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The Uncertainty in Illness Questionnaire (UIQ): development and validation of a clinically oriented measure for patients and caregivers

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Abstract

Objective The present research aimed to develop and validate the Uncertainty in Illness Questionnaire (UIQ), a self-report tool designed to assess uncertainty in illness (UI) among Italian-speaking patients and caregivers. Across three studies, the psychometric properties of the UIQ were rigorously evaluated in large, diverse samples.

Methods & results In Study 1, the novel exploratory graph analysis (EGA) revealed a robust four-factor structure – uncertainty about symptoms, treatments, future change, and relationships (optimal stability > .90, negligible cross-loadings). Such structure was then confirmed in Study 2, in an independent sample, through confirmatory factor analysis (CFA) with a hierarchical model with four first-order factors showing good fit (robust RMSEA = 0.065[90% CI: 0.056–0.075]; robust CFI=0.958; robust TLI=0.949; SRMR=0.043). UIQ demonstrated strong reliability, internal consistency, and both convergent and divergent validity. Measurement invariance analyses reached latent means invariance, revealing that UIQ is interpreted equivalently by patients and caregivers, supporting meaningful group comparisons. Following recent methodological guidelines, Study 3 demonstrated the discriminant validity of the UIQ with the Intolerance of Uncertainty Scale-Revised, measuring dispositional intolerance of uncertainty.

Conclusions The tool's brevity and clarity make it suitable for both clinical and research settings, especially where respondent burden must be minimized. The UIQ addresses an important gap in the Italian context, providing a validated, context-specific measure of UI. Convenience sampling, predominantly female participants (> 85%), cross-sectional design, and lack of clinical subgroup analyses limit generalizability. The tool requires cross-cultural validation beyond Italian-speaking populations. UIQ offers clinicians and researchers a reliable means to assess and address UI, ultimately supporting tailored interventions to improve psychological health in medical contexts.

Keywords Uncertainty in illness, Patients, Caregivers, Health psychology, Clinical psychology

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Introduction

The scientific literature has shown that when individuals confront illness in the process from diagnosis to long-term treatment, *uncertainty* plays a key role [82, 81]. There is uncertainty regarding prognosis, treatments, and the future, and this uncertainty is associated with negative psychological states, leading to worry, anxiety, and depression. The uncertainty in illness (UI) construct was first formulated within UI theory (UIT; [53]). UI is defined as "the inability to determine the meaning of illness-related events and accurately anticipate or predict health outcomes" [53, p. 225]. UI is a cognitive state occurring "when illness-related events are inconsistent with expectations, occur unpredictably, or have unclear causes, triggers, or patterns" [35, p. 2]. Thus, UI occurs in ambiguous, unpredictable, and complex illness-related situations. Uncertainty is experienced not only by patients, but also by their informal caregivers and family members, providing practical and emotional assistance [76, 77]. UI is significant because it can greatly impact both patients and caregivers, hindering their mental well-being, diminishing quality of life, and reducing satisfaction with treatment results [35].

Moreover, the dispositional trait of intolerance of uncertainty (IU) can amplify doubts and the unpredictability of situations [52]. IU is defined as a tendency to fear future events that are unpredictable and uncertain, with the conviction that uncertainty is undesirable [4, 9]. According to Freeston et al. [25], the construct of IU represents the cognitive, emotional, and behavioral reactions to uncertainty in daily life. According to Carleton [11, 12], IU is the dispositional inability to sustain the adverse reaction triggered by the perception that significant, key, or sufficient information is lacking and supported by the simultaneous uncertainty perception. High IU levels can lead individuals to negatively interpret uncertain circumstances, to perceive themselves as incapable of dealing with uncertainty, and to endure distress in emotions and affects [13]. Both IU and uncertainty distress during illness can significantly worsen the psycho-physical health of patients and caregivers. Specifically, they are linked to a greater risk of developing worry and severe anxious symptoms [6]. Additionally, as psychological health is connected to physical health, it can negatively impact therapy and physical condition.

Constructs differences and overlap

UI and IU are two distinct but strongly related constructs. IU is a general overarching transdiagnostic cognitive construct, and it is defined as the (dispositional) tendency to experience as deeply adverse those situations (situational IU) whose outcomes are unknown (but potentially known), independent of the valence of the potential result. Importantly, IU is not strictly related to a situation (e.g., illness) or given stimuli. In contrast, UI is specifically related to the health context; it can be considered context-specific and not a dispositional trait. However, people with high IU are more likely to also have higher perceived uncertainty and thus higher UI when dealing with illness. According to the uncertainty distress model [26], illness represents a life disruption that can increase dispositional IU; in turn, IU leads to situational and illness-related uncertainty (i.e., UI), with the associated psychological distress mostly in the form of worry and anxiety. Finally, UI is not only future-oriented as IU but also refers to events and circumstances in the present time, thus being related to ambiguity. In scale development and validation, assessing discriminant validity (DV) with similar scales is important [61] to avoid the jingle-jangle fallacy [34]; otherwise, one may measure something other than intended. DV concerns "the degree to which two measures designed to measure similar, but conceptually different, constructs are related. A low to moderate correlation is often considered evidence of discriminant validity" [59, p. 13].

Theoretical developments and measurement challenges in uncertainty in illness

While Mishel's ([53], p. 225) foundational UIT established UI as "the inability to determine the meaning of illness-related events and accurately anticipate or predict health outcomes", subsequent decades have witnessed significant theoretical refinements and accumulating evidence of measurement limitations in existing instrumentation. Understanding both theoretical evolution and psychometric challenges provides essential context for contemporary UI measurement development.

Kuang's [46] comprehensive reconceptualization, based on systematic analysis of 127 empirical studies, revealed that UI had been inadequately conceptualized as predominantly future-oriented prognostic uncertainty. His multidimensional framework demonstrated that UI encompasses temporally distinct dimensions (present-focused symptom ambiguity, future-oriented prognostic unpredictability, and retrospective doubts about disease causation), extends to relational uncertainty (interpersonal dynamics, stigma, role disruption), and includes existential dimensions (meaning-making, identity concerns). Complementing this expansion, Brashers and colleagues' [7] Uncertainty Management Theory reconceptualized UI as a neutral construct whose valence depends on appraisal processes, demonstrating that UI can be adaptive (e.g., diagnostic ambiguity maintaining hope) and is actively managed through information-seeking, information-avoiding, or reappraisal strategies mediated by social support. These theoretical developments suggested that measurement tools should capture UI's multidimensional nature and its subjectively experienced distress rather than mere perception.

Psychometric limitations in existing instrumentation

The Mishel Uncertainty in Illness Scale (MUIS; [52]) has served as the predominant UI measure globally, with numerous international adaptations. However, convergent evidence from recent psychometric re-evaluations reveals systematic limitations, including an outdated theoretical background (more than 40 years ago, 1981), suboptimal validation procedures with not completely satisfactory results, and redundancy in some items [48, 52]. Zhang's [81] systematic measurement review identified critical gaps: most MUIS applications proceeded without psychometric re-evaluation, adaptation studies rarely employed confirmatory factor analysis (CFA), disease-specific versions showed inconsistent factorial structures across samples, and no studies established DV with related constructs. Empirical validation studies documented these concerns across multiple contexts. Italian validation in chronic illness [28, 29] found only two of four original dimensions exhibited satisfactory properties, with inter-factor correlations exceeding 0.80, supporting unidimensional structure. Moreover, the MUIS Italian version is not accessible [28]; it has 33 items across 3 dimensions (ambiguity, inconsistency, complexity; the original unpredictability dimension was dropped), and despite their strong correlation, different CFA models were fitted for each scale independently. Spanish validation in multiple sclerosis using item response theory [71] identified only two stable dimensions in a refined 12-item version. Norwegian breast cancer validation [37] supported a simplified two-factor structure in a 5-item short form. Most recently, validation in cancer patients and caregivers [36] confirmed a two-factor structure with adequate-to-acceptable internal consistency (α = .66 - .78). These convergent findings reveal: *(1)* the theoretical four-factor structure rarely replicates empirically; *(2)* items exhibit cross-loadings and redundancy; *(3)* unpredictability and complexity dimensions show particular instability; and *(4)* high inter-factor correlations (> .80) indicate insufficient DV among subscales.

Methodological advances in psychometric evaluation

Contemporary scale development standards emphasize grounding instruments in current theoretical frameworks, employing rigorous methodologies beyond classical exploratory factor analysis, establishing measurement invariance, and demonstrating DV [1, 14, 55]. Recent methodological innovations have enabled more sophisticated psychometric evaluation, such as network psychometrics approaches [3, 24] conceptualizing items as causally interacting nodes rather than passive indicators of latent constructs, proving particularly valuable for multidimensional health constructs where dimensions are conceptually interconnected. Exploratory Graph Analysis (EGA; [32]), a network-based method, demonstrated superior accuracy over traditional exploratory factor analysis for detecting dimensional structure, particularly when inter-factor correlations are moderate-to-high [33] - a characteristic typical of UI, where symptom, treatment, prognostic, and relational uncertainties are interconnected. These methodological advances enable both more accurate dimensional identification and rigorous evaluation of structural stability through bootstrap resampling.

The present research: integrating theoretical advances, methodological rigor, and clinical challenges

The UIQ development responds to both theoretical evolution and identified measurement limitations by: *(1)* incorporating Kuang's [46] multidimensional reconceptualization through four dimensions capturing present symptoms, future changes, treatments, and relational/social impact; *(2)* addressing Brashers et al.;s [7] insight that UI valence matters by framing items as distressing UI ("How uncomfortable it is for you…") rather than mere perception; *(3)* employing rigorous validation absent in MUIS adaptations, including EGA for dimensional detection, CFA, measurement invariance testing across patients and caregivers, and explicit DV evaluation with dispositional IU; and *(4)* applying contemporary psychometric techniques to identify natural item clustering reflecting theorized causal interconnections among UI facets. The UIQ assesses four theoretically-derived dimensions of UI, consistent with Mishel's reconceptualized framework from 1990 and recent empirical findings [46], rather than claiming exhaustive coverage of all possible uncertainty facets.

Research gap

Despite significant theoretical advances and accumulating psychometric evidence, a validated, clinically-oriented tool for measuring UI in the Italian context is still lacking. From a clinical standpoint, most original research has relied on qualitative methodologies in restricted samples [7, 23, 77, 80], leaving key empirical questions unaddressed: how UI relates to other psychological constructs such as IU, health anxiety, anxiety, and depression, and how it associates with protective factors like self-esteem and resilience. Notably, the DV between UI and IU has never been empirically tested, either in Italy or internationally, despite their conceptual proximity.

This gap is especially consequential in the Italian context, where informal caregiving is a widespread and markedly gendered phenomenon. The family caregivers are approximately 3.5 million (34.4% of individuals with caregiving responsibilities). Females represent up to 80–90% of caregivers, predominantly aged between 45 and 55 [2, 40, 62]. This pattern mirrors broader Southern European trends, where traditional family models are associated with a higher proportion of female caregivers and with greater sex disparities in self-perceived health compared to Northern European countries [2]. Caregiving thus constitutes a prototypical sex inequality, with significant implications for females' psychophysical health and their broader socioeconomic participation.

Summarizing, there remains an unaddressed research gap consisting of a scale to measure UI that *(a)* considers the theoretical developments in recent decades (uncertainty vs. ambiguity); *(b)* has been validated *via* robust methodological process in Italian patients and caregivers; *(c)* does not contain instable or redundant items; *(d)* enables accurate measurement; and *(e)* has DV with similar but distinct constructs (e.g., IU).

The present research

This research aim was articulated into 3 Studies. Study 1 aims to develop an Italian self-report measurement tool evaluating UI, the Uncertainty in Illness Questionnaire (UIQ), so that it is updated, accurate in terms of content validity, and applicable to both patients and informal caregivers. In the first sample, Study 1 examined the UIQ validity and psychometric properties (e.g., item statistics, structural validity, consistency); EGA explored the UIQ dimensionality and selection of the best items for a short and psychometrically sound tool. Study 2 aims to confirm the goodness of the factorial solution emerged from Study 1 and tests it through a CFA in a second sample; psychometric properties (e.g., internal consistency, convergent-divergent validity, measurement invariance) across patients and caregivers were studied. Study 3 aimed to test the DV of the UIQ with the Intolerance of Uncertainty Scale-Revised (IUS-R), which is the gold standard measure to assess IU (see [5, 83]). As UI and IU are distinct despite similar constructs, the latent correlation between UIQ and the IUS-R was hypothesized to be moderate-high but not too high, thus supporting the DV of the UIQ with the IUS-R.

Study 1. Development of the UIQ and exploratory graph analysis

Methods

UIQ was developed, then its factorial structure was studied through exploratory graph analysis (EGA).

Development procedure

To develop the questionnaire, a well-established procedure was used (e.g., [68]). A group of expert clinical psychologists and methodologists with scientific expertise in both the clinical and the methodological domains formulated a pool of items assessing various components of illness-related uncertainty.

The item development procedure followed the theoretical operationalization to distinguish UI from IU. Items were explicitly designed to capture context-specific, illness-related uncertainty (UI) rather than dispositional IU. Operationally: IU items (e.g., IUS-R) assess trait-like tendencies: 'Unforeseen events upset me greatly' (situation-independent, dispositional); UI items (UIQ) assess state-specific UI: 'Not knowing when treatments will make you feel better' (illness-bound, present-focused or prospective).

The items were able to capture distress due to the uncertainty and unpredictability related to illness, including different aspects: information, symptoms, limitations, future change, medical treatments, physical impact, and relational impact. As these items reflect various facets of the same construct, the existence of a general overarching dimension of UI was hypothesized. The general instruction was "*How uncomfortable it is for you …*", which was then followed by the items, some examples are: '*not knowing enough about the medical condition*', *'not knowing how it will change your life'*, *'when the treatments will make you feel better'*, and *'if I will be able to physically handle what will happen.'* [1] Each item was rated on a 5-point Likert-type scale from 1 (= not at all) to 5 (= very much).

Second, items were selected by expert clinicians with a methodological background using clinical criterion: the best content validity, also considering each item for illness-specificity vs dispositional generality. Items with ambiguous referents were revised or eliminated. This process ensured that UIQ items are anchored to illness experiences, aligning with Mishel's [53] definition of UI as 'inability to determine meaning of illness-related events' rather than Carleton's [84] definition of IU as dispositional inability to endure adverse reactions to perceived lack of information.

UIQ contains items that are not specific to a given country or context. Only item #10 includes healthcare-specific references (nursing assistance, general practitioner, hospital support), capturing uncertainty about service availability, an aspect identified across various national health systems [7, 46].

In the Supplementary Materials, Table S1 shows the item selection results. A theoretical mapping table (in Supplementary Materials) systematically operationalizes the UI theoretical construct by linking each UIQ item to its facets from theoretical foundations: Mishel's reconceptualized UIT [54] distinguishing present vs. future uncertainty, Kuang's [46] multidimensional framework

[1] Translation in English for comprehensibility purposes only, not to be considered a validated English version of the items.

(temporal and relational dimensions), and Brashers et al.;s [7] medical-personal-social uncertainty sources.

Third, items underwent qualitative evaluation with a small sample (5 patients, 5 caregivers; diverse illness contexts) to verify comprehensibility and appropriateness. Participants evaluated all items' comprehensibility as good, identified ambiguous wording, unanimous consensus on relevance to illness experience was provided. While formal cognitive interviewing protocols (e.g., think-aloud, audio-recording) were not employed, this pretesting informed minor wording refinements before large-scale psychometric evaluation. At the end of this process, 16 items were obtained.

Psychometric properties and validity

To study the tool psychometric properties and validity, a cross-sectional design was used.

Inclusion and exclusion criteria

Participants with various types of physical and mental illness and medical conditions (e.g. oncological, cardiovascular, neurological diseases; degenerative conditions; genetic syndromes; mental illnesses) were recruited via public advertisements on social media platforms and snowball sampling [42]. Participants reported that these conditions were diagnosed by a specialist and resulted in significant physical and/or psychological limitations for the affected individuals and/or their caregivers. The inclusion criteria were: being aged 18 years or older; being a patient with physical or mental illness or their caregiver; reporting a diagnosis confirmed by a health professional. The exclusion criterion was inability to complete the survey because of perceptive, cognitive, or other impairments.

Measures

A self-report survey containing the following tools, in addition to the UIQ, was administered.

- *Demographic information sheet*: it collects information such as age, biological sex, nationality, civil status, education, employment status, previous mental and physical issues.
- *Illness information*: it included details such as type and duration of illness, relationship between patient and caregiver, length of caregiving role, daily caregiving time, reduction of work due to caregiving.
- *Intolerance of Uncertainty Scale-R* (IUS-R; [5, 79]): It is a self-report questionnaire assessing IU throughout the lifespan with 12 items rated on a 5-point Likert scale (1 = "Not at all", 5 = "very much"). The Italian version has a robust general factor; the total score is used as a measure of the construct [5].

Statistical analysis

All statistical analyses were conducted via R [64, version 4.3.0, RRID: SCR_001905] with bootnet [24], EGAnet [30], networkTools [43] packages. Preliminary analyses [17, 20] evaluated item normality, items' correlations ($\rho > .85$) [75], and item informativeness [58]. The novel EGA approach from psychometric networks [15] with GLASSO estimation [20, 32], polychoric correlations [85, 32], the 'Louvain algorithm' and parametric bootstrap (10,000 iterations) explored UIQ dimensionality and inspected whether the items are grouped together as hypothesized. EGA provides insight into whether each identified dimension represents a unique aspect of the construct, free from confusion caused by overlap with other dimensions. EGA was selected based on simulation studies demonstrating superior accuracy in dimension detection compared to parallel analysis and traditional EFA [21, 33]. Moreover, EGA offers advantages for visualizing item clustering and evaluating structural stability through bootstrap item stability indices, complementing rather than categorically surpassing traditional approaches. EGA has increasingly been applied successfully in measurement scales' validation [21, 47, 68] because of its multiple advantages over traditional exploratory factor analysis methods, offering improved accuracy in determining the precise number of dimensions [21, 17, 20, 18, 32] by illustrating how items group together and the strength of their relationships [86, 19, 32]. Then, item-level statistics were examined. Item stability (IS) measures how often the original dimension is precisely replicated across bootstrap, evaluating how consistently each item appears within a particular dimension (> .80 = stable item) [18]. The role of each node in maintaining the integrity of the dimensions was examined through network loadings, with sizes interpreted as small ($\lambda EGA > 0.15$), moderate ($\lambda EGA > 0.25$), large ($\lambda EGA > 0.35$) [18, 33]. McDonald's ω and Cronbach's α assessed dimensions' internal consistency. The Spearman ρ assessed the dimensions' correlations [22].

Results of study 1

Participants

The sample of Study 1 consisted of 408 participants (caregivers $n = 243$, patients = 165; 353 females (86.5%), males 55 (13.5%); aged 18 to 93 y.o., mean age 44.54 years with SD = 13.41). The sample demographic characteristics are in Table S2 in Supplementary Materials. Half of the sample was married (50%), and nearly a quarter were in a relationship (24.7%). Over half had a high school diploma (52.9%), and 64.4% were employed. Approximately 52.6% reported never having mental health issues. Among caregivers, 50.3% assisted their parents, 20% assisted their partners, and 19.4% assisted their children. Most caregivers (39.4%) had been providing care for more than five years, with the remainder providing care for shorter durations. The most common diagnoses among care recipients were cancer (16.13%), mental illness (14.26%), neurological disorders (10.14%), and dementia (9.68%). Patients primarily had inflammatory diseases (41.03%), autoimmune diseases (10.26%), and cardiovascular diseases (10.3%).

Preliminary analyses

UIQ items demonstrated normal distributions. No item was poorly informative (SD < 2.5 SD below the mean informativeness level, M_{SD} = 1.000 ± 0.140), so each item exhibited variability and contributed meaningful information. No correlation exceeded the critical level (0.85) [74]. There were greater associations between items of the same dimension and slightly lower correlations among items of different dimensions (lowest correlation between R_37 and S_4; highest correlation=0.84 between S_6 "Not knowing how severe the symptoms will be" and S_7 "Not knowing how long the symptoms will last"). Despite strongly correlated, S_6 and S_7 capture distinct facets of UI related to symptoms, the first focuses on the severity (e.g., pain intensity), the second on temporal persistence (e.g., pain duration), capturing different contents/facets of the construct [66]. Preliminary analysis tables and figures are in Supplementary Materials (Figure S1, S2).

Exploratory graph analysis

The bootstrapped EGA accurately detected the expected four-factor structure, revealing distinct subnetworks and correctly assigning each item to its hypothesized factor (Fig. 1) (median 4, 95%CI[4, 4], likelihood = 1). Investigation of items' semantic content confirmed that the EGA grouped the items in line with their initial development.

EGA-based item statistics Figure 1 shows the proportion of times each item is replicated in its empirical structure across bootstraps. Structural consistency (SC) expresses the extent to which each empirically derived dimension was exactly retrieved from the bootstrap. IS analysis showed that almost all the items (except 2) had an empirical dimension equal to 1 (100% replicated on their dimension in bootstrap) (see Supplementary Materials). SC and IS values > .75–.80 indicate sufficient stability [18], all items demonstrated excellent replication index (> 0.80) and optimal stability (≥ 0.80). These results exhibit the robustness of the UIQ four-dimensional structure.

EGA-based network loading The EGA-based network loadings (λEGA) (Supplementary Materials, Table S4) evaluate how much each node contributes to the dimensions' coherence, indicating the strength of each item's association with its dimension. Although some UIQ items had negligible EGA cross-loadings, they did not pose any concern regarding the UIQ's structure (see Supplemen-

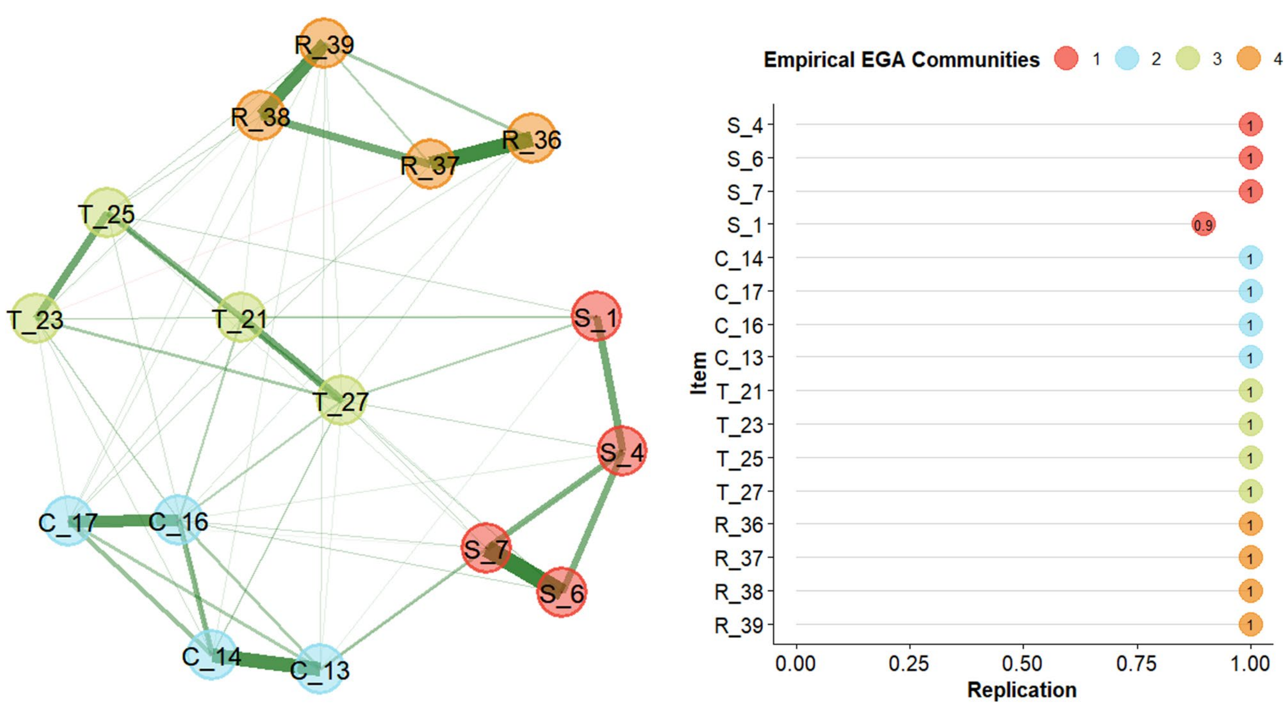

Fig. 1 Graphical representation of the bootstrapped EGA and the item stability analysis (Study 1). Note: dimension 1 in red = uncertainty about symptoms; dimension 2 in light blue = uncertainty about changes in the future; dimension 3 in green = uncertainty about treatments; dimension 4 in orange = uncertainty about relationships

tary Materials) (in general, they were consistently lower than their loadings on the original dimension or factor). Each UIQ domain showed good internal consistency (symptoms: ω = .786, α = .778; change: ω = .812, α = .804; treatments: ω = .872, α = .867; relationships: ω = .881, α = .868. UIQ total showed high correlations with all the dimensions; the highest correlation was with the 'change' dimension (ρ = .85), followed by 'treatments' (ρ = .84), 'symptoms' (ρ = .76), and 'relationships' (ρ = .70). The highest dimension correlations were between 'treatments' and 'change' (ρ = .65) and between 'symptoms' and 'treatments' and 'change' (both ρ = .61). The smallest difference was between 'symptoms' and 'relations' (ρ = .28). In Supplementary Materials, Figure S3 depicts the associations of EGA-based dimensions and the total score, and Table S4 shows descriptive statistics.

Comment of study 1

Study 1 tested the UIQ factorial structure and investigated its psychometric properties. EGA revealed that the UIQ items create four dimensions of UI: about symptoms, about treatments, about changes in the future, and about relationships. Each item had strong loadings on its designated dimension, supported by excellent indicators of IS, replication, and minimal cross-loadings. Item S_1 ("Not knowing enough about the medical condition") merits specific discussion. While created for the symptoms dimension and showing its strongest EGA loading there ($\lambda_{symptoms}$ = .154), it also exhibited a comparable loading on the treatments dimension ($\lambda_{treatments}$ = .139). The symptoms loading marginally exceeds the simulation-derived threshold for meaningful dimensional contribution (λ ≥ .15; [18]), while the treatments loading falls below it. This near-threshold pattern and the small difference between loadings (Δλ = 0.015) suggest that S_1 may capture a more general informational uncertainty spanning multiple domains rather than symptom-specific uncertainty. This interpretation aligns with the item's broad wording ("about the medical condition" vs. symptom-specific content in S_2–S_4). The appropriateness of the S_1 item on the first dimension is confirmed by the IS index derived from 10.000 bootstrapped EGA showing that item S1 has a stability of 0.90 (90% of the 10,000 times the item goes into the first dimension), which is optimal (> .80) and close to 1. Also item T_27 ("Not knowing whether the treatments will be effective") shows a loading of .139 on Symptoms and a way smaller cross-loading of .095 on Change, but its IS index is perfect (= 1). Study 2's CFA will provide critical evidence regarding whether S1's loadings stabilize distinctly on the symptoms factor in an independent sample, informing potential item revision or reassignment in future scale refinements.

Overall, these findings offer support for the construct validity of the identified dimensions [21] which all demonstrate reciprocal links [16, 69]. Although the dimensions exhibited noticeable correlations and interconnections, they remained distinctly separate, each item is grouped accurately within its theoretically predicted dimension, reflecting an optimal outcome [46, 54, 81]. The dimensions themselves preserve independence and differentiation within the overall structure. Furthermore, the EGA findings provide valuable insights into the items' relationships and spatial arrangement and the four dimensions [16, 69]. An accurate graphical representation further clarifies these associations, allowing for meaningful interpretation. All UIQ items resulted in stability within and across the dimensions for which they were intended.

Study 2. Construct validity of the UIQ

Study 2 had two aims: testing UIQ structural validity via CFA, and evaluating convergent-divergent validity; testing the UIQ MI between patients and caregivers.

Methods

Using a cross-sectional design. participants were recruited online via the same procedure as in Study 1.

Sample size determination for CFA

To predetermine the CFA sample size, the number of parameters was considered. With items with a response scale of less than 5 points, estimators for categorical items should be used [65], and the parameters should include thresholds. The "n: q criterion" [70, 8, 39, 44] calculates the sample size a priori relying on the number of respondents (n) and the number of estimated parameters (q): recommended minimum is 5 (or 10) respondents per free parameter. A ratio of at least 15 respondents per parameter was ensured (551\36 = 15.31) [86, 87].

Procedure

Study 1 procedure was replicated. A survey including UIQ and other questionnaires was pilot-tested (30 participants) to estimate completion times (10–20 min) and verify items' clarity. Participants were recruited from the general population through social media via snowball sampling [42]. Invitations outlined the study's participation criteria, those who consented were allowed to complete the survey. Inclusion criteria matched those of Study 1. This study adhered to the ethical guidelines set by the Psychology Ethical Committee of the University of Padua (protocol #4277) and included all three studies of this research.

Measures

The sociodemographic questionnaire from Study 1, along with UIQ, gathered general demographic data and assessed UI.

The demographic information sheet gathers information such as age, biological sex, nationality, civil status, education, employment, previous mental and medical difficulties (10 items).

Illness information It includes details such as the type and duration of the illness, relationship between the patient and caregiver (parent, partner, etc.), duration of caregiving role, daily caregiving time, and any reduction or cessation of work dedicated to caregiving (10 items).

Psychological variables were measured via the following self-reports all validated in Italian.

Uncertainty domain *Intolerance of Uncertainty Scale-R* (IUS-R; [79]; Italian version by [5]): It is a self-report assessing IU throughout one's lifetime with 12 items rated on a 5-point Likert scale (1 = "Not at all," 5 = "very much"). The Italian version has a robust general factor; the total score is used as a measure of the construct [5]. ω in this study was .93.

Uncertainty in Illness Questionnaire (UIQ): A self-report to measure UI with 16 items rated on a 5-point Likert scale (1 = not at all to 5 = very much) across 4 subscales, each of 4 items: uncertainty about symptoms, about treatments, about future change, and about relationships.

Health-illness domain *Health Anxiety Questionnaire* (HAQ; [49]): it is a self-report with 21 items rated on a 4-point Likert scale (1 = "Never or rarely" to 4 = "Almost always") to investigate health anxiety and associated behaviors. HAQ has 4 subscales probing health anxiety characteristic manifestations along with the cognitive-behavioral model: "Fear of death and illness" (ω = .92), "Concern about health status" (ω = .86), "Seeking reassurance" (ω = .78), and "Interference with daily activities" (ω = .87).

Psychological impact domain *Patient Health Questionnaire* (PHQ-9; [45, 72]): It has 9 items with a Likert scale (0 = never, 3 = nearly every day) assessing depressive symptoms. ω in this study was .89.

Generalized Anxiety Disorder Scale (GAD-7; [72, 73]): it has 7 items measuring state anxiety severity using a Likert scale (0 = never, 3 = nearly every day). In this study, ω was .94.

Scheda Ansia-Depressione forma Ridotta: Ansia (AD-R Anx; [57]); it was created to measure anxiety in patients dealing with physical illness. It has 10 items scored on a 4-point Likert-type scale. Higher scores indicate higher anxiety. ω in this study was .94.

Scheda Ansia-Depressione forma Ridotta: Depressione (AD-R Dep; [57]); it was created to measure depression in patients with physical illness. It has 15 items scored on a dichotomous scale (false = 0, true = 1). Higher scores indicate higher depression. ω in this study was .84.

Penn State Worry Questionnaire (PSWQ) [6, 51, 56]: The most widely used scale to measure worry severity, the anxiety cognitive component. It has 16 Likert items ranging from 1 to 5, including 5 reverse-scored items. ω in this study was .94. A recent study [6] showed that the PSWQ-11, without the reverse item, represents a better measure of worry, in this study it showed optimal internal consistency (ω .=95).

Protective factor domain *Resilience Scale* (RS-14; [10, 78]): It investigates resilience, the ability to cope with and adapt to stressors and positively reorganize one's life in the face of difficulties. Comprises 14 items asking about the level of agreement on a 7-point Likert scale (1 = strongly disagree, 7 = strongly agree). In this study, ω was .94.

Rosenberg Self-Esteem Scale (RSES) [63, 67] is a widely utilized unidimensional self-report measuring self-esteem. It has 10 items, with a mix of positively and negatively phrased statements. Participants rated their level of agreement on a 4-point Likert scale from 1 ("not at all") to 4 ("always"). Higher scores reflect higher self-esteem. In this study, ω was .93.

Statistical analysis

R software [64]; version 4.3.0, RRID: SCR_001905) was used with the packages *lavaan* [88] and *psych* [89]. The factorial structure emerging from EGA results was specified and tested in a CFA model testing the UIQ factorial structure with maximum likelihood (MLM) estimator [8, 38, 44], item thresholds were estimated. Considering the Study 1 results and the construct nature, a hierarchical second-order structure was specified [8]: each item loaded on its specific first-order factor, and each first-order factor loaded on a 'general' factor called 'uncertainty in illness'. Model goodness of fit was evaluated through various indices, relying on the conventional cutoffs [8, 38, 44, 90. 91]: χ^2 with $p > .05$ - but the χ^2 statistic is sensitive to large sample sizes and produces statistically significant χ^2; root-mean-square error of approximation (RMSEA) < 0.05 for good fit and < 0.08 for acceptable fit; CFI > 0.90 for acceptable fit and > 0.95 for good fit; Tucker–Lewis index (TLI) greater than 0.90 or 0.95 indicates a reasonable fit; standardized root mean square residual (SRMR) < 0.08 for good fit. [92] and [93] assessed scales' internal consistency. Spearman's coefficients assessed convergent-divergent validity.

UIQ invariance between patients and caregivers was tested via MI multigroup CFAs, testing a succession of hierarchical (nested) models in which specific model parameters are sequentially constrained to be equal (invariant) across groups, following an increasingly restrictive and ordered modality [50]. When dealing with ordinal response scale [8], the 'classical' procedure can be followed [50, 94, 90, 95], as described in the Supplementary Materials.

Results of study 2

A sample of 551 participants (484 females, 87.8%; 67 males, 12.2%) aged 18–93 y.o. (mean = 43.93, SD = 13.354) completed the survey. In Supplementary Materials, Table S5 reports the demographics' descriptives. Most participants were married (44.7%), had a high school diploma (49.2%), were employed (65%), and reported no history of mental health issues (54.9%). Most caregivers cared for parents (56.1%), partners (18.4%), or children (12.1%), 29.1% provided care for > 5 years. Common diagnoses among care recipients were cancer (14.55%), dementia (9.45%), mental illness (9.09%). Patients most frequently had inflammatory diseases (27.27%), Meniere syndrome (10.91%), and cancer (10.91%).

Items' response distributions showed acceptable skewness and kurtosis (<|2|), with no severe floor or ceiling effects; full descriptives are reported in Table S7 (N = 551). Regarding the distribution of items' responses across categories, item C_13 had the highest value, and item R_36 had the lowest scores. Regarding the correlations among UIQ items, the highest was between S_7 and S_6 (ρ = .84), and the lowest was between S_4 and R_36 (ρ = .15) and between R_38 and S_1 (ρ = .15). The item properties are reported in the Supplementary Materials (Table S6, Figure S4; Figure S5; Table S7).

Structural validity of the UIQ

A second-order hierarchical CFA tested the UIQ structural validity and provided a non-acceptable fit to the data ($_{robust}$CFI=0.934, $_{robust}$TLI=0.931, $_{robust}$RMSEA=0.082, 90%CI of $_{robust}$RMSEA[0.073–0.090], SRMR=0.053. All loadings were statistically significant and high (Supplementary Materials, Table S8). Modification indices inspection [8, 38, 96] revealed that correlating the residuals of R_36 ("Not knowing how others will react - friends, family, colleagues") and R_37 ("Not knowing whether and how my relationships with others will change") could improve the model fit ($\Delta\chi^2$ = 154.114). A deep examination of their content and meaning indicated potential nonindependence, because of substantial semantic and content overlap with the relationships of others, while still capturing theoretically distinct facets (R_36: focuses on the others' reactions, R_37: focuses more on self, relationships and social roles). Following established guidelines [8], residuals were correlated because: *(1)* items belonged to the same subscale, *(2)* semantic similarity was evident, and *(3)* modification indices exceeded 10.

After correlating R_36 and R_37 residuals, the model fit improved (R_36-R_37 latent correlation = 0.558). Despite a statistically significant χ^2[$SB\chi^2_{(99)}$ = 278.529; p<.001], other fit indices suggested good model fit: $_{robust}$RMSEA=0.065 [90%CI: 0.056–0.075], $_{robust}$CFI=0.958, $_{robust}$TLI=0.949, and SRMR = 0.043. Figure 2 shows the graph of the final CFA model of UIQ. In the CFA model with correlated residuals each UIQ item significantly loaded on its latent factor ($_{mean\ loading}$= 0.773; $_{SD\ loading}$ = 0.109),

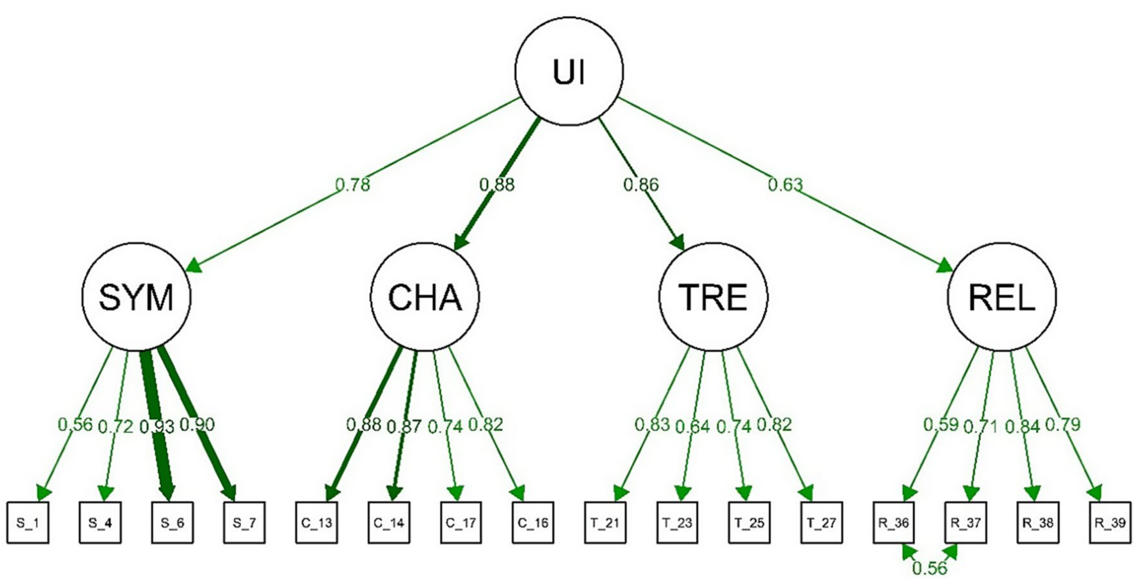

Fig. 2 Representation of the structural model of Uncertainty in Illness Questionnaire (Study 2)

ranging from 0.557 (S_1) to 0.932 (S_6). The variance explained by the items (R^2) ranged between 0.310 (S_1) and 0.869 (S_6) (mean = 0.608, SD = 0.163) (SM, Table S9).

Psychometric properties of UIQ

Each UIQ dimension showed optimal internal consistency (ω_{total}: 'symptoms'=0.886; 'change'=0.928; 'treatments'=0.869; 'relationships'=0.901) and for the general total score ($\omega_{hierarchical}$ = 0.767; α: 'symptoms'=0.86 with 95%CI[0.83, 0.87]; 'change' = 0.89 with 95%CI[0.88, 0.91]; 'treatments' = 0.85, 95%CI[0.82, 0.87]; 'relationships'=.85, 95%CI[.82, .87]; and general total score = .91, 95%CI[.89, .93]). Table S10 shows the descriptives of the UIQ-observed dimensions, Figure S6 shows the correlations among UIQ factors and general total score.

With respect to convergent validity (Supplementary Materials, Figure S7), UIQ total score shows high positive associations with constructs related to negative affectivity (anxiety ρ = .48, IU ρ = .44, worry ρ = .47, health anxiety ρ = .38, depression with PHQ-9 ρ = .39, with AD-R ρ = .43). The pattern is the same for the UIQ dimensions. These findings support the UIQ convergent validity. About divergent validity, the UIQ total score was negatively correlated with the protective factors: resilience (ρ = −.24), self-esteem (ρ = −.34). The scales' descriptive statistics are in the Supplementary Materials (Table S10).

The MI of the UIQ between patients and caregivers was tested using the ML estimator and robust fit indices: UIQ reached configural, metric, scalar, and latent means invariance. Table 1 shows the models' fit and model comparison results. Detailed information about MI models is in the Supplementary Materials.

Comment on study 2

Study 2 tested the UIQ factorial structure through a confirmatory approach in a new independent sample. The specified structure was the one identified by the EGA in Study 1. As the four dimensions of the UIQ all reflect distinct but similar and correlated facets of the general construct of the UI, a second-order factor structure was specified, with 4 first-order factors reflecting the general construct of the UI. The residuals of items #36 and #37 were correlated because of semantic and content redundancy – nevertheless, correlated residuals represent a pragmatic rather than ideal solution. Still, this practice is considered acceptable when items belong to the same dimension [97, 68]. Moreover, a semantic inspection of the item content confirmed that the overlap is statistical rather than conceptual, with each item capturing a distinct facet of the construct. The CFA subsequently supported the UIQ strong structural validity, with all dimensions demonstrating good fit indices. Each item showed strong loadings on its intended latent

Table 1 Fit of the models for measurement invariance of the UIQ across patients and caregivers (Study 2)

Models	df	AIC	BIC	Robust χ^2	Robust $\Delta\chi^2$	Δ df	Δ pr(>χ^2)	Robust CFI	Robust TLI	Robust RMSEA	Δ CFI	Δ RMSEA
Patients	99	13254.513	13394.855	204.697	-	-	-	0.959	0.950	0.065	-	-
Caregivers	99	9439.364	9565.429	208.258	-	-	-	0.937	0.924	0.079	-	-
Configural	198	22,758	23,215	412.897	-	-	-	0.950	0.940	0.071	-	-
Loadings	213	22,752	23,145	439.593	-26.696	15	0.027*	0.949	0.942	0.070	0.002	0.001
Intercepts	224	22,785	23,130	492.013	-52.42	11	< 0.001***	0.940	0.936	0.073	0.008	0.004
Means	229	22,824	23,148	542.765	-50.752	5	< 0.001***	0.932	0.928	0.078	0.009	0.004

Note: df = degrees of freedom; AIC = Akaike Information Criterion; BIC = Bayesian Information Criterion; χ^2 = chi-square test of model fit; $\Delta\chi^2$ = chi-square difference from the previous (less constrained) model; Δdf = change in degrees of freedom; pr(>χ^2) = p-value for chi-square difference test. CFI = Comparative Fit Index; TLI = Tucker-Lewis Index; RMSEA = Root Mean Square Error of Approximation; ΔCFI and ΔRMSEA represent changes in CFI and RMSEA relative to the less constrained model. A ΔCFI ≤ 0.01 and ΔRMSEA ≤ 0.015 indicate acceptable invariance. $p < .05$ (*), $p < .001$ (***)

factor, indicating that the items effectively represented the underlying constructs [8, 44]. The four first-order dimensions of 'uncertainty about symptoms', 'uncertainty about treatments', 'uncertainty about change in the future', and 'uncertainty about relationships' all load onto a latent general factor of higher order that captures general UI. Additionally, UIQ had strong psychometric properties. Convergent validity was supported by significant positive correlations with IU, anxiety, worry, and depression. Divergent validity was evidenced by negative correlations with resilience and self-esteem. The MI results indicated that the UIQ demonstrated invariance between patients and caregivers: UIQ fits well for both patients and caregivers separately; UIQ has the same configural structure for both patients and caregivers (multigroup configural, same structure); UIQ met the criteria for metric invariance, patients and caregivers interpret the items with the same mean strength (equal loadings); scalar invariance, the items are interpreted by patients and caregivers starting from the same level (equal loadings and equal intercepts); and latent mean invariance, both groups had equivalent expected means for the latent trait. Thus, patients and caregivers can be compared by using the UIQ. Evaluating and reaching MI across diverse populations is crucial for scale validation. While UIQ achieved latent means invariance between patients and caregivers (ΔCFI<.01, ΔRMSEA<.015), several caveats limit practical interpretability: female over-representation in both groups (beyond caregivers being mostly female) may mask sex-specific measurement differences, MI should be re-tested in sex-balanced samples; we established patient-caregiver equivalence across illness types, not within specific diagnoses, the role of illness heterogeneity remains unknown (e.g., cancer patients interpret items equivalently to dementia patients; acute vs. chronic illness contexts affect item meaning).

Study 3. Assessing the UIQ Discriminant Validity

Materials and methods

Study 3 included 925 participants: 548 patients (85.2% females, age_{mean} 42.27 ± 12.88) and 377 caregivers (89.9% females, age_{mean} 47.340 ± 13.698). Most caregivers assisted a parent (53.8%), partner (18.8%), or child (15.4%). About one-third (33.2%) had been providing care for >5 years, while the rest had shorter durations. The most common patients' diagnoses were cancer (15.7%), mental illness (12.2%), dementia (10.9%), neurological disorders (10.5%), Alzheimer's disease (8.0%), cardiovascular (8.0%) and Parkinson's disease (7.8%). Among patients, inflammatory diseases were most prevalent (33%), followed by cancer, autoimmune, and neurological diseases (each approximately 6.8%), Meniere syndrome (5.9%). Table S11 in Supplementary Materials shows the variables' descriptives.

Sample size was determined a priori in line with the "n: q criterion" [39, 98], ensuring a ratio of 5 respondents (n) for each free parameter (q) (n = 146), the minimum sample size was 725.

Measures

The measures to assess DVs were the IUS-R and the UIQ as in the previous studies.

Statistical analysis

R software [64] was used for statistical analyses. DV was assessed following recent methodological recommendations [66]. A structural equation model (SEM) incorporated both the UIQ and IUS-R measurement models. Latent variable scaling was applied, the diagonal weighted least squares (DWLS) estimator was chosen [8, 38, 99], Correlations between latent factors were freely estimated with their 95%CI. A recent review [66] identified CFA and SEM as the most effective methods for assessing DV, focusing on latent correlations and model fit comparisons: rxx(cut) supports DV when the latent correlation is < 0.85, whereas CIxx(cut) checks if the upper bound of the 95%CI for the correlation is < 0.85. SEM fit is assessed via nonsignificant χ^2, CFI > 0.95, RMSEA with 90%CI < 0.08, and SRMR < 0.08 [8, 38, 44]. More about techniques assessing DV is in the Supplementary Materials [61].

Results

Initially, correlation-based methods were applied, focusing on the point estimate of latent correlation and its 95% CI. Model fit criteria (e.g., $\Delta\chi^2$ cutoff and ΔCFI cutoff) were employed as cutoff indicators.

Unconstrained model: ρxx(cut) & CIxx(cut)

The SEM with the two measurement models showed excellent fit to the data: $\chi^2_{(df = 345)} = 1906.924$ with p<.001, CFI = 0.99; RMSEA = 0.070, RMSEA 90%CI[0.067, 0.073]; SRMR = 0.059. All items demonstrated strong and statistically significant loadings on their respective constructs (p <.001), supporting scale's dimensionality and construct validity. UIQ showed a strong and statistically significant latent correlation with the IUS-R: 0.523, 95%CI[0.513, 0.533]. As all correlations between latent factors were below the recommended cutoff (0.85), the relatively low correlation between UIQ and IUS-R supported DV. In Supplementary Materials, Table S12 presents the latent correlations along with their 95%CIs in the unconstrained model, and Figure S8 shows the SEM diagram.

Comparison of unconstrained and constrained models: χ^2(cut) & CFI(cut)

The χ^2(cut) and CFI(cut) methods assessed DV. The χ^2 fit of the unconstrained model (latent correlation freely estimated) was compared to a model in which the latent correlation between UIQ and IUS-R was exactly 0.85. χ^2(cut) and CFI(cut) criteria evaluated the models' comparison (Table S13). Considering $\Delta\chi^2$(cut), when the latent correlation of UIQ and IUS-R was 0.85, the model did not reach an acceptable fit (RMSEA=0.125; SRMR=0.105). The $\Delta\chi^2$(cut) was 3461.6 and was different from 0 (p <.001). The correlation between the UIQ and IUS-R was significantly different (< 0.85), thus supporting the DV between UIQ and IUS-R. Regarding ΔCFI(cut), the models ΔCFI= 0.021 supported the unconstrained model with latent correlation = 0.523, supporting the DV presence (CFIunconstrained=0.990; CFIconstrained_.85=0.969).

Comment on Study 3

Study 3 aimed at assessing the DV of the IUS-R, the gold standard measure of IU, with UIQ in a large sample of patients and caregivers, results supported their DV. The unconstrained model (latent variable correlation freely estimated) with its 95%CI fell below the 0.85 threshold indicating DV; the unconstrained provided better fit, supporting DV. DV of UIQ with IUS-R is theoretically explained by the fact that the IUS-R measures IU as a dispositional and overarching transdiagnostic construct. The UIQ is strongly related to the IUS-R, but they measure distinct constructs. UIQ specifically assesses uncertainty related to illness in its facets related to symptoms, treatments, future change, and relationships. Indeed, UI represents a specific illness-related subdomain of situational IU. UI is exclusively related to the health context and could be considered context-specific but definitely not a dispositional trait such as IU. Moreover, according to the uncertainty distress model [26], when dealing with illness, persons with higher dispositional IU are more likely to also perceive higher situational uncertainty and thus higher UI. Moreover, the illness experience represents a life disruptor, and situational IU associated with illness may coincide with context-specific UI [26]. Finally, although IU is future oriented, UI not only is future oriented but also refers to events and circumstances that are present, thus being related to ambiguity.

Discussion

This research developed and validated a self-report to measure UI in patients and informal caregivers, the UIQ, across three studies involving adult patients and caregivers from the Italian population. Study 1 revealed a stable four-dimensional structure (uncertainty about symptoms, treatments, future changes, and relationships) each dimension representing a distinct yet interconnected facet of UI. This factorial clarity aligns well with extant theoretical frameworks [46, 54], confirming that the UIQ captures the UI multi-layered nature. Building upon these findings, Study 2 validated the four-factor structure with a hierarchical model representing a general UI construct, demonstrating excellent fit and strong item loadings, supporting structural validity. All subscales demonstrated internal consistency, theoretically consistent correlations with related constructs (e.g., IU, anxiety, resilience, self-esteem) supporting convergent-divergent validity. MI demonstrated that UIQ operates equivalently among patients and caregivers. While UIQ's transdiagnostic design enables application across diverse conditions, formal MI testing across specific diagnostic categories (e.g., cancer vs. neurological vs. chronic illness) was not conducted. Future research should examine whether item interpretation remains equivalent across diagnostic groups, particularly acute vs. chronic contexts and diseases with vs. without clear prognosis. Study 3 supported the DV of the UIQ with the IUS-R, the current gold standard for assessing dispositional IU. While UIQ and IUS-R are related, they measure distinct constructs: the UIQ captures situational, illness-specific uncertainty, whereas the IUS-R reflects a dispositional, trait-like tendency toward uncertainty. This distinction aligns with the uncertainty distress model [26] positing that dispositional IU predisposes to perceiving heightened situational UI.

Together, these findings position the UIQ as a psychometrically sound, theoretically grounded tool for assessing the complexity of UI. Its multidimensional structure and validity pave the way for nuanced assessment and intervention targeting UI, with implications for research and clinical practice. UIQ demonstrates promising psychometric properties including structural validity, internal consistency, and convergent-divergent-discriminant validity in Italian-speaking convenience samples. However, some limitations require remediation, future studies should explore longitudinal stability and responsiveness to interventions, further consolidating the UIQ's utility in diverse illness populations.

This study has some limitations. Convenience snowball sampling *via* social media [27] introduces selection bias, likely attracting digitally-engaged individuals may limit the representativeness and generalizability of the results. While this approach enabled large sample recruitment (age_{range} 18–93 years), reflecting the fact that UI can affect individuals throughout their lifespan, it limits representativeness of clinical populations (e.g., those with severe functional impairment, low digital literacy, hospitalized patients). The female predominance likely (85%) reflects sex disparities in caregiving roles - females comprise 80–90% of Italian informal caregivers [2, 40, 41] - but nonetheless limits generalizability to males. Future clinical recruitment studies should adopt stratified sampling by sex, illness severity, and treatment stage. Additionally, only using self-reports implies limitations (e.g., lack of self-awareness, social desirability). In EGA, item S_1 showed near-threshold and comparable loadings across dimensions (λ_symptoms=0.154, λ_treatments=0.139), suggesting potential cross-dimensional content requiring evaluation in future validation studies. The use of MLM estimator in Study 2 and DWLS in Study 3 may limit the direct comparability of fit indices across studies. The cross-sectional design cannot establish temporal stability (test-retest reliability), nor sensitivity to change (responsiveness), predictive validity (whether UI predicts treatment adherence, QoL decline, psychological distress over time). Future longitudinal cohort studies examining UI trajectories over time will further validate the UIQ psychometric properties as well as its utility in medical settings [100].

In this research, pooling heterogeneous diagnoses assumes that UI operates equivalently across conditions as motivated by theoretical literature [7, 46], but disease-specific manifestations remain unexplored. The absence of psychometric invariance testing across illness types (e.g., cancer vs. dementia vs. mental illness) is a significant limitation - future studies will provide disease-specific psychometric validation and potential adaptation. Regarding practical implications, statistical MI supports group mean comparisons, but clinical interpretation requires benchmarks; normative data stratified by population characteristics; cut-point validation for identifying clinical vs. non-clinical UI levels; established associations between UIQ scores and clinical outcomes. Thus, we recommend that until illness-specific analyses are conducted, UIQ should be used primarily for dimensional assessment (continuous scores) rather than categorical classification or cross-illness comparisons. In conclusion, UIQ should currently be considered a theoretically-grounded, psychometrically-promising tool for Italian research contexts, but not yet a gold-standard clinical diagnostic instrument.

Despite these limitations, this research offers several notable strengths from both clinical and methodological perspectives. Importantly, this is the first study to develop and validate UIQ from a clinical standpoint, providing a tool for accurate and efficient assessment of this construct with minimal administration time and reduced burden for persons coping with illness. UIQ brevity makes it well suited for inclusion within longer batteries in clinical and research settings, particularly in clinical environments where patients experience fatigue, loss of focus, limited attention span during evaluations and may become easily disengaged by lengthy questionnaires.

Regarding methodological strengths, the EGA innovative approach [31] was selected based on simulation studies demonstrating it outperforms traditional methods in accurately identifying a measure's underlying dimensions when compared to parallel analysis and traditional EFA [101], generating a visual plot revealing item clusters, interrelations, and the optimal number of dimensions, offering valuable clinical insights [21, 32]. EGA offers advantages for visualizing item clustering and evaluating structural stability through bootstrap IS indices, complementing rather than categorically surpassing traditional approaches. CFA subsequently validated the dimensional structure identified by EGA.

Regarding clinical strengths, UIQ holds significant clinical relevance as a valuable assessment instrument in medical contexts and health psychology research, facilitating efficient and accurate UI evaluation, aiding clinicians in understanding the severity and impact of symptoms on quality of life, which supports informed decision-making and tailored interventions. UI seems to be common to patients and caregivers; it is shared by various diagnoses and diseases and is associated with psychological difficulties of different severity.

This study employed rigorous and reliable statistics, enabling precise estimation of latent factors and their interrelationships while minimizing measurement error [102, 103]. Assessing UI is essential given its complex role; it can act as a cause, consequence, and sustaining factor of psychological suffering, offering valuable insights for both the conceptual understanding and treatment of clinical conditions. Also, UIQ serves as a useful tool to deepen the understanding of psychological challenges and to guide the development of targeted psychological interventions.

Regarding the clinical validation requirements, future research must validate UIQ in clinically recruited samples (hospital-based, disease-specific cohorts), using sex-balanced populations, stratified by illness severity, duration, and type, in non-digital/vulnerable populations.

Regarding the research implications in the clinical context, it would be valuable for future research to explore the characteristics and relationships of the UIQ within diagnosis-specific populations (e.g., only caregivers vs. only patients, different age phases, diagnosis-specific groups, various settings). To this end, psychological network analysis [60] represents a promising method for examining whether item configurations are consistent or vary across different populations. Future cross-cultural research will offer independent validation and evaluation of the UIQ across various countries, languages, populations, and age groups. Additional studies are necessary to confirm or challenge these results in diverse populations (e.g., community samples from Italy and other nations). International adaptation requires culturally appropriate items while preserving the underlying construct (e.g., adapting item 10 healthcare-specific terminology as needed).

This research positions UIQ as a second-generation measure incorporating 35+ years of conceptual refinement since Mishel's original formulation while maintaining theoretical continuity with the foundational UIT framework. Critically, UIQ addresses the recognized need for UI instrumentation that reflects contemporary theory, employs modern psychometric methodology, and demonstrates both convergent and DV requirements articulated by Zhang [81] and inadequately addressed by existing measures in the Italian context or internationally.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12955-026-02515-x.

Supplementary Material 1

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Author contributions

Conceptualization and methodology: AP, GB, GV; formal analysis: AP, AAR; writing first draft: AP, GB; Reviewing: AAR, GB, GV, AS, MG; Supervision: GB, GV, AP.

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Data availability

The datasets generated and/or analyzed during the current study are not publicly available due to privacy reasons but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study adhered to the ethical guidelines set by the Psychology Ethical Committee of the University of Padua (protocol#4277) and included all three studies of this research. All participants voluntarily accepted and provided consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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