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Review Article

The Phenomenal Body and Lay Pharmacology in Lifelong Treatment Adherence: A Review of an Interpretivist Perspective

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Abstract

Introduction: Medication non-adherence in chronic illness remains a critical bottleneck to optimal healthcare delivery, directly associated with elevated morbidity, mortality, and systemic expenditures. This narrative review was aimed to explore the emic perspectives of patients undergoing lifelong treatments, examining how they generate unique experiential knowledge to navigate the daily realities of chronic disease.

Methods: This study employed a conceptual/narrative review design informed by an interpretivist epistemology. A systematic search of PubMed, Scopus, and Google Scholar was conducted for literature published from database inception to date of review. Given the conceptual nature of the review, the author prioritized theoretical, philosophical, and empirical qualitative studies that explicitly addressed patient subjective experience in lifelong treatment. Data synthesis followed a reflexive thematic approach, iteratively identifying core constructs across the selected literature. Utilizing an interpretivist approach, this review synthesizes Maurice Merleau-Ponty's phenomenology of the "phenomenal body" alongside contemporary frameworks of subjective medication experiences, Leventhal's Common-Sense Model, and Social Comparison Theory.

Results: Lifelong treatment alters the phenomenal body and disrupts the pre-reflective, silent experience of daily life. To cope with disease chronicity, the unbounded duration of treatment, and psychosocial changes, patients actively construct an alternative framework of meaning, termed "lay pharmacology". This patient-constructed knowledge dictates intentional non-adherence as a rational mechanism to regain personal autonomy and control.

Conclusion: Resolving non-adherence requires a paradigm shift from expert-driven compliance metrics toward frameworks that validate patient-constructed knowledge. Integrating Shared Medical Decision-Making, Narrative Medicine, and Critical Health Literacy into clinical practice is essential to align clinical guidelines with the patient's lived reality.

Keywords: Medication adherence, Chronic disease, Health knowledge, Self-concept

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Introduction

The Conceptual Divergence of Disease and Illness

The concepts of disease, illness and sickness have basically different aspects of phenomena related to human healthcare. The terms are the subject of discussion because they are usually employed as synonyms; efforts are there to differentiate one from the other. Most heath researches define disease as a pathological process, deviation from a biological norm, whereas illness is the patient's experience of ill health and sickness is the role negotiated with society.[1,2]

There is a various definition for chronic illnesses with variation in the time a disease must be present for something to be referred to as chronic, therefore making it difficult to reach a consensus. According World Health Organization (WHO) and Center for Disease control (CDC) chronic diseases are long-lasting conditions that usually can be controlled but not cured.[3,4] People living with chronic illnesses often must manage daily symptoms that affect their quality of life, and experience acute health problems and complications that can shorten their life expectancy.

For the purpose of philosophical assumptions and consistency of meaning for terms used in this document, we will use the term illness to refer to those all chronic conditions for which patients take medications for their life long period.

The Stagnation of Medication Adherence Paradigms

WHO, defined adherence as "the extent to which a person's behavior, taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations[3,5] Non-adherence is a major reason why treatments shown to be efficacious in trials are often less effective in clinical practice. Of great importance for the development of tailored solutions to non-adherence is awareness of intentional and unintentional adherence. [6,7] For the purpose of focus and consistency, we will give more attention to an intentional non-adherence(INA).

The effectiveness of treatments reported in clinical trials are usually based on atypical levels of medication adherence. Whilst it is recognized that such outcomes may

not be replicated in 'real world' clinical practice, patients need to be optimally adherent to their medication in order to achieve the best clinical outcomes. Adherence is defined as the extent to which the patient's behavior (medication usage) matches agreed recommendations from the clinician. High levels of adherence are a crucial component of effective self-management for many people living with long-term conditions and viewed as one of the key mediators between medical practice and clinical outcomes. However, adherence rates in those with long-term conditions are low, with people typically taking only half of their prescribed medication. The World Health Organization (WHO) views non-adherence as an important public health concern, with implications for treatment response mortality, and additional healthcare costs, including increased number of hospital admissions and appointments, wasted resources, disease progression and need for more aggressive medications.[3,8]

Medication non-adherence is a key obstacle to individuals receiving the full treatment benefits of prescribed medications and is associated with significant morbidity and mortality. While it is often easy to focus solely on patients' behavior, medication non-adherence results from complex systems. To date, interventions to reduce medication non-adherence (ie, improve adherence) are only modestly effective.

Unintentional non-adherence (UNA):- occurs when the patient wants to adhere but is unable to because they lack capacity or resources. For example, they may not have understood the instructions, cannot afford copayment costs, or find it difficult to schedule, administer or remember the treatment. [3,9]

Intentional non-adherence (INA):- is when a patient actively decides not to take a drug or follow treatment recommendations. It is likely to reflect the patient's attitudes to medicines in general, and their specific beliefs and concerns about the treatment recommended and the disease being treated.[10]

Patients' knowledge and beliefs about their illness, motivation to manage it, confidence (self-efficacy) in their ability to engage in illness-management behaviors, and expectations regarding the outcome of treatment and the consequences of poor adherence, interact in ways not yet fully understood to influence adherence behavior. Perceptions of personal need for medication are influenced by symptoms, expectations and experiences and by illness cognitions. Concerns about medication typically arise from beliefs about side-effects and disruption of lifestyle, and from more abstract worries about the long-term effects, dependence and lack of hope.[6,11,12]

Rationale for an Interpretivist Paradigm shift

Adherence to long term treatment for chronic conditions has been and continuing to be a major problem for modern healthcare delivery. Despite 50 years of adherence research and greater understanding of more than 200 factors known to influence patients' adherence, non-adherence rates remain relatively unchanged. It is a key obstacle to individuals receiving the full treatment benefits of prescribed medications and is associated with significant morbidity and mortality [7]

Many health researches that were conducted so far identified many factors affecting patient adherence to treatment but none of them brought a best possible intervention to tackle the problem. Almost all previously conducted researches and intervention strategies used simplistic (objective) approaches that only accepts observable or measurable (i.e., empirical) experiences of the problem as data for analysis and reporting, which could not give clear understanding of their experiences.

What is needed is a systematic exploration of the patient's emic perspective their internal, culturally and experientially situated viewpoint regarding lifelong treatment. By utilizing an interpretivist research philosophy, which posits that reality is subjective, socially constructed, and composed of multiple co-existing perspectives, healthcare researchers can move beyond superficial compliance tracking. This review addresses this critical gap by synthesizing Maurice Merleau-Ponty's phenomenological theoretical framework alongside contemporary clinical models developed by Nascimento et al, exploring how the subjective medication experience fosters a unique, patient-constructed knowledge base that directly dictates treatment adherence. [13,14]

Methods

Study design and search strategy

This study employed a conceptual/narrative review design informed by an interpretivist epistemology. A systematic search of PubMed, Scopus, and Google Scholar was conducted from database inception to March 2026. No lower date limit was applied to ensure inclusion of foundational phenomenological works like Merleau-Ponty 1945, Bury 1982, and others which date back to earlier periods.

The search strategy combined keywords related to chronic illness ("chronic disease," "lifelong treatment," "lifelong therapy"), adherence behaviors ("medication adherence," "non-adherence," "non-compliance," "intentional non-adherence"), and interpretivist frameworks ("lay pharmacology," "phenomenal body," "Merleau-Ponty," "emic perspective"). Additional hand-searching of reference lists was performed. Studies were included if they addressed patient medication experiences in chronic conditions requiring long-term treatment. Data synthesis followed a reflexive thematic approach, identifying core constructs including phenomenal body disruption, lay pharmacology, cognitive drivers (necessity-concern framework, common-sense model, social comparison theory), and clinical translation frameworks. Given the conceptual nature of this review, no formal quality appraisal checklist was applied.

Theoretical Framework: The Phenomenology of Long-Term Medication use

Merleau-Ponty and the Disruption of the Phenomenal body

To understand the emic perspective of a patient bound to lifelong pharmacotherapy, health literature must

transcend purely behavioral models and engage with the phenomenology of the body. Maurice Merleau-Ponty introduced a foundational distinction between the objective body (the anatomical, biological organism studied by medicine) and the phenomenal body (the body as it is subjectively lived and experienced by the individual). [13,14]

In a healthy state, the phenomenal body exists in a state of pre-reflective harmony or "biological silence" the body is an unexamined vehicle through which an individual seamlessly interacts with their environment. The onset of a chronic illness and the subsequent introduction of lifelong medication permanently disrupt this prerelective harmony. As Merleau-Ponty observed, medications interrupt the silent experience of life and break the integrity of the phenomenal body. Rather than existing as an invisible background function, the body suddenly demands conscious attention and effort. The daily, non-negotiable routine of taking medication acts as a constant, tangible proxy for the underlying disease. It forces the patient to acquire entirely new habits and routines, which paradoxically introduces a profound sense of ambiguity into their daily existence. While the medication is biochemically intended to preserve the objective body, its daily consumption disrupts the autonomy, freedom, and identity of the phenomenal body, shifting the patient's relationship with their own physical self from subconscious trust to active, daily negotiation.

The Emergence of "Lay Pharmacology"

When patients face a permanent alteration in how they experience their physical selves, they do not remain passive consumers of clinical instructions. Instead, they enter an active process of meaning-making. Driven by the continuous challenges of chronic illness, a perceived shrinkage of their life-world, and the emotional weight of a condition that lacks a definitive cure, patients systematically construct an alternative conceptual framework for their treatments a phenomenon termed lay pharmacology. Lay pharmacology represents a patient-constructed knowledge system regarding medications and the precise role they play in their lives. [14,15]

Within this emic framework, a drug is no longer evaluated solely on the clinical parameters defined by a physician (such as biomarker stabilization or pharmacokinetic properties). Rather, the patient evaluates the medication through the lens of lived experience: its immediate impact on physical function, its perceived toll on personal autonomy, and the bodily changes both positive and negative experienced from day to day (Figure 1). This coping strategy yields an experiential knowledge base that allows patients to regain a sense of personal agency over an existential situation they feel they have lost control over. [15]

Results and Discussion

Disease Chronicity as an endless Existential battle

The primary internal catalyst forcing patients to construct lay pharmacology is the unique, unyielding nature of chronic disease. Unlike acute clinical episodes that follow a predictable trajectory toward recovery, a chronic illness imposes an "endless battle" between the patient and their condition. Because chronic symptoms and bodily states fluctuate, clinical control over the disease is always temporary or partial. Consequently, the act of self-caring becomes entirely open-ended; patients are perpetually confronted with new physical anomalies or unexpected functional limitations to manage. This continuous battle is severely compounded by the unbounded, lifetime duration of treatment. Being told that a disease will persist throughout their entire lifespan creates deep, long-term anxiety. To survive this exhausting reality, patients use their experiential knowledge to design alternative, highly localized coping strategies aimed at neutralizing daily negative symptoms and maximizing personal comfort. Because these temporary coping strategies are rooted in personal bodily feedback rather than medical theory, the resulting patient-constructed behaviors are

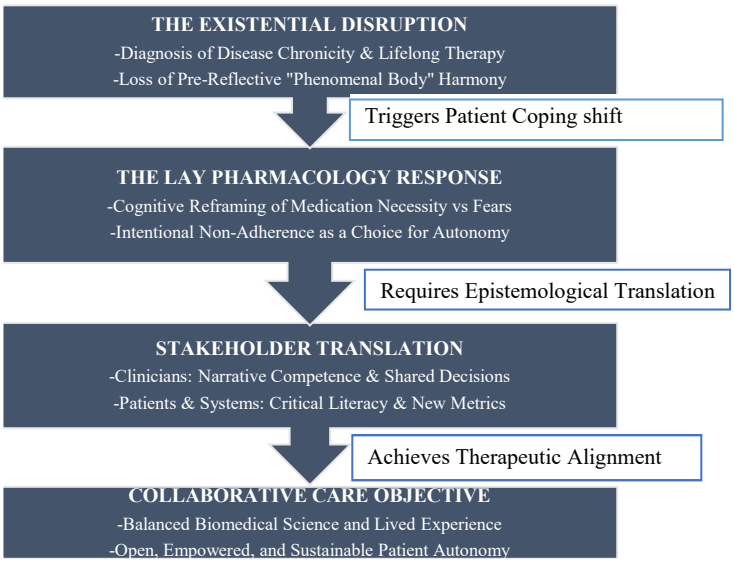

Figure 1. From disrupted autonomy to collaborative care: an interpretivist framework for Lay Pharmacology and lifelong treatment adherence

frequently directly contrary to their physician's clinical recommendations, ultimately manifesting as intentional non-adherence.[14,16]

This finding challenges the dominant biomedical paradigm that treats non-adherence as a behavioral deficit or knowledge gap requiring correction through didactic instruction.[3,7] Instead, the synthesis supports an interpretivist understanding in which intentional non-adherence represents a rational, meaning-driven response to the existential disruption of chronic disease. The concept of "*biographical disruption*" introduced by [2] Bury resonates here, chronic illness shatters not only bodily function but also the patient's life narrative, forcing a fundamental re-negotiation of identity and future expectations.

Cognitive Representations: The Necessity-Concern and Common-sense Models

The psychological mechanisms through which lay pharmacology dictates adherence behavior can be effectively mapped using established behavioral frameworks, most notably the Necessity-Concern Framework and Leventhal's common-sense model of illness representation.[17] According to the Necessity-Concern Framework, a patient's adherence choice is a continuous, dynamic cognitive calculus. Patients actively weigh their perceived personal need for a treatment against their salient, abstract concerns regarding adverse side effects, long-term toxicities, lifestyle disruption, and the threat of chemical dependence. Quantitative data has long shown that optimal medication adherence occurs only when a patient's belief in the absolute necessity of the drug significantly outweighs their concerns. This cost-benefit analysis is heavily fed by the core cognitive domains outlined in Leventhal's Common-Sense Model, which notes that individuals use both emotional and cognitive representations to interpret somatic symptoms and judge treatment efficacy:

Identity: The subjective label and symptomatic profile the patient attaches to their illness, setting the parameters for somatic evaluation.

Timeline: The patient's personal perception of the duration of their illness (e.g., acute vs. permanent).

Consequences: Subjective beliefs regarding the seriousness of the disease and its holistic impact on daily life.

Control/Cure: Perceptions regarding how amenable the illness is to being managed, cured, or prevented.

Cause: The patient's underlying beliefs regarding the root cause of their condition.

When a clinician fails to uncover or integrate these internal domains during a consultation, the patient's lay pharmacology takes over, driving them to alter their dosage or schedule to align with their internal common sense rather than clinical guidelines.

Qualitative findings from Pagès-Puigdemont et al. (2016) exemplify this process. One patient with chronic illness explicitly described altering prescribed doses "*to feel like myself again*," directly prioritizing subjective embodied comfort over biomarker optimization. Such accounts demonstrate that intentional non-adherence is not irrational but rather a reasoned response to perceived threats to phenomenal body integrity. [17] The Necessity-Concern Framework correctly identifies that patients perform a cognitive calculus weighing perceived need against concerns. However, this framework remains largely cognitive-rationalist and does not adequately capture the embodied, pre-reflective dimensions of medication decision-making. The phenomenal body perspective adds that patients' concerns are not merely abstract beliefs about side-effects but are rooted in visceral, lived experiences of bodily disruption. When a patient reports feeling "*not like myself*" on medication, this is not a belief but an embodied judgment that may override rational cost-benefit calculations. Leventhal's Common-Sense Model provides a useful taxonomy of illness representations, but the current findings suggest that an additional domain should be considered: bodily integrity, the patient's perception of whether the treatment supports or undermines their sense of embodied selfhood.

Social Comparison and the Search for Benchmarks

The construction of lay pharmacology does not occur in a vacuum; it is highly influenced by the patient's social environment. The Social Comparison Theory mentions that a lack of information and uncertainty can trigger social comparison processes, and this is particularly common in the case of chronic illness. [18] Patients are using long term treatment for their chronic illness try to adopt such social comparison strategies as a way of coping with their illness. The patients often make comparisons with each other, which can have effects on their psychological and physical well-being. [18,19] Social comparisons may be particularly important for such patients; as they often experience insecurity and anxiety about their health, which increase the likelihood and utility of social comparisons. Among patients, social comparisons can have both positive and negative health-related consequences (for affect, motivation to improve one's health care behaviors, etc.), depending upon several contextual features. [20]

Upward comparisons

Most patients living with chronic diseases do compare themselves with those patients who are better off (upward comparisons). This positive focus on limitations may be responsible for the better psychological adjustment to illness among this group, in comparison with those who make downward comparisons.

Downward comparisons

Patients tend to compare themselves with patients worse off with them, only when experiencing difficulties and make upward comparisons with people healthier than themselves when setting standards for their recovery.

Arigo et al. (2014) provide concrete examples from patients with Type 2 diabetes. One patient reported: "*She manages her insulin and still travels, maybe I can too*" (an upward comparison promoting self-efficacy). [19] Conversely, another patient noted: "*At least I don't need dialysis like him*" (a

downward comparison protecting self-esteem). These comparisons directly shape how patients evaluate their treatment necessity and, consequently, their adherence decisions.

Social comparison processes are not merely passive observations but active meaning-making strategies that directly inform lay pharmacology. When patients observe peers experiencing better health outcomes (upward comparison), they may feel motivated to adhere more strictly. Conversely, downward comparisons may reduce perceived urgency for adherence (*"I'm not as bad as him"*). Clinicians should be aware that patients' adherence decisions are shaped not only by clinical information but also by their social reference groups. Peer support groups and patient mentorship programs may leverage upward comparisons constructively to promote adherence while avoiding the demoralization that can accompany unfavorable comparisons.

Epistemological Frameworks for Clinical Translation

To reconcile the divide between medical expectations and the patient's lived experience, healthcare delivery must adopt explicit epistemological frameworks that validate patient-constructed knowledge. Three complementary frameworks offer practical entry points for modern clinical pharmacy and medicine (Figure 1).

Shared Decision-Making (SDM

SDM reimagines the clinical consultation as a collaborative meeting of two distinct but equally valid knowledge bases. While the clinician contributes objective, evidence-based medical data regarding therapeutic options, the patient contributes critical emic data regarding their personal values, lifestyle preferences, and subjective capacity. By acknowledging patient knowledge and preferences as valid inputs, SDM builds a shared ownership of the treatment plan. Evidence demonstrates that involving patients directly in long-term treatment decisions dramatically improves satisfaction, fosters self-empowerment, builds a favorable therapeutic attitude, and substantially increases long-term adherence and clinical outcomes. [21,22]

Narrative Medicine and Hermeneutics

It provide the practical tools necessary to operationalize phenomenological principles in busy clinical environments.[23] These frameworks assert that illness is fundamentally an emotional and social experience rather than a purely biological breakdown. Narrative medicine bridges the communication gap by encouraging clinicians to actively listen to the stories patients tell about their illnesses, recognizing that these narratives are essential components of accurate diagnosis and tailored care. By paying close attention to patient stories, clinicians gain rare access to the patient's interior fears, hopes, and lay pharmacology systems. This interpretive approach builds deep therapeutic trust, enables empathetic communication, and allows providers to customize solutions that align perfectly with the patient's lived reality, thereby improving long-term adherence.

Critical Health Literacy

Critical Health Literacy moves beyond the baseline ability to read a prescription label; it represents a patient's capacity to critically analyze health information, question potential bias, and make highly informed health choices based on their personal values.[24,25] This framework actively challenges the archaic notion that medical knowledge must be exclusively expert-driven. Patients possessing strong critical health literacy skills are far better equipped to systematically evaluate the real-world benefits, risks, and side effects of their treatments. This literacy empowers them to confidently negotiate treatment adaptations with their healthcare providers rather than modifying regimens secretly. To cultivate this capacity, clinicians should actively counsel patients to ask candid questions about their options and encourage peer-to-peer experiential sharing, fostering a secure, collaborative relationship built on mutual transparency.[24–26]

The systematic review by Achterbosch et al. on shared decision-making interventions for patients with chronic respiratory diseases found that three out of four included RCTs demonstrated significant positive effects of SDM on medication adherence, though the quality of evidence was moderate to low. [27] Importantly, the authors identified three pathways through which SDM may improve adherence: patient activation, education, and personalized treatment planning. These mechanisms map directly onto the lay pharmacology construct described in the current review, when patients are actively engaged in decision-making (activation), when their experiential knowledge is validated (education), and when treatment plans accommodate their lived realities (personalization), intentional non-adherence may be reduced through collaborative rather than secret regimen modification.

Furthermore, recent empirical work by Chen et al. on multidimensional health literacy found that different socioeconomic groups rely on different health literacy dimensions for effective self-management. [26] In low socioeconomic status groups, communicative health literacy ($\beta = 0.262$, $P < 0.01$) and distributed health literacy ($\beta = 0.343$, $P < 0.01$) showed significant positive impacts on self-management behaviors. In high socioeconomic status groups, critical health literacy ($\beta = 0.253$, $P < 0.05$) and distributed health literacy ($\beta = 0.267$, $P < 0.01$) were the significant predictors. Especially, functional health literacy (basic reading and numeracy skills) showed no significant impact in either group. These findings suggest that interventions to support patient-constructed knowledge must be tailored to patients' socioeconomic contexts and should prioritize communicative and critical literacy skills over basic instructional compliance.

Limitations

This review has the following limitations. First, there is a risk of over-romanticizing patient knowledge; not all lay pharmacology decisions are safe. Second, the framework

draws primarily from Western traditions (Merleau-Ponty, social comparison theory); cross-cultural validation is needed. Third, illness type differences matter, visible vs. invisible conditions, high symptom burden vs. preventive treatments may yield different patterns. Fourth, this is a conceptual review, not primary empirical research; future interpretive phenomenological studies are required.

Conclusion

Medication non-adherence remains a severe public health challenge that cannot be resolved through the traditional deployment of objective behavioral metrics. This review highlights that patients bound to lifelong pharmacotherapy are not passive vessels; they are active, cognitive agents who construct a highly sophisticated "*lay pharmacology*" to protect the autonomy of their phenomenal body against the existential disruption of chronic disease. To break the historic stagnation in global adherence rates, modern medicine and clinical pharmacy must implement a definitive paradigm shift. Healthcare providers must stop viewing patient-constructed experiential knowledge as an obstacle or a set of "*errors*" to be corrected. Instead, it must be embraced as an essential clinical baseline. By systematically combining the practical insights of Shared Decision-Making, Narrative Medicine, and Critical Health Literacy, clinical teams can safely translate patient meaning-making into tailored, context-appropriate adherence strategies that honor both clinical science and the human lived experience.

Recommendations

For Healthcare Workers: Clinicians and clinical pharmacists must pivot from transactional compliance monitoring to phenomenologically-informed consultations. Using open-ended hermeneutic queries, providers should routinely evaluate the patient's subjective medication experience and map internal illness representations early. When long-term regimens threaten a patient's personal autonomy, clinicians must utilize Shared Decision-Making (SDM) to co-design adaptable schedules. Securing mutual agreement on a modified, slightly sub-optimal regimen that preserves the patient's felt control is clinically superior to enforcing an uncompromising biomedical ideal that inevitably triggers secret, complete treatment discontinuation.

For Patients: Interventions should move away from top-down didactic instruction toward actively fostering critical health literacy. Patients must be empowered to safely monitor somatic feedback, critically analyze therapeutic benefits, and transparently articulate treatment doubts or deviations without fear of clinical judgment.

For Researchers: Academic investigations must break away from reductionist, positivist surveillance frameworks that treat non-adherence merely as a behavioral deficit. Future studies should prioritize qualitative, interpretivist methodologies to investigate the experiential logic of "lay pharmacology" and track holistic composite outcomes that measure both biomarker stabilization and the preservation of patient quality of life.

For Policy Makers: Institutional healthcare guidelines and professional curricula should incorporate explicit training in narrative medicine and hermeneutics to build narrative competence within health systems. Quality-of-care evaluation frameworks must be restructured to incentivize collaborative, patient-centered care models rather than purely punishing clinical teams based on rigid, expert-driven adherence metrics.

Competing Interests

None

Ethical Approval

Not applicable

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