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Tackling chronic respiratory disease in low-resource settings

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CHAPTER

GENERAL INTRODUCTION



GENERAL INTRODUCTION

A story of chronic respiratory disease in a setting where resources are limited

The story of Asel

In a mountaneous village in Kyrgyzstan, Central-Asia, lives a proud mother of three. While her husband herds the sheep, Asel takes care of the children. Every day, she keeps them by her side while she spends several hours cooking, just like her mother had done when Asel herself was a little girl. Asel cannot afford gas or electricity, but luckily dung from the sheep is a free and easily available fuel.

Asel's husband is a smoker. In combination with burning the dung for heating and cooking, the house becomes quite smoky. One day, people from the capital, or maybe even further away, had given her a special cookstove. They said this stove was better, but it was not true. The food had no taste and the stove generated less heat. The low temperatures in winter required Asel to use their traditional stove besides the new one, until at some point her husband needed the metals of that stove and now the remainders are still stored behind the house.



For the last three years, Asel notices that she feels tired and breathless more quickly than others of her age. She has a constant cough that produces sputum, especially in the mornings. It has been increasing over time, and now makes it harder to carry the dung uphill. Once the nurse had given her antibiotics, but these did not help. It's not clear what's going on, probably something with the lungs because of the cold weather.

The story of Asel is a story of chronic respiratory disease (CRD) in low-resource settings, of exposure to risk factors (already affecting health before birth), of health perceptions and behaviours, social structures, and the socioeconomic impact of chronic respiratory symptoms. It also shows the importance of aligning health interventions with their context and the consequences of failure to do so. In this thesis, the elements of the story are studied in depth. Together, these elements form an image that shows the importance of understanding CRD in its context, and how to design and implement context-driven lung health interventions that people adhere to over time.

The burden of chronic respiratory disease is highest in low- and middle-income settings

CRD is a silent, growing pandemic. Most prevalent is chronic obstructive pulmonary disease (COPD), followed by asthma (Box 1). COPD has become the third cause of death worldwide, annually killing 3.3 million people. This accounts for 5.8% of all deaths, which is more deaths than HIV, malaria and tuberculosis combined.^{1,2} Although the highest prevalence of CRD occurs in high-income countries (HICs) with ageing populations,³ the highest burden of disease occurs in low- and middle-income countries (LMICs), where 90% of the COPD-related deaths and most of the asthma-related deaths occur.^{4,5}

Unlike infectious diseases such as pneumonia and COVID-19, manifestations of CRD develop slowly and silently. Meanwhile, especially due to its chronic nature, CRD severely impacts people's lives. COPD ranks sixth for global DALYs (74.4 million) and asthma ranks 34th (21.6 million); most DALYs occur in LMICs.³ Besides the direct burden, CRD also has a high socio-economic impact. CRD can severely impair daily activities; patients are more likely to miss school or work, and suffer from social isolation.⁶⁻⁸

Chronic respiratory disease

The category 'chronic respiratory disease' (CRD) includes chronic obstructive pulmonary disease (COPD), asthma, pneumoconiosis, interstitial lung disease and pulmonary sarcoidosis, and others. In this thesis, 'CRD' refers to COPD and asthma, which together constitute around 90% of the global burden of CRD.⁹

COPD:

COPD is a slowly progressive, inflammatory disease affecting the airways and alveoli. COPD includes emphysema and chronic bronchitis, and is characterised by a persistent reduction of airflow. The most common symptoms are breathlessness, chronic cough, and sputum production. In time, patients can experience problems in daily activities (walking upstairs and even getting dressed). Patients can suffer from episodes of severe symptoms that last from several days to weeks. Such exacerbations can be seriously disabling, require urgent medical care including hospitalisation, and may result in death.⁴

Asthma:

Asthma is characterised by recurrent attacks of breathlessness and wheezing caused by inflammation, and hence narrowing, of the airways. Symptoms vary in severity and frequency from person to person. Triggers for the attacks include indoor allergens (house dust mites in carpets), outdoor allergens (pollens), tobacco smoke, occupational irritants or air pollution.⁵ COPD and asthma cannot be cured; treatment is focused on disease control. If managed well as a chronic condition, symptoms can be relieved, quality of life improved, and risk of death reduced.^{5,10}

Contributors to the high burden of chronic respiratory disease in low- and middle-income settings

High exposure to risk factors

An important reason for the high burden of CRD is the high exposure to risk factors in LMICs. First, tobacco is traditionally considered the main risk factor to CRD; for men tobacco is the leading risk factor for CRD-related disabilities.¹¹ Over 80% of the tobacco users live in LMICs.¹² While tobacco use is decreasing globally, in many LMICs the rate of tobacco use is still rising.¹³ Tobacco prevention and cessation policies are less in place in LMICs; even more so, marketing campaigns of tobacco companies have recently switched to target these areas.¹² Second, air pollution is now recognised as another major risk factor, and the leading cause for CRD-related disabilities among women. The process of rapid industrialisation and urbanisation in LMICs is accompanied by still rising levels of ambient air pollution, whereas levels have declined in high-income countries.¹⁴ Furthermore, household air pollution globally affects around 3 billion people daily, predominantly from LMICs, as they rely on solid fuels as their main energy source. Burning solid fuels, such as dung, wood, and coal, generates high levels of air pollution and impacts health on many dimensions, also beyond respiratory health. Particularly at risk are women – often responsible for cooking – and their children who are kept close to their mothers.¹⁵ Moreover, as exposure to air pollution among pregnant women impacts the lung development of their foetus, increased predisposition to CRD already starts in-utero.¹⁶ Third, disadvantageous factors associated with poorer living conditions, such as malnutrition and a history of tuberculosis, co-occur and interrelate in LMICs. These risk factors further contribute to a higher burden of CRD.⁷

Poor access to adequate healthcare

Besides the higher prevalence of risk factors that contribute to the development and progression of CRD, access to adequate healthcare is generally more limited in LMICs than in HICs. Awareness regarding CRD and related risk factors is poor among communities and their healthcare professionals, and hence the potential benefit of healthcare is under-recognised. Additionally, there are multiple barriers to healthcare. These include fear of stigma (assuming chronic respiratory symptoms could lead to a diagnosis of tuberculosis), financial barriers, large distances to health facilities, lack of trained staff, lack of equipment, and lack of (affordable) diagnostic- and treatment options.¹⁷ Smoking cessation support and pulmonary rehabilitation programmes are not yet widely available in LMICs.^{18,19} Furthermore, research is relatively scarce for LMICs, which makes it challenging to have an evidence-based approach to CRD.¹⁷ The poor awareness of CRD, limited diagnostic options such as spirometry and the skills needed for their interpretation, lead to an underdiagnosis of CRD.²⁰ This, in turn, results in an underestimation of the scale of the problem. Therefore, policymakers may be unaware of the importance and potential cost-effectiveness of prioritising CRD in their setting.

Failure to integrate evidence-based lung health programmes in routine practice

To combat the high prevalence of CRD and related risk factors in LMICs, evidence-based programmes exist, such as smoking cessation, cleaner cooking solutions to tackle household air pollution, pulmonary rehabilitation, and self-management interventions. However, many of these programmes were developed and proven effective in high-income settings with completely different health- and political infrastructures, financial options, health-related beliefs and behaviours, and cultural traditions. They cannot simply be transferred to low-resource settings without adaptations to the local circumstances. Even when developed locally, programmes often fail to translate into meaningful outcomes due to unsuccessful implementation processes.²¹⁻²³

Implementation is a typically effortful, complex process. In this thesis, 'implementation' is defined as the act of carrying an intervention into widespread use,²⁴ ranging from the dissemination of an intervention to its sustained use. Particularly in LMICs, implementation failure can have dramatic consequences, as it drains resources from settings where they are scarce already while it undermines health outcomes. Therefore, the World Health Organization (WHO), global health funders and others institutions have urged for more and better implementation research, in particular for these settings.²⁵⁻²⁸

Numerous factors interact at multiple levels to determine implementation success or failure of health interventions.²⁹ A central and critical factor is the alignment of interventions and their implementation strategy with the local context.²⁴ The word 'context' – derived from the Latin *cum* (with) *texere* (to weave) – is often referred to as 'setting' or 'environment'.³⁰ In this thesis, context is interpreted broadly: a set of characteristics and circumstances that surround the implementation effort,³¹ such as settings' epidemiological or anthropological characteristics (e.g. prevalence data and local health beliefs), their health- and political infrastructure, their socioeconomic aspects, and their network of relevant stakeholders. Adequate understanding of the local context is indispensable for leveraging the contextual characteristics to facilitate a successful implementation process.³²

The Horizon 2020 FRESH AIR implementation research project

To generate evidence on how to effectively implement lung health programmes in low-resource contexts, we conducted the Free Respiratory Evaluation and Smoke-exposure reduction by primary Health cAre Integrated gRoups (FRESH AIR) research project.³³ Within FRESH AIR, we studied the implementation of CRD-related interventions, ranging from preventive measures (an awareness-raising programme about CRD and related risk factors, a cleaner cooking programme, very brief advice for smoking cessation) to diagnostic measures (online spirometry training for healthcare workers, testing a phone-based application as diagnostic tool for CRD,

improving diagnosing asthma for children under five years old) to therapeutic measures (pulmonary rehabilitation) (Figure 1).

Fourteen institutions from nine countries teamed up to conduct these interrelated studies in diverse low-resource settings: in Uganda, Kyrgyzstan, Vietnam, and Greece. The settings were selected based on the high levels of risk exposure (tobacco consumption and/or exposure to household air pollution). Also, these countries presented a range of different implementation challenges for their diverse demographic-, geographic-, economic-, health system- and cultural characteristics. Furthermore, with this selection, we could build on existing collaborations, as each country was part of the International Primary Care Respiratory Group's global network.

In our approach, we focused on engaging important local and international stakeholders throughout the entire process. For example, relevant stakeholders were a Minister of Health, a district health educator, or a patient representative. Collaboratively with the stakeholders, we first mapped the CRD-related context: we assessed the prevalence of CRD, measured the socioeconomic burden and studied health beliefs and behaviours. Next, we used the findings to facilitate the design of context-driven interventions and hence increase their implementation success. The FRESH AIR project was funded by the European Commission Horizon 2020 research programme (680997) and registered in the Netherlands Trial Register (NTR5759).

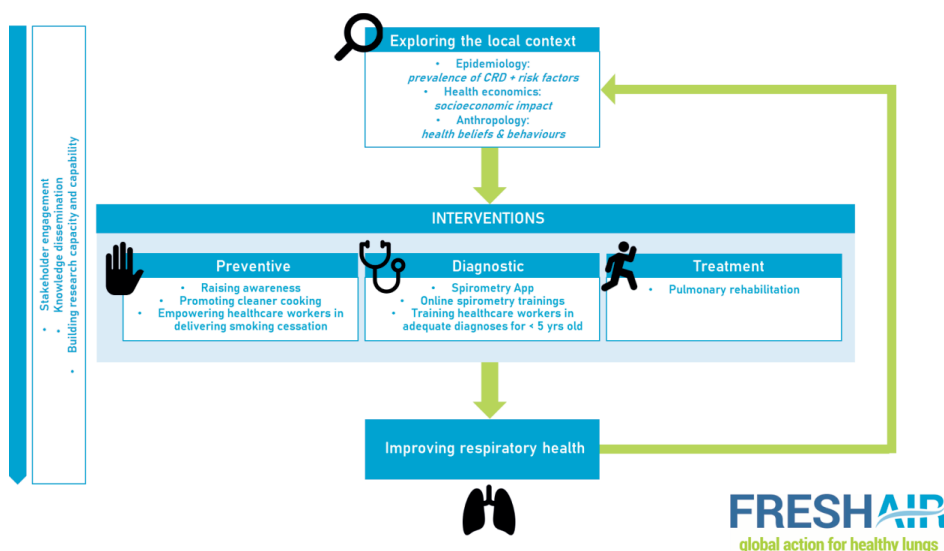


FIGURE 1. The FRESH AIR studies; exploration of the local context served the development of the implementation strategies of the interventions. This was a dynamic, iterative process. CRD = chronic respiratory disease.

Aims and outline of this thesis

This thesis addresses the challenge of tackling CRD in low-resource settings, and capitalises on the role of context. It is composed of two parts: the first focuses on exploring and understanding the problem in its context, the second works towards a solution. Many of the FRESH AIR substudies form the basis of the chapters in this thesis. How these studies relate to the remaining FRESH AIR studies (e.g. how a context assessment resulted in tailored implementation strategies for pulmonary rehabilitation programmes) is discussed throughout the chapters and in the General Discussion of this thesis.

Part I – Understanding the problem; exploring chronic respiratory disease in its local context

Chapter 2 illustrates the burden of CRD in low-resource settings in Kyrgyzstan. This epidemiological study details the prevalence of COPD and its risk factors, and demonstrates the importance of understanding different contexts even within neighbouring settings within the same country. **Chapter 3** details how the many risk factors for CRD in low-resource settings co-occur and interrelate, and elaborates on what this implies for potential solutions. Next, **chapter 4** moves beyond the direct burden and shows the socioeconomic burden of CRD in low-resource settings; this health economics study describes the impact of CRD on patients' work productivity and activity impairment in their daily lives in each of the FRESHAIR countries. **Chapter 5**, a systematic review, demonstrates through the example of smoking cessation how different contexts (such as different health infrastructures, medication availability, or cultures) can result in similarities and differences in national guidelines across the globe.

Part II – Towards a solution; facilitating implementation success of lung health programmes by engaging and leveraging their local context

To optimise the effect of health interventions, **chapter 6** details the factors that are critical to a successful implementation process for interventions targeting CRD in LMICs. The factors identified in this systematic review and meta-synthesis are translated into a hands-on implementation tool to assist implementers in practice. During this review process, an abundance of evidence on the implementation of cleaner cooking interventions was revealed. Due to the discrepancy between all the available evidence on implementation of cleaner cooking interventions on the one hand and the continued large-scale implementation failure on the other hand, **chapter 7** was written. This opinion paper calls for urgent consolidation of the fragmented evidence and translation of the evidence to practice. As a start, we engaged with other researchers in this field, the Clean Cooking Implementation Science Network and the World Bank, and conducted a systematic umbrella review to develop practical Cleaner Cooking implementation tools. This review of reviews involved a more complex methodology, and therefore we first published a protocol paper to enhance transparency (**chapter 8**) before publishing the results (**chapter 9**). One factor identified as critical to successful implementation in both the general

lung health intervention review and the cleaner cooking intervention umbrella review (chapters 6 & 9), is ensuring compatibility between the intervention, the implementation strategy and the local context. However, to do so, no evidence was available on how to systematically map the local context first. Therefore, in **chapter 10**, we designed a systematic context-mapping tool and validated it in the four FRESH AIR countries. **Chapter 11** details the results of the application of this context-mapping methodology; in this mixed-methods approach we mapped local beliefs and behaviours across settings in Uganda, Kyrgyzstan, Vietnam, and Greece. Next, **chapter 12** brings this thesis full circle by illustrating how all the previous findings can result in a context-driven implementation strategy for a subsequent FRESH AIR health intervention; a train-the-trainer awareness programme on CRD and related risk factors was implemented, tailored to local beliefs and behaviours. Lastly, in **chapter 13**, the General Discussion, all findings are collated, and the implications and recommendations are discussed.

Overall, the aim of this thesis is to provide policymakers, healthcare professionals, and researchers with data that can contribute to reducing the burden of CRD in low-resource settings across the globe (figure 2). Evidence on how to map local contextual characteristics and leverage these throughout the implementation process of relevant interventions should facilitate implementation success. Implementation success can optimise the use of resources in settings where these are scarce already, and ultimately, improve communities' health outcomes.



FIGURE 2. *The relevance for practice of this thesis, specified for several stakeholders.*

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