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Self-Management and Knowledge Gaps in Chronic Disease Care: A Phenomenological Study of Patients with Hypertension, Diabetes Mellitus, and COPD in Indonesia

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Abstract

Background: Non-communicable diseases (NCDs), including hypertension, diabetes mellitus, and chronic obstructive pulmonary disease (COPD), remain significant public health challenges in Indonesia. Despite advances in clinical management, patients' lived experiences, particularly regarding disease-related knowledge and self-care practices, have received limited scholarly attention. **Methods:** A qualitative phenomenological approach was employed using focus group discussions and in-depth interviews with 19 participants, including 12 patients with hypertension, diabetes mellitus, and COPD; five primary health workers from community health center; and two district health office staff. The research was conducted between February and June 2024. Data were analyzed using descriptive phenomenological methods. **Results:** Three interrelated themes emerged. First, participants described delayed symptom recognition accompanied by limited initial understanding of their disease. Second, deeply entrenched lifestyle-related risk factors, including smoking, high salt and sugar intake, and physical inactivity. Third, inconsistent self-management practices following diagnosis. Although some participants attempted to adhere to medical advice and adopt healthier behaviors, these efforts were frequently constrained by inadequate health literacy, low motivation, and barriers to healthcare access. Persistent misconceptions regarding disease etiology were evident, reflected in culturally embedded terms such as "sweet urine" for diabetes and "lung pain" for COPD. Family support and religious beliefs were found to exert a dual influence, functioning as both facilitators and barriers to treatment adherence. **Conclusion:** Improving chronic disease outcomes in Indonesia requires the integration of culturally responsive health education, patient-centered communication, continuous follow-up, and health literacy interventions that are aligned with the sociocultural context of affected communities.

Keywords: Chronicity; Self-management; Knowledge; Phenomenology; Primary care

Introduction

Non-communicable diseases (NCDs), including heart disease, stroke, cancer, diabetes mellitus, chronic respiratory diseases, and mental health disorders, are responsible for nearly 75% of deaths globally, with approximately 86% of these deaths occurring in low- and middle-income countries (Ndubuisi, 2021). As the leading cause of mortality worldwide, NCDs pose a significant and growing threat to public health systems, particularly in resource-limited settings such as Indonesia. Among these, hypertension (Putri et al., 2025), diabetes mellitus (Wahidin et al., 2024), and chronic obstructive pulmonary disease (COPD) (Gozali et al., 2025) are increasingly prevalent and impose a substantial burden on individuals, families, and healthcare services. Hypertension has become a major public health concern that contributes significantly to the escalation of healthcare costs. Cardiovascular diseases alone accounted for approximately 19 million deaths in 2021, followed by cancer (10 million), chronic respiratory disease (4 million), and diabetes (over 2 million), including diabetes-related kidney disease (Marthias et al., 2021).

The quality of life (QoL) of patients living with chronic diseases is closely tied to diagnostic accuracy, treatment adequacy, and the ability to maintain physical function and reduce fatigue. QoL encompasses physical, psychological, and social domains that influence a person's ability to perform daily activities, engage in meaningful roles, and maintain mental well-being. In clinical practice, especially within outpatient and rehabilitation settings, assessing QoL has become an essential component of chronic disease management (Ahmed et al., 2022; Alzarea et al., 2024). Notably, the ability of patients to self-manage their conditions plays a crucial role in achieving better health outcomes. However, the success of self-management relies heavily on patients' knowledge and understanding of their condition, treatment regimens, and lifestyle adjustments.

Several studies have highlighted substantial knowledge gaps among patients with non-communicable diseases, particularly in relation to disease causes, symptom recognition, and long-term self-management. For instance, in type 2 diabetes mellitus, patients often demonstrate limited understanding of disease etiology, risk factors, and complications, despite having moderate knowledge of management and prevention strategies. This insufficient knowledge has been linked to poor adherence to treatment and lifestyle recommendations, ultimately leading to inadequate disease control (ElSayed et al., 2023). Similarly, patients with COPD experience frequent exacerbations and functional decline, which significantly impair their QoL. Despite efforts to promote self-management, many COPD patients continue to suffer from persistent fatigue and shortness of breath. A lack of disease-specific knowledge and limited empowerment further hinder their ability to participate actively in care decisions (Patel, 2024; Stöber et al., 2021). Together, these findings underscore that persistent knowledge gaps and limited patient empowerment remain key barriers to effective self-management across chronic disease conditions.

While much has been documented about the clinical aspects of hypertension, diabetes, and COPD, there remains a significant research gap regarding patients lived experiences, their self-management practices, and their understanding of these chronic conditions, particularly in the Indonesian context. Existing literature in Indonesia is largely quantitative and tends to overlook the nuanced, personal, and sociocultural dimensions of chronic disease management from the patient perspective (Lukman et al., 2020; Rai et al., 2020). Addressing this gap requires qualitative inquiry that foregrounds patients' lived experiences to better understand how chronic illness is perceived and managed in everyday life.

Therefore, this study aims to explore self-management practices and knowledge gaps among patients with hypertension, diabetes mellitus, and COPD in Indonesia using a qualitative approach. Understanding how patients perceive and manage their illness, and identifying where knowledge deficiencies lie, is crucial to designing more targeted and culturally appropriate interventions. The findings of this study are expected to inform healthcare providers, educators, and policymakers in improving chronic disease care strategies, promoting patient empowerment, and ultimately enhancing the quality of life for individuals living with NCDs in Indonesia. This study aims to explore the subjective experiences and meanings of patients and health workers regarding self-management practices in the care of hypertension, diabetes mellitus, and COPD through a phenomenological approach. Patient and healthcare worker perspectives were analyzed separately and were collected through face-to-face interviews.

Methods

This qualitative phenomenological study was conducted from February to April 2024. Focus group discussions were conducted with 12 patients and seven health workers. This study adopted phenomenological design as described by Giorgi and Giorgi (Giorgi and Giorgi, 2003). The aim of this method is to capture the essential structure of a phenomenon as it is consciously experienced, without imposing theoretical interpretations. The analysis emphasizes a descriptive rather than explanatory stance, focusing purely on the data to uncover meaning as expressed by participants themselves. Although phenomenology influenced the epistemological stance and research design, the data were analyzed using qualitative content analysis following Graneheim and Lundman. Thematic patterns are derived as part of the analytical process to capture the manifest and latent meanings of the participants' life experiences. According to Graneheim and Lundman, qualitative content analysis is strictly applied as an analytical process rather than as a separate epistemological approach (Graneheim and Lundman, 2004). This analysis is used to systematically organize interview data by identifying units of meaning, condensation, and abstraction. Theme development is treated as an analytical outcome of the content analysis process, aiming to capture both apparent and hidden meanings, rather than as an independent approach.

Data analysis followed five systematic steps. First, all interview transcripts were read in full to gain a holistic understanding of the participants' experiences. Second, the researcher adopted a phenomenological reduction by bracketing personal and theoretical preconceptions, allowing the phenomenon to be re-experienced through the participants' descriptions. Third, meaning units were identified by rereading the transcripts and marking significant shifts in meaning, derived directly from first-person statements to preserve authenticity.

In the fourth step, imaginative variation was applied to reformulate each meaning unit, exploring multiple expressions of the underlying meanings without relying on psychological jargon. Rather than coding, each unit was examined for its relevance in revealing knowledge gaps in chronic disease care. Finally, in the fifth step, transformed meaning units from all transcripts were synthesized into a general meaning structure, representing the essence of participants' experiences. This reflective process allowed for the integration of individual narratives into a coherent and comprehensive understanding of the studied phenomenon (Baklien et al., 2023).

This study was conducted in Pidie district, Aceh province, Indonesia. This is a largely rural area where primary healthcare services are primarily provided by community health centers, also known as puskesmas. This facility serves as the first level of care for the prevention and long-term management of non-communicable diseases such as hypertension, diabetes, and chronic obstructive pulmonary disease (COPD). They serve a defined catchment area through outpatient and community-based services.

The district comprises rural and semi-urban subdistricts, with rural communities forming the majority. Geographic dispersion and limited access to specialized care influence patterns of healthcare utilization and shape patients' experiences of chronic disease self-management as well as interactions with healthcare providers. Pidie District was purposefully chosen to enhance the transferability of the study's findings, as it relies heavily on primary care for chronic diseases management and reflects challenges commonly faced in similar primary healthcare settings across Indonesia.

Participants were recruited using purposive sampling based on predefined inclusion criteria, which is consistent with a descriptive phenomenological approach. Two distinct participant groups were included: patients with non-communicable diseases and primary healthcare providers involved in chronic disease management. The study set an initial target of approximately 15 to 20 participants from various stakeholder groups to ensure adequate representation of perspectives. The principles of data saturation and information robustness guided data collection, and recruitment ceased when no new themes or sufficient depth of information emerged. The final sample consisted of 19 participants, including 12 patients, five community health center (*Puskesmas*) health workers, and two district health office officers. Focus group discussions (FGDs) and in-depth interviews (IDIs) were conducted to collect data. The FGDs involved 12 participants, and the IDIs were conducted with health workers and district health office officers. Each FGD and IDI lasted approximately 60 to 90 minutes.

Patients were recruited through *Puskesmas* in Pidie District. The recruitment process was facilitated by clinicians at the *Puskesmas*, who identified potential participants based on predefined inclusion criteria. Eligible patients were those who had been medically diagnosed with hypertension, diabetes mellitus, or chronic obstructive pulmonary disease (COPD) by a physician, aged between 30 and 70 years, residing within the *Puskesmas* catchment area, and able to communicate verbally. Patients who met these criteria were approached by healthcare staff and provided with information about the study, after which those willing to participate were contacted by the research team.

Healthcare providers were recruited separately through the same *puskesmas*. Inclusion criteria for healthcare providers included having more than three years of experience in the management of non-communicable diseases at the primary care level. This group included nurses and other health professionals directly involved in patient care and chronic disease management programs. The sampling strategy aims to capture the variation in experiences related to the type of illness, duration of illness, and professional roles, rather than to achieve statistical representativeness. Recruitment continues until the strength of the information and thematic adequacy are achieved.

Data from patients and healthcare providers were initially collected and analyzed as separate datasets to maintain the specificity of each group's lived experiences. Subsequently, findings from both groups were examined together to identify common and distinct meanings related to self-management in the context of primary care. To ensure compliance with inclusion criteria and recruitment eligibility, the research team first consulted with the District Health Office and participating primary healthcare centers.

Patients and healthcare workers were sampled separately because they represent different participant groups with distinct roles and experiences. Patients were involved in exploring their lived experiences with and managing chronic conditions, while healthcare providers offered perspectives on service delivery and care implementation. Data from patients and healthcare workers were analyzed separately. The findings were then compared at an interpretive level to identify similarities and differences across various perspectives, supporting triangulation and a more comprehensive understanding of the phenomenon. During the analysis, no data were combined.

Data Collection

The interviews were conducted by the first author. Focus group discussions (FGDs) with patients were conducted using the local Acehnese language. In-depth interviews (IDIs) with healthcare workers were conducted in Indonesian. The FGD and IDI guides were developed based on the research objectives and relevant literature and were reviewed by qualitative research experts. The pilot discussion/interview was conducted to assess the clarity and flow of the questions, resulting in minor improvements before data collection.

The FGD guide was reviewed by a qualitative research expert to assess content relevance, clarity, and suitability for group discussion. Minor revisions were suggested to improve question flow, reduce redundancy, and enhance interaction among participants. The guide was used flexibly during the FGD, with probing questions applied as needed to encourage discussion and depth of response. Data collection continued until thematic saturation and sufficient information strength were achieved, as indicated by the repetition of themes and the absence of new codes.

Each interview session lasted 60-90 minutes. Audio recordings were made by pre-trained assistants, third-year nursing students. The assistants recorded the discussion and observed and documented the process using two digital recorders. Participants were asked open-ended questions on most topics to obtain comprehensive responses on the themes. All audio-recorded discussions were transcribed verbatim. The transcripts were then verified against the original audio recordings to ensure accuracy.

Data Analysis

Data were analyzed using descriptive phenomenological analysis guided by Giorgi to describe participants' lived experiences of the phenomenon. Meaning units relevant to the research question were identified and systematically transformed from participants' everyday expressions into phenomenologically sensitive statements while retaining their original meaning. These transformed meaning units were then synthesized to develop the essential structure of the phenomenon.

The analysis was conducted independently by two researchers and refined through consensus discussions. NVivo 12 was used solely to support data organization and auditability, not to replace the interpretive analytical process. To ensure accuracy, the researchers engaged in reflective bracketing by documenting their assumptions and analytical decisions. Audit trails and peer reviews were used periodically to enhance credibility and transparency.

Results

These findings pertain to the nineteen participants recruited in this study. Twelve participants were patients, and seven were healthcare workers. Participants ranged in age from 30 to 70 years. Most participants were female (61.9%), all were married, and all identified as Muslim. Several participants were no longer working and relied on their children for financial support, while others worked as farmers, laborers, or employees. All participants had received formal education, with ten having completed education up to the high school level.

The results are presented as a general meaning structure derived from all interview transcripts. Three interrelated constituents form this meaning structure and are presented sequentially in the following subsections.

General Meaning Structure of Self-Care Management Phenomenon

Self-care practices emerged after participants became aware of their health conditions. Initially, participants failed to recognize their illnesses and misinterpreted early symptoms as common or temporary complaints.

This limited awareness delayed healthcare-seeking behavior until participants eventually visited a health facility and consulted medical professionals. Following clinical assessment, participants were diagnosed with non-communicable diseases.

Table 1 Transformation of meaning units

Raw Meaning Unit (Participant Quote)	Condensed Meaning Unit	Transformed Meaning (Phenomenological Expression)	Constituent
Initially, I thot it was just a common illness, just fatigue (P7, patient, male, 59 years, self-employed)	A disease considered to be ordinary fatigue	This illness was initially experienced as ordinary physical discomfort and was not yet considered a medical condition.	Facing Illness as a Foreign and Confusing Condition
"Only when I went to the health center did I find out they said it was COPD, but I didn't understand what that was either" (P7, patient, male, 59 years, self-employed)	The diagnosis has been given but is poorly understood.	That diagnosis marked a shift toward medical recognition, but its meaning remained unclear and abstract for the participants.	Facing Illness as a Foreign and Confusing Condition
"If I do heavy work, I get tired quickly, sometimes even dizzy and nauseous" (P7, patient, male, 59 years, self-employed)	Physical limitations during work	The body is perceived as something limiting and unreliable, thus restricting the ability to perform daily work activities.	Living with an Unpredictable and Limited Body
"My lungs have difficulty taking in air, so I often feel short of breath" (P6, patient, male, 65 years, self-employed)	My lungs have difficulty breathing, so I often feel short of breath. (P6)	Difficulty breathing is experienced as a constant physical constraint that affects daily functioning.	Living with an Unpredictable and Limited Body
"Now I'm starting to cut back on smoking and walk too, but slowly" (P3, patient, female, 55 years, farmer)	Partial lifestyle adjustment	Self-care is experienced as a gradual negotiation, not a direct behavioral change.	Negotiating Self-Care Between Habits, Advice, and Personal Meaning
"I take my blood pressure medication, but sometimes I also use traditional medicine" (P9, patient, male, 45 years, self-employed)	Combining medical and traditional treatments	Treatment is considered a selective practice shaped by personal beliefs and perceptions of its effectiveness	Negotiating Self-Care Between Habits, Advice, and Personal Meaning
"I've reduced the salty things, but I can't stop immediately" (P11, patient, male, 48 years, farmer)	Difficulty changing eating habits	Changes in eating patterns are perceived as obstacles caused by long-established habits, not a lack of awareness.	Negotiating Self-Care Between Habits, Advice, and Personal Meaning

Prior to diagnosis, participants commonly reported unhealthy lifestyles, including smoking, irregular sleep patterns, excessive coffee consumption, unhealthy dietary habits characterized by high salt and sugar intake, and exposure to poor environmental conditions such as inadequate sanitation and air quality. These factors were perceived by participants as contributing to disease development and progression. After receiving their diagnosis, participants described efforts to improve their quality of life by modifying dietary practices, adopting more structured daily routines, and reducing behaviors perceived as exacerbating their conditions. Participants also reported increased awareness of how previous unhealthy habits negatively affected their current health status and posed risks for future complications.

The meaning structure of the self-care management phenomenon comprises three interrelated components. The first involves recognition of illness, including symptom awareness and understanding disease characteristics. The second concerns identification of modifiable risk factors, particularly lifestyle behaviors such as diet and smoking. The third relates to self-care management, encompassing health practices, barriers to adherence, and perceived consequences of non-compliance.

Case recognition, symptoms, and characteristics of non-communicable diseases

This component describes how non-communicable diseases developed gradually without participants' initial awareness. In daily life, participants commonly report headaches, excessive fatigue, and neck pain. However, these complaints were not recognized as symptoms of chronic disease. Instead, they were often perceived as normal physical conditions that did not require medical attention. Due to limited knowledge, participants were unable to understand their conditions or engage in appropriate treatment based on disease characteristics.

Participants with hypertension were often unable to recognize early symptoms, reflecting limited understanding of the condition.

> “When I have a relapse of my illness, my head usually becomes dizzy, my neck aches, and sometimes my heart feels like it is pounding. My blood pressure is often above 160, and when I am sick, it never goes down from that level” [P12, patient, female, 51 years, housewife, hypertension].

> “The most common thing I feel is a heavy dizziness, sometimes to the point of near syncope (*hoyong*), then the world seems to be spinning. This usually happens when I am exhausted from work, sometimes accompanied by nausea and flickering vision. I have also experienced a stiff neck and a pounding chest, like a frightened person” [P9, patient, male, 45 years, self-employed, hypertension].

Participants commonly described diabetes mellitus using colloquial terms such as “sweet urine,” indicating limited biomedical understanding of the condition.

> "I used to not know what DM is, all I knew was sugar sickness, some also call it sweet urine [P10, patient, female, 53 years, housewife, diabetes mellitus]"

> "I just feel that my body is often tired and thirsty, sometimes I often go back to the bathroom to urinate at night" [P4, patient, female, 70 years, housewife, diabetes mellitus].

Participants reported limited understanding of COPD and often described it only as respiratory pain. Their knowledge was largely based on informal information from their surroundings, and formal recognition of COPD typically occurred only after consultation with a healthcare provider.

> "I only knew that I had lung disease, then I went for treatment, then the doctor said it was COPD like a breathing pain, tightness if you say." [P65, patient, male, 57 years, labor, COPD]

Participants reported having little understanding of their condition at the onset of illness, which they attributed to limited exposure to information about the symptoms they experienced. After visiting a health facility, participants reported receiving explanations from health workers regarding the symptoms they had experienced.

> "Honestly, I didn't understand at all, at first I thought it was a normal illness when I went to the primary health care centers and they said it was COPD; they explained that COPD is a problem in the lungs" [P5, patient, male, 57 years, labor, COPD].

> "I thought for a long time how come the cough didn't go away. I lost weight drastically and became thin, my appetite decreased, my clothes became loose. Breathing sometimes feels heavy too, especially when doing strenuous activities" [P6, patient, male, 65 years, self-employed COPD].

Perceived Risk Factors and Lifestyle Practices Influencing Disease Management

Participants described several lifestyle practices that they perceived as contributing to the development and progression of their conditions. These practices were often deeply embedded in daily routines and cultural habits, making them difficult to change despite awareness of potential health risks. Participants also reported resistance to dietary recommendations and lifestyle advice, particularly when these conflicted with long-standing personal and social practices.

> “I used to really like salty foods such as salted fish and instant noodles. Foods with *micin* (monosodium glutamate) were my favorites because they were easy and not complicated to prepare” (P12, patient, male, 51 years, housewife, hypertension).

Frequent consumption of sweet foods was a common behavior among participants, particularly the habit of consuming sugary beverages after meals.

> "I like to eat sweet foods, such as sweet tea, cakes, and market snacks. Every time I eat rice, it feels incomplete if I have not eaten sweets"[P2, patient, female, 53 years, housewife, diabetes mellitus]

> “People are unwilling to follow the taboos and recommendations that are suggested. When we give advice, it is always refuted, ma'am. For example, when we tell them to reduce salty or sweet foods, or when we tell them to cut back on smoking and heavy work. They said we could not do it because we were already Acehnese, or that it was just a habit to smoke, and it did not feel good if we did not” [P13, health worker, female, 30 years, Professional experience of health Less than 5 years]

The participant reported a history of heavy smoking during early adulthood, along with a long-standing habit of coffee consumption that was difficult to discontinue.

> "My habit of drinking coffee and smoking is difficult for me to leave because it is a habit from a young age"[P6, patient, male, 48 years, self-employed COPD]

These accounts illustrate how lifestyle practices such as smoking and coffee consumption were deeply embedded in participants’ daily routines and identities, making behavior change particularly challenging. Despite awareness of potential health consequences, participants described difficulty abandoning long-standing habits formed earlier in life, highlighting the tension between knowledge and sustained behavioral change in the management of chronic conditions.

Self-Care Practices, Adherence, and Follow-Up Behavior

Participants perceived that lifestyle modifications and adherence to prescribed treatment did not provide an immediate cure but could slow disease progression, limit organ damage, and improve quality of life. Participants reported efforts to reduce smoking, adopt healthier dietary patterns, and take medications consistently, reflecting awareness that sustained lifestyle changes could prevent further disease deterioration.

> "Mostly I just reduce cigarettes and reduce oily food, so I do not cough and take medicine if I get sick." [P6, patient, male, 65 years, self-employed COPD]

Participants described regular self-care as important in managing their conditions, including routine follow-up visits to health facilities for disease monitoring and sustained lifestyle modifications. Participants also reported a shift from episodic care-seeking when symptomatic to more consistent medication adherence and regular clinic visits

> "Sometimes I take medicine to the nearest clinic, in the past I had never seen a doctor or checked my blood sugar because I didn't think I was seriously ill." [P4, patient, female, 60 years, housewife, diabetes mellitus]"

Participants reported infrequent and reluctant attendance at health facilities due to perceived time constraints and work obligations, indicating limited adherence to healthcare providers’ recommendations.

> “Well, this is the situation, ma’am. In our community, people tend to be reluctant to attend follow-up visits. As I mentioned earlier, they prefer to come to the community health center only when they feel

> symptoms of a relapse. Otherwise, they obtain medicine from pharmacies or nurses, and some even leave the condition untreated. When we recommend a follow-up visit the following week, it is not certain that the patient will return as scheduled. Some patients come back after two weeks, one month, and some do not return for follow-up at all. Even when we visited the village, some people were still unwilling to come to the *Meunasah*, even though we were providing free health check-ups" (P1, health worker, female, 51 years, self-employed, hypertension).
>
> "We also lack adequate media for health education in community health centers [P13, health worker, female, 30 years, Professional experience of health Less than 5 years].

Overall, the findings highlight that self-care practices and treatment adherence were shaped by a combination of individual motivation, structural constraints, and limited health system support. While participants demonstrated growing awareness of the importance of lifestyle modification and follow-up care, sustained adherence was often challenged by work demands, access barriers, and limited educational resources at the primary care level. These experiences underscore the complex interaction between personal responsibility and system-level factors in the long-term management of non-communicable diseases.

Discussion

This study provides a phenomenological understanding of how patients with hypertension, diabetes mellitus, and chronic obstructive pulmonary disease (COPD) in Indonesia experience and manage their chronic conditions within primary healthcare settings. Across disease categories, participants described a shared experiential pattern characterized by delayed symptom recognition, deeply embedded lifestyle-related risk behaviors, and an inconsistent transition toward sustained self-care following diagnosis. These findings suggest that self-management challenges among patients with non-communicable diseases (NCDs) cannot be explained solely by insufficient biomedical knowledge, but rather emerge from the interaction between illness meaning-making, sociocultural norms, and structural limitations within primary care services.

A central finding of this study is the delayed recognition of early symptoms, which often led to postponed healthcare seeking. Participants commonly perceived symptoms such as dizziness, fatigue, chronic cough, or frequent urination as normal conditions related to aging, work exhaustion, or temporary illness. This pattern is consistent with national data indicating that a substantial proportion of individuals with hypertension and diabetes in Indonesia remain undiagnosed until symptoms become severe (Ministry of Health, 2023; Wahidin et al., 2024). However, this study extends previous quantitative findings by showing that delayed recognition is closely linked to how patients interpret bodily changes and construct the meaning of illness in everyday life. Colloquial terms such as "sweet urine" for diabetes or "lung pain" for COPD reflect culturally embedded explanatory models that may limit patients' perception of disease severity and urgency for long-term management, as also reported in other Indonesian studies (Lukman et al., 2020; Rai et al., 2020).

Lifestyle-related risk factors, including smoking, high salt and sugar consumption, and physical inactivity, were deeply integrated into participants' daily routines and social identities. Although many participants acknowledged the health risks associated with these behaviors, behavior change was often described as difficult and inconsistent. This finding aligns with national reports showing persistently high smoking prevalence and unhealthy dietary patterns among Indonesian adults (Marthias et al., 2021; Ministry of Health, 2023). From a phenomenological perspective, these behaviors were not merely individual choices, but socially reinforced practices shaped by cultural norms, economic constraints, and family environments. As a result, health advice that focuses solely on individual responsibility may be insufficient to support sustained lifestyle modification.

Following diagnosis, participants reported increased awareness of their condition and attempts to engage in self-care practices, including medication adherence and dietary changes. However, self-management was often enacted as a fluctuating process rather than a stable routine. Participants described cycles of adherence and non-adherence influenced by symptom severity, work demands, motivation, and access to healthcare services. Similar patterns have been documented in studies of chronic disease management in low- and middle-income settings, where improvements in knowledge do not consistently translate into long-term behavioral change (Patel, 2024; Stöber et al., 2021). This study highlights that partial understanding of disease trajectories and limited follow-up support in primary care may contribute to episodic rather than sustained self-management.

Another important finding concerns the limited effectiveness of health education in fostering functional health literacy. Despite receiving information from healthcare providers, participants continued to hold misconceptions about disease causation and management. This suggests that health education in primary care often prioritizes information delivery over patients' comprehension and contextual relevance. Previous studies have similarly noted that health education materials are frequently generic, overly technical, and poorly adapted to patients' literacy levels and sociocultural contexts (Gozali et al., 2025; Lukman et al., 2020). Moreover, family and religious beliefs played a dual role, functioning as sources of emotional support while at times reinforcing fatalistic attitudes toward illness.

Overall, these findings underscore the need for a shift in chronic disease management strategies within primary healthcare. Effective self-management support should move beyond one-time education toward continuous, culturally responsive health literacy interventions that address patients' lived experiences and evolving understanding of illness. Strengthening patient–provider communication, integrating family involvement, and ensuring consistent follow-up may help bridge the gap between diagnosis and sustained self-care. Such approaches are essential for improving chronic disease outcomes in resource-limited primary care settings in Indonesia.

The Limitation of Study

This study has several limitations that should be considered when interpreting the findings. First, the study was conducted in a single district, which may limit the transferability of the results to other regions with different sociocultural and healthcare contexts. Second, data collected through focus group discussions may have been influenced by social desirability bias, potentially affecting the openness of participants' responses. Third, although patient and healthcare provider perspectives were analyzed separately, interpreting them within shared experiential themes may introduce analytical complexity. Finally, the translation of interviews from the local language into English may have led to subtle loss of meaning, despite careful transcription and verification procedures.

Conclusions

This study demonstrates that patients with hypertension, diabetes mellitus, and chronic obstructive pulmonary disease in Indonesia experience chronic illness as a gradual and negotiated process shaped by delayed symptom recognition, culturally embedded lifestyle practices, and inconsistent self-management following diagnosis. These findings highlight that challenges in chronic disease management are not solely the result of limited biomedical knowledge but arise from the interplay of illness meaning-making, sociocultural norms, and structural constraints within primary healthcare. Strengthening culturally responsive health literacy, enhancing patient–provider communication, and supporting sustained, family-oriented self-management strategies are essential to improving chronic disease care in primary care settings.

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Conflict of Interest

The authors declare no potential conflict of interest concerning this article's research, authorship, and publication.

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