Illness representations of Chronic Obstructive Pulmonary Disease (COPD) to inform health education strategies and research design – learning from rural Uganda

Emily M Nagourney MSPH[1,2], Nicole M Robertson [2,3], Natalie Rykiel MSc[3], Trishul Siddharthan MD[2,3], Patricia Alupo MBChB, MMED[4], Marysol Encarnacion MSPH[1], Bruce J Kirenga MBChB, MMed[4,5], Robert Kalyesubula MBChB, MMed[6], Shumonta A Quaderi MBBS, BSc[7], John R Hurst PhD, FRCP[7], William Checkley MD, PhD[1,2,3], Suzanne L Pollard PhD[1,2,3], GECo Study Investigators.

1. Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA
2. Center for Global Non-Communicable Disease Research and Training, Johns Hopkins University, Baltimore USA
3. Division of Pulmonary and Critical Care, School of Medicine, Johns Hopkins University, Baltimore, USA
4. Lung Institute, College of Health Sciences, Makerere University, Kampala, Uganda
5. Department of Medicine, College of Health Sciences, Makerere University, Kampala, Uganda
6. Department of Physiology, College of Health Sciences, Makerere University, Kampala, Uganda
7. UCL Respiratory, University College London, London, UK

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Correspondence:
Suzanne L Pollard
Email: spollard@jhu.edu
Phone: 703-927-5566

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Abstract

More than 90% of COPD-related deaths occur in low- and middle-income countries (LMICs); however, few studies have examined the illness experiences of individuals living with and providing treatment for COPD in these settings. This study characterizes illness representations for COPD in Nakaseke, Uganda from the perspectives of healthcare providers (HPs), village health teams (VHTs), and community members (CMs) with COPD. We conducted 40 in-depth, semi-structured interviews (16 HCPs, 12 VHTs and 12 CMs, aged 25-80 years). Interviews were analyzed using inductive coding, and the Illness Representations Model (IRM) guided our analysis. Stakeholder groups showed concordance in identifying causal mechanisms of COPD, but showed disagreement in reasons for care seeking behaviors and treatment preferences. CMs did not use a distinct label to differentiate COPD from other respiratory illnesses, and described both the physical and social consequences of COPD. Local representations can inform development of adapted educational and self-management tools for COPD.

Introduction

Chronic obstructive pulmonary disease (COPD) is a treatable and preventable long-term lung disease [1,2]. The biomedical term COPD is used to characterize multiple progressive lung pathologies causing limitation of air flow, daily symptoms and activity limitation, and intermittent periods of worsening symptoms, known as acute exacerbations [1,3]. COPD is the third leading cause of death worldwide and is expected to become the leading cause of death within the next 15 years [4,5,6,7]. Once considered a disease of high-income countries, COPD is now recognized as a major public health concern in low- and middle-income countries (LMICs), with over 90% of COPD-related deaths occurring in LMICs [5,8-10]. Previous research has found that the prevalence of COPD in Uganda is 12.4% [11-14], with individuals living in rural areas experiencing a greater burden than those living in urban areas [15].

The Illness Representations Model (IRM) is a cognitive framework for understanding an individual's conceptualization of illness [16]. A component of the larger Common-Sense Model (CSM) of Self-Regulation, the IRM examines the multi-layered processes involved in how individuals experience their disease based on five dimensions: (1) identity of the illness in terms of symptoms or labels; (2) causal attributions behind the illness; (3) timeline of the illness; (4) consequences of the illness; and (5) illness management in terms of curability, controllability and coherence [17-19]. The IRM is centered around how an individual perceives and experiences these dimensions guides their motivation to carry out health-related behaviors.

Research has demonstrated the important role that illness representations play in health seeking behaviors, adherence to self-management practices, and clinical outcomes [20]. Illness

representations are inextricably linked to the sociocultural and environmental contexts in which they are formed, highlighting the importance of incorporating local illness representations when developing intervention strategies in a global health context. Thus, a guiding framework and approach to characterizing these local representations is critical to designing effective and locally adapted strategies. However, few such strategies have been developed to address chronic respiratory diseases in LMICs.

As COPD is both treatable and preventable, there are evidence-based treatments and self-management practices to help control symptoms and improve quality of life. Previous research addressing chronic disease management has shown that patient-centered education is a key component of effective strategies to manage long-term health behaviors in LMICs [11,21]. However, incorporating local, or "emic," illness representations into these strategies is critical to ensuring the effectiveness of these strategies and is a central component of patient-centeredness [22]. Patient-provider communication and, by extension, quality of care, can also be better facilitated if healthcare providers are trained in cultural competence surrounding illness representations, particularly for chronic conditions such as COPD.

Our objective was to characterize illness representations for COPD in a rural community of Uganda from the perspectives of community members with COPD (CMs), health care providers (HCPs), and community health workers (known as village health teams, or VHTs, in Uganda). We sought to use the IRM as a framework to inform the systematic development of intervention strategies for COPD disease management at the clinic, community, and household levels. Characterizing these representations will help with understanding the health seeking behaviors

and management practices in the context of the Ugandan social, cultural, and health system environments, with the ultimate effect of improving the effectiveness of patient-centered educational interventions and facilitating communication between medical professionals and local community members surrounding chronic lung disease. Moreover, this analysis demonstrates the benefit of using IRM to inform the development of COPD studies in LMIC settings.

Methods

Study Design

The purpose of this formative qualitative research study was to inform a multi-center, community health worker-based COPD self-management intervention trial in Uganda, Peru, and Nepal [23]. We sought to understand illness representations for COPD from the perspectives of three stakeholder groups.

Eligibility for participation in the Uganda arm of the study was ascertained by the following criteria: CMs had to live in Nakaseke and had been identified as having COPD (FEV_1/FVC ratio below the lower limit of normal as per spirometry testing) in a prior, population-based study (Lung function in Nakaseke and Kampala, or LiNK) [24]. Participants in the LiNK study were randomly selected from a community census, and all participants in the study underwent spirometry; thus, CMs were largely representative of individuals with COPD in the overall population of Nakaseke. HCPs and VHTs had to be above 18 years of age and have worked in Nakaseke for at least one year prior to enrollment.

The study was approved by the Institutional Review Boards at University College London in London, UK, the Bloomberg School of Public Health, Johns Hopkins University in Baltimore, US, and the Makerere School of Medicine Research Ethics Committee and the Uganda National Council for Science and Technology in Kampala, Uganda.

Study Setting

The district of Nakaseke, Uganda, is located 70 kilometers north of Kampala – Uganda's largest and capital city. Interviews were conducted throughout Nakaseke district, a rural district composed of 15 sub-counties. Data collection sites included four government-sponsored health facilities, one private clinic and two private pharmacies. For interviews conducted with VHTs and CMs, data collection took place in private homes.

In Uganda, VHTs comprise the first line of care for individuals living in rural communities with limited healthcare resources. VHTs are a major component of the country's decentralized approach to delivering essential health services. The VHT strategy was established in 2001 to address the disparities in community health care delivery and to encourage communities to assume a more active role in improving delivery of health services at the community and household levels [25]. VHTs are either male or female adult volunteers, constitute a range of education levels, and are selected among members of their communities based on established government guidelines [26]. VHTs are unpaid volunteers that receive incentives such as job training, certificates, t-shirts, bags, etc. in exchange for their duties. District health systems are responsible for training VHTs in health promotion, service delivery, community participation, and empowerment strategies.

Sampling and recruitment

From August to October 2017, we conducted a total of 40 semi-structured in-depth interviews (IDIs) - 16 IDIs with HCPs and 12 interviews each with VHTs and CMs. We purposively selected CMs to target the most information-rich cases and achieve maximum variation on sex, age, and geographic distribution. Additionally, purposive sampling was used to identify HCPs and VHTs that were known to treat and work with non-communicable diseases (NCDs). Snowball sampling was used to recruit additional HCPs and VHTs. We obtained oral informed consent from HCPs and written informed consent from CMs and VHTs.

In-depth interviews

Eleven IDIs were conducted in English, and the remaining 29 IDIs were conducted by supervised local research assistants in the local language of Luganda. Interviews ranged from twenty minutes to one hour. All interviews were audio-recorded and transcribed by members of the research team. Interviews conducted in Luganda were translated and transcribed directly into English. Field notes and memos were recorded after the interview to expand upon each interaction.

Interviewers used three separate semi-structured interview guides for each group (HCP, VHT, CM). Each guide consisted of open-ended questions regarding understanding and perception of NCDs. Interviewers used probes to expand upon COPD experiences, causes, diagnosis, treatment, and management.

Data Analysis

Two members of the research team reviewed each transcript for quality control by reviewing transcription completeness and comparing to the audio recording. Through iterative team discussion and reflection, a codebook was developed using Grounded Theory [27]. Dedoose software version 8.0.35 (Socio Cultural Research Consultants, LLC, Los Angeles, CA) was used to organize and code the data [28]. Topical codes included: language used to describe respiratory distress and/or COPD; causes, symptoms, diagnosis, management, and treatment of COPD; physical, financial, and social barriers to care; facilitators to care; and interactions among CMs, VHTs and HCPs. After coding transcripts, the IRM emerged as a framework that could be used to frame the illness experiences of individuals living with COPD. We thus used the five dimensions of the IRM to guide presentation of our results.

Terminology

We use the term "COPD" throughout this manuscript to refer to a biomedically defined set of progressive lung pathologies causing limitation of air flow, daily symptoms and activity limitation, and intermittent periods of worsening symptoms. However, the purpose of this analysis was to describe the *local terms and understandings* that are used by community members, VHTs, and health providers in the rural Ugandan context to refer to the same or similar conditions, regardless of whether they also use the term "COPD" to describe them.

Results

Study Sample

We obtained informed consent from 40 individuals in Nakaseke. The study team interviewed 12 CMs, 12 VHTs, and 16 HCPs. CMs ranged in age from 45 to 80 years old and VHTs ranged in age from 25 to 57 years old. HCPs represented a variety of professions within the medical sphere (Table 1).

Table 1. Socio-demographic details of respondents

N=40	CMs n=12	VHTs n=12	HCPs n=16
Sex			
Female	7 (58.3%)	7 (58.3%)	10 (62.5%)
Male	5 (41.7%)	5 (41.7%)	6 (37.5%)
Age (years)			
41-50	6 (50.0%)	1 (8.3%)	-
51-60	1 (8.3%)	3 (25.0%)	-
61-70	3 (25.0%)	4 (33.3%)	-
>70	2 (16.7%)	4 (33.3%)	-
Occupation			
Medical Officer *	-	-	1 (6.3%)
Clinical Officer**	-	-	5 (31.3%)
Clinical Officer Student	-	-	1 (6.3%)
Nursing Officer***	-	-	1 (6.3%)
Enrolled Nurse****	-	-	3 (18.8%)
Nursing Student	-	-	2 (12.5%)
Pharmacist	-	-	1 (6.3%)
Drug Dispenser	-	-	2 (12.5%)

*A medical officer holds a Bachelor in medicine and surgery degree. Medical officers with experience typically supervise clinical officers [29].
**A clinical officer has diploma in Clinical Medicine and Community Health, which are sometimes referred to as physician assistants in other settings. These biomedical providers practice in both rural and urban settings in Uganda [30].
***A nursing officer holds a Bachelor's degree in nursing and manages the delivery of nursing care in health centers and the community.
****An enrolled nurse assists a nursing officer holding an Enrolled or Comprehensive Nursing Certificate.

Identity

Overall, we found that CMs in most cases did not assign a singular label to their condition, but rather used symptom-related terms. The most commonly mentioned symptoms among CMs were chronic cough (n=30) and suffocation (n=13), along with chest pain, headache, and fever. VHTs (n=6) and HCPs (n=5) also used the word "suffocation" when probed about symptoms they treat for individuals presenting with chronic respiratory diseases.

No CMs were familiar with the term COPD, and there was no direct translation for COPD in the local language of Luganda. Rather, the term 'kifuba' is an emic term referring to symptoms of respiratory distress, particularly cough and TB.

> "Here in our community, a person who is always in smoke gets flu. When someone stays in a smoky environment, he gets what they call cough, what is called TB here in our community... It is what we call 'kifuba.'" [CM, Male, 59 years old]

Many HCPs and a few VHTs were familiar with the term COPD from their prior medical training. Twenty-seven out of 40 HCP, VHT, and CM participants used terms for respiratory diseases that were more clearly recognized in the community, such as asthma, tuberculosis, pneumonia, bronchitis, fibrosis, and the flu, to describe COPD.

Cause

Informants described several causal mechanisms of COPD and recurring breathing illnesses. These factors can be categorized into *controllable* and *uncontrollable* factors. The most common controllable factors included smoking (n=25) and exposure to indoor air pollution and biomass smoke (n=17). The most common uncontrollable causes of COPD according to stakeholders included weather and temperature (n=25), witchcraft (n=9), and heredity (n=7).

Controllable factors

Smoking cigarettes was the most common cause of respiratory disease mentioned by all stakeholder groups (CMs (n=7), HCPs (n=8) and VHTs (n=10)). CMs (n=5), HCPs (n=12), and

VHTs (n=7) also explained that indoor air pollution and biomass smoke cause respiratory disease. One VHT described how daily activities, like cooking, could impact respiratory health.

"We [community members] also cook in kitchens that do not have enough aeration for smoke where you end-up inhaling and being suffocated by the smoke, things like that." [VHT, Female, 57 years]

Uncontrollable factors

Weather and temperature

Respondents across all three participant types attributed acute changes in respiratory symptoms to weather-related factors. Dust, colder weather, rain, and changing weather patterns were consistently cited by HCPs (n=5), VHTs (n=4), and CMs (n=6).

"Every time the weather changes, they have a bad experience because it is painful and they are sick inside…when it's cold, when it's dusty, when it shines so much…you see the patient is disturbed." [VHT, Female, 38 years old]

"When I am sleeping, in my lungs I hear a sound, there is a sound from the lungs, when the cold wind comes... The smoke from the kitchen and when someone sweeps dust, I feel bad." [CM, Female, 45 years old]

Witchcraft

Some HCPs (n=7) and VHTs (n=2) mentioned that individuals in the community understand their respiratory condition as being caused by external forces, such as charms, curses, or bewitching. Providers (n= 4) and VHTs (n=2) suggested that the connotative relationship of witchcraft with respiratory symptoms contributed to delays or refusals in health-seeking behaviors within the community.

"If you do not follow up very well they die because most of them think it is witchcraft… When you tell them 'let us go to the facility for management' still some people are hesitant to doing what they have been advised to do. They are so reluctant and they just tell you, *'oba nfa, nfe! lino ddogo'* meaning 'let me die if I have to! This is witchcraft.'" [VHT, Female, 52 years old]

However, no CMs mentioned bewitching when asked about the source of their respiratory distress when interviewed.

Heredity

Some HCPs (n= 2) and CMs (n= 5) described genetics or heredity as an additional risk factor for COPD. One CM explained that a healthcare provider said COPD was inherited:

"And [my healthcare provider] told me this disease [COPD], he did not place any machine on me or anything, he told me that cough is in the blood [inherited]. And I explained to him that I have taken every kind of medicine but the cough has done what?... And he told me that disease is in the blood [inherited]." [CM, Female, 63 years]

CMs conceptualized their respiratory condition by referring to both acute and chronic aspects of their disease. Several CMs described their respiratory condition as a prior acute illness that had persisted inside the body. For example, one respondent described his symptoms as "the flu that never leaves you" [CM, Male, 59 years old].

Some CMs (n=5) reported the transition of their illness from acute, isolated episodes to chronic, long-term symptoms. Participants explained how recurring symptoms were one of the key factors to drive treatment seeking.

> "Back then I would get the usual cough, and even when I did not go to the hospital, it would get cured. But nowadays, it gets cured, but not for a long time. I can buy medicine and take it for like two months and then it comes again." [CM, Male, 47 years old].

For many CMs, the persistence of these symptoms over time was a defining feature of the condition. Another common trend among participants who sought out providers for their respiratory illness, was the increasing severity of symptoms over time.

> "It has been a long time really but some time back it really got worse. I got cough and coughed for a long time…I would feel hot without sweating but my body would feel hot. This happened for some time and I just thought I was going to get TB and [so] I went for a checkup." [CM, Female, 80 years old]

HCPs and VHTs focused more on the chronic nature of these symptoms when defining COPD. HCPs (n=8) and VHTs (n=2) also expressed that persisting symptoms drove individuals with respiratory distress to seek treatment.

Consequences of illness

CMs described multiple ways in which their illness affects daily life through physical manifestations such as poor sleep and reduced energy levels to complete housework and labor-associated activities, such as gardening and farming, that participants depend upon for income.

> "I do not have energy. I no longer have enough energy…I was about to get out of [the garden]…slowly, slowly, I do so little now, so little because of feeling weak… I overwork my body, then you feel like eh, you feel dizzy." [CM, Female, 62 years].

CMs also described social consequences of their illness. Because of the strong association of cough with contagious illnesses such as TB, CMs (n=5), HCPs (n=4), and one VHT discussed fear of contagion. One CM described how this fear of contagion has led to stigma and social isolation.

> "It used to affect me a lot when someone dies in the community, I could not go [to the funeral] because of the way in which I was always coughing… When I am among people, I would cough and saliva would come in my mouth and there is nowhere for me to spit when I am among people." [CM, Female, 63 years old]

Similarly, one CM expressed that symptoms of COPD, such as coughing, affect her social interactions.

> "From the time [my roommate] chased me away, [community members] mistreated me so much and I felt bad. Now there they really discriminated against me…because of the cough." [CM, Female, 48 years]

One VHT further explained stigma surrounding COPD for community members.

> "Because people have been having stigma and isolation thinking they will also contract this disease [COPD] where people say, "ogufuba gwe gwantama tegugenda kunkwatira bwerere" meaning am fed up of this person's cough I don't want to get it." [VHT, Female, 42 years]

Control (COPD Prevention and Management)

Participants in all three categories explained using both biomedical and traditional methods to both prevent and treat COPD. HCPs, VHTs, and CMs discussed barriers to treatment as well as the role that prevention plays in COPD treatment strategies.

HCPs commonly described advising individuals with respiratory distress to avoid certain risk factors, such as smoking cigarettes, exposure to smoke resulting from combustion of biomass, or outdoor air pollution.

"The chronic ones, we advise them, in most cases, it is aggravated by the smoke. So, you tell them to do away with that smoke. To avoid that pollution. So that is the advice we usually give them." [HCP, Clinical Officer, Female]

"You do not be around lots of smoke...you do not stay around where there is lots of smoke. And this dust, it also should be reduced." [CM, Female, 63 years]

All three respondent groups also reported significant barriers to receiving diagnosis and treatment. These included lack of awareness of COPD, lack of diagnostic equipment, limited availability of COPD medications, high cost of COPD medications, and lack of transport to health centers (HCPs (n=9), VHTs (n=11), CMs (n=7)).

"It [chronic cough] can make someone die. If someone is poor, you don't have money to get better treatment, you end up losing your life...what they do is they go to the main hospital, but no medication, so they just tell you to go to the hospital and you go home. No money." [HCP, Dispenser, Female]

"I can get this disease [COPD] and I have to go [to] the health provider but I do not have money. Now what do I do because of transport that would get to the hospital quickly? Maybe in the night, I can run short of breath and the cough makes it difficult for me but…transport may be difficult for me." [CM, Female, 45 years]

HCPs and VHTs mentioned that individuals experiencing respiratory symptoms prefer to initially seek out treatment from herbalists or traditional providers and visit providers at health facilities "as a last resort" [HCP, Male, Student Clinical Officer] when herbal treatments do not

work. Some CMs reported using both herbal treatments from traditional providers and medications prescribed by allopathic providers to treat their symptoms.

Aside from herbalists, other traditional practices included providing an offering to a traditional healer to alleviate curses or charms. More so, "smoking [out the curse] ...covering someone in a blanket smoking them" [HCP, Male, Clinical Officer], was a mentioned practice for respiratory disease treatment, such as COPD. It involves an individual putting their head under a blanket over a fire. The provider explained: "People with COPD...they go and smoke them...steaming them with the pure smoke that contains a lot of carbon...they [community members] think the smoking will chase the bad something [external forces]." [HCP, Male, Clinical Officer]

Although most HCPs (n=9) did not believe that COPD was caused by external forces, such as witchcraft, many HCPs continued to recommend both traditional and biomedical practices to individuals suffering from respiratory distress.

Discussion

We used the IRM as a framework to guide our understanding of local conceptions of COPD in a rural Ugandan community and their potential implications for clinical practice and educational intervention design. We found that COPD was not conceived as a distinct disease by CMs, but rather as a group of associated symptoms, or as other bio-medically defined conditions such as asthma or TB. Our results show considerable concordance among stakeholder groups in recognizing factors such as smoking and exposure to indoor and outdoor pollution as causal factors. However, HCPs and VHTs described CMs' belief in witchcraft as a reason for delaying

care seeking for COPD. Our findings also highlight both the physical and social consequences of COPD and respiratory illness.

We found that CMs did not have a single label to describe COPD or to differentiate COPD from other respiratory illnesses. Similarly, there was no direct translation for COPD in the local language; rather, the emic term "kifuba" is used to describe cough related to COPD or other illnesses thought to originate from the chest. Our results differ from one study conducted in the United States, where individuals with the disease used a singular label such as "my COPD" or "my emphysema" to describe their disease [31]. This difference in strength of disease identity between U.S. and Ugandan populations is likely attributable in part to vast differences in local resources for diagnosing and treating COPD. Under current guidelines, diagnosing COPD requires resources for pulmonary function testing, which are almost non-existent in many LMICs, particularly in rural settings [32]. Thus, strengthening of health infrastructure for diagnosis and treatment of respiratory diseases in these communities also has the potential to strengthen disease identity and, consequently, health seeking and self-management behaviors for COPD.

An inconsistent local understanding of COPD in this context (in addition to an inconsistent clinical definition of COPD in both other LMICs and high-income countries) has important implications for delivery of effective intervention strategies. Studies of individuals with other conditions show that people who seek care for their illness are more likely to have a concrete identity and distinct label for their illness than those who do not [33,34]. Thus, strategies should focus on methods for empowering individuals to recognize symptoms, view their disease in a

cohesive manner, and differentiate them from other diseases with different biological underpinnings, such as TB or asthma. Action planning is one such strategy that, if adapted to a local context and combined with comprehensive education, could help strengthen COPD identity and encourage appropriate and timely health seeking behaviors [25]. At the same time, incorporating emic terms and leveraging local representations in the design of health education curricula is critical to fostering effective communication and health behavior change.

Perceived causes of respiratory illness were largely concordant across groups and included both controllable (smoking, exposure to indoor cooking smoke) and non-controllable (heredity, weather, witchcraft) factors. Patient-provider concordance has been shown to be associated with better patient care and outcomes and to have a positive impact on patient-provider communication [21,35,36]. Previous research conducted in Uganda has shown that better communication between patients and providers can increase confidence in self-management practices for individuals living with NCDs [37,38]. In contrast, communication challenges are often exacerbated in clinical interactions where there is a strong mismatch between patient and provider illness representations [39]. Identifying the cause of a disease as controllable or preventable can lead to positive risk reduction and prevention behaviors by increasing an individual's sense of agency and self-efficacy [40,41]. Perceived risk and level of self-efficacy are also important predictors of health seeking and self-management behaviors [42]. Educational strategies should therefore incorporate targeted messaging designed to encourage agency in self-management of COPD. At the same time, strategies should consider the environmental barriers constraining an individual's ability to adopt self-management practices or receive access to basic tools and resources.

In addition to physical consequences such as symptoms and lack of energy for daily activities, participants also reported consequences of their illness that were social in nature: stigma due to its being perceived as contagious, as well as social isolation. Stigma associated with COPD has also been shown to be associated with negative patient outcomes [43]. In high-income settings, much of the stigma, both internalized and external, surrounding COPD relates to the perceived controllability of an individual's smoking behaviors [43]. However, in LMIC settings such as Nakaseke with high TB incidence, the conflation of COPD with other infectious diseases such as TB appears to exacerbate the stigma experienced by individuals with non-communicable, chronic respiratory diseases that include cough as a major symptom. Health awareness campaigns and COPD intervention strategies should therefore emphasize the non-communicable nature of respiratory diseases such as COPD and asthma to distinguish these respiratory disease from diseases like TB. Home visits and support groups, which have been shown to be effective in reducing anticipated and internalized stigma for TB [44], may also be useful in reducing stigma for COPD in settings with high TB incidence.

Although our findings suggest that participants viewed their illness as containing both acute and chronic components, it was the chronic component of the disease (the recurring symptoms) that ultimately drove individuals to seek care. Many studies have demonstrated that holding an acute model for a biologically chronic condition can lead to lower levels of adoption and sustained use of self-management practices and routine care seeking, as well as delays in care seeking [19]. For example, Kaptein et al. demonstrated that individuals holding an acute model of illness were less likely to use their peak flow meter, a tool used for self-management of asthma, or to attend

routine clinic visits for asthma [45]. Alternatively, individuals with a longer time since diagnosis

are more likely to view their condition as a chronic, long-term disease requiring regular

treatment and follow-up [46]. Thus, effectively communicating the chronic nature of COPD,

particularly in LMIC settings such as Uganda where diagnosis is limited, will be critical to

incorporate into clinical practice and community-based intervention strategies for COPD.

Our results also reveal that individuals use both pharmaceuticals and complementary alternative

medicine (CAM) when seeking treatment for respiratory symptoms. We found that in Nakaseke,

individuals turn first to herbalists or traditional providers before visiting formal health facilities

because herbalists and traditional providers are more accessible and well-known to community

members. Yet, individuals commonly reported incorporating remedies from both types of

providers into treatment. This is consistent with other research on use of CAM in Uganda [47].

The tendency to seek treatment from multiple providers should be considered when designing

intervention tools that encourage certain care seeking behaviors.

While our analysis focuses largely on the illness representations of individuals, it is critical to

acknowledge the dynamic interaction between one's external environment and how an individual

conceptualizes their illness. Indeed, there are many environmental barriers to treatment that

significantly impact the illness experience in Nakaseke from all three stakeholder perspectives

and are important to consider when constructing an illness representation. These barriers include:

lack of transport to health facilities and inability to afford medications (CMs); weak referral

systems, ineffective forms of incentives, limited career advancement opportunities (VHTs);

limited access to medications and diagnostic equipment (such as spirometers and peak-flow

measurements, both of which are costly and rarely available in low-resource settings) and poor patient-provider communication (HCPs) [13,26,32,48]. Previous research has also found these barriers in similar settings, which indicates that NCD management is influenced not only by the cognitive processing of the individual providing or receiving care, but also by the capacity of the health system. Thus, prior to implementing any future intervention strategies to address NCDs in LMIC settings, a thorough and systematic understanding of local barriers and facilitators to care is essential.

This study has some potential shortcomings. First, the majority of the data collected during IDIs was translated into English from audio-recordings of the interviews conducted in Luganda. It is possible that nuances and specific local terminology may have been lost in translation through the transcription processes. Second, the use of purposive sampling and snowball sampling to find HCPs and VHTs that treated individuals with NCDs may have yielded HCPs and VHTs with greater knowledge of NCDs and COPD. Likewise, CMs recruited to participate had COPD confirmed by prior spirometry testing in the LiNK study population based study in rural and urban settings in Uganda [49], and thus all participants had previously undergone lung function test. This implies some prior exposure to this procedure, which may not be representative of the larger community. Despite these limitations, this is the first study to explicitly examine illness representations of COPD in Uganda or other LMICs. This study benefits from the multiple stakeholder perspectives, which allows for a rich, multi-dimensional analysis of COPD representations.

Our findings shed light on several implications for intervention design and policy for COPD management from the lens of multiple stakeholder perspectives in rural Uganda. Our study highlights the importance of local context and illness representations in informing future patient education interventions, and it is an example of how the IRM can serve as a guiding framework for designing and adapting such strategies across diverse LMIC settings. Interventions should incorporate environmental and structural factors that impact an individual's ability to carry out self-management behaviors. Health systems strengthening and continued investment in improving access to treatment is essential – self-management at the household and community levels cannot be achieved in a vacuum. In the future, interventions should encourage self-efficacy and empowerment by providing tools to improve self-management at these levels, and improve connections between individuals and the healthcare system. In the Ugandan setting, the VHT system represents a potentially powerful avenue to achieve this empowerment that can and should be leveraged in NCD care and management.

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