npj primary care respiratory medicine

www.nature.com/npjpcrm

ARTICLE OPEN

Check for updates

Revealing inequities in chronic respiratory disease (CRD) care: An adapted Photovoice qualitative study in Malaysian primary care settings

Hani Salim[1]✉, Nik Sherina Hanafi[2], Ai Theng Cheong[1], Shariff Ghazali Sazlina[1], Fadzilah Mohamad[1], Norita Hussein[2], Siti Nurkamilla Ramdzan[2], Rizawati Ramli[2], Hooi Chin Beh[2], Abd-Malek Fatin-Syazwani[2], Bee Kiau Ho[3], Salbiah Mohammad Isa[3], Zienna Zufida Zainol Rashid[4], Hamidah Amin[5], Zuzana Aman[5], Siti Fairus Asahar[6], Ee Ming Khoo[2] and Hilary Pinnock[7]

Chronic respiratory diseases (CRDs), particularly asthma and chronic obstructive pulmonary disease (COPD), impose significant burdens on patients and their families in low- and middle-income countries (LMICs). Little is known about the experience of living with CRD in low- and middle-income countries (LMIC), and the impact of systemic inequities in primary care settings. To explore patient experiences of systemic inequities in CRD care in Klang District, Malaysia. We employed an adapted qualitative Photovoice study conducted between December 2023 and October 2024. The study involved adult patients with self-reported CRDs from five primary care clinics in Klang District, Malaysia. In-depth interviews were conducted at two time points using an interview guide and focused on the topics chosen by participants in their photographs. We transcribed audio-recordings verbatim, checked for accuracy and analysed them thematically. Patient and public involvement (PPI) was integral throughout the study, enhancing cultural relevance and ethical oversight. Fourteen participants (mean age 54 years; 57.1% men, 42.9% Malay, 50% diagnosed with asthma) completed the study. Four interconnected themes emerged: (1) indoor and outdoor air pollution (e.g. smoking and haze) worsened respiratory symptoms; (2) financial strain due to out-of-pocket expenses despite provision of universal healthcare; (3) occupational vulnerabilities, including transitions to precarious informal work due to health limitations; and (4) gendered caregiving burdens, including caring responsibilities while ill, pregnancy-related vulnerability, stigma, and household misunderstanding. Participants consistently showed resilience, proactively adopting coping strategies despite systemic barriers. This study highlights intersectional inequities faced by people with CRDs in Klang, Malaysia, emphasising environmental, financial, occupational, and gender-specific challenges. The use of participatory visual methodologies like Photovoice gives voice to people, allowing their narratives to advocate for culturally sensitive change to the lived environment supported by equitable provision of healthcare.

npj Primary Care Respiratory Medicine (2026)36:28 ; https://doi.org/10.1038/s41533-025-00476-0

INTRODUCTION

Asthma and chronic obstructive pulmonary disease (COPD) are the most prevalent chronic respiratory diseases (CRDs)[1,2]. Together, they account for the vast majority of CRD-related deaths globally, with COPD being the leading cause[1]. If current trends persist, the overall burden of CRDs is projected to rise by 23% by 2050[2]. Low- and middle-income countries (LMICs), including Malaysia, bear a disproportionate share of this rising burden due to persistent social, environmental, and structural inequities that hinder timely diagnosis and effective management[3–6].

The recent WHO European Region Lung Health Report 2025 highlights that, even within Europe, within-region inequities in CRD outcomes remain stark, contributed by social determinants such as poverty, overcrowded housing, occupational exposures, and widespread air pollution, with lower-income communities facing the greatest barriers to diagnosis and continuity of care[7]. These CRD inequities linked to poverty, pollution, and healthcare access are reflected – or likely magnified - in LMICs, including Malaysia[4,5,8]. Economic impacts are substantial; in Europe alone, lost productivity due to CRDs is estimated to cost over US$20.7 billion annually, highlighting the pressing socioeconomic consequences in resource-limited settings where informal economies predominate[7].

In response, the 78th World Health Assembly (WHA78.5) recently urged Member States to adopt a multisectoral, integrated lung health strategy that addresses both communicable and noncommunicable lung conditions, strengthens primary health care, and ensures equitable access to cost-effective interventions such as tobacco control, clean air initiatives, affordable diagnostics, and essential medicines[9]. This global mandate aligns with Malaysia's commitment under the Declaration of Astana and the WHO Framework Convention on Tobacco Control, but implementation gaps persist, particularly at the primary care level, where most CRD patients first seek care[10,11].

While quantitative burden estimates are well documented[12], there remains a paucity of context-specific qualitative evidence capturing how people living with CRDs in LMICs experience these systemic inequities in their daily lives[13]. We employed Photovoice as it enables participants to visually document and reflect on the everyday circumstances shaping their respiratory experiences, offering insights that interviews alone might overlook[14]. This participatory approach aligns with our aim of using a culturally

[1]Department of Family Medicine, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, 43400 Serdang, Malaysia. [2]Department of Primary Care Medicine, Faculty of Medicine, Universiti Malaya, 50603 Kuala Lumpur, Malaysia. [3]Botanic Health Clinic, Klang District, Klang 41200 Selangor, Malaysia. [4]Pandamaran Health Clinic, Klang District, Klang 42000 Selangor, Malaysia. [5]Kapar Health Clinic, Klang District, Klang 42200 Selangor, Malaysia. [6]Bukit Kuda Health Clinic, Klang District, Klang 41300 Selangor, Malaysia. [7]Usher Institute, The University of Edinburgh, EH16 4UX Edinburgh, UK. ✉email: hanisyahida@upm.edu.my

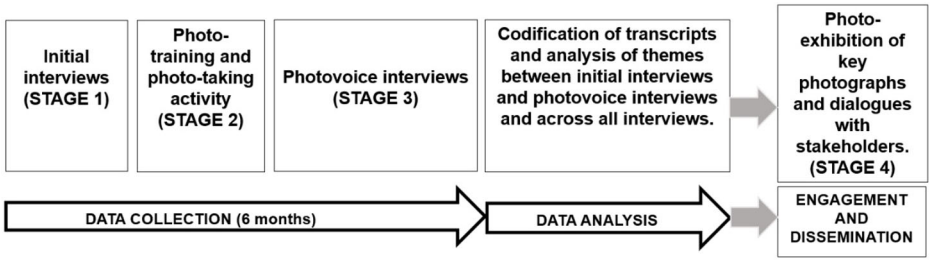

Fig. 1 Steps used in this study.

Table 1. Multicultural Malaysia and the health system.

- Malaysia operates a dual healthcare system comprising public and private sectors.
- Public healthcare is largely funded through taxation, while the private sector functions on a fee-for-service basis, contributed by private insurance.
- The government provides comprehensive universal healthcare services at primary, secondary, and tertiary levels. Specialised care is delivered through National Referral Centres that also support primary care services[6].
- Public healthcare is heavily subsidised, with minimal co-payments for services - typically MYR 1 (GBP 0.17) to MYR 5 (GBP 0.87) for outpatient visits and MYR 3 (GBP 0.54) per day for hospital admissions. Specialist consultations cost up to MYR 5 (GBP 0.87)[37].
- These co-payments are waived for specific groups, such as children and students, senior citizens over 60 years old, individuals with disabilities and targeted groups (e.g., people living with infectious diseases of public concern such as tuberculosis and maternal and child health services).
- Malaysia is a multicultural society with three major ethnic groups: Malays, Chinese, and Indians, each contributing distinct cultural and linguistic heritage.
- In Malaysia's multilingual context, *Bahasa Malaysia* serves as the national language and medium of instruction in schools, whereas English is taught as the second language.

adapted method to capture intersectional inequities in primary care settings in Malaysia through the lens of people living with CRD in Klang District. By foregrounding patient-generated photographs and narratives, the study addresses a key qualitative evidence gap and deepens understanding of how CRD-related inequities are experienced in daily life. Importantly, Photovoice supports the study's goal of generating participant-informed insights that can guide subsequent engagement, reflections and dialogue within primary care settings.

METHODS

The study took place between December 2023 and October 2024, with ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (ID: NMRR ID-23-02011-WZO (IIR)) and the Edinburgh Medical School Research Ethics Committee (Ref: EMREC-RESPIRE-23-03). Sponsorship approval was obtained from the Academic and Clinical Central Office for Research & Development at the University of Edinburgh (ACCORD) (ID: AC23004). All participants provided informed consent. The reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) to ensure methodological transparency and rigour[15].

Study design

We used a participatory action research (PAR) approach, informed by a constructivist qualitative orientation, using an adapted Photovoice design conducted in four distinct stages. We invited all participants to join the photo taking. Photovoice interviews and the final multi-stakeholder photo-exhibition.

Each participant's engagement in the study, including recruitment, interviews, photo-taking and follow-up, lasted about 6 months (Fig. 1). Because recruitment occurred in stages and participants' timelines overlapped, the overall fieldwork spanned 11 months.

Unlike the original group-based approach outlined by Wang and Burris[14], the adapted method included one-on-one engagements and initial in-depth interviews to build rapport with participants[16]. This approach was also informed by direct feedback from PPI members (see section on PPI), who highlighted concerns about privacy and local norms around illness disclosure.

Study setting

We conducted the study in Klang, a central urban district in Malaysia. The district is one of the country's most industrialised coastal areas, bordered by major highways and port facilities along the Straits of Malacca, one of the world's busiest shipping routes. Industrial emissions and open burning frequently push the Air Pollutant Index (API) to unhealthy levels, particularly during seasonal transboundary haze[17]. Thick smog and chemical odours may have become part of residents' daily experiences, shaping breathing practices and planning of outdoor activities.

Table 1 provides an overview of Malaysia's healthcare system and societal diversity. It took place at five public primary care clinics in the Klang District, which collectively serve over 50% of the local population. We selected clinics to include populations from urban and suburban areas, ensuring a diverse participant pool without implying judgment.

Recruitment and sample

Healthcare professionals at the study sites identified potential participants based on the eligibility criteria: adults (≥18 years) with self-reported chronic respiratory disease or symptoms. We purposively recruited participants for initial interviews using a maximum variation sampling strategy to ensure diversity in age, gender, CRD type, and ethnicity. All participants were invited to take part in all phases of the study, including Photovoice[18,19], but the commitment to photo-taking was explained fully following the initial interview.

We obtained written consent before the initial interview. We offered eligible individuals who agreed to participate a time and place most convenient to them for an initial interview.

Data collection

We collected in the form of self-reported brief socio-demographic data, audio-recorded interviews, and the photographs taken by the participants with the captions they provided. Each participant received a reimbursement of approximately GBP 20 to cover travel expenses and data-transfer costs, in accordance with the amount permitted by the local ethics board.

Stage 1: Initial interviews Two trained qualitative researchers, HS and AF, conducted semi-structured interviews using a topic guide (Appendix 1) lasting 60–90 min. We audio-recorded all interviews and transcribed them verbatim.

Stage 2: Training and photo-taking

After the initial interview, a subset of participants who agreed to continue received training on ethical photo-taking and were given photo-taking guide (Appendix 2). Participants could take an unlimited number of photographs as they wished, and the photo-interviews were scheduled once they had captured 15 photographs or after one month, whichever came first. All participants provided between 10–15 photographs.

All participants used their own mobile phones to capture photographs. We offered disposable cameras to those who did not own a mobile camera device, although none were used. Participants shared their photographs progressively at their own pace throughout the individual photo-taking period, before the follow-up interview session. They did so via an end-to-end encrypted messaging application (WhatsApp) to a dedicated research phone before the next interview session. The research team provided support for the transfer to all participants and encouraged them to write simple notes or audio-recorded reflections of the photographs they took. Participants received one reminder after one week to complete the photo-taking task.

We obtained written consent for individuals who were recognisable in photos. We informed participants that recognisable images of children were discouraged, and parental consent would be required if these were included. In line with the consent agreement, participants retained ownership of their photographs but were asked to refrain from sharing them on public or social media platforms until study completion to protect confidentiality and ensure responsible dissemination.

Stage 3: Photo-interviews

Photo-interviews lasted 60 to 90 min. Using the SHOWED technique (Appendix 2), participants discussed the meanings of all their photographs. Although the photo-taking training involved only participants, family members occasionally assisted with taking photographs, at the participant's request, but were not involved in the interviews. Participants then independently selected up to five key photographs and wrote captions to represent their experiences for dissemination, including photo-exhibitions (Stage 4). We provided guidance on the ethical and technical aspects of their selection.

Although participants were informed that a subset of photographs might be included in a later exhibition, participation in the exhibition was optional. At the end of the photo-interviews, we asked participants a general prompt about their experience of the Photovoice and photo-exhibition process (Appendix 1); however, this prompt was used to understand their engagement with the method and not to influence photo-taking. Our discussions and participants' reflections did not indicate that awareness of a possible exhibition shaped how photographs were captured or selected. Participants consistently chose images based on personal meaning rather than visual or aesthetic considerations.

Stage 4: Photo-exhibitions and dissemination

Small group discussions were held with participants who consented to participate in the community photo exhibitions and multi-stakeholder dialogues. These sessions allowed us to gather their reflections on the findings. The research team documented these reflections in brief field notes, which later supported the preparation of exhibition materials. We used these insights to guide the curation of the exhibition and the compilation of a photo book for broader dissemination and to inform dialogue with local health policymakers.

Data analysis

We anonymised, transcribed interviews verbatim in their original language, then checked for accuracy before analysis. Thematic analysis was employed, as outlined by Braun and Clark (2019)[20], to identify, analyse and report themes within the data. Familiarisation with the data was done by reading, re-reading and noting down initial ideas ('memoing'). The transcripts were then coded independently by HS and AF. We developed the coding tree inductively, beginning with initial codes derived from the data, which were then grouped into subthemes and organised under broader thematic categories. We compared themes between interviews across two time points to identify converging and diverging perspectives by HS and AF. We iteratively reviewed the themes by checking the coherence of the data within a theme and ascertaining whether the themes reflected the meanings of the data as a whole. The thematic analysis followed an inductive and descriptive approach, with themes developed to summarise and reflect participants' accounts.

We considered data saturation achieved when no new themes or insights emerged from the final set of interviews. This was observed after completing the 13th Photovoice interview, with the 14th interview yielding no new themes. HS and AF monitored data sufficiency throughout the analysis, supported by the research team and thematic repetition across cases confirmed that the dataset was rich and comprehensive for addressing the study objectives. NVivo Version 12 was used to support data management and analysis[21].

Experienced post-doctoral qualitative researchers and bilingual native speakers (HS and SNR) translated selected quotes for publication and reporting into English using a back-to-back translation approach[22]. In instances where metaphors or idioms could not be translated, the original language was maintained with explanatory footnotes[22–24].

Patient and Public Involvement (PPI) throughout the study conduct

Patient and Public Involvement (PPI) sustained throughout the study enhanced its cultural appropriateness, ethical conduct, and participant empowerment. Initially, three PPI contributors shaped the study design and materials, ensuring sensitivity to privacy, visual methods, and cultural norms. Two participants continued in advisory roles post-study, co-leading community events and policy discussions, including a public exhibition, stakeholder photo-walk, and co-design of a draft policy brief promoting equitable CRD care. Further details on the PPI process and its influence on the study's design, implementation, and policy outcomes are described in Appendix 3, structured according to the GRIPP2-SF (Guidance for Reporting Involvement of Patients and the Public – Short Form) framework.

Table 2. Trustworthiness criteria, research strategies and their application in this study.

Trustworthiness criteria	Strategies applied	Application in this study
Credibility	1. Field notes and memos 2. Audio recordings 3. Collaborative coding and analysis	1. Prolonged engagement - the Photovoice process spanned around 11 months, involving initial semi-structured interviews, ongoing contact (phone, messaging apps, in-person visits), and multiple follow-ups, building rapport and trust. 2. Member checking - participants reviewed captions and narratives of their photos and discussed preliminary themes during follow-up sessions. A subset co-curated community photo exhibitions and joined policy roundtables, ensuring accurate representation. 3. Peer debriefing - multidisciplinary team (family medicine clinicians, academics) analysed data collaboratively. Findings were discussed through conferences and seminars for external validation. 4. Reflexive journaling by the lead investigator to monitor assumptions and positionality.
Transferability	1. Purposeful, maximum variation sampling 2. Data displays (photos, captions, narratives) 3. Ongoing literature review	1. Sampling strategy - recruitment via clinician referrals, snowballing, and clinic staff; purposive selection ensured diversity in age, gender, ethnicity, and CRD type. 2. Thick description - detailed contextual description of study sites and participant characteristics provided.
Dependability	1. Field notes and memos 2. Iterative coding 3. Systematic documentation	1. Audit trail - research journal documented methodological adaptations, coding decisions, and analytic steps. 2. Collaborative review of coding framework
Conformability	1. Reflexive documentation 2. Team-based interpretation	1. Reflexivity - ongoing critical reflection on the researcher's positionality and influence. 2. Audit trail of analytic memos and coding framework. 3. Collaborative review of themes across two interview points to validate consistency and reduce individual bias

Table 3. Participants and caregivers' characteristics, n = 14.

Profile	Sub-profile	Description, n (%)
Gender	Male	8 (57.1)
	Female	6 (42.9)
Age, year	Mean (SD), Range	53.93 (14.31), (36–84)
Ethnicity	Malay	6 (42.9)
	Indian	5 (35.7)
	Chinese	3 (21.4)
Diagnosis	Asthma	7 (50.0)
	COPD	6 (42.9)
	Cancer	1 (7.1)

Table 4. Summary of inequities experienced by people living with CRD.

Theme	Sub-themes
Theme 1: Indoor and outdoor pollution	*Seasonal haze and illegal burning*
	Indoor smoking
Theme 2: Financial burdens despite the presence of universal healthcare coverage	*Hidden costs of universal care*
	Paying to bypass the public system barrier
Theme 3: Occupational vulnerability	*Transition to informal work and coping with income loss*
	Job-related health risks
Theme 4: Gendered caregiving burdens	*Caregiving while ill*
	Pregnancy and CRD
	Stigma and household misunderstanding

Trustworthiness and reflexivity of research

Rigour and reflexivity in research are critical considerations for ensuring the quality and integrity of a study. We evaluated trustworthiness through Lincoln and Guba's four criteria[25,26]. We applied these criteria to enhance the study's trustworthiness. Reflexivity is the process of critically reflecting on the researcher's role and recognising that qualitative research is shaped by the researcher's methods, perspectives, and interactions. Table 2 outlines the strategies that were used in our study, and Appendix 4 provides further details.

RESULTS

Description of participants' characteristics

In total, 18 eligible participants agreed to take part in the interview; two withdrew due to health reasons, and two only completed the initial interview. Fourteen participants completed initial and Photovoice interviews. More than half were men (57%), with a mean age of 53.9 (SD14.3) years. About 42.9% self-reported to be Malay in ethnicity, and half (50%) have asthma. Table 3 summarises the participants' characteristics.

Presentations of findings

We identified four interlinked themes that emerged from the analysis. The themes and sub-themes are summarised in Table 4. Detailed narratives of the accompanying figures for each theme are provided in Appendix 5.

As shown in the distribution of participant characteristics, all individuals with COPD in this study were men, and their narratives centred on occupational strain, financial responsibility, and environmental exposures. In contrast, the caregiving-related

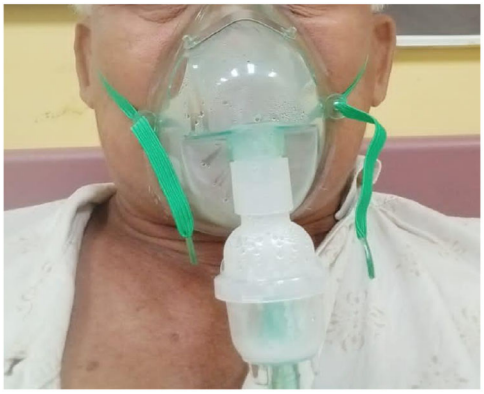

Fig. 2 Accessing emergency car. "When the haze comes, I don't dare go outside. I have to close the windows, turn on the fan, and stay indoors. When the haze is bad, I get breathless and have to use the blue inhaler repeatedly, up to 20 times. But sometimes, I still can't cope. At this point, I was breathless, and my oxygen dropped. I was in the ward for days. When the haze comes, I can't breathe, and it hurts so much." A 62-year-old man with COPD.

Fig. 3 Exercising around the neighbourhood. "Today the sky is clear, it's a bit hot, but at least it's not raining and no haze. Walking for 15–30 min makes my body feel lighter, a little healthier. The doctor encourages me to exercise a bit." An 84-year-old man with COPD.

burdens presented later in the findings were described almost entirely by women with asthma. These patterns indicate how gender and disease type intersect within the dataset and shape where participants' experiences were represented across themes.

Theme 1: Indoor and outdoor pollution

Seasonal haze and illegal burning. Participants reported that seasonal haze (Fig. 2), aggravated by illegal industrial waste burning and open burning practices near residential areas. The thick smoke, sometimes mixed with potentially chemical fumes, causes severe breathlessness, frequent hospitalisations, and fear during high-pollution days.

Many resorted to staying indoors, closing windows, or using fans and purifiers, which were not always effective. Despite these conditions, participants expressed determination and resourcefulness. Some maintained hope and actively tried to self-manage in ways they knew. For example, reinforcing preventive habits like consistently using inhalers before heading out for exercise, if the weather permits (Fig. 3).

Fig. 4 A disposable cigarette lighter. "I used to be strong, lifting hundreds of gas cylinders, but now I'm often sick and have difficulty moving. Young people today don't understand that if they keep smoking at home or remain inactive, they will regret it when they're older. I want my children, grandchildren to know the harmful effects." A 72-year-old man with COPD.

Indoor smoking. Some participants highlighted how smoking by family members inside the house worsened their symptoms, with attempts to mitigate the impact by asking smokers to smoke outside. Reflections from participants who used to smoke highlighted personal regret about past smoking habits and concerns about the health of children and grandchildren exposed to household cigarette smoke (Fig. 4). They reflected on their motivation to encourage healthier habits among family members:

Theme 2: Financial burdens despite the presence of universal healthcare coverage

Hidden costs of universal care. Participants reported having to purchase inhalers and other medications out-of-pocket when their supply did not last until the next clinic appointment or when certain drugs were unavailable at public facilities. For some, combination inhalers such as Symbicort were used both for daily control and as a reliever, causing the supply to deplete faster and forcing additional purchases (Fig. 5).

Beyond medications, participants also highlighted practical costs such as transport to clinics, after-hours emergency visits, and

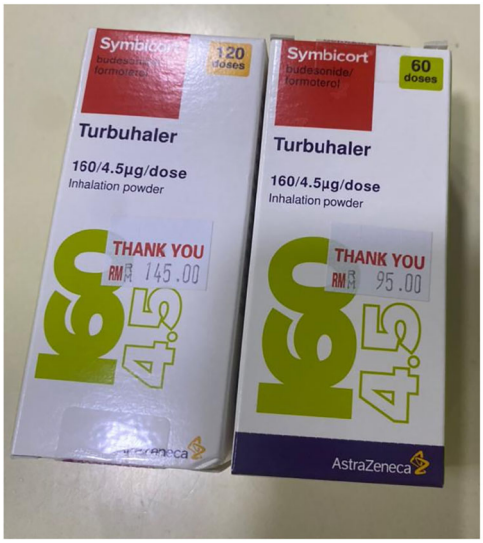

Fig. 5 The costs of inhalers outside the public health system. "Without Symbicort (a combination inhaler), I really can't manage, I get breathless. When the medicine runs out before the appointment, I have to buy it myself. If I don't have it, I get scared, and I can't work." A 42-year-old man with asthma.

Fig. 6 A typical primary care clinic. "Coming here really takes a lot of time. Sometimes, it can take up to half a day, so attending regular follow-ups is challenging. First, I have to queue to make payment, then queue again for vital signs and other checks, and a third time to wait for the doctor. Sometimes, when I'm in a hurry, I just go to a private clinic and pay, just spend a bit of money. I think, maybe, I just hope that one day there will be a better system." A 32-year-old man with asthma.

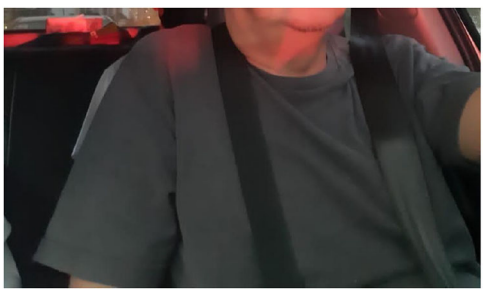

Fig. 7 At work as an e-hailing cab driver. "Being a Grab driver is my part-time job. I can go home to cook, pick up my child from school, attend appointments, and at the same time, earn a bit of money. Even though it's not much, it's enough for our needs. I only drive in the mornings, so the weather isn't too hot, and I can take care of my health while working." A 55-year-old man with lung cancer (in remission).

Fig. 8 Photocopying machines at work. "My workplace is full of dust, so I have to wear a mask to cover my nose. Without it, my asthma gets worse. The dust and polluted air here are major reasons my asthma is difficult to control. If I'm not careful, I struggle to breathe and end up with a relentless cough". A 40-year-old woman with asthma.

the need to buy supportive devices like spacers. Despite these financial burdens, participants remained motivated to prioritise their health and described adhering to treatment protocols to sustain their well-being.

Paying to bypass public system barriers. Overcrowded public facilities and long waiting times discouraged some participants from seeking timely follow-up care (Fig. 6). To avoid delays and ensure continuity, they turned to private clinics when they could afford it, accepting the extra financial strain. These accounts highlight how systemic barriers within the public sector created inequities, with those who could pay accessing care more quickly.

These accounts highlight how systemic barriers within the public sector created inequities, with those who could pay accessing care more quickly.

Theme 3: Occupational vulnerability

Transition to informal work and coping with income loss. Participants often changed their formal, physically demanding, or inflexible jobs to informal or 'gig' work such as e-hailing cab driving (e.g. Grab: Fig. 7), which allowed them to pace their working hours and take rest breaks. They highlighted that this helped them manage unpredictable breathlessness and medical appointments, but often came with unstable income.

Despite these difficulties, they found personal satisfaction and hope in being able to remain productive and contribute to their household income. Although these accounts were primarily linked to occupational strain, several men also described the pressure of sustaining their role as the family provider. This expectation intensified their fears about job loss, income instability, and the consequences of stopping work due to breathlessness, highlighting that men, too, experienced gendered responsibilities, expressed through financial rather than caregiving roles.

Job-related health risks. Participants expressed fear about how their health affected work performance, safety, and job security.

Fig. 9 Wear multiple layers of clothing. "Even in the heat, I wear two layers of clothing and a jacket. If I'm cold, my breathing will be difficult. I have to endure these layers because I think of my children; if anything happens to me, who will take care of them? That thought keeps me going. No matter where I am or how I feel, I have to stay strong." A 50-year-old woman with asthma.

Many avoided distant assignments or physically demanding tasks due to worry about fear of forgetting medication, or a sudden attack when they were unable to access emergency help. For some, work settings posed exposure risks (e.g., construction sites, car washes, stairs, photocopying shop: Fig. 8). Despite wearing masks, constant exposure triggered exacerbations, worsened lung conditions, and required frequent use of inhalers at work. Still, participants persisted in these challenging environments, driven by their commitment to maintaining financial independence and supporting their families:

Theme 4: Gendered caregiving burdens

Caregiving while ill. Despite their own poor health, women frequently described the unrelenting responsibility of caring for young children, elderly dependents or sick family members. The double burden intensified fatigue, limited their capacity to rest, and increased anxiety about their own health deterioration. Despite these difficulties, women consistently found motivation and emotional strength from their sense of duty and deep family bonds (Fig. 9):

Pregnancy and CRD. Pregnancy added an additional layer of vulnerability for women living with CRDs. Some participants described how their asthma worsened during pregnancy, heightening fears of severe attacks and limiting their ability to care for other children or consider future pregnancies. Nonetheless, they showed determination and resourcefulness, closely following medical advice to manage symptoms and protect their unborn child, while finding comfort through spiritual practices (Fig. 10).

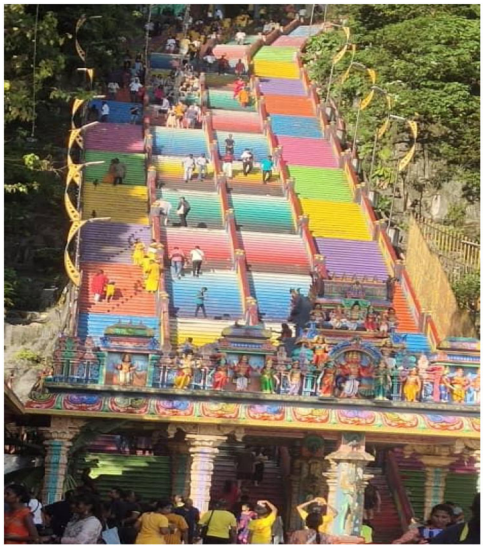

Fig. 10 Visiting a temple. "Whenever I feel an attack coming, I immediately use my inhaler to ease my breathing. I follow the doctor's advice and use the inhaler to control my asthma, especially during pregnancy, when it tends to get worse. But I also pray and ask God to keep everything safe and well." A 37-year-old woman with asthma.

Stigma and household misunderstanding. Women described experiencing blame and misunderstanding from spouses or family members, who sometimes perceived their breathlessness and physical limitations as excuses to avoid household chores (Fig. 11). This disbelief and lack of empathy heightened feelings of guilt and emotional strain, further undermining the support they needed.

Yet, despite these challenges, many women demonstrated profound emotional resilience and personal strength, and internal motivation.

DISCUSSION

Summary of principal findings

This Photovoice study offers insights into the everyday challenges faced by people living with CRDs in Malaysia. Participants described how seasonal haze, illegal burning, and second-hand smoke aggravated breathlessness and exacerbations, despite personal efforts to reduce exposure. Many experienced financial strains from out-of-pocket costs for medications, supportive devices, and private care, particularly to avoid public system barriers. Frequent symptoms and exacerbations disrupted stable employment, pushing some into lower-paying informal work while others remained exposed to occupational hazards. Women faced added burdens, coping with their illness alongside caregiving, pregnancy-related vulnerability, and household stigma.

Despite these challenges, participants expressed strong motivation to stay well, drawing strength from faith, family, and hope for better health. Many would adapt routines, adhere to treatment, and show resilience through lifestyle changes in their efforts to sustain supportive roles and caring responsibilities. These findings revealed not only the structural inequities in CRD care but also the everyday perseverance and agency of those affected.

Strengths and weaknesses of the study

The adapted one-to-one Photovoice method encouraged deeper emotional expression and richer contextual insight than conventional interviews. Allowing participants to choose and caption

Fig. 11 Cooking for family. "Even the smell of fried onions triggers my coughing when I'm cooking for my family. My chest tightens and I feel pain, and sometimes I have to stop everything for a while before continuing. But my husband sometimes thinks I'm just making excuses. Still, I cook every day because caring for my family is my responsibility." A 44-year-old woman with asthma.

their own images gave them control over the narrative and produced more nuanced portrayals of lived experiences, such as the unseen health effects of polluted air or the tension between health and work. Although photo-taking training involved only participants, family members sometimes assisted at their request. This reflected the realities of multi-generational households and community interdependence in this setting[27]. Their involvement helped participants capture experiences more authentically, especially when they wished to appear in the images themselves. However, it may also have influenced photo composition and framing; a contextual strength but also a potential limitation of participatory visual methods in family-oriented cultures[28].

Stakeholder engagement further enhanced cultural and contextual relevance. Our PPI partners were involved at key stages of design and planning. The stages include refining recruitment materials, advising on appropriate language, and ensuring cultural sensitivity around privacy and visual methods. Our study participants co-curated community exhibitions that showcased their photographs and narratives. These complementary roles helped strengthen trust and allowed participants to see their contributions recognised in ways that supported their sense of involvement and agency. This is particularly important in Malaysia, where longstanding cultural norms around privacy, illness stigma, and deference to medical authority have contributed to hesitancy toward engaging in research[16,29,30], as also reflected in concerns raised by our PPI partner. By creating a supportive and participatory process, the study framing enriched the data and ensured that findings reflected issues that mattered most to participants, rather than researcher-defined priorities.

We identified several limitations. First, fluctuating health status and work obligations prevented a single, full-group dialogue session[14], potentially diluting Photovoice's collective-empowerment dimension. Second, although gender balance was achieved among participants with asthma, all the COPD participants were men, which reflects the underlying epidemiology of COPD in this setting, rather than a selection bias[31]. No other participants had other CRD diagnoses, such as interstitial lung disease, which are typically managed in secondary care. Although only one lung cancer participant took part, conceptual saturation was achieved. The participant provided an extensive, internally coherent set of images and narratives covering symptom burden, surgical sequelae, employment loss, environmental triggers and navigation of the health system. These echoed the main themes identified by participants with asthma and COPD without introducing new categories during the final coding cycle. Consistent with information-power principles for purposive, heterogeneous samples, the depth and convergence of this participant's data were sufficient to support the study's analytic claims.

Third, the need to handle a smartphone camera and share digital images may have deterred individuals with very limited digital literacy, which may introduce selection bias. However, training was given to all consenting participants, and support was offered for differing needs.

Fourth, although the photovoice prompts invited participants to reflect on how their images could educate others or prompt community action, such advocacy-oriented reflections were limited. This likely reflects cultural norms in which illness is viewed as a private or family responsibility rather than a collective issue for public mobilisation[27,29,30]. However, participants involved in dissemination activities showed emerging awareness of shared responsibility, suggesting gradual shifts toward community-oriented perspectives.

Finally, because the research was conducted in a coastal district affected by open burning and cross-border haze, environmental themes may be over-represented, which could limit transferability to settings with different pollution profiles.

Comparison with previous literature

Our findings reinforce priorities outlined in the WHO European Region Lung Health Report 2025, highlighting the need for multisectoral responses addressing environmental and social determinants of CRD[7]. Participants' experiences with indoor and outdoor pollution, employment insecurity, and caregiving burdens exemplify intersectional challenges identified as gaps in current national responses. Their suggestions align closely with the report's advocacy for integrated clean air policies, occupational health protections, and enhanced social support mechanisms within primary care[7].

Our results contribute to existing literature on structural inequities affecting CRD management in LMICs. Consistent with Meghji et al.[8], air pollution, particularly seasonal haze and open burning, emerged as significant contributors to symptom exacerbations and hospitalisation among participants[8]. In contrast to many LMIC contexts, where household biomass smoke is the predominant exposure[32], our findings highlight urban–industrial and transboundary haze exposures as dominant triggers. At the household level, participants described exposure to second-hand tobacco smoke, highlighting that indoor smoking remains a persistent and overlooked driver of symptom exacerbations[33]. This highlights the importance of regional air quality governance and the need for efforts to reduce second-hand smoke exposure through education and awareness initiatives.

The reported financial barriers to accessing essential medications in this study echo findings from a local study, which showed that despite subsidised public care, asthma patients still incurred out-of-pocket expenses[34]. These costs were mainly for medications, transport, and complementary treatments, with a small but significant proportion experiencing catastrophic health expenditure and medical impoverishment[34]. This highlights that universal healthcare alone is insufficient without addressing medication affordability and supply chain inefficiencies[4].

Participants' experiences of exchanging stable employment or informal work due to CRD-related health limitations resonate with findings from a recent review[5]. The resulting economic vulnerability highlights the urgent need for integrated occupational health interventions and social support within primary care. Yet, unlike high-income country contexts, where social protection buffers income loss[35], participants in this study reported an absence of institutional safety nets, revealing inequities in global CRD care.

Table 5. Implications for practice, research and policy.

Practice	Address financial and occupational vulnerabilities through flexible, patient-centred care models.
	Recognise and respond to the hidden burdens of caregiving, especially among women.
Policy	Enforce anti-pollution laws and improve indoor air quality to reduce CRD exacerbations.
	Ensure equitable access to essential medications and diagnostics.
	Involve patients and communities in policy planning to ensure cultural relevance and legitimacy.
Research	Explore gender caregiving roles and their impact on disease management.
	Develop sustainable strategies for embedding participatory methods into primary care research.

This study also highlights gendered differences in experience. Women described caregiving responsibilities, pregnancy-related vulnerability, and stigma, aligning with calls for gender-sensitive chronic disease management[13] and with evidence that gender remains under-analysed in health research[36]. Men, in contrast, spoke about expectations to maintain employment and support household finances despite symptoms. These differing pressures were reflected in the themes: all COPD participants were men and emphasised occupational exposures and financial strain, while women, most of whom had asthma, focused on caregiving and family dynamics. Although themes were developed inductively across diagnoses, these patterns show how gender and disease type together shaped lived experiences of CRD. Acknowledging these dual perspectives aligns with recommendations for clearer gender-based analysis in health research[36].

Methodologically, the adapted Photovoice approach employed here builds upon foundational participatory research by Wang and Burris (1997)[14]. By placing patient experiences at the centre of the research, this study directly supports WHO's Resolution WHA78.5[9], advocating for participatory, patient-informed primary care strategies to advance equitable lung health in Malaysia and similar LMIC settings. Importantly, the visual participatory approach captured experiences often 'invisible' to routine surveys, such as stigma, caregiving strain and faith as coping resources; thereby moving beyond tokenistic inclusion by positioning participants as active co-creators of knowledge and priority-setters in CRD management in primary care.

Implications for practice, research and policy

The key implications of the study are summarised in Table 5.

CONCLUSION

This study shows how people living with CRDs in Malaysia navigate intersecting inequities: environmental, financial, occupational, and gendered. Through an adapted Photovoice approach, participants shared personal experiences that illustrated the need for equity-focused, patient-informed approaches to respiratory care in LMICs. The intersection of structural and social determinants offers a vital lens for reshaping primary care. Embedding participatory visual methods like Photovoice can help LMIC health systems identify and address inequities, informing culturally relevant, patient-driven policy.

DATA AVAILABILITY

All relevant data supporting the findings of this study are included within the manuscript. De-identified excerpts of participant narratives may be made available upon reasonable request to the corresponding author, subject to ethical approval and participant confidentiality agreements. Full interview transcripts will not be shared due to consent restrictions and the sensitive nature of the data.

Received: 24 September 2025; Accepted: 22 December 2025;
Published online: 14 March 2026

REFERENCES

1. Feng, H., Li, Z. & Zheng, R. The global burden of chronic respiratory diseases attributable to tobacco from 1990 to 2021: a global burden of disease study 2021. *BMC Public. Health* **25**, 456 (2025).
2. Global burden of chronic respiratory diseases and risk factors, 1990–2019: an update from the Global Burden of Disease Study 2019. *EClinicalMedicine* **59**, 101936. https://doi.org/10.1016/j.eclinm.2023.101936 (2023).
3. Soriano, J. B. et al. Prevalence and attributable health burden of chronic respiratory diseases, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet Respir. Med.* **8**, 585–596 (2020).
4. Stolbrink, M. et al. Availability, cost and affordability of essential medicines for chronic respiratory diseases in low-income and middle-income countries: a cross-sectional study. *Thorax* **79**, 676–679 (2024).
5. Santoni, A. et al. Improving care for people with chronic respiratory diseases: taking a policy lens. *Adv. Ther.* **42**, 2569–2586 (2025).
6. Thomas, S., Beh, L. & Nordin, R. Health care delivery in Malaysia: changes, challenges and champions. *J. Public. Health Afr.* **2**, e23 (2011).
7. *Chronic respiratory diseases in the WHO European Region*. https://www.who.int/europe/publications/i/item/WHO-EURO-2025-12340-52112-79990 (2025).
8. Meghji, J. et al. Improving lung health in low-income and middle-income countries: from challenges to solutions. *Lancet* **397**, 928–940 (2021).
9. *Promoting and prioritizing an integrated lung health approach*, https://apps.who.int/gb/ebwha/pdf_files/WHA78/A78_R5-en.pdf (2025).
10. *Delivering quality health services: A global imperative for universal health coverage*, https://iris.who.int/bitstream/handle/10665/328123/WHO-HIS-SDS-2018.61-eng.pdf?sequence=1 (2018).
11. *WHO Framework Convention on Tobacco Control*, https://iris.who.int/bitstream/handle/10665/42811/9241591013.pdf?sequence=1 (2003).
12. Hanafi, N. S. et al. Chronic respiratory disease surveys in adults in low- and middle-income countries: A systematic scoping review of methodological approaches and outcomes. *J. Glob. Health* **11**, 04026 (2021).
13. Lim, Z. N. et al. Exploring the disease experience and supportive care for people with very severe chronic obstructive pulmonary disease in Malaysia: a multi-perspective qualitative study. *J. Glob. Health* **15**, 04127 (2025).
14. Wang, C. & Burris, M. A. Photovoice: concept, methodology, and use for participatory needs assessment. *Health Educ. Behav.* **24**, 369–387 (1997).
15. Tong, A., Sainsbury, P. & Craig, J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int. J. Qual. Health Care* **19**, 349–357 (2007).
16. Salim, H. et al. Insights into how Malaysian adults with limited health literacy self-manage and live with asthma: a Photovoice qualitative study. *Health Expect.* **25**, 163–176 (2022).
17. Mohd Shafie, S. H. et al. Influence of urban air pollution on the population in the Klang Valley, Malaysia: a spatial approach. *Ecol. Process.* **11**, 3 (2022).
18. Creswell, J. W. & Poth, C. N. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. (SAGE Publications, 2017).
19. Liamputtong, P. *Qualitative Research Methods*. (Oxford University Press, 2019).
20. Braun, V. & Clarke, V. Reflecting on reflexive thematic analysis. *Qual. Res. Sport. Exerc. Health* **11**, 589–597 (2019).
21. QSR International Pty Ltd. (2015) NVivo (Version 11), https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.
22. van Nes, F., Abma, T., Jonsson, H. & Deeg, D. Language differences in qualitative research: is meaning lost in translation?. *Eur. J. Ageing* **7**, 313–316 (2010).

23. Oxley, J., Günhan, E., Kaniamattam, M. & Damico, J. Multilingual issues in qualitative research. *Clin. Linguist. Phon.* **31**, 612–630 (2017).
24. Al-Amer, R., Ramjan, L., Glew, P., Darwish, M. & Salamonson, Y. Language translation challenges with Arabic speakers participating in qualitative research studies. *Int. J. Nurs. Stud.* **54**, 150–157 (2016).
25. Lincoln, Y. S. *Naturalistic inquiry*. (Sage Publications, 1985).
26. Guba, E. G. *Fourth generation evaluation*. (Sage Publication, 1989).
27. Salim, H. et al. Contextualising COPD self-management in Malaysia: insights from a qualitative photo-elicitation study of patients-caregiver dyads. *J. Glob. Health* **15**, 04301 (2025).
28. Harper, D. Talking about pictures: a case for photo elicitation. *Vis. Stud.* **17**, 13–26 (2002).
29. Lee, Y. K. & Ng, C. J. The state of shared decision making in Malaysia. *Z. Evid. Fortbild. Qual. Gesundhwes* **123-124**, 66–68 (2017).
30. Lim, M. T. et al. Patient experience on self-management support among primary care patients with diabetes and hypertension. *Int. J. Qual. Health Care* **31**, 37–43 (2019).
31. *Malaysian Burden of Disease and Injury Study 2009-2014*, https://iku.nih.gov.my/images/IKU/Document/REPORT/BOD/BOD2009-2014.pdf (2017).
32. Siddharthan, T. et al. Association between household air pollution exposure and chronic obstructive pulmonary disease outcomes in 13 low- and middle-income country settings. *Am. J. Respir. Crit. Care Med.* **197**, 611–620 (2018).
33. Oberg, M., Jaakkola, M. S., Woodward, A., Peruga, A. & Prüss-Ustün, A. Worldwide burden of disease from exposure to second-hand smoke: a retrospective analysis of data from 192 countries. *Lancet* **377**, 139–146 (2011).
34. Hussein, N. et al. Assessing catastrophic health expenditure and impoverishment in adult asthma care: a cross-sectional study of patients attending six public health clinics in Klang District, Malaysia. *BMC Health Serv. Res.* **24**, 327 (2024).
35. Gershon, A. S., Dolmage, T. E., Stephenson, A. & Jackson, B. Chronic obstructive pulmonary disease and socioeconomic status: a systematic review. *COPD* **9**, 216–226 (2012).
36. Heidari, S., Babor, T. F., De Castro, P., Tort, S. & Curno, M. Sex and gender equity in research: rationale for the SAGER guidelines and recommended use. *Res. Integr. Peer Rev.* **1**, 2 (2016).
37. Tangcharoensathien, V. et al. Health-financing reforms in southeast Asia: challenges in achieving universal coverage. *Lancet* **377**, 863–873 (2011).

ACKNOWLEDGEMENTS

We would like to thank all the participants and caregivers who participated in this study, as well as their families, and the healthcare professionals who made this study possible. We are grateful to the Ministry of Health Malaysia for granting permission to carry out this study at their facilities and to the RESPIRE collaborations for their support in this work. The RESPIRE collaboration comprises the UK and LMIC Grant holders, Partners and research teams as listed on the RESPIRE website (www.ed.ac.uk/usher/respire). RESPIRE research was funded by the NIHR (Global Health Research Unit on Respiratory Health (RESPIRE); NIHR16/136/109 and NIHR132826) using UK international development funding from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK government. The RESPIRE collaboration comprises the UK Grant holders, Partners, and research teams as listed on the RESPIRE website (www.ed.ac.uk/usher/respire).

AUTHOR CONTRIBUTIONS

H.S., H.P., and N.S.H. conceived the study and drafted the initial protocol with input from all site team members (H.C.B., B.K.H., S.M.I., Z.Z.Z.R., H.A., Z.A., S.F.A.). H.S. and A.F. conducted the interviews. Data analysis was performed by H.S. and A.F. in consultation with A.T.C., S.G.S. and F.M. H.S. led the drafting of the manuscript, which was critically reviewed by N.S.H., S.N.R., R.R., E.M.K. and revised by all authors. All authors approved the final version of the manuscript.

COMPETING INTERESTS

E.M.K. reports grants from the National Institute for Health Research Global Health Research Unit on Respiratory Health (RESPIRE) UK and UK Medical Research Council; personal fees from AstraZeneca, Board of Directors of the International Primary Care Respiratory Group; the President of the Primary Care Respiratory Group Malaysia, Council Member and Ethics Committee Member of Hospis Malaysia. The other authors declare no competing interests.

CONSENT FOR PUBLICATION

Written consent for publication was obtained from all participants for the use of their interview data and participant-generated photographs. All photographs included in this manuscript are de-identified and published with explicit, non-commercial consent.

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s41533-025-00476-0.

Correspondence and requests for materials should be addressed to Hani Salim.

Reprints and permission information is available at http://www.nature.com/reprints

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.