Validation of a Brief Measure of Uncertainty in Vasculitis and Other Rheumatic Disease

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Background

- Patients with vasculitis and other rheumatic diseases are tasked with monitoring ambiguous and unpredictable physical symptoms on their own.
- Higher levels of uncertainty in rheumatic disease (URD) are associated with increased anxiety, depression, and sickness impact
- We aimed to develop and validate a brief measure of uncertainty.

Results

- The development step included 132 patients, 41 (31%) with AAV, 61 (46%) with IgG4-RD, and 30 (23%) with SSc.
- The EFA of the 22-item MUIS-S retained 7-items and captured 2-factors: ambiguity and unpredictability (**Table 1**).
- There was high internal consistency for the composite 7-item URD measure (α=0.85) and its subscales: ambiguity (α =0.79) and unpredictability (α =0.81).
- Convergent validity was found with anxiety (r=0.42, p<0.001), depression (r=0.47, p<0.001), and sickness impact (r=0.34, p<0.001).
- After controlling for age and sex, URD explained 23.2% of the variance in depression (p<.001),14.8% of the variance in sickness impact (p<0.001), and 14.2% of the variance in anxiety (p<0.001).
- In the CFA (validation), we included n=475 participants from the VPPRN (62% AAV) and confirmed good fit of the two subscale, 7-item measure
- Most patients expressed interest in a trial evaluating a mind-body intervention for vasculitis (**Figure 1A and 1B**).
- Most patients reported use of at least one mind-body practice in the prior month (**Figure 2**).

Limitations

- Both cohorts used in this study consisted of majority white, non-Hispanic, female respondents which may limit generalizability.
- Additional validation in vasculitis and other forms of rheumatic disease is needed

Conclusions

- We developed a brief, 7-item measure of URD with high internal consistency and convergent validity with measures of anxiety, depression, and sickness impact.
- URD explained a signification portion of the variation in anxiety, depression, and sickness impact and may be an important target for interventions to improve mental health and well-being
- Given the burden of anxiety, depression, and other mental health comorbidities in these conditions, this instrument can be useful for tailoring screening and referral pathways for healthcare services and consultation visits (e.g., specialists, supportive care).
- This measure may also be useful as part of research studies developing interventions aimed at improving resiliency in those facing high uncertainty and addressing modifiable causes of uncertainty

References

- Wallace ZS, Cook C, Finkelstein-Fox L, Fu X, Castelino FV, Choi HK, Perugino C, Stone JH, Park ER, Hall DL. The Association of Illness-related Uncertainty With Mental Health in Systemic Autoimmune Rheumatic Diseases. J Rheumatol. 2022 Sep;49(9):1058-1066. doi: 10.3899/jrheum.211084. Epub 2022 Apr 1. PMID: 35365580; PMCID: PMC9525460.
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Methods

Development of Brief Measure of URD

- Patients with antibody-associated vasculitis (AAV), IgG4-related disease (IgG4-RD), and systemic sclerosis (SSc) completed an online survey assessing URD (rheumatology-adapted version of the Mishel Uncertainty in Illness Scale, Survivor Version; MUIS-S), anxiety (GAD-7), depression (PHQ-8), and sickness impact (SIP).
- We performed a principal components exploratory factor analysis (EFA), with varimax rotation, of the previously adapted rheumatology-specific 22-item MUIS-S. Items were iteratively removed based on single factor low loadings (<0.6) or high cross loadings.
- We tested the brief URD measure for internal consistency (Cronbach’s alpha) and convergent validity (Pearson’s coefficient) with theoretically similar constructs (depression, anxiety, and sickness impact).
- We performed a series of hierarchal regression models assessing variance explained, by total uncertainty, controlling for age and sex.

Validation of the Brief Measure of URD

- Patients from the Vasculitis Patient Powered Research Network (VPPRN) were invited in an email to complete the brief 7-item measure and a confirmatory factor analysis was performed.
- VPPRN participants were asked about their interest in participating in a mind-body intervention trial for uncertainty and resiliency.

Table 1: The 7 Item Brief Measure of Uncertainty in Rheumatic Disease

Factor 1: Ambiguity	Factor 2: Unpredictability
1. The explanations that my rheumatology providers give about my condition seem unclear to me.	5. The course of my rheumatology condition keeps changing. I have good and bad days.
2. I have a lot of questions without answers.	6. The symptoms of my rheumatology condition continue to change unpredictably.
3. My rheumatology providers say things to me that could mean many things.	7. The results of my rheumatology tests are always changing.
4. I see so many different types of providers; it is unclear who is responsible for what.	*Responses are recorded on a scale: (1) Strongly Disagree; (2) Disagree; (3) Undecided; (4) Agree; (5) Strongly Agree*

Figure 1A: Interest in participating in an RCT that evaluates a mind-body intervention

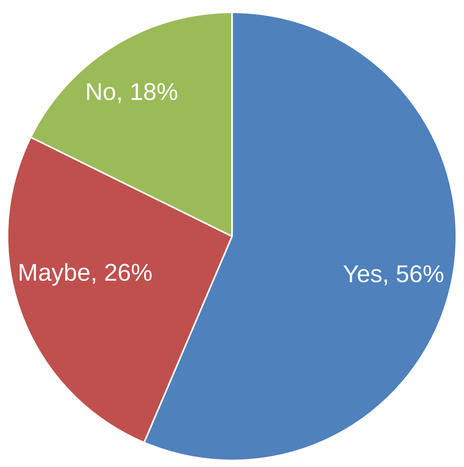

Figure 1B: Interest in participating if the visits were held over Zoom

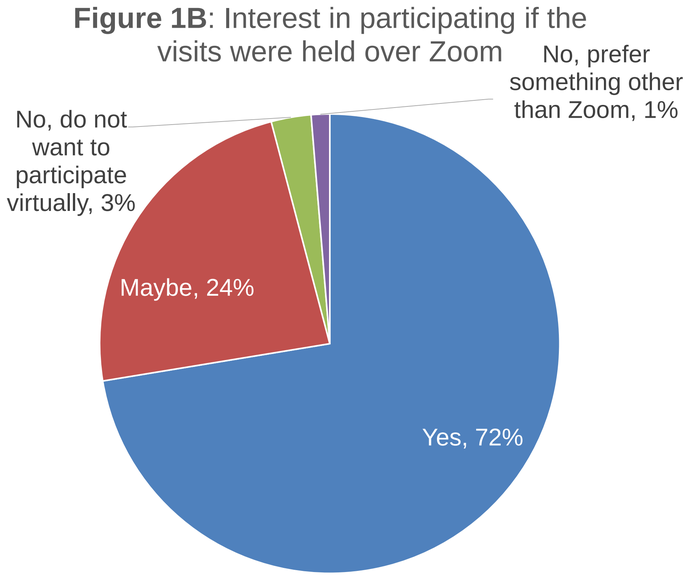

Figure 2: Mind-Body Practices Used in the Month Prior