

Psychological Adjustment Measures for Chronic Illness: A Narrative Review

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Abstract

Objective: Chronic illnesses carry substantial psychological implications, emphasizing the critical nature of psychological adaptation to these conditions. Adequate assessment tools are essential for gauging adaptation levels within this context. Thus, this study aims to conduct a thorough review of psychological adaptation instruments designed for chronic illnesses.

Method: This narrative review scrutinizes articles published from 1990 to November 2024 in both Persian and English languages, focusing on psychological adaptation to chronic illnesses. The search encompassed prominent scientific databases, including "SID", "IranDoc", "Web of Science", "PubMed", and "Scopus". Relevant keywords were employed to retrieve articles discussing adaptation tools for chronic illnesses. Subsequently, the "consensus-based standards for the selection of health measurement instruments" were applied to assess the psychometric properties of the identified tools.

Results: Within this study, the exploration identified 8 instruments tailored to measure psychological adaptation to chronic illnesses. These instruments encompass measures for psychological adaptation to cancer (Mini-Mac), adaptation to ostomy (OAS), adaptation to type 1 diabetes (DAS_1), adaptation to drug-resistant tuberculosis (AS_DRTBP), adaptation to type 2 diabetes (DAAS), psychosocial adaptation to Parkinson's disease (Psychosocial Adaptation in PD), psychosocial adaptation to HIV infection (MAHIVS), and adaptation to breast cancer (AIMI-IBC). However, comprehensive reporting of psychometric properties was often lacking for the majority of these instruments.

Conclusion: The outcomes of this study underscore the significance of employing valid and dependable instruments tailored to the unique requirements of individuals grappling with chronic illnesses. Given the pivotal role of psychological adaptation, the careful formulation and implementation of specialized measures are recommended to facilitate the design and psychometric evaluation of adaptation measurement tools pertinent to diverse chronic illnesses in Iran.

Key words: *Chronic Diseases; Chronic Illness; Measure; Psychological Adaptation; Psychological Adjustment*

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The prevalence of chronic illnesses is rapidly increasing due to the aging of the population and the extended lifespans of individuals affected by these conditions, expanding at a remarkable pace (1). Chronic diseases have evolved into a primary concern within the realm of health (2). Chronic illness stands as the foremost cause of health-related issues in developed and even developing countries, surpassing new infectious diseases. Frequently, chronic diseases represent a significant contributor to adult mortality worldwide. Over 35 million individuals across the globe succumb to chronic diseases (3).

Chronic illness is an encompassing term that entails various physical and psychological changes in health. It is characterized by one or more of the following features: lasting alterations resulting from irreversible changes in anatomy and natural physiology, necessitating specialized training for disability, and requiring long-term care or support. Typically, chronic illness exhibits a gradual onset and cycles through periods of temporary relief (when the illness is present but symptoms are not experienced) and peak symptom intensity (manifesting symptoms) (4).

Living with a chronic illness usually involves undergoing prolonged treatments, regular monitoring, and navigating significant life changes that could impact all facets of affected individuals' lives (5). The ramifications of chronic illness extend beyond the individual to encompass all those with whom they interact (6). The negative effects of living with chronic diseases can encompass diminished physical health and function, endurance of pain, potential reduction in lifespan, as well as challenges such as loneliness, diminished self-confidence, and altered social roles. The escalating prevalence of chronic diseases places an additional burden on societal levels, leading to prolonged hospitalizations, heightened utilization of healthcare resources, and decreased productivity (7).

One of the most crucial human attributes, essential for human survival and mental well-being, which has gained significant attention in recent years due to its role in disease recovery, is adaptability (8). Adaptation is a process wherein an individual employs all of their adaptive mechanisms to overcome stimuli that may be novel or threatening, resulting in adaptability. This process yields a positive and constructive outcome when an individual aligns with a stimulus; conversely, maladaptive behavior emerges when alignment is lacking (9). Maladaptive or maladjusted behaviors encompass chronic and recurrent responses, or patterns of response, that do not serve the goals of adaptability. These goals include physical or bodily health, achieving desired levels of fitness, mental health, and overall well-being (such as happiness, life satisfaction, and positive mood), as well as enhancing social functioning, including work, family, social relationships, and positive interactions (10).

The process of adapting to a chronic illness is dynamic and influenced continuously by individual and environmental factors. Within this process, individuals must confront personal and environmental challenges to achieve an acceptable level of health and physical, psychological, and social functioning, ultimately resulting in successful adaptation (11). The psychological dimensions of chronic diseases are frequently underestimated. In other words, there is often an assumption that most patients adapt well to the psychological aspects of chronic diseases; however, when patients experience deficits in their physical health status, achieving psychological adaptation becomes more challenging. It is generally observed that around 20 to 25 percent of chronic patients clinically manifest significant psychological symptoms (12).

Maladaptation manifests as anxiety, depression, despondency, and behavioral issues (13). Impairments in psychological adaptation can lead to problems such as sleep disorders, restlessness, irritability, nervousness, fatigue, anxiety, difficulties in maintaining focus, emotional control challenges, and social isolation (14). Inadequate adaptation to illness is linked with increased utilization of healthcare services and poorer health outcomes. Samadzadeh's research demonstrated that among 215 individuals with chronic diseases, those with lower levels of illness adaptation use healthcare services 2 to 6 times more frequently than those with higher levels of adaptation, resulting in 2.5 to 4 times greater costs (13). A patient's inability to adapt can lead to negative outcomes like treatment non-acceptance and diminished quality of life (15). Studies suggest that poor adaptation to illness reduces treatment adherence (16) and recovery rates (17).

Taking the aforementioned into consideration, adaptation can be seen as a surface-level behavior wherein the patient adheres to clinical recommendations, such as medication usage, necessary dietary regimens, or the implementation of other lifestyle changes. Symptoms, side effects, and various factors related to chronic diseases (including treatments, medications, disruptions in family relationships, changes in body image, etc.) can become stress-inducing factors that impact an individual's ability to adapt to all disease-related aspects, thereby affecting treatment progress. Moreover, comprehending the challenges within the adaptation process, formulating appropriate coping strategies, and devising supportive care interventions all play a significant role in influencing the quality of life (18).

In contemporary research, the selection of suitable and relevant assessment tools stands as a delicate topic, carrying equal importance to the research itself and the provision of scientific documentation (19). Researchers and therapists, in need of precise measurement and assessment tools to evaluate, plan, and execute effective interventions for chronic disease adaptation, require appropriate instruments tailored for chronic patients. If

professionals know the level of psychosocial adaptation of patients, by carrying out appropriate interventions, they can help patients to improve their health, facilitate better adaptation to the disease, control the disease properly, reduce the complications of the disease, and consequently reduce the death rate and economic and psychosocial costs, and ultimately improve their quality of life. The existing tools were highly scattered, and the need to consolidate, review, and classify them in a single study was felt for ease of use by therapists. Thus, the present study seeks to identify and introduce specialized existing tools for assessing psychological adaptation among patients with chronic diseases and to examine their psychometric properties.

Materials and Methods

This study employs a narrative review methodology to compile psychological adaptation tools for chronic illnesses. The execution of the method involves two distinct search stages: the initial phase revolves around the collection of tool names, followed by the subsequent phase focusing on the accumulation of tool characteristics.

For the first stage of identifying existing tools, a comprehensive search was conducted within both domestic and international scientific journals. These encompassed articles written in both Persian and English. The search process employed keywords such as "questionnaire", "scale", "adaptation", "conformity", "Measure," "Adjustment," and "chronic illness."

Databases including the Scientific Information Database (SID), Iran's Research Institute for Information and Documentation (Irاندو), Web of Science, PubMed, and Scopus were utilized. The temporal scope for this search spanned from 1990 to September 2024. The general syntax used for the search included terms such as "questionnaire" OR "scale" OR "Measure" AND "Adaptation," OR "Adjustment" OR "Adaptation with chronic illness" OR "adjustment with chronic illness".

During the initial phase, articles whose titles and abstracts encompassed psychological adaptation tools for chronic illnesses were meticulously assessed. These articles, available in both Persian and English, were meticulously selected from various domains of psychology, namely Clinical Psychology, Experimental Psychology, Developmental Psychology, Educational Psychology, Multidisciplinary Psychology, Social Psychology, and Applied Psychology. The selection was contingent upon the availability of full-text versions. Throughout the process of reviewing articles, those written in languages other than English and Persian, as well as articles not aligned with the study's objectives, were methodically excluded.

The inclusion criteria included full-text access to original articles, being published in either English or Persian between 1990 and November 2024, involving individuals with chronic illnesses, using self-report

format to assess psychological adaptation in all areas related to health.

Subsequently, the second stage involved delving deeper into the identified tools by searching their names in the aforementioned databases and extracting pertinent articles. Following this, comprehensive information from articles that fulfilled the inclusion criteria was acquired, encompassing demographic attributes, tool characteristics, developmental processes, and psychometric properties.

To increase the validity of findings, three researchers independently performed a literature search in different databases, initial assessment of articles, qualifying articles, and checking their compliance with inclusion and exclusion criteria. In the case of disagreement, consensus was reached with the help of a fifth researcher. In this study, the researchers observed ethical considerations in all steps and were required to collect the data honestly, accurately, and completely.

Results

As depicted in Figure 1, following an advanced search across the previously mentioned databases using the provided keywords and a subsequent comprehensive evaluation of the full-text articles, eight instruments were incorporated into this study. The primary reasons for excluding other studies were as follows:

The instruments discussed in those studies were developed for the assessment of role mastery, social adaptation, body image adaptation, and sexual adaptation. The instruments were specifically tailored for diseases other than chronic illnesses, encompassing hereditary conditions, infertility, etc. Certain instruments were intended to measure the adaptation of caregivers for patients.

The eight instruments scrutinized in this study are as follows: The Mini-Mental Adjustment to Cancer Scale (MAC) is designed to assess psychological adaptation to cancer (20). The Ostomy Adjustment Scale (OAS) is designed for adaptation to ostomy (21). The Diabetes Adjustment Scale (DAS_1) is crafted for adaptation to type 1 diabetes (22). The Adaptation Status Assessment of Drug-Resistant Tuberculosis Patients (AS_DRTBP) is tailored for adaptation among drug-resistant tuberculosis patients (23). The Diabetes Adjustment Assessment Scale (DAAS) was developed for adaptation to type 2 diabetes (24). The Psychosocial Adaptation Scale for Parkinson's Disease is intended to assess social-psychological adaptation to Parkinson's disease (25). The Mental Adjustment to HIV Scale (MAHIVS) is created for cognitive adaptation to HIV infection (26). The Adjustment to Illness Measurement Inventory for Iranian Women with Breast Cancer (AIMI-IBC) is formulated for adaptation to breast cancer (27).

In recent years, these tools have been used in many studies to measure psychological adjustment to chronic illnesses such as various types of cancer, diabetes, heart failure, and Parkinson's disease (28-33).

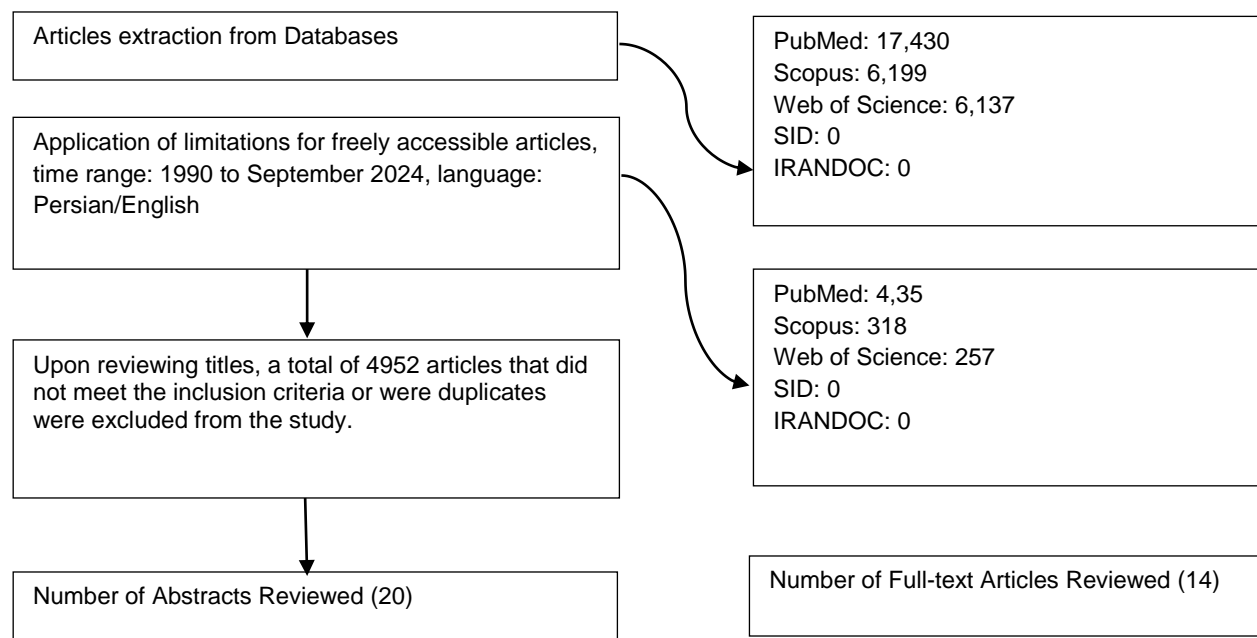


Figure 1. Study Selection Process to Review Psychological Adjustment Measures

Upon identifying the instruments, data were gathered within four primary domains as outlined below:

Cognitive Population Characteristics of Studied Instruments: As shown in Table 1, instruments assessing adaptation in cancer patients with colorectal, breast, stomach, and various other types of cancer, along with instruments evaluating adaptation in patients with ulcerative colitis, Crohn's disease, colostomy, and ileostomy, have undergone validation. Furthermore, instruments relating to adaptation in drug-resistant tuberculosis patients, adaptation in type 1 diabetes, adaptation in type 2 diabetes, adaptation in breast cancer, adaptation in HIV infection, and adaptation in Parkinson's disease have all been validated within their respective target populations. Notably, all eight instruments have been employed among the adult population.

Psychometric Characteristics: Among instruments about cancer adaptation, drug-resistant tuberculosis adaptation, Parkinson's disease adaptation, type 2 diabetes adaptation, stoma adaptation, and breast cancer adaptation, cognitive population attributes such as age, gender, marital status, education, and type of disease

have been taken into consideration. Treatment type has been specified exclusively in the context of four instruments: cancer adaptation, type 2 diabetes adaptation, stoma adaptation, and breast cancer adaptation. However, the duration of disease or treatment is not mentioned in three instruments: cancer adaptation, drug-resistant tuberculosis adaptation, and Parkinson's disease adaptation.

Tool Specifications

The assessment tools have been organized in Table 2 according to their year of publication, with the oldest dating back to the year 2000 and the most recent to 2023. Out of the eight assessment tools, two have been developed in Iran, two in Spain, two in China, and the remaining two in Australia and Norway, as indicated in Table 2. The dimensions of all tools have been defined, and the number of subscales within these tools ranges from 4 to 10. Notably, the Diabetes Adjustment Scale (DAS_1) stands as the only single-dimensional tool. The scoring method employed in all tools is based on the Likert scale.

Table 1. Sociodemographic Characteristics of Research Sample in the Studies on Psychological Adjustment Measures

Instruments	Type of Disease	Gender (Female/Male) / Count	Age (Mean)	Age (Range)	Age (Standard Deviation)	Duration of Illness (Diagnosis- Treatment)
Mini-Mac	Colorectal Cancer, Breast Cancer, Stomach Cancer, Colon Cancer, Heart Failure, and Other Cases	Male (441) / Female (577)	59.4	24-84	12.20	Not mentioned
OAS	Ulcerative Colitis, Crohn's Disease, Colostomy, Ileostomy and Ontological Addiction	Male (296) / Female (215)	63.3	-	14.6	More than 3 months
AS_DRTBP	Drug-Resistant Tuberculosis Patients	Male (268) / Female (165)	34.92	18-78	14.35	Not mentioned
DAS-1	Type 1 Diabetes	Male (98) / Female (106)	33.82	15-65	11.09	Duration of illness in years (Mean: 15.16 and Standard Deviation: 9.64)
AIMI-IBC	Breast Cancer	Female (480)	-	28-73	-	One year has passed since the start of diagnosis or treatment
DAAS	Type 2 Diabetes, Depression Anxiety and Stress	Total Sample (1000) / Female (68.6%)	55.9	-	11	Duration of illness in years (Mean: 8.97 and Standard Deviation: 6.36)
Psychosocial Adaptation in Parkinson's Disease	Parkinson's Disease	Male (301) / Female (270)	3.7% 28.8% 30.5% 37%	< 50 50-60 60-70 > 70		Not mentioned
MAHIVES	Positive HIV Infection	Male (164)	35.9	20-60	8.6	Duration of diagnosis (1 to 114 months) / Mean: 42.8

Table 2. Tools for Measuring Psychological Adaptation to Chronic Illness

Tool Name	Year of Publication	Country of Origin	Target Population	Sample Size	Tool Dimensions	Number of Items	Scoring Method
Mini-Mac	2021	Spain	Patients with cancer	914	Helplessness/hopelessness, overwhelming concern, cognitive avoidance, positive attitude	29	Likert Scale Scoring (1 = Does not apply to me at all, 4 = Applies completely).
OAS	2021	Norway	Patients with colostomy, ileostomy	302	Sexual desires, self-esteem, knowledge and skills, psychological well-being, health, healthcare professionals, daily activities	34	Likert Scale Scoring (1 = Completely agree, 6 = Completely disagree).

AS_DRTBP	2020	China	Patients with drug-resistant tuberculosis	433	Physiological functioning, self-concept, role performance, mutual dependence	26	After physiological: Sum of scores, for the other three dimensions: Likert Scale Scoring (1 = Completely disagree, 5 = Completely agree).
DAS-1	2020	Spain	Patients with type 1 diabetes	204	Unifactorial diabetes adaptation (negative emotions, diabetes impact on patients and relatives, coping style, treatment adherence, interference)	20	Likert Scale Scoring (1 = Not at all, 5 = Very much).
AIMI-IBC	2016	Iran	Patients with breast cancer	340	Guilt, avoidance/abstinence, role maintenance and seeking support, threat control efforts, coping, fear and anxiety, role loss, maturity and growth, isolation, belief in fate	49	Likert Scale Scoring with 5 possible responses ranging from "Always" to "Never".
DAAS	2016	Iran	Patients with type 2 diabetes	1000	Transformation, disease acceptance, living normally with the disease, initial self-management, comparison, initial disease imagery, returning to resources, advanced self-management	43	Likert Scale Scoring (1 = Completely agree, 6 = Completely disagree).
Psychosocial Adaptation in Parkinson's Disease	2015	China	Patients with Parkinson's disease	420	Anxiety, self-esteem, perception, self-acceptance, self-efficacy, social support	35	Likert Scale Scoring (1 = Completely inappropriate, 4 = Completely appropriate).
MAHIVES	2000	Australia	Patients with AIDS	164	Self-efficacy, hopelessness, personal control, minimizing diagnostic outcomes	40	Likert Scale Scoring (1 = Definitely does not apply to me, 4 = Definitely applies to me).

Tool Development Process

The initial development of tools can be categorized into standardized, inductive, or a combination of both methods. Standardized methods involve creating scales based on an extensive literature review and existing scales (34). Inductive methods employ a qualitative approach to define the concept and related constructs, resulting in a set of items. Qualitative methods encompass content analysis, grounded theory, phenomenology, or other qualitative research approaches. In certain instances, researchers utilize both standardized and inductive approaches to define the

measured concept and derive items (35). In light of the aforementioned context, researchers have employed both standardized and inductive methods in constructing items for the Drug-Resistant Tuberculosis Patients Adaptation Scale, Parkinson's Adaptation Scale, and Type 1 Diabetes Adaptation Scale. Furthermore, a standardized approach was employed in developing the Type 2 Diabetes Adaptation Scale and the HIV Adaptation Scale, while an inductive method was utilized to construct the Breast Cancer Adaptation Scale and the Ostomy Adaptation Scale (refer to Table 3).

Table 3. Development Process and Formation of the Psychological Adjustment Measures

Tool Name	Method of Scale Development (Empirical/Literature Review)	Method of Scale Development (Empirical/Existing Scales)	Method of Scale Development (Exploratory/Development based on Qualitative Information)	Method of Scale Development (Quantitative-Exploratory)
Mini-MAC	-	✓	-	-
OAS	-	-	✓	-
AS_DRTBP	-	-	-	✓
DAS-1	-	-	-	✓
AIMI-IBC	-	-	✓	-
DAAS	✓	-	-	-
Psychosocial Adaptation in Parkinson's Disease	-	✓	-	✓
MAHIVES	-	-	-	-

Psychometric Properties

In this systematic review, we meticulously examined instruments that measure adjustment to chronic illnesses using the comprehensive COSMIN checklist, known as the "Consensus-based Standards for the Selection of Health Measurement Instruments." Developed by Mokkink and colleagues through the Delphi technique, this checklist was utilized to thoroughly assess the psychometric attributes of these instruments. This assessment encompassed content validity, criterion validity, and construct validity. Additionally, we evaluated their reliability in terms of internal consistency, test-retest reliability, and the Standard Error of Measurement. Responsiveness in terms of sensitivity and the ability to detect changes, as well as interpretability regarding the minimum significant alterations in instrument scores, were also considered (19).

Content validity, a renowned and prevalent methodology for validating newly devised tools, traditionally captures researchers' attention during the initial stages of tool formulation (36). Our findings reveal that the content validity of instruments evaluating adaptation to drug-resistant tuberculosis, type 2 diabetes, and breast cancer

was assessed using the Content Validity Ratio (CVR) and Content Validity Index (CVI). Conversely, expert judgment was employed to assess the content validity of tools measuring adaptation to Parkinson's disease, colostomy, and type 1 diabetes. Notably, the disclosure of content validity was absent for instruments assessing adaptation to HIV-positive infection and colorectal cancer.

Validity and reliability facets are of utmost importance, enabling us to effectively utilize these instruments (37). Each selected instrument employed a specific methodology to assess its reliability. Among these, instruments evaluating adaptation to breast cancer (test-retest reliability for each subscale ranging from 0.64 to 0.89, α values for each subscale ranging from 0.60 to 0.90), drug-resistant tuberculosis (test-retest reliability of 0.853, α value of 0.893), adaptation to Parkinson's disease (test-retest reliability of 0.99, α value of 0.938), HIV-positive infection (α values for each subscale ranging from 0.52 to 0.84), and colorectal cancer (test-retest reliability ranging from 0.87 to 0.94, α values ranging from 0.78 to 0.87) adopted the test-retest reliability approach and internal consistency. In the case of the instrument assessing adaptation to type 2 diabetes,

the Cronbach's alpha method was employed ($\alpha = 0.75$), while the instrument evaluating adaptation to colostomy utilized the test-retest method (0.6918).

Criterion Validity

Criterion validity, also known as criterion-related validity, serves as an indicator of the appropriateness of an instrument in comparison to other measurement tools or predictive instruments. It provides quantitative evidence of the tool's accuracy when compared to alternative methods for establishing validity (38). In this context, four instruments assessing adaptation to Parkinson's disease, breast cancer, drug-resistant tuberculosis, and type 1 diabetes utilized concurrent validity. Additionally, the instrument measuring adaptation to HIV-positive infection employed both concurrent and predictive validity. However, the instruments evaluating adaptation to breast cancer, type 2 diabetes, and colostomy did not report criterion validity.

Construct Validity

Construct validity, a crucial aspect of validity is often evaluated through factor analysis, with exploratory and confirmatory factor analyses being prominent methodologies. According to our study, all eight instruments emphasized the utilization of exploratory and confirmatory factor analyses to assess construct validity. Notably, instruments measuring adaptation to breast cancer and drug-resistant tuberculosis employed both exploratory and confirmatory factor analyses.

Responsiveness

Responsiveness, characterized by the instrument's ability to detect changes within the evaluated construct (39), was assessed using the receiver operating characteristic (ROC) curve for the instrument measuring adaptation to type 1 diabetes over a specific period.

Interpretability

Interpretability refers to the meaningfulness of qualitative changes, particularly the minimal essential alterations in instrument scores (40). Interestingly, none of the instruments explored interpretability (refer to Table 4).

Table 4. Psychometric Characteristics of the Psychological Adjustment Measures

Tool	Validity (Face / Content)	Reliability (Internal consistency)	Reliability (Stability)	Criterion Validity (Concurrent)	Criterion Validity (Predictive)	Structural Validity (Exploratory)	Structural Validity (Confirmatory)	Interpretability	Responsiveness
Mini-MAC	-	✓	✓	✓	-	✓	✓	-	-
OAS	✓	-	✓	-	-	-	✓	-	-
AS_DRTBP	✓	✓	✓	✓	-	✓	✓	-	-
DAS-1	✓	-	✓	✓	-	-	✓	-	✓
AIMI-IBC	✓	✓	✓	-	-	✓	-	-	-
DAAS	✓	✓	-	-	-	✓	-	-	-
Psychosocial Adaptation in Parkinson's Disease	✓	✓	✓	✓	-	✓	-	-	-
MAHIVES	-	✓	✓	✓	✓	✓	-	-	-

Discussion

The literature from the past two decades has significantly contributed to the understanding of adaptation to chronic illnesses. Empirical evidence confirms that living with a chronic disease requires adaptation across various aspects of life. While substantial progress has been made in comprehending adaptation to chronic illnesses in preceding decades, several questions remain unresolved (25). As the primary goal of treating and caring for patients with chronic illnesses is to assist them in adapting to the illness and its consequences, there arises a need for tools

capable of measuring the extent of adaptation. The present study reveals a rise in the number of published articles focused on measuring adaptation to chronic illnesses in recent years. However, only a limited number of articles have concentrated on assessing psychological adaptation to chronic illnesses. In this study, only 8 self-report instruments were identified, highlighting the scarcity in this area. Furthermore, research findings emphasize the absence of a comprehensive tool encompassing adaptation to the majority of chronic illnesses.

The design of an instrument is a meticulous process that requires careful adherence to its specifications and

guidelines to produce a quality tool. Within this framework, data collection and establishing trust in the results can be achieved (41). Creating appropriate items necessitates a theoretical foundation that mirrors the content domains of a new instrument (35). The most effective approach to scale development involves a combination of both classical and exploratory methods to define the domain and formulate assessment questions. While a literature review provides a theoretical basis for domain definition, qualitative techniques facilitate the transition from an abstract concept to identifying its manifestations (42). Based on the findings about the trend in tool development and formulation, future efforts should involve creating instruments that employ a well-suited conceptual domain definition, built on the integration of both classical and exploratory approaches. Although there is no fixed rule for determining the number of items (41), it is important to acknowledge that tools with fewer items exhibit reduced response error (due to decreased respondent intercorrelation) (35). The total number of extracted items for all instruments remained below 50, a range deemed suitable for individuals dealing with chronic illnesses. After item extraction, the response spectrum for each item or query should be established (35). Across all scrutinized instruments in this study, the scoring method for each item has been explicitly outlined, utilizing the Likert scale.

Once items are determined, the validity and reliability of the tool, as the two primary psychometric properties, must be examined to establish a standardized instrument (41). Content validity represents the first category of validity that should be ensured throughout the tool's design process (43). Concerning content validity, the content that the test claims to measure is scrutinized (38). The importance of content validity in questionnaire design goes beyond ensuring desired content validity indicators (appropriateness, clarity, and comprehensiveness). Besides achieving psychometric properties, which are crucial for every developed instrument, enhancing reliability indicators and aiding the reduction of resources required for questionnaire preparation are benefits not easily overlooked (43). Despite the pivotal role of content validity in linking abstract concepts with observable and measurable indicators in tool development, its study remains somewhat superficial and cursory (44). According to the findings of this study, content validity had not been addressed for two relevant instruments.

Structural validity is relevant when a test is employed to measure attributes or qualities that are not operationally defined. Without evaluating structural validity, the estimation and correction of the impacts of random errors and method variance cannot occur, leading to ambiguous and conflicting research outcomes (45). Given the centrality of structural validity in tools, it has been assessed in all studies under consideration.

Reliability entails a level of consistency in results over a specified period, under similar circumstances, and with a consistent measurement method, evaluated through repeatability and reproducibility capabilities (46). According to the COSMIN checklist, measurement error stands as a critical measurement property in terms of reliability (47). Measurement error remains uncalculated in any of the tools; therefore, in evaluating reliability, attention should extend beyond reporting internal consistency alone, encompassing the reporting of stability indices and standard errors of the instrument (41).

Measurement tools should be attuned to changes and exhibit responsiveness (34). Responsiveness is appraised by contrasting the Minimal Important Change (MIC) with the Smallest Detectable Change (SDC). If the MIC surpasses the SDC, the questionnaire's responsiveness is confirmed. Moreover, the Area Under the Curve (AUC) of the Receiver Operating Characteristic (ROC) can be employed, signifying the instrument's capability to discriminate between patients with and without change based on an external criterion. An AUC equal to or exceeding 0.7 indicates satisfactory responsiveness (48). Despite many authors not yet deeming this a psychometric attribute, contemporary classifications underscore its significance for assessing score change reliability (39). The Diabetes Adjustment Scale Type 1 (DAS-1) questionnaire is the only instrument in this study in which responsiveness been explored. In this questionnaire, the AUC under the curve is 0.85, affirming the responsiveness of this tool.

Interpretability emerges as a critical feature of a measurement tool (39). If means and standard deviations are reported for at least four subgroups, interpretability is investigated. Furthermore, the Minimal Clinically Important Change (MCIC) must be defined to enable the interpretation of changes over time (48). In none of the mentioned tools within this study, interpretability has been examined. Remaining psychometric attributes such as ceiling and floor effects and the cutoff point have been scarcely assessed. All the introduced tools possess adaptability, requiring minimal resources and equipment, which indeed stands as a significant attribute of these self-report instruments.

Studies suggest that in the majority of health assessment tools that have been designed or utilized, researchers have predominantly focused on validity and reliability, often overlooking other essential psychometric criteria. In a systematic review article by Huang and Yang, which examined the psychometric and performance aspects of self-efficacy instruments among cancer populations, it was concluded that a primary constraint in the validation process was the failure to evaluate critical features of the instruments, including retest reliability, criterion validity, responsiveness, and interpretability (49). Bautista and colleagues conducted a review of psychometric properties and theoretical foundations of instruments assessing self-care behaviors

or barriers in individuals with type 2 diabetes. They identified significant methodological flaws in cognition in many of the selected tools (50). In a systematic review by Reneman and associates, evaluating the psychometric properties of chronic pain acceptance questionnaires, the results indicated that none of the questionnaires met all the quality psychometric criteria (51). In a review study by Frei and Svarin, which explored the psychometric properties of self-efficacy instruments for patients with chronic diseases, it was concluded that the development and validation processes of most self-efficacy instruments exhibited significant limitations. Often, the objectives of the instruments remained unspecified, and not all measurement attributes crucial for fulfilling the specific purpose of the instrument were assessed (52). However, these criteria form the fundamental basis for evaluating the utility of tools according to the COSMIN checklist. These shortcomings within these instruments highlight a notable area for advancing the development of future tools (53). Consequently, it is advised that all psychometric criteria receive consideration during the instrument's design phase.

Limitation

This study encountered several limitations, including its objective to review instruments compatible with chronic diseases. Therefore, it is recommended that studies regarding compatibility tools be conducted not solely confined to chronic diseases. Furthermore, due to the breadth of compatibility dimensions, studies addressing other dimensions of compatibility, such as body image compatibility, sexual compatibility, social compatibility, etc., about diseases are recommended. Another limitation of this study is that only instruments discussed in full English-language articles were taken into account. Therefore, addressing these limitations is recommended for future studies.

Conclusion

The influence of disease adaptation on the well-being of individuals with chronic conditions has prompted psychologists to incorporate the assessment of disease adaptation into the health evaluation protocols for chronic patients. Nevertheless, despite the availability of numerous specialized tools for gauging disease adaptation, many have omitted a comprehensive presentation of all psychometric attributes. For formulating interventions aimed at enhancing health outcomes, instruments designed to evaluate disease adaptation need to possess lucid conceptual definitions and psychometric properties applicable across diverse age groups (attending to physical and psychological requisites) and the cultural and societal contexts of the specific community under consideration. A more pragmatic suggestion underscores the imperative of developing instruments characterized by sound psychometric attributes and substantial effectiveness

among chronic patients, adaptable to the distinct cultural and social milieu of each community.

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Conflict of Interest

None.

References

1. Bonomi AE, Wagner EH, Glasgow RE, VonKorff M. Assessment of chronic illness care (ACIC): a practical tool to measure quality improvement. *Health Serv Res.* 2002;37(3):791-820.
2. Ambrosio L, Portillo MC, Rodríguez-Blázquez C, Rodríguez-Violante M, Castrillo JCM, Arillo VC, et al. Living with chronic illness scale: international validation of a new self-report measure in Parkinson's disease. *NPJ Parkinsons Dis.* 2016;2:16022.
3. Brunner LS. Brunner & Suddarth's textbook of medical-surgical nursing: Lippincott Williams & Wilkins; 2010.
4. Conroy T, Feo R, Alderman J, Kitson A. Building nursing practice: The fundamentals of care framework. In: Potter & Perry's Fundamentals of Nursing: Australia and New Zealand 6th Edition 2021 (pp. 19-33). Elsevier Australia.
5. Forestier B, Anthoine E, Reguiat Z, Fohrer C, Blanchin M. A systematic review of dimensions evaluating patient experience in chronic illness. *Health Qual Life Outcomes.* 2019;17(1):19.
6. Falvo D, Holland BE. Medical and psychosocial aspects of chronic illness and disability: Jones & Bartlett Learning; 2017.
7. Izadi-avanji FS, Hasani P, Rakhshan M, Alavi Majd H. Structure of resilience in older adults with chronic conditions. *Journal of Qualitative Research in Health Sciences.* 2017;6(4):314-25.
8. Vahidi A, Shaker Dioulagh A. The role of caregiver burden, marital stress, and mindfulness in predicting psychosocial adjustment to illness in people with coronary artery disease. *J Cardiovasc Nurs.* 2018;7(1):50-9.
9. Memarian R. The application of nursing concepts and theories. Tehran: Tarbiat Modarres University. Office of Publishing Scientific Works; 1999.
10. Yoder LH, Cengiz A, Hinkley T, Hertel RA, Gallagher-Ford L, Koshy Thomas B. Medical-surgical nurses' EBP beliefs and competencies. *Worldviews on Evidence-Based Nursing.* 2022 Apr;19(2):149-59.
11. Fegghi H, SAADATJOO SA, Dastjerdi R. Psychosocial adaptation in patients with Type 2

- diabetes referring to Diabetes Research Center of Birjand in 2013. 2013.
12. Yousefy A, Nekouei ZK. Basis of Cognitive-Behavioral Trainings and its Applications in Recovery of Chronic Diseases. *J Med Educ.* 2011;10(5):792-800.
13. Samadzade N, Poursharifi H, Babapour J. The effectiveness of cognitive-behavioral therapy on the psycho-social adjustment to illness and symptoms of depression in individuals with type II diabetes. *Clinical Psychology Studies.* 2014;5(17):77-96.
14. Hassani SN, Tabiee S, Saadatjoo S, Kazemi T. The effect of an educational program based on Roy adaptation model on the psychological adaptation of patients with heart failure. *Modern Care Journal.* 2013;10(4).
15. Aghakhani N, Hazrati Marangaloo A, Vahabzadeh D, Tayyar F. The effect of Roy's adaptation model-based care plan on the severity of depression, anxiety and stress in hospitalized patients with colorectal cancer. *Hayat.* 2019;25(2):208-19.
16. Halford J, Brown T. Cognitive-behavioural therapy as an adjunctive treatment in chronic physical illness. *Adv Psychiatr Treat.* 2009;15(4):306-17.
17. Sahranavard S, Ahadi H, Taghdisi MH, Kazemi T, Krasekian A. The role of psychological factors on the psychological and social adjustment through the mediation of ischemic heart disease hypertension. *Hypertension.* 2017;5(2):139-46.
18. Atik D, Karatepe H. Scale development study: adaptation to chronic illness. *Acta Medica Mediterranea.* 2016;32(1):135-42.
19. Nazari S, Foroughan M, Mohammadi Shahbolaghi F, Rassouli M, Sadegh Moghadam L, Farhadi A, et al. Analysis of the psychometric properties of the perceived social support scales in older adults. *Iranian Journal of Ageing.* 2016;10(4):210-8.
20. Calderon C, Lorenzo-Seva U, Ferrando PJ, Gómez-Sánchez D, Ferreira E, Ciria-Suarez L, et al. Psychometric properties of Spanish version of the Mini-Mental Adjustment to Cancer Scale. *Int J Clin Health Psychol.* 2021;21(1):100185.
21. Indrebø KL, Aasprang A, Olsen TE, Andersen JR. Psychometric Properties of New Subscales of the Ostomy Adjustment Scale: A Cross-Sectional Study. *Patient Relat Outcome Meas.* 2021;12:65-75.
22. Rivas T, Carreira M, Domínguez-López M, Ruiz de Adana MS, Anarte MT. Development and Preliminary Validation of a New Type 1 Diabetes Adjustment Scale (DAS-1). *Front Psychol.* 2020;11:533.
23. Liu H, Zhao J, Cao Y, Jiang H, Zhang S, Hua Z, et al. Developing and Validating an Adjustment Scale: The Adaptation Status Assessment of Drug-Resistant Tuberculosis Patients. *Psychol Res Behav Manag.* 2020;13:67-78.
24. Ebrahimi H, Karimi Moonaghi H, Asghari Jafarabadi M, Namdar Areshtanab H, Jouybari L. Development and Preliminary Validation of Diabetes Adjustment Assessment Scale (DAAS): a New Measure of Adjustment with Type 2 Diabetes. *J Caring Sci.* 2016;5(2):145-52.
25. Zhang T, Yin A, Sun X, Liu Q, Song G, Li L. Development, reliability and validity of the psychosocial adaptation scale for Parkinson's disease in Chinese population. *Int J Clin Exp Med.* 2015;8(10):19731-8.
26. Kelly B, Raphael B, Burrows G, Judd F, Kernutt G, Burnett P, et al. Measuring psychological adjustment to HIV infection. *Int J Psychiatry Med.* 2000;30(1):41-59.
27. Hajian S, Mehrabi E, Simbar M, Houshyari M, Zayeri F, Hajian P. Designing and Psychometric Evaluation of Adjustment to Illness Measurement Inventory for Iranian Women With Breast Cancer. *Iran J Cancer Prev.* 2016;9(4):e5461.
28. Antoniadis D, Giakoustidis A, Papadopoulos V, Fountoulakis KN, Watson M. Quality of life, distress and psychological adjustment in patients with colon cancer. *Eur J Oncol Nurs.* 2024;68:102467.
29. Rodríguez-González A, Velasco-Durántez V, Cruz-Castellanos P, Hernández R, Fernández-Montes A, Jiménez-Fonseca P, et al. Mental Adjustment, Functional Status, and Depression in Advanced Cancer Patients. *Int J Environ Res Public Health.* 2023;20(4):3015.
30. Siennicka A, Goscińska-Bis K, Waga K, Wójcik M, Błaszczak R, et al. Derivation and Validation of a Scale Assessing Constructive and Destructive Styles of Mental Adjustment to Heart Failure Based on the Mini-MAC Scale Used in Psycho oncology: The Results of Multicenter Caps-Lock-HF (Complex Assessment of Psychological Status Located in Heart Failure) Study. *Front Med Health Res.* 2017;1(1):1-10.
31. Okati-Aliabad H, Ansari-Moghadam A, Mohammadi M, Kargar S, Shahraki-Sanavi F. The prevalence of anxiety and depression and its association with coping strategies, supportive care needs, and social support among women with breast cancer. *Support Care Cancer.* 2022;30(1):703-10.
32. Cao CH, Liao XL, Gamble JH, Li LL, Jiang XY, Li XD, et al. Evaluating the psychometric properties of the Chinese Depression Anxiety Stress Scale for Youth (DASS-Y) and DASS-21. *Child Adolesc Psychiatry Ment Health.* 2023;17(1):106.
33. Pontone GM, McDaniels B, Keener AM, Subramanian I. A Wellness Prescription for Parkinson's: Mid to Late-Stage Disease. *Am J Geriatr Psychiatry.* 2023;31(9):737-47.
34. Morgado FFR, Meireles JFF, Neves CM, Amaral ACS, Ferreira MEC. Scale development: ten main limitations and recommendations to improve future research practices. *Psicol Reflex Crit.* 2017;30(1):3.
35. Taghizadeh Z, Ebadi A, Montazeri A, Shahvari Z, Tavousi M, Bagherzadeh R. Psychometric

- properties of health related measures. Part 1: Translation, development, and content and face validity. Payesh (Health Monitor). 2017;16(3):343-57.
36. Vakili MM, Jahangiri N. Content validity and reliability of the measurement tools in educational, behavioral, and health sciences research. Journal of Medical Education Development. 2018;10(28):106-18.
37. Tabatabaei MS, Kamran F, Jalaei S. A Review of Assessment Tools for Oral Feeding in Term and Preterm Infants. Journal of Mazandaran University of Medical Sciences. 2019;29(172):160-9.
38. Shabankareh K, Hamidi A. Validity Assessment in the Knowledge & Information Science Researches. Iranian Journal of Information Processing and Management. 2019;34(3):1103-24.
39. Echevarría-Guanilo ME, Gonçalves N, Romanoski PJ. Psychometric properties of measurement instruments: conceptual bases and evaluation methods-part I. Texto & Contexto-Enfermagem. 2018;26.
40. Shirinabadi Farahani A, Rassouli M, Yaghmaei F, Alavi Majd H. Index for selecting an appropriate instrument to conduct research in health sciences: Introducing the COSMIN checklist. Journal of Health Promotion Management. 2015;4(4):1-13.
41. Nademi MS, Bahmani B, Maarefvand M, Motamedi SV, Mardani MA, Biglarian A. Psychometric properties of attitude questionnaire to prayer: construction, development, validity and reliability. 2018.
42. Boateng GO, Neilands TB, Frongillo EA, Melgar-Quinonez HR, Young SL. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. Front Public Health. 2018;6:149.
43. Abdollahpour I, Nedjat S, Noroozian M, Majdzadeh R. Performing content validation process in development of questionnaires. Iranian Journal of Epidemiology. 2011;6(4):66-74.
44. Zamanzadeh V, Ghahramanian A, Rassouli M, Abbaszadeh A, Alavi-Majd H, Nikanfar AR. Design and Implementation Content Validity Study: Development of an instrument for measuring Patient-Centered Communication. J Caring Sci. 2015;4(2):165-78.
45. Vakili MM. Assessment of construct validity questionnaires in psychological, educational and Health research: applications, methods, and interpretation of exploratory factor analysis. Journal of Medical Education Development. 2018;11(30):4-19.
46. Mohammadbeigi A, Mohammadsalehi N, Aligol M. Validity and reliability of the instruments and types of measurements in health applied researches. Journal of rafsanjan university of medical sciences. 2015;13(12):1153-70.
47. Tian L, Cao X, Feng X. Evaluation of psychometric properties of needs assessment tools in cancer patients: A systematic literature review. PLoS One. 2019;14(1):e0210242.
48. Ebadi A, Taghizadeh Z, Montazeri A, Shahvari Z, Tavousi M, Bagherzadeh R. Translation, development and psychometric properties of health related measures-Part 2: construct validity, reliability and responsiveness. Payesh (Health Monitor). 2017;16(4):445-55.
49. Huang FF, Yang Q, Wang AN, Zhang JP. Psychometric properties and performance of existing self-efficacy instruments in cancer populations: a systematic review. Health Qual Life Outcomes. 2018;16(1):241.
50. Caro-Bautista J, Martín-Santos FJ, Morales-Asencio JM. Systematic review of the psychometric properties and theoretical grounding of instruments evaluating self-care in people with type 2 diabetes mellitus. J Adv Nurs. 2014;70(6):1209-27.
51. Reneman MF, Dijkstra A, Geertzen JH, Dijkstra PU. Psychometric properties of Chronic Pain Acceptance Questionnaires: a systematic review. Eur J Pain. 2010;14(5):457-65.
52. Frei A, Svarin A, Steurer-Stey C, Puhan MA. Self-efficacy instruments for patients with chronic diseases suffer from methodological limitations--a systematic review. Health Qual Life Outcomes. 2009;7:86.
53. Yazdani N, Sharif F, Elahi N, Ebadi A, Hosseini SV. Psychometric properties of quality of life assessment tools in morbid obesity: a review of literature. Evidence Based Care Journal. 2018;7(4):7-21.