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# Spiritual well-being and quality of life are impaired in chronic urticaria

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## KEY WORDS

*Angioedema; chronic inducible urticaria; chronic spontaneous urticaria; quality of life; spirituality.*

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10.23822/EurAnnACI.1764-1489.189

## Summary

**Background.** Patients with chronic urticaria (CU) often report an impaired quality of life (QoL). Although a positive effect of addressing spirituality in health care has been proved in several chronic diseases, its potential role in CU has received no attention. **Objective.** We aim to evaluate spirituality and QoL in CU subjects. **Methods.** In a single-centre observational study, 100 CU subjects were investigated using Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12) scale, Chronic Urticaria Quality of life Questionnaire (CU-Q2oL) and Urticaria Control Test (UCT). **Results.** Of 100 subjects, 82 were female and 18 were male. It was observed that subjects with poorly controlled CU presented FACIT Sp-12 meaning/peace ( $p = 0.004$ ) significantly lower, and CU-Q2oL ( $p < 0.0001$ ) significantly higher (worst QoL) than subjects with controlled CU. There was no difference in the FACIT Sp-12 faith ( $p = 0.43$ ) between groups. There was moderate direct correlation between FACIT Sp-12 faith and FACIT Sp-12 meaning/peace ( $r = 0.483$ ;  $p < 0.0001$ ;  $n = 100$ ). There was a significant strong inverse correlation between the CU-Q2oL and the UCT ( $r = -0.762$ ;  $p < 0.0001$ ;  $n = 100$ ). No correlation was found between the FACIT Sp-12 faith and CU-Q2oL, neither with UCT. **Conclusions.** No study has ever investigated the role of spirituality in managing patients with urticaria. Our findings support the impact of poorly controlled urticaria in spiritual well-being and QoL. Therefore, clinicians should pay more attention to spirituality among CU patients. We suggest that urticaria guidelines should include specific recommendations on spirituality assessment.

## Impact statement

*The burden of poorly controlled chronic urticaria impaires patients' quality of life and spiritual well-being.*

## Abbreviations

**AAS:** Angioedema Activity Score  
**AE-QoL:** Angioedema Quality of Life Questionnaire  
**CIndU:** Chronic Inducible Urticaria  
**CSU:** Chronic Spontaneous Urticaria  
**CU:** Chronic Urticaria

**CU-Q2oL:** Chronic Urticaria Quality of life Questionnaire  
**FACIT-Sp-12:** Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being scale  
**MBS:** Mind-Body-Soul  
**PROs:** Patient Reported Outcomes

**QoL:** Quality of Life  
**SpWB:** Spiritual Well-being  
**GA2LEN UCARE:** Urticaria Center of Reference and Excellence  
**UCT:** Urticaria Control Test  
**UAS7:** Weekly Urticaria Activity Score

## Introduction

Chronic urticaria (CU) is a skin disorder in which red, swollen, itchy, and sometimes painful hives (wheals), angioedema, or both, repeatedly occur for more than 6 weeks (1). Prevalence is estimated up to 1% in the general population (2), with those aged between 30 and 50 years most affected, and females affected approximately twice as often as males (3-6). The current guidelines classify CU as spontaneous (chronic spontaneous urticaria (CSU), with no specified eliciting factor involved) or inducible (chronic inducible urticaria (CIndU), with a specific eliciting factor involved) (1). Patients may concurrently experience CSU and CIndU in approximately 20% of cases (4).

Existing evidence indicates that symptoms of CU have a deleterious effect on the quality of life (QoL) (2, 7-9). It impacts daily activities and emotional well-being; some patients' health status is comparable to that of coronary artery disease and severe asthma patients. It also causes inconvenience in family structures, compromising performance at work, school, and negatively impacting on leisure activities. It compromises patients' QoL, mainly those with more severe disease or who are diagnosed with chronic spontaneous urticaria (7, 10). Until now there are no reliable biomarkers to identify and measure disease activity in CSU. Consequently, use of patient reported outcomes (PROs) is crucial when evaluating and monitoring different aspects of chronic urticaria such as disease activity/severity, disease control, and QoL. Five different PROs that measure various aspects of disease severity/activity and QoL are used routinely in research and clinical practice of chronic urticaria. Three of these PROs are urticaria-specific: weekly Urticaria Activity Score (UAS7), Urticaria Control Test (UCT), and Chronic Urticaria Quality of Life Questionnaire (CU-Q2oL); and then two for angioedema: Angioedema Activity Score (AAS) and Angioedema Quality of Life Questionnaire (AE-QoL) (11-15).

In 1999, the World Health Organization (WHO) started to describe the QoL as multidimensional, in the physical, psychological, social and spiritual dimensions (16). Among those likely to be important is spiritual well-being (SpWB). Viewed as a multifaceted construct, SpWB usually refers to a sense of meaning or purpose in life, inner peace and harmony, and the strength and comfort drawn from faith (17). SpWB has been measured over two dimensions (Meaning/Peace and Faith). Recent studies suggest a broad protective relationship between religious participation and population health (18). Although a positive effect of addressing spirituality in health care has been proved in several chronic diseases, spiritual well-being in patients with CU has never received attention.

The aim of this study was to evaluate spirituality and QoL in CU subjects with different control levels (subjects with controlled CU and those with poorly controlled CU).

## Methods

### Patients

We conducted a prospective single-centre observational study with 100 consecutive patients from the outpatient clinic of a Urticaria Center of Reference and Excellence (GA2 LEN UCARE, www.ga2len-ucare.com) (18) at the Immunology Service of a university hospital. Patients were enrolled after informed consent was obtained. The study was submitted and approved by Comitê de Ética em Pesquisa do Hospital Universitário Clementino Fraga Filho (HUCFF-UFRJ), CAAE 45067715.5.0000.5257.

### Measures

#### *Urticaria control assessment*

The UCT is a developed and validated instrument to determine the level of disease control in all forms of CU. It was originally developed in German and it has been validated to Brazilian Portuguese by our group. Two forms of the UCT are available: the long form UCT (UCTlg) (8 questions) and the short form UCT (UCTsh) (4 questions). Because the results of both UCT forms have been found to correlate extensively, the more convenient UCTsh is primarily used, both, in clinical trials and routine patient care. The categorizing recommendation is poorly controlled CU (UCT < 12) and well controlled CU (UCT ≥ 12) (12, 15).

#### *Spiritual Well-Being*

SpWB was measured using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12) Questionnaire (20-22). This is a valid and reliable instrument, developed in 1990, to provide an inclusive measure of spirituality in research and clinical practice. It is a self-administered questionnaire that contains twelve, four point Likert scale, closed questions (0 = Not at all, 1 = little bit, 2 = Some-what, 3 = Quite a bit, 4 = Very Much) and 2 subscales in the Brazilian version: meaning/peace (items 1-8) and faith (items 9-12) (22-24) (**figure 1**). The total score was obtained by summing all individual items (range, 0-48, with higher scores indicating greater spiritual well-being), and the subscale scores were obtained by summing all items in each domain. The meaning/peace subscale measures sense of meaning, peace and harmony, and purpose in life (range, 0-32). The faith subscale assesses the association between illness, faith, and spiritual beliefs as well as how one finds solace in one's faith (range, 0-16) (23, 24).

#### *Quality of Life*

Quality of life was measured using the CU-Q2oL. The CU-Q2oL is a CSU-specific health-related QoL questionnaire consisting of 23 questions. The questions cover different aspects of CSU's impact on patients' lives including pruritus, swelling, daily life activities, sleep, appearance, and limitations. CU-Q2oL scores range from 23 to 115, with a higher score indicating stronger impairment of health-related QoL (13, 14).

**Figure 1** - FACIT-Sp-12 questions and punctuation (20, 21).

		Not at all	A little bit	Some -what	Quite a bit	Very much
Sp1	I feel peaceful.....	0	1	2	3	4
Sp2	I have a reason for living.....	0	1	2	3	4
Sp3	My life has been productive.....	0	1	2	3	4
Sp4	I have trouble feeling peace of mind.....	0	1	2	3	4
Sp5	I feel a sense of purpose in my life.....	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort.....	0	1	2	3	4
Sp7	I feel a sense of harmony within myself.....	0	1	2	3	4
Sp8	My life lacks meaning and purpose.....	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs.....	0	1	2	3	4
Sp11	My illness has strenghtened my faith or spiritual beliefs....	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay.....	0	1	2	3	4

Above is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

### Statistical analysis

First, to compare SpWB and QoL between the 2 groups (subjects with controlled CU and those with not controlled CU), univariate analyses were performed using a Mann-Whitney U test. Association between SpWB, QoL and disease control was assessed by Spearman's rank correlation coefficient.

Nonparametric models were performed because the scores had a non-Gaussian distribution, according to the rejection of the hypothesis by the Shapiro-Wilk normality test. A p value of < 0.05 was regarded as statistically significant. All statistical analyses were performed using SAS® System statistical software, version 6.11 (SAS Institute, Inc., Cary, North Carolina).

### Results

#### Subject Characteristics

Of 100 subjects, 82 were female and 18 were male (mean  $\pm$  standard deviation (SD) age, 43  $\pm$  15 years) (**table I**). Subjects distribution by age range are presented in **figure 2**, and characteristics of the subjects are summarized in **table I**.

#### Score Characteristics

**Table II** provides a description of the scores, in the total sample and by groups: poorly controlled CU (n = 45) and controlled CU (n = 55). The scores did not present a normal distribution (Gaussian), according to the Shapiro-Wilk normality test, at the level of 5%.

Therefore, the most appropriate measures for summarizing the data were by quartiles (median, interquartile range (Q1-Q3), minimum and maximum).

#### FACIT-Sp-12 Meaning/Peace, FACIT-Sp-12 Faith and CU-Q2oL between controlled and not controlled subjects

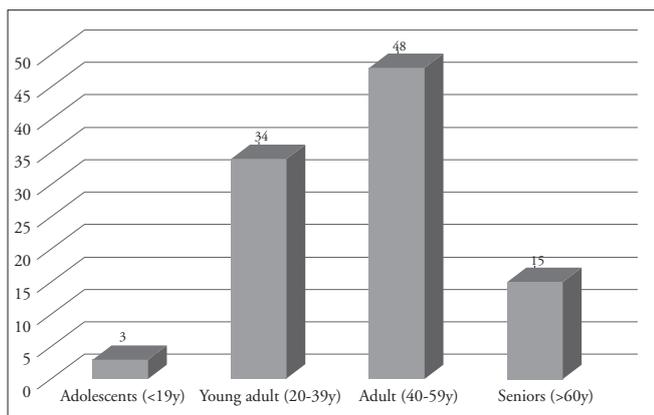
It was observed that subjects with poorly controlled CU presented FACIT Sp-12 meaning/peace (p = 0.004) significantly lower, and CU-Q2oL (p < 0.0001) significantly higher (worst QoL) than subjects with controlled CU. There was no difference in the FACIT Sp-12 faith (p = 0.43) between the groups.

#### FACIT-Sp-12 Meaning/Peace, FACIT-Sp-12 Faith, CU-Q2oL and UCT correlation

There was moderate direct correlation between FACIT Sp-12 faith and FACIT Sp-12 meaning/peace (r = 0.483; p < 0.0001). Significant moderate inverse correlation was found between FACIT Sp-12 meaning/peace and CU-Q2oL (r = - 0.457; p < 0.0001). FACIT-Sp-12 meaning/peace correlated weak with UCT (r = 0.331; p = 0.0007) (**figure 3**).

No correlation was found between the FACIT Sp-12 faith with UCT (r = 0.055; p = 0.58) (**figure 4**), neither with CU-Q2oL (r = - 0.113; p = 0.26).

There was a significant strong inverse correlation between the CU-Q2oL and the UCT (r = - 0.762; p < 0.0001) (**figure 5**).

**Figure 2** - Subjects distribution by age range.

## Discussion

To the best of our knowledge, this is the first study to assess spiritual well-being in subjects with CU. We found that subjects with poorly controlled CU appeared to experience spiritual well-being on a worst level than those with controlled CU. The skin is the largest organ of the human body and seems to be closely related to changes in emotions, psychological state, and spirituality. A very common example is how skin flushing, or pallor reflect some emotional states. Some authors mention that modern understanding of skin disorders and how to treat them have brought important advances, but sometimes treatment is hindered until the spiritual aspect is adequately addressed (25). Our study measured QoL and SpWB concurrently. We found that not controlled CU subjects present negatively associated with SpWB and QoL. This is in accordance with recent research which mostly demonstrated emotional distress affect CU and other skin disease patients QoL, leading them to have a low SpWB (9, 26, 27). Therefore, providing spiritual care might improve QoL among such patients.

In accordance with Brady *et al.* study on the evaluation of spirituality impact in quality of life of oncology patients we found that the faith subscale evidenced significantly smaller correlations with QoL than did the meaning/peace subscale (28). Faith's contribution seems to be smaller and not significant, having no impact patients' life enjoyment despite chronic symptoms. In a recent study which aim was to identify the different aspects of a family member's QoL that may be affected by having a family member with skin disease, faith was mentioned by a few participants (8%). Interestingly, the father of a patient with atopic eczema said: "my faith in God helps me, it gives me strength, hope and patience" (29).

Meaning/Peace was the best predictor of QoL in the CU patients' evaluated.

**Table I** - Patient sample characteristics.

<b>N. of patients</b>	100
<b>Gender</b>	
Females (n of patients)	82
Males (n of patients)	18
<b>Age <math>\pm</math> SD (range), years</b>	43 $\pm$ 15, (13-78)
<b>Types of Chronic Urticaria</b>	
CSU	51
CSU + CIndU	40
CIndU	9
<b>Angioedema</b>	65

SD: Standard deviation; CSU: chronic spontaneous urticaria; CIndU: chronic inducible urticaria.

In line with the UCT development study there was a strong correlation between UCT scores and CU-Q2oL (12). In this study we found that UCT scores didn't well correlate with FAC-IT-Sp-12 subscales, indicating that SpWB were not associated with CU patients' control status.

Current literature suggests several potential interventions intended to help individuals engage in positive spiritual coping. Life review has been suggested as a potential intervention. This intervention is targeted at helping individuals work through the meaning-making process to achieve a positive view of past and present life events (30).

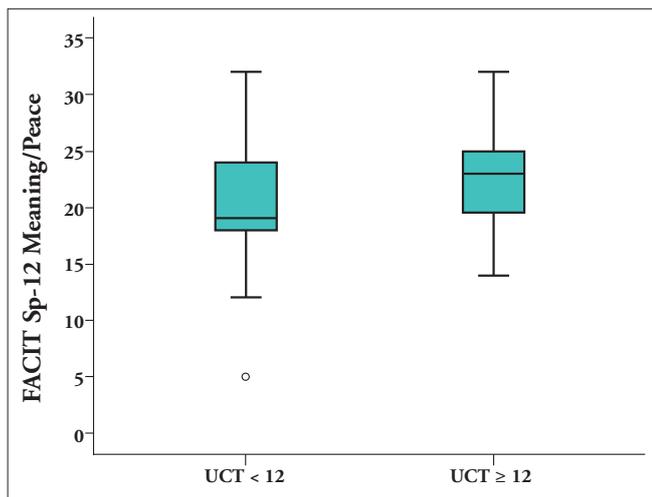
Mindful living and spirituality have been emphasized and promoted by the NIH (31), Mayo Clinic, and the National Psoriasis Foundation as a means to decrease stress and improve quality of life and as an adjunct to pharmacological therapy.

The literature indicates some patient-generated suggestions for interventions. Regarding spiritually related needs, some patients with end-stage heart failure suggested that home visits, visits from volunteers, and a supporting attitude from health care providers were important for their well-being (32).

Therefore, clinicians should pay more attention to spirituality among CU patients. Meditation, mind-body-soul (MBS) therapies, and yoga seems to improve stress and anxiety levels (33, 34).

## Conclusions

Spirituality as marked by the meaning of self and inner independence cooperates with the affective states to determine the QoL of patients with CU. Considering patients' spiritual concerns in the clinical setting is critical in enhancing QoL. No study has

**Figure 3** - FACIT Sp-12 Meaning/Peace correlation to UCT.

ever investigated the role of spirituality in managing patients with urticaria.

Facit-Sp-12 may be a complementary tool to clinical management and evaluation, but this does not substitute CU-Q2oL. Thereby, the clinical management can be doing through looking for self-knowlegde such as psychological approaches.

Our findings support the impact of poorly controlled urticaria in SpWB and QoL. For many patients, spiritual, existential, or religious beliefs can affect their understanding of illness and can influence treatment decisions. In line with worldwide promotion of patient-centered care we suggest that urticaria guidelines should include specific recommendations on focusing patients' spirituality assessment, such as using FACIT-Sp-12 in each medical appointment.

### Ethics

This research has been submitted and Approved by Comitê de Ética em Pesquisa do Hospital Universitário Clementino Fraga Filho (HUCFF-UFRJ), number CAAE 45067715.5.0000.5257.

### Fundings

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

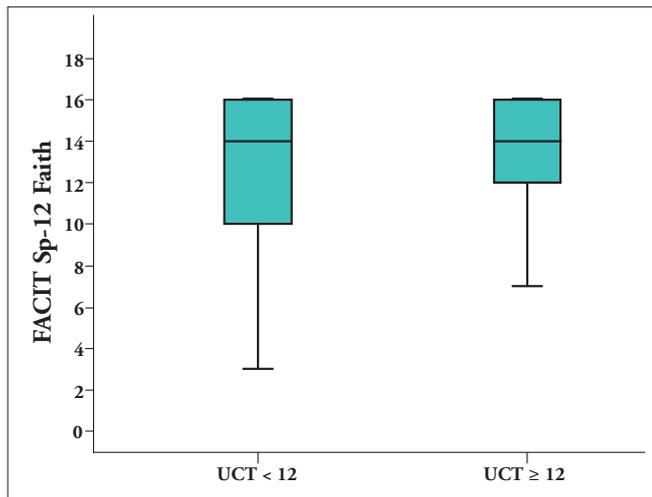
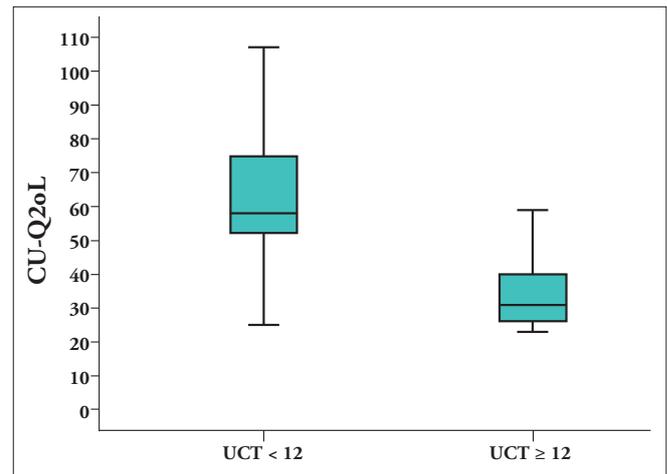
### Contributors

Sergio Dortas Junior analyzed data and drafted the manuscript. Guilherme Azizi analyzed data. Rafael Moret, Rossy Bastos Junior and Solange Valle drafted the manuscript. All authors approved the final manuscript.

**Table II** - Scores results and comparison between controlled and poorly controlled urticaria groups.

Scores	n	mean	SD	median	IQR	UCT	
						r <sub>s</sub>	p value
<b>Total</b>							
Facit Sp-12 meaning/peace	100	21.6	4.9	21.5	18 - 24	0.331	0.0007
Facit Sp-12 faith	100	13.1	3.1	14	12 - 16	0.055	0.58
CU-Q2oL	100	46.8	19.9	44	28 - 58	- 0.762	< 0.0001
UCT	100	10.9	4.7	12	8 - 15		
<b>UCT &lt; 12</b>							
Facit Sp-12 meaning/peace	45	20.0	5.0	19	17.5 - 24		
Facit Sp-12 faith	45	12.7	3.5	14	10 - 16		
CU-Q2oL	45	62.1	17.8	58	51 - 75		
UCT	45	6.8	3.7	8	4 - 11		
<b>UCT ≥ 12</b>							
Facit Sp-12 meaning/peace	55	22.9	4.4	23	19 - 25		
Facit Sp-12 faith	55	13.4	2.7	14	12 - 16		
CU-Q2oL	55	34.3	10.7	31	26 - 41		
UCT	55	14.3	1.6	14	13 - 16		

SD: Standard deviation; IQR: interquartile range; r<sub>s</sub>: Spearman correlation coefficient.

**Figure 4** - FACIT Sp-12 Faith correlation to UCT.**Figure 5** - CU-Q2oL correlation to UCT.

### Conflict of interests

Sergio Dortas Junior declares he received lecture fees from AstraZeneca Brazil. Sergio Dortas Junior and Solange Valle declare they received lecture fees from Novartis Brazil. Rossy Bastos Junior and Solange Valle declare they received lecture fees from Takeda Brazil. Guilherme Azizi and Rafael Moret have no conflicts of interest to declare.

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