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An interpretative phenomenological analysis of the lived experience of people with multimorbidity in low- and middle-income countries

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ABSTRACT

People living with multimorbidity (PLWMM) have multiple needs and require long-term personalised care, which necessitates an integrated people-centred approach to healthcare. However, people-centred care may risk being a buzzword in global health and cannot be achieved unless we consider and prioritise the lived experience of the people themselves. This study captures the lived experiences of PLWMM in low- and middle-income countries (LMICs) by exploring their perspectives, experiences, and aspirations.

We analysed 50 semi-structured interview responses from 10 LMICs across three regions—South Asia, Latin America, and Western Africa—using an interpretative phenomenological analysis approach.

The bodily, social, and system experiences of illness by respondents were multidirectional and interactive, and largely captured the complexity of living with multimorbidity. Despite expensive treatments, many experienced little improvements in their conditions and felt that healthcare was not tailored to their needs. Disease management involved multiple and fragmented healthcare providers with lack of guidance, resulting in repetitive procedures, loss of time, confusion, and frustration. Financial burden was exacerbated by lost productivity and extreme finance coping strategies, creating a vicious cycle. Against the backdrop of uncertainty and disruption due to illness, many demonstrated an ability to cope with their conditions and navigate the healthcare system. Respondents' priorities were reflective of their desire to return to a pre-illness way of life—resuming work, caring for family, and maintaining a sense of independence and normalcy despite illness. Respondents had a wide range of needs that required financial, health education, integrated care, and mental health support.

In discussion with respondents on outcomes, it appeared that many have complementary views about what is important and relevant, which may differ from the outcomes established by clinicians and researchers. This knowledge needs to complement and be incorporated into existing research and treatment models to ensure healthcare remains focused on the human and our evolving needs.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Multimorbidity is on the rise in low- and middle-income countries (LMICs).
- ⇒ There is a lack of alignment between the priorities of people living with multimorbidity (PLWMM) and clinicians.
- ⇒ The lived experience of PLWMM has been extensively researched in high-income countries; however, there is a scarcity of research on this topic in LMICs.
- ⇒ To enable a more integrated people-centred approach to healthcare for PLWMM, their perspectives and priorities must be understood and incorporated.

WHAT THIS STUDY ADDS

- ⇒ This study captured the experiences of PLWMM in LMICs and revealed that individuals perceived and navigated their lives through the lens of the physical, mental, and social consequences of their conditions.
- ⇒ The burden of treatment was substantial and exacerbated by a lack of coordination among healthcare providers, resulting in duplicated care, increased costs, and confusion for individuals with multimorbidity, potentially exacerbating their conditions.
- ⇒ Living with multimorbidity required individuals and their caregivers to assume significant responsibilities and exercise agency in managing their conditions.
- ⇒ Individuals had a wide range of social, psychological, and practical needs that went beyond their physical health.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Living with multimorbidity is a multifaceted experience that goes beyond the number of health conditions and symptom severity, emphasising the need for a more integrated and people-centred approach to healthcare.
- ⇒ As PLWMM's views about what is important and relevant differ from those established by clinicians and researchers, more efforts need to be made to systematically include their voices in research and treatment models.

BACKGROUND

In low- and middle-income countries (LMICs), there has been a significant increase in the prevalence of multimorbidity.¹ A more integrated and people-centred approach to healthcare is required to meet the long-term and diverse needs of people living with multimorbidity (PLWMM).² However, people-centred care may risk being a buzzword in global health research and cannot be achieved unless we consider and prioritise the lived experience of the people themselves.

Multimorbidity often refers to the presence of two or more co-existing chronic conditions in a person.³ It is a common occurrence, particularly among older adults, and can make the management of a person's health more complex.⁴ Rigorously developed clinical guidelines have improved consistency in treatment, but their focus on single conditions has raised concerns about their adequacy for addressing overall health.⁵ This can lead to single illness 'siloes' that fail to address other conditions experienced by PLWMM. PLWMM may be harmed by the isolated implementation of different guidelines and the risk of polypharmacy, leading to an increased risk of side effects, medication non-adherence due to high treatment burden, and potential drug interactions.⁶ Additionally, clinicians may have difficulty managing multiple, potentially contradictory clinical protocols when treating PLWMM.⁷ The use of clinical protocols for multimorbidity that consider holistic health status, rather than individual diseases, is needed to address these concerns.^{7,8}

There is increasing evidence on the epidemiology and impact of chronic diseases, including multimorbidity, in both high-income and low-income countries.^{9–12} Particularly in LMICs, the burden of disease has shifted towards non-communicable diseases (NCDs) due to the combined effects of demographic ageing and the increased prevalence of key modifiable behavioural risks.^{13–15} This presents a significant challenge for healthcare systems in these countries, which often have limited resources and unequal access to healthcare.¹⁶ Moreover, LMIC health systems are ill-equipped to handle multimorbidity due to fragmentation, and inadequate resources and infrastructure.¹⁷ NCD diagnosis and management are often delayed due to underfunded primary care and a focus on reactive acute care, leading to a lack of continuity of care for these conditions.¹⁷ Consequently, PLWMM in LMICs often experience poorer health outcomes, increased disability and reduced quality of life compared with those with a single chronic condition.^{15 18 19} This is exacerbated by challenges in addressing the wider determinants of health such as poverty, poor living conditions, limited access to education, as well as the ongoing burden of infectious, maternal, neonatal, and nutritional diseases.^{15 18 20}

Despite mounting evidence showing the growing impact of chronic diseases in both high-income and low-income countries, as well as the shifting burden of disease in LMICs, the perspectives of PLWMM remain under-represented,⁵ particularly in LMICs. A systematic

review and qualitative meta-synthesis of the lived experience of mental and physical multimorbidity identified only 19 published studies on this topic, all of which were from high-income countries.²¹ Another review on a similar topic identified 28 studies, none of which were from LMICs.²² A quick online search yielded one study exploring the lived experience of PLWMM in a LMIC, specifically Malawi.²³ The unequal distribution of knowledge on the perspectives of PLWMM between the Global North and Global South is not only negligent, but also unjust and 'an ignoring or rejection of the plurality of knowledge'.²⁴ It is essential and urgent that the perspectives of PLWMM in LMICs are explored, acknowledged, and incorporated into future studies of chronic diseases and multimorbidity.²⁵ Understanding the experiences and perspectives of PLWMM can inform the development of more effective and people-centred healthcare strategies to accommodate the needs, preferences, and cultural contexts of the people.²⁶

It has been found that there is a lack of alignment between the priorities of PLWMM and clinicians; and that prioritisation by PLWMM was mainly shaped by their illness experiences, while clinicians focused on longer term risks.²⁶ Therefore, this study provides an alternative perspective to existing studies that explored multimorbidity outcomes from a clinical perspective. Rather than imposing a preconceived model, our approach aimed to understand and address the unique needs and concerns of PLWMM, starting from their lived experience.

The choice of language reflects the roles and responsibilities we assume for people which can encourage or hinder a shared effort between different groups.²⁷ For instance, the word 'patients' takes away other roles of people as part of the healthcare system, such as producers, who promote and protect their own health.^{28 29} Therefore, this study portrays PLWMM as 'people' with unique characteristics and active participation, rather than solely as 'passive patients' characterised by their health conditions. In doing so, we embrace a perspective that promotes collaborative efforts between different groups.

Aim

This study captures the lived experience of people living with multimorbidity—by bringing in the picture their perspectives, experiences, challenges, and aspirations.

METHODS

Design

In this qualitative study, we conducted a secondary analysis using primary data collected for the project 'Development of a core outcome set for multimorbidity trials in low/middle-income countries (COSMOS)' (online supplemental file 2).³⁰ We analysed 50 semi-structured interview responses from 10 LMICs across three regions (figure 1): South Asia (Afghanistan, Bangladesh, Nepal, Pakistan), Latin America (Mexico, Peru, Suriname) and Western Africa (Burkina Faso, Ghana, Nigeria), using

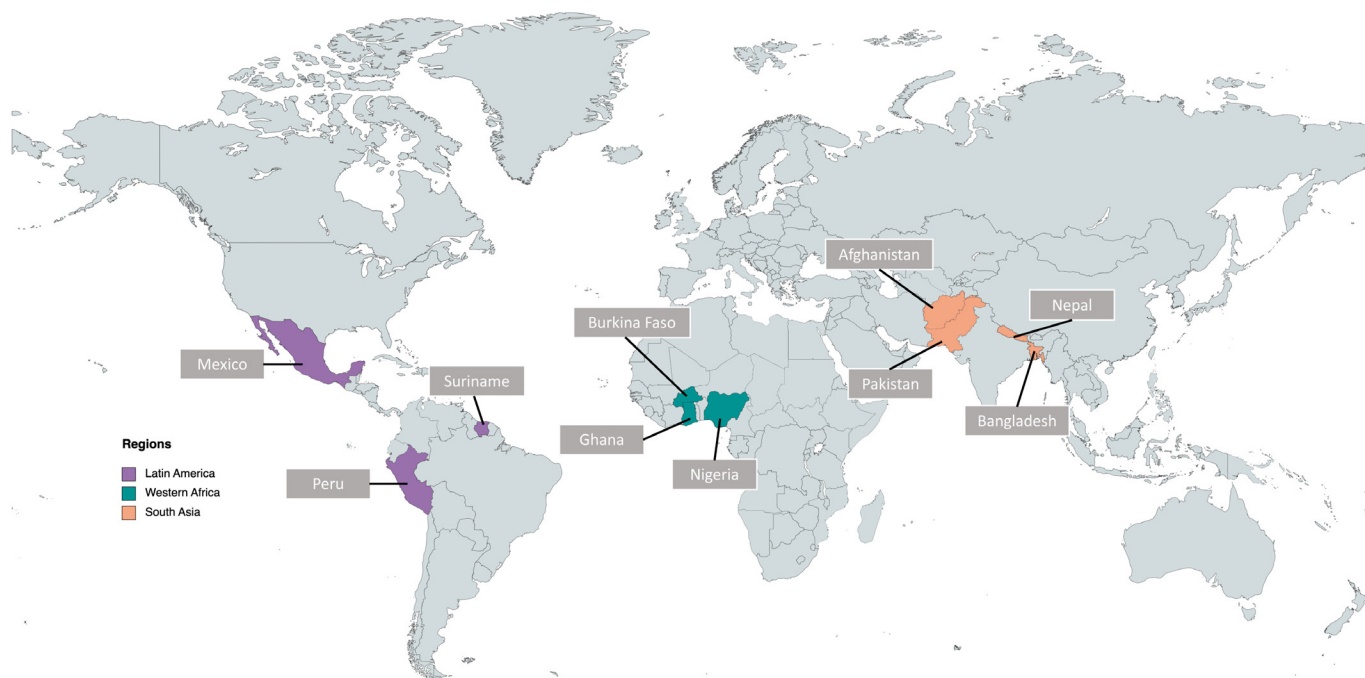


Figure 1 Geographical locations of study settings.

interpretative phenomenological analysis (IPA) with an inductive approach.³¹ The study adhered to the Consolidated Criteria for Reporting Qualitative Research guidelines in its reporting³² (online supplemental file 3).

The phenomenological approach seeks to understand how people experience and interpret the world around them.³³ In our study, we employed this method to explore how individuals and their caregivers encountered illness and healthcare. We examined how these encounters influenced their perceptions of illness, as well as their healthcare-seeking behaviours and self-management strategies. The approach involves studying the daily experiences of individuals while setting aside any pre-existing assumptions that the researchers may have about the phenomenon, especially based on a priori clinical knowledge.³⁴

IPA emphasises the importance of interpreting the data in the context of the individual's unique perspective and emphasises the subjective meanings they attribute to their experiences.³¹ The aim of applying IPA in this context is to develop a rich and detailed account of the respondents' experiences and to gain insight into the challenges and expectations they have in managing their health conditions. This information can be used to inform the development of interventions and policies that are responsive to the needs of PLWMM and can help improve their quality of life.

Applying IPA to secondary data, such as interviews collected for a different research purpose, is a challenging but feasible process. Adapting IPA to secondary data involves a reflexive and iterative process to ensure the data fit our new research question while maintaining the integrity of the IPA methodology. While we did not have control over the original interview process, we still

leveraged the depth of responses, by focusing on aspects such as the respondents' descriptions of their experiences, emotions, and perceptions within the existing interviews.

Study settings

South Asia

The healthcare systems in South Asia face challenges in providing appropriate care for multimorbidity due to a lack of well-developed primary care infrastructure and resources, a shortage of healthcare professionals with expertise in managing multiple chronic conditions, and limited access to healthcare, particularly in rural areas.^{35,36} Social and economic inequalities contribute to the development of chronic diseases making it important to address the social determinants of health to reduce the burden of multimorbidity in the region.³⁷

Western Africa

Similar to the South Asian context, healthcare systems in Western Africa also face significant challenges in providing appropriate care to PLWMM. There is generally a shortage of healthcare professionals, limited access to healthcare, and a lack of continuity of care for patients with multimorbidity.^{38,39} Additionally, the high burden of infectious diseases takes priority over NCDs, resulting in a healthcare system that is not tailored to managing NCDs.⁴⁰ Lack of awareness of NCDs also leads to delayed diagnosis and treatment, poor management and control, and stigma and discrimination against people living with these conditions.³⁹

Latin America

In addition to the characteristics similar to that of the other settings, there are structural and cultural barriers in Latin

America that hamper efforts towards health equity. Political/social instability and the marginalisation of indigenous populations are significant challenges.⁴¹ Political/social instability disrupts healthcare systems, making it difficult for people to access essential health services. Indigenous populations in Latin America face barriers to healthcare, including isolation and discrimination, and may have distinct health beliefs and practices.⁴²

Study participants

Target participants were people over 18 years old with at least two co-existing chronic conditions, and/or caregivers. Participants were recruited through healthcare professionals/services, support and advocacy groups, charities, patient involvement websites, personal contacts, public ads, Twitter ads and other social media. Both convenient and purposive sampling were employed. The study used convenience criteria to select sites in LMICs where the research teams already had partnerships for data collection. Purposive criteria were also used to ensure a diverse sample, including a range of ages (over and under 65), genders, care settings (community/primary and secondary/specialist), and World Bank country income classifications (low-, lower-middle, and upper-middle income). We conducted 50 interviews, with five interviews from each of the 10 countries.

Data collection

Data were gathered through interviews with participants and their caregivers. These interviews were conducted by local health researchers holding Master's degrees from a related field or equivalent experiences. In some cases, the researcher conducted online or phone interviews instead of in-person meetings due to the COVID-19 restriction.

Ethics consideration

Before conducting any in-person interviews, the researchers provided written and verbal information concerning the potential benefits and risks of taking part in the study. This included clarifying the purpose and content of the interview. When they agreed to participate, the researcher read the information sheets aloud to the participant in their home language. Interviews were conducted with participants after they had provided informed consent.

Data collection tool

Basic demographic information was gathered from participants (age, gender, marital status, highest level of education, socioeconomic status, occupation, and disability). A semi-structured interview guide was prepared, which was then translated into the participants' home languages by the local research teams and backward translated to ensure consistency.³⁰ All interviews were audio recorded—and where not possible, contemporaneous notes were taken. The interview guide focused on the perceptions, experiences, and expectations of respondents on daily living and care pathways. The initial analysis of the data was conducted to examine patient perspectives

on health outcomes from the clinical perspective.³⁰ The subsequent analysis reported in this paper concentrated on the broader experiences of individuals with respect to their daily life, healthcare interactions, and aspirations.

Analysis

Data were analysed by a team of six researchers using NVivo V.1.7,⁴³ through three rounds of coding and subsequent discussions. Following a pilot round of coding, the primary author (PBT) developed and shared an open codebook, and organised a joint meeting with all coders to reflect on the initial codes. The codebook was revised and a second round of coding was conducted on 50% of the interviews, which was followed by a meeting to discuss the quality of the coding, preliminary findings, and collectively refine the code tree. The researchers conducted a final round of coding on the remaining interviews. After a final quality control check on all 50 interviews, patterns and themes were identified by the primary author, and a visual representation of the main themes was constructed. A meeting was held to discuss the themes/sub-themes, structure of the manuscript, important insights, and draw meaningful conclusions about the phenomena being studied. Two rounds of revisions were conducted to seek agreement on the final categorisation of phenomena, links between phenomena, and underlying meanings.

Patient and public involvement

At what stage in the research process were patients/the public first involved in the research and how?

Our research team has a broad global and LMIC representation, as well as experiences of working in LMICs. The Core Outcome Set for Multimorbidity Studies (COSMOS) working group supporting the study draws on a network of 38 research teams mainly located in LMICs, that were actively involved in different stages of COS development. We ensured patient, community, and public involvement throughout the development and delivery of the project and included people with lived experience and their caregivers as members in the core research team.

Patients/the public have been involved in the preparation phase as co-thinkers (involvement matrix), in the execution phase as advisors, and in the analysis/writing phase as partners (eg, VJP-A is a patient representative and a co-author).

How were the research question(s) and outcome measures developed and informed by their priorities, experience and preferences?

The project aimed to identify and explore the outcomes that are important to individuals from LMICs who are living with multimorbidity, as well as their families or caregivers. The research questions were designed specifically to gain insights into their perspectives, experiences,

and priorities. In this study, an inductive approach was employed, combined with the use of IPA, to ensure that no pre-existing assumptions or biases influenced the researchers' understanding of the phenomenon, particularly based on prior clinical knowledge.

How were patients/the public involved in the design of this study?

Patients and the public were involved in the design of this study during the preparation phase. They were included as co-thinkers using an involvement matrix approach. Their valuable input and perspectives were sought to ensure that the study's objectives, methods, and outcomes were relevant and meaningful to them. This involvement helped shape the research questions and design, ensuring that the study was patient-centred and addressed their priorities and concerns.

How were they involved in the recruitment to and conduct of the study?

Participants were identified through contacts with relevant healthcare services, support and advocacy groups, charities, social media including Twitter, adverts placed on public and patient involvement websites, snowballing techniques, and personal contacts.

Were they asked to assess the burden of the intervention and time required to participate in the research?

Before conducting any in-person interviews, the researchers provided written and verbal information concerning the potential benefits and risks of taking part in the study. This included clarifying the purpose, content, and the approximate duration of the interview.

How were (or will) they be involved in your plans to disseminate the study results to participants and relevant wider patient communities (eg, by choosing what information/results to share, when and in what format)?

Our co-author (VJP-A), who is also a patient representative, will be involved in the dissemination plan. Plans to disseminate the study results to participants and the relevant wider patient communities will also be further discussed with the COSMOS group.

RESULTS

Respondents' characteristics

Respondents reported having from two to five coexisting conditions, including tuberculosis, asthma, hypertension, diabetes, cardiovascular disease, HIV, cancer, stroke, chronic obstructive pulmonary disease, mental health disorders, and others. The respondents reported having lived with chronic diseases for 2–30 years. Though age was not always reported, most respondents were from 50 to 70 years old. Many respondents reported having jobs/occupations before/during illness, including craftsmanship, farming, teaching, information technology, and other jobs.

Caregivers were present in around 20% of all interviews. All of the caregivers reported to be family members

of the PLWMM; specifically children, children-in-law, husband/wife, and sometimes siblings/siblings-in-law of those living with multimorbidity (LWMM).

Main themes

Interview responses were classified into four recurrent themes (figure 2). Further supporting quotes for each theme can be found in online supplemental file 4.

1. Respondents' illness behaviours, including bodily and social experiences of illness.
2. Respondents' experiences and expectations of the healthcare system.
3. Respondents' agency, including exercising agency or experiencing disempowerment, and expectations.
4. Caregivers' perceptions, experiences, and expectations.

Illness behaviours

The respondents' descriptions of their illness experience extended beyond the number and type of conditions, or even the manifestation of the symptoms on the body. Many expressed their experience of illness on the social aspects, including but not limited to their interactions with others, loss of livelihood and financial hardship.

Bodily experience of illness

Overall, respondents perceived their health as poor, with symptoms such as tiredness, weakness, chronic pain, and in some cases, loss of consciousness. The frequency and severity of these symptoms were used as a point of reference for respondents to assess the effectiveness of treatment. Respondents mentioned various aspects of daily functioning and mobility, with many feeling limited in their ability to walk or move. Further, PLWMM and their caregivers reported experiencing stress, anxiety, depression, and emotional breakdowns. In addition to worrying about their health condition, respondents also emphasised the endless cycle of health seeking, which also has a negative effect on their mental well-being. '*[...] the patient's mental state is destroyed by doing so many tests...*' (B2). They also expressed existential worries, such as the future of their family. '*[...] if something will happen to me then who will look after my family. My family will devastate. I panic about it and now my kidney stopped working*' (N2). Respondents have identified the need for mental health support, such as counselling and emotional support. They recognised that chronic illnesses could have significant emotional and psychological impacts, and that addressing these impacts was critical to helping people manage their conditions and improving health-related quality of life. '*An individual is suffering from financial issues. An individual had engaged in different types of domestic matters, doctors should listen to them talk about the mental health condition*' (P1).

Social experience of illness

Multimorbidity perpetuated a cycle of financial hardship, significantly impacting the social experience of illness (figure 3). Respondents required frequent medical care and medications, which were expensive and difficult to

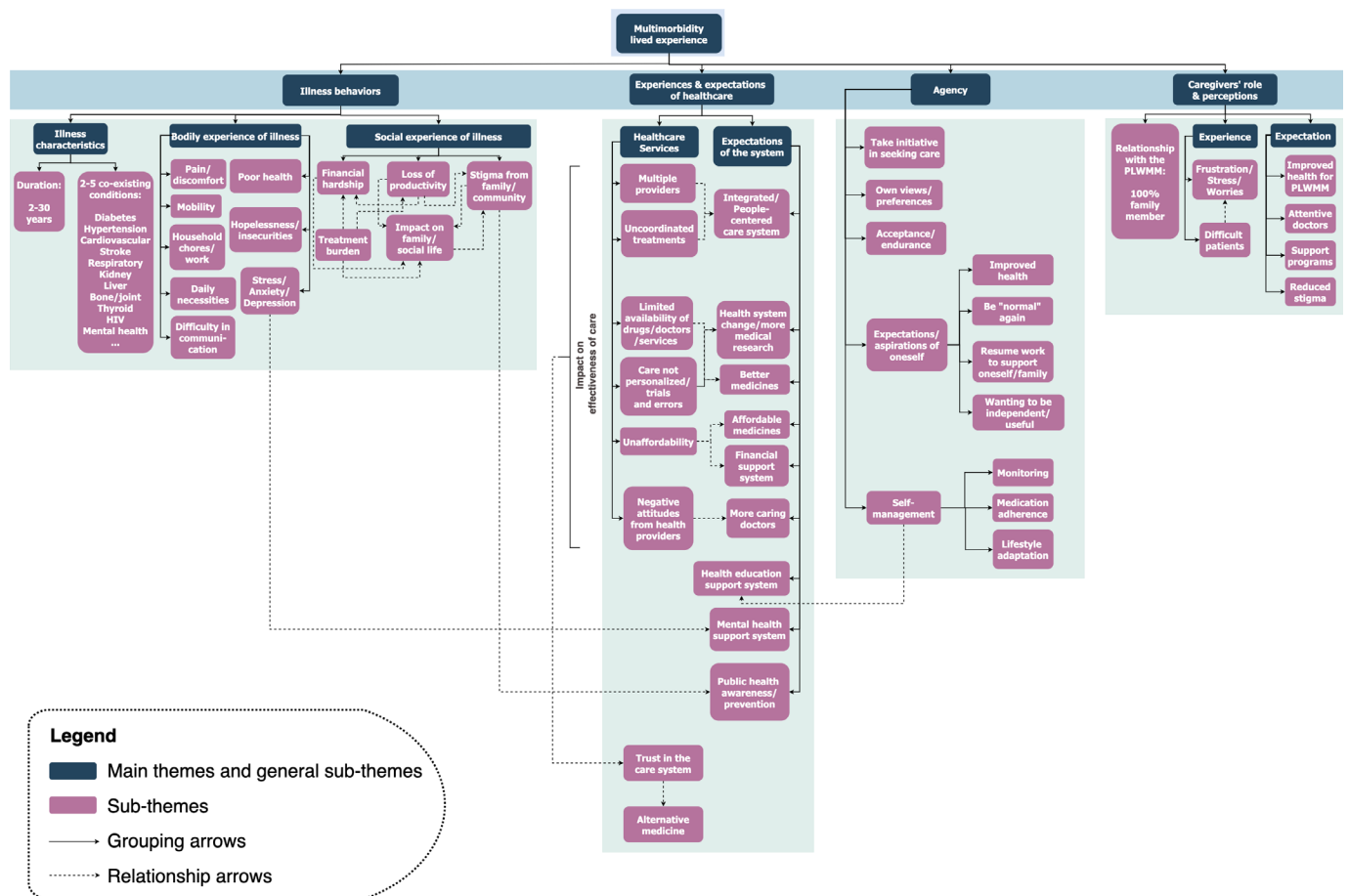


Figure 2 Main themes, general sub-themes, and sub-themes. PLWMM: people living with multimorbidity.

finance. This was exacerbated by the increased cost of seeking care from multiple providers. The extended waiting times, repetitive diagnostics, back-and-forth visits to the same facility due to lack of guidance, and increased transportation costs made healthcare cost prohibitive for many people. ‘For medical treatment, which requires running to different places for testing, there is also a cost, and it’s very difficult to bear’ (B1). Additionally, respondents required additional support and care from family members, impacting their ability to work and contribute to household income, which in turn further exacerbating poverty. Coping strategies comprised: obtaining loans, keeping children out of school, early hospital discharge, and medication abstinence, some of which worsened health status and socioeconomic disparities. ‘It’s hard to maintain farming. I can’t afford people for farming as well. I can’t stay very long at the hospital as I don’t have money to pay. My financial status is very poor because of all these’ (N2). Some respondents mentioned the lack of government support for their healthcare journey, particularly when it came to financing it. Respondents emphasised the importance of financial support to assist with treatments, medications, transportations, accommodations, and other costs associated with accessing care, as well as livelihood support. They also emphasised the importance of equal access to quality medicines, regardless of income. ‘Because of poverty, there is lack of access to treatment so the provision of

either free treatment or at least affordable treatment should be managed from the government level’ (N1).

Both PLWMM and caregivers reported that multimorbidity had a significant impact on their family life, with tension between family members, lack of social interaction, and financial burden being common issues. In some cases, LMM changed a person’s behaviour and personality, hence distancing them from family members. ‘He gets angrier so we have been giving him space and try to keep distance from him’ (P3). Respondents also reported experiencing stigma associated with chronic illnesses. ‘These illnesses had brought untold hardship unto the family, and some of my family members together with some community members try to ostracize me from the house and the community at large’ (G1). Ostracisation stems from the stigma attached to chronic illnesses. Stigma labels and discriminates against individuals due to misconceptions about their conditions, leading to social isolation. This exclusion exacerbated the emotional toll of living with chronic illnesses by undermining a sense of acceptance and worth within their community. Perceived stigma extended beyond family and community to the workplace, and even healthcare professionals. For instance, one respondent recounted losing a job promotion due to health issues. This is indicative of stigma because it implies that the individual faced discrimination or bias in the workplace based on their health conditions, and suggests that the

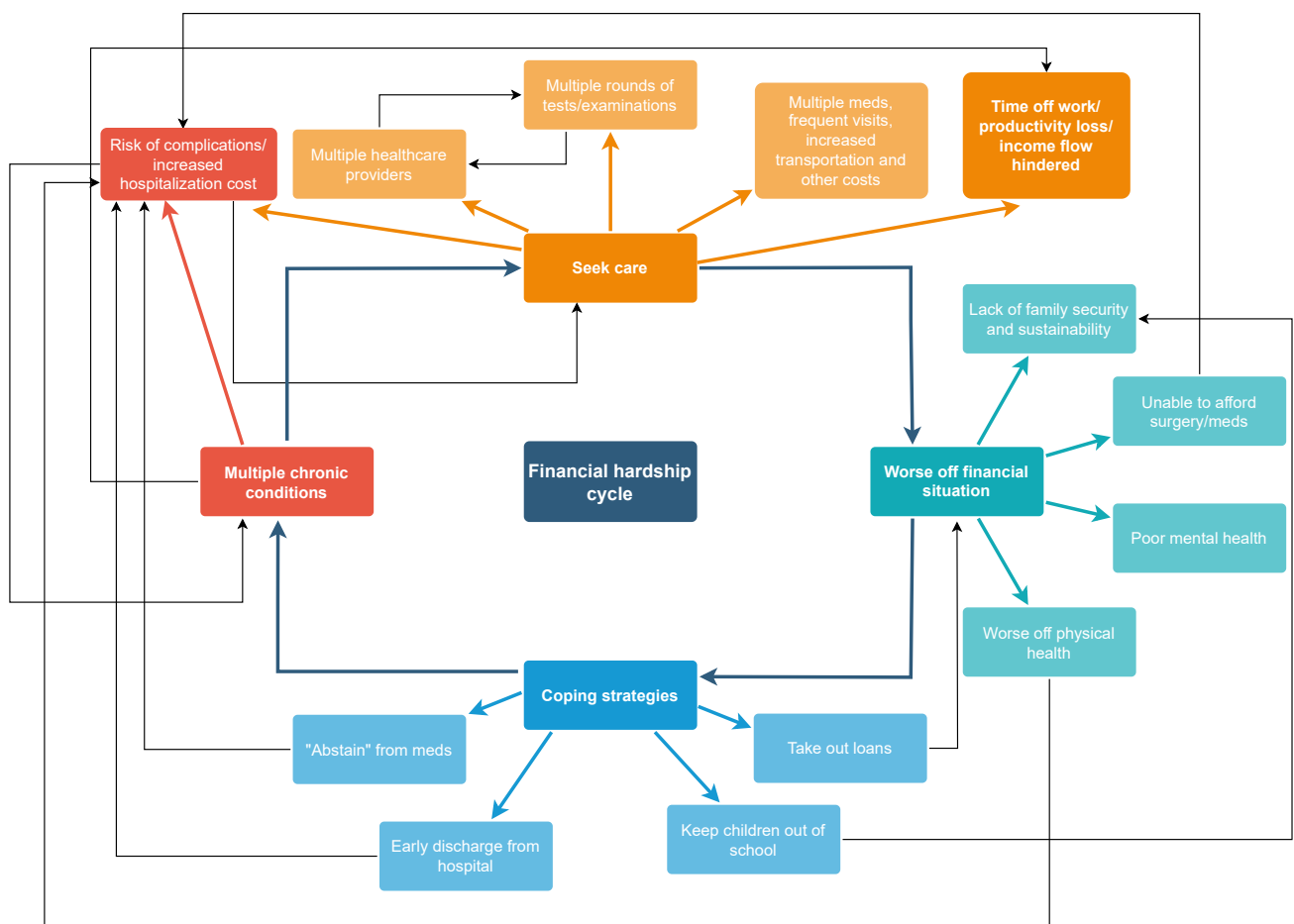


Figure 3 The financial hardship cycles.

employer or decision-makers may have held negative stereotypes or judgements about the individual's abilities or reliabilities due to their illness. *I was definitely going to be promoted to be the General Manager. During that time, heart problems came up. [...] I was the senior out of five; four of them were given promotions and I wasn't* (B4). Other experiences with workplace discrimination entailed challenges in taking time off work to attend medical appointments or being rushed to retirement due to chronic illnesses.

Experiences with and expectations of the healthcare system

Respondents reported a multitude of challenges when it came to their experiences accessing the healthcare system, for which they had clear expectations. These experiences shaped their perceptions of the effectiveness of care as well as the level of trust or mistrust they had in the health system.

Multiple providers and uncoordinated treatment

Respondents often had a hard time navigating the healthcare system and had to visit multiple healthcare providers throughout their care journey. A lack of coordination—with inconsistent advice and unclear guidance from different healthcare providers—created confusion. Additionally, visiting multiple healthcare providers

sometimes led to a wrong/delayed diagnosis or adverse effects of medications. Respondents shared that their treatment regimens were uncoordinated between the different specialists who managed their different conditions, creating confusion. *They pass us to the residents, the R3 or the R2. One day one sees me, and the other day another one. One tells me to take 1½ pill, and the other (tells me to take) 1¼* (M5). Respondents have stressed—in their own words—the need for an integrated and patient-centred approach to healthcare, which focuses on the person's individual needs and goals. They suggested that this approach would improve communication and coordination among healthcare providers as well as between care seekers and care providers, which can lead to better health outcomes.

I believe that few people really have comprehensive care. I believe this is what is missing. How can you integrate different medical specialties to see a patient as a whole, not a heart or a brain. One heart, then you're only a cardiologist; one brain, then you're only a neurologist. See it as a whole, create multidisciplinary groups, include the emotional part, the nutritional part, to really have a complete approach of the person. I believe those who receive a multidisciplinary approach, they do better. (M2)

Effectiveness of care

The respondents' perceptions of the treatment effects were often 'little improvements' and 'temporary relief only'. Respondents also reported that not all healthcare providers had the right expertise and there was a lack of specialists, especially in public health facilities. Many respondents felt that their treatment was a process of trial and error. In some cases, the doctor repeatedly adjusted their medications in an attempt to find something that worked. Additionally, with every change in treatment plan, further testing and analysis were required. *'There was one I was taking, they just changed it. They gave me this and another one that's not here. It was yesterday. They now gave me this one'* (NG1). Others reported to have received 'mass medication' while they believed that personalised treatment plans would better address their unique needs and symptoms.

[...] They gave me the same pill for 10 years, they gave me a lot of little boxes so that I didn't return in 6 months, but there was never a formal follow-up from the doctor [...] Then I got used to the high blood pressure, to the cough, to those headaches, as if they were part of my every day. And I was like that for 10 years. Then, when I got more specialized care in cardiology and endocrinology, well everything changed completely. (M3)

Respondents would like to see improvements in healthcare for chronic diseases through innovative medical research and alternatives to daily medication, such as a *'one-pill solution'*. Respondents desired better access to new effective medications, generic versions of expensive drugs, specialised therapies such as kidney transplant, transparency in treatment costs and options, and financial support. This would allow them to make informed decisions about their care without being limited by financial constraints. *'In other countries there are other drugs that of course are very expensive here, but they do solve problems, but that would be in other countries, in Europe perhaps, in the first world, but as we are in the third world...'* (PE2).

Negative attitudes from healthcare providers

Respondents encountered difficulties in accessing healthcare, often due to bureaucracy. *'They treat it like police investigation. Like go here and there, sit here and there, stand here and there [...]'* (P1). Some healthcare providers were reported to have exhibited dismissive or rude behaviour, a lack of empathy, unclear communication, and not taking the concerns of patients and their caregivers seriously. *'Our doctors [...] do not understand the patients' situation. They always speak bitter and are always in anger with patients. They don't give us the chance to complete the conversation'* (P2). Respondents preferred doctors who are compassionate, polite, attentive and respectful, who have positive attitudes and understand the challenges of living with chronic illnesses. They preferred doctors who would take the time to listen to their concerns, explain their condition and treatment options clearly, and involve them in decision-making. *'Doctors should treat patients politely. When doctors do this, half of the patient's disease is gone*

and when doctors talk to the patients rudely, they become more anxious and upset' (P5).

Trust in the healthcare system

In general, the level of trust that respondents had in the healthcare system was influenced by various factors, including past experiences navigating the multi-provider system, perceptions of the effectiveness of their treatment, attitude of the healthcare providers, and religious or cultural beliefs. These factors shaped their perspectives and attitudes towards the healthcare system and the treatment options on offer. A few respondents expressed their mistrust in the healthcare system. *'Sometimes so many investigations are done because they want to grab the money, because all those who are in high power, only steal, and steal, and steal and do nothing...'* (PE4). Due to those loopholes in the healthcare system, respondents sometimes resorted to complementary/alternative treatments (eg, medicinal plants, homeopathy, yoga and meditation, spiritual healing), which was common in South Asia. Respondents recognised the importance of community-wide efforts to address chronic diseases and believed that preventative screenings and policies promoting healthy environments could play a role.

Respondents' agency

Patient agency encompasses a patient's autonomy, self-determination, and the extent to which they can exercise control over their healthcare journey. Despite the various disruptions caused by illness, many respondents demonstrated resilience and proactivity in coping with their health conditions. They took initiative in seeking care and information, expressed their own views and preferences regarding their treatment and needs, engaged in self-management, and displayed self-reflection and self-assurance.

Proactive in seeking care/answers

Many respondents felt responsible for adhering to their treatment regimen and took initiative to find answers to their health problems. One person even created an application to help self-manage their conditions. Many made efforts to understand their conditions and treatment options and asked questions to better understand their needs.

I take care of myself, that is what I try to do. My sister tells me 'Hey you are always at the doctor'— and I tell her — '[...] but if something hurts, I have to go, [...] it is good, now I know what I have.' [...] When a doctor examines me, I tell him about the rectum tests I did before. Why? To help him save time, to make an early diagnosis that allows me to have at least 10 more years of life. (M5)

Own views/preferences

Respondents had their own views and preferences regarding treatment options. Though many hoped for better and more affordable medicines for their conditions, what most respondents desired was actually to

reduce medication intake for fear of adverse effects and toxicity. Some expressed a preference for non-pharmacological treatments, such as exercise, dieting, and lifestyle changes, in addition to or instead of medications, because they believed that these alternatives were less harmful and likely to cause side effects.

Self-management of illness

Respondents acknowledged the challenges associated with the self-management of illness. Dietary restrictions ranged from avoiding certain food to extreme diets with abstinence. Some respondents also had to forego movement, while others had to increase light exercise. Respondents understood the importance of taking medications regularly, but the challenge of adhering to self-management routines on a daily basis persisted due to having multiple conditions and the concerns for potential side effects. Regular monitoring of health indicators was particularly common among those with diabetes and/or hypertension, ranging from three times per day to once every two weeks. Some respondents expressed that technology/telemedicine can support them in monitoring their health indicators, adapting to changes in their lifestyle, and communicating with healthcare providers. *‘It would be good to have a telephone support line [...] to generate a*

little more peace of mind with information could be a good option’ (M2). Both respondents and caregivers stressed the need for accurate information about their conditions, as well as information on how to manage their symptoms and maintain a healthy lifestyle. They wished to be informed about the causes of their symptoms, the rationale for certain tests, and the effects of their medications. This could increase the sense of control over their health, lead to better self-management, and enable them to take an active role in their care.

I believe that there has to be much more information readily available to the patient. With my sister, when the doctor tells her something, she immediately tells me, then I explain it to her, make it easier for her to understand, and that makes her feel calmer. I think that is what is missing... (Caregiver-M2)

Expectations of oneself

Respondents also asserted their agency by expressing the desires and aspirations in their lives. [Figure 4](#) maps the linkages between ill health and changes in the lives of the respondents: illness-induced restricted mobility hindered daily life, requiring dependency in care, which triggered a feeling of burdening others and shifts in self-perception.

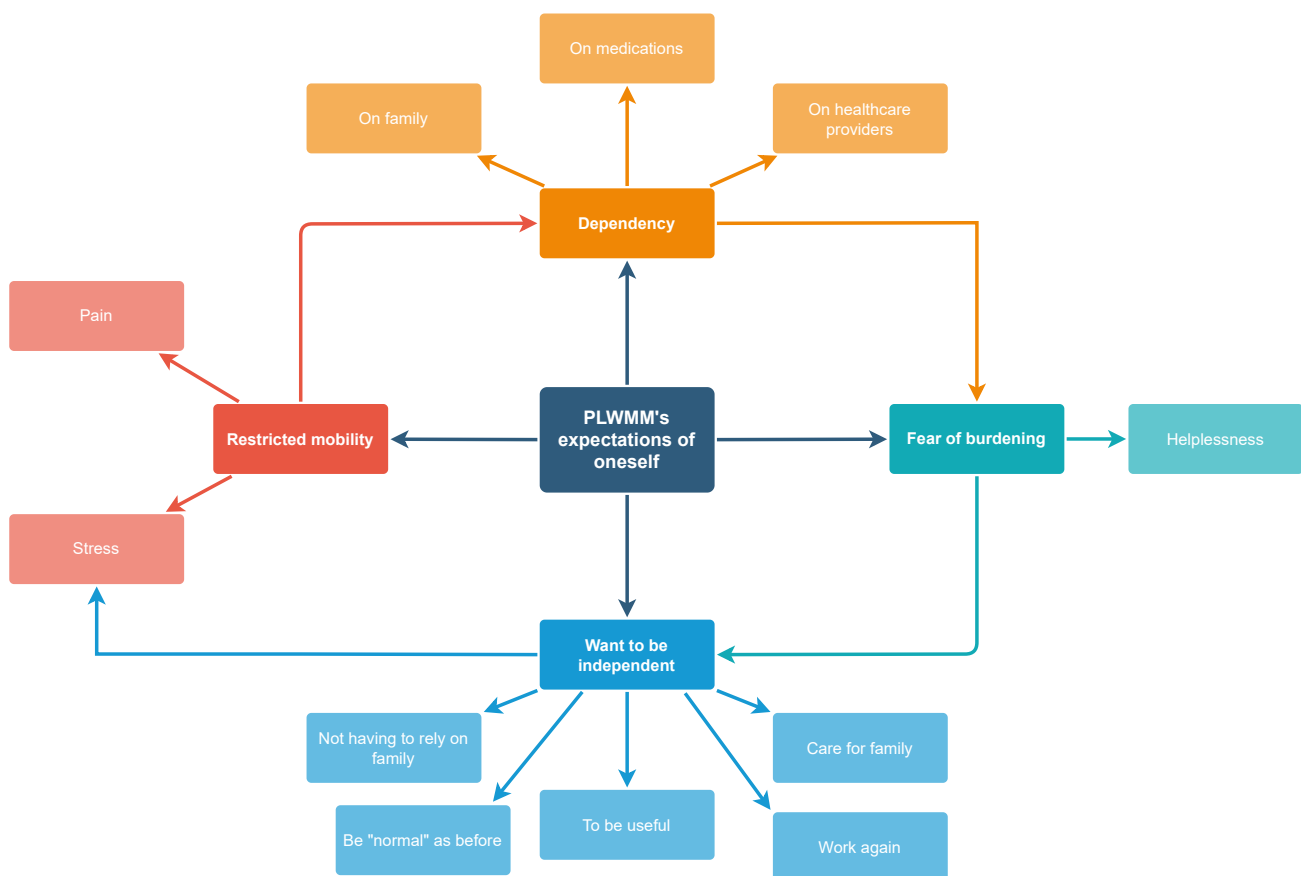


Figure 4 Respondents' expectations of themselves. PLWMM, people living with multimorbidity.

Consequently, this process shaped respondents' self-expectations, potentially increasing stress levels.

The aspirations of the respondents were interconnected and influenced by both their physical and mental states. The expectations and priorities of respondents could vary greatly depending on the individual and the specific chronic illnesses they were living with. Some prioritised the effective management and control of their symptoms, while others' priorities were expressed through the reminiscence of what they considered their 'normal' lives were before the illness: being able to work in the garden, feeding the cows and chickens, being able to go back to work and take care of the family. Many of the respondents were once head of the household, and they deemed it important to resume their means of livelihood and be able to support their family. *'I am a skilled carpet weaver and knitting expert. I want to start my work to help my family'* (A3).

Respondents were concerned about being a burden on their family, particularly those who relied on family members for care. The physical experience of illness made them feel dependent, which led to feelings of helplessness and being a burden to others. In general, individuals expressed a desire for increased independence and autonomy, seeking reduced dependency on allopathic treatment, healthcare providers, hospitals and family for support. Instead, they longed for greater inclusion in social and family circles and to be seen as useful.

Endurance/acceptance

While many respondents hoped to recover from their illness, most were often realistic and practical when it came to managing their expectations. They understood that their conditions were long term and, in many cases, not possible to be cured completely. Thus, they focused on the management and control of their symptoms and improvement of their quality of life. *'Everything will continue as usual. These are the things I want. But now it is seen that they do not happen. The fact that I will be well after taking medicine cannot be expected'* (B2).

Caregiver's experiences and expectations

Caregiver's perceived roles

Caregivers of those with chronic illnesses recognised their role in managing the conditions through providing care within and outside of the home, using personal and financial resources, treating the patient with compassion and respect, and ensuring adherence to treatment regimens. It is common for family members to be the primary caregivers for PLWMM in LMICs, particularly in collectivist societies where there is a strong emphasis on family and community support. Caregivers also acknowledged the challenges and demanding role of providing care for PLWMM. They noted that PLWMM could be 'unpredictable' and might at times experience mood swings and behavioural changes. Caregivers also needed to stay vigilant in monitoring for any signs of emergency healthcare needs and ensuring adherence to the treatment plan,

while attending to other aspects of the caregiver's own life. While most provided emotional and practical assistance, a few PLWMM reported frustration due to neglect. *'Family members that I had taken care of were not there for me during my illnesses'* (B4).

Caregiver's mental state

Assuming the caregiver role also led to experienced stress, frustration and anxiety due to the challenging, time-consuming, and financially demanding nature of caring for PLWMM. Caregivers faced many of the same barriers and challenges as PLWMM, such as difficulty accessing healthcare and concerns about the quality of care.

I am a human being, not a robot. I get upset, frustrated, annoyed and sometimes rude to my father. In our culture, we hardly disrespect our elders but I found it very hard to control my feelings. Our family also get disturbed because of unstable income flow that hinders his treatment. It's very disturbing that we haven't seen any improvement in his conditions. (Caregiver-A1)

Caregiver's expectations

The effective treatment for family members LWMM and the improvement of their mental, physical, and overall health were top priorities for caregivers. Additionally, ensuring financial stability to support the family members LWMM also emerged as a high priority. Caregivers also wished to see improvements in the healthcare system, with more attentive and compassionate doctors, more support programmes and resources for caring for PLWMM, and efforts to reduce the stigma associated with chronic illnesses. *'We also need to understand what is happening to our family member. We need information that's easy to understand, about what to expect, what to do, something of the sort'* (Caregiver-M2).

DISCUSSION

This study explored the lived experiences of PLWMM in selected LMICs. The primary findings can be summarised into three key points:

- ▶ Respondents experience their life through the lens of their physical, mental and social consequences of their conditions.
- ▶ The treatment burden is significant due to the lack of coordination among healthcare providers, resulting in duplicated care, increased costs and confusion for respondents, which can sometimes worsen their conditions.
- ▶ LWMM requires individuals and caregivers to take on significant responsibilities and actively manage their conditions, while also fostering the pursuit of their goals and aspirations.

There have been demands to broaden the biomedical perception of multimorbidity, which mainly focuses on the medical aspect, to encompass a broader understanding of the complexities of dealing with multiple

health conditions.^{21 44} The biopsychosocial model of health and illness suggests that health outcomes are not determined by a single factor, but by the interactions among people's genetics, mental health and behaviour, and social and cultural contexts.⁴⁵ In the context of multimorbidity, the *bodily, social, and system experiences of illness* are multidirectional and interactive, and largely capture the complexity of LWMM.⁴⁶ While acknowledging the importance of both physical and mental health, our study found that respondents tend to evaluate the effectiveness of their treatment primarily based on the improvement of somatic rather than cognitive symptoms. Some cultures may attach a stigma to discussing mental health problems openly, associating them with shame or moral failing.⁴⁷ Inadequate recognition of these concerns within healthcare systems⁴⁸ and the perceived power distance with therapists, for example, in Southeast Asia, further discourage patients from seeking help for their mental well-being.⁴⁹ Some respondents did, in their own ways, express concerns beyond physical symptoms. The significance of addressing mental health was evident in respondents' expectations of healthcare staff to receive training in emotional management and demonstrate kindness. Additionally, they believed that a positive home environment could exert a more substantial influence on health improvement than medication alone. The concerns of the respondents with mental and social sequelae of multimorbidity and their expectations of healthcare providers clearly illustrate the need for a more holistic approach to healthcare. The health system, family, and community can all provide a collective effort in making care more people-centred, which may include providing workshops on disease management, emotional support, healthy coping strategies, and community-based programmes, such as support groups or peer counselling.

The interviews with respondents revealed their *experiences and expectations of the healthcare system*. In the study context, financial hardship is evident and while healthcare is often expensive, it is fragmented and lacks personalisation. According to the World Health Organization, universal health coverage (UHC) is essential in ensuring that all individuals have access to quality health services without experiencing financial hardship.⁵⁰ The study reveals that more needs to be done in order to achieve UHC for people with complex care needs such as PLWMM. The exorbitant cost of treatment is not solely attributed to steep fees; it is exacerbated by the substantial treatment demands. Consequently, health disparities emerge, with unequal access to healthcare. While a few can afford private healthcare, others resort to drastic measures like taking loans, preventing their children from attending school or even abstaining from medications. The financial burden—also can be coined as 'financial toxicity'⁵¹—extends beyond medical care and medications, loss of productivity, and extreme coping strategies; it is exacerbated by navigating care from multiple providers, extended wait times, and repetitive diagnostics. The lack of guidance on where and when to

seek care for what, as well as poor provider–provider/provider–care seeker communication, and negative attitudes from care providers, creates confusion and frustration for PLWMM and their caregivers. In addition to the fragmented public/private healthcare system, some respondents, for example, in South Asia, sought alternative therapies, which further compound treatment burdens and care-seeking complexities. In many countries, cultural and historical practices have perpetuated the use of alternative healing methods alongside modern healthcare. In essence, the utilisation of alternative therapies and traditional medicine is a compelling contextual issue that weaves a complex tapestry within the larger narrative of healthcare-seeking behaviours. It highlights the need for a comprehensive understanding of healthcare dynamics, where patients are not merely passive recipients but active agents navigating a diverse spectrum of treatment options. Recognising and respecting these choices, while addressing the underlying factors that drive them (eg, dissatisfaction with conventional healthcare and negative health staff attitudes), is essential for promoting holistic patient-centred care systems. The risks and consequences of fragmented care on both a system and individual level, especially in the context of multimorbidity, have been observed universally in both high and low-income contexts.^{52 53} To improve the quality of care and enable integrated people-centred care, several approaches can be taken, including promoting care coordination and communication, incorporating technology, providing education and training for healthcare providers, increasing patient engagement and involvement,⁵⁴ ensuring cultural competence in healthcare, and addressing social determinants of health.

Patient agency is one of the important findings of this study. Despite all the disruptions stemming from illness, many respondents displayed an ability to cope with their health conditions and manoeuvre through the healthcare system. Indeed, people with health problems experience a loss of agency on a certain dimension of their life (eg, bodily health), but continue to exercise agency in a different way on that same dimension or across other dimensions of their life (eg, social-relational dimension).^{55–57} According to the model of agency in illness, people practise their agency in four different ways: by rescaling a single dimension, shifting across multiple dimensions, embedding dimensions within one another or submitting to certain limitations.⁵⁸ However, agency is dynamic; and cultural and social contexts may foster or hamper patient agency. For instance, diverse cultures in Australia, Canada and the USA often delay seeking healthcare compared with the majority community.^{47 59} Similar trends have been observed in general populations across LMICs in Asia and Southeast Asia.⁴⁷ Moreover, when agency does exist, it may manifest differently due to cultural and systemic factors. In the contexts studied, patients frequently have limited involvement in healthcare decision-making, and information provision is often inadequate. Consequently, many respondents

and their caregivers have expressed a strong desire for improved information about their conditions and available treatment options. Systemic barriers in these countries—such as healthcare systems prioritising efficiency over people-centred care and marginalised communities facing language or access barriers—can hinder people's agentic involvement.⁶⁰ However, there is growing evidence that involving patients in decision-making can lead to better health outcomes, increased patient satisfaction, and improved adherence to treatment.⁶¹ The three-step model entailing choice talk, option talk, and decision talk—a process of deliberation that takes into account individual preferences and values—may be a good starting point.⁶²

This study differs from others in that it focused on *the respondents' priorities* and on the internal aspects; for example, the respondents' shifting mindset and self-perception. Specifically, it described the internalisation of the various socioeconomic experiences that shaped PLWMM's priorities. Multimorbidity can affect people's social identity by forcing them to make choices about work, leisure, and lifestyle, which can have adverse implications on their sense of self.⁵ A considerable strand of data speaks to their longing of maintaining a sense of independence and normalcy in daily activities despite illness, such as resuming work and caring for their families. Pursuing normalcy is a common goal, but normalcy can be challenging to define. LWMM involves constant fluxes of change and adaptation, and adjusting one's self-perception is a necessary coping mechanism.⁶³ This process of continual adjustment is known as the 'emergent present',⁶⁴ as individuals navigate the shifting reality and cope with the demands of their condition. The uncertainty and constant change in themselves are the 'new normal' for PLWMM. This phenomenon aligns with the shifting perspectives model of chronic illness that suggests PLWMM may place illness in the foreground or the background of their 'world', depending on the context.⁶⁵ For instance, our study found that many respondents adapted to change, such that it became normal. '*All the time I had a lot of coughs, I saw it as a chronic issue, I lived with coughs*' (M3).⁶⁶ In addition, many expressed a desire for greater independence and autonomy over their own lives, which included being less reliant on doctors, hospitals and family for support, but greater inclusion in social and family circles. In the theory of social identity, it is found that illness compromises the valued social identities of PLWMM in some ways, resulting in a conflict between managing symptoms and maintaining control over social roles.^{46 67} In Asia, Africa, and Latin America, collectivist cultures predominate.⁶⁸ Within these cultures, individuals often attribute personal strength to external sources such as faith in God, family and friends, rather than emphasising internal or personal attributes.⁴⁹ Furthermore, the primary motivation often revolves around the betterment and actualisation of family members rather than oneself. In times of adversity, people within these cultures commonly cope by providing comfort to others,

staying engaged in various activities, and volunteering to assist those in need.⁴⁹ Indeed, the well-being of family and caring for family are recurrent themes that cut across the respondents' aspirations in their lives. In accordance with literature, some respondents in our study expressed a tendency to feel excluded and perceived themselves as unequal contributors compared with others.^{46 69} Examining respondents' priorities reveals the intricate layers of complexity that characterise multimorbidity, where their aspirations centred on reclaiming a sense of normalcy and regaining their independence and social identity.

Limitations and strengths

Our study is a secondary analysis, conducted using primary data collected for the larger COSMOS project on core outcomes. Hence, some relevant topics to this study could not be explored in further detail. IPA on secondary data offers the advantage of leveraging existing in-depth narratives and contexts; it saves time and resources compared with collecting new data, and is especially valuable when the existing data already contain rich narratives about respondents' experiences. It adds value by uncovering new themes that may not have been the primary focus of the original research, providing a nuanced understanding of the phenomenon, contributing to the existing body of knowledge, and adding depth and nuance to the analysis. However, we acknowledge our position as secondary data analysts and have also discussed in the team the limitations of using secondary data and how they might affect the validity of the findings. Further, we did not personally collect the data, relying instead on translations, which may have limited our ability to fully grasp nuanced and non-verbal information conveyed during the interviews. Moreover, there may be language barriers and cultural elements that could limit the authors' abilities to fully comprehend and interpret the meanings and contexts of the data. The interviews were relatively short, and respondents may have felt limitations in providing a complete picture of their experiences.

Despite similarities in experiences across contexts, it is crucial to acknowledge the diversity and nuances within LMICs. Contextual factors, for instance, reluctance to voice or religious belief, can influence participants' experiences, decisions, and responses. Our approach hinges on the collection and presentation of personal narratives and underscores the importance of embracing a multiplicity of perspectives, demonstrating how similar ideas can be perceived and moulded differently across diverse geographical, temporal, and hierarchical contexts. This extends beyond the traditional 'Global North/South' dichotomy and transcends boundaries even within these regions. We acknowledge and celebrate the intricate tapestry of perspectives that enrich our understanding of these critical challenges, and we recognise that local, cultural knowledge and nuanced interpretations must form the cornerstone of our research and practice in the realms of global health and person-centred care.

The strength of our study lies in the diversity of our study population—from 10 LMICs across three continents. The study is relatively novel in that it is centred around the lived experience of PLWMM. By adopting a phenomenological approach, the study was able to capture the subjective experiences of these individuals and highlight the importance of understanding their perspectives, in light of promoting intersectoral partnership in healthcare.

CONCLUSION

This study captured the experiences of LWMM in LMICs and revealed that individuals perceived and navigated their lives through the lens of the physical, mental, and social consequences of their conditions. The burden of treatment was substantial, exacerbated by a lack of coordination among healthcare providers, resulting in duplicated care, increased costs, and confusion for individuals with multimorbidity, potentially exacerbating their conditions. LWMM required individuals and their caregivers to assume significant responsibilities and exercise agency in managing their conditions, while also facilitating the pursuit of their goals and aspirations. Individuals had a wide range of social, psychological, and practical needs that went beyond their physical health.

LWMM is a complex experience that involves more than just the number of health conditions and symptom severity. It also includes psychosocial issues that occur amidst constant uncertainty and change. In discussions with respondents LWMM on outcomes, it appeared that these individuals had complementary views about what is important and relevant, which may differ from the outcomes established by clinicians and researchers. This knowledge needs to complement and be incorporated into the existing research and treatment models to ensure healthcare remains focused on the human and our ever-changing needs.

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