ORIGINAL RESEARCH—CLINICAL

Health State Questionnaires Deployed in Ulcerative Colitis Patients: The Medical, Psychological, and Economic Perspective

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BACKGROUND AND AIMS: To determine how the health state of ulcerative colitis patients is impacted by their disease, different health state questionnaires are deployed. This study examines to what extent these health state questionnaires determine the same underlying health state concept and to what extent the complementary use of the health state questionnaires has added value for physicians. **METHODS:** In total, 307 patients were enrolled in this cross-sectional multicenter cohort study. Medical, psychological, economic, and composite health state questionnaires were administered to determine reliability, convergent validity, and explained variance. Reliability was determined using Cronbach's alpha. Convergent validity was measured using Spearman's correlation coefficients. Explained variance was interpreted using R-squared coefficients. **RESULTS:** All questionnaires can be considered reliable. The medical, psychological, and economic health state questionnaires show weak to moderate convergent validity with each other. The medical, psychological, and economic health state questionnaires also explain limited variance in each other's outcomes. The composite health state questionnaire shows moderate to strong convergent validity with the other health state questionnaires. The composite health state questionnaire further explains considerable variance in the outcomes of the other health state questionnaires. **CONCLUSION:** Deploying divergent medical, psychological, and economic health state questionnaires may have added value as they provide a multiperspective holistic insight into patients' health states. Deploying the composite health state questionnaire combined with other health state questionnaires may have added value as it provides additional understanding of their outcomes. Deploying an independent psychological health state questionnaire may have added value as it shows particularly limited convergent validity and explained variance regarding other health state questionnaires.

Keywords: Health state; Health state questionnaire; Ulcerative colitis; Disease severity; Health experience; Health utility

Introduction

More than 50,000 patients in the Netherlands are affected by ulcerative colitis (UC) and recent data suggest that the incidence and prevalence of this disease is still increasing.[1,2] UC is a condition that is characterized by relapsing-remitting chronic inflammation of the gastrointestinal tract.[1,2] Symptoms may include persistent diarrhea, abdominal pain, rectal blood loss, anemia, and fatigue.[3,4] These symptoms cause a negative impact on the health state of UC patients.[5–7] The World Health Organization refers to the concept of health state as 'the description and/or measurement of the health of an individual or population at a particular point in time against identifiable standards, usually by reference to health indicators[8], [p. 358]. To determine to what extent the health state of UC patients is impacted, several health state questionnaires have been deployed by physicians.[9] A health state questionnaire is an instrument used to determine the different manifestations of disease in a given patient including symptoms, functional limitation, and quality of life.[9] In the current healthcare sector, physicians are expected to apply different medical, psychological, and economic health state questionnaires in UC patients as providing holistic and cost-effective care has become increasingly important over the last decade.[10] Medical health state questionnaires (eg, SCCAI, CUCQ-32) conceptualize health state in terms of disease activity and

are used to determine the extent to which dysfunction, symptoms, and side effects occur in UC patients.[11] Psychological health state questionnaires (eg, SHE model) conceptualize health state in terms of subjective experienced health and are used to determine the psychosocial disease burden experienced by UC patients.[12–15] Economic health state questionnaires (eg, EQ-5D, SF-6D) conceptualize health state in terms of universal health state determinants and are used to measure the collective health utility values (ie, cardinal values that denote the strength of an individual's preferences for certain health-related outcomes) of UC patients necessary for cross-population comparisons and health economic evaluation.[16] Research suggests that these different ways of conceptualizing and determining the health state of UC patients could potentially result in fragmented, incoherent, incompatible, and counterproductive treatments and policy practices.[17,18] However, little research has been conducted to explore the degree to which the different health state concepts actually differ from each other and how these different conceptualizations and their subsequent measurement could be useful or even mutually reinforcing in clinical and research practice. To bridge this gap in existing scientific literature, this study examines (1) to what extent the different health state questionnaires determine the same underlying health state concept and (2) to what extent the complementary use of the different health state questionnaires has added value for physicians.

Materials and methods

Clinical cohort

A cross-sectional multicenter cohort study was performed with UC patients included in a registry for inflammatory bowel diseases in the Netherlands (IBDREAM registry).[19,20] The patients included in the IBDREAM registry were recruited in 5 Dutch hospitals during outpatient visits and provided informed consent for the use of their data. The patients included in this particular study (1) completed, at least, one of the administered health state questionnaires; (2) completed the health state questionnaires within a week ensuring minimal intermediate change in health state; and (3) were officially diagnosed with UC based on a combination of internationally defined and accepted clinical, endoscopic, histologic, and radiologic criteria.[21,22]

Data collection

The data for this study were gathered between 2018 and 2021. The relevant population characteristics (eg, age, disease duration, body mass index, gender, smoking behavior, disease extent, disease activity, medication) were collected and medical, psychological, economic, and composite health state questionnaires measuring the current health state of UC patients were administered at the point of inclusion in the study.

Medical health state questionnaire. The medical health state questionnaire used in this study was the Simple Clinical Colitis Activity Index (SCCAI) questionnaire.[11] This medical health state questionnaire is specifically developed for and repeatedly validated in UC patients.[11] The SCCAI questionnaire considers 6 exclusively clinical and diagnostic parameters, namely 'bowel frequency (day)', 'bowel frequency (night)', 'urgency of defecation', 'blood in stool', 'general well-being', and 'extracolonic manifestations'.[11] The items were measured on ordinal scales with ascending response categories resulting in a total score between 0 and 19.[11]

Psychological health state questionnaire. The psychological health state questionnaire deployed in this study was the Subjective Health Experience (SHE) model questionnaire.[12–15] This psychological health state questionnaire is one of the few validated questionnaires that actually measures the determinant of SHE.[12–15] The SHE model questionnaire measures 6 items covering 2 determinants of subjective health experience, namely 'perceived control' and 'acceptance'.[12–15] Based on these determinants, a model encompassing 4 segments (Figure 1) was established with each segment delineating a distinct subjective health experience profile.[12–15] Patients in segment I are able to come to terms with their health state and try to manage it. Patients in segment II are able to internalize their health state but often ascribe control over their life externally. Patients in segment III exert considerable control over their health state but experience adversity spending their lives in poor health. Patients in segment IV are unable to acknowledge their health state and are also unable or unwilling to obtain control over their own health.[12–15] The items are measured with a 7-point Likert scale.[12–15] Based on the mean scores for both determinants, patients were positioned in one of 4 segments of the SHE model (Figure 1).[12–15]

Economic health state questionnaire. The economic health state questionnaire used in this study was the EuroQol Five-dimensions Three-level (EQ-5D-3L) questionnaire in combination with the preference-based time-trade-off method.[24,25] This questionnaire and validation method are the golden standard in health economic evaluation and are deployed all over the world.[24,25] The EQ-5D-3L questionnaire consists of 5 dimensions, namely 'mobility', 'self-care', 'usual activities', 'pain and discomfort', and 'anxiety and depression'.[24,25] The items were measured with a 3-point Likert scale resulting in generic health state profiles.[24,25] Based on these generic health state profiles, a standard collective health utility value was assigned.[26] These collective health utility values were generated by a large-scale preference-based time-trade-off study among the Dutch population that inquired about the length of remaining life expectancy a person prefers to trade-off to avoid remaining in a subperfect health state.[26]

Composite health state questionnaire. Medical, psychological, and economic health state questionnaires are, to a certain extent, combined in the Inflammatory Bowel Disease Control eight subscore (IBD-Control-8) questionnaire.[27,28] This questionnaire is an internationally recognized instrument that is repeatedly validated in UC patients and is composed of a particularly broad scope of dimensions.[27,28] The IBD-Control-8 questionnaire consists of 8 items spanning 4 core domains, namely 'physical', 'social', 'emotional', and 'treatment'.[27,28] The items are measured on a nominal scale consisting of yes', 'no', and 'not sure' resulting in a total score ranging from 0 to 16.[27,28]

Statistical analysis

The population characteristics were described using descriptive statistics. The continuous variables were expressed
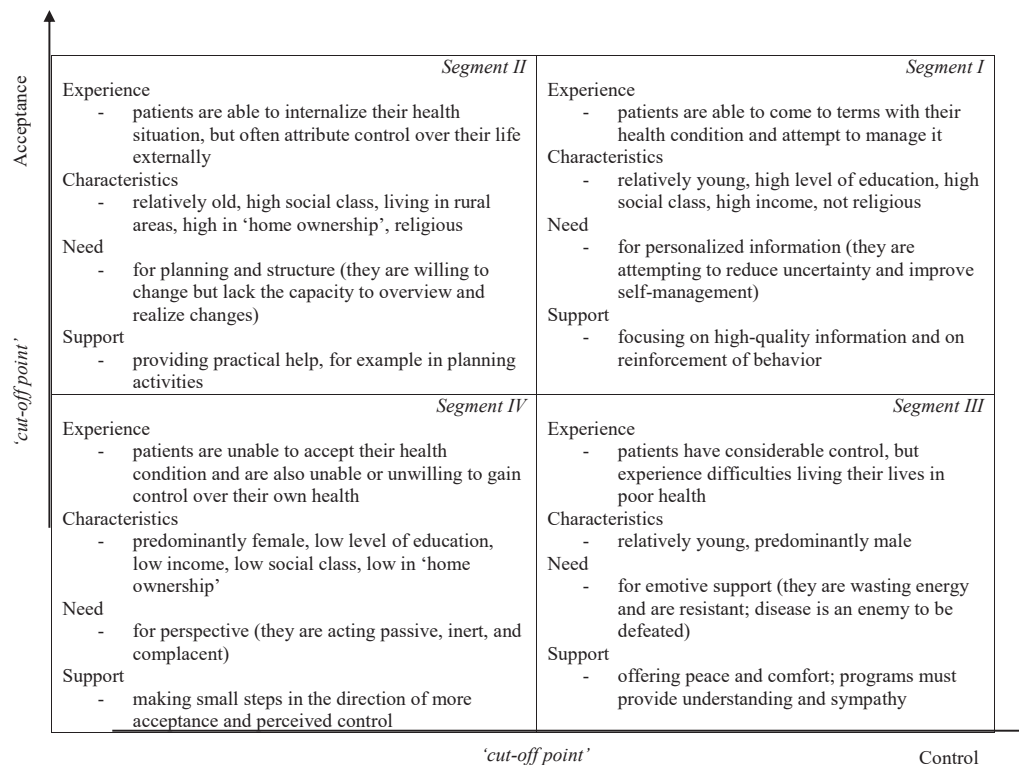
Figure 1. Updated SHE model adopted from Broekharst et al.[23]

as means with standard deviation ($\pm$ SD), while the categorical variables were expressed in percentages. The reliability of the health state questionnaires was assessed using Cronbach's alpha and a value of 0.70 was considered a threshold for good reliability.[29] Cronbach's alpha constitutes a way of assessing reliability by comparing the level of shared variance, or covariance, among the items included in a health state questionnaire to the level of overall variance.[29] The rationale is that if the health state questionnaire is reliable, there should be a lot of covariance among its items relative to the variance.[29] To examine to what extent these health state questionnaires assess the same underlying health state construct, convergent validity was determined.[30,31] Convergent validity refers to the degree to which 2 or more health state questionnaires, intended to measure the health state of UC patients, correspond with each other. To examine the convergent validity among the health state questionnaires, a correlation matrix containing Spearman's correlation coefficients (ρ) was established. This coefficient ranges between $+1$, which indicates perfect positive relatedness, and -1, which indicates perfect negative relatedness. The strength of correlation was interpreted as very weak ($\rho < 0.20$), weak ($\rho = 0.20$–0.40), moderate ($\rho = 0.40$–0.60), strong ($\rho = 0.60$–0.80), and very strong ($\rho > 0.80$). The same thresholds were applied to negative correlation coefficients. To examine to what extent these health state questionnaires complement each other explained variance was calculated.[32–34] Explained variance refers to the proportion of variance in the outcomes of one health state questionnaire that can be explained by the other health state questionnaires. The change of the explained variance in the dependent variable was examined by executing a hierarchical linear regression analysis in which population characteristics (Table) and separate health state questionnaires were sequentially added in different blocks. In this analysis, the R-squared (R^2) and delta R-squared (ΔR^2) coefficients were interpreted. The statistical analysis performed to determine the population characteristics, reliability, convergent validity, and explained variance was conducted using IBM SPSS Statistics, version 27.

Results

Population characteristics

In total, 307 patients were enrolled in this cross-sectional multicenter cohort study. The population characteristics are reported for each health state questionnaire used in this study. The population characteristics are displayed in Table.

All health state questionnaires used in this study were reliable in UC patients ($\alpha > 0.70$). The psychological health state questionnaire shows the highest Cronbach's alpha ($\alpha = 0.917$) followed by the composite health state questionnaire ($\alpha = 0.825$), the medical health state questionnaire ($\alpha = 0.715$), and the economic health state questionnaire ($\alpha = 0.704$). The reliability of each health state questionnaire is depicted in Figure 2.

Convergent validity

The medical health state questionnaire and the psychological health state questionnaire do not necessarily measure the same health state concepts as they show weak

Table. Population Characteristics

Variables	Medical	Psychological	Economic	Composite
N	228	307	285	286
Age in y	46.6 (15.5)	47.1 (15.9)	47.2 (15.8)	47.3 (15.8)
Disease duration in y	11.4 (8.3)	11.5 (8.4)	11.5 (8.1)	11.5 (8.1)
BMI	25.2 (4.3)	25.4 (4.4)	25.5 (4.4)	25.5 (4.4)
Gender				
Male	54.8%	53.1%	52.6%	52.8%
Female	45.2%	46.9%	47.4%	47.2%
Smoking				
Never smoker	54.0%	52.8%	52.8%	52.6%
Ex-smoker	37.2%	38.0%	38.1%	38.3%
Current smoker	8.8%	9.2%	9.1%	9.1%
Disease extent				
Proctitis	12.8%	11.8%	12.4%	12.0%
Left sided	43.0%	43.8%	44.3%	44.5%
Pancolitis	44.2%	44.4%	43.3%	43.5%
Laboratory markers				
C-reactive protein in mg/L	4.7 (10.3)	4.7 (9.4)	4.7 (9.8)	4.7 (9.7)
Calprotectin in μg/g	296.1 (590.1)	282.8 (574.0)	262.8 (531.5)	263.6 (532.6)
Medication				
Thiopurine	57.9%	56.4%	56.1%	56.3%
Methotrexate	0.9%	0.7%	0.7%	0.7%
Infliximab	25.4%	25.7%	25.3%	25.2%
Adalimumab	12.3%	10.4%	9.8%	9.8%
Golimumab	0.4%	1.0%	1.1%	1.0%
Vedolizumab	3.9%	2.9%	3.2%	3.1%
Ustekinumab	0.9%	0.7%	0.4%	0.3%
Tofactinib	1.3%	1.0%	1.1%	1.0%

convergent validity in UC patients ($\rho = 0.342$, $P < .01$). The economic health state questionnaire and the psychological health state questionnaire are not likely to measure the same health state concepts as they indicate moderate

Figure 2. Reliability, convergent validity, and explained variance in health state questionnaires.

convergent validity in UC patients ($\rho = -0.421$, $P < .01$). The medical health state questionnaire and the economic health state questionnaire do not necessarily measure the same health state concepts as they show moderate convergent validity in UC patients ($\rho = -0.411$, $P < .01$). The psychological health state questionnaire and the composite health state questionnaire do possibly measure certain aspects of the same health state concepts as they indicate moderate convergent validity in UC patients ($\rho = -0.534$, $P < .01$). The medical health state questionnaire and the composite health state questionnaire are likely to measure the same health state concepts as they show strong convergent validity in UC patients ($\rho = -0.644$, $P < .01$). The economic health state questionnaire and the composite health state questionnaire are likely to measure the same health state concepts as they indicate strong convergent validity in UC patients ($\rho = 0.614$, $P < .01$). The convergent validity between each health state questionnaire is depicted in Figure 2.
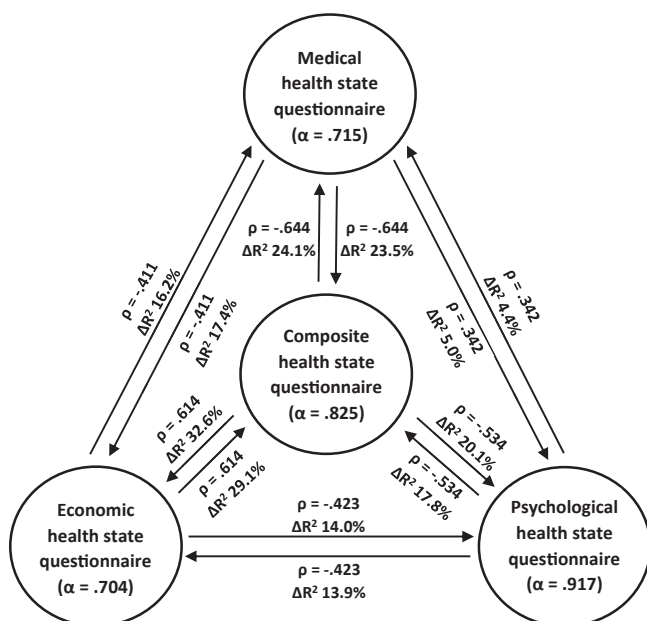
Explained variance

The psychological health state questionnaire explained 4.4% of variance in the medical health state questionnaire additional to the variance demonstrated by population characteristics (R^2 20.6% vs 25.0%, ΔR^2 4.4%, $P < .001$). The economic health state questionnaire accounted for 16.2% of explained variance in the medical health state

questionnaire in addition to the variance determined by population characteristics (R^2 21.3% vs 37.5%, ΔR^2 16.2%, $P < .001$). The composite health state questionnaire explained 24.1% of variance in the medical health state questionnaire additional to the variance demonstrated by population characteristics (R^2 21.3% vs 45.4%, ΔR^2 24.1%, $P < .001$). The medical health state questionnaire accounted for 5.0% of explained variance in the psychological health state questionnaire in addition to the variance determined by population characteristics (R^2 9.7% vs 14.7%, ΔR^2 5.0%, $P < .001$). The economic health state questionnaire explained 14.0% of variance in the psychological health state questionnaire additional to the variance demonstrated by population characteristics (R^2 8.4% vs 22.4%, ΔR^2 14.0%, $P < .001$). The composite health state questionnaire accounted for 20.1% of explained variance in the psychological health state questionnaire in addition to the variance determined by population characteristics (R^2 8.5% vs 28.6%, ΔR^2 20.1%, $P < .001$). The medical health state questionnaire explained 17.4% of variance in the economic health state questionnaire additional to the variance demonstrated by population characteristics (R^2 15.5% vs 32.9%, ΔR^2 17.4%, $P < .001$). The psychological health state questionnaire accounted for 13.9% of explained variance in the economic health state questionnaire in addition to the variance determined by population characteristics (R^2 9.1% vs 23.0%, ΔR^2 13.9%, $P < .001$). The composite health state questionnaire explained 32.6% of variance in the economic health state questionnaire additional to the variance demonstrated by population characteristics (R^2 9.1% vs 41.7%, ΔR^2 32.6%, $P < .001$). The medical health state questionnaire accounted for 23.5% of explained variance in the composite health state questionnaire in addition to the variance determined by population characteristics (R^2 23.3% vs 46.8%, ΔR^2 23.5%, $P < .001$). The psychological health state questionnaire explained 17.8% of variance in the composite health state questionnaire additional to the variance demonstrated by population characteristics (R^2 19.0% vs 36.8%, ΔR^2 17.8%, $P < .001$). The economic health state questionnaire accounted for 29.1% of explained variance in the composite health state questionnaire in addition to the variance determined by population characteristics (R^2 19.0% vs 48.1%, ΔR^2 29.1%, $P < .001$). The explained variance between each health state questionnaire is depicted in Figure 2.

Discussion

This study examined to what extent the different health state questionnaires determine the same underlying health state concept in UC patients and to what extent the complementary use of the different health state questionnaires has added value for physicians.

Previous research shows that medical, psychological, and economic health state questionnaires deployed in UC patients conceptualize the health state concept in a different manner.[10–15] The medical health state questionnaires often emphasize disease activity, psychological health state questionnaires often emphasize subjective experienced health, and economic health state questionnaires often emphasize health utility.[10–15] In accordance, the findings of this study suggest that the medical, psychological, and economic health state questionnaires show weak to moderate convergent validity (Figure 2). This indicates that they do not or only partially determine the same underlying health state concept. In addition, the results of this study show that the medical, psychological, and economic health state questionnaires explain limited variance in each other's outcomes (Figure 2). This suggests that the complementary use of different health state questionnaires in UC patients may have added value for physicians as each health state questionnaire provides its own unique perspective on the health state concept allowing for a more holistic insight into the health state of UC patients. The complementary use of different health state questionnaires in UC patients may have further added value for physicians as it allows for achieving congruence between medical treatment, psychological counseling, and underlying health economic policy.

Prior studies also show that the composite health state questionnaire deployed in UC patients combines elements of the medical, psychological, and economic health state questionnaires.[27,28] The 'treatment' and 'physical' scales show similarities to the medical health state questionnaire, the 'emotional' scale incorporates elements of the psychological health state questionnaire, and the 'physical' and 'social' scales integrate aspects of the economic health state questionnaire.[27,28] In accordance, the results of the present study show that the composite health state questionnaire has moderate to strong convergent validity with the medical, psychological, and economic health state questionnaires (Figure 2). This suggests that the composite health state questionnaire determines the same underlying health state concepts as the other health state questionnaires to a considerable degree. In addition, the findings of this study suggest that the composite health state questionnaire explains considerable variance in the outcomes of the medical, psychological, and economic health state questionnaires (Figure 2). This suggests that the complementary use of the composite health state questionnaire and the other health state questionnaires in UC patients could have added value for physicians as it may provide additional understanding and allows for more accurate interpretation of the outcomes of the other health state questionnaires.

It should be mentioned that the psychological health state questionnaire not just shows weak convergent validity and explained variance regarding the medical and economic health state questionnaires but also displays only moderate convergent validity and explained variance regarding the composite health state questionnaire. This suggests that the psychological health state of UC patients is determined to a particularly limited degree by these other health state questionnaires and that the use of independent psychological health state questionnaires may be considered. It should

further be noted that the psychological health state questionnaire used in this study not only determines the health state of UC patients as is the case for most health state questionnaires but also allows for their segmentation in a model that assigns specific care needs to these patients (Figure 1).[12–15] Each segment of the model represents a different type of UC patient and informs the physician on the specific care this patient needs (Figure 1).[12–15] It may be prudent to develop and implement more health state questionnaires that not only determine the health state of UC patients but also provide physicians with detailed guidance on necessary medical treatment, psychological counseling, or health economic policy.

Strengths and limitations

The most important strength of this study is that it considers multiple perspectives on the health state of UC patients. By adopting and understanding these different perspectives, physicians are able to holistically evaluate the health state of their patients. Another strength of this study is that it is based on real-world data gathered from patients with different levels of complexity. Based on these data, relatively reliable and generalizable conclusions can be drawn with regards to the convergent validity and explained variance between different health state questionnaires used in UC patients. A limitation of this study is that the sample may be biased as it is characterized by a relatively high percentage of males and a relatively low prevalence of proctitis. This potential bias could skew the results of this study thwarting its reliability and generalizability. Another limitation of this study is that the answers to the health state questionnaires might be influenced by the clinical activity an UC patient experiences. This possible bias might skew the findings of this study limiting its reliability and generalizability.

Practical implications

This study has several implications for clinical and research practice. The outcomes of this study imply that physicians could use medical, psychological, and economic health state questionnaires to acquire a multiperspective holistic insight into the health state of UC patients. The results of this study also imply that physicians could use composite health state questionnaires in combination with medical, psychological, and economic health state questionnaires to obtain an additional insight into the health state of UC patients. The findings of this study further imply that it may be especially beneficial for physicians to use independent psychological health state questionnaires as they show particularly limited convergent validity and explained variance with regard to the other health state questionnaires. If physicians choose to deploy the aforementioned combination of health state questionnaires, they may use these holistic insights to improve diagnosis or treatment, practice shared decision-making, provide value-based healthcare, determine quality of life, and conduct clinical trials or other research activities.[35–37]

Future research

This study indicates several avenues for future research. First, this study examines different health state questionnaires that are often deployed in UC patients by physicians. However, there are other health state questionnaires deployed in UC patients (eg, CUCQ-32, IBDQ) that could be useful to physicians and it may be beneficial to also examine the convergent validity and explained variance of these other health state questionnaires. Second, this study considers health state questionnaires that determine the health state concept from 3 different perspectives. However, there may be health state questionnaires that determine the health state concept from other perspectives (eg, social, spiritual) and it could be beneficial to also determine the convergent validity and explained variance of these particular health state questionnaires. Third, this study examines the use of different health state questionnaires in UC patients. However, there are many other diseases in which the determination of health state plays an important role and it could be beneficial to repeat this type of research in different populations. Fourth, this study shows the variance in different health state questionnaires explained in each other's outcomes. However, it may also be interesting to calculate the variance these different health state questionnaires explain in other important dependent variables (eg, health behavior).

Conclusion

The medical, psychological, and economic health state questionnaires do not or only partially determine the same underlying health state concept and explain limited variance in each other's outcomes. These divergent perspectives may have added value for physicians as it could provide them with a holistic insight into the health state of UC patients. Furthermore, the composite health state questionnaire largely determines the same underlying health state concept as the other health state questionnaires and explains considerable variance in each other's outcomes. The use of a composite health state questionnaire in combination with the other health state questionnaires may have added value for physicians as it could provide additional understanding of their outcomes. Moreover, the psychological health state questionnaire shows particularly limited convergent validity and explained variance regarding the other health state questionnaires. This indicates that the psychological health state of UC patients is determined to a particularly limited degree by the other health state questionnaires and that the use of an independent psychological health state questionnaire may be considered.

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Authors' Contributions:
Damien S.E. Broekharst designed and wrote the manuscript. Tessa E. H. Römkens and Sjaak Bloem supervised this study. Pepijn W. A. Thomas and Maurice G. V. M. Russel provided the data. All authors read and revised the manuscript. All authors approved the final manuscript.

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The authors disclose no conflicts.

Ethical Statement:
The corresponding author, on behalf of all authors, jointly and severally, certifies that their institution has approved the protocol for any investigation involving humans or animals and that all experimentation was conducted in conformity with ethical and humane principles of research.

Data Transparency Statement:
The database can be made available from corresponding author upon reasonable request and with permission of the IBDREAM registry.

Reporting Guidelines:
SAGER, STROBE.