**Journal Of Nursing Practice**
https://thejnp.org/ Vol. 10 No.1 October. Page Page 52-63
ISSN: 2614-3488 (print); 2614-3496 (online) https://doi.org/10.30994/jnp.v10i1.786

# Life Satisfaction in People Affected by Thalassemia: A Scoping Review of Patient, Family, and Couple Perspectives

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## ABSTRACT

**Background:** Thalassemia can affect the experiences of patients and their families. Life satisfaction is a cognitive appraisal of life and should not be conflated with quality of life. This review maps the evidence across affected populations.

**Purpose:** To map studies examining life satisfaction among patients with thalassemia, their family members, and couples with thalassemia minor, and identify gaps relevant to nursing.

**Methods:** This scoping review followed the Arksey and O'Malley framework. PubMed, Scopus, and CINAHL were searched through 30 October 2024 for English-language empirical articles published from 2014 to 2024. Two reviewers independently screened, charted, and synthesized the evidence, resolving differences by discussion to consensus and consulting a third author if consensus could not be reached. Five studies were included.

**Results:** Five studies were mapped: three patient studies from Italy and Iran, one study of family members in Türkiye, and one study of couples with thalassemia minor in Iran. Patient studies addressed perceived support, self-efficacy, satisfaction domains, and affective experiences; the remaining studies described satisfaction among relatives or couples. Population and measurement heterogeneity precluded direct comparisons.

**Conclusion:** The five studies provide a limited and heterogeneous evidence map of life satisfaction across people affected by thalassemia. Patient, family, and couple outcomes should be interpreted separately. Further research using clearly specified instruments and longitudinal designs is needed.

**Keywords** : Family; Life Satisfaction; Scoping Review; Thalassemia

## BACKGROUND

Thalassemia is a genetic blood disorder characterized by the production of abnormal hemoglobin, causing chronic anemia and long-term health complications (Badawy et al., 2021).

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Received: December 10, 2025; Revised: April 15, 2026; Accepted: October 10, 2026; Available Online: October 22, 2026
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Thalassemia requires lifelong care, including routine blood transfusions and iron chelation therapy, which significantly influences the quality of life of patients (Platania et al., 2017). In addition to physical burdens, patients often face psychosocial challenges, such as social stigma, limitations in physical activity, and financial burdens related to treatment (Porter et al., 2012).

It is estimated that approximately 270 million people worldwide are thalassemia gene carriers, with more than 60,000 children born each year with thalassemia major or other severe forms of thalassemia (Husna et al., 2017). In India, it is estimated that around 10,000 to 12,000 newborns are born with thalassemia major every year, making it one of the countries with the highest burden globally (Khamoushi et al., 2015). The prevalence of thalassemia gene carriers in India is estimated to be about 3-4% of the total population, or around 35 million people. In Southeast Asia, the prevalence of thalassemia gene carriers is also high; for instance, in Thailand, 3-9% of the population carries the thalassemia gene, with about 1% estimated to suffer from thalassemia major (He et al., 2019). In Indonesia, the prevalence of thalassemia gene carriers is estimated to reach 6-10% of the population, with approximately 3,000 to 4,000 thalassemia major patients requiring routine blood transfusions (Sleiman et al., 2018).

Thalassemia significantly impacts the daily lives of patients, especially due to physical limitations caused by chronic anemia, as well as the burden of lifelong care, which includes routine blood transfusions and iron chelation therapy (Zolaly et al., 2020). This treatment process often limits patients' activities in education, work, and social life, and also causes chronic fatigue that disrupts their daily lives. In addition, social stigma related to thalassemia in underprivileged communities, due to a lack of understanding about the disease, often leads to discrimination and social isolation. This chronic health condition is also closely connected with psychosocial issues, such as depression, anxiety, and low self-esteem (Zolaly et al., 2020). Thalassemia patients often experience emotional stress due to the burden of the disease, which is exacerbated by physical limitations and social isolation, potentially lowering their level of life satisfaction (Khamoushi et al., 2015).

Life satisfaction is a cognitive judgement about one’s overall life or specific life domains. It is not synonymous with quality of life (QoL): QoL and health-related QoL encompass broader aspects of functioning and health. This review therefore includes studies measuring life satisfaction directly and reports QoL findings only where necessary to explain the instruments and contexts used. A general QoL outcome alone does not establish an effect on life satisfaction.

Social support plays an important role, especially from family, community, and healthcare professionals. Emotional and instrumental support from family can provide a sense of security and help patients manage physical challenges and psychosocial problems (Senol et al., 2016). Economic welfare is also an important factor, considering the high cost of treatments like routine blood transfusions and iron chelation therapy. Patients who face financial difficulties tend to have lower life satisfaction due to the economic pressure that adds to the disease burden (Hatami & Motamed, 2014). Access to quality care, including the availability of blood transfusions, effective therapy, and continuity of medical care, strongly influences patients’ perception of their well-being (Sevinç, 2023). Psychological management through psychosocial interventions is also important in helping patients develop coping skills (Hatami & Motamed, 2014).

Although thalassemia-related quality of life has been widely discussed, findings specifically addressing life satisfaction appear across heterogeneous groups: people receiving care, their relatives, and couples affected by thalassemia trait. Pooling these groups would obscure whose life satisfaction was assessed. This scoping review maps their distinct perspectives, instruments, and evidence gaps rather than estimating causal effects.

To map the populations, measurements, and findings of original empirical studies addressing life satisfaction among patients with thalassemia, family members of individuals with thalassemia, and couples with thalassemia minor, and to identify evidence gaps relevant to nursing practice.

## METHODS

### Design and Setting

This scoping review used the five-stage methodological framework (Arksey & O'Malley, 2005): formulation of the question, identification of studies, selection, data charting, and collation and reporting of findings. Reporting was structured in accordance with PRISMA-ScR. The review question was: What has been reported about life satisfaction among patients with thalassemia, their family members, and couples with thalassemia minor?

### Participants and Sampling

Population: individuals living with thalassemia, family members of individuals with thalassemia, and couples with thalassemia minor. Concept: life satisfaction measured by an explicitly identified life-satisfaction scale or assessed as a clearly identified study outcome; quality of life was considered contextual evidence but not substituted for life satisfaction. Context: any country or healthcare/community setting. Eligible designs were original empirical quantitative, qualitative, or mixed-methods studies published in English between 2014 and 30 October 2024. Reviews, commentaries, protocols, and reports without life-satisfaction findings were excluded. Findings were categorized by participant population rather than pooled.

PubMed, Scopus, and CINAHL were searched on 30 October 2024 for English-language original empirical studies published between 1 January 2014 and 30 October 2024. Search terms combined thalassemia-related terminology with life satisfaction and related satisfaction constructs. The original database-specific search strategies, including language and publication-date limits, are presented in Table 1. Retrieved records were deduplicated and screened against

**Table 1.** Database-adapted Search Strategies

| Database | Apply English and publication-date limits (2014–30 Oct 2024) |
|---|---|
| PubMed | ("Thalassemia"[Mesh] OR thalassemia*[tiab] OR thalassaemia*[tiab]) AND ("personal satisfaction"[tiab] OR "life satisfaction"[tiab] OR "satisfaction with life"[tiab] OR "quality of life"[Mesh] OR "quality of life"[tiab]) |
| Scopus | TITLE-ABS-KEY (thalassemia* OR thalassaemia*) AND TITLE-ABS-KEY("life satisfaction" OR "satisfaction with life" OR "personal satisfaction" OR "quality of life") AND PUBYEAR > 2013 AND PUBYEAR < 2025 AND (LIMIT-TO(LANGUAGE,"English")) |
| CINAHL (EBSCOhost) | (MH "Thalassemia+" OR TI (thalassemia* OR thalassaemia*) OR AB (thalassemia* OR thalassaemia*)) AND (TI ("life satisfaction" OR |

| Database | Apply English and publication-date limits (2014–30 Oct 2024) |
|---|---|
| | "satisfaction with life" OR "quality of life") OR AB ("life satisfaction" OR "satisfaction with life" OR "quality of life") OR MH "Quality of Life") |

**Instruments and Data Collection**

Two reviewers independently charted study authorship, year, country, participant group, study design, sample, measures, and principal findings in a structured table. Disagreements were discussed through deliberation until consensus was achieved; if agreement was not possible, the third author was invited to arbitrate.

**Data Analysis**

Two reviewers independently mapped findings descriptively by participant group, study measure, and reported association or experience. Differences in interpretation were resolved by discussion to consensus, with third-author consultation when necessary. Each mapped finding was attributed to its contributing primary study. No meta-analysis or formal assessment of intervention effectiveness was undertaken.

**Ethical Considerations**

This scoping review synthesized information from previously published studies and did not recruit human participants or collect identifiable individual-level data; therefore, research ethics approval and participant informed consent were not applicable.

**RESULTS**

The database searches identified 142 records (Scopus, n = 75; PubMed, n = 44; CINAHL, n = 23). After removing 10 duplicates, 132 records were screened. At the initial screening stage, 81 records were excluded because of ineligible populations, study designs, or concepts, non-English publication language, or publication outside the 2014–2024 eligibility period. Of the remaining 51 records, a further 41 were excluded because the populations were not eligible, the studies did not focus on thalassemia, or the publications were review articles. Consequently, 10 full-text reports were assessed for eligibility; five were excluded and five studies were included in the final review (Figure 1).

Five original studies were included (Table 2): three involving patients (Platania et al., 2017; Hatami & Motamed, 2014; Mento et al., 2015), one involving family members (Sevinç, 2023), and one involving couples with thalassemia minor (Safarpour et al., 2016). Designs comprised observational quantitative and mixed-methods approaches; no intervention effectiveness conclusion was drawn. Studies were conducted in Italy, Iran, and Türkiye, and participant denominators varied by study.

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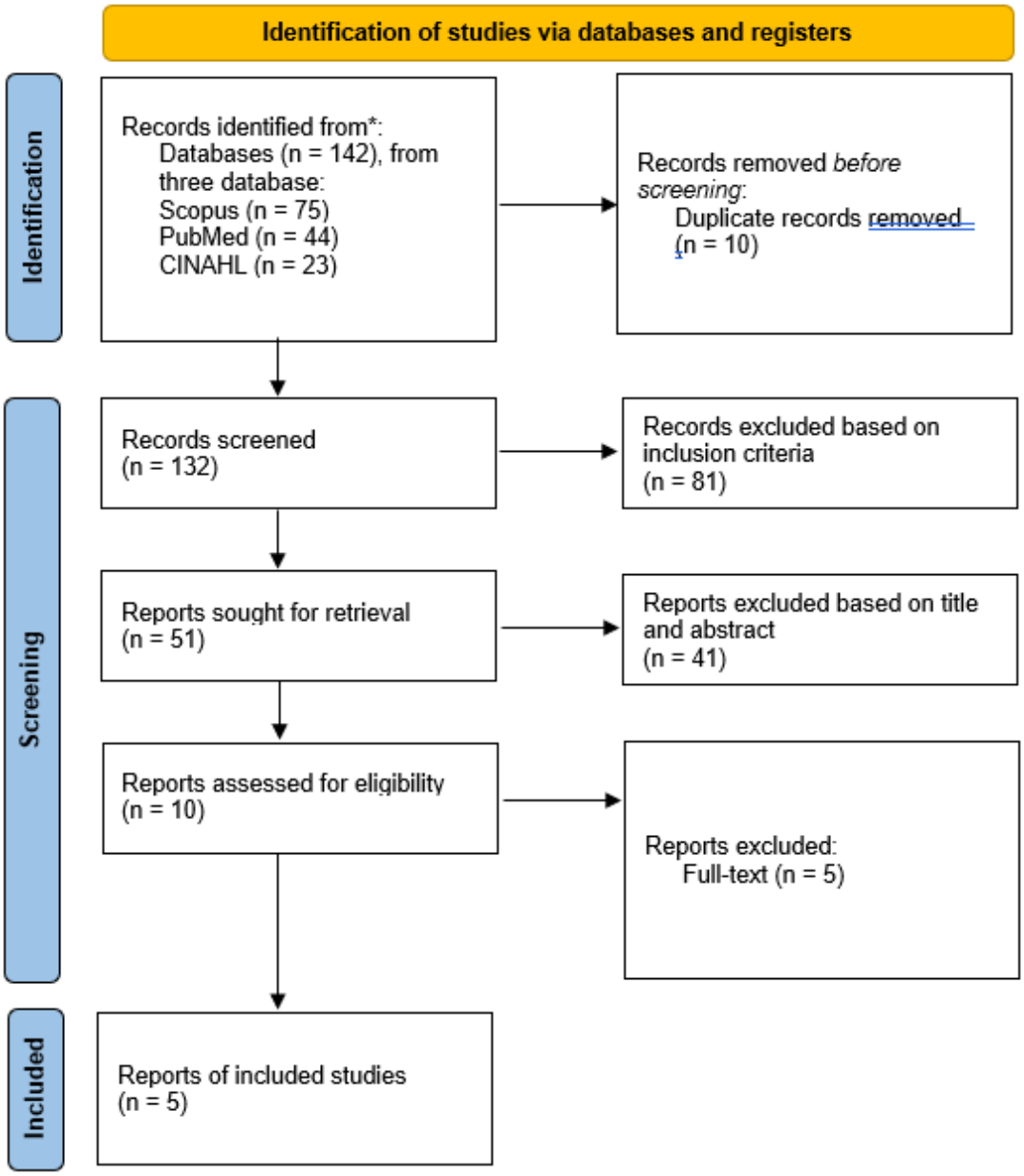



**Figure 1.** PRISMA Flow Diagram

**Table 2.** Data Extraction

| Study and country | Population and sample | Study design | Life-satisfaction measure | Principal finding | Population category |
|---|---|---|---|---|---|
| (Platania et al., 2017); Italy | 300 patients with thalassemia major | Cross-sectional | Satisfaction With Life Scale | Self-efficacy related to life satisfaction, mediated by social support | Patients |

| Study and country | Population and sample | Study design | Life-satisfaction measure | Principal finding | Population category |
|---|---|---|---|---|---|
| (Hatami & Motamed, 2014); Iran | 89 patients; 100 healthy controls | Controlled cross-sectional | Multidimensional Students' Life Satisfaction Scale | Higher scores for school, friends, living environment, and total score among patients | Patients |
| (Mento et al., 2015); Italy | 31 patients with major/intermedia thalassemia | Cross-sectional | Quality of Life Enjoyment and Satisfaction Questionnaire; Profile of Mood States | Described affective control, tension, and satisfaction-related experiences | Patients |
| (Sevinç, 2023); Türkiye | 22 family members | Mixed methods | Satisfaction With Life Scale; interviews | Relative-reported satisfaction and difficulties; submitted mean 11.18 ± 5.13 | Family members |
| (Safarpour et al., 2016); Iran | 62 individuals in couples with thalassemia minor | Descriptive observational | Short-form Satisfaction With Life Scale (SWLS) | 67.7% reported low life satisfaction; associated with number of children and duration of marriage, not age or sex | Couples with thalassemia minor |

**Social Support and Individual Life Satisfaction**

In an Italian cross-sectional sample of 300 patients with thalassemia major, life satisfaction was associated with self-efficacy, with social support identified as a mediator (Platania et al., 2017). This observational association does not demonstrate a causal intervention effect.

In Iran, a controlled cross-sectional study included 89 children/adolescents with beta-thalassemia major who completed the questionnaire and 100 healthy controls. School, friends, and living-environment satisfaction domains, together with the total score, were higher in the

thalassemia group after adjustment for selected demographic variables (Hatami & Motamed, 2014).

The Italian study involving 31 patients with thalassemia major or intermedia examined mood, affective control, and quality-of-life enjoyment/satisfaction using several measures. Relationships involving tension and satisfaction-related outcomes were described, but the Q-LES-Q is not equivalent to a global Satisfaction With Life Scale (Mento et al., 2015).

**Family and Couple Perspectives**

In Türkiye, a mixed-methods study investigated 22 family members of individuals with thalassemia rather than the patients themselves. The study reported a mean Satisfaction With Life Scale score of 11.18 ± 5.13 and an inverse association with maternal age; these findings apply to participating relatives (Sevinç, 2023).

Safarpour et al. (2016) examined life satisfaction among 62 individuals in couples affected by thalassemia minor in Bojnourd, Iran, using the short-form Satisfaction With Life Scale (SWLS). Approximately 67.7% of respondents reported low life satisfaction (dissatisfied or slightly dissatisfied). Life satisfaction was significantly associated with number of children and duration of marriage (reported $p < 0.001$), but not with age or sex. These findings pertain to people with thalassemia minor in the studied marital context and should not be generalized to patients with thalassemia major.

**Gaps in the Mapped Evidence**

The included studies address heterogeneous populations and predominantly observational questions (Table 3). The five-study map did not identify evidence establishing the effectiveness of a psychosocial intervention for increasing life satisfaction; this is not equivalent to demonstrating that no such interventions exist.

Longitudinal trajectories and changes in satisfaction over time were not directly established by the cross-sectional or descriptive evidence in this map. Studies using consistently defined life-satisfaction outcomes and specified patient or caregiver samples could help clarify these trajectories.

The five included reports, as listed, are from Iran, Italy and Turkey. These locations limit the geographic breadth of this particular review, not necessarily the existence of research in other countries. Replication in additional social and healthcare contexts could be useful.

**Table 3.** Study-to-Finding Evidence Map

| Mapped domain | Supporting included studies |
|---|---|
| Social support and self-efficacy | (Platania et al., 2017) |
| Child/adolescent life-satisfaction domains | (Hatami & Motamed, 2014) |
| Affective control and satisfaction-related outcomes | (Mento et al., 2015) |
| Family members' satisfaction and challenges | (Sevinç, 2023) |
| Couples' life satisfaction and marital context | (Safarpour et al., 2016) |

## DISCUSSION

This review mapped a small but informative body of evidence on life satisfaction across three distinct groups affected by thalassemia: patients, family members, and couples with thalassemia minor. These perspectives cannot be treated as interchangeable because they reflect

different health experiences, social roles, and measurement contexts. The predominance of observational studies also means that reported relationships should be understood as associations or descriptions rather than causal effects. Consequently, the principal contribution of this scoping review is to clarify what has been measured, in whom, and where important evidence gaps remain (Hatami & Motamed, 2014; Platania et al., 2017; Sevinç, 2023).

Among patients, perceived social support emerged as a relevant correlate of life satisfaction in the Italian study of thalassemia major. The reported mediating role of social support in the association between self-efficacy and life satisfaction suggests that individual confidence and interpersonal resources may be interrelated in patients' assessments of their lives. However, statistical mediation within cross-sectional data cannot establish that support precedes or causes improvements in satisfaction. For nursing practice, the findings provide a rationale for assessing perceived support and self-efficacy, while further longitudinal research is required to test the direction and stability of these relationships (Platania et al., 2017).

The study involving children and adolescents with beta-thalassemia major adds a developmentally specific perspective to this evidence map. Higher reported satisfaction in selected school, peer, and living-environment domains compared with healthy controls should be interpreted within the measured domains and the study's setting, not as evidence that living with thalassemia confers an overall advantage. Young people's relationships with friends, participation in education, and perceptions of their surroundings may therefore warrant attention alongside clinical management. Nevertheless, domain-specific satisfaction scores do not necessarily represent global life satisfaction, and comparisons across developmental groups require compatible instruments and age-appropriate interpretation (Hatami & Motamed, 2014).

Psychological experiences offer another potentially important dimension, although the relevant evidence is limited. In the small Italian sample, mood, affective control, tension, and enjoyment- or satisfaction-related experiences were examined together, highlighting the complexity of subjective adjustment to thalassemia. Importantly, the Quality of Life Enjoyment and Satisfaction Questionnaire is not equivalent to a global Satisfaction With Life Scale, and its findings should not be presented as if the same construct were measured. Wider research has documented symptoms of depression, anxiety, and stress in thalassemia, but those observations constitute contextual literature rather than additional life-satisfaction findings from the five included studies (Mento et al., 2015; Zolaly et al., 2020).

Family members represent a distinct population whose reported life satisfaction reflects caregiving and family circumstances rather than the patient's own evaluation. The mixed-methods study in Türkiye documented life-satisfaction scores and difficulties experienced by relatives, indicating the value of investigating family experiences in their own right. Such evidence may help nurses recognize that family-centered care involves assessing relatives' needs without substituting proxy assessments for patients' perspectives. The broader nursing literature also addresses supportive interventions for children and adolescents with thalassemia, but quality-of-life intervention findings should not be interpreted as direct evidence of improved family members' life satisfaction (Mardhiyah et al., 2023; Sevinç, 2023).

The study of couples with thalassemia minor extends the scope beyond patients receiving treatment for more severe disease. Life satisfaction within a couple may reflect

marital and family circumstances, reproductive concerns, or wider socioeconomic context, which differ from the clinical and developmental circumstances of patients with thalassemia major. Safarpour et al. (2016) surveyed 62 individuals, reporting low life satisfaction in 67.7% and associations with number of children and duration of marriage, but not age or sex. These observational findings should not be generalized to transfusion-dependent patients or interpreted as causal effects of marital characteristics (Safarpour et al., 2016).

Across the five studies, the distinction between life satisfaction and quality of life is essential for a valid synthesis. Life satisfaction concerns a person's subjective cognitive evaluation, whereas health-related quality of life typically incorporates physical, psychological, and social functioning or health impacts. The included reports used different scales and domains, and their samples ranged from children and adults with thalassemia to relatives and couples with thalassemia minor. Future studies should explicitly name their primary construct, justify their measurement instrument, and report results separately for each population to allow meaningful comparisons (Hatami & Motamed, 2014; Mento et al., 2015; Platania et al., 2017; Sevinç, 2023).

Several evidence gaps follow directly from the mapped studies. The reviewed evidence does not establish longitudinal patterns of life satisfaction or the effectiveness of psychosocial interventions designed specifically to improve that outcome. Repeated measurements could clarify how satisfaction changes with developmental transitions, treatment demands, and evolving family relationships, while carefully designed interventions could test approaches suggested by the observational findings. The included studies were conducted in Iran, Italy, and Türkiye, so additional contexts and health systems deserve investigation; this restricted coverage should not be interpreted as proof that research from other settings does not exist (Hatami & Motamed, 2014; Safarpour et al., 2016; Platania et al., 2017; Sevinç, 2023).

**Limitations**

Interpretation is further constrained by only five heterogeneous studies, predominantly observational designs, variable measures, incomplete historical search-strategy records, and limited detail about exclusions in the retained PRISMA diagram; these limitations reduce reproducibility and preclude firm causal or pooled conclusions (Arksey & O'Malley, 2005; Mardhiyah et al., 2023; Platania et al., 2017).

This review is limited by the small number of included studies, heterogeneous participant populations and outcome measures, and predominantly observational study designs. These characteristics restrict cross-study comparisons and prevent pooled or causal conclusions. Moreover, the evidence map covers studies from only three countries, which limits the geographic transferability of its findings.

**Implication**

The nursing implications are therefore practical but necessarily cautious. Assessments may benefit from distinguishing patient satisfaction, caregiver satisfaction, and couple or family concerns, and from documenting the specific measure used rather than treating all psychosocial outcomes as equivalent. Potential areas for supportive care include communication, social resources, coping needs, and referral for psychological concerns, but

the effectiveness of these approaches on life satisfaction cannot be inferred from the present review.

## CONCLUSION

This scoping review mapped five empirical studies published between 2014 and 2024 that addressed satisfaction-related outcomes among people affected by thalassemia. Three studies involved patients, one examined family members, and one investigated couples with thalassemia minor; their findings consequently represent different perspectives rather than a single homogeneous population. Patient studies described associations involving perceived social support, self-efficacy, developmental satisfaction domains, and affective experiences, while family and couple studies focused on relatives' or partners' own circumstances. Variation in samples, study designs, and measurement instruments limits comparability, and no causal inference or evidence of intervention effectiveness can be drawn from these findings.

For nursing, the review highlights the importance of distinguishing whose life satisfaction is being assessed and of considering psychosocial concerns within patient- and family-centered care. Nurses and researchers should avoid treating quality of life, enjoyment and satisfaction, and global life satisfaction as interchangeable outcomes. Future research would benefit from clearly defined populations, validated construct-specific measures, transparent search and reporting procedures, and longitudinal and intervention designs that can evaluate change over time. Broader geographic representation and separate reporting for patients, caregivers, and couples would also strengthen the applicability of evidence to different clinical and community settings.

## ACKNOWLEDGMENTS

The authors would like to express their sincere gratitude to Universitas Padjadjaran, Indonesia, for its academic and institutional support throughout the research process and manuscript preparation.

## AUTHOR CONTRIBUTIONS

**Mochamad Ilham Kurnia:** Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing – original draft. **Ai Mardhiyah:** Conceptualization, Methodology, Supervision, Validation, Writing – review and editing. **Ema Arum Rukmasari:** Methodology, Supervision, Validation, Writing – review and editing. All authors reviewed and approved the final version of the manuscript and agree to be accountable for all aspects of the work.

## FUNDING

This research received no funding.

## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

## DECLARATION OF AI USE

During manuscript preparation, the authors used OpenAI ChatGPT (GPT-6) to assist with language editing, grammatical refinement, and manuscript formatting. The authors reviewed and edited the output and remain fully responsible for the accuracy, originality, content, and integrity of the article.

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