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Reimagining Quality of Life in Medicine: Moving From Symptom Reduction Toward Meaning, Identity, Relationships, and Social Participation

Maria Gonzales[1]*, Jose Santos[1], Anna Cruz[2], Carlos Reyes[3]

[1]Department of Quality of Life and Patient-Centered Outcomes, Faculty of Medicine, University of the Philippines Manila, Manila, Philippines.
[2]Department of Psychosocial Oncology and Meaning-Making, Faculty of Medicine, University of Santo Tomas, Manila, Philippines.
[3]Department of Health-Related Quality of Life, Faculty of Medicine, Ateneo de Manila University, Quezon City, Philippines.

***E-mail** ✉ maria.gonzales@upm.edu.ph

Abstract

Quality of life is often treated in clinical medicine as an outcome that improves when symptoms, impairment, or disease activity improve. That assumption is useful but incomplete. People can experience substantial symptom burden while retaining meaning, valued roles, relationships, agency, and social participation, while others can achieve biomedical stability yet remain unable to live in ways they regard as worthwhile. This article develops a proposed multidimensional theory of quality of life that distinguishes symptom burden from meaning, identity continuity, relational belonging, participation, and autonomy within social and material opportunity. The model treats these dimensions as analytically distinct but dynamically interdependent. It also separates capacity from realized participation, autonomy from unsupported independence, and adaptation from simple acceptance. Quality of life is therefore framed not as a residual subjective score after clinical outcomes are counted, but as an evolving appraisal of whether a person can sustain or reconstruct a life experienced as viable and valued. The framework remains explicitly non-empirical: it organizes evidence from patient-reported outcomes, illness identity, social support, participation, person-centred care, and measurement research into testable propositions rather than claiming validation. It further identifies response shift, inequitable opportunity, cultural context, organizational design, and measurement choice as boundary conditions for clinical interpretation.

Keywords: Quality of life, Patient-reported outcomes, Illness identity, Social participation, Person-centred care, Response shift

Introduction

Medicine has strong reasons to prioritize symptoms, survival, organ function, and treatment toxicity. These outcomes are observable, actionable, and often essential to preventing harm. Yet patient-centred care repeatedly reveals that clinical improvement and living well are not interchangeable. Integrated-care evidence in long-term neurological disease shows that broader, person-centred approaches can address needs extending beyond disease control, while effects on quality of life remain heterogeneous rather than automatic [1]. Work mapping patient-reported outcome and experience domains likewise shows that patients judge care across encounters and whole care journeys, including domains not consistently represented in established measures [2].

The conceptual problem is therefore not that symptom outcomes are unimportant, but that they are often allowed to organize the entire interpretation of quality of life. This article proposes a different logic. Quality of life is treated as an evolving appraisal of whether illness, treatment, relationships, social conditions, and available resources still permit a life that is recognizable, meaningful, participatory, and sufficiently self-directed. The model

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developed below is not a validated causal structure. It is an evidence-bounded theoretical synthesis designed to make explicit distinctions that conventional symptom-centred reasoning can obscure.

The clinical dominance of symptom-based outcomes

Clinical outcome systems naturally privilege variables that can be monitored against treatment goals. Patient-reported measures broaden that field, but collection alone does not guarantee a more patient-centred interpretation. A systematic review of PROM use found that patient-reported data can operate at patient, organizational, and policy levels, yet improvement depends on how the information is embedded and acted upon [3]. An umbrella review similarly identified workflow, training, feedback, electronic integration, resources, privacy, and digital literacy as conditions shaping routine PROM implementation [4]. Measurement infrastructure can therefore reproduce the same narrowness it was intended to correct if broader patient reports are reduced to another score without interpretive use.

A second limitation concerns level of inference. Group-level changes in a validated PROM can establish important average patterns, but they do not fully explain why a particular patient's life has improved, worsened, or remained difficult. Methodological work on patient-causal singularism emphasizes the gap between population summaries and the explanatory narrative of an individual case [5]. The proposed theory therefore places symptoms within quality of life rather than above it: symptom burden is one important condition that can constrain living, but its practical meaning depends on what it disrupts, what remains possible, and what the person values.

What quality of life represents

Quality of life is often discussed as though it were a stable basket of domains. Evidence instead suggests that its content depends partly on what is asked, how it is measured, and whose priorities are permitted to define relevance. Cancer-survivorship research identifies psychological and social functioning, life disruption, communication, and support needs alongside physical concerns; broader health-and-well-being measures can reveal dimensions that conventional health-status instruments treat differently; and individualized patient-generated approaches allow people to nominate concerns that standardized domain sets may miss [6-8].

These findings support a conceptual distinction between health status and quality of life. Health status describes aspects of functioning, symptoms, or impairment. Quality of life additionally requires evaluation: whether those conditions permit, obstruct, or transform what the person experiences as a worthwhile life. The same functional limitation may therefore carry different significance depending on valued activities, relationships, expectations, resources, and time. The article consequently proposes that quality of life should not be represented by a single hierarchy in which physical functioning mechanically determines psychological and social outcomes. Instead, it is multidimensional and relational, with several domains capable of constraining or compensating for one another without becoming interchangeable.

Meaning and valued life direction

Meaning concerns whether life continues to contain purposes, commitments, relationships, or projects that make effort and adaptation worthwhile. It is not synonymous with positive mood, spirituality, or acceptance. Evidence from meaning-focused interventions in cancer shows that meaning-oriented approaches have been studied in relation to spiritual, psychological, and quality-of-life outcomes [9]. Such evidence is clinically relevant but context-bounded; it does not establish meaning as a universal causal mechanism or imply that patients should reinterpret suffering positively.

The proposed model instead treats valued life direction as an evaluative reference point. Symptoms and disability matter partly because they may obstruct what a person is trying to preserve, resume, or become. Conversely, severe illness does not necessarily eliminate meaning if valued directions remain available in revised form. This proposition also creates an ethical boundary: clinicians can elicit what matters and remove avoidable barriers, but they cannot prescribe the meaning a patient ought to find in illness.

Identity and continuity of self

Illness can affect quality of life by altering not only what a person can do but how they understand who they are. In inflammatory bowel disease, illness identity and health-related quality of life are associated with flourishing, supporting a distinction among disease experience, self-positioning, and positive functioning [10]. Long COVID provides a different form of evidence:

patient communities helped establish recognition of persistent illness when early clinical narratives did not adequately represent their experience, demonstrating how legitimacy and collective knowledge can shape the social conditions under which illness is incorporated into identity [11].

Continuity of self should therefore not be equated with returning to a pre-illness identity. Some people may preserve prior roles with limited identity disruption; others may incorporate illness as one bounded part of self; still others may experience identity dominance, contested legitimacy, or deliberate reconstruction around changed capacities. These are proposed analytic positions, not diagnostic categories or a universal sequence. Their value lies in making testable the possibility that similar symptom states can produce different quality-of-life consequences depending on whether important identities can be sustained, revised, or socially recognized.

The identity problem is compactly expressed in **Table 1** because the theoretical propositions differ not only in state description but also in competing explanation, boundary condition, and implication for interpretation.

Table 1. Proposed testability register for identity continuity as a quality-of-life process

Proposed identity position	Process affecting continuity	Context that may modify the position	Competing interpretation or uncertainty	Boundary requiring caution	Testable consequence for quality-of-life interpretation
Prior self remains largely workable	Illness is contained within existing biography	Stable roles, recognition, manageable disruption	Low disruption may reflect mild disease rather than preserved identity	Cannot infer continuity from functioning alone	Similar symptoms may have limited identity cost when valued self-definitions remain viable
Illness becomes identity-dominant	Daily demands repeatedly displace other self-definitions	Severe unpredictability, repeated care demands, stigma	Dominance may be temporary during acute disruption	Must not pathologize necessary illness attention	Quality-of-life loss may exceed what symptom intensity predicts
Illness is acknowledged but bounded	Person incorporates illness without allowing it to define the whole self	Flexible roles, supportive relationships, credible recognition	May represent adaptive integration or constrained compromise	No assumption that bounded identity is universally preferable	Preserved non-illness identities may support continuity despite persistent symptoms
Self is actively reconstructed	Values and roles are revised around changed capacities	Time, accessible alternatives, material and relational support	Reconstruction can reflect agency or forced adaptation	Adaptation must not conceal avoidable social barriers	Stable quality-of-life scores may coexist with major changes in what gives life value
Identity remains socially contested	Lived experience lacks recognition or legitimacy	Diagnostic uncertainty, stigma, institutional disbelief	Distress may arise from illness, invalidation, or both	Clinical uncertainty does not justify identity inference	Recognition may influence quality of life independently of biomedical change

Relationships and social belonging

Quality of life is also relational. Social identity research shows an overall association between identification and health-related behavior, but with substantial heterogeneity across identities and behaviors [12]. In breast-cancer survivorship, social support during re-entry has been associated longitudinally with later quality of life [13]. Qualitative evidence from people with multiple long-term conditions adds an important counterpoint: relationships can provide practical and emotional support while illness simultaneously creates loneliness, dependence, changed roles, and fear of burdening others [14].

Belonging should therefore not be reduced to the size of a social network or the presence of a caregiver. The proposed theory distinguishes recognition, reciprocity, practical support, companionship, and role continuity because each can shape whether relationships expand or narrow the person's life. It also allows reciprocal influence: worsening quality of life can reduce participation and strain relationships, just as strained relationships can reduce opportunities for participation

and adaptation. Neither direction should be assumed without longitudinal evidence.

Participation, roles, and everyday function

Function is often interpreted as capacity: what a person can physically or cognitively do. Participation is different. It concerns whether that capacity can be enacted in social roles and everyday settings that matter. Psychometric work on the PROMIS ability-to-participate domain supports social-role participation as a distinct measurable construct whose adequate assessment depends on item targeting across levels of participation [15]. Patient involvement in treatment decisions illustrates a parallel distinction within care: being offered a decision is not the same as having the resources, information, relational support, confidence, or preference needed to participate meaningfully [16].

This distinction is central to the article's theory. A person may retain physical capacity yet lose work, family, community, or civic participation because schedules, environments, stigma, transport, fatigue, digital systems, or inflexible institutions make participation impractical. Conversely, accommodations or role redesign can preserve participation despite persistent impairment. The quality-of-life consequence therefore arises from the relation between capacity and opportunity rather than from capacity alone.

Table 2 organizes these mechanism-context cases around equity because the same functional state can produce very different participation possibilities when access, flexibility, and social expectations differ.

Table 2. Equity-sensitive pathway matrix for translating capacity into valued participation

Mechanism shaping everyday enactment	Opportunity context	What a symptom-centred assessment may miss	Principal uncertainty	Proposed interpretive consequence
Participation condition — Capacity is present but opportunity is restricted				
Environmental or institutional barriers block enactment	Inaccessible transport, rigid work, unsuitable digital or physical environments	Preserved capacity can coexist with low participation	Relative contribution of illness and context varies	Low participation should not automatically be read as low motivation
Participation condition — Capacity is reduced but roles are redesigned				
Accommodation preserves valued contribution	Flexible schedules, assistive support, negotiated roles	Persistent impairment may coexist with meaningful participation	Adaptation may depend on resources unavailable to others	Symptom persistence need not imply equivalent loss of life possibility
Participation condition — Participation is formally offered but relationally constrained				
Power, communication, or fear of burden limits engagement	Clinical or family relationships with unequal decision influence	Apparent non-participation may be treated as preference	Preference, confidence and constraint can be difficult to separate	Participation should be interpreted through opportunity and power
Participation condition — Participation is sustained through interdependence				
Practical and emotional support makes roles feasible	Reliable family, peer, community, or service support	Dependence may be mistaken for loss of autonomy	Support may also create obligation or strain	Supported participation can represent agency rather than failure of independence
Participation condition — Participation contracts across several roles				
Cumulative demands consume time and energy	Multimorbidity, repeated appointments, unstable resources	Each clinical problem may appear modest in isolation	Cross-role burden may fluctuate over time	Quality-of-life loss may reflect cumulative role displacement rather than one dominant symptom

Autonomy, dependence, and adaptation

Autonomy is frequently interpreted as independence, self-management, or the ability to make decisions without assistance. That framing can inadvertently turn the burden of adaptation into an individual responsibility. Qualitative evaluation of person-centred chronic-illness care suggests that self-management can instead involve whole-person understanding, hope, relationships, and supported use of personal resources [17]. Research on technology-supported long-term-condition care similarly

shows that digital tools may enable co-management among patients, carers, and professionals rather than simply transferring responsibility to the individual [18].

The proposed theory therefore defines autonomy as meaningful agency within legitimate interdependence. A person can be highly dependent on treatment, assistive technology, family support, or professional care while retaining substantial autonomy if those dependencies preserve valued choices and participation. Conversely, apparent independence may coexist with low autonomy when a person is left to manage inaccessible systems, financial constraints, or unwanted responsibility alone.

Adaptation also requires careful interpretation. Changes in routines, aspirations, roles, and expectations may represent creative agency, but they may also reflect constraint. Clinical reasoning should not celebrate adaptation when the person has merely accommodated barriers that could have been removed. The distinction becomes especially important when quality-of-life scores stabilize: stability may mean that life has genuinely become more workable, that values and comparison standards have changed, or that expectations have narrowed under pressure. The next sections therefore examine the difference between disease burden and life possibility before integrating these dimensions into the article's proposed multidimensional model.

Disease burden versus life possibility

Disease burden describes symptoms, impairment, treatment demands, uncertainty, and other consequences attributable to illness. Life possibility is different: it concerns what a person can realistically continue, recover, negotiate, or newly pursue within those constraints. A systematic review of chronic disease found that health-related quality of life is patterned by social determinants including income, education, employment, support, and other contextual conditions [19]. In drug-resistant tuberculosis, stigma and social support are likewise associated with health-related quality of life, while qualitative research during the COVID-19 pandemic showed that capacity to manage long-term conditions depended partly on material, environmental, and relational resources [20, 21]. These findings do not establish a single causal pathway, but they make it difficult to interpret quality of life as a direct readout of disease severity.

Information and healthcare access can create another layer of constraint. People living with Long COVID have described everyday disruption together with barriers to health information and care [22]. Under such conditions, the lived consequence of illness is produced partly through the interaction between disease and the environment in which it must be managed.

The proposed distinction between disease burden and life possibility therefore prevents two opposite errors. The first is biomedical reductionism: assuming that reducing symptoms necessarily restores a valued life. The second is psychosocial romanticism: implying that meaning, resilience, or support can compensate for any level of untreated disease or material deprivation. Clinical burden and contextual opportunity should instead be examined together.

Because similar disease burdens can create different practical futures, **Table 3** identifies the boundary conditions that must be checked before interpreting quality-of-life differences as primarily patient-level phenomena.

Table 3. Boundary conditions separating clinical burden from the possibility of living a valued life

Clinical burden	Life-domain effect	Available capacity	Participation condition	Meaning modifier	QoL implication
Relational or system condition — Material resources are secure					
How it changes life possibility	Treatment, transport, housing, nutrition, and role continuity may remain more feasible	**What remains clinically important**	Symptoms and treatment burden still constrain activity	**Competing explanation**	Better outcomes may reflect disease differences as well as resources
Boundary against overinterpretation	Resource advantage must not be treated as psychological resilience	**Proposed implication**	Similar disease burden may produce less disruption when practical options remain available		
Relational or system condition — Material resources are unstable					

How it changes life possibility	Illness demands compete with employment, housing, caregiving, and basic needs	**What remains clinically important**	Disease control remains necessary	**Competing explanation**	Distress may reflect both illness and socioeconomic insecurity
Boundary against overinterpretation	Clinical severity cannot be inferred from social hardship alone	**Proposed implication**	Quality-of-life loss may arise from cumulative constraint rather than symptom intensity alone		
Relational or system condition — Social recognition is supportive					
How it changes life possibility	Illness and limitation may be legitimized, enabling help and accommodation	**What remains clinically important**	Functional limitations remain real	**Competing explanation**	Support can coincide with greater disease severity
Boundary against overinterpretation	Recognition is not itself treatment	**Proposed implication**	Social legitimacy may preserve participation even when symptoms persist		
Relational or system condition — Stigma or disbelief is prominent					
How it changes life possibility	Help-seeking, disclosure, role negotiation, and belonging may become more difficult	**What remains clinically important**	Diagnostic and treatment uncertainty still require clinical evaluation	**Competing explanation**	Distress can derive from symptoms, invalidation, or both
Boundary against overinterpretation	Do not convert contested illness into assumed psychological causation	**Proposed implication**	Poor quality of life may partly reflect social exclusion rather than biomedical state alone		
Relational or system condition — Services and information are accessible					
How it changes life possibility	Patients can understand options, coordinate care, and adapt routines	**What remains clinically important**	Treatment burden and prognosis remain central	**Competing explanation**	High service use may reflect greater need rather than better access
Boundary against overinterpretation	Access should not be equated with utilization	**Proposed implication**	Accessible care can widen feasible choices without guaranteeing improved quality of life		
Relational or system condition — Services are fragmented or inaccessible					
How it changes life possibility	Time, uncertainty, coordination work, and unmet need narrow everyday options	**What remains clinically important**	Disease management cannot be displaced by system critique	**Competing explanation**	Some barriers may be illness-specific or temporary
Boundary against overinterpretation	System-level constraint should not erase patient preference	**Proposed implication**	Life possibility can shrink through care-system burden even without biomedical deterioration		

A multidimensional quality-of-life model

Existing patient-reported measurement systems already recognize that physical, mental, and social domains should not automatically be collapsed. Psychometric evaluation of PROMIS instruments demonstrates that multidomain health constructs can be separately tested for reliability, structural validity, invariance, and construct validity [23, 24]. Evidence from culturally specific chronic-disease populations also shows that psychosocial factors can covary with health-related quality of life in ways that require contextual interpretation rather than universal assumptions [25].

Building on those premises, this article proposes a multidimensional quality-of-life model with seven analytically distinct components: symptom and treatment burden; meaning and valued direction; identity

continuity; relational belonging; participation in valued roles; autonomy within interdependence; and contextual opportunity. These components are not intended as seven subscales of a new total score. Their purpose is explanatory. Each asks a different question about why a person's life may feel viable or constrained.

The model is also non-hierarchical. Symptoms can limit participation directly, but participation may also be constrained by inaccessible environments despite stable symptoms. Relationships can support identity continuity, while identity disruption can alter willingness to participate socially. Material resources can widen autonomy, while dependency that is chosen and supportive may preserve rather than diminish agency. Meaning can change the significance of functional loss without eliminating the loss itself.

A further distinction concerns time. Quality of life can change because health changes, because circumstances change, because valued roles change, or because the person's interpretation of what constitutes an acceptable or worthwhile life changes. The proposed framework therefore treats adaptation as dynamic rather than as a terminal state.

Figure 1 is required because these conditional and reciprocal relationships cannot be represented adequately as a single symptom-to-outcome pathway.

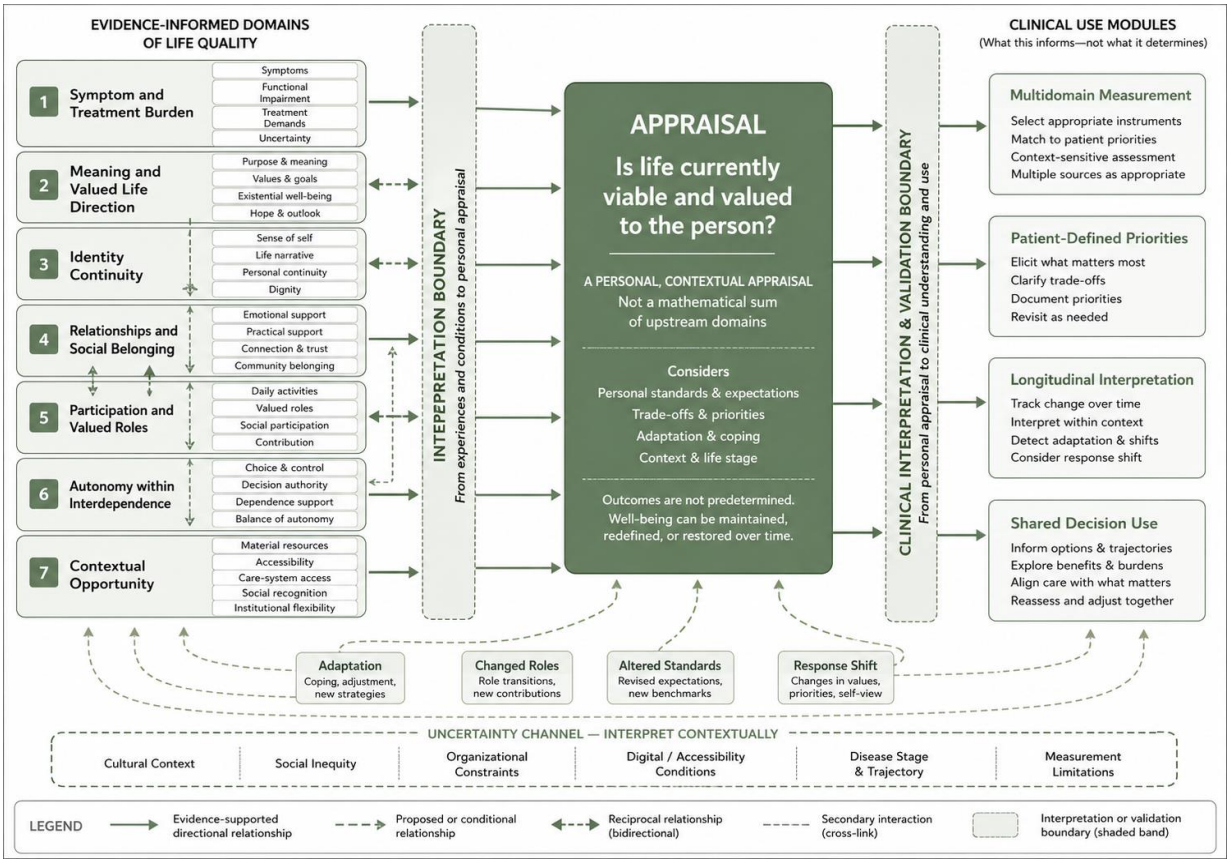

Figure 1. Conditional translation of multidimensional life conditions into clinically interpretable quality of life

Measurement and clinical decision implications

A multidimensional theory creates a measurement problem: more dimensions do not necessarily justify a longer questionnaire or a larger composite score. The clinical task is to identify which dimensions are relevant to the decision being made, which are changing over time, and which cannot be inferred from another measure.

Longitudinal interpretation is particularly important. Response-shift theory shows that a change in patient-reported scores may reflect not only change in the target construct but also changes in internal standards or in the way the construct is understood [26]. Qualitative and quantitative reviews further indicate that recalibration and reconceptualization can modify the interpretation of longitudinal outcomes, although their impact varies

across studies and instruments [27-29]. Stable quality-of-life scores therefore should not automatically be interpreted as stable lived circumstances.

Measurement selection must also remain population- and purpose-sensitive. A review of generic patient-reported measures for primary care found important differences in psychometric evidence and cultural appropriateness, with continuing gaps in responsiveness and cross-cultural validity [30]. The proposed model therefore favors layered assessment: retain clinically necessary symptom and function measures, add relevant multidomain measures, and create space for patient-defined priorities where standardized instruments are unlikely to capture what is most consequential.

Clinical use should follow the same logic. A low score should trigger inquiry rather than an automatic explanation. The clinician may need to determine whether the principal constraint lies in symptoms, treatment demands, identity disruption, relational strain, lost roles, reduced agency, or structural opportunity. Conversely, an apparently acceptable score should not end inquiry when the patient reports major adaptation, narrowed expectations, or loss of previously valued possibilities.

Results and Discussion

The central argument of this article is not that medicine should move away from symptom reduction. It is that symptom reduction and quality of life answer different questions. Symptoms describe important aspects of disease experience; quality of life concerns what those experiences mean for the person's ability to sustain or reconstruct a valued life.

The literature assembled here supports the relevance of multiple domains but not a universal causal hierarchy among them. Social support may relate to later quality of life, participation can be independently measured, social determinants are associated with chronic-disease HRQoL, and PROM implementation depends on organizational conditions [4, 13, 15, 19]. None of these findings proves the proposed architecture as a complete mechanism. The model should therefore be tested rather than treated as an established taxonomy.

Several implications follow. First, future longitudinal research should distinguish changes in symptoms from changes in participation, identity, meaning, and relational conditions. Second, studies should test whether similar clinical states produce different quality-of-life trajectories under different opportunity structures. Third, qualitative and individualized measures remain important for detecting reconceptualization and patient-defined priorities that fixed instruments may miss. Fourth, equity must be treated as part of the explanatory structure rather than as a subgroup adjustment performed after measurement.

The model also has limits. It does not specify universal weights for its dimensions, and it should not be converted into a fixed checklist without validation. Dimensions may overlap differently across illnesses, cultures, life stages, and care settings. Dependence may be supportive in one context and coercive in another. Adaptation may reflect agency, changed values, unavoidable disease progression, or constrained expectations. Digital systems may increase access for some patients while excluding others. These contingencies are not noise around the model; they define where interpretation must remain cautious.

Conclusion

Quality of life cannot be inferred reliably from symptom reduction alone. A person's life may improve, deteriorate, or become differently valued through changes in meaning, identity, relationships, participation, autonomy, and the opportunities created or restricted by social and healthcare environments.

The theory proposed here treats these dimensions as distinct but interacting conditions that shape whether life remains viable and valued. Its purpose is not to replace biomedical outcomes or to create another universal score. It is to make clinical interpretation more precise by separating disease burden from what people are able to preserve, recover, negotiate, or pursue.

The framework remains non-empirical and requires longitudinal, comparative, culturally responsive, and implementation-focused testing. Its value will ultimately depend on whether it helps researchers and clinicians distinguish genuine improvement from numerical change, adaptation from forced accommodation, autonomy from unsupported independence, and symptom control from the broader possibility of living well.

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References

1. Bartolomeu Pires S, Kunkel D, Kipps C, Goodwin N, Portillo MC. Person-centred integrated care for people living with Parkinson's, Huntington's and multiple sclerosis: A systematic review. Health Expect. 2024;27(1). doi:10.1111/hex.13948
2. Dukhanin V, Gamper MJ, Gleason KT, McDonald KM. Patient-reported outcome and experience domains for diagnostic excellence: A scoping review to inform future measure development. Qual Life Res. 2024;33(11):2883-97. doi:10.1007/s11136-024-03709-w
3. Bonsel JM, Itiola AJ, Huberts AS, Bonsel GJ, Penton H. The use of patient-reported outcome measures to improve patient-related outcomes—a systematic review. Health Qual Life Outcomes. 2024;22(1):101. doi:10.1186/s12955-024-02312-4
4. Anderson M, van Kessel R, Wood E, Stokes A, Fistein J, Porter I, et al. Understanding factors impacting patient-reported outcome measures integration in routine clinical practice: An umbrella review. Qual Life Res. 2024;33(10):2611-29. doi:10.1007/s11136-024-03728-7
5. Meadows KA, Reaney M. Understanding the unique patient-causal singularism and patient reported outcomes. Qual Life Res. 2025;34(5):1221-31. doi:10.1007/s11136-025-03905-2
6. Amat-Fernandez C, Garin O, Luer-Aguila R, Pardo Y, Briseño R, Lizano-Barrantes C, et al. Systematic review of the needs and health-related quality of life domains relevant to people surviving cancer in Europe. Qual Life Res. 2025;34(4):913-36. doi:10.1007/s11136-024-03884-w
7. Long C, Mao Z, Yang Z. A head-to-head comparison of EQ-HWB and EQ-5D-5L in patients, carers, and general public in China. Value Health. 2024;27(7):848-56. doi:10.1016/j.jval.2024.02.012
8. Humayun MM, Brouillette MJ, Fellows LK, Mayo NE. The Patient Generated Index (PGI) as an early-warning system for predicting brain health challenges: A prospective cohort study for people living with human immunodeficiency virus (HIV). Qual Life Res. 2023;32(12):3439-52. doi:10.1007/s11136-023-03475-1
9. Sun M, Tian X, Peng Y, Wang Z, Lu Y, Xiao W. Effects of meaning therapy on spirituality, psychological health, and quality of life in patients with cancer: A systematic review and meta-analysis of randomized controlled trials. Asia Pac J Oncol Nurs. 2024;11(4):100388. doi:10.1016/j.apjon.2024.100388
10. Krömeke A, Shani M. Flourishing in life in patients with inflammatory bowel disease: The role of illness identity and health-related quality of life. J Health Psychol. 2025;30(5):1089-103. doi:10.1177/13591053241260288
11. Callard F, Perego E. How and why patients made Long Covid. Soc Sci Med. 2021;268:113426. doi:10.1016/j.socscimed.2020.113426
12. de Hoog N, Pat-El R. Social identity and health-related behavior: A systematic review and meta-analysis. Soc Sci Med. 2024;344:116629. doi:10.1016/j.socscimed.2024.116629
13. Cho H, Kang D, Shin DW, Kim N, Lee SK, Lee JE, et al. Social support during re-entry period and long-term quality of life in breast cancer survivors: A 10-year longitudinal cohort study. Qual Life Res. 2024;33(5):1287-95. doi:10.1007/s11136-024-03599-y
14. Hounkpatin H, Morrison L, Richards A, Santer M. Experiences of social relationships for adults living with multiple long-term conditions: A qualitative interview study. Health Expect. 2025;28(5). doi:10.1111/hex.70335
15. Williams GL, Flens G, Terwee CB, de Beurs E, Spinhoven P, Paap MCS. Extending the PROMIS item bank “ability to participate in social roles and activities”: A psychometric evaluation using IRT. Qual Life Res. 2024;33(8):2129-44. doi:10.1007/s11136-024-03666-4
16. Buljac-Samardzic M, Clark MA, van Exel NJA, van Wijngaarden JDH. Patients as team members: Factors affecting involvement in treatment decisions from the perspective of patients with a chronic condition. Health Expect. 2022;25(1):138-48. doi:10.1111/hex.13358
17. Heggdal K, Mendelsohn JB, Stepanian N, Oftedal BF, Larsen MH. Health-care professionals' assessment of a person-centred intervention to empower self-management and health across chronic illness: Qualitative findings from a process evaluation study. Health Expect. 2021;24(4):1367-77. doi:10.1111/hex.13271

18. Varey S, Dixon M, Hernández A, Mateus C, Palmer TM, Milligan C. The role of combinatorial health technologies in supporting older people with long-term conditions: Responsibilisation or co-management of healthcare? Soc Sci Med. 2021;269:113545. doi:10.1016/j.socscimed.2020.113545
19. Kangas T, Milis SL, Vanthomme K, Vandenheede H. The social determinants of health-related quality of life among people with chronic disease: A systematic literature review. Qual Life Res. 2025;34(9):2501-11. doi:10.1007/s11136-025-03976-1
20. Adejumo OA, Jinabhai C, Daniel O, Haffejee F. The effects of stigma and social support on the health-related quality of life of people with drug resistance tuberculosis in Lagos, Nigeria. Qual Life Res. 2025;34(5):1305-16. doi:10.1007/s11136-025-03902-5
21. Morris S, Wildman JM, Gibson K, Moffatt S, Pollard TM. Managing disruption at a distance: Unequal experiences of people living with long-term conditions during the COVID-19 pandemic. Soc Sci Med. 2022;302:114963. doi:10.1016/j.socscimed.2022.114963
22. Ortega-Martin E, Alvarez-Galvez J. Living with Long COVID: Everyday experiences, health information barriers and patients' quality of life. Health Expect. 2025;28(3). doi:10.1111/hex.70290
23. Rimehaug SA, Kaat AJ, Nordvik JE, Klokkerud M, Robinson HS. Psychometric properties of the PROMIS-57 questionnaire, Norwegian version. Qual Life Res. 2022;31(1):269-80. doi:10.1007/s11136-021-02906-1
24. Elsman EBM, Roorda LD, Smidt N, de Vet HCW, Terwee CB. Measurement properties of the Dutch PROMIS-29 v2.1 profile in people with and without chronic conditions. Qual Life Res. 2022;31(12):3447-58. doi:10.1007/s11136-022-03171-6
25. Scarton L, Hebert LE, Goins RT, Umans JG, Jiang L, Comiford A, et al. Diabetes and health-related quality of life among American Indians: The role of psychosocial factors. Qual Life Res. 2021;30(9):2497-507. doi:10.1007/s11136-021-02830-4
26. Vanier A, Oort FJ, McClimans L, Ow N, Gulek BG, Böhnke JR, et al. Response shift in patient-reported outcomes: Definition, theory, and a revised model. Qual Life Res. 2021;30(12):3309-22. doi:10.1007/s11136-021-02846-w
27. Schwartz CE, Huang IC, Rohde G, Skolasky RL. Uncovering the story within the story: A scoping review of response shift in qualitative research. Qual Life Res. 2025;34(1):131-50. doi:10.1007/s11136-024-03803-z
28. Schick-Makaroff K, Davey AF, Sébille V, Sprangers MAG, Sawatzky R; Response Shift–in Sync Working Group. Response shifting: A qualitative meta-synthesis on response shift. Qual Life Res. 2026;35(7):178. doi:10.1007/s11136-026-04290-0
29. Verdam MGE, Kwon JY, Russell L, Sébille V, Sprangers MAG, Sawatzky R; Response Shift–in Sync Working Group. Impact of response shift on change in patient-reported outcomes: A systematic review. Qual Life Res. 2026;35(8):203. doi:10.1007/s11136-026-04307-8
30. Doran CM, Bryant J, Langham E, Bainbridge R, Shakeshaft A, Hobden B, et al. Psychometric properties, and cultural appropriateness, of patient reported outcome measures for use in primary healthcare: A scoping review. Qual Life Res. 2025;34(8):2137-49. doi:10.1007/s11136-025-03956-5