

Reconstructing the Patient Identity After Diagnosis: A Theory of Illness Meaning, Self-Concept Transformation, and Social Role Adaptation

Omar Zayed^{1*}, Leila Ibrahim¹, Ahmed Mansour²

¹Department of Health Psychology and Identity, Faculty of Medicine, Cairo University, Cairo, Egypt

²Department of Psychosocial Adaptation and Chronic Illness, Faculty of Medicine, Alexandria University, Alexandria, Egypt.

*E-mail ✉ omar.zayed@cu.edu.eg

Abstract

Diagnosis can alter how a person explains the past, anticipates the future, understands the body, occupies social roles, and decides what aspects of illness should become visible to others. Yet identity change is often described as either biographical disruption or adaptation, leaving insufficient space for continuity, rejection, enrichment, ambivalence, recurrent rupture, and context-dependent reconstruction. This article develops a non-empirical theory that distinguishes the diagnostic event from the meaning assigned to it, illness identity from the wider self-concept, and intrapersonal change from relational negotiation. Engulfment, rejection, acceptance, and enrichment are treated as possible identity positions rather than ordered stages or fixed patient types. Disclosure, reflected appraisals, cultural expectations, embodiment, legitimacy, and access to relational or digital resources may redirect identity trajectories. Agency is conceptualized as constrained and relational rather than as an individual capacity to “accept” illness. Reconstruction is therefore recursive: accommodation can be followed by renewed disruption when symptoms, treatment demands, roles, or social responses change. The theory generates bounded, testable implications for healthcare engagement without assuming that a coherent illness identity is universally desirable or clinically beneficial.

Keywords: Illness identity, Self-concept, Biographical disruption, Chronic illness, Social roles, Identity reconstruction

Introduction

A diagnosis enters a life already organized by identities, obligations, relationships, embodied routines, and expectations. Its significance therefore cannot be reduced to receiving a biomedical label. “Illness identity” itself is conceptually heterogeneous: recent work distinguishes identity as being, acting, and social judgment, showing that self-definition, illness-related conduct, and how others position the person are not interchangeable [1]. Social identification is associated with health-related behavior, but the strength and meaning of that relationship vary by identity and behavior [2]. Nor can

clinicians assume that incorporating a condition into identity is linguistically desirable; preferences for person-first and identity-first language differ across users [3].

This article treats patient identity as a dynamic organization of self-meanings rather than a synonym for diagnosis, adherence, coping, or social category. Its central claim is that diagnosis becomes identity-relevant through interpretation. A label may confirm feared decline, explain confusing experiences, confer legitimacy, threaten valued roles, or leave core self-definitions largely intact. The proposed theory links these possibilities to bodily experience, social response, role demands, and opportunities for action without treating them as a universal sequence.

Access this article online

<https://smerpub.com/>

Received: 20 February 2026; Accepted: 04 April 2026

Copyright CC BY-NC-SA 4.0

How to cite this article: Zayed O, Ibrahim L, Mansour A. Reconstructing the Patient Identity After Diagnosis: A Theory of Illness Meaning, Self-Concept Transformation, and Social Role Adaptation. Int J Soc Psychol Asp Healthc. 2026;6(1):141-50. <https://doi.org/10.51847/CBXEEse0pE>

Diagnosis as an identity-disrupting event

Biographical disruption remains powerful because illness can interrupt assumptions about the body, competence, independence, and future. Long COVID narratives

document profound discontinuity in which participants described an inaccessible former self [4]. Such accounts show how symptoms can become evidence that previous expectations about who one is and what one can do no longer hold.

Yet disruption does not begin or end when a label is assigned. In POTS, diagnostic uncertainty and label-seeking were intertwined with symptom interpretation and illness identity, indicating that the pre-diagnostic period can already reorganize self-understanding [5]. Conversely, naming Long COVID provided legitimacy and a shared category through which patients could articulate suffering despite diagnostic uncertainty [6]. Diagnosis can therefore threaten identity while simultaneously making an incoherent experience socially intelligible.

A disruption-only account also fails because diagnosis can clarify biography. Later autism diagnosis has been described as “biographical illumination,” in which a label can reinterpret past experiences and cultivate a more coherent self-understanding [7]. The proposed theory therefore treats diagnosis as an identity-relevance event. Whether it becomes rupture, continuity, legitimation, illumination, or a mixture depends on the meaning assigned to the label and the contexts in which that meaning is lived.

Illness meaning and biographical interpretation

Illness meaning is the interpretive bridge between medical classification and its place in the self. Qualitative work describes meaning-making as central to rebuilding a coherent and worthwhile sense of self after chronic disease [8]. The task includes interpreting what illness says about the past, anticipated futures, valued roles, and whether the condition is experienced as external to, constitutive of, or variably salient within the self.

Biography is culturally organized. Among ethnic-minority adults receiving haemodialysis, illness disrupted religious and cultural practices as well as everyday routines [9]. Culture, religion, family position, and normative expectations therefore help define what counts as loss, continuity, duty, stigma, or acceptable adaptation; they are not merely background modifiers.

Embodiment also prevents reconstruction from being reduced to narrative cognition. An embodied account of biographical disruption shows that physically serious illness does not produce identical biographical consequences: disruption depends partly on altered capacity for habitual action, and some transplant

recipients did not experience the expected disruption [10]. In treatment-intensive illness, biographical work may remain active long after diagnosis; “biographical dialectics” captures recurring problem-solving as treatment repeatedly enters everyday life [11].

The proposed theory thus treats illness meaning as revisable. Prior biography, embodied change, culture, treatment burden, anticipated futures, and recognition interact to organize meaning temporarily, while relapse, new treatment, altered prognosis, or role transitions may reopen previously settled interpretations.

Changes in self-concept

Illness identity is not equivalent to the whole self-concept. Narratives from emerging adults with congenital heart disease include illness-related identity, acknowledgement, bodily experience, the self in relation to others, and accounts of little perceived impact [12]. Illness can therefore matter without becoming the organizing center of identity.

Bodily experience may nevertheless make illness difficult to compartmentalize. Emerging adults with type 1 diabetes describe identity and embodiment as intertwined but distinguishable [13]. A person may regard diabetes as one aspect of self while organizing daily life around treatment and bodily surveillance. Conversely, strong illness identification need not imply severe functional limitation. The theory therefore separates illness salience, bodily constraint, self-evaluation, and social identification.

Life stage changes the stakes. Young adults with long-term conditions have described feeling ill or abnormal relative to former selves and perceived “normal” others while confronting uncertainty about future roles [14]. The proposed account therefore asks three separate questions: how salient illness becomes, how much continuity with the pre-diagnosis self remains, and whether illness-linked meanings are evaluated as diminishing, neutral, mixed, or generative. These dimensions need not move together.

Engulfment, rejection, acceptance, and enrichment

Illness-identity research distinguishes engulfment, rejection, acceptance, and enrichment. Longitudinal work in congenital heart disease and type 1 diabetes shows that these dimensions have distinguishable developmental and well-being associations rather than forming a single continuum [15–17]. They are therefore useful as dynamic positions, not fixed patient types.

Engulfment describes illness dominating identity and constricting other self-definitions. Rejection describes keeping illness outside the self. Acceptance permits acknowledgment without monopoly, while enrichment describes illness becoming associated with valued growth or meaning. These positions should not become a moral hierarchy. Rejection may preserve continuity or resist imposed labeling; apparent acceptance can reflect accommodation to constrained choices; enrichment should never be expected after suffering.

Behavioral associations require similar restraint. In inflammatory bowel disease, acceptance and enrichment

were positively associated with self-management, but the design does not establish that changing identity improves behavior [18]. In adults with congenital heart disease, trajectory classes differed in patient-reported outcomes and healthcare use, yet those configurations were sample-derived rather than universal phenotypes [19]. The boundary conditions separating apparently similar identity responses are analytically difficult to recover from prose alone; **Table 1** therefore makes those contingencies explicit.

Table 1. Boundary conditions that alter the meaning of illness-identity positions after diagnosis

Identity position	Interpretive meaning	Contextual modifier	Trajectory consequence
Identity configuration — Illness dominates			
Organizing logic	Other identities lose space	Context that changes interpretation	Severe symptoms, intensive treatment, restricted roles
Key uncertainty or exception	Dominance may reflect objective constraint rather than identity process alone	Consequence for the proposed theory	Engulfment must be interpreted against feasible role alternatives
Identity configuration — Illness is kept outside self			
Organizing logic	Prior identity is protected	Context that changes interpretation	Stigma, contested diagnosis, fear of dependency
Key uncertainty or exception	Rejection may be strategic resistance rather than maladaptation	Consequence for the proposed theory	Limited identification can coexist with competent management
Identity configuration — Illness is acknowledged but bounded			
Organizing logic	Condition is incorporated without monopolizing self	Context that changes interpretation	Stable routines, preserved roles, supportive relationships
Key uncertainty or exception	Acceptance does not imply emotional resolution	Consequence for the proposed theory	Acceptance is a position, not an endpoint
Identity configuration — Illness contributes valued meaning			
Organizing logic	Experience informs priorities, affiliation, or insight	Context that changes interpretation	Recognition, community, revised values
Key uncertainty or exception	Growth can coexist with loss and distress	Consequence for the proposed theory	Enrichment must not become a clinical expectation
Identity configuration — Positions mix or shift			
Organizing logic	Several meanings coexist or alternate	Context that changes interpretation	Relapse, life transition, relationship or treatment change
Key uncertainty or exception	A single measurement may capture only a temporary configuration	Consequence for the proposed theory	Reconstruction requires temporal analysis

Social roles and relational renegotiation

Identity is sustained through roles as well as private self-description. Diagnosis can alter expectations about partnership, friendship, work, education, independence, and caregiving. Evidence across couples, peers, and parent–youth relationships shows that chronic illness management unfolds within communication and coping

systems: relationships can influence illness-related processes and can themselves change in response to them [20–22]. Social context therefore does not merely respond to a completed internal identity transformation. Roles provide repeated feedback about who the patient is allowed or expected to be. Assistance may preserve participation while intensifying dependency; workplace

accommodation may enable valued activity while making illness more visible; peer involvement may support self-management while accentuating difference. In emerging adulthood, type 1 diabetes intersects with intimacy, autonomy, work, and future planning [23].

The proposed theory calls this relational renegotiation: altered capacity or disclosure changes expectations, expectations affect reflected self-understanding, and identity then shapes subsequent participation. Support can expand agency, overprotection can constrain it, and concealment may protect a valued role while limiting assistance. Material and relational power matter because people differ in their ability to negotiate accommodations, privacy, dependency, and role continuity.

Disclosure and reflected appraisals

Diagnosis does not automatically make illness socially visible. Disclosure determines which audiences can reinterpret the person through the condition. Among young adults with chronic illness, strategies ranged from broad openness to selective sharing and non-disclosure, partly according to expectations of peer understanding

[24]. These strategies should not be ordered from unhealthy avoidance to healthy openness: selective disclosure may protect privacy or ordinary interaction, while openness can enable support and accommodation. Disclosure becomes identity-relevant through reflected appraisals. In contested illness, online communities can become sites where credibility, biomedical legitimacy, illness literacy, and identity are negotiated [25]. Digital spaces may provide alternative audiences when offline contexts are invalidating, but access, platform norms, and unequal digital literacy constrain that possibility. Clinical language is part of the same process: preferred person-first or identity-first terminology cannot be inferred from diagnosis alone.

Reflected appraisal is therefore broader than stigma. It includes recognition, disbelief, normalization, overprotection, sympathy, clinical categorization, and expectations of recovery or compliance. These responses can feed back into illness meaning and self-concept. Because disclosure outcomes depend on both the mechanism and the audience through which illness becomes visible, **Table 2** crosswalks the encounter conditions that can redirect reconstruction.

Table 2. Disclosure contexts and appraisal mechanisms that redirect patient-identity reconstruction

Identity-management process	Appraisal route	Context modifier	Role in the proposed reconstruction process
Encounter condition — Broad openness			
Illness is available for repeated social interpretation	Recognition, support, stereotyping, overidentification	Relationship safety and illness visibility	May stabilize legitimacy while increasing illness salience
Encounter condition — Selective sharing			
Information is matched to audience and need	Controlled access to validation or accommodation	Trust, intimacy, peer or workplace norms	Allows identity visibility to differ across roles
Encounter condition — Concealment			
Illness-related identity is withheld	Appraisal is deferred or avoided	Stigma and perceived social cost	May preserve continuity while reducing support
Encounter condition — Contested legitimacy			
Credibility of illness must be established	Belief, disbelief, biomedical recognition	Diagnostic uncertainty and cultural illness narratives	Can intensify identity work around credibility
Encounter condition — Digital participation			
Identity claims reach condition-specific or dispersed audiences	Solidarity, comparison, narrative recognition	Access, literacy, platform norms	Can provide alternative resources for reconstruction
Encounter condition — Clinical naming			
Professional language positions the person in care	Recognition or misrecognition	Patient preference and clinical power	Can reinforce or resist imposed patient identities

Agency and identity reconstruction

Agency enters reconstruction when patients interpret, select, resist, revise, or enact possible meanings of

illness. It should not be confused with unrestricted choice. Chronic-disease identity work can involve deliberate meaning-making, but it occurs within bodily limits, treatment demands, relationships, and socially credible narratives [8]. Agency may involve accepting help, defending continuity, resisting a stigmatizing label, joining a community, revising a role, or refusing to make illness central to biography.

Digital communities illustrate why agency is relational. In a Chinese online depression community, narratives operated across personal, enacted, relational, and communal identity levels and displayed multiplicity and ambivalence rather than a single downward illness story [26]. Such spaces can provide vocabulary, comparison, recognition, and solidarity, but these resources are culturally and technologically situated.

The proposed theory therefore defines reconstructive agency as the context-bounded capacity to negotiate the place of illness within a wider self and role system. This avoids equating successful reconstruction with acceptance and avoids individualizing failure. Engulfment, concealment, or disrupted roles may reflect severe symptoms, discrimination, economic insecurity, inaccessible services, or lack of recognition rather than deficient coping. Constraints are not external footnotes to identity reconstruction; they help determine which identity positions are practically available.

Identity across the illness trajectory

Identity reconstruction is unlikely to follow a stable sequence because illness itself rarely remains static. Symptoms fluctuate, treatments change, roles are entered or lost, and previously manageable differences may acquire new meaning when relationships, employment, fertility, caregiving, or prognosis change. In young women with polycystic ovary syndrome, illness identity has been described as oscillating between disruption and

attempts at repair rather than moving steadily toward resolution [27]. A broader narrative review of qualitative chronic-illness research likewise depicts becoming “whole again” as heterogeneous work involving adjustment, reconciliation, and reconfiguration rather than a universal endpoint [28].

Multimorbidity further exposes the weakness of single-diagnosis models. Older adults living with multiple conditions may have to decide which illnesses deserve attention, which can be backgrounded, and how several disease identities coexist with self-management demands [29]. The relevant unit is therefore not always “the identity attached to diagnosis X,” but the changing arrangement of bodily constraints, illness meanings, roles, and treatment responsibilities across a life course. Temporal change also creates a measurement problem. A score obtained during diagnostic uncertainty, acute treatment, or role disruption may not represent a durable identity configuration. The same measured degree of illness salience can reflect very different processes: recent fear, routinized self-management, social labeling, or a deliberate decision to foreground illness in advocacy. Longitudinal interpretation therefore requires attention to the events occurring between observations, not only to whether a score rises or falls.

The proposed theory treats trajectory as path-dependent and revisable. Earlier meanings influence later interpretation, but they do not determine it. A person who has integrated illness may experience renewed rupture after relapse, disability progression, a stigmatizing encounter, or loss of a valued role. Conversely, a period of engulfment can recede when treatment stabilizes symptoms or alternative identities regain practical space. Because these exceptions are central rather than peripheral, **Table 3** begins with conditions under which a superficially coherent reconstruction can fail, reverse, or become indeterminate.

Table 3. Trajectory conditions that interrupt, reverse, or complicate identity reconstruction

Destabilizing condition	What a cross-sectional reading may misinterpret	Likely temporal consequence	Requirement for the proposed theory
Exception or failure state — Renewed rupture after apparent accommodation			
Relapse, progression, new treatment burden, altered prognosis	Earlier acceptance as permanent resolution	Previously integrated illness becomes newly salient	Permit re-entry into disruption without treating it as failure
Exception or failure state — Role transition changes illness meaning			
Employment, partnership, parenthood, caregiving, education	Stable symptom burden as stable identity impact	Meaning shifts because valued roles change	Model biography and role demands as time-varying

Exception or failure state — Several diagnoses compete for salience			
Multimorbidity and treatment complexity	One disease-specific identity score as the whole illness self	Attention and identification shift among conditions	Allow multiple concurrent illness meanings
Exception or failure state — Social legitimacy changes			
New diagnosis, contested recognition, stigma, supportive community	Identity change as purely intrapsychic	Reflected appraisals alter self-interpretation	Include relational and institutional feedback
Exception or failure state — Symptoms improve while identity remains altered			
Recovery, remission, successful management	Better health as automatic restoration of prior self	New self-understanding persists despite reduced burden	Separate clinical state from identity state
Exception or failure state — Symptoms persist while illness becomes less central			
Adaptation, role restoration, routinized management	Persistent impairment as continuing engulfment	Other identities regain salience	Separate bodily constraint from identity dominance

The diagnosis-to-reconstruction model

The evidence assembled above supports individual components of identity change, but no selected study validates the integrated architecture proposed here. The Diagnosis-to-Reconstruction Model is therefore a theoretical synthesis rather than an empirical pathway model. It begins with an identity-relevant diagnostic or illness event, but does not assume that diagnosis itself causes disruption. The event enters biography through an interpretive field composed of illness meaning, bodily experience, prior self-concept, cultural expectations, perceived legitimacy, and anticipated futures.

From this field, several identity responses may emerge. Illness may dominate self-definition, be actively rejected, become acknowledged but bounded, contribute valued meaning, or remain only weakly identity-relevant. These responses are braided with a relational pathway in which social roles are renegotiated and illness becomes variably visible through disclosure. Reflected appraisals from family, peers, clinicians, workplaces, communities, and digital audiences feed back into meaning and self-concept. Agency operates within the braid rather than outside it: patients can reinterpret, resist, disclose, conceal, seek recognition, or restore roles, but the feasible options are constrained by symptoms, material resources, power, accessibility, and social credibility.

A second distinction concerns the difference between *position* and *process*. Engulfment, rejection, acceptance, enrichment, or low illness salience describe ways illness may currently relate to self, whereas interpretation, disclosure, appraisal, role negotiation, and agency

describe processes capable of changing that relationship. Keeping these levels separate prevents the theory from explaining identity change circularly by saying that people reconstruct identity because their identity changed.

The model is recursive. A workable reconstruction may stabilize participation temporarily, yet later illness change or social rupture can reopen interpretation and alter identity positioning. Conversely, recognition, symptom control, role restoration, or community affiliation may reduce engulfment without requiring the person to adopt an illness-centered identity. The model also separates reconstruction from restoration. A reconstructed identity need not reproduce the pre-illness self, and continuity may be maintained through reinterpreting valued roles rather than recovering prior capacity. Equally, an altered self-concept is not necessarily evidence of pathology. Evaluation depends on whether an identity arrangement remains workable for the person under current bodily, relational, cultural, and care conditions.

The model therefore predicts conditional transitions rather than stages and treats uncertainty as intrinsic where temporal direction or contextual transfer has not been demonstrated.

Because this argument depends on concurrent pathways and feedback rather than a linear chain, **Figure 1** compresses the model as a braided architecture with explicit rupture–repair loops and boundaries separating supported relationships from the article’s proposed integrations.

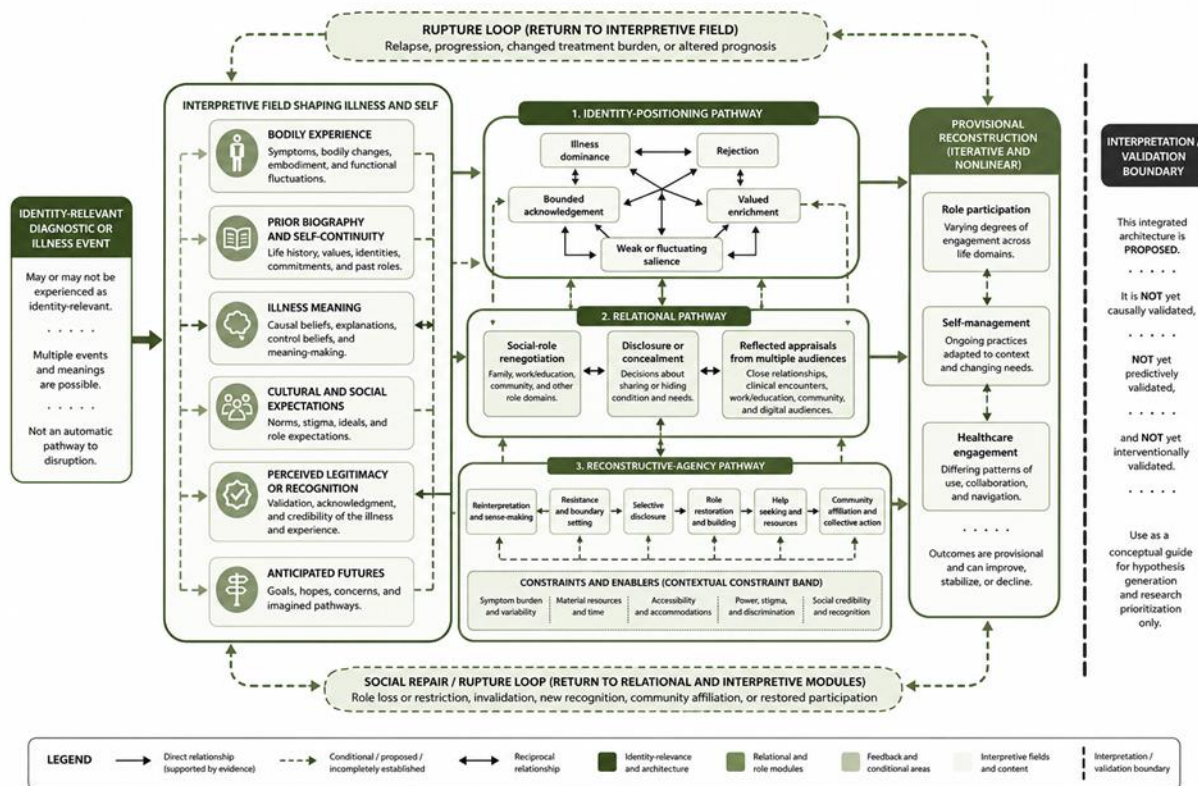


Figure 1. Recursive identity reconstruction under diagnostic rupture, social appraisal, and role change

Predictions for healthcare engagement and adaptation

The model yields testable predictions but does not assume that one identity position is clinically optimal. First, the association between illness identity and healthcare engagement should depend on whether a given identity configuration expands or constrains feasible action. Social identification has a measurable association with health-related behaviour at a broader level [2], while illness identity is associated with self-management in inflammatory bowel disease [18]. These findings justify examining identity as a correlate of participation, not treating it as a causal treatment target. Second, relational context should modify these associations. An identity position that supports self-management in a validating environment may produce different behaviour where disclosure threatens employment, family standing, or social belonging. Third, temporal instability should matter: trajectory work in congenital heart disease shows that illness-identity configurations can differ in healthcare-use profiles over time [19]. A single baseline score may therefore miss clinically relevant movement.

Fourth, associations should differ according to what outcome is measured. Appointment attendance, medication use, self-monitoring, help-seeking, shared decision-making, perceived participation, and clinical status are not interchangeable indicators of “engagement.” An identity arrangement may support one form of participation while complicating another, particularly when disclosure or treatment makes illness more socially visible.

Fourth, multimorbidity should weaken disease-specific predictions because competing treatment demands can change which diagnosis is identity-salient [29]. Finally, later healthcare use should be tested as one downstream domain rather than as proof of successful adaptation. Prospective CHD research has shown that illness-identity dimensions can statistically predict subsequent healthcare use [30], but such prediction does not demonstrate that modifying identity would improve outcomes. Future validation should therefore compare repeated identity measurement with behavioural, care-process, and clinical outcomes while preserving access, disease severity, social context, and healthcare opportunity as alternative explanations.

Results and Discussion

This theory reframes post-diagnosis identity as reconstruction under conditions rather than movement toward a single adaptive endpoint. The literature establishes that illness can disrupt biography [4], but it also provides counterexamples in which diagnosis clarifies prior experience [7], bodily illness does not necessarily disrupt biography [10], or patients report little effect on identity [12]. These contrasts are not anomalies to be averaged away; they define the boundary conditions that an adequate theory must explain.

The model's main contribution is to separate processes that are often compressed together. Diagnosis is distinguished from illness meaning; illness identity from the wider self-concept; bodily limitation from identity dominance; disclosure from acceptance; relational support from reflected appraisal; and healthcare participation from clinical outcome. These distinctions make it possible to understand why apparently similar patients may occupy different identity positions and why the same patient may move among them over time.

A further implication concerns clinical interpretation. Clinicians encounter identity indirectly through language, disclosure, behavior, treatment choices, and accounts of role difficulty. None of these is a transparent measure of how illness is situated within the self. Non-disclosure, missed monitoring, emotional distress, or a preference for identity-first language cannot be read automatically as rejection, engulfment, or acceptance. The model therefore supports inquiry into meaning rather than diagnostic inference about identity from isolated behavior.

The theory also resists two normative errors. The first is assuming that successful adaptation requires incorporating illness deeply into identity. Rejection or low salience may preserve valued continuity and can coexist with competent management. The second is treating reconstruction as individual psychological labor while relegating social and structural constraints to context. Cultural practice, diagnostic legitimacy, relationship expectations, digital communities, material resources, accessibility, and institutional power can determine which identity options are viable.

Equity and power sharpen this caution. The practical ability to keep illness peripheral may depend on symptom control, job security, accessible environments, affordable care, family flexibility, and freedom from discriminatory scrutiny. Likewise, visible illness identification may be

required to obtain accommodations or recognition in one setting while producing stigma in another. What appears psychologically adaptive can therefore partly reflect unequal opportunity structures rather than an intrinsic quality of the identity position itself.

The model remains intentionally bounded. Much of the quantitative illness-identity literature comes from congenital heart disease and type 1 diabetes, while qualitative sources include conditions with distinctive problems of visibility, legitimacy, embodiment, or treatment burden. Measures also differ in whether they capture identity content, salience, adjustment, behavior, or social appraisal. Cross-sectional associations cannot establish temporal direction, and even longitudinal associations do not validate the integrated model proposed here.

The framework also makes a methodological prediction: studies that collapse identity, distress, adherence, and quality of life into a single adaptation construct should show weaker explanatory precision than studies that measure these domains separately. Qualitative work is particularly important for identifying meanings that standardized illness-identity scales may miss, while longitudinal quantitative designs are needed to test temporal ordering. Neither evidence form should be treated as sufficient on its own to validate the integrated theory.

Clinical use should likewise remain interpretive rather than classificatory. The model is not intended to sort patients into fixed identity profiles or prescribe a preferred identity. Its practical value would lie in identifying when a change in care, role, recognition, or illness meaning may have reopened identity work that routine clinical measures fail to detect.

Validation should therefore proceed by testing components before testing the entire architecture. Repeated-measures studies could examine whether changes in illness meaning precede, follow, or reciprocally track identity positioning; dyadic designs could test reflected appraisal and role negotiation; cross-cultural studies could assess whether the same identity categories retain meaning under different moral and family systems; and multimorbidity studies could determine when disease-specific identity measures become inadequate. Intervention research should come later and should not presume that increasing acceptance, disclosure, or illness identification is universally beneficial.

Conclusion

Patient identity after diagnosis is neither a fixed consequence of disease nor a linear journey from disruption to acceptance. Diagnosis becomes identity-relevant through meaning, embodiment, biography, relationships, social recognition, and the practical possibilities available to the person. Illness may dominate, be rejected, be integrated, enrich selected aspects of self, remain peripheral, or move among these positions as life and illness change.

The proposed Diagnosis-to-Reconstruction Model organizes these processes as braided, recursive pathways rather than stages. Its central implication is that reconstruction must be evaluated in context: continuity can be adaptive, acceptance can coexist with loss, agency can be constrained, and renewed rupture can occur after apparent stability. The model offers testable propositions for healthcare engagement while remaining unvalidated as an integrated causal or predictive theory.

Acknowledgments: None

Conflict of Interest: None

Financial Support: None

Ethics Statement: None

References

- Pelters P. I am what I am?—An integrative review of understandings of ‘health identity’ and ‘illness identity’ in scientific literature. *Sociol Health Illn.* 2024;46(6):1169-91. doi:10.1111/1467-9566.13771
- 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
- Grech LB, Koller D, Olley A. Person-first and identity-first disability language: Informing client centred care. *Soc Sci Med.* 2024;362:117444. doi:10.1016/j.socscimed.2024.117444
- Fang C, Baz SA, Sheard L, Carpentieri JD. ‘I am just a shadow of who I used to be’—Exploring existential loss of identity among people living with chronic conditions of Long COVID. *Sociol Health Illn.* 2024;46(1):59-77. doi:10.1111/1467-9566.13690
- Knoop I, Gu S, Fareghzadeh S, Jones ASK, Gall N, Moss-Morris R. Exploring the complexities of illness identity and symptom management in seeking a diagnostic label of postural orthostatic tachycardia syndrome (POTS): An inductive approach. *Br J Health Psychol.* 2024;29(2):297-316. doi:10.1111/bjhp.12700
- Kaplan K, Mendenhall E. Framing Long Covid through patient activism in the United States: Patient, provider, academic, and policymaker views. *Soc Sci Med.* 2024;350:116901. doi:10.1016/j.socscimed.2024.116901
- Tan CD. “I’m a normal autistic person, not an abnormal neurotypical”: Autism spectrum disorder diagnosis as biographical illumination. *Soc Sci Med.* 2018;197:161-7. doi:10.1016/j.socscimed.2017.12.008
- Clur LS, Barnard A. Reconstructing a meaningful self: The identity work of people living with chronic disease. *Qual Health Res.* 2025;35(13):1410-22. doi:10.1177/10497323241303393
- Cluley V, Trivedi A, Burton JO. Chronic illness as cultural disruption: The impact of chronic illness on religious and cultural practice. *Sociol Health Illn.* 2024;46(8):1901-22. doi:10.1111/1467-9566.13816
- Engman A. Embodiment and the foundation of biographical disruption. *Soc Sci Med.* 2019;225:120-7. doi:10.1016/j.socscimed.2019.02.019
- Cluley V, Burton JO, Quann N, Hull KL, Eborall H. Biographical dialectics: The ongoing and creative problem solving required to negotiate the biographical disruption of chronic illness. *Soc Sci Med.* 2023;325:115900. doi:10.1016/j.socscimed.2023.115900
- Campens S, Vanderhaegen J, Van Laere E, Claes L, Moons P, Luyckx K. Identity and body in emerging adults with congenital heart disease: A qualitative exploration. *J Adv Nurs.* 2026;82(5):5272-87. doi:10.1111/jan.70177
- Vanderhaegen J, Campens S, Vankerckhoven L, Claes L, Hilbrands R, Luyckx K. Identity and bodily experiences in emerging adults with type 1 diabetes (T1D): A qualitative exploration. *Psychol Health.* 2026;41(7):1075-102. doi:10.1080/08870446.2025.2501065
- Wilson C, Stock J. The impact of living with long-term conditions in young adulthood on mental health

- and identity: What can help? *Health Expect.* 2019;22(5):1111-21. doi:10.1111/hex.12944
15. Campens S, Van Laere E, Vanderhaegen J, Van Bulck L, Moons P, Luyckx K. Illness identity and well-being in congenital heart disease: Directionality of effects and developmental trajectories. *Health Psychol.* 2024;43(3):203-13. doi:10.1037/hea0001330
 16. Vanderhaegen J, Raymaekers K, Prikken S, Claes L, Van Laere E, Campens S, et al. Personal and illness identity in youth with type 1 diabetes: Developmental trajectories and associations. *Health Psychol.* 2024;43(5):328-38. doi:10.1037/hea0001366
 17. Rassart J, Oris L, Prikken S, Goethals ER, Raymaekers K, Weets I, et al. Illness identity and adjusting to type I diabetes: A four-wave longitudinal study. *Health Psychol.* 2021;40(5):326-36. doi:10.1037/hea0001063
 18. Peters LA, Brown EM. The relationship between illness identity and the self-management of inflammatory bowel disease. *Br J Health Psychol.* 2022;27(3):956-70. doi:10.1111/bjhp.12584
 19. Van Bulck L, Goossens E, Apers S, Moons P, Luyckx K. Illness identity in adults with congenital heart disease: Longitudinal trajectories and associations with patient-reported outcomes and healthcare use. *J Adv Nurs.* 2021;77(12):4743-54. doi:10.1111/jan.14949
 20. Shrout MR, Weigel DJ, Laurenceau JP. Couples and concealable chronic illness: Investigating couples' communication, coping, and relational well-being over time. *J Fam Psychol.* 2024;38(1):136-48. doi:10.1037/fam0001136
 21. Flick U, Röhnsch G. Self-management and relationships: Perspectives of young adults with chronic conditions and their peers. *Qual Health Res.* 2025;35(8):916-31. doi:10.1177/10497323241285761
 22. Raymaekers K, Prikken S, Vanhalst J, Moons P, Goossens E, Oris L, et al. The social context and illness identity in youth with type 1 diabetes: A three-wave longitudinal study. *J Youth Adolesc.* 2020;49(2):449-66. doi:10.1007/s10964-019-01180-2
 23. Fioretti C, Mugnaini C. Living with type 1 diabetes mellitus in emerging adulthood: A qualitative study. *Br J Health Psychol.* 2022;27(4):1226-40. doi:10.1111/bjhp.12596
 24. Flick U, Röhnsch G. Young adults living with chronic illness: Disclosure strategies and peers' understanding. *Disabil Rehabil.* 2025;47(11):2778-89. doi:10.1080/09638288.2024.2400598
 25. Kerr JM, DeMichelis C. Contested illness, contested identity: How women with fibromyalgia construct legitimacy online. *Soc Sci Med.* 2025;381:118251. doi:10.1016/j.socscimed.2025.118251
 26. Li X, Xu K. "Accepting the poem of destiny": Identity reconstruction in a Chinese online depression community. *Qual Health Res.* 2025;35(7):755-67. doi:10.1177/10497323241274723
 27. Yang N, Ma J, He T. From biographical disruption to oscillation: Exploring illness identity tensions among young women with polycystic ovary syndrome in China. *Sociol Health Illn.* 2025;47(8). doi:10.1111/1467-9566.70100
 28. Hajdarevic S, Norberg A, Lundman B, Hörnsten Å. Becoming whole again—Caring for the self in chronic illness—A narrative review of qualitative empirical studies. *J Clin Nurs.* 2025;34(3):754-71. doi:10.1111/jocn.17332
 29. Coklar-Okutkan I, Harvey S, Doyle J, Teixeira F, Dinsmore J. Illness identity and its influence on self-management in older adults with multimorbidity: A hybrid thematic analysis. *Qual Health Res.* 2026;10497323261470629. doi:10.1177/10497323261470629
 30. Van Bulck L, Goossens E, Luyckx K, Oris L, Apers S, Moons P. Illness identity: A novel predictor for healthcare use in adults with congenital heart disease. *J Am Heart Assoc.* 2018;7(11). doi:10.1161/JAHA.118.008723