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The Social Life of Chronic Disease: How Illness Reshapes Identity, Relationships, Adaptation, and Long-Term Healthcare Engagement

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Abstract

Chronic disease is commonly organized clinically around diagnoses, symptoms, treatments, and measurable outcomes, yet its consequences also unfold through biography, identity, relationships, social recognition, everyday participation, and repeated encounters with healthcare. This article develops a social-life account of chronic disease in which these domains are treated as interacting but analytically distinct processes. The central argument is that long-term illness does not simply impose a stable psychosocial burden. Rather, it repeatedly changes what people can do, how they understand themselves, how responsibilities are distributed across relationships, which aspects of illness become socially recognizable, and what forms of healthcare engagement remain feasible. Adaptation is therefore conceptualized as a changing fit among embodied illness, identity continuity, relational resources, material conditions, and care environments rather than as a final psychological state. The article distinguishes subjective experience from behaviour, relational processes from institutional conditions, and healthcare participation from adherence or clinical outcome. It then develops the Social-Life-of-Chronic-Disease Model and derives bounded comparative and longitudinal predictions for subsequent testing. The proposed theory does not assume universal disruption, linear adaptation, or uniformly beneficial support. Instead, it foregrounds temporal change, reciprocal influence, unequal resources, cultural conditions, diagnostic legitimacy, digital accessibility, and the organizational production of opportunities for engagement.

Keywords: Chronic illness, Illness identity, Biographical disruption, Psychosocial adaptation, Relational coping, Healthcare engagement

Introduction

Chronic disease is clinically durable but socially dynamic. Multimorbidity illustrates the inadequacy of treating long-term illness as a collection of independent biomedical problems: interacting diseases, treatments, self-management demands, and service arrangements can create burdens whose meaning depends on how they enter everyday life [1]. Yet psychosocial accounts can become equally reductive when identity, adjustment, coping, support, and engagement are treated as interchangeable manifestations of a generalized "illness experience." An integrative review of health and illness identity demonstrates substantial conceptual heterogeneity in how identity itself is defined and operationalized [2]. This matters because a change in self-understanding is not equivalent to psychological distress, social withdrawal, treatment behaviour, or clinical deterioration.

Person-centred chronic care likewise cannot be reduced to asking patients for preferences while leaving the architecture of care unchanged. Work on care planning for people with multiple chronic conditions emphasizes goals, coordination, social needs, communication, and practical conditions surrounding care [3]. These observations suggest a larger theoretical problem:

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chronic disease is lived through a changing relationship among bodily states, biography, close relationships, social recognition, resources, and healthcare systems.

This article therefore proposes that chronic disease has a social life. The term does not imply that every illness produces social disruption or that social processes determine biomedical outcomes. It denotes the recurring ways illness enters identity, relationships, participation, caregiving, disclosure, self-management, and encounters with institutions. The argument developed below distinguishes what existing evidence establishes from an original theoretical synthesis. In particular, it treats adaptation as conditional and reversible, engagement as jointly produced rather than solely patient-owned, and temporal transitions as potentially reorganizing several levels of chronic living at once.

Chronic disease as a social and biographical process

The idea of biographical disruption remains useful only if disruption is understood as contingent rather than inevitable. Engman's analysis locates disruption in embodiment: illness becomes biographically consequential partly through changes in practical possibilities, bodily familiarity, and participation in valued activities [4]. The relevant comparison is therefore not simply health versus disease but the relationship between an altered body and a life that had previously been organized around different expectations.

Chronicity also complicates the assumption that disruption is concentrated around diagnosis. Narratives of young adults with inflammatory bowel disease show how disruption can be reconstructed repeatedly across remembered pasts, difficult presents, and anticipated futures [5]. Related work describes chronic illness as requiring continuing creative problem-solving rather than one completed act of adjustment [6]. These accounts support a temporal interpretation in which apparently stable periods remain vulnerable to renewed disruption when symptoms, treatments, roles, or expectations change.

Multimorbidity makes this instability especially visible. Older adults may have to keep disease-specific recommendations, competing priorities, symptoms, and ordinary life "in balance," making management resemble an ongoing negotiation rather than straightforward implementation [7]. The same principle extends beyond biomedical tasks. Chronic illness may interrupt religious and cultural practices while those same practices can remain important sources of continuity and meaning [8]. Multiple conditions can also be experienced as embodied entanglements that do not map neatly onto separate diagnoses [9].

These findings do not establish a universal disruption pathway. They instead suggest that biography supplies a changing reference structure against which illness acquires significance. The article therefore proposes that the social consequences of chronicity depend on alterations in a person's feasible life repertoire: the identities, activities, relationships, obligations, and futures that remain practically imaginable and socially supportable.

Illness identity and changes in the self

Identity change is one possible consequence of altered feasibility, but it should not be represented as an inevitable loss of a former self. Long COVID narratives nevertheless demonstrate how persistent symptoms and uncertainty can produce profound discontinuity between previous identity, current capacity, and anticipated futures [10]. In such circumstances, illness affects not only what a person does but the narrative resources available for explaining who that person has become.

Identity reconstruction can also involve active meaning-making. Qualitative work on chronic disease describes cognitive and existential work through which people attempt to reconstruct a meaningful sense of self [11]. Longitudinal evidence in type 1 diabetes further demonstrates why illness identity should not be collapsed into acceptance versus rejection: dimensions such as acceptance, engulfment, rejection, and enrichment can follow different trajectories and relate differently to adjustment [12]. In inflammatory bowel disease, illness-identity dimensions have likewise been associated with self-management and activation, although such relationships do not establish that identity itself causally determines behaviour [13].

The distinction is important for theory. A person may integrate illness into identity while remaining distressed, resist an illness label while engaging effectively in treatment, or experience identity continuity despite substantial physical limitation. The proposed account therefore treats illness identity as a negotiated configuration of self-relevance, not as a stage through which all patients progress. Its direction depends partly on disease visibility, predictability, social recognition, age and life stage, prior identities, and the extent to which illness restricts or transforms valued roles.

Family, partnership, and social-role reorganization

Chronic illness enters relationships by redistributing information, responsibility, uncertainty, and practical work. With concealable illness, communication itself becomes consequential because partners must negotiate what is disclosed, how symptoms are interpreted, and how support is provided over time [14]. Relational adaptation consequently cannot be inferred from the amount of help a patient receives.

Dyadic-coping research provides stronger evidence for interdependence. Meta-analytic actor–partner modelling indicates that one partner's coping can be associated with both their own and the other partner's relationship satisfaction, while these associations vary across illness and study conditions [15]. Chronic illness can therefore reorganize relationships reciprocally rather than producing a simple one-way transfer of support from a healthy caregiver to an ill recipient.

Research on Long COVID extends this relational logic by describing interembodiment between people living with persistent illness and those caring for them [16]. Symptoms remain located in one body, but schedules, vigilance, uncertainty, household responsibilities, emotional labour, and future planning may become distributed across several people. Such redistribution can sustain everyday life while also generating fatigue, dependency, conflict, or altered role identities.

The proposed theoretical distinction is between role redistribution and relational adaptation. Redistribution describes who performs which forms of work; adaptation concerns whether the resulting arrangement remains workable, recognized, and revisable. A family may redistribute tasks without achieving relational equilibrium, while a partnership may preserve closeness despite substantial changes in responsibility.

Because the same illness transition can reorganize responsibility, disclosure, reciprocity, and relational identity in different directions, a temporal comparison is more informative than treating "social support" as a single exposure [14]. The actor–partner evidence reinforces the need to represent both partners rather than only the identified patient [15]. Interembodiment further requires attention to responsibilities that cross bodily and household boundaries [16] **(Table 1)**.

Table 1. Relational Reorganization Across Changing Conditions of Chronic Illness

Relational process undergoing change	Temporal trigger or transition	What may be redistributed	Competing interpretation or uncertainty	Boundary or exception	Proposed consequence
Mechanism–context case — Concealable or intermittently visible illness					
Disclosure and interpretation	New symptoms, recurrence, changing visibility	Information, reassurance, vigilance	Reduced disclosure may reflect privacy rather than relational failure	Disclosure norms and relationship safety differ	Relationship quality cannot be inferred from disclosure frequency
Mechanism–context case — Increasing treatment or symptom burden					
Practical interdependence	Escalation of everyday illness work	Household tasks, appointments, monitoring, planning	Additional help can sustain participation but may also increase dependency or strain	Caregiver capacity and external support constrain redistribution	Adaptation depends on whether redistributed work remains sustainable
Mechanism–context case — Dyadic coping under uncertainty					
Reciprocal emotional regulation	Threat, uncertainty, changing prognosis	Emotional labour, appraisal, decision work	One partner's coping may not benefit both partners equally	Pre-existing relationship quality and illness context matter	The patient cannot be treated as the only unit of adaptation
Mechanism–context case — Disruption of established family roles					
Role renegotiation	Loss or modification of previous capacity	Employment, parenting, household and social roles	Role change may be experienced as loss, relief, or necessary accommodation	Gendered, cultural and economic expectations can shape available alternatives	Identity and relationship change may reinforce one another
Mechanism–context case — Long-term relational accommodation					
Ongoing recalibration	Relative stability interrupted by new demands	Responsibility, autonomy, future planning	Apparent stability may conceal unequal burden	Proposed classification; requires	Proposed: relational adaptation is better understood as

				longitudinal testing across illnesses	revisable coordination than as a completed adjustment state

Stigma, disclosure, and social recognition

The social meaning of chronic disease depends partly on whether illness is believed, legitimized, concealed, stigmatized, or institutionally recognized. A systematic review and meta-analysis of stigma interventions for chronic non-communicable diseases found an uneven evidence base, with substantial attention to intrapersonal targets and less resolution of structural forms of stigma [17]. This imbalance matters theoretically because stigma is not simply a negative attitude located within either the patient or another individual.

Disclosure illustrates the relational dimension. Decisions about revealing illness are shaped by visibility, anticipated response, the need for accommodation, relationship safety, and the costs of being misunderstood. Recognition then extends beyond disclosure: a condition can be known yet still treated as exaggerated, morally suspect, insufficiently disabling, or administratively illegible.

The proposed concept of recognition conditions captures this distinction. Recognition conditions are the interpersonal and institutional circumstances under which an illness account is treated as sufficiently legitimate to warrant understanding, accommodation, or care. They do not determine psychological outcomes, and group membership alone cannot establish stigma or identity. Rather, they define an unequal social environment within which disclosure, help-seeking, and participation become more or less feasible.

Psychosocial adaptation across the illness trajectory

Adaptation is often discussed as though people move toward a stable psychological endpoint. The available evidence is more consistent with a conditional process. Across chronic-illness studies, self-compassion is associated with lower psychological distress, but the association does not by itself establish that increasing self-compassion will cause improved adjustment in every population [18]. Qualitative synthesis similarly portrays caring for the self as involving preservation or reconstruction of personhood alongside the practical management of illness [19].

Social connection also resists simple interpretation. Accounts of loneliness among people with chronic illness show meanings involving disrupted participation, altered relationships, and disconnection from previous social worlds, rather than merely an insufficient number of social contacts [20]. Adaptation can therefore improve in one domain while deteriorating in another. A person may become skilled at managing medication but feel increasingly socially displaced, or preserve identity continuity while lacking the resources needed to implement care.

This article consequently proposes adaptive fit as a time-specific relationship among embodied demands, identity continuity, relational resources, meaningful participation, and usable care. It is not an outcome score and does not imply psychological acceptance. Fit can improve through reduced demands, greater resources, renegotiated expectations, supportive relationships, or more usable healthcare; it can deteriorate when any of those conditions change. The concept is intentionally reciprocal: identity affects how illness is interpreted, but changing symptoms can reshape identity; relationships support coping, but illness work can alter relationships.

The evidence therefore requires a multilevel view in which potentially helpful psychological resources remain distinguishable from relational participation and from material or organizational opportunity. **Table 2** separates these conditions so that adaptation is not misclassified as an exclusively individual achievement.

Table 2. Constraints on Adaptive Fit Across the Chronic-Illness Trajectory

Level at which the constraint operates	Adaptation process affected	Context that changes its meaning	Alternative explanation or uncertainty	Boundary for interpretation	Consequence for adaptive fit
Relational or system condition — Persistent or changing illness demands					
Embodied and everyday-life	Continuity, pacing,	Symptom predictability and treatment burden	Distress may reflect current disease	Disease courses are heterogeneous	Fit may require repeated recalibration rather than stable acceptance

	expectation revision		burden rather than failed adaptation		
Relational or system condition — Self-directed responding to difficulty					
Psychological	Emotional regulation and self-evaluation	Type and severity of distress	Association does not establish intervention effectiveness	Psychological resources differ across people and settings	A resource may support adaptation without being necessary or sufficient
Relational or system condition — Changing participation and loneliness					
Relational and social	Belonging, role continuity, meaningful activity	Availability and accessibility of valued relationships	Social contact quantity may not capture experienced connection	Solitude and loneliness are not equivalent	Reduced participation can destabilize otherwise successful disease management
Relational or system condition — Unequal access to usable support					
Material and social	Capacity to enact coping or self-management	Income, literacy, language, transport, caregiving resources	Lower engagement may reflect constrained opportunity rather than motivation	Resource requirements differ by care system	Adaptive possibilities are socially distributed
Relational or system condition — Clinical or digital environments that demand sustained participation					
Organizational and technological	Healthcare engagement	Usability, communication quality and accessibility	Non-use may reflect burden or mismatch rather than disengagement	Access and utilization must remain distinct	Proposed: adaptive fit depends partly on whether care environments are permeable to patients' changing capacities

These distinctions also require a visual architecture that preserves parallel processes rather than implying a single sequence. **Figure 1** therefore represents adaptation as movement within several interacting lanes whose connections become easier or harder to traverse under different contextual conditions.

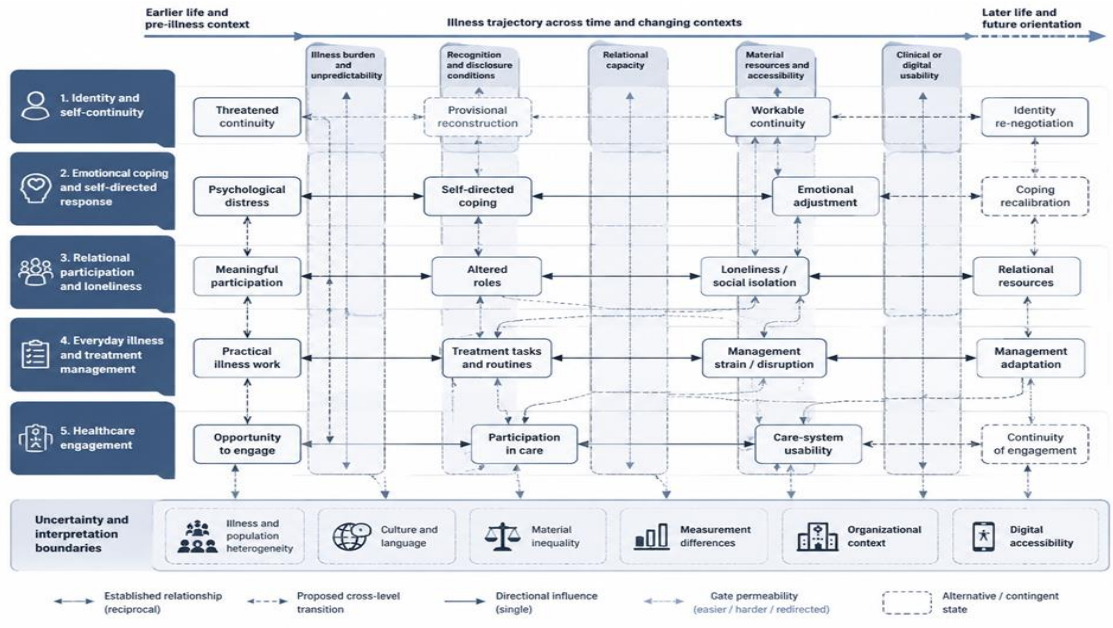

Figure. Multilevel architecture of psychosocial adaptation in chronic illness. Five analytic domains operate in parallel across an illness trajectory. Vertical permeability gates—illness burden and unpredictability; recognition and disclosure conditions; relational capacity; material resources and accessibility; and clinical or digital usability—shape movement within and between domains. Solid bidirectional connectors indicate established reciprocal relationships within domains; dashed connectors indicate proposed cross-level transitions (e.g., changes in recognition conditions influencing relational participation and subsequent opportunity for care engagement). The uncertainty and interpretation boundaries constrain how this architecture is understood and applied across populations and settings.

Figure 1. Contextual Permeability Determines Which Forms of Adaptation Remain Practically Available

Coping, support, and relational resources

Once adaptation is understood as conditional fit, "support" cannot be treated as an undifferentiated protective factor. Resources become consequential through their availability, usability, meaning, timing, and compatibility with the person's circumstances. This is apparent in evidence on self-management support for socioeconomically disadvantaged older adults, where tailoring to literacy, language, practical constraints, and delivery context affects whether support can actually be used [21].

Relational resources likewise operate through reciprocity rather than simple receipt. Dyadic coping may assist both partners, yet its consequences depend on what each person does, how responsibilities are interpreted, and whether care demands remain sustainable. Cultural or religious practices can supply continuity while also being disrupted by illness. Social contact may exist without restoring belonging.

The proposed distinction is therefore between nominal support and usable relational resources. Nominal support describes the presence of people, services, information, or technologies; usable resources are those that a person can access without unacceptable cost, stigma, cognitive burden, role conflict, or loss of autonomy. This distinction prevents low resource use from being interpreted automatically as low motivation and prepares the transition from psychosocial adaptation to healthcare engagement.

Self-management and healthcare engagement

Self-management is often presented as the behavioural expression of successful adjustment, but this conflates capacity, responsibility, participation, and morality. Qualitative analysis of the "good self-manager" shows how expectations surrounding knowledge, activity, and responsibility can become normative judgments about what patients ought to do [22]. Such judgments risk individualizing difficulties produced by symptom burden or care-system design.

Actual self-care is more variable. Ecological daily assessment indicates that symptom characteristics, causal interpretations, and immediate context can influence whether people initiate self-care behaviours [23]. Measurement adds another layer: evaluation of the Partners in Health scale in a multi-ethnic population demonstrates that self-management constructs require psychometric and contextual scrutiny rather than assumption of universal equivalence [24].

Healthcare relationships also matter. A mixed-studies review associates patient-provider communication with self-management through informational, relational, and collaborative processes [25]. Yet participation itself is heterogeneous. Qualitative evidence from interprofessional chronic-disease care indicates that patients differ in how they wish to engage and what role they can practically assume [26]. Engagement should therefore not be represented as a stable personal disposition ranging from passive to active.

Longitudinal primary-care evidence further suggests that perceived self-management support is associated with subsequent improvement in patient activation [27]. This relationship supports attention to care processes but does not establish that activation necessarily causes better clinical outcomes. Similarly, community self-management programs may teach patient-oriented engagement strategies while measuring outcomes that do not map directly onto those strategies [28]. Behaviour, activation, participation, and clinical outcome must therefore remain separate constructs.

Digital systems make this distinction especially important. In chronic-disease mHealth, patterns of engagement can change over time, and the burden of self-reporting can influence both participation and the data subsequently available for computational analysis [29]. Patient-portal use is also socially patterned, with disparities associated with characteristics including health literacy and multimorbidity [30]. Digital non-use consequently cannot be read straightforwardly as disengagement.

The article therefore proposes healthcare engagement as a negotiated accomplishment produced at the intersection of patient capacity, illness demands, relational conditions, communication, service organization, and accessibility. A person may be highly committed to managing illness yet unable to navigate fragmented or burdensome care; another may deliberately limit participation while making informed decisions consistent with personal priorities. Engagement is thus neither synonymous with adherence nor sufficient evidence of successful adaptation. Its meaning can only be interpreted relative to what participation is being requested, what resources it requires, and whether the healthcare environment makes that participation realistically possible.

Temporal transitions and critical turning points

Chronic illness trajectories are not simply sequences of biomedical events. They are also reorganized through encounters in which symptoms, explanations, responsibilities, and possible futures are renegotiated. Ethnographic work on specialized outpatient care for people with multiple chronic illnesses shows that symptoms, causes, and solutions are repeatedly "tinkered with" rather than mechanically derived from fixed diagnostic categories [31]. A clinical encounter may therefore become consequential when it changes what a person, family, or clinician believes can or should happen next.

Diagnostic uncertainty can itself constitute such a transition. Among young adults living near the limits of conventional diagnostic categories, uncertainty can become part of chronic living rather than a temporary state preceding definitive classification [32]. Institutional interpretation matters as well. In fibromyalgia care, chronicity rhetoric has been shown to shape how recovery and future possibility are understood within healthcare and welfare systems [33]. Where illness legitimacy is strongly contested, marginalization can extend across medical and social domains, restricting recognition and support [34].

The article therefore defines a critical turning point not by a predetermined event such as diagnosis or hospitalization, but by whether a transition materially reorganizes illness meaning, social relations, available resources, or feasible healthcare engagement. The same event may be transformative for one person and relatively inconsequential for another.

The distinctions required to identify such transitions are summarized below **(Table 3)**.

Table 3. Distinguishing Chronic-Illness Events from Socially Consequential Turning Points

Evidence pattern or boundary case	What changes	Why it may become a turning point	What should not be inferred	Context determining significance	Proposed discrimination rule
Diagnostic clarification	Illness explanation and legitimacy	New interpretation can reorganize identity, disclosure, treatment, or expectations	Diagnosis does not automatically produce adaptation	Prior uncertainty, social recognition, treatment options	A turning point requires downstream reorganization, not merely a new label
Persistent diagnostic ambiguity	Certainty remains unavailable	Uncertainty itself can reshape identity and care-seeking	Absence of diagnosis does not imply absence of illness impact	Age, symptom visibility, professional recognition	Prolonged uncertainty may function as a chronic state
Symptom or functional change	Everyday capability	Roles and practical demands may need renegotiation	Greater symptoms do not specify psychological response	Prior roles, resources, predictability	Consequence depends on alteration of feasible activities
Clinically negotiated reinterpretation	Meaning of symptoms or treatment	Changed explanations can redirect management	Clinical reinterpretation is not necessarily objective resolution	Continuity, communication, competing diagnoses	Encounter significance depends on whether future action changes
Institutional recognition or delegitimation	Eligibility, credibility, accommodation	Social and healthcare options may expand or contract	Recognition should not be treated as a patient personality attribute	Welfare rules, diagnostic culture, professional authority	Institutional transitions can alter trajectories independently of symptoms
Relative stability	Few obvious external events	Accumulated adaptations may temporarily sustain everyday life	Stability does not imply absence of illness work	Ongoing resources and relational capacity	Proposed: stability is a maintained configuration, not the absence of change

The social-life-of-chronic-disease model

The preceding sections suggest that chronic disease acquires social consequences through multiple connected but non-equivalent processes. The proposed Social-Life-of-Chronic-Disease Model organizes these processes across four nested analytical scales.

At the most immediate scale, embodied illness alters symptoms, energy, function, uncertainty, and treatment

work. These changes interact with identity and the interpretation of what remains possible. A second scale concerns relationships: responsibilities, disclosure, caregiving, reciprocity, and social participation. A third concerns healthcare encounters and organizational environments, which influence whether needs are recognized and whether participation is practicable. The outer scale contains material, cultural, digital, and institutional conditions that distribute resources and legitimacy unequally.

The model is explicitly reciprocal. Identity can affect engagement, but experiences of care can also reshape identity. Relationships can enable management while management demands reorganize relationships. Social recognition may facilitate participation, whereas repeated delegitimation may narrow the range of feasible actions. No single level is assumed to dominate universally.

The architecture therefore requires explicit boundaries between evidence-supported component relationships and the article's proposed scale-transfer logic **(Figure 2)**.

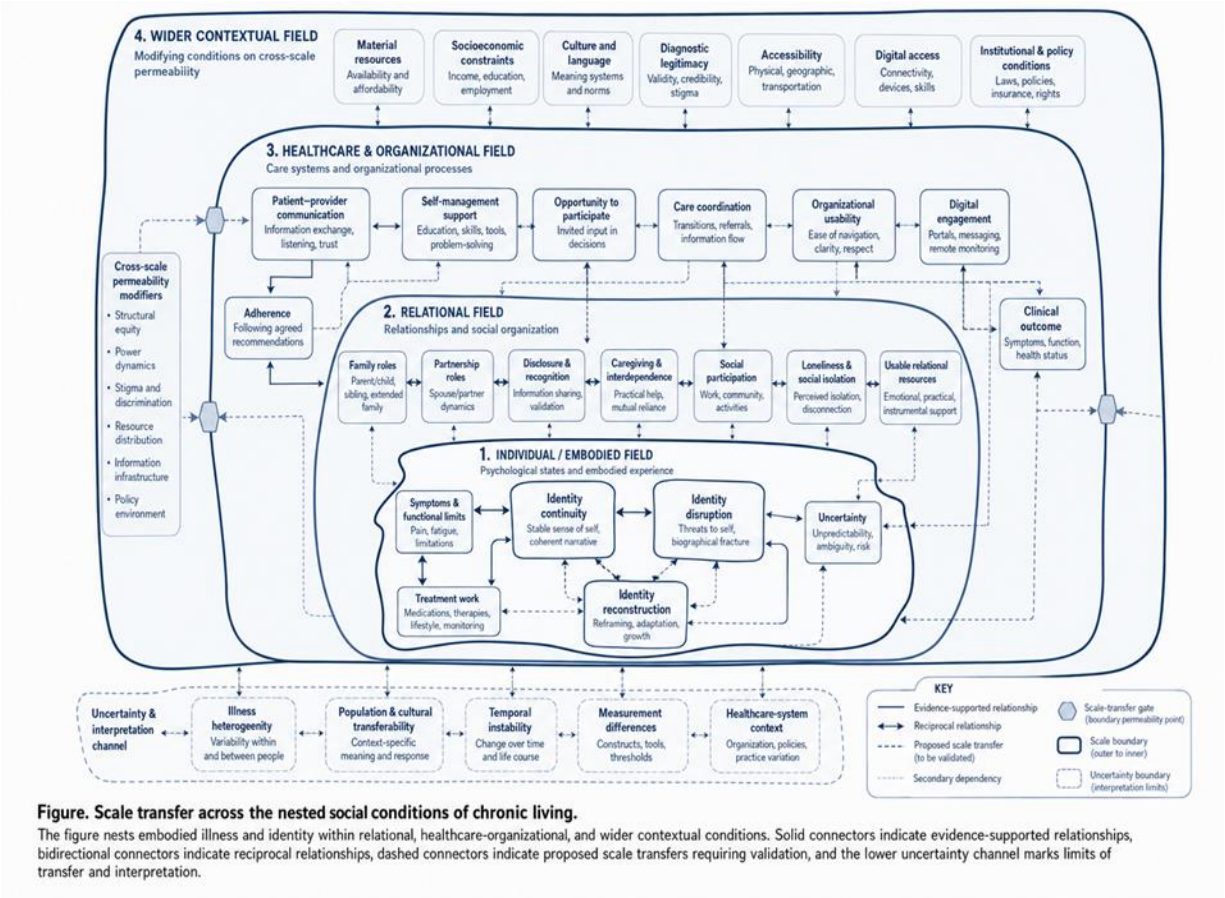

Figure. Scale transfer across the nested social conditions of chronic living.
The figure nests embodied illness and identity within relational, healthcare-organizational, and wider contextual conditions. Solid connectors indicate evidence-supported relationships, bidirectional connectors indicate reciprocal relationships, dashed connectors indicate proposed scale transfers requiring validation, and the lower uncertainty channel marks limits of transfer and interpretation.

Figure 2. Scale Transfer Across the Nested Social Conditions of Chronic Living

Comparative and longitudinal predictions

Because the model is proposed rather than validated, its value depends on whether it generates discriminating tests. First, longitudinal studies should examine whether identity, relationship organization, and healthcare engagement change together or independently around clinically and socially meaningful transitions. Second, effects should differ where illness is visible versus concealable, diagnostically secure versus contested, and relatively predictable versus unstable. Third, similar symptom burdens should produce different engagement trajectories where relational, material, or organizational resources differ.

Within-person evidence already indicates that self-management can change with symptoms and context, while longitudinal work demonstrates change in illness identity and activation. These observations justify

longitudinal testing but do not prove the proposed cross-level pathways.

The predictions are therefore framed as decisions about what must be compared rather than forecasts of universal outcomes **(Table 4)**.

Table 4. Decision Register for Testing Comparative and Longitudinal Predictions

Patient or care-context state	Proposed longitudinal comparison	Competing explanation to retain	Required contextual observation	Evidence needed before clinical interpretation	Decision implication
Stable symptoms with declining participation	Determine whether relational or organizational conditions changed	Reduced participation may be intentional	Roles, accessibility, care burden	Repeated patient-reported and contextual measures	Do not label disengagement without establishing opportunity and preference
Identity disruption after a transition	Compare identity change with functional and relational change	Distress may reflect symptom burden directly	Life stage, visibility, legitimacy	Repeated multidomain assessment	Test identity as one pathway, not the sole mechanism
High treatment burden with preserved engagement	Examine resources sustaining participation	High engagement may conceal unsustainable effort	Caregiver work, time, financial burden	Longitudinal burden and participation data	Sustainability should be assessed separately from current participation
Digital non-use	Compare access, usability, preference, and capacity	Non-use may represent informed choice	Literacy, accessibility, device and service conditions	Mixed digital and qualitative evidence	Avoid treating digital uptake as a universal engagement proxy
Contested diagnosis	Compare trajectories before and after changes in recognition	Symptom course may change independently	Institutional and interpersonal legitimacy	Longitudinal clinical and social data	Test recognition as contextual exposure rather than personal trait
Cross-system comparison	Examine whether similar patient states produce different engagement patterns	Population composition may differ	Organization, financing, continuity, access	Comparative multilevel designs	Proposed: model transferability should be demonstrated rather than assumed

Implications for chronic care

The model implies that good chronic care requires more than disease surveillance and instructions for self-management. Care planning should periodically reassess whether treatment demands remain compatible with the patient's current capacities, roles, resources, and goals. Communication should identify not only what patients understand but what forms of participation they can realistically sustain.

Digital care makes this requirement especially important. Conversational agents and related self-management technologies are expanding, but systematic review evidence remains heterogeneous in design, reporting, and evaluation [35]. Digital scalability therefore should not be mistaken for universal accessibility or established clinical benefit.

The proposed practical implication is context-sensitive reassessment. Changes in participation, missed monitoring, reduced disclosure, or altered self-management should prompt inquiry into changing illness, relational, material, organizational, and digital conditions before they are interpreted as deficient motivation. This is a care-design principle derived from the theory, not an intervention whose effectiveness has already been demonstrated.

Results and Discussion

The social life of chronic disease is neither a secondary consequence of biomedical pathology nor a universal pathway from diagnosis to disruption and eventual acceptance. The evidence instead supports a more conditional account. Illness may disrupt biography, but

disruption can recur, diminish, or coexist with continuity. Identity may become engulfed, reconstructed, or integrated without mapping directly onto clinical status. Relationships can provide resources while simultaneously acquiring additional work. Healthcare engagement can reflect patient agency, but it also depends on communication, accessibility, organizational design, and material capacity.

The proposed model integrates these observations while preserving their boundaries. Its principal claim is that chronic living emerges through reciprocal adjustments across embodied, identity, relational, healthcare, and contextual levels. The complete architecture has not been empirically validated. Qualitative studies illuminate meaning and process but do not establish population-level causal effects; observational longitudinal evidence can establish temporal association without resolving all confounding; intervention and review evidence varies substantially by disease, setting, measurement, and follow-up.

Future evaluation should therefore prioritize repeated multilevel measurement around meaningful transitions, comparison across illnesses and healthcare systems, and designs capable of separating changing disease severity from changing social and organizational conditions. Particular attention is required where poverty, disability, language, culture, digital exclusion, caregiving burden, or diagnostic delegitimation constrain available choices. These are not residual confounders to the social life of chronic disease; when directly measured, they are conditions under which its processes may operate differently.

Conclusion

Chronic disease persists biologically, but its lived and healthcare consequences are continually reorganized. Illness can alter identity, redistribute relational responsibilities, reshape social recognition, change the resources available for adaptation, and modify what healthcare participation is practically possible. These processes should not be collapsed into a single concept of adjustment or patient engagement.

The Social-Life-of-Chronic-Disease Model proposes that chronic living is best understood as a dynamic fit across embodied, personal, relational, organizational, and wider contextual conditions. Its pathways are conditional, reciprocal, and unequal rather than universal or linear. The model therefore offers a bounded theoretical basis for longitudinal and comparative testing while cautioning against interpreting difficult engagement, altered identity, or constrained self-management without examining the social and healthcare environments in which they occur.

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References

1. Skou ST, Mair FS, Fortin M, Guthrie B, Nunes BP, Miranda JJ, et al. Multimorbidity. Nat Rev Dis Primers. 2022;8(1):48. doi:10.1038/s41572-022-00376-4
2. 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
3. Watson BN, Estenson L, Eden AR, Gerstein MT, Carney MT, Dotson VM, et al. Person-centered care planning for people living with or at risk for multiple chronic conditions. JAMA Netw Open. 2024;7(10). doi:10.1001/jamanetworkopen.2024.39851
4. Engman A. Embodiment and the foundation of biographical disruption. Soc Sci Med. 2019;225:120-7. doi:10.1016/j.socscimed.2019.02.019
5. Saunders B. ‘It seems like you’re going around in circles’: Recurrent biographical disruption constructed through the past, present and anticipated future in the narratives of young adults with inflammatory bowel disease. Sociol Health Illn. 2017;39(5):726-40. doi:10.1111/1467-9566.12561
6. 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
7. Fudge N, Swinglehurst D. Keeping in balance on the multimorbidity tightrope: A narrative analysis of older patients’ experiences of living with and managing multimorbidity. Soc Sci Med.

2022;292:114532. doi:10.1016/j.socscimed.2021.114532
8. 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
9. Oikkonen V, Helosvuori E, Ganesh A, Rokkonen LA. Entangled illnesses: Embodied experiences of managing multimorbidity. Sociol Health Illn. 2025;47(2). doi:10.1111/1467-9566.70006
10. Fang C, Akhtar Baz S, 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
11. 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
12. 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
13. 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
14. 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
15. Hou J, Falconier MK, Tam W, Cheung MWL, Fu R, Bu H, et al. Dyadic coping and relationship satisfaction among couples with a chronic illness: A meta-analytical actor-partner interdependence model. Clin Psychol Rev. 2025;119:102587. doi:10.1016/j.cpr.2025.102587
16. Mendenhall E, Banerjee S, Wahlberg A. Interembodiment among Long Haulers and their carers. Soc Sci Med. 2025;381:118282. doi:10.1016/j.socscimed.2025.118282
17. Akyirem S, Ekpor E, Batten J, Brady V. Reducing health-related stigma in adults living with chronic non-communicable diseases: A systematic review and meta-analysis. Soc Sci Med. 2024;356:117153. doi:10.1016/j.socscimed.2024.117153
18. Baxter R, Sirois FM. Self-compassion and psychological distress in chronic illness: A meta-analysis. Br J Health Psychol. 2025;30(1). doi:10.1111/bjhp.12761
19. 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
20. Lewis S, Willis K, Smith L, Dubbin L, Rogers A, Moensted ML, et al. There but not really involved: The meanings of loneliness for people with chronic illness. Soc Sci Med. 2024;343:116596. doi:10.1016/j.socscimed.2024.116596
21. Lawless MT, Oster C, Block H, Cash B, Bulto LN, Pinero de Plaza MA, et al. Self-management support interventions for socioeconomically disadvantaged older adults with chronic conditions: A systematic review. Patient Educ Couns. 2025;141:109305. doi:10.1016/j.pec.2025.109305
22. Ellis J, Boger E, Latter S, Kennedy A, Jones F, Foster C, et al. Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions. Soc Sci Med. 2017;176:25-33. doi:10.1016/j.socscimed.2017.01.018
23. Riegel B, Page SD, Aryal S, Lee CS, Belfiglio A, Freedland KE, et al. Symptom characteristics, perceived causal attributions, and contextual factors influencing self-care behaviors: An ecological daily assessment study of adults with chronic illness. Patient Educ Couns. 2024;123:108227. doi:10.1016/j.pec.2024.108227
24. Shou Y, Smith D, Ng JX, Battersby M, Chen C, Fong NP. Assessing disease self-management in multi-ethnic patients with chronic conditions and evaluating psychometric properties of the Partners in Health scale. Soc Sci Med. 2024;363:117490. doi:10.1016/j.socscimed.2024.117490
25. Iroegbu C, Tuot DS, Lewis L, Matura LA. The influence of patient-provider communication on self-management among patients with chronic illness: A systematic mixed studies review. J Adv Nurs. 2025;81(4):1678-99. doi:10.1111/jan.16492
26. Law B, Chhatwal PK, Licskai C, Scurr T, Sibbald SL. Patient engagement in interprofessional team-based chronic disease management: A qualitative description of a Canadian program. Patient Educ

Couns. 2023;114:107836. doi:10.1016/j.pec.2023.107836
27. McCusker J, Lambert SD, Haggerty J, Yaffe MJ, Belzile E, Ciampi A. Self-management support in primary care is associated with improvement in patient activation. Patient Educ Couns. 2019;102(3):571-7. doi:10.1016/j.pec.2018.10.026
28. Warner G, Packer TL, Kervin E, Sibbald K, Audulv Å. A systematic review examining whether community-based self-management programs for older adults with chronic conditions actively engage participants and teach them patient-oriented self-management strategies. Patient Educ Couns. 2019;102(12):2162-82. doi:10.1016/j.pec.2019.07.002
29. Duckworth C, Cliffe B, Pickering B, Ainsworth B, Blythin A, Kirk A, et al. Characterising user engagement with mHealth for chronic disease self-management and impact on machine learning performance. NPJ Digit Med. 2024;7(1):66. doi:10.1038/s41746-024-01063-2
30. Yoon E, Hur S, Opsasnick L, Huang W, Batio S, Curtis LM, et al. Disparities in patient portal use among adults with chronic conditions. JAMA Netw Open. 2024;7(2). doi:10.1001/jamanetworkopen.2024.0680
31. Skovgaard AL, Jørgensen MJ, Tjørnhøj-Thomsen T, Høybye MT. Tinkering with symptoms, causes and solutions: Tracing the enactments of multiple chronic illnesses in specialised outpatient check-ups. Sociol Health Illn. 2024;46(4):627-43. doi:10.1111/1467-9566.13738
32. Harper I, Kenny K, Broom A. Navigating the limits of diagnosis: Young adults' experiences of chronic living. Sociol Health Illn. 2025;47(2). doi:10.1111/1467-9566.13861
33. Cupit C, Finlay T, Pope C, Hollick R, Jones GT, Locock L, et al. Chronicity rhetoric in health and welfare systems inhibits patient recovery: A qualitative, ethnographic study of fibromyalgia care. Soc Sci Med. 2025;382:118313. doi:10.1016/j.socscimed.2025.118313
34. Nezamdoust B, Ruel E. Contested and neglected: Social and medical marginalization in severe Chronic Fatigue Syndrome. Soc Sci Med. 2026;388:118766. doi:10.1016/j.socscimed.2025.118766
35. Peerbolte TF, van Diggelen RJA, van den Haak P, Geurts K, Evers LJW, Bloem BR, et al. Conversational agents supporting self-management in people with a chronic disease: Systematic review. J Med Internet Res. 2025;27. doi:10.2196/72309