerged in the qualitative data align with previous thematic studies concerning those with LC. Specifically, our findings support Fang and colleagues' (2023) and Lieberwerth & Niemeijer's (2024) findings of existential concerns including meaning, identity, and uncertainty within our sample. It is important to note that while similar themes emerged as in the LC studies, our findings included responses from individuals who not only experienced LC and post-viral syndromes, but genetic and various acquired causes.

The theme "Acknowledging loss and finding new meaning" both supports prior work showing that many individuals eventually come to terms with their illness and adapt their sense of meaning, and helps contextualize the positive association between symptom duration and Presence of MIL, suggesting that the longer one lives with the condition, the better able they may be to develop new, adjusted sources of meaning. That is not to take away from the disabling nature of dysautonomia, which is evidenced in themes "Uncertain futures and narrowed worlds" and "Loss of meaning, identity, and self-worth." The theme "Religion as a source of meaning, comfort and hope," aligns with the positive relationship between active religious practice and Presence of MIL; however, the accounts depicting a loss of faith and a sense of being cheated by God demonstrate why practicing religion may not be beneficial for all individuals.

Clinical and Existential Implications

Although the qualitative responses emphasize the detrimental effects of dysautonomia on existential well-being, they also illustrate the potential to rediscover meaning despite ongoing symptoms. Participants described seeking meaning through attainable pathways, such as advocating for others with similar experiences,

engaging in religious or spiritual practices, and cultivating attitudes of acceptance, transcendence, and purpose. This aligns with Frankl's logotherapy (1963), which proposes that meaning can be found in three main domains: (1) purposeful work or creative projects, (2) relationships with others, and (3) the attitude one adopts towards inevitable suffering. Participants' narratives captured profound experience of loss, particularly through forfeiting careers, valued activities, and social connections, which often led to isolation and an altered sense of identity. Yet, many described turning to faith, creativity, relationships, and advocacy to restore a sense of meaning and comfort amid their struggles. These narratives illustrate existential resilience, a developing construct conceptualized as resilience grounded in a meaningful view of the world and one's place within it (Segersvård et al., 2025). Existential resilience has been studied in the context of adverse events (e.g., wartime conditions, COVID-19 restrictions) and is theorized to help maintain a sense of order and protect against nihilism in the face of existential threats (Shevchuk et al., 2023). In our sample, existential resilience was evident in participants' efforts to find new and adapted sources of meaning despite profound suffering, suggesting it may be a crucial therapeutic target for those with dysautonomia. Additionally, while the present study did not directly test Frankl's theory, the existential threat posed by dysautonomia suggests that future research should examine the utility of meaning-making and existential therapies.

Future Directions and Limitations

This cross-sectional design limits inferences about how MIL changes over time. Longitudinal studies could clarify whether Presence and Search of MIL shift as dysautonomia progresses and help disentangle why longer symptom duration relates to higher Presence whereas greater symptom count relates to lower Presence. Moreover, because the models explained only a small proportion of variance, future research should examine additional predictors such as social support (family, friends, partners, medical providers) and more nuanced spiritual or existential variables that may shape MIL for individuals with dysautonomia.

Once again, the 28-item autonomic checklist used to assess symptom count has not been previously validated. However, this measure is continually used by the previously mentioned autonomic clinic to guide patients' treatment and assess symptoms, which points to the measure's ecological validity and clinical utility. Critically, patients may only report a small number of symptoms yet experience their condition as severe. Thus, although the measure captures total symptom count, it does not capture symptom severity, which future studies should assess using validated severity or intensity measures.

Another limitation is that all responses were self-report. Some participants may have answered 'yes' to qualifying questions (e.g., "Have you been diagnosed with dysautonomia by a physician") inaccurately to complete the study for a chance at reimbursement. Despite this possibility, the sample closely matched the demographic profile of people with dysautonomia described in existing literature, in which White women of child-bearing age predominate (Bourne et al., 2021). This pattern is consistent with current epidemiological data but limits the generalizability of our findings to men and racially and ethnically diverse groups.

Finally, dysautonomia often has multiple, overlapping

etiological factors, and participants could endorse several origins. This overlap limits the precision with which etiological subgroups can be classified.

Conclusion

The present study found that symptom duration and active religious practice were positively associated with Presence of MIL, while symptom count was negatively related. Additionally, age negatively predicted Search for MIL. Taken together, these patterns and the qualitative themes illustrate both the existentially threatening nature of dysautonomia, and the existential resilience shown in attempts to maintain meaning despite ongoing symptoms. With increasing numbers of individuals affected by LC and related forms of dysautonomia, there is a pressing need for research to further examine psychological well-being and meaning in this population. Research on MIL in those with dysautonomia can inform future therapeutic treatment approaches that may help individuals find meaning despite their suffering.

Compliance with Ethical Standards

Disclosure of Potential Conflicts of Interest. The authors declare no conflicts of interest related to the research, authorship and/or publication of this article.

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Ethical Approval. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of a university on the East Coast of the United States (IRB: IRB-FY2025-68; Date: 18.2.2025).

Informed Consent. Consent was obtained from all participants included in the study.

Data Sharing Statement. The data file for this study is available upon request.

Author Contributions. Matthew Yeager conceptualized and designed the study, collected data, and drafted all sections of the manuscript. Jennifer Lyke guided conceptualization of the study, recommended edits for each section, and assisted in interpreting results and preparing methods and results sections. Zornitsa Kalibatseva assisted in conceptualization and study design and recommended edits for all sections besides the qualitative analysis. Matthew Yeager and Jennifer Lyke contributed to the final editing of the manuscript for requested revisions.

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